



UNIVERSITY OF
BIRMINGHAM

**THE PHENOMENOLOGICAL ATTITUDE, 'AUTISTIC'
PERSONS' INNER LIVES AND SPIRITUALITY**

A thesis submitted to
the University of Birmingham
for the degree of
Doctor of Philosophy

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ABSTRACT

The aim of this study was to explore the inner lives of 'autistic' people and their meaning-making as individuals, as well as members of a family unit, over a lifespan. I had significant ethical dilemmas about my not being 'autistic' and worried about what I might project on to 'autistic' people. I therefore took up a reflexive standpoint, dialogued with my own spiritual / religious values as an Alevi and realised that phenomenology was a possible way to move forward in carrying out ethical research. I gradually became aware that I am a reflexive, embodied and non-embodied paradoxical, dynamic, mysterious self and this is my lens through which I view the world; this is what I also deem to be my phenomenological attitude. Therefore, my phenomenological attitude has informed each stage of this research and each chapter of this thesis. Hence, this study and thesis is research design oriented and focuses on how a researcher(s) can prepare for working with 'autistic' people and their families. Thus, forethought is at the forefront of this study.

The methods process(es) of this study involved my exercising a phenomenological attitude with the use of Interpretative Phenomenological Analysis (IPA) and the narratives of 'autistic' people so as to learn about their inner lives. I analysed 'autistic' people's autobiographies in three stages. The first involved carrying out a pilot analysis of an autobiography. The second involved analysing three individuals' autobiographies in-depth. The third stage involved analysing eight vignettes, from various authors, of experiences they had within the family context(s) over a lifespan. I was also able to create potential interview protocols from the analyses in stage three, which can be used for future research.

The findings and insights of this study are that (i) the approach and methods process(es) in itself is a finding, (ii) that the body and senses of 'autistic' people create and shape their meaning-making, and (iii) that a focus on, in, with and through the phenomenological attitude may enable us to gain deeper insights into 'autistic' persons' ways of being as well as our own, leading to more sensitive and ethical research.

DEDICATION

I dedicate this thesis to my mother, Kiraz Pelge, my father, Ali Rıza Pelge, my brother Mehdi Nisa Pelge, his wife Nil Linda Eski-Pelge, to my 'autistic' friends and teachers Donald and Matthew, to our cat Güzel, to our pigeon Gökçe, to our nightingales Güzel and Prenseler, to our home and garden, and to The One.

Teşekkür ederim. Thank you.

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Thank you Donald and Matthew for (re-)teaching me that 'autistic' people can be, and usually are, a lot more sensitive than that which meets the eye.

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Hayrunisa Pelge

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LIST OF ABBREVIATIONS

ABA	Applied Behavioural Analysis
ADD	Attention Deficit Disorder
APA	American Psychiatric Association
ASAN	Autistic Self Advocacy Network
DSM-5	Diagnostic and Statistical Manual of Mental Disorders, 5th version (2013)
ICD-11	International Statistical Classification of Diseases and Related Health Problems, 11th edition (2018)
IPA	Interpretative Phenomenological Analysis
IQ	Intelligence Quotient
NAS	National Autistic Society
PARC	Participatory Autism Research Collective
PR	Participatory Research
PTSD	Post-Traumatic Stress Disorder
WHO	World Health Organisation

GLOSSARY OF TERMS

'Autism': I use this term as so due to two main reasons. One being that for me autism exists in that the person has a certain kind of embodied makeup that means that they experience and exhibit hyper and hypo bodily senses, however, simultaneously it does not exist in that the person is still an individual and has their own unique way of being. This is not to ignore the fact that being 'autistic' creates and influences such persons' uniqueness, because I believe that it does, however, it is in recognition of the fact that we are all unique due to the mysterious and not-knowable aspect(s) of ourselves. The second reason is that communication is a two-way process and is the responsibility of at least two agents – it is an intersubjective and a transactional process(es). To state that "That person is autistic" and only focus on them as having a social communication problem ignores the intersubjective element. In that if the 'other' seems to exhibit communication difficulties then I too do so because I have as much responsibility for the communication as they do. Hence my preference for the use of apostrophes when using the term 'autism'.

Autobiography: I use this term flexibly to refer to books that are officially published as autobiographies as well as reflective narratives written by 'autistic' persons regarding their lived experiences – which may not be officially recognised as being autobiographical.

Bias(es): I use this term with regards to how my subjectivity is likely to have influenced this study. This includes not only aspects of my subjectivity that are to do with my personal, historical, geographical and age related identity, but also my existential standpoint and my concepts regarding it. This is in an attempt to acknowledge what I am conscious of, and also what I may not be conscious of, so as to try and bring to the fore the things that I may be projecting on to the 'other'.

Bracketing: this is the practice within phenomenology and Interpretative Phenomenological Analysis whereby a researcher attempts to set aside one's

own assumptions to learn about the insider's perspective. Although simultaneously one seeks to be aware of one's own biases.

Emotional connectedness&non-connectedness: I use this term especially in the analyses of this study. This is because I found that 'autistic' people can, and do, experience emotion in a paradoxical manner. For example, Christopher Goodchild (2009) outlines how one can experience emotion so intensely that one has to distance oneself. Hence there can be a 'connectedness&non-connectedness' simultaneously. I view emotional connectedness&non-connectedness as being an aspect of intersubjectivity.

Inner life: a person's inner meaning-making, or / and not, of their lived experiences. This term is one that I use synonymously with the term 'spirituality'. This is because turning inwards so as to examine one's inner life and attempting to make meaning of one's lived experience(s) often involves a spiritual aspect(s).

Inner&intersubjectivity: I use this term in the analyses as a more explicit way of referring to intersubjectivity.

Intersubjectivity: the embodied and non-embodied self. For example, an individual has a body (embodied self) and experiences life through one's senses (the non-embodied self). Another example of this is the recognition of another being / person / environment as an aspect of oneself.

My reflexive embodied and non-embodied paradoxical, dynamic, mysterious self and lens: I use this concept as an understanding of my 'self', what I am bringing to this research in terms of my worldview and lens, and is what I deem to be my phenomenological attitude. I am a reflexive being in that I am able to reflect and make meaning, or not, of my lived experiences and behave in line with this. I am embodied in that I have a body and senses that create and influence my way of being, simultaneously, my senses enable me to experience life and therefore I am also a non-embodied self. I have a paradoxical aspect to my self, in that I have my likes and dislikes, weaknesses and strengths etc. There is a dynamic aspect to my self, in that I am changing, e.g. my views have significantly changed since I was a teenager. I have a mysterious aspect to my self, that which is unknowable by

my mind and senses. Therefore, consciously acknowledging this makes me realise that the words written herein are not the 'be all' or 'end all' for me and nor for this study. These elements help to create my sense of 'I' and my outlook on, in, with and through life – i.e. my lens.

'Other': a being or person who is recognised as being embodied in another body and is simultaneously recognised as being an aspect of oneself.

Phenomenological attitude: this is my reflexive embodied and non-embodied paradoxical, dynamic, mysterious self and lens. I have worked with my phenomenological attitude to carry out this study and to write this thesis.

Reflexivity: the ability to self-reflect and to change one's thinking, behaviour and approach(es) in line with such reflections.

Self-reflection: the ability to self-reflect and make meaning (or not) over, in, with and through one's lived experiences or / and thoughts.

Shems&Rumi: this is a term I use to refer to Shems of Tebriz, an Alevi Sufi spiritual teacher of his time, and his pupil Muhammed Mevlana Celalleddin-i Rumi. They both lived in what is now known as Konya, Turkey, during certain periods of their lives in the thirteenth century. The divine love that created itself through them enabled Mevlana to grow into a person of wisdom ('insan-i kamil'), and really both were each other's teacher and pupil. Their experience(s) and writings have influenced me and this study deeply due to their conscious recognition of the 'other' as being an aspect of oneself.

Spirituality: that all beings and each moment of life consist(s) of the energy of life and death – in other words Allah / Buddha light / God / Brahma etc. I use this term synonymously with the term 'inner life' because the attempt to make meaning of one's lived experiences often involves a spiritual aspect(s) and turning inwards for self-examination.

1. INTRODUCTION

1.1. THE BACKGROUND OF THIS STUDY AND HOW THE STUDY TRANSFORMED DUE TO MY ETHICAL DILEMMAS

This study began with a question regarding amalgamating the spiritual or / and religious beliefs of families with a member(s) on the 'autism' spectrum with the cognitive behavioural theories and practices of Applied Behavioural Analysis (ABA). This is traditionally referred to as 'the Lovaas Method', after the American clinical psychologist Dr. Ole Ivar Lovaas, who drew upon the works of various theorists in the field of cognitive behavioural psychology during the 1950s to come up with a method of teaching children on the 'autism' spectrum. The underlying tenet of the method is that it utilises a token economy approach; breaking down set educational tasks, e.g. reading, writing etc., into smaller sub-tasks and rewarding the child as the process goes on. There are several criticisms of ABA, the main one being that it is entirely behaviour based and does not focus on the lived experiences and voices of people on the 'autism' spectrum (Dawson, 2004; Waltz, 2007; Milton, 2012; Lawlor and Solomon, 2017), i.e. the inner life and meaning-making of 'autistic' people are ignored.

I had worked with people with various 'disabilities' in special needs schools, home settings, elderly care homes, a youth centre and at universities and enjoyed this kind of work. Such people challenged my understanding of my own lived experiences and what is meant by 'reality'. I feel an affinity with people on the 'autism' spectrum in particular due to the communication difficulties I experienced as a refugee child growing up in London from the age of five, experiencing and knowing what it is like to be the 'other'. During and after completing my degrees in psychology and psychological research methods I worked with two families with a son on the 'autism' spectrum as an ABA Tutor; I was trained by the ABA consultants who worked with these families. This was, and still is, the most common form of educational approach with people on the 'autism' spectrum so I undertook the role as it is. During this work I saw that one of the sons, both mothers and one father drew upon religious and spiritual rituals such as prayer and singing hymns as a source of meaning-making and motivation. My own inner life, spirituality and religious beliefs as well as

practices of Alevism have always been a source of meaning-making and motivation for me so I recognised the importance of this factor for these particular families and wanted to research into this further. Simultaneously, because my inner life has always been a very prominent aspect of my identity I also wondered about the inner life / lives of people on the 'autism' spectrum. I thought to myself, "If we knew more about such person's inner lives and how they make meaning then maybe we can work with them and their families to create educational approaches that are more suitable for such families".

1.1.1. Ethical dilemmas

When I started this research I fell into significantly deep ethical dilemmas. I had concerns about not being on the 'autism' spectrum myself, i.e. my not having the insider's perspective and yet attempting to write about such persons, which led to severe writer's blocks. Furthermore, I was not satisfied with a significant amount of current literature in the field because it did not resonate with my lived experiences with 'autistic' people and their families and there was a lack of the presence of the voices of such persons within the reported research. Therefore, these dilemmas have led to my taking up a reflexive standpoint, whereby I have openly stated and outlined my own spiritual worldview and understanding throughout this study whilst turning to the autobiographical narratives of 'autistic' persons – i.e. the lived experiences of people on the 'autism' spectrum.

I have taken up phenomenology as a methodology due to it being the closest conceptual methodology or worldview to that of people on the 'autism' spectrum - as going by the explicitly phenomenological nature of the narratives I have read and as has been recommended by 'autistic' academics such as Damian Milton and Donna Williams. Phenomenology is also in line with my own spiritual worldview of Alevism, enabling me to 'find my place' within the field of western social science research and to explore the 'other' in me and my meaning-making and that of the 'other' and 'their' meaning-making.

Therefore, due to these ethical dilemmas, my focus became that of reflexively studying the inner lives and lived experiences of people on the 'autism' spectrum, particularly in the family context over a lifespan as this is usually a person's primal

social context into which they are born and grow up in (Bronfenbrenner, 1979; Bowlby, 1988 / 2005). This kind of a reflexive study can be an example of how a researcher can attempt to fathom the meaning-making of the 'other' in their everyday life.

Now I shall provide the rationale for this study and set out the overall research aim and the research questions.

1.2. THE RATIONALE, RESEARCH AIM AND RESEARCH QUESTIONS

My dilemmas and the lack of a focus on the lived experiences and voices of people on the 'autism' spectrum within the literature (Waltz, 2005, 2007; MacLeod, Lewis and Robertson, 2013; Lawlor and Solomon, 2017) led to my realising that my very questions had to be questioned throughout this study. I was mindful that the kinds of research questions we ask lead to the different kinds of knowledge that we create and learn (de Vaus, 2001; Yin, 2009; van Manen, 2014; Silverman, 2016), which coupled with my need to be open and ethical about my Alevi worldview, meant that I had to take up a phenomenological attitude and exercise this throughout the study.

Definitions of the 'phenomenological attitude' vary, although Finlay (2008; p.2) defines it in a way that is meaningful for me as a researcher with an aim to explore the inner lives of people on the 'autism' spectrum:

"The "phenomenological attitude" involves a radical transformation in our approach where we strive to suspend presuppositions and go beyond the natural attitude of taken-for-granted understanding. It involves the researcher engaging a certain sense of wonder and openness to the world while, at the same time, reflexively restraining pre-understandings. Most phenomenologists would agree that this stance—or perhaps more accurately process—is one of the more (if not the most) significant dimensions of phenomenological research."

She views this process as a dance which entails contradictions and tensions for the researcher who is undergoing it, although also highlights that it is likely to "reward the researcher with special, if fleeting, moments of disclosure in which the phenomenon reveals something of itself in a fresh way" (Finlay, 2008; p.1). I did not know how I could carry out this dance and needed to create a tool that enabled me to dance with regards to fulfilling the aim of this research. Therefore, interestingly, thanks to exercising the phenomenological attitude, a tool that enabled me to

exercise a phenomenological attitude specifically with regards to this study emerged. I realised that my exercising a reflexive worldview that seeks to understand the paradoxical, dynamic and mysterious elements of the embodied and non-embodied self (or lived experience) – both as elements to focus on conceptually (i.e. content wise) and as a lens to utilize as a theoretical framework throughout this study – was the way that I could fulfil my aim, therefore enabling me to dance as required.

Furthermore, current research in the field tends to focus on children and therefore research that focuses on the voices of adults on the ‘autism’ spectrum is less (Waltz, 2005; MacLeod et al., 2013; Autistica, 2019). Research that utilises a developmental lens of the inner lives of people on the ‘autism’ spectrum that proceeds beyond childhood and focuses on the family context is even less, as I have yet to find such a study. However, the possibility of going into interviews with adults on the ‘autism’ spectrum and asking them questions about their inner lives over their lifetime so far – including questions about their experiences in the family context – without any prior preparation frightened me psychologically, emotionally and professionally. I thought to myself “How can I learn about the inner lives of people on the ‘autism’ spectrum whilst being as reflexive as possible so as to create questions that are sensitive of the ways of being experienced and exhibited by them?” A way forward was highlighted by van Manen (1990; pp.1-2):

“A research method is only a way of investigating certain kinds of questions. The questions themselves and the way one understands the questions are the important starting points, not the method as such. But of course it is true as well that the way in which one articulates certain questions has something to do with the research method that one tends to identify with. So there exists a certain dialectic between question and method. Why then should one adopt one research approach over another? The choice should reflect more than mere whim, preference, taste, or fashion. Rather, the method one chooses ought to maintain a certain harmony with the deep interest that makes one an educator (a parent or teacher) in the first place.”

Therefore, the research aim and questions of this study are very much tied in with the research method that has emerged thanks to attempting to fulfil the research aim and questions herein. Furthermore, in an attempt to create as well as to maintain a certain harmony within myself as an Alevi and an educator, reading and analysing the autobiographical writings of people on the ‘autism’ spectrum has enabled me to hold up a mirror(s). I questioned my questions as I proceeded and was able to

dialogue and interact with the inner lives and meaning-making of people on the 'autism' spectrum in a gradual and non-overwhelming manner, finally creating draft protocols for interviews from the very lived experiences of people on the 'autism' spectrum. This also enabled me to gain an insight into the development of their inner lives and family context(s) over several years. I ought to highlight here that I use the terms 'inner life' and 'spirituality' interchangeably; this is because when focusing on the inner life of oneself or / and of the 'other' I often find that inevitably there evolves a spiritual dimension to the endeavour, and when focusing on spirituality there is often a turn inwards towards the inner life.

In summary, the research aim and questions, both in terms of the main research questions of this thesis as well as the ones I was seeking to create for interview purposes, became that much more important. My need to question my questions became the main thread and activity of this study, thereby creating research that demonstrates how a phenomenological attitude can be exercised by a researcher in a very reflexive manner to the extent of creating sensitive questions. Furthermore, I learned how a researcher can learn to open oneself up to the 'other's' experiences by bracketing one's own experiences, therefore, creating a gap in one's thinking style such that one is able to step into the shoes of the 'other' to a certain degree and understand her or / and him / them. The approach I have undertaken is explicitly outlined, discussed and illustrated throughout this thesis; 'autistic' people and their families may benefit from such findings in terms of the insights learned and researchers may benefit from it by being able to adapt such an approach for their own research aims when studying the 'other'.

Now I shall outline the research aim and the main research questions of this study so that the reader is aware of the focal point from which this study has emerged.

1.2.1. The research aim

The research aim was to explore how a researcher with spiritual beliefs can carry out research that is as ethical as possible with a family with a member on the 'autism' spectrum who also practice spiritual beliefs so as to enhance self-knowledge for herself and for the family.

1.2.2. The research questions

There are two research questions of this study:

- (i) How do I as a researcher with spiritual or / and religious values attempt to be as ethical and reflexive as possible?
 - How do I make meaning?
 - How can I enhance my understanding of self?

- (ii) How do people on the 'autism' spectrum make meaning of their everyday life experiences with respect to their spirituality and in the family context?
 - How can this be worked with to enhance understanding within the family setting?

This in turn has led to three underlying areas of interest for me: (i) what is self-knowledge and how does it develop?; (ii) what is meaning and how does it develop?; and (iii) what is perception and how does it develop? I am aware that these factors are very much researched and debated in various fields. However, I have focused with, in and through them specifically in relation to this study's aim and the very lived experiences of 'autistic' persons. This has enabled me to gain deeper insights into 'autistic' persons' ways of being and into my own ways of being as well. Other researchers may learn from this kind of act by undergoing a similar process(es) of asking themselves such questions in relation to their research aims. 'Autistic' people and their families may also learn new insights by taking up an interest in these kinds of areas.

I shall now move on to describe the process(es) and the structure of this study so as to illustrate how I then moved on to attempt to fulfil the research aim and answer the main research questions above.

1.3. THE PROCESS(ES) AND THE STRUCTURE OF THIS THESIS

This thesis consists of eight chapters (including this *Introduction* chapter) that are intertwined and have fed into each other in a concentric manner; the process(es) and structure of this study are outlined here as follows.

Chapter Two is *What is Alevism / Sufism?* In this chapter I have outlined how my personal spiritual and religious beliefs of Alevism influence my worldview and interpretations; I have included a narrative regarding an Alevi / Sufi by the name of Nasreddin Hoja who lived in Turkey in the 13th century. This is so as to be as reflexive as possible in setting out my standpoint and bias(es). It is also an attempt to enable the reader(s) to formulate a well-informed understanding of this study and to begin to see the value in such a worldview. Other researchers may be able to work with this kind of a chapter to question their own worldview – whether they agree or / and disagree; it might enable them to use it as a sounding board to help them create and develop their voice(s) with regards to their understanding of ‘self’ and their bias(es). ‘Autistic’ people and their family members may be able to do the same and they might become more aware of their own and each other’s worldviews in a more insightful manner.

Chapter Three is *What is Phenomenology?* Here I have outlined the concepts and techniques within phenomenology that have been useful for this study. I have highlighted the kind of worldview Edmund Husserl put forward and demonstrated this through the writings of Maurice Merleau-Ponty and Ludwig Wittgenstein. This is also so that the reader – who may be an ‘autistic’ person or / and an academic or otherwise – can begin to understand what the phenomenological worldview and approach is and what it entails. Again, other researchers may be able to reflect with this kind of a chapter to question their own worldview. It might help them to become more conscious of their understanding of ‘self’ and their bias(es). ‘Autistic’ people and their family members may be able to do the same. Hopefully, the reader will be able to recognise and appreciate the value and significance of phenomenology.

Chapter Four is *Bridging Alevism / Sufism and Phenomenology: My Phenomenological Attitude*. This chapter outlines and discusses the theoretical

framework of this study. Here I demonstrate how an Alevi / Sufi worldview of what is meant by 'reality' and 'self' seems to be very closely linked with a phenomenological worldview of 'phenomena' and 'the lived experience'. The underlying bridge between the two is what can be termed in the English language as 'a Sophianic worldview', with three main links with regards to the aim(s), approach(es) and the attempt of developing a perceptual standpoint that can be termed as 'a phenomenological attitude'. My reflexive embodied and non-embodied paradoxical, dynamic, mysterious self and lens is what I understand to be what and who I am as well as my definition of my phenomenological attitude. I am a reflexive being in that I self-reflect in such a way that enables me to think and behave in a sensitive manner, both with regards to myself as an individual and with regards to the 'other'; I am embodied, in that I have a body, and I am non-embodied, in that it is through my body that I am able to sense the world and to be in it; I am paradoxical, e.g. I have my likes and my dislikes, weaknesses and strengths etc.; I am dynamic in that I change and so do my views, e.g. I am not the same person I was a year ago and my views differ to how I thought then; I am mysterious in the sense that I do not know myself entirely and I do not think that I ever can; I am a 'self' in that I acknowledge that I experience a sense of 'I'; and it is through all these aspects of myself that I am able to be in the world and to view the world, i.e. my reflexive, paradoxical, dynamic and mysterious self is also my lens through which I see the world.

Firstly, it has emerged because of my ethical dilemmas and has simultaneously enabled me to acknowledge and work with my dilemmas as far as possible, e.g. as an Alevi and as a social science researcher I now feel less anxious about this academic endeavour. Secondly, it has enabled me to develop a conscious understanding of what I deem to be 'self' – both with regards to myself and 'others', placing me in a position where I am able to become more conscious of my biases and subjective ways of being, reporting these as openly as I can. Thirdly, I have come to accept this understanding of 'self' as the theoretical framework of this study, therefore making it a conceptual lens through which I have been able to fulfil the overall aim of this study insofar as has been possible. My exercising of this kind of lens throughout this study has become my definition of the phenomenological attitude, which has enabled me to question myself and to question my questions. Therefore, my reflexive embodied and non-embodied paradoxical, dynamic and

mysterious self and lens is the theoretical framework of this study and my phenomenological attitude in action throughout the study.

Hence, there are six ways in which I have come to exercise my phenomenological attitude throughout this study and thesis as a whole. Firstly, that it is my understanding of my 'self', in that I am a reflexive, paradoxical, dynamic and mysterious being who views the world as such, and hence my use of the term 'lens'. Secondly, that this worldview is what I am projecting on to and through my lived experiences, which includes this study. Thirdly, that it was / is a lens and approach to discuss literature in the field of 'autism' studies, methods of research and findings in the past. Fourth, it was / is a research methods process(es) to select and analyse 'autistic' persons' narratives and lived experiences so as to question myself and create more sensitive research questions that are reflective of 'autistic' persons' ways of being. Fifth, it is an ongoing exercise to try and develop one's insight(s) and thinking whilst attempting to maintain an open mind to various possibilities and ideas – being as reflexive and open about this as possible. Sixth of all, it is the thread throughout this study and thesis that has finally enabled me to write these chapters as they are. Although, it is worth bearing in mind that my understanding of myself and my phenomenological attitude is simultaneously a concept / an idea, therefore, this worldview and approach should not be viewed as the 'be-all' or the 'end-all' of my understanding. Rather, it is an ongoing 'opening up' to the possible ways of being and ideas that may be present in the lived experience(s).

Other researchers may be able to benefit from this chapter by becoming aware of one possible way in which a researcher can attempt to grapple with such dilemmas and finally bridge one's own personal spiritual / religious worldview with a methodology within the social sciences – and to do so in an explicit manner. 'Autistic' people and their families may be able to draw from this kind of process(es) so as to become aware of the kinds of inner conflicts that researchers / professionals can have when attempting to work with them, and they may be able to develop their own standpoints.

Chapter Five is *My Phenomenological Attitude and a Review of Literature in the Field of 'Autism' Studies*. In this chapter I illustrate how I have focused my gaze and worldview of a reflexive, embodied and non-embodied paradoxical, dynamic,

mysterious self and lens (i.e. my phenomenological attitude) upon some of the research in the field of 'autism' studies. I have highlighted the gaps that I have observed in past and current research, i.e. how the pioneers were reflective but not necessarily reflexive when taking up the term 'autism' and creating the criteria, how research has generally tended to focus on the behaviour of children only and has not utilised a developmental lens that focuses on the inner lives of people on the 'autism' spectrum, and the contexts of the research having generally been medical settings rather than the natural home settings of people on the 'autism' spectrum. This in turn has led to a rationale for the research aim, questions and method of this study as outlined in sections 1.1. and 1.2. above.

Other researchers might learn from this chapter by seeing how I exercised my phenomenological attitude in relation to the literature in the field, questioning the assumptions made and simultaneously laying down the foundations and rationale for this study. If they choose to, utilizing such a phenomenological attitude may enable them to reflexively focus on, in and through studies in their field(s) and become more consciously aware of the assumptions made. This in turn may lead to more reflexive and insightful ideas for future research. Families with an 'autistic' member may be able to learn more about the kinds of research that have led to the creation of the concept now termed as 'autism' and might become more insightful about how assumptions in research affect(s) them and their families.

Chapter Six is *The Methods Process(es) and the Phenomenological Attitude*. This chapter reflects how my taking up a theoretical standpoint of a reflexive, embodied and non-embodied paradoxical, dynamic, mysterious self and lens has led to a three-stage process(es) of analysing the autobiographical writings (i.e. data) of people on the 'autism' spectrum using Interpretative Phenomenological Analysis (IPA) (Smith, Flowers and Larkin, 2009). A rationale as to why IPA was used has been provided, e.g. IPA is very much influenced by the works of phenomenologists, has a focus on the lived experience and a focus on the body. During the first stage I analysed an 'autistic' author's autobiography, that of Christopher Goodchild (2009), to create the selection criteria. During the second stage I analysed three 'autistic' persons' autobiographies, focusing on their lived experiences and meaning-making at the individual level. These were Chris Mitchell (2009), Donna Williams (1998) and Edgar Schneider (1999). I then proceeded to select eight vignettes from different

'autistic' authors' autobiographical writings to carry out the third stage of analyses, focusing on their lived experiences and meaning-making at an interactional level within the family context over a lifespan. They were as follows: for the infancy phase I selected a vignette from Temple Grandin (1986) and one from Erika Hammerschmidt (2008); for the childhood phase I selected a vignette from Luke Jackson (2002) and one from Wendy Lawson (1998); for the teenagehood stage I selected a vignette from Chris Mitchell (2005) and another from Donna Williams (1992); and for the adulthood phase I selected a vignette from Edgar Schneider (1999) and one from Donna Williams (1992). Although, due to the word count restriction of this thesis, I have reported one vignette analysis per life phase.

Therefore, this chapter simultaneously illustrates how a researcher can exercise one's phenomenological attitude so as to (i) question one's own questions, (ii) to create research questions as findings that are sensitive to the lived experiences of 'autistic' persons or / and those who may be considered as the 'other', whilst (iii) utilizing a longitudinal developmental lens that focuses on the inner lives of such people from infancy to adulthood, homing into their experiences within the family context. Overall, this method of research and analysis is a blend of my worldview, the research questions in mind regarding the inner lives and voices of people on the 'autism' spectrum and IPA that has a narrative oriented focus.

Researchers in various fields who research the 'other' can adapt and use the step-by-step approach outlined in this chapter for their own aims. This might enable them to become more insightful and to create research questions that are more reflective of the ways of the 'other' – and therefore that are also sensitive. Of course, researchers in the field of 'autism' studies could also benefit in a similar manner by utilizing such a methods process(es). This is likely to create research that is more ethical in nature. 'Autistic' people and their families may benefit from this chapter in terms of future research that could emerge that involves questions and approaches that are more reflective of their ways of being, leading to more collaborative participatory research. They might also benefit in terms of becoming aware of the different possible kinds of research with narratives and may even be influenced to write their own life stories, which in itself can be a self-empowering act.

Chapter Seven is the *Findings and Discussion: Insights via the Phenomenological Attitude*. This chapter outlines and discusses the insights I have learned thanks to exercising my phenomenological attitude with the autobiographies of 'autistic' people and IPA. It also presents research questions as findings – these are questions that have been created thanks to my analysing such texts. It would seem that 'autistic' persons' embodied and non-embodied self plays a significant role in their lived experiences and that the theory of the 'double empathy problem' (Milton, 2012, 2014a) may well be a useful way to approach matters regarding family contexts. This chapter might enable families with an 'autistic' member to become more insightful of the 'autistic' member's way of being and, hopefully, the insights herein might lead to more harmonious moments or / and relationships. Researchers in the field of 'autism' studies may learn more about 'autistic' people's inner lives and meaning-making, especially in the family context, and this might lead to ideas for future participatory research.

Researchers in other fields, as well as those in the field of 'autism' studies, may benefit from these insights by becoming aware of the kinds of knowledge that can emerge when one takes up a phenomenological attitude and exercises it throughout a study. In that, right from the outset one questions one's self and one's questions; recognizing the significance of this might give them the motivation to take up a phenomenological attitude. Furthermore, they will have at least one methods process(es), as outlined in Chapter Six *The Methods Process(es) and the Phenomenological Attitude*, from which they can draw upon so as to fulfil such a task.

Chapter Eight is *'Conclusion', the Phenomenological Attitude and Future Research*. In this chapter I have addressed the research aim and have answered the research questions as far as I can. I have highlighted that this new knowledge contributes to the field of 'autism' studies in developing one's insight(s) and creating research questions that are sensitive to the lived experiences of 'autistic' people, which is hopefully more ethical. I have discussed the methods process(es) further, working with 'autistic' persons' narratives and IPA, and the findings. I have also made recommendations for future research and provided examples of two possible vignette interview protocols for possible research with adults on the 'autism' spectrum and their families.

Researchers in the field of 'autism' studies could learn and benefit from this chapter by seeing how (i) insights can prepare them to create participatory research designs that are ethical and how (ii) future interview protocols can be created thanks to exercising a phenomenological attitude whilst using IPA and autobiographies. 'Autistic' people and their families might benefit from this chapter by being able to read and dialogue with the vignettes of the interview protocols and have meaningful discussions about it amongst themselves or / and with the researcher, therefore, leading to deeper insights and knowledge about each other's ways of being.

Chapter Eight is then followed by the *References* and the final section of the thesis is that of the *Appendices*.

1.4. CONCLUSION

I have introduced the thesis and have set out its structure. In an attempt to begin to address my ethical dilemmas and exercise reflexivity I will now proceed to outline my worldview and bias(es) in Chapter Two *What is Alevism / Sufism?*

2. WHAT IS ALEVISM / SUFISM?

2.1. INTRODUCTION

I was born into an Alevi Turkish family and was brought up with an identity that is very much created and shaped by an Alevi worldview and ways of being. Alevis believe in the teachings of Prophet Muhammed (Peace Be Upon Him, PBUH) and his family around the centuries of 500 A.D. and 600 A.D. in the region of the Middle East. Alevis specifically follow the teachings of the Prophet's cousin and son-in-law the Honourable Ali and the rest of the descendants of Mother Fatima and Father Ali's lineage, referred to as 'the Twelve Imams' (the Twelve Teachers of the path), particularly drawing from the teachings of the sixth imam HH. Cafer-i Sadık. The aim of this chapter is to outline my personal spiritual and religious beliefs of Alevism and its aim(s) as these are elements that affect and shape my worldview and interpretations of life. This is so as to be reflexive and explicit about the biases I am bringing to this research and to enable the reader to begin to develop a well-informed understanding of this study. Note, when I use the term 'bias(es)' I use it with regards to my historical and geographical identity(ies) that has affected this study and I also use it in the existential sense, i.e. 'Who am I? What am I? What am I projecting on to the 'other'?'

I use the terms 'Alevism' and 'Sufism' interchangeably throughout this study because it is known that due to his very direct relationship with God, Prophet Muhammed (PBUH) himself was a Sufi and so were his family. The term 'Sufi' comes from the Arabic word 'safa', meaning 'pure', and it is said that God promised Prophet Muhammed a pure lineage that is equivalent to the pure and abundant river known as 'Kevser' in heaven through his daughter Fatima and son-in-law Ali (Quran, approx. 600 A.D.; Surah Kevser). It is also suggested that the term 'Sufi' is connected to the term 'Sophia' (Galian, 2003). In this chapter I shall draw from teachings in Alevism to illustrate my worldview by providing a brief history of what Alevism / Sufism is and then I will delve into a particular story in detail about an Alevi / Sufi that emphasises the importance of self-reflective behaviour; this is so as to illustrate my need to examine myself so as to know myself. For a practicing Alevi, a self-reflective style of being, thinking and way of behaving or not behaving – which

includes one's use (or not) of language – is exercised in every activity that one undergoes in one's life, leading to a meditative way of navigating in the world. This kind of conduct is an aspect of 'edep' (Turkish) or 'adab' (Arabic) and could be seen as what is referred to as 'reflexivity' within the social sciences. In Alevism one's reflections are brought forth into one's heart and inform one's learning and conduct; Alevis / Sufis have created and used various forms of science and art, be it alchemical experiments, stories, poetry, music, dance, symbols etc., to focus on the nuances and phenomena of life as well as to express them (Sadık, approx. 700 A.D.; Shems&Rumi, 1263 / 2011; Shah, 1990). I shall address this more in-depth for the purposes of this study in Chapter Four *Bridging Alevism / Sufism and Phenomenology: My Phenomenological Attitude*. Although now I shall proceed to provide a brief history of what Alevism / Sufism is.

2.2. WHAT ALEVISM / SUFISM IS AND A BRIEF HISTORY

Alevism / Sufism is traced back to the beginnings of humankind, whereby one seeks a direct relationship with Allah, whom is also referred to as 'Aşk' (Love), 'Sevgili' or 'Yar' (Beloved), 'Dost' (Friend) and other similar names (Fuzuli, 1556 / 1965; Shah, 1978 / 1985; Smith, 2009). This is why practicing Alevis / Sufis are often referred to as 'Aşık' (a Lover), implying one who is in love with Allah – lovers of the One. Simply put, there is a focus on loving one's essence that is Allah and surrendering oneself so as to be loved by Allah; it is through this self-reflective relationship that one comes to know oneself. Therefore, self-reflection and self-examination is crucial and is practiced as often as possible via 'edep' / 'adab'. It is conduct that is in remembrance of Allah and has an ethics oriented dimension to it.

Sufism or Alevism is the mystical dimension of Islam, whereby after undergoing the process of self-annihilation the practitioner or mystic is in union with God with all their being and everything one does, or does not do, is informed by this relationship. My interpretation of Alevism is that as much as it is at the heart of Islam, simultaneously, it is beyond Islam. As Shah (1990) states, Sufism is neither western nor eastern, it is human, a science of developing one's perception. Alevis / Sufis believe that all beings and religions carry the essence of God, and as someone who is also a Turkish Brit having grown up in a multicultural city since infancy, i.e. London, I very

much relate with this inclusive worldview as it is a reflection of my own individual identity.

Amongst Alevis it is said that the term 'Alevi' means 'those of Ali's home', as in those who follow the teachings of the Honourable Ali. The core tenet of Alevism is that Allah / God / Mataji / Babaji / Waheguru – whichever name one may prefer to use to refer to the energy of life and death – resides in our hearts. Allah is also viewed as being the entire universe itself (Shems&Rumi, 1263 / 2011); this is a similar cosmological understanding to that of the Hermetic and Gnostic traditions that state 'as above, so below, as within, so without, as the universe, so the soul' (Three Initiates, 1908 / 2014). The Alevi / Sufi seeks to have a very direct relationship with God to the extent that one merges and becomes one with God (Sadık, approx. 700 A.D. / 2013; Shems&Rumi, 1263 / 2011). One undergoes a process of self-annihilation, 'fana' in Arabic, or what Carl Gustav Jung (1961 / 1995) terms as the process of 'individuation'; the alchemical process(es) of the psyche whereby one integrates one's shadow self via the means of becoming consciously aware of that which one was not consciously aware of to begin with. This gradually leads to what various traditions refer to as 'enlightenment', 'nirvana', 'Christ consciousness' etc. In Alevi philosophy a person who is enlightened is referred to as 'insan-i kamil' (Sadık, approx. 700 A.D. / 2013), 'a person of wisdom'.

Alevis / Sufis believe that the most recent teachings from Aşk / Allah and of self-love have been bequeathed by Prophet Muhammad (PBUH), who lived in the seventh century (A.D.) and whose family are referred to as the 'Ehl-i Beyt' or 'Ahl-ul Bayt' in the Quran. Consisting of Prophet Muhammed, his daughter HH. (Her Honourable) Fatima, the Prophet's cousin and son-in-law (Fatima's husband) HH. (His Honourable) Ali, and their children HH. Hasan and HH. Hüseyin. Amongst Alevis the family and descendants who were teachers in what is now more so known as Islam, but was then known as 'Muhammedilik' – pertaining to those who follow the teachings of Muhammed (PBUH), there are Twelve Imams (Twelve Teachers of the path). People who heed their teachings and practice them are referred to by many names, be it 'Muhammedis', 'Alevis', 'Bektashis', 'Caferis', 'Alawites', 'Shias', 'Muslims', 'Kızılbaş', 'Nusayris', 'Hazaras' and various other names. The names and rituals differ from region to region yet the main principle of heeding the teachings of the Ehli-Beyt is at the core of them all. There have been conflicts in relation to

whether Prophet Muhammed had bequeathed his role as a teacher to HH. Ali or another person by the name of Abu Bekir, though Alevis believe that Ali is the one he had asked to continue the teachings. Furthermore, the Prophet's family lineage is of HH. Ishmael, the brother of HH. Isaac and one of the sons of HH. Abraham, who was a descendant of Adam and Eve (Fuzuli, 1556 / 1965). I accept that Adam and Eve lived, I do not accept that they were the only human beings that were ever created and I have a more metaphorical interpretation of their story. Though all in all, Alevism / Sufism is traced back to the early times of human existence and accepts the teachings of all the Prophets / Teachers before, during and after the times of HH. Jesus Christ (Fuzuli, 1556 / 1965; Quran, approx. 600 A.D.; Surah Nisa).

Alevis believe that the Quran can be read in the literal sense as well as in the esoteric sense, though there is more of a focus on the esoteric meanings, and that in order to know oneself one should seek a deeply intimate relationship with Allah. When a person is in union with Allah they are referred to as 'Dilli Kuran', literally meaning 'The Quran with a tongue', and implying that the person is the living embodiment of Allah's wishes and the teachings. One offers the burning of, or the annihilation of, one's ego to become one with God. An example of this kind of love affair with the Beloved is that of the Sufi mystic Hallaj-ı Mansur (approx. 900 A.D.), who was so enraptured by the love of Allah that he stated "anâ'al-haqq" (in Schimmel, 1962, p.161), 'I am one with God', and yet was condemned by the people of his time for blasphemy and killed for it. It is recognised that Mother Rabia of Basra, who lived approximately during 717 A.D. to 793 A.D., is the first Sufi to have verbally expressed this kind of enraptured love with Allah and her poems and sayings are a testament to it. She was a slave in Basra, today's Iraq, and was set free by her master once he saw that she was a being of divine love. Unlike most of the women in her geographic location and culture at the time she chose to live a celibate life due to her love for God, and the following poem is attributed to her love for Allah (Smith, 1928 / 2010, p.99):

"I have loved Thee with two loves, a selfish love and a love that is worthy (of Thee),
As for the love which is selfish, I occupy myself therein with remembrance of Thee to the exclusion of all others,
As for that which is worthy of Thee, therein Thou raisest the veil that I may see Thee.
But the praise is to Thee, whether in that or this."

She is referring to her own love for Allah, “the love which is selfish”, and Allah’s love for her, “Thou raisest the veil that I may see Thee”, and recognizes the oneness of Love – “praise is to Thee, whether in that or this”. Her perceptual style is that of a being who is consciously aware of the ‘two-sidedness’ of love, which is actually one whole. This is because the mystic’s aim is to become one with the One, which is known as the state of ‘Hakikat’ (Truth). Before passing away from the physical realm (‘dying’) Mevlana Celalleddin Rumi refers to the final state of ‘Hakikat’ as his wedding night with his Beloved - "şeb-i arûs / gerdek gecesi" (Rumi Mevlevi, 2013; online). Therefore, the day of his passing away, 17th of December 1273, is referred to as “Mevlana’nin düğün gecesi”, “Mevlana’s wedding night”, and is celebrated each year in Konya, Turkey.

To reach the state of being ‘a person of wisdom’ (insan-i kamil) and ‘Hakikat’ (Truth) one usually proceeds through four stages; what Ahmet Yesevi (approximately 1094 – 1166) and Haj-ı Bektaş Veli (1200s / 2001) refer to as ‘Dört kapı kırk makam’ in the latter’s book ‘Vilayetname’, the ways or paths of the ‘Four doors and forty states’. Each door opens to ten states of being in the world, hence the term ‘Four doors and forty states’. I shall not delve into the forty states, however, the four doors are ‘Şeriat’ (to learn and become knowledgeable about the way/s or path/s), Tarikat (to put into practice what one is learning), Marifet (to constantly be in remembrance of Allah and manifest God’s wishes), and Hakikat (to constantly live in conscious union with Allah). The ‘four doors’ and the ‘forty states’ are ways of being that are actually inter-linked and the process(es) manifests in a unique way for each individual. Whilst seeking self-knowledge in a reflexive manner via the constant remembrance of Allah the seeker develops a perceptual state of being that enables one to proceed in both the visible and non-visible realm(s) that is unique to their soul and relationship with God.

Alevism / Sufism varies in its form from region to region, so one may see different practices in different regions of the world, e.g. some may worship by sitting in silence and being in remembrance of Allah whilst others may sing in remembrance of Allah. While there is a strong emphasis on knowing oneself via self-reflection, self-discipline and exercising such beliefs and practices in everyday life there is also an emphasis on fluidity and living in tune with the waves of current times, for one’s heart

is accepted as being one's true guide (Shems&Rumi, 1263 / 2011; Shah, 1990). In the Mesnevi / Mathnawi, a much valued book in Islam that is comprised of six books, Shems&Rumi (1263 / 2011; p.32) state that:

[Turkish] "Gönül nurunun nuru da akıl ve duygu nurundan olmayan, onlardan ayrı bulunan Allah nurudur."

Translation: "The light within the heart, it is not a light of the mind or emotion(s), it is found separately from them and is the light of God."

This suggests that the mind, thoughts and emotions are senses – means through which one can come to know oneself. Although it is also suggested that as much as one's mind, emotions and senses are a part of Allah, the light of God is beyond such senses. Hence, one's body is recognized and accepted as a source of – and for – knowledge, as Allah's abode is within one's heart. All this emphasizes the importance of researching, learning and behaving in line with Love and living according to knowledge that is loving of oneself and the 'other'. As a human being, a researcher and a practitioner I feel a deep affinity with such values, for as Shems&Rumi state (1263 / 2011, p.96), "mâna Allah'dır", "meaning is God".

As much as Alevi / Sufi scholarship is within the religious organizations of Islam, simultaneously, due to its recognition of the fluid nature of our being, it is also outside of it. Haque (2004; p.358) states that:

"If we examine the historical background under which Muslim scholarship developed, we will find that it arose under the umbrella of philosophy, which encompassed almost all areas of human enquiry. Philosophy, in most simplistic terms, refers to knowledge of all things, both divine and human."

Therefore highlighting the possible rich knowledge that can be derived from the philosophy(ies) of such past teachers, scholars, saints etc., and its possible use with regards to the aim of this research, knowing myself better and in focusing on the inner lives of people, i.e. in this case those on the 'autism' spectrum. It may also give other academics in the social sciences ('autistic' or not), who may not be as acquainted with such aspects of Islam, an opportunity to begin to explore valuable knowledge that exists within what could be considered as 'Islamic' or 'Eastern' philosophy(ies) – especially those working in multicultural settings.

Now that I have given a brief history of Alevism / Sufism, I shall proceed to give an example of an Alevi / Sufi narrative that may help the reader to gain a better understanding of how one can live according to the love and wisdom within one's heart. This will also begin to help to demonstrate the value and significance of exercising such a way of being.

2.3. NASREDDIN HOJA'S CLOTHES AND SELF-REFLECTION

As a child when being told stories about an Alevi Sufi teacher by the name of Nasreddin Hoja (Teacher), whom many deem to be a 'wise fool' and who lived in Turkey during the 13th century, I used to laugh at his 'quirky' behaviour. Yet I simultaneously felt a deep respect for the message from him as well as about him. The following is an example of a humorous yet poignant story of his regarding how a lack of self-reflection can lead to people thinking and behaving in conditioned ways that lead to unjust behaviour against the 'other' and also oneself (in Baynham, 1986; p.117):

“One day Mullah [Teacher] Nasreddin was invited to a party. He went to the party without changing out of his ordinary clothes. When he arrived at the party, the doorman stopped him from going in. ‘You can’t come in here wearing ragged clothes like that,’ he said. So Mullah Nasreddin rushed back home and changed his clothes. He put on the smartest clothes he had. Then he hurried back to the party. Everyone bowed at him when he arrived and offered him a nice place to sit down. It was time for dinner. They served the best food. But Mullah, instead of eating the food, started putting the food in his sleeves. Everyone was astonished. What was he doing? They thought he was mad. Then somebody asked him: ‘Why are you putting food in your sleeves?’ And Mullah said: ‘My clothes have been invited to the party, not me. So I’m feeding them’.”

There is another version of this narrative whereby Nasreddin Hoja goes home, puts on a regal coat, returns and enters the party, and when served a bowl of soup he places a sleeve of the coat into the soup and says “Eat it my coat, eat it, it has been served for you”. Nasreddin Hoja's story can be interpreted in several ways and different lessons can be learned from it; the following is my interpretation of it and the lesson I learned from it and continue to re-learn.

The narrative illustrates how people can, and usually do, pick up and practice cultural patterns of behaviour that are in line with the status quo rather than through self-reflection or / and one's own inner voice. This can lead to becoming attached to worldly ways of being that are unbalanced and more so oriented towards a purely materialistic treatment of the 'other' and oneself, forgetting the non-visible and non-measurable aspects of the 'other's' humanness and that of oneself. People often attempt to live according to certain expectations which may not necessarily be a reflection of the kind of person they actually are or / and deny the reality of a given situation they are in.

Nasreddin Hoja's behaviour is one that actually lives up to the expected norm, i.e. he changes his outfit and displays himself to be as someone he is not, and simultaneously he challenges the expected norm by holding up a mirror to such a state of being, i.e. his seemingly inappropriate behaviour in serving the food to his clothes. He does not verbally rebuke the people, does not say anything to them that is condemning, and nor does he try and force them to behave in a specific way. Although this is not to say that there is not a time or place to rebuke others so as to help them on their way, for the Sufi is of service to Allah and all beings in contextually and culturally specific ways, therefore, she / he behaves as the moment requires. Nasreddin Hoja places his own sense of pride aside by acting in a way that the people at the party deem as being madness and holds up a mirror that puts them in a position to reflect about their own way(s) of being. It is then down to the individual(s) to search within and fathom what may be amiss, even if it is but for a moment, creating a gap in their thinking and helping to create the possibility of another way of seeing and being in the world.

Nasreddin Hoja's actions could also be viewed as bringing to light what Edmund Husserl (1900 / 2001, 1901 / 2001), the founder of phenomenology, refers to as the 'natural attitude'. In that, people usually live their everyday lives in a taken-for-granted manner that does not question or examine the moments and phenomena of their lives, and social norms are a reflection of this. I am not stating that social norms are bad and I do not think that Nasreddin Hoja was implying this either. However, when such norms are put into practice with the intention to exclude or / and belittle another being – and are also used to justify one's own unjust behaviour – then an inner conflict is created within the human being. For what one does to the so-called

'other' is a reflection of what one does to oneself (Shems&Rumi, 1263 / 2011; Jung, 1961 / 1995). In that, Nasreddin's exclusion from the party on the basis of his clothing is a reflection of how the people at the party struggle to self-reflect and genuinely appreciate and love an aspect of themselves that is both within and beyond their own worldly attire. Furthermore, by putting up a mirror for the people at the party Nasreddin Hoja recognises that which exists within himself, i.e. individuals who lack self-reflection. Hence, he acts as what Jung (2009) may refer to as the 'transformative factor' or 'the third factor'; the conscious witness whose mere presence can help individuals to become more conscious of themselves and their behaviour.

Nasreddin Hoja lived during the 13th century in Turkey, however, what this then lived experience – and now a timeless narrative and lesson(s) – brings to light is one of many norms and practices within current societies. Whereby people exercise a rejection of the 'other' on the basis of what they are supposed to be like rather than who or what the 'other' actually is like. Individuals can, and usually do, behave in line with societal norms and expectations to the degree that they become inauthentic with themselves and therefore also each other. This in turn leads to masses of individuals living in an illusion(s) – and scientists are not exempt from this (Shah, 1990). A lack of self-reflection and self-examination leads to inauthentic ways of being and creates a sense of anxiety and conflict within individuals and between people, leading to people feeling that something is missing yet not knowing exactly what. For some individuals the inner conflict can manifest into the 'outer' world and can gradually even lead to wars between nations (Jung, 2002; Meade, 2010). Nasreddin Hoja knew this very well and therefore behaved the way he did so as to try and bring people back to the well of self-reflection and to look within.

In more recent times academics, practitioners, mystics and healers such as Carl Gustav Jung, James Hillman, Clarissa Pinkola Estés, Michael Meade, Caroline Myss, Llewellyn Vaughan-Lee and others make very similar, if not the same, point(s) about 'modern' individuals and 'modern' societies. Highlighting that self-reflection and self-reflective behaviour that is in tune with one's heart's calling needs to be carried out by individuals – including behaviour that may not involve taking action per se. This is so as to remediate the anxiety and conflict-ridden polluted conditions

which humans find themselves / ourselves in psychologically, physically, spiritually and environmentally.

Thanks to my family, Nasreddin Hoja and many other lovers of the divine, I learned from a very young age that if one seeks to help to create a more harmonious and understanding world then the work of getting to know oneself through self-reflection and self-examination must begin at the individual level (Quran, approx. 600 A.D.; Holy Bible, New Testament, approx. 100 A.D.; Bhagavad Gita, approx. 200 – 500 B.C.E.; Sri Guru Granth Sahib Ji, approx. 1700s; Tao Tê Ching, approx. 2000 years ago). As a human being, an Alevi and a social scientist, my life purpose is to know myself; this study is one way in which I have attempted to achieve this and I continue to do so. As this thesis proceeds, the implications of my Alevi worldview and standpoint will be further brought to light, discussed and put into practice(s). In addition, other researchers may be able to reflect with this chapter to question their own worldview and it might enable them to use it as a sounding board, helping them to create and develop their voice(s) with regards to their understanding of 'self' and their bias(es). 'Autistic' people and their family members may be able to carry out a similar activity and this might enable them to become more aware of their own worldview, as well as each other's worldviews, in a deeper manner.

Now that I have given a brief history of what Alevism / Sufism is and have also provided an example of how an Alevi / Sufi can, and may, teach and learn a lesson(s) of Love I shall conclude this chapter.

2.4. CONCLUSION

In summary, the aim of Alevism / Sufism is to turn 'inwards' and live a direct relationship with Allah, such that one is able to live in love and peace with oneself and navigate in both the visible and non-visible realm(s) in a loving and ethical manner. This can be achieved via self-reflection and self-examination (e.g. via meditation, reading narratives about mystics from the past, writing, painting, dancing etc.); remembering Allah in every moment and exercising 'edep'; undergoing the process(es) of self-annihilation via the 'Four doors and forty states' which is unique to each person in the way that it manifests; and finally leading to oneness with the One. Other researchers who also have a similar life purpose to know oneself – and

especially those who have spiritual / religious values – may be able to benefit from this chapter and thesis by learning how one can be reflexive as an academic. It may also help ‘autistic’ people and their families both directly and indirectly in terms of the insights learned throughout this thesis and the contributions made to the field of ‘autism’ studies.

I will now move on to Chapter Three and will focus on what phenomenology is as it is the closest worldview within western social sciences to my Alevi worldview. Although I will return to Alevism / Sufism for Chapter Four so as to demonstrate the bridge(s) between the two and proceed to illustrate how this has created and shaped this study and thesis.

3. WHAT IS PHENOMENOLOGY?

3.1. INTRODUCTION

The term 'phenomenology' means 'the study of phenomena', or in other words, the study of the lived experience(s). According to Merleau-Ponty (1945 / 2013; p.xx) phenomenology is:

“the study of essences, and it holds that all problems amount to defining essences, such as the essence of perception or the essence of consciousness. And yet phenomenology is also a philosophy that places essences back within existence and thinks that the only way to understand man and the world is by beginning from their “facticity”. Although it is a transcendental philosophy that suspends the affirmations of the natural attitude in order to understand them, it is also a philosophy for which the world is always “already there” prior to reflection – like an inalienable presence – and whose entire effort is to rediscover this naïve contact with the world in order to finally raise it to a philosophical status.”

He points to the paradoxical nature of participating in the endeavour of attempting to understand; in that as much as we may attempt to focus on a phenomenon / phenoma and what constitutes the “essence” or “essences” of this occurrence by trying to put aside our own lens(es) of how we see the world, simultaneously, our very perception and consciousness of a phenomena also constitutes the phenomena itself / themselves. Thereby leaving a researcher in a position whereby one is continuously attempting to reflect and to gain insights into the everyday phenomena that we take as a given, i.e. one's natural attitude, whilst also continuously rediscovering this “naïve contact with the world” – partaking in an ongoing circular motion(s) of acknowledging one's understanding(s) and non-understanding(s). My hope is that this study and thesis reflects this ongoing circular motion(s) insofar as is possible via the means of the use of written language in the form of English.

Connelly (2010, p.127) highlights that phenomenology is a philosophy as well as a research method that:

“focuses on consciousness and the content of conscious experience, such as judgments, perceptions, and emotions (Balls, 2009). Phenomenology also focuses on humans as embodied beings, meaning they experience life through their physical bodies.

Phenomenologists want to know what the experience was like to live it, not just the person's reaction to the experience (Munhall, 2007)."

She adds that phenomenology is utilized in education, psychology and in health care so as to develop detailed insights of people's lived experiences and how they make meaning. This is in order to create meaningful and effective approaches of education or / and health care programmes. Therefore, phenomenology as a philosophy and a research approach is very suitable for me as a researcher who is focusing on, with, in and through 'autistic' persons' lived experiences, which will be further outlined and discussed in Chapter Four *Bridging Alevism / Sufism and Phenomenology: My Phenomenological Attitude* and Chapter Six *The Methods Process(es) and the Phenomenological Attitude*.

This chapter will outline and discuss certain phenomenological concepts and techniques that have been useful for this study. I will also provide examples from two phenomenologists so as to give the reader insights into how I have worked with the way phenomenologists can, and do, perceive and interpret the world. This is so that I am being as explicit as possible, inviting the reader to understand the significance and value in exercising such a worldview. It will also help to begin to illustrate why and how I have carried out this study. In addition, like Chapter Two, this chapter might help other researchers, within and outside of the field of 'autism' studies, to become more conscious of their bias(es) and understanding(s) of 'self'; making them more insightful about the influences of why and how they carry out the kinds of research that they carry out. 'Autistic' people and their family members who read this kind of work may be able to do the same in terms of reflecting about their own worldview, and may also learn about the kinds of influences that affect research and researchers who may seek to work with them.

3.2. PHENOMENOLOGY: USEFUL CONCEPTS AND TECHNIQUES

There were and are many phenomenological thinkers, ranging from Franz Brentano (1838 – 1917) to Martin Heidegger (1889 –1976) to Gerda Walter (1897 – 1977). However, by publishing his work *Logical Investigations* (1900 – 1901) Edmund Husserl came to be recognised as the founder of phenomenology (Glendinning, 2004; Finlay, 2008). He was very much influenced by the works of

Franz Brentano – who in turn was influenced by Aristotle and William James (Edie, 1970; Spiegelberg, 1981). Husserl begins *Logical Investigations (Volume I)* with the following (1900 / 2001; p.11):

“There is accordingly as much difference of opinion in regard to the definition of logic as there is in the treatment of the science itself. This was only to be expected in the case of a subject, in regard to which most writers have only employed the same words to express different thoughts’ (John Stuart Mill, *Logic*, Introduction, §1). Many decades have passed since John Stuart Mill introduced his valuable work on logic with these sentences, and important thinkers here and beyond the Channel have devoted their best powers to logic and have enriched its literature with ever new presentations. But even today these sentences could serve as a suitable expression of the state of logical science, even today we are very far from complete agreement as to the definition of logic and the content of its essential doctrines.”

It seems that Husserl was very much aware of the different ideas regarding ‘logic’, considered as a significant factor in creating and shaping thinking within academia, and so he recognised John Stuart Mill’s quote as being of importance. He agreed with Mill in that there is no unifying definition of ‘logic’ and what actually constitutes ‘logic’. Mill was also highlighting an issue regarding the use of language and thought; “writers have only employed the same words to express different thoughts”. Hence, for Husserl there seemed to be two issues. Firstly, that in the field of philosophy there seems to be no agreement upon what ‘logic’ is, implying that no-one really knows what it is. Therefore, one could ask the question does ‘logic’ even exist? Secondly, that the connection between language and thought has not been considered regarding how ‘logic’ is viewed and conceptualised and this has affected how ‘logic’ is understood or / and not understood. It is this kind of reflective attitude and insight that led Husserl to put forward a case on focusing on the phenomenon / phenomena itself.

According to Bermudez, Crane and Sullivan (2001; p.xxii):

“Phenomenology, in line with a general turn away from idealism then current, was to be a science of ‘concrete’ issues. According to Husserl’s Introduction, phenomenology aimed to avoid speculative constructions in philosophy (exemplified, in his view, by Hegel). The *Investigations* impressed its early readers as exemplifying a radically new way of doing philosophy, focusing directly on analysis of the things themselves - the matters at issue (*die Sachen selbst*) - without the usual detour through the history of philosophy, ‘merely criticising traditional

philosophemes' as Husserl put it (LI VI, Intro., Findlay II: 187; Hua XIX/2: 543), or making partisan declarations in favour of some philosophical system (such as empiricism, positivism, rationalism, Hegelianism or Neo-Kantianism)."

It would seem that what Husserl was putting forward is a way of seeing the world and navigating in the world, a certain kind of being in the world, rather than just a philosophy that focuses on ideas, thoughts and which camp one identifies with. Hence his recommendation that one attempts to continuously reflect by 'returning to the things themselves' and to become aware of one's own 'natural attitude' (the taken-for-granted moments and values of everyday life) so as to know oneself and the world deeper (Husserl, 1900 / 2001, 1901 / 2001). Glendinning (2004, p.40) states that:

"When Husserl wrote this [*Logical Investigations*] in 1900 the shift back was essentially a shift against the then dominant school of philosophy in Germany, whose slogan was 'Back to Kant'. What Husserl had in mind with his alternative rallying-call was not a kind of thinking which would concern itself with (obviously very Kantian) things-of-which-we-have-no-experience but, precisely to 'intuitions' of phenomena that can in some way be imaginatively or directly presented to us."

Therefore, by my interpretation, phenomenology was / is a way of being in the world, a philosophy and also a social movement within western academia. In addition, rather than viewing 'subject' and 'object' as being separate there was / is a recognition of the thread between the two.

The phenomenologist seeks to reflect through, in, on and with one's own nature of being in the world, including one's body, whilst simultaneously attempting to make meaning of, with, in and through the world (Merleau-Ponty and Bannan, 1956; Finlay, 2011). Through this ongoing act(s) of self-reflection and seeking self-knowledge the phenomenologist recognises oneself as being part of the world and the world as being a part of oneself; this is termed as 'intersubjectivity'. This is a key element that logical positivist thinkers may not consciously acknowledge. Therefore, they may exercise a standpoint of carrying out thinking and research that may be more imposing of theories or ideas rather than being open to various interpretations that could all be plausible simultaneously. This in turn may lead some positivist

thinkers to believe that the ideas or concepts are the actual things themselves, which are not (Husserl, 1900 / 2001, 1901 / 2001, 1913 / 2012). This is part of the reason why Husserl (1901 / 2001) emphasised 'returning to the things themselves'.

Merleau-Ponty and Bannan (1956, pp.69-70) state that:

“Phenomenology as a revelation of the world rests on itself and is its own basis.⁽¹⁷⁾ All knowledge is rooted in a ground of postulates and finally our own communication with the world, which communication is the primary domain of rationality. Philosophy as a radical reflection is in principle deprived of that resource. Since it too is in history it also makes use of the world and reasons already formulated. It must then interrogate itself as it does every type of knowledge. It will double back upon itself indefinitely, then, and will be, as Husserl said, an infinite dialogue or meditation. To the extent that it remains faithful to its own intention, it will never know where it is going. The incompleteness of phenomenology and the allure of its inchoative state are not signs of failure. They are inevitable because phenomenology has for its task the revelation of the mystery of the world and the mystery of reason.⁽¹⁸⁾

It is not accidental that phenomenology was a movement before being a doctrine or a system.”

The authors emphasise the importance of the circular process(es) of reflexivity – the ability to reflect and conduct one’s thinking and behaviour in line with the insights learned. In that the philosopher ought to interrogate oneself, philosophical theory(ies), knowledge itself, the “postulates” or assumptions that underlie knowledge and one’s own thinking, and communication or / and language. Exercising such a way of being leads to a certain style of perception and a standpoint of “infinite dialogue or meditation”, or what Merleau-Ponty and Bannan (1956) later refer to as a need for exercising attention and wonder. According to Finlay (2008) this very meditative state of being is the kind of worldview that Husserl put forward and could be termed as ‘the phenomenological attitude’.

During Edmund Husserl’s time phenomenology as a philosophy was varied and still is, whereby there are many schools of thought, ranging from Transcendental Constitutive Phenomenology Studies to Naturalistic Constitutive Phenomenology Studies to Existential Phenomenology Studies (Stanford Encyclopedia of Philosophy, 2003). I am not a well tenured reader in academic philosophy, which includes phenomenology. However, due to the aims and the nature of this study, I have drawn from the writings of phenomenologists such as Edmund Husserl, Martin

Heidegger, Maurice Merleau-Ponty, Emmanuel Lévinas, Ludwig Wittgenstein, Linda Finlay, Max van Manen and many others who may not necessarily be officially recognised as phenomenologists, e.g. some of the ‘autistic’ persons and academics referred to in this study. This will be demonstrated during this chapter as well as in the upcoming chapters of this thesis.

Having outlined the concepts and techniques of the natural attitude and ‘returning to the things themselves’ via reflexivity (i.e. the phenomenological attitude), I shall proceed to give the reader an insight(s) into how some phenomenologists self-reflect and think and the value in this kind of way of seeing and being in the world.

3.2.1. Illustrations of the phenomenologist’s endeavour: the dialectic thread between self-reflection and ‘returning to the things themselves’ (Husserl, 1901 / 2001)

Here I shall demonstrate the dialectic connection between how self-reflection is a way in which a phenomenologist can ‘return to the things themselves’ and ‘returning to the things themselves’ can be a way of self-reflection. Initially, I shall draw from Maurice Merleau-Ponty’s writings regarding intersubjectivity so as to demonstrate how a phenomenologist can self-reflect in a way that leads to one consciously acknowledging one’s connectedness with all beings, recognising that one is a part of what one studies and vice versa. I shall then draw from Ludwig Wittgenstein’s reflective writings regarding the sense of pain so as to demonstrate how a phenomenologist can consciously acknowledge that the concept or idea of ‘pain’ is not the actual pain itself, hence reflecting and thinking in a way that acknowledges the phenomenon / phenomena of pain in a way that ‘turns to the things themselves’. The reader will hopefully experience how one is ‘pulled in’ to understand the phenomena thanks to the phenomenologist’s insight(s) whilst also being consciously reminded that one cannot entirely understand via the means of thought.

An example of a recognition of one’s intersubjective nature and being self-reflective is provided by Maurice Merleau-Ponty; he states that (1964 / 1968, p.114):

“The things – here, there, now, then – are no longer in themselves, in their own place, in their own time; they exist only at the end of those rays of spatiality and of temporality emitted in the secrecy of my flesh.

And their solidity is not that of a pure object which the mind soars over; I experience their solidity from within insofar as I am among them and insofar as they communicate through me as a sentient thing.”

Therefore, he consciously acknowledges the implicit thread between himself, i.e. ‘subject’, and the ‘object’ – or between what one deems to be ‘within’ and ‘without’; this is what can be referred to as ‘intersubjectivity’ or one’s ‘embodied and non-embodied self’. By my interpretation this awareness and recognition in itself then brings to the fore an ethical dimension, in that the ‘object’ or the ‘other’ is recognised as an aspect of oneself and therefore one is placed in a position to work with and through possible tensions in as sensitive a manner as possible. Hence, if a researcher wants there to be more understanding and harmony in the world, whereby one thinks and behaves in ways that are ethical and respectful of the world (e.g. ‘objects’) and the ways of the ‘other’ (e.g. human beings) – or to behave in a sensitive manner that does not require action per se – then one ought to begin with oneself. In that, attempting to know oneself can lead to knowing the ‘other’ and the world, and attempting to know the ‘other’ can lead to knowing oneself and the world; there is a dialectic thread here. Therefore, self-reflection is a way of ‘returning to the things themselves’.

Regarding self-reflection and ‘returning to the things themselves’, Ludwig Wittgenstein’s writings about the sense of touch and feeling pain provide a good example (1953 / 1986; p.56 – note, the line numbers below are within the original text):

“Let us imagine the following: The surfaces of the things around us (stones, plants, etc.) have patches and regions which produce pain in our skin when we touch them. (Perhaps through the chemical composition of these surfaces. But we need not know that.) In this case we should speak of pain-patches on the leaf of a particular plant just as at present we speak of red patches. I am supposing that it is useful to us to notice these patches and their shapes; that we can infer important properties of the objects from them.

313. I can exhibit pain, as I exhibit red, and as I exhibit straight and crooked and trees and stones.—That is what we call "exhibiting".

314. It shews a fundamental misunderstanding, if I am inclined to study the headache I have now in order to get clear about the philosophical problem of sensation.

315. Could someone understand the word "pain", who had never felt pain?—Is experience to teach me whether this is so or not? — And if we say "A man could not imagine pain without having sometime felt it"—how do we know? How can it be decided whether it is true?"

Wittgenstein seems to be implying that there is an innate 'corresponding' sensation or / and 'property' within a human being's sense of touch to that of the stones, plants etc. in one's surroundings, and this may well also be the case for the stones, plants etc. regarding a human being and other beings in its / their surroundings. This is what he seems to mean by the term "exhibiting", which I deem to be an aspect of the embodied and non-embodied self / intersubjectivity. He then highlights that this in itself presents a philosophical problem when one is studying 'sensation', implying that, for example, if one is studying the experience of having a headache then one ought to focus with an intersubjective lens, 'within' and 'without'. He then asks some very poignant questions with regards to 'pain' as a word, as a lived experience and as a way of knowing, finally 'arriving' at a standpoint that leaves him and the reader in acknowledgement of the mysterious aspect of 'pain'. Knowing that he does not entirely know – and neither does the reader.

Therefore, Wittgenstein has demonstrated how 'returning to the things themselves' is a way of self-reflection and he has put into practice the age old knowing that one does not know. Hence, the dialectic process(es) of self-reflection and intersubjectivity can lead to deeper insights beyond the natural attitude, and this in turn enables the phenomenologist to develop one's perception, seeing the world in a more meditative manner and continuously delving deeper. I hope that this enables other researchers reading this chapter to recognize the importance of the concepts and approaches outlined above. In that, exercising a phenomenological attitude can enable a researcher to approach each moment and phenomenon with a certain kind of wonder and openness to the 'newness' of it, leading to deeper insight(s) and knowledge that can help to create more sensitive ways of being and carrying out research. This in itself might benefit 'autistic' people or / and their families, and even other groups of people, who participate in research.

3.2.2. Summary of phenomenology: useful concepts and techniques

Therefore, the phenomenological approach as a way of being in the world, a philosophy and a research approach is ever-open and dynamic, consciously recognising and acknowledging that the world is also a mysterious place. This includes one's ability to reason and therefore leads to a mysterious aspect of reason itself. In that one's thoughts and concepts are limited and one can only understand so much through thinking. Although, it is worth highlighting that the phenomenological attitude as a perceptual style, i.e. a heightened manner of reflexivity and a meditative way(s) of being, is not unique to phenomenology. Many mystics have exercised such a meditative way of being for thousands of years and religions have also propagated meditative practices and prayers (Smith, 2009; Vaughan-Lee, 2009, 2015). Therefore, phenomenology as a philosophy and a social movement within western academia is ironically in itself a 'return' to a way of being that has been present in human culture and history(ies) as way back as humans have existed.

3.3. CONCLUSION

Phenomenology is the studying of phenomena, or the lived experience, and is a meditative way of seeing and being in the world, a philosophy, a research approach(es) and a social movement within western academia. The phenomenological attitude is one that of self-reflection and meditation, to the degree of attempting to learn insights that are beyond one's every day taken-for-granted ways of being, i.e. one's natural attitude. Therefore, Husserl (1900 / 2001, 1901 / 2001) put forward the need for self-reflection and to 'return to the things themselves', which in itself consists of a dialectic element, and I have provided examples of this from Maurice Merleau-Ponty and Ludwig Wittgenstein. I have worked in this kind of dialectic way throughout this study, attempting to be as self-reflective as far as possible whilst also attempting to 'return to the things themselves', i.e. the lived experiences of 'autistic' persons, and by turning to such persons' lived experiences I have been able to self-reflect. Hopefully, the reader (who may be 'autistic' or / and a researcher) has begun to see the value and significance of the phenomenological attitude for this study as well as potential research. This will be further explored and

discussed in the next chapter, *Bridging Alevism / Sufism and Phenomenology: My Phenomenological Attitude*, and will continue throughout this thesis.

4. BRIDGING ALEVISM / SUFISM AND PHENOMENOLOGY: MY PHENOMENOLOGICAL ATTITUDE

4.1. INTRODUCTION

The aim of this chapter is to outline and discuss the theoretical framework of this study; my phenomenological attitude, which I refer to as my reflexive, embodied and non-embodied paradoxical, dynamic, mysterious self and lens. This theoretical framework emerged because of my ethical dilemmas, whereby I have had to ask myself the questions “Who or and what is my ‘self’? How is my understanding of ‘self’ creating and influencing this research?” Therefore, due to having anxieties about how my subjectivity and biases influence this research, I felt the need to question myself and to question my questions. How was I to achieve this?

As I proceeded I realised that I had to harmonise my Alevi worldview with my worldview as a social scientist. Hence, the theoretical framework herein has emerged thanks to my dilemmas and dialoguing with, and amalgamating, Alevism and phenomenology insofar as has been possible. It has enabled me to question myself throughout this study and has formed an approach and a tool through which I have been able to question my questions throughout as well. The former two chapters have outlined and discussed Alevism and phenomenology separately in their own rights for the purposes of clarity, and so in this chapter I have demonstrated how they have been bridged together. Other researchers may be able to learn from this by becoming aware of one possible way that a researcher can attempt to negotiate and work with such dilemmas, finally bridging one’s own personal spiritual / religious worldview with a methodology within the social sciences – and to do so in an explicit manner. ‘Autistic’ people and their families may be able to draw from this kind of process(es) so as to be aware of the kinds of inner conflicts that researchers / professionals can have when attempting to work with them and it might enable the family members to develop their own standpoints.

Structure wise I shall initially introduce what I recognise as the underlying bridge between Alevism and phenomenology, which I have termed as ‘Sophianic philosophy’, and I will proceed to illustrate and discuss the three linking pathways of

the bridge between Alevism and phenomenology. I will then move on to outline and discuss the theoretical framework as well as its implications for this study.

Having introduced this chapter I shall now outline and discuss what I deem to be the underlying bridge between Alevism and phenomenology.

4.2. THE UNDERLYING BRIDGE BETWEEN ALEVISM AND PHENOMENOLOGY: SOPHIANIC PHILOSOPHY

The ethical dilemmas that I experienced, as outlined in the *Introduction* chapter of this thesis, has led to my having to attempt to harmonise my worldview as an Alevi and a researcher in the social sciences in a western context; I have had to make a conscious effort to bridge and amalgamate these two aspects of myself. Whilst doing so I was guided to phenomenology by my supervisors and felt a pull to it. As I proceeded I realized that there seems to be an underlying bridge of Sophianic philosophy between Alevism and phenomenology. This bridge has enabled me to create and amalgamate the theoretical framework of my reflexive embodied and non-embodied paradoxical, dynamic, mysterious self and lens. However, this framework is also a theory, hence it is simultaneously a conceptual lens, so it is likely to have its limitations and can only be explained insofar as I and the English language are able to do it justice.

“Sophia” is derived from Greek, meaning ‘wisdom, ‘cleverness’ and ‘skill’, and is a worldview that sees the entire cosmos as being consciousness itself (Powell, 2007), although in different cultures it is referred to with different terms. According to the philosopher George S. Fullerton (1915, online):

“The Greek historian Herodotus (484-424 B.C.) appears to have been the first to use the verb "to philosophize." He makes Croesus tell Solon how he has heard that he "from a desire of knowledge has, philosophizing, journeyed through many lands." The word "philosophizing" seems to indicate that Solon pursued knowledge for its own sake, and was what we call an investigator. As for the word "philosopher" (etymologically, a lover of wisdom), a certain somewhat unreliable tradition traces it back to Pythagoras (about 582-500 B.C.). As told by Cicero, the story is that, in a conversation with Leon, the ruler of Phlius, in the Peloponnesus, he described himself as a philosopher, and said that his business was an investigation into the nature of things.”

It is known that Sophianic philosophy was exercised by philosophers like Plato, his teacher Socrates and Socrates's teacher Pythagoras. Simultaneously, it was recognised that the principle that Sophia represents was and is always in relationship with 'Logos', the 'word' or 'reason' (Powell, 2007). Therefore, a love for seeking wisdom within and through one's very own being was combined with a want to express such wisdom – which is what many scientists or / and artists attempt to do to this day. Furthermore, Alevi too seek this kind of loving wisdom, self-knowledge and awareness. Muslim scholars and teachers have dialogued with Greek, Persian and Indian philosophies and have been influenced by them (Von Franz, 1980; Smith, 2009). Hence, there is a very rich source of philosophy(ies) within Islamic literature (Haque, 2004) – especially philosophy that is of the Sophianic tradition – that I as a researcher have found to be very useful in undertaking this study.

Alevi philosophy(ies) acknowledges that the world and the cosmos is God (or consciousness) incarnate and therefore everything is alive, whereby nature and life is not just simply some kind of mechanic process(es) but is organic and constantly in a flux of motion and change (Shems&Rumi, 1263 / 2011); this is what could be deemed as 'Sophianic philosophy'. Therefore, thanks to the dialogue(s) with 'other' philosophies, Islamic scholarship has been significantly shaped and influenced by the Sophianic tradition. Furthermore, phenomenological philosophy(ies) is also very much influenced by Sophianic philosophers such as Socrates and Plato whereby there is an emphasis on seeking self-knowledge via a love for, and of, wisdom (Powell, 2007). I have come to recognise that the underlying bridge between Alevism and phenomenology is that both acknowledge and share what in the English language could be termed as a 'Sophianic philosophy and worldview'. I as a human being with my own lived experiences, as an Alevi and as a social scientist have come to realise that I too uphold a Sophianic worldview, as is made clear by the way in which the theoretical framework of this study has emerged, the way it has been bridged together and the very nature of it as a framework and lens.

For the purposes of this study I have identified three linking pathways of the underlying Sophianic bridge between Alevism and phenomenology; the first being with regards to the aim of Alevism and phenomenology, the second being with regards to the techniques of Alevism and phenomenology and the third being with

regards to the attempted perceptual standpoint by Alevi and phenomenologists. These will be discussed in detail now.

4.2.1. The first linking pathway: the aim of Alevism and phenomenology

There seems to be a difference between Alevism and phenomenology in that Alevi philosophy focuses on the direct relationship with Allah and becoming one with it, i.e. Alevi can be mystics, whilst phenomenological philosophy makes no attempt to become one with Being – at least not explicitly, i.e. phenomenologists aim to be philosophers only. However, some phenomenologists do believe that one can achieve a certain style of perception that navigates beyond the given. For example, Edmund Husserl, the philosopher who is viewed as the founder of phenomenology, argued that a philosopher can develop a style of perception whereby pure consciousness can be experienced without subjective experience or ego (Husserl, 1913 / 2012; Finlay, 2008).

In order to know oneself Alevi seek a deeply intimate relationship with Allah and refer to it as 'Aşk' (Love) and 'Sevgili' (the Beloved). Alevi mystics offer the burning of and the annihilation of one's ego to become one with Allah. An example of this kind of love affair with the Beloved is that of the Sufi mystic Hallaj-ı Mansur (approx. 900 A.D.), who stated "anâ'al-haqq" (in Schimmel, 1962, p.161), 'I am one with God'. As far as I am aware phenomenological philosophy does not have these kinds of terms per se, however, if one pays attention to the age old statement from the temple of Apollo at Delphi in Greece, "γνώθι σεαυτόν" - "Know thyself", which was later attributed to the philosopher Socrates and who has influenced the fields of current day philosophy, then here emerges a linking pathway.

Both Alevi and phenomenologists share the aim of seeking self-knowledge and attempting to understand Allah or Being in the very lived experience(s) of being human and of life itself. For example, Shems&Rumi (1263 / 2011) emphasise the journey of turning inwards towards one's heart so as to develop self-knowledge. Whilst Merleau-Ponty (1945 / 2013, 1964 / 1968) emphasises the importance of perception in our everyday ways of being and that one ought to be reflexive and examine one's own embodied and non-embodied perception(s) whilst seeking self-knowledge. Hence, there is a shared aim between Alevism and phenomenology in

terms of seeking self-knowledge as a human being through the endeavour of studying oneself and 'others'.

My purpose is to seek self-knowledge for myself, for people on the 'autism' spectrum and their families as well as the field of academia. The aim of seeking self-knowledge is prevalent in both Alevism and phenomenology and, therefore, seeking such knowledge inevitably has led to my taking up a reflexive worldview and standpoint.

The second linking pathway will now highlight how Alevis and phenomenologists have exercised such an aim through the techniques or approaches of learning prevalent within 'both' philosophies.

4.2.2. The second linking pathway: the techniques or approaches of Alevism and phenomenology

There are many techniques or approaches that Alevis exercise so as to be as reflexive as possible and to act in line with the self-knowledge that arises thanks to these endeavours, e.g. semah (a whirling 'dance'), singing poetic prayers, playing music etc. However, I will focus on two techniques for the purposes of this research; meditation and narratives. This is because of my wanting to address my ethical dilemmas in a reflexive manner for the purposes of this academic endeavour.

Sufis refer to one's personality-level based behaviours as being the results of one's conditioned ways of being, in that since one's birth one is taught how to put a mask(s) on and act in line with social cultural norms that are set by one's family or / and culture to the extent that one identifies oneself as being one's personality only (Shah, 1978 / 1985). However, when one seeks a deeper relationship with Allah this may, and usually does, lead to behaviours that challenge the status quo because the Sufi is navigating from a place that is more consciously in tune with the deeper depths and tides of life (Vaughan-Lee, 2008, 2015). As Doris Lessing outlines in Idris Shah's *Learning How to Learn* (1978 / 1985; p.10), "Sufism respects all religions, saying that the Truth is at the core of each" and further warns us about our conditioned ways of being, in that "We are all conditioned, as we now claim so easily and trippingly; but perhaps being able to say that is not enough to enable us to see

how.” Implying that self-reflection and reflective action, i.e. reflexivity, is crucial in moving with and beyond our conditioned ways of being. This is also Nasreddin Hoja’s lesson, as discussed in Chapter Two, section 2.3.

Within phenomenology Husserl (1913 / 2012) makes a similar claim. He states that most of us exercise a ‘natural attitude’, whereby the objects, ideas and experiences of our lives are taken as a given and not necessarily questioned or investigated in-depth. He views this attitude as being naïve because Being cannot be simply reduced to objects, ideas and experience alone. Therefore, he recommends that phenomenologists seek knowledge beyond the given, leading one to exercise a reflexive standpoint so as to gain deeper understanding of oneself and everyday lived experiences or phenomena – as outlined and discussed throughout Chapter Three.

A technique by which Alevis carry out self-reflection in every moment of one’s life are within the philosophy and practice(s) of ‘edep’ or ‘adab’ (ethical behaviour); a way whereby one seeks to conduct oneself in remembrance of Allah in every moment. This initially begins with the practice of the ‘zıkr’, meditation that focuses on Allah either in complete silence or via the uttering of ‘Allah’ or / and the ninety-nine names of Allah. One attempts to carry out this act with one’s heart – not just simply with one’s mind or tongue (Vaughan-Lee, 2009). The zıkr can be carried out alone or in a group and can also be carried out in the form of a semah (a ‘dance’ of remembering Allah), with a saz (a lute like instrument) or other instruments, as a ‘değiş’ (prayerful songs) etc.; the form the zıkr takes varies amidst Alevis and from region to region (Yaman Dede, 2004). In a way the form the zıkr takes does not matter, the main intention is to remember Allah with one’s entire heart in all moments. As time goes by one becomes able to carry out the zıkr during one’s everyday activities and can reach a stage whereby one is so absolutely absorbed in and as God’s love that there is no longer a need to remember Allah. When this occurs there is no longer a need to meditate because one is constantly in the state of meditation (Shah, 1990; Vaughan-Lee, 2015). This style of perception and being in the world enables one to live as consciously as possible.

Phenomenologists on the other hand may not seek such a relationship with God and may not practice this kind of meditation. However, when considering the focus on

seeking self-knowledge as philosophers and the use of the term 'Being' to refer to the non-describable essence of the energy of life and death, it would seem that when Husserl (1913 / 2012) asserted that one ought to 'go back to the things themselves' he was asserting that one ought to reflexively seek deeper into the essence of Being. This may not necessarily be a conscious way of carrying out a 'zikr' per se. However, the circular process(es) of thought that is required to be reflexive and to continue re-examining one's own natural attitude and those of the 'other' could very well be a similar exercise of the continually circular thought process(es) of attempting to seek deeper knowledge about Being (or Allah) in all phenomena. This in turn usually creates a gap in one's thinking and enables one to play with various ideas, including those that may be viewed as being completely in contradiction with one another. Therefore, both Alevism and phenomenology seem to share a linking path in terms of a reflexive technique that is exercised. By my interpretation the Alevi seeks to be reflexive in every moment of one's lived experience via the meditative technique of the 'zikr' whilst the phenomenologist carries out a similar act by continuously 'returning to the things themselves' with a reflexive mind's eye.

Another technique by which Alevis / Sufis teach and learn in a reflexive manner is through the use of narratives (Nurbakhsh, 2003; Shah, 1990). For example, Cafer-i Sadik's *Buyruk (The Offered Teachings)* (approx. 700 A.D. / 2013) consists of stories so as to illustrate the points made whilst Shems&Rumi's (1263 / 2011) *Mesnevi* is full of poetic stories within stories. Many of the narratives within these books are based on real-life lived experiences, either by the authors themselves or events that have taken place within the culture in which they lived, and they have used the examples to convey the necessary meanings and teachings to the reader. When one thinks about the Quran (Islam) and other holy books such as the Bhagavad Gita (Hinduism), the Shri Guru Granth Sahib Ji (Sikhism) and the Bible (Christianity), they are full of stories with reflective meanings and teachings which can be, and usually are, paradoxical and nuanced.

When phenomenologists focus on the lived experience, seeking to understand beyond the surface level meaning(s) of phenomena, i.e. seeking knowledge with and beyond the natural attitude, it seems that a similar activity is carried out both in terms of reading about phenomena / the lived experience and in terms of observing the phenomena and writing about them. For example, when reading Maurice Merleau-

Ponty's works such as *Phenomenology of Perception* (1945 / 2013) and *The Visible and the Invisible* (1964 / 1968) they include observations about his experiences of touching his own hand and touching a table. This kind of reflective activity in which narratives and the lived experience itself serve a practical purpose of seeking knowledge of 'self' (be it about oneself or / and the 'other'), leads to creating new thoughts, re-shaping one's thinking and writing, as well as conducting other physical actions or / and non-actions that are in line with such insights – which are all aspects of reflexive learning. As van Manen (1990, p.70) states:

“Literature, poetry, or other story forms serve as a fountain of experiences to which the phenomenologist may turn to increase practical insights.”

Therefore, both Alevis and phenomenologists can, and do, turn to the lived experience of phenomena via the use of narratives for the purposes of reflexive learning. This in turn also places language and writing in a very important position for the purposes of developing insight(s) and self-knowledge. It is of no sheer coincidence that Alevi / Sufi literature is full of reflexive paradoxical circular dynamic writings that point to the mysterious in life and simultaneously demonstrate this way of thinking through the writing(s) itself. For example, Shems&Rumi's *Mesnevi / Mathnawi* (1263 / 2011) and Fariduddin Attar's *Mantıq-ı-Ṭayr* or *The Conference of the Birds* (1177 / 1984), and the writings of phenomenologists such as Husserl (1913 / 2012), Lévinas (1961 / 1979) and Merleau-Ponty (1945 / 2013, 1964 / 1968) are of a similar nature.

It would seem that despite the differences in the aim and the specific techniques or approaches that Alevis and phenomenologists can and do exercise, there appears to be a linking pathway between the two in terms of meditative reflexive learning and using narratives. I deem this style of an attempted perceptual standpoint to be what is referred to as a 'phenomenological attitude' within phenomenology and shall now proceed to outline and discuss this.

4.2.3. The third linking pathway: the attempted perceptual standpoint by Alevi and phenomenologists

Whilst seeking self-knowledge in a reflexive manner via the focus on the lived experience or phenomena, the Alevi attempts to become aware of the mysteries of Allah and the phenomenologist attempts to become conscious of the unknown nature of Being. Given the somewhat similar aims and techniques by which Alevi and phenomenologists seek to achieve this, both therefore inevitably end up developing a perceptual standpoint that seems to be similar in nature. I view this to be the 'phenomenological attitude'. According to Finlay (2008, p.2) Husserl's understanding and exercising of the phenomenological attitude is the core of the phenomenological approach, and that:

“One of his greatest contributions was to articulate the reduction¹ as a radical self-meditative process where the philosopher “brackets” the natural world and world of interpretation in order to see the phenomenon in its essence.”

Hence, this attempted perceptual standpoint and approach leads to one having to become consciously aware of one's own nature and that of the 'other' or / and phenomena in a constantly dynamic manner. The mere act of seeking to 'bracket' one's own interpretation of the world and the natural world leads one to understand life not just simply in its dualistic ways (i.e. viewing the world in terms of cause and effect – the play of 'opposites'), but also deeper in terms of its nuanced and dynamic ways so as to constantly find oneself 'arriving' at the “essence” or mystery of phenomena.

Having outlined and discussed the three main linking pathways of the underlying bridge of Sophianic philosophy between Alevism and phenomenology I will now summarise this section of the chapter.

4.2.4. Summary of the underlying bridge between Alevism and phenomenology

There exists a bridge of Sophianic philosophy between Alevism and phenomenology whereby the viewpoint that the entire cosmos is consciousness itself

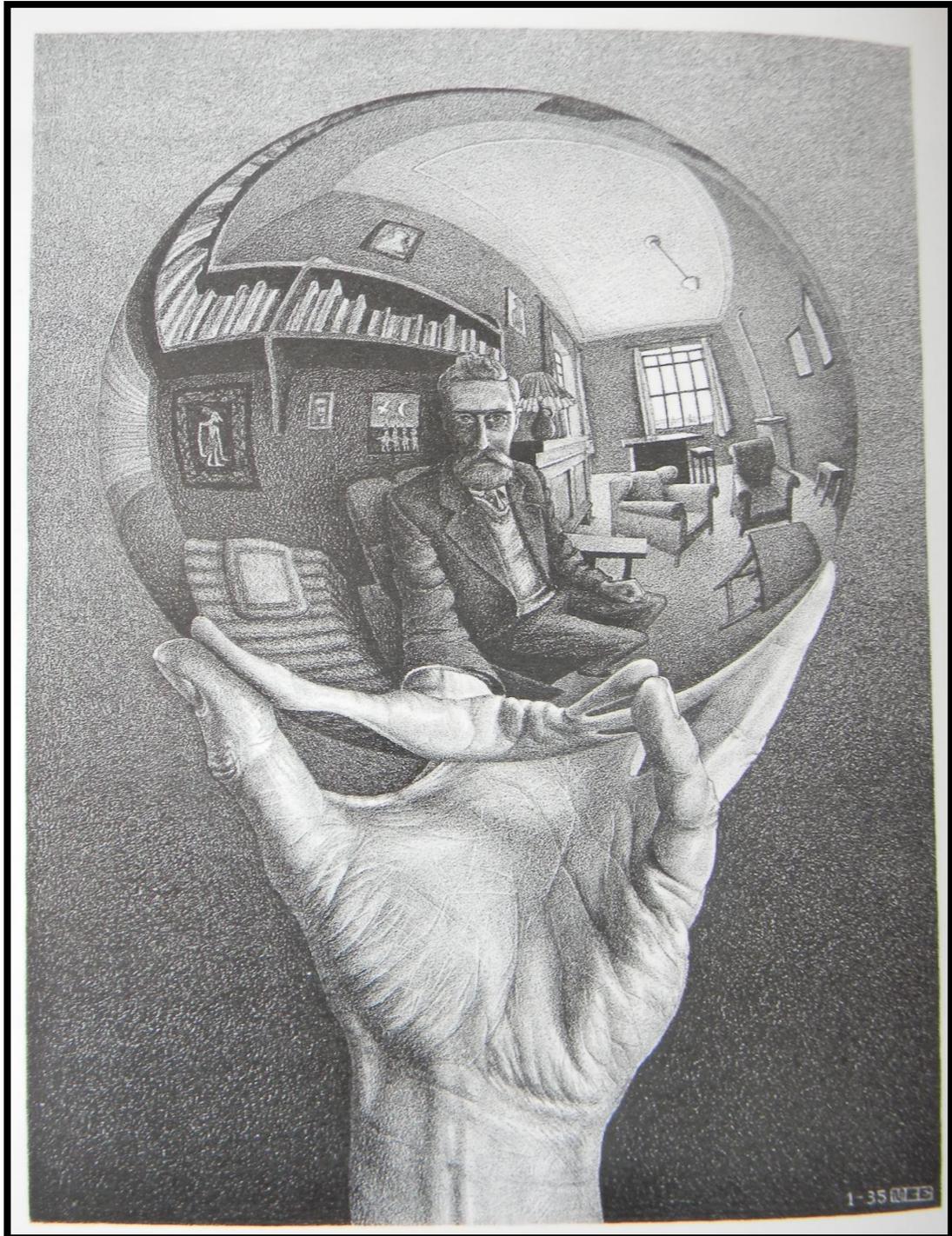
is a shared tenet. The focus on meditative self-reflective behaviour or reflexivity is the core approach by which both Alevis and phenomenologists seek self-knowledge. Whereupon by getting to know oneself one is able to understand 'others' and the cosmos better, and by getting to know the cosmos and 'others' better one is able to know oneself better. This in turn leads to an ongoing circular and dialectic style of perceiving the world in a reflexive or meditative manner, also referred to as the 'phenomenological attitude'.

I will now illustrate what I view to be the more detailed aspects of my Sophianic understanding of my 'self', insofar as is possible, as well as my 'lens' for the purposes of this study and how it emerged whilst undergoing this research.

4.3. THE THEORETICAL FRAMEWORK OF THIS STUDY: MY REFLEXIVE EMBODIED AND NON-EMBODIED PARADOXICAL, DYNAMIC, MYSTERIOUS SELF AND LENS

Addressing my ethical dilemmas has led to the emergence and amalgamation of the theoretical framework herein. Asking myself the question "Who or and what is my 'self'? How is my understanding of 'self' creating and influencing this research?" led to my having to create a conceptual lens that reflects my 'self' as well as what I understand to be my 'self'. Attempting to fathom this also enabled me to question my questions – not just simply at the beginning of this study but all throughout. Simply put, I have developed a certain perceptual stance and definition of the 'phenomenological attitude' for the purposes of this study. The following illustration has enabled me to visualise what I mean by this and I hope it will also help the reader to do so.

Figure 1: M.C. Escher's 'Hand with reflecting globe' in *M.C. Escher The Graphic Work* (1959 / 1992, p.51)



The drawing above is by Maurits Cornelis Escher with a self-portrait included in it. I often find myself in this situation when carrying out research. Whereby I have a reflective spherical ball in my hand and there is a to-ing and fro-ing between the

image(s) and myself as the perceiver, and the lived experiences I am gazing at, on, with and through act as objects and ways of exploring my inner life and understanding myself. Simultaneously, this enables me to develop my insight(s) into the lived experiences of the 'other'.

Just as the curvature of the glass ball and the merging of the image(es) emphasizes, they are all inter-linked and dynamic, and I often find myself re-gazing many more times as I proceed. Furthermore, something is always lost and or invisible, for just as we see many things in this picture simultaneously there are many things that we do not see yet are present. Therefore, there is a paradox(es) and a mystery(ies) to our being and understanding; so reflexivity – the ability to reflect and act – plays a crucial role as it feeds into my understanding of my 'self' and the 'other'. In turn, this shapes my thinking and way of researching as well as living.

The very awareness and acceptance of such a way of being has led to my focus on the embodied and non-embodied self, with elements such as paradox, dynamics and mystery being acknowledged and incorporated into this research. This has been, and continues to be, an ongoing reflexive circular standpoint(s) that has set out my approach and methods, although if one element is missing (e.g. not acknowledging paradox or dynamics or mystery etc.) then the ball is no longer spherical and this is no longer the phenomenological attitude. In addition, the mirrors that I have utilized throughout this study and thesis, e.g. the lived experiences of 'autistic' people, have influenced my use of language. Therefore, my acknowledging and exercising my reflexive embodied and non-embodied paradoxical, dynamic, mysterious self and lens as (i) my 'self' and (ii) as a conceptual lens is my phenomenological attitude in action throughout this study.

Having given the reader a little taste of what I mean by 'my reflexive embodied and non-embodied paradoxical, dynamic, mysterious self and lens' I will now focus on this theoretical framework through its various elements and explain how they came to be acknowledged and incorporated. Whilst doing so I will also illustrate the links between the elements as it is not possible to outline and discuss each aspect without mention of the other. This is because they all form the 'reflecting globe' as above and I have merely focused more so on one aspect at a time so as to try and give the reader as clear an understanding as I can.

4.3.1. My reflexive self and lens

Within Alevi philosophy there is a strong focus on self-reflection, learning and then conducting oneself according to this learning (Sadık, approx. 700 A.D. / 2013; Shah, 1978 / 1985, 1990). This is exercised by Alevis in acknowledgement of the dialectic link between one's 'inner' state of being and the 'outer' world, which can lead to what psychologists refer to as 'transference' or 'projection' (Jung, 1961 / 1995). In that, our worldview and biases affect our interpretations and interactions with 'others' / our environment. In order to be aware of this process(es) of transference or projection, and to enable oneself to be in harmony with one's own 'inner' and 'outer' states of interaction, self-reflective behaviour is crucial.

Within the social sciences, action that is in line with one's self-reflective learning is referred to as 'reflexivity' (Silverman, 2009). Phenomenologists highlight the importance of reflexivity for the purposes of developing self-awareness and self-knowledge (Husserl, 1913 / 2012; Merleau-Ponty, 1945 / 2013; Lévinas, 1961 / 1979). My ethical dilemmas arose due to my reflexive Alevi worldview with regards to being a human being with my own biases and subjectivity as well as my not being on the 'autism' spectrum and therefore not having an insider's view. If it was another researcher they may well not have experienced such dilemmas; I came to address these dilemmas by taking up a reflexive standpoint and being drawn to phenomenology within the social sciences because of its emphasis on reflexivity. Therefore, being reflexive has enabled me to become that much more conscious of my worldview and biases and has also enabled me to report these as openly as I can.

My approach and lens with regards to the entire endeavour of this study became reflexive and I was influenced by the phenomenologist van Manen (1990; pp.1-2):

"So there exists a certain dialectic between question and method. Why then should one adopt one research approach over another? The choice should reflect more than mere whim, preference, taste, or fashion. Rather, the method one chooses ought to maintain a certain harmony with the deep interest that makes one an educator (a parent or teacher) in the first place."

Hence, in an attempt to address my subjective ethical dilemmas and to practice in line with the fact that the research question(s) and method(s) of a study are

dialectically intertwined, has led to my exercising a reflexive standpoint throughout the whole process(es) of this research. This means that I have been able to acknowledge and exercise a Sophianic way of being reflexive throughout this study.

Now I shall proceed to how the embodied and non-embodied aspect of the theoretical framework emerged.

4.3.2. The embodied and non-embodied aspect of my self and lens

The Quran states that Allah is closer to us than our jugular vein (Quran, approx. 600 A.D.; Surah Qaf). In that God resides within our hearts (is embodied) and yet is simultaneously beyond this because Allah is infinite (non-embodied). Hence, the universe is in one's body and one's body is in the universe, i.e. the embodied and non-embodied self. This also implies the interconnectedness of all beings as the One. Within phenomenology this is referred to as 'intersubjectivity', whereby one's perception is embodied and that when one looks at another person or object there is something of oneself in that 'other' (Lévinas, 1961 / 1979; Merleau-Ponty, 1945 / 2013). This in turn has very significant implications for oneself as a researcher, in that I am a subjective being with my own biases and that I am as intertwined with the 'other' as I am with myself. Hence, making the practicing of reflexivity that much more crucial so as to think and behave in as ethical a manner as possible when researching the 'other'.

The embodied and non-embodied aspect of this theoretical framework came to be incorporated as such because whilst working with people on the 'autism' spectrum I noticed that they were responding to emotions of mine that I had not verbalised or expressed through my body language. My readings of the autobiographical writings of some people on the 'autism' spectrum, e.g. Christopher Goodchild's *A Painful Gift: The Journey of a Soul with Autism* (2009) and Donna Williams's *Nobody Nowhere* (1992), enabled me to learn and realise that people on the 'autism' spectrum can be highly sensitive to the emotional energy of others. My lived experiences in my work settings coupled with my readings enabled me to not just learn but also to realise that as much as the 'other' is an aspect of my self I too am an aspect of 'their' self. Becoming aware of this and exercising it as a lens throughout this research means

that I have been able to carry out a Sophianic worldview in terms of acknowledging that we are all in relationship(s) and connected as One.

Now I shall proceed to how the paradoxical, dynamic and mysterious elements of the theoretical framework emerged.

4.3.3. The paradoxical, dynamic and mysterious elements of my self and lens

Whilst attempting to work with my ethical dilemma regarding my 'self', my understanding and lens of 'self' and my focus on my lived experience as well as that of the 'other', I ended up asking the question "Which aspects of my 'self' and the lived experience, or phenomena, do I focus on and how?" Around the time I was asking myself this I came across a particular piece of insight during my readings of the Alevi Sufi book the *Mesnevi / Mathnawi* (Shems&Rumi, 1263 / 2011), and this helped me to work with my dilemma and question.

I will utilise extensive quotes here. This is so as to include the source in its original nature and give the reader the freedom to seek their own translation if they wish, and to simultaneously give my translation of it in English as well as my interpretation.

"1130. Allah; bu zıddiyetle gönul hoşluğu meydana gelsin, her şey iyice anlaşılın diye hastalığı ve kederi yarattı. Şu halde gizli olan şeyler, zıddıyla meydana çıkar. Hak'kın zıddı olmadığından gizlidir. Ev-velâ nura bakılır, sonra renge. Çünkü beyaz ve zenci, birbirine zıt olduğu için meydana çıkar. Sen nuru, zıddıyla bildin. Zıt, zıddı meydana çıkarır, gösterir. Varlık âleminde Hak nurunun zıddı yoktur ki açıkça görünebilsin." (Shems&Rumi, 1263 / 2011; p.32, Turkish)

I have translated it as follows into English:

"So that with and through opposites one's heart may flourish with happiness, so that everything will be well-understood, illness, pain and suffering were created by God. For in this state those things that are hidden come into being via their opposites. As God has no opposite it is hidden, it is not visible and is a mystery. Firstly the light is looked upon and then the colour. It is because white skin and black skin are one another's opposites that they come into being and are recognised as so. You know the light by its opposite. An opposite brings to the fore opposites and displays them as such. In the realm of existence the light of Truth has no opposite for it to be openly visible."

Which I interpret as follows within the square brackets:

“So that with and through opposites [paradox] one’s heart may flourish [motion / dynamics] with happiness [self-realization], so that everything will be well-understood, illness, pain and suffering were created by God. For in this state those things that are hidden come into being via their opposites. As God has no opposite it is hidden, it is not visible and is a mystery [mystery]. Firstly the light is looked upon and then the colour. It is because white skin and black skin are one another’s opposites that they come into being and are recognised as so [intersubjectivity]. You know the light by its opposite. An opposite brings to the fore opposites and displays them as such. In the realm of existence the light of Truth [meaning God] has no opposite for it to be openly visible.”

Hence it would seem that my ‘self’ and the lived experience consists of three intertwining elements; that of paradox, dynamics and mystery.

The paradoxical element is to do with my being a self that has a dual nature, e.g. I have likes and dislikes. The dynamic element seems to be the aspect of myself which is always revolving in and as a dance of change, e.g. my values change over time – things I understood to be ‘right’ and ‘wrong’ a year ago are no longer so. As for the non-visible or mysterious element of myself, this is the most difficult one to explain in words, although I will try to provide an example; there are times that I do not understand myself and I think or do things that seem to be illogical, however, it is only afterwards that I realise why.

Furthermore, it would seem that our paradoxical nature of ‘self’ involves an intersubjective element, in that I am a part of the ‘other’ and the ‘other’ is a part of me; as is highlighted by Shems&Rumi above when they focus on how the one light of Truth manifests into white and black skin. Or in other words, my self is intersubjective and my individual perception is intrinsically intertwined with my environment and the ‘other’ (Lévinas, 1961 / 1979; Merleau-Ponty, 1945 / 2013). So then the lived experience or phenomena that I experience and observe are also paradoxical, dynamic and mysterious. I am not stating that these are the only elements of my ‘self’ or the lived experience, however, what I am stating is that this is the closest manner of a conceptual understanding I have been able to develop of my ‘self’ and of the lived experience so as to address my ethical dilemmas and to be as reflexive as possible.

In order to provide supporting evidence of the nature of 'self' that Shems&Rumi (1263/ 2011) have outlined, and to illustrate the similarity of the understanding of 'self' within phenomenological philosophy, I will now draw upon the works of Maurice Merleau-Ponty, a phenomenologist who particularly focused on consciousness and the body. Merleau-Ponty (1964 / 1968, p.136) states that:

“Since the total visible is always behind, or after, or between the aspects we see of it, there is access to it only through an experience which, like it, is wholly outside of itself. It is thus, and not as the bearer of a knowing subject, that our body commands the visible for us, but it does not explain it, does not clarify it, it only concentrates the mystery of its scattered visibility; and it is indeed a paradox of Being, not a paradox of man, that we are dealing with here.”

Merleau-Ponty too recognizes the paradoxical element of one's 'self' as being a quality of Being or God and has illustrated an intersubjective understanding of 'self'. He has referred to that which is not visible – the aspect of self and of the lived experience that is a mystery – that is manifested as so by the “scattered visibility” of the body. So he has focused on the body to demonstrate the paradoxical nature of the invisible Being made visible. Shems&Rumi have made a similar point by referring to how the one light of Truth manifests into the realm of existence, e.g. the example regarding white and black skin colours.

In Alevi philosophy there is a saying that the visible realm, e.g. the world we live in, is God's non-visible face (Shems&Rumi, 1263 / 2011); there is a practice whereby one is told to look in the mirror and see the non-visible face of Allah and remember that every being that one encounters carries the essence of God. Therefore, the paradoxical, dynamic and mysterious elements of self enables one to witness that which is visible and also to be aware of the aspect of one's self that is not visible, i.e. that which is mysterious. Simply being consciously aware of one's 'self' and nature as such then places one in a position whereby one continuously acknowledges that one is not able to form concrete states of being, nor any everlasting thoughts or statements, for our paradoxical, dynamic and mysterious nature renders these obsolete.

To provide further supporting evidence for that of Shems&Rumi and Maurice Merleau-Ponty's understanding of the 'self' I will now draw from the works of Dr. Carl Gustav Jung from the field of psychology.

Jung was a Swiss psychiatrist who is known to be one of the most influential psychiatrists, if not the most influential one, within the field of psychiatry in the twentieth century (Von Franz, 1980; Shamdasani, 2009). In addition to attending to his clients' psychological difficulties, Jung delved into the realms of his own inner being and documented it over his lifetime in a deeply reflexive manner (Johnson, 1989; Shamdasani, 2009), recognizing his intersubjective nature and working with it in a very conscious style. He stated that (Jung, 1961 / 1995, p.383):

“All conceivable statements are made by the psyche. Among other things, the psyche appears as a dynamic process which rests on a foundation of antithesis, on a flow of energy between two poles.”

It would seem that Jung was referring to the psyche or self as having a quality of awareness to it, in that it conceives things and makes statements. In addition, he viewed the self as consisting of two poles – what could be viewed as a paradoxical element of 'self', and there being a dynamic element to it as well, i.e. “a flow of energy between two poles”.

He goes on to add that our concepts and language become redundant in the face of the one that is not visible, i.e. that which is not knowable (Jung, 1961 / 1995, p.388):

“Man can try to name love, showering upon it all the names at his command, and still he will involve himself in endless self-deceptions. If he possesses a grain of wisdom, he will lay down his arms and name the unknown by the more unknown, *ignotum per ignotius* – that is, by the name of God. This is a confession of his subjection, his imperfection, and his dependence; but at the same time a testimony to his freedom to choose between truth and error.”

Jung's understanding of 'self' therefore includes paradoxical and dynamic elements, with an acknowledgement that the essence of all things is unknown – this is what I deem to be 'mystery' or “God” as he also has put it. Simultaneously, considering that he felt that the action of offering an explanation which is more difficult to understand than the thing it is meant to explain, i.e. “*ignotum per ignotius*”, suggests that maybe he realized that a certain style of perception that does not involve the use of names

and language per se may be the route through which one can recognize one's essence – laying down his arms and naming the unknown as God. Thereby acknowledging and accepting the invisible essence of one's self and of one's lived experiences, which is a very similar stance taken by Shems&Rumi and Merleau-Ponty. My interpretation of this is that Jung viewed the psyche or soul of man as God incarnate; Alevi philosophy too views it as so and it would seem that some phenomenological philosophy also views it as such. Therefore, it would seem that there is a paradoxical, dynamic and mysterious aspect to my 'self' and that of the phenomena that I experience and observe, making me an embodied and non-embodied (intersubjective) self as well (Shems&Rumi, 1263 / 2011; Merleau-Ponty, 1945 / 2013, 1964 / 1968; Jung, 1961 / 1995).

Now I shall proceed to provide a summary of this sub-section and how I came to realise that the theoretical framework of this study is simultaneously also my phenomenological attitude in action.

4.3.4. Summary of the theoretical framework of this study

My reflexive embodied and non-embodied paradoxical, dynamic and mysterious self and lens as a theoretical framework has served three purposes. Firstly, it has emerged because of my ethical dilemmas and has simultaneously enabled me to acknowledge and work with my dilemmas as far as possible, e.g. as an Alevi and as a social science researcher I came to feel less anxious about this academic endeavour. Secondly, it has enabled me to develop a conscious understanding of what I deem to be 'self' – both with regards to myself and 'others', placing me in a position where I am able to become more conscious of my biases and subjective ways of being, reporting these as openly as I can. Thirdly, I have come to accept this understanding of 'self' as the theoretical framework of this study, therefore making it a conceptual lens through which I have been able to fulfil the overall aim of this study insofar as has been possible. My exercising of this reflexive lens throughout this study has become my definition of the phenomenological attitude, which has enabled me to question myself and to question my questions. Therefore, my reflexive embodied and non-embodied paradoxical, dynamic and mysterious self and lens is

the theoretical framework of this study and my phenomenological attitude in action throughout this study.

Having summarised this section of the chapter I shall now focus on the implications of my reflexive embodied and non-embodied paradoxical, dynamic, mysterious self and lens with regards to this study.

4.4. THE IMPLICATIONS OF THE THEORETICAL FRAMEWORK FOR THIS STUDY

The underlying bridge between Alevism and phenomenology is the Sophianic worldview and philosophy(ies), whereby I, the world and the entire cosmos are one, alive and full of consciousness. Due to experiencing myself as this, i.e. my reflexive embodied and non-embodied, paradoxical, dynamic, mysterious self and lens, it then follows suit that I interpret myself and life as such whilst simultaneously behaving in line with such a worldview. Therefore, for the purposes of this study I will now discuss the implications of my reflexive embodied and non-embodied paradoxical, dynamic, mysterious self and lens with regards to the aim, techniques or approaches and the attempted perceptual standpoint of Alevism and phenomenology.

4.4.1. Implications: my aim

My reflexive embodied and non-embodied paradoxical, dynamic, mysterious self and lens is my worldview of myself as well as life in general. My awareness and recognition of it as this has now enabled me to conceptualise and amalgamate a theoretical framework that serves the purpose of exercising a phenomenological attitude so as to address my ethical dilemmas, thereby deepening my self-knowledge and seeing what I may be projecting on to the 'other' insofar as I can.

Llewellyn Vaughan-Lee (2008), a Sufi teacher and an academic scholar, refers to the mythical story of Perseus and Medusa with regards to becoming conscious and aware. By simply looking at Medusa – or in other words ignorance – Perseus kills Medusa. He achieves this via the power of reflection; Perseus's shield, given to him by a goddess, enables him to look at Medusa (another goddess) through the

reflection of his shield without himself turning to stone. Therefore, killing the ignorance within himself and transforming as well as integrating it into his own understanding and psyche. Hence, self-reflection is a spark of consciousness that enables one to simply witness and observe that which needs to be seen both 'within' and 'without' so as to deepen one's self-knowledge. Action or / and non-action that is taken in line with this kind of self-knowledge enables one to live in harmony with oneself and the 'other'.

Furthermore, it is known that the way one observes an object or situation has an effect on it. The double-slit experiments within the field of physics by Thomas Young in 1801 (American Physical Society, 2008) and then later in 1927 by Clinton Davisson and Lester Germer demonstrated that the human eye and gaze leads to atom particles behaving in different ways than if they had not been observed (Davisson and Germer, 1928). If one's mere presence and gaze is enough to lead to changes in the behaviour of atom particles then imagine the effect of how much one's mere presence as a researcher has upon the research questions of a study as well as the participants one is likely to dialogue with. Within the field of social psychology this is referred to as 'the observer effect' or the 'Hawthorne effect', whereby people modify their behaviour when they are being observed and studied (Landsberger, 1958).

Therefore, it is vital to sit down as a researcher beforehand and carry out some self-reflection. To ask oneself questions regarding one's own nature and how this is creating and shaping the study at hand. I have asked myself "Who am I? What am I? How is this creating as well as affecting this research? How are my research questions created and influenced by this? What are the implications? How can I create research questions that are sensitive to the lived experiences of the so-called 'other'?" To undergo this process is crucial for any human being who aims to know oneself. It also enables one to carry out research that exercises a phenomenological attitude throughout the study, becoming aware of one's projections and transferences of bias insofar as is possible, and thus leads to more sensitive and ethical questions / research.

I may have been wrong in taking up a phenomenological attitude that comprises of the theoretical framework discussed within this chapter, however, given my own lived

experiences and dialogues with people on the 'autism' spectrum, my reflexive endeavours and my readings, this is the most suitable approach and theoretical framework I have been able to amalgamate and work with so as to address my dilemmas. Therefore, becoming conscious of the theoretical framework herein enabled me to recognise that the implication of it is that my aim is simply to be conscious and aware. This means that I do not adhere to any particular theory or concept within the field of 'autism' studies. I acknowledge them and I accept them for what they are, however, simultaneously, when it is time to put down the glass globe and accept the non-visible and mysterious aspect of life then I also try and do this.

4.4.2. Implications: the techniques or approaches

My want to know myself has led to an aim to harmonise the Alevi in me with the social scientist in me. The phenomenologist Max van Manen (1990, 2014) states that the research question and approach are tied together and so the researcher ought to exercise an approach that is in harmony with oneself as say an educator, parent etc. Recognising this has further added to my want to take up and exercise a reflexive lens throughout this study.

The approaches or techniques of Alevism and phenomenology, e.g. exercising a reflexive standpoint by 'going back to the things themselves' (Husserl, 1901 / 2001) or exercising 'edep' in terms of the meditation of 'zikir', has led to my focus on my lived experiences with people on the 'autism' spectrum. My theoretical understanding of 'autism' had been challenged and I had become curious about their inner lives and meaning-making. Being aware that I have my conditioned ways of being and that I at least ought to attempt to understand the 'other' insofar as I can added to this curiosity. Simultaneously, this awareness and my reflexive standpoint enabled me to turn to the autobiographical writings of people on the 'autism' spectrum, viewing their narratives as tools and mirrors of self-reflection. This was so as to attempt to exercise a phenomenological attitude that enabled me to gain the 'insider's view' as far as I could. It also enabled me to create sensitive research questions, being as mindful as I can about my use of language.

The theoretical framework and my focus on the lived experiences of people on the 'autism' spectrum via the use of their narratives enabled me to question myself, my

questions as well as the language in creating such questions. I have used the English language for the purposes of this thesis and have translated some Alevi writings in Turkish into English for the purposes of accessibility for the reader. However, I have found that to-ing and fro-ing between English and Turkish has made me that much more aware that I myself think and write in a dynamic manner between two languages as I have been bilingual since the age of five. I have also realised more so that some languages are more poetic and include terms and aphorisms that are open to several meanings at a time, in this case Turkish, whilst some are not as open in this kind of way, in this case English. For example, when translating from Turkish to English Shems&Rumi's (1263 / 2011) statement about the nature of self, as above, I have tried to translate and provide descriptions insofar as I can so as to provide the reader with as much of an understanding as can be put into words in the format of the English language. Therefore, my reflexive embodied and non-embodied paradoxical, dynamic, mysterious self and lens is not only an amalgamated theoretical framework between my Alevi worldview and myself as a researcher attempting to carry out phenomenological research, it is also an amalgamation of two styles of thinking and languages merged into the language of English.

I therefore found it freeing when reading Merleau-Ponty's (1945 / 2013) recommendation that one be open to creating new terms and language so as to describe the phenomena one observes; this has enabled me to amalgamate and express the theoretical framework of this study as well as to be more open to creating new terms whilst reading the narratives of people on the 'autism' spectrum. Maybe it is more so the sense of exploration that Merleau-Ponty's recommendation creates in oneself, enabling me to exercise a phenomenological attitude that is willing to play with words and language so as to explore my understanding of 'self' as well as the 'other'. Therefore, reflecting the process(es) of my questioning myself and my research questions throughout this study whilst simultaneously seeking to create research questions that are reflective of, and sensitive to, the lived experiences of people on the 'autism' spectrum. This in itself is likely to lead to a deeper understanding of the inner lives and meaning-making process(es) carried out by people on the 'autism' spectrum, adding to the field of 'autism' studies by attempting to unveil some of the more nuanced ways of being that such persons

experience and exhibit. Therefore, the theoretical framework has also enabled me to practically exercise a phenomenological attitude throughout this study via the use of narratives and my writing.

Although, the dynamic nature of 'self' has an implication for one's use of language, in that it leads to having to create language that is paradoxical and for one to write as such. Jung states that (1961 / 1995, p.384):

“Now if the dynamic conception of the psyche is correct, all statements which seek to overstep the limits of the psyche's polarity – statements about a metaphysical reality for example – must be paradoxical if they are to lay claim to any sort of validity.”

Jung (1961 / 1995) then proceeds to add that our concepts and language are rendered redundant in the face of the one that is not visible and not knowable. In light of my self being paradoxical, dynamic and mysterious the endeavour of seeking self-knowledge becomes meaningless in this sense. As much as the writings and statements throughout this thesis about 'self' and 'the lived experience' are carried out in an attempt for my seeking self-knowledge and for 'others', simultaneously, my lived experience and my knowledge of it is continually escaping me. In one of his papers Stolberg (2006; p.427) asks the question “What if the language of explanation were itself in motion?” Implying that the questions are also in motion and that something is always 'lost'. In an attempt to address this I have exercised what Jung has recommended above insofar as is possible, i.e. to write paradoxically as and when is required.

Therefore, my writing is created and influenced by my reflexive embodied and non-embodied paradoxical, dynamic and mysterious self and lens. The writings within this thesis are reflexive, in that, for example, I do not pertain to a particular school of thought in the field of 'autism' studies yet am open to explore all the ideas thus far in a dynamic manner, creating and using language as it suits this endeavour; paradoxical in that, for example, my aim is to seek self-knowledge and yet simultaneously I acknowledge that when facing the mystery of life I cannot do this with language and concepts alone; dynamic in the sense that, for example, I have been to-ing and fro-ing between two languages in a paradoxical manner in order to create and amalgamate this theoretical framework; and mysterious in the sense that as much as some things may have been unveiled and understood by me and also

hopefully by the reader. Simultaneously, a lot more questions have emerged, whereby my questioning is (i) a reflection of my attempt to understand the mysterious and (ii) is itself a part of the mystery.

Furthermore, my recognition of the embodied and non-embodied aspect of self has led to my creating the term 'embodied&non-embodied' so as to visually reflect the chiasm or intertwining of flesh and consciousness that Merleau-Ponty (1964 / 1968) and the Quran (approx. 600 A.D.; Surah Qaf) refer to. It is a term that reflects the paradoxical aspect of 'self', i.e. that it is embodied and non-embodied simultaneously, and it being visually expressed as an entire term without any spaces reflects the oneness – or the unifying invisible / mysterious – element of 'self'. I have also taken up the term 'autism' to reflect the notion that for me 'autism' exists in the sense that the person has a neurological makeup that means they have certain hyper and hypo bodily senses that create and shape their worldview. However, seeing as all beings are unique – or mysterious in their own ways – and no one person on the 'autism' spectrum is the same as another, simultaneously 'autism' does not exist. In addition, 'autism' is viewed as a syndrome that affects one's ability to interact in a way that is according to the social norms of the given culture, however, communication is transactional and intersubjective, occurring between at least two agents (Sacks, 1985; Hobson, 2010). Therefore, to focus on the 'autistic' person only as having a 'severe impairment of social interaction' (Wing and Gould, 1979) is unethical as both agents are responsible for the effectiveness of communication. Hence, in recognition of these two factors, I use the term 'autism' with apostrophes. I will continue to use both terms, i.e. 'embodied&non-embodied' and 'autism', from the next chapter onwards so as to demonstrate my thinking and how I have used them.

To sum up, the implication(s) of being aware of my reflexive embodied and non-embodied paradoxical, dynamic, mysterious self and lens has led me to question myself and my questions, to focus on the lived experiences and autobiographical writings of people on the 'autism' spectrum and to create sensitive research questions that in themselves are created with thoughts, words, language and concepts that reflect a Sophianic worldview and lens.

I shall proceed to focus on the implications of my phenomenological attitude for this study.

4.4.3. Implications: the attempted perceptual standpoint

The attempted perceptual standpoint by Alevism and phenomenologists is that of what I have come to recognise and define as the 'phenomenological attitude'. For the purposes of this study the theoretical framework of this thesis, i.e. my reflexive embodied and non-embodied paradoxical, dynamic, mysterious self and lens, in action throughout this research is simultaneously my phenomenological attitude in action. This in turn has influenced my perception, self-knowledge and meaning-making as well as this research – both in terms of the approach I have developed and in terms of exercising it throughout this study, which includes my creation and use of language and writing. I have attempted to be as open about this process(es) as much as I can and have reported it throughout this thesis.

My phenomenological attitude has implications for this study in that each stage of this research has fed into the next stage whilst simultaneously re-shaping the prior given concepts and writings of these chapters – right from the outset of creating questions through to the literature review, methods, analyses, findings, discussion and future research. Therefore, concentric and reiterative dynamic processes of my reflexive experiences, readings and thought(s) have informed, and continue to inform, to create this study and thesis. Becoming aware of this aspect of the theoretical framework, i.e. my phenomenological attitude, has enabled me to exercise a Sophianic lens of seeking self-knowledge throughout this study, e.g. questioning myself and my questions throughout and writing as so.

Having outlined and discussed the creation and bridging of the various elements of the theoretical framework herein I shall now summarise this sub-section.

4.4.4. Summary of the implications

In summary, I seek self-knowledge and to be consciously aware. The technique and approaches within Alevism and phenomenology have led to the creation – or

maybe simply the conscious recognition of – my reflexive embodied and non-embodied paradoxical, dynamic and mysterious self as my understanding of my self and as a lens. This has enabled me to address my ethical dilemmas by forming a conceptual glass globe through which I can examine and question myself as well as my questions; which has been a demonstration of my phenomenological attitude in action and has brought clarity to my confusions. I have been able to turn to the narratives of people on the ‘autism’ spectrum so as to gain as much of an insider’s view of the ‘other’ as far as I can and I have come to feel less anxious about what my projections and transferences upon the ‘other’ may be – albeit this sense of anxiety is still present and I continue to work with it. Therefore, my attempted perceptual standpoint of exercising a phenomenological attitude throughout this study has enabled me to dance as an Alevi and as a social science researcher in as harmonious a manner as I can whilst attempting to seek self-knowledge of myself and the ‘other’, reporting it as reflexively as possible. Researchers who have an intention to know themselves could take up and adapt this approach, i.e. exercising a phenomenological attitude whilst working with participants’ life stories and lived experiences, which could enable them to work with participants in a more sensitive and ethical manner. ‘Autistic’ people and their families who are seeking to understand their lived experience(s) and themselves better could also carry out a similar endeavour(s); this might lead to all family members making better informed decisions and behaving in more sensitive ways.

4.5. CONCLUSION

In this chapter I have introduced and discussed the theoretical framework of this study and how it came to be. I have come to view and understand my ‘self’ as a reflexive embodied and non-embodied paradoxical, dynamic and mysterious being and have also recognised this as a conceptual lens through which I have exercised my phenomenological attitude. This has enabled me to address my ethical dilemmas as far as possible and to amalgamate my worldviews as a social scientist and as an Alevi via the underlying bridge of the Sophianic worldview present within both phenomenology and Alevism. I have also discussed the implications of this with regards to my reflexive approach to, and of, this study, including my use of

narratives, language and writing; acknowledging that language can only go so far in pointing to the non-visible or mysterious aspect of our lived experiences. Others, e.g. 'autistic' people, their families and researchers etc., could benefit in taking up such an approach and adapting it for their endeavours so as to create more sensitive ways of being within families and more ethical research in the field of 'autism' studies.

The next chapter, *My Phenomenological Attitude and a Review of Literature in the Field of 'Autism' Studies* (Chapter Five), shall outline and discuss how the theoretical framework was exercised with regards to past and current literature in the field of 'autism' studies. Therefore, I will have begun to demonstrate how the implications highlighted above have been exercised in terms of the specific practical actions I took with regards to this research.

5. MY PHENOMENOLOGICAL ATTITUDE AND A REVIEW OF LITERATURE IN THE FIELD OF 'AUTISM' STUDIES

5.1. INTRODUCTION

In this chapter I shall illustrate how I have focused my gaze and worldview of a reflexive embodied&non-embodied paradoxical, dynamic and mysterious self and lens (my phenomenological attitude) upon research in the field of 'autism' studies. I highlight the gaps that I have observed in past and current research, e.g. how the pioneers were reflective but not necessarily reflexive when taking up the term 'autism' and creating the criteria for recognising 'autism', how research has tended to focus on the behaviour of children only – ignoring their inner lives and lived experiences, how research has not utilised a developmental lens that focuses on the inner lives of people on the 'autism' spectrum from childhood into adulthood, and how the contexts of the studies have tended to be in medical settings rather than the home settings of people on the 'autism' spectrum, therefore affecting what was observed. This in turn has led to a rationale for the research aim, questions and method of this study, as outlined earlier in Chapter One, sections 1.2.1. *The research aim* and 1.2.2. *The research questions* in the *Introduction* chapter, and here in this chapter's sub-section 5.4. *Focusing on what is missing in the current field of 'autism' studies: a rationale for the study herein.*

The word 'autism' is derived from the Greek word 'autos', meaning "self", and it is recorded as being first used by the Swiss psychiatrist Eugen Bleuler in 1911 to refer to a sub-group of children then viewed as experiencing 'schizophrenic autism' (in Asperger, 1943). However, it was later taken up by Ssucharewa (1926 in Wolff, 1996; Posar and Visconti, 2017), Asperger (1943) and Kanner (1943) to describe a set of behaviours they observed in young children whom they did not deem to be schizophrenic in the usual way, and other researchers since then have used these criteria. I shall initially critique how the three pioneers mentioned above have seemed to have utilised a reflective, though not necessarily a reflexive, lens that focused on what I view to be the embodied&non-embodied paradoxical, dynamic and mysterious behaviours and abilities of children on the 'autism' spectrum, thereby creating the label and criteria of 'autism'. I have read the original works of Dr. Grunya

Efimovna Ssucharewa (1926) (translated in Wolff, 1996), Hans Asperger (1943, translated) and Leo Kanner (1943) and I discuss them here. It is important to focus on, with and through such works because the current criteria in recognising an 'autistic' person as being 'autistic' "still retains strong echoes of ideas and even language put forth seven decades earlier" (Sheffer, 2018; p.15). Therefore, reading such works anew whilst exercising a phenomenological attitude may enable further insight(s) to be developed from such researchers and their work.

I will then proceed to discuss how the concept and label of the term 'autism' has changed over the years without much literature focusing on the very lived experiences of 'autistic' people themselves – which also include adults (Waltz, 2005; Davidson and Smith, 2009; Lawlor and Solomon, 2017) – this being the case down to the very manner in which we as researchers generate research questions. I shall include accounts and literature from academics, some of whom are themselves 'autistic', and who are advocating for more phenomenological research in the field of 'autism' studies that focus on the lived experiences of people on the 'autism' spectrum and their voices, e.g. Zahavi and Parnas (2003), Milton (2012, 2014a, 2014b) and Lawlor and Solomon (2017). They state that phenomenology as a methodology is more suitable and ethical to utilize for the purposes of carrying out research with people on the 'autism' spectrum as it enables researchers to focus on 'autistic' persons' voices whilst simultaneously acknowledging one's own biases. In terms of creating and using more sensitive language, I shall use the terms 'autistic' or 'autism', as outlined in section 4.4.2. in Chapter Four. I also use other terms such as "autistic' people' or 'people on the 'autism' spectrum'. Furthermore, I will provide a rationale for taking up a developmental lens that focuses on the inner lives of people on the 'autism' spectrum within the family context over a lifespan from infancy to adulthood.

The implications for this study both in terms of the methodology (the manner in which I am thinking about the study epistemologically) and the methods (the action oriented behaviour with regards to my epistemological standpoint) will also be outlined. I will provide a rationale for utilising the narratives of 'autistic' people to question my own worldview and beliefs, to question my position of power as a researcher and to create what I hope were and are sensitive questions. Beginning to demonstrate how exercising a phenomenological attitude may help to form a more

ethical bridge through which theorising about ‘autistic’ people and their lived experiences in an explicit manner, changing our very own assumptions, research approaches and practices may take place.

5.2. WHAT IS ‘AUTISM’? FOCUSING ON THE RESEARCH OF SOME OF THE PIONEERS

Here I shall focus my reflexive embodied&non-embodied paradoxical, dynamic mysterious self and lens upon the research of some of the researchers who are regarded as being pioneers in the field with regards to recognising ‘autistic’ children and for creating a theory regarding them. I shall initially focus on the work of Dr. Grunya Efimovna Ssucharewa’s work (1926) and then proceed to focus on Dr. Hans Asperger (1943) and then Dr. Leo Kanner’s (1943) work, teasing out the paradoxical, dynamic, mysterious, embodied and non-embodied as well as reflective elements of their research. I shall use extensive quotes here so as to enable the reader to read the original words of the pioneers as well as to demonstrate how I engaged with their theories.

5.2.1. What is ‘autism’? Dr. Grunya Efimovna Ssucharewa’s (1926) Criteria

In 1996 the child psychiatrist Sula Wolff published an article in the journal of *European Child and Adolescent Psychiatry* (5, pp.119-132) which was an English translation of Dr. Grunya E. Ssucharewa’s 1926 paper. The title of Wolff’s (1996) paper is “The first account of the syndrome Asperger described? Translation of a paper entitled “Die schizoiden Psychopathien im Kindesalter” by Dr. G.E. Ssucharewa; scientific assistant, which appeared in 1926 in the *Monatsschrift für Psychiatrie und Neurologie* 60:235-261”, outlining how Dr. Ssucharewa described in detail the kinds of children that Hans Asperger too had later described. Ssucharewa was a female psychiatrist working in a hospital in Moscow at the time of publishing her paper and Wolff (1996) provided a complete translation of it; having been translated by the Director Professor M.O. Gurewitsch at the Hospital School of the Psychoneurological Department for Children in Moscow. Wolff (1996) did this so that Ssucharewa’s work and contribution to the field be given credit for what it was and is,

highlighting that despite the use of different terms then, Ssucharewa's observations and discussion then are as relevant as they are today in recognising 'autistic' children.

When reading Ssucharewa's (1926) paper one can see how she drew upon the works of other psychiatrists in the field who had begun to recognise a group of children who were deemed to be schizophrenic but whose developmental pathway was significantly different to their peers. For example, she referred to the works of German psychiatrists such as Ernst Kretschmer, Josef Berze, Emil Kraepelin and the Swiss psychiatrist Paul Eugene Bleuler so as to set the context for her study and to provide a rationale for undertaking the research that she did. Therefore, Ssucharewa exercised a paradoxical way of thinking, e.g. she compared the children whilst working with them to then notice that there was a group who were different, which then led her to seek out the then current literature in the field regarding this group.

Her literature review is entitled "Schizoid personality disorders of childhood" (in Wolff, 1996; p.120), therefore suggesting that 'autistic' children then were viewed as having 'schizoid personality disorders' and were labelled as such. Her aim was to attempt to create criteria whereby some clarity could be achieved in recognising this different group of children. Ssucharewa stated that (in Wolff, 1996; p.121):

"Conflicting views about schizoid personality disorders are best resolved clinically (by means of a thorough study of the patient, observed longitudinally). Here the study of children has the advantage that the essential features of the clinical picture remain much clearer, unobscured by extraneous factors (such as the social milieu, including culture and occupation; the use of alcohol and other narcotics etc.)."

Therefore, Ssucharewa acknowledged the lack of knowledge, or the mystery, regarding this different group of children and so she undertook the dynamic dialogue(s) with the then current literature – and later the dynamic endeavour of the method of investigation within her field – to help create a concept(s) and criteria regarding how to recognise such children. Her scientific standpoint seems to have been that of a logical positivist, focusing on behavioural observations in a clinical setting and attempting to decrease the possibility of the effect(s) of the social environment(s) of the child in order to attain as much of a clear picture as possible of the "essential features of the clinical picture". Hence, she was working from a roughly

preconceived idea of 'autistic' children and was seeking to gather data via the use of case studies so as to bring forth some knowledge regarding such children.

Ssucharewa observed six boys aged ten to thirteen years old over a span of three years. They were in-patients at the Psychoneurological Department for Children at the hospital in Moscow. She described each boy in-depth, case by case, providing detailed information with regards to their social background and personal history, and gave various observational measurements, e.g. their height and weight, body shape and features, their nervous system, results of psychological testing etc. Ssucharewa then proceeded to outline three criteria for recognising this different group; the following is an excerpt from the paper (in Wolff, 1996; p.129):

"An odd type of thinking

- a) a tendency towards abstraction and schematization (the introduction of concrete concepts does not improve, but rather impedes thought processes);
- b) this characteristic of thinking is often combined with a tendency to rationalization and absurd rumination (see cases 1, 2, 3, 4, 5). This last feature often marks the personality as odd.

An autistic attitude

All affected children keep themselves apart from their peers, find it hard to adapt to and are never fully themselves among other children. Case 1, 2 and 3 became objects of ridicule for the other children after their admission to our school. Cases 4 and 5 carried no weight among their peers and were nick-named "talking machine", although their level of overall functioning was far above that of the other children. Case 6 himself avoids the company of children because he finds it painful.

All these children manifest a tendency towards solitude and avoidance of other people from early childhood onwards; they keep themselves apart, avoid communal games and prefer fantastic stories and fairy tales.

Emotional life

There is a certain flatness and superficiality of emotions (cases 2, 3, 5). The latter is often combined with what Kretschmer has aptly called the **Psychasthetic aspect of mood**. This mixture of insensitive and oversensitive elements was seen in all our cases.

Case 1 had affective sluggishness as well as exaggerated sensitivity; case 2 demonstrated increased irritability resulting in explosive emotional outbursts, combined with affective sluggishness, in line with Bleuler's description of spasms and paralysis of emotions. Case 5 had a generally calm mood state and was at the same time passionately

tender towards some of the people close to him. Case 4 was a gloomy, irritable misanthrope but also a tender loving son.”

Therefore, Ssucharewa identified an “odd type of thinking”, an “autistic attitude” and the children’s different kind of “emotional life” as the factors to focus on when attempting to differentiate and recognise the child with a “schizoid personality disorder”. It would seem that she was one of the first psychiatrists to begin to use the term “autistic” in relation to this group of different children. She had concluded that (in Wolff, 1996; p.130):

“Our description of the *symptomatology of schizoid personality disorder* is similar to that of Kraepelin’s eccentric type and to Kretschmer’s schizoid group. The core features of schizoid people, as described by Kretschmer: autism and psychasthetic mood were present in all our cases.”

Although as the quote above illustrates, different terms were being used by different psychiatrists to refer to a group of children that were being described in similar detail by them in their writings; demonstrating the dynamic nature of the creation and the use of such concepts and terms as well as what was being emphasised about the observed nature of ‘autism’, e.g. in Ssucharewa’s case it is “autism” and “psychasthetic mood”.

Furthermore, Ssucharewa had highlighted other characteristics such as “a *tendency towards automatism*” (e.g. difficulties in adapting to new situations), “*impulsive odd behaviour*”, “*clowning, with a tendency to rhyming* and stereotypic neologisms” and “a tendency to *obsessive compulsive behaviour*” (in Wolff, 1996; p.129). She also included details about “*motor impairments*” that all the boys displayed, e.g. clumsiness, “abruptness of movements”, “synkinesias”, lack of “facial expressiveness and of expressive movements” and “oddities and lack of modulation of speech” (in Wolff, 1996; p.129). Hence, in order to collect the necessary data for this study, Ssucharewa had focused on the embodied nature of these children and how they navigated in their environment(s). This is an implicit intersubjective way of thinking of the interaction(s) between the embodied self (i.e. the embodied child in this case) and the non-embodied self (i.e. the environment). However, she did not reflexively consider how the specific group of children she observed, and the

environment in which she observed them – which was outside of their familial environment – may have influenced her observations and thinking.

Regarding the concept of schizophrenia, Ssucharewa stated that (in Wolff, 1996; p.131):

“In analysing our case material we took as our starting point the concept of schizophrenia as a disease process with a definite tendency towards disintegration of the personality. Our patients had none of the features which might suggest that they belonged to this group.

[.....]

Our observations force us to conclude that there is a group of personality disorders whose clinical picture shares certain features with schizophrenia, but which yet differs profoundly from schizophrenia in terms of its pathogenesis. At present we can only speculate about the possible biological / pathogenetic substrate of this disorder. The explanation that best fits the clinical phenomena is that schizoid personality disorder arises on the basis of an inborn deficiency of those systems which are also affected in schizophrenia (but that in the latter condition other, additional, influences are at play).”

Therefore, Ssucharewa recognized a group of children whom she deemed to have a “schizoid personality disorder” from birth and whose developmental pathway / pathology differed from the then understanding and concept of ‘schizophrenia’, speculating over the ‘cause(s)’.

In summary, Ssucharewa’s dynamic endeavour, which involved paradoxical ways of thinking, led her to carry out research that focused on the embodied and non-embodied nature of this different group of children with “schizoid personality disorder”. It led her to identify and create three main criteria and several other characteristics by which to recognise ‘autistic’ children as so, therefore, unveiling an element of the mystery, or the not-knowing, regarding these children – to a certain degree. Ssucharewa was reflective insofar as attempting to allow her observations to enable her to refine her thinking and to consider the use of a more specific concept and term within the umbrella term of ‘schizophrenia’, i.e. “autism”, with regards to the different group of children she observed. However, she did not provide any details as to what kinds of implications these findings had for her as a researcher and for her practice(es) at an individual level, hence, she was not necessarily reflexive (at least not in this 1926 study and paper). Although considering her aim, the then research

paradigm that she worked in as a psychiatrist, as well as the then cultural norms – which may not have included asking children how they experienced reality(ies) and made sense of their ways of being, she still provided very insightful detailed knowledge regarding ‘autistic’ children.

I have illustrated how I have attempted to exercise my phenomenological attitude to focus on and discuss Dr. Ssucharewa’s criteria regarding what ‘autism’ is. Now I shall proceed to Dr. Hans Asperger’s 1943 paper regarding what ‘autism’ is.

5.2.2. What is ‘autism’? Dr. Hans Asperger’s (1943) Criteria

Hans Asperger was an Austrian paediatrician and Director of the Special Education Department of the hospital within the Medical Faculty of the University of Vienna. In October 1943 he published a paper in the *Archiv für Psychiatrie und Nervenkrankheiten* (pp.76 -136) entitled “Die “Autistischen Psychopathen” im Kindesalter”, “The “autistic psychopaths” in childhood”. The original paper was in German and in 2013 a colleague, Rod Morris, and I were able to have the original translated into English by Dr. Herbert Murbach, a German native whose fields of study also included psychology. This study and paper is viewed as being one of the pioneering pieces of knowledge in mainstream ‘autism’ studies as it led to the emergence of the term “autistic psychopaths” regarding children who were deemed to be schizophrenic but whose developmental pathway differed to the then concept of schizophrenia. Asperger (1943, p.76) began the paper with the following paragraphs:

“Order and knowledge of the structure of things is one of the ultimate goals of science. Life’s phenomena are full of contradictions, which merge with blurred boundaries. The rational mind seeks a fixed point of view. Phenomena are named and distinguished from other phenomena. Relationships, similarities and differences bring them into an order system. This is an essential prerequisite of cognition.

The science of man had to walk a similar path. But the difficulties are nowhere as great as here:

Each person is a unique, unrepeatable, indivisible creature ("individual") and incomparable with another person. It seems there exist contradicting traits in each character - but life lives especially of contrasts and tensions.

Finally, man is the most enigmatic creature on earth; his true personality he does not know himself, nor anybody else who wishes to explore him.

Since ever thinking people made effort to classify images of human characters. So a typology was set up with the purpose to segregate the diversity of life.”

Asperger was beginning to touch upon the “contradictions”, “contrasts” and “tensions” – or the paradoxical elements – of the nature of being as well as the way in which one’s cognition seeks to understand via the means of comparing and contrasting, e.g. focusing on similarities and differences. He implied that for the scientist this is so as to attempt to project some kind of an order of meaning upon life’s phenomena, despite their merging “blurred boundaries” – or in other words their dynamic nature. It seems that for Asperger it is the “fixed point of view”, or a focus on “a typology” or “image”, that then leads to the separate notions regarding the “diversity of life” and phenomena. Furthermore, he acknowledged that the human being is an “enigmatic creature” – or in other words a mysterious being, implying that attempting to research the nature of a human being is always an attempt(s) and can never be fully achieved. Therefore, it would seem that Asperger was on the brink of a certain kind of knowledge that meant that he was viewing his endeavour as entailing paradoxical, dynamic and mysterious elements. However, given that Asperger solely focused on the ‘autistic’ children it would seem that he wrote these opening statements to his paper in relation to the ‘other’ and left it at that. He did not reflexively acknowledge that he was implicated in such statements because he too is / was a unique and enigmatic human being.

After a discussion of the then literature, drawing upon the works of, for example, Ernst Kretschmer, Kurt Schneider, Carl Gustav Jung and Paul Eugene Bleuler, Asperger then proceeded to highlight why he chose the term “autistic psychopaths” to describe the children he focused on and to create a relevant concept (p.84):

“We have chosen the term "autistic psychopaths" for this group of abnormal children, in an effort to find a term which describes that basic defect which apparently organizes their personality. The name is derived from the term “autism”, it is mistakenly over-used regarding schizophrenic persons. It is generally known, the term was created by Bleuler – in our opinion one of the greatest linguistic and conceptual creations in the field of medical naming.

While people normally live in continuous interaction with the environment, constantly reacting to it, the "autistics" in these relationships are seriously disturbed and constricted.

The Autistic is only "himself" (hence the word *αυτος*), he is not a living part of a larger constantly influencing organism, which acts constantly on him."

Therefore, via a paradoxical way of viewing interactions, i.e. that between the child and their environment, Asperger identified a core aspect of his theory of "autism" or "autistic psychopaths" – children of the 'self', inner-life oriented persons who struggled to live in a continuous interaction(s) with the environment. He referred to Paul Eugen Bleuler and quoted from him regarding a concept that he (Bleuler) had identified / constructed as "schizophrenic autism" (p.84):

““Schizophrenics lose contact with reality” to differing extents, “no longer worried about the outside world”. There is a "lack of initiative, a lack of a certain goal, ignoring many facts of reality, an incoherence, sudden incursions and oddities". [.....] “They live in an imaginary world of all kinds of wish-fulfillment and ideas of persecution”. This thinking is not determined by reality, but by wishes, by affects and it is called by Bleuler "autistic" or "derealistic" thinking¹; it can also be found in non-psychotic people, in everyday thinking, superstition, and in pseudo-science.”

Therefore, it would seem that Bleuler had recognised a group of individuals whom he deemed as being 'schizophrenic autistics', whereby they were self-oriented and seemed to have lost contact with reality to some degree or another, lacking the want or initiative to dialogue with the outside world. Asperger highlighted that the developmental pathway or "psychopath" of this group of children was / is different to that of the usual pathway of the then concept of schizophrenia (p.85), hence, he wanted to create a concept and criteria that is in recognition of this developmental difference.

Asperger provided in-depth case studies of research regarding four boys who were pupils at the Special Education Department of the Vienna University Children's Hospital. Their ages ranged from six years old to eleven years old and details regarding their psychiatric history, behaviour, educational requirements, physical attributes, intelligence test results, reading abilities, dictation abilities and calculation abilities were provided. Asperger then began to focus on the similarities between the

children whilst simultaneously stressing that they are individuals and have their differences (p.111); this is one way in which he seems to have exercised a paradoxical and dynamic worldview so as to create his criteria. Another way in which he exercised this worldview is by comparing the children to other schizophrenic people. He observed and stated that children who are “autistic psychopaths” can be identified from the age of two onwards and that they are ‘autistic’ throughout their lives (pp.111-112), implying that there seems to be an inborn factor regarding children who are “autistic psychopaths” which pervades throughout their entire lifespan. Asperger stated that (p.112):

“Certainly, intellectual and character abilities develop; some characteristics go back or go forward in the course of individual development, so there are different images of the difficulties. But the essence remains the same. The toddler has difficulties learning the simple skills of practical life and social adjustment. The one and same disorder causes the difficulties in learning and behaviour at school as well as the difficulties in profession and the special skills of the young, as of the marriage and the social conflicts of the adult.”

Therefore, the core aspect – or “essence” – of Asperger’s understanding of ‘autistic’ children was / is their self-oriented way of being, whereby there seems to be a lack of interactional behaviour regarding socialising as well as their environment. He used a lens or worldview that focused on that which is embodied, i.e. the child in this case, and non-embodied, i.e. the social environment at the school hospital, to identify and express the core factor he deemed to be indicative of the “autistic psychopath” in a child. In an attempt to provide as much of a rounded picture as possible of the children and his understanding, Asperger also wrote about pedagogical considerations (pp.91-97), “autistic intelligence” (p.114), the children’s behaviour in the community (pp.120-123), the “Sex life and emotional life of Autistic persons” (pp.123-128), biological heredity (pp.128-132) and the “Social significance of the autistic psychopaths” (pp.132-135).

Asperger’s aim and method of inquiry was very similar to the aim and method of research carried out by Dr. Ssucharewa (1926), and despite there being differences in some of the themes each covered, both of their studies were in line with the then positivist standpoint of research that was / is more so behaviour oriented. Like Ssucharewa (1926), his focus on attaining observational and measurable data only

meant that he did not reflexively consider the influence of (i) the group of children and (ii) the possible effects of the clinical environment he was observing them in upon his own thinking. Furthermore, Asperger too did not provide a reflexive account of what implications the findings in this study had for him as a researcher at the individual level and for his practices of research – at least not in this 1943 paper or the other papers I have read of his (Asperger, 1938, 1968, 1974, 1977). Again, the possible effects of cultural norms of not asking children about their inner lives, lived experiences and how they make / made meaning probably exacerbated the effects of this method of research, leading to the exclusion of the meaning-making of the ‘other’. However, given his aim to create a theory and criteria for recognising a group of children whose development was / is different to those who experience ‘schizophrenia’, he was able to achieve his aim.

Having attempted to focus my phenomenological attitude on Dr. Hans Asperger’s criteria regarding what ‘autism’ is I shall now focus on Dr. Leo Kanner’s 1943 paper regarding what ‘autism’ is.

5.2.3. What is ‘autism’? Dr. Leo Kanner’s (1943) Criteria

Dr. Leo Kanner was an Austrian American psychiatrist working in the United States, Maryland, for Johns Hopkins Hospital. In 1943 he published a paper entitled “Autistic Disturbances of Affective Contact” in the journal *Nervous Child* (number 2, pp.217-250). This research was viewed in the field of ‘autism’ studies as another major contribution and an influential piece of work in recognising people now viewed as ‘autistic’. Kanner set out his aim as follows (p.217):

“Since 1938 there have come to our attention a number of children whose condition differs so markedly and uniquely from anything reported so far, that each case merits – and I hope, will eventually receive – a detailed consideration of its fascinating peculiarities.”

Therefore, it would seem that Kanner, like Ssucharewa and Asperger, had recognised a group of children who were different yet did not fit any of the then available psychiatric concepts regarding children. There was a lack of knowledge, or a not-knowing / mystery, regarding these children and Kanner sought to attempt to address this.

He proceeded to describe eleven children, ranging from two and a half years old to eleven years old and eight of whom were males and three were females, on a case by case basis – just as Ssucharewa (1926) and Asperger (1943) did. He provided detailed information regarding the children’s families (e.g. their parents’ occupations, siblings etc.), their personal history in terms of their developmental pathway derived from accounts from their parents (e.g. when the child could walk, how he or she communicated – and not, use or / and non-use of language, her / his memory abilities and behaviour). Kanner also wrote about their Intelligence Quotient (IQ) test results, although I do not want to delve into the use of IQ tests and ethics here, as ‘intelligence’ itself is an attribute and a concept that is hotly contested by many researchers and this in itself could be an entire thesis. Ssucharewa (1926) and Asperger (1943) too had used such tests and Kanner followed suit – as seems to be the case in psychiatric methods of research. All in all, Kanner exercised a dynamic way of thinking by practically undertaking this study so as to try and fill in the gap of knowledge and shed some light on the mystery.

He utilized a paradoxical lens in terms of focusing on the children and their abilities. For example, regarding Virginia, an eleven year old female at the time, he quoted a psychologist from Virginia’s school as reporting (p.230):

“With the nonlanguage items of the Binet and Merrill-Palmer tests, she achieved an IQ of 94. “Without a doubt,” commented the psychologist, “Her intelligence is superior to this.... She is quiet, solemn, composed.””

He later wrote (p.231):

“When a group was formed around the piano, one child playing and the others singing, Virginia sat among the children, seemingly not even noticing what went on, and gave the impression of being self-absorbed.”

Therefore, he had focused on Virginia being intelligent as well as seemingly not wanting to socialise in the usual sense – which is a paradoxical way of viewing a person. Another example of this is with Donald T., a five year old boy, whose parents Kanner quoted (p.217):

“At the age of 1 year “he could hum and sing many tunes accurately.” Before he was 2 years old, he had “an unusual memory for faces and names, knew the names of a great number of houses” in his home town. The parents observed that “he was not learning to ask questions

or to answer questions unless they pertained to rhymes or things of this nature, and often then he would ask no question except in single words.””

Kanner had also selected the observations of Donald’s parents in a paradoxical manner, in that he quoted their reports of Donald being able to do things, e.g. “sing tunes accurately”, and yet was not asking questions – at least not in the way that the parents would have expected him to ask questions. Hence, it would seem that Kanner too had utilized a paradoxical way of thinking and focused on the children’s intersubjective nature, i.e. their embodied and non-embodied ways of being, to tease out traits he deemed to be a part of ‘autistic disturbances of affective contact’.

After describing each child case by case Kanner moved on to the discussion section (pp.241-248) whereby he began to summarise the findings (pp.241-242):

“The eleven children (eight boys and three girls) whose histories have been briefly presented offer, as is to be expected, individual differences in the degree of their disturbance, the manifestation of specific features, the family constellation, and the step-by-step development in the course of years. But even a quick review of the material makes the emergence of a number of essential common characteristics appear inevitable. These characteristics form a unique “syndrome,” not heretofore reported, which seems to be rare enough, yet is probably more frequent than is indicated by the paucity of observed cases. It is quite possible that some such children have been viewed as feebleminded or schizophrenic.”

Kanner acknowledged the individual differences of – and between – the children he observed; he seems to have exercised a paradoxical lens in the two ways that Ssucharewa and Asperger did. Firstly, he exercised such a lens with regards to the individual herself / himself, e.g. the things a child could do and not do. Secondly, he exercised such a lens to focus on the similarities the eleven children shared as well as their differences. The entire process(es) enabled Kanner to formulate a concept of a “syndrome” he termed “autistic disturbances in affective contact”, whereby he suggested that the kinds of children he focused on may well be misunderstood or mis-recognized as being “feebleminded” or “schizophrenic”. What this also implied was that an ‘autistic’ child was not necessarily “feebleminded” (e.g. did not lack intelligence) and that such children were not schizophrenic. Hence, he was moving

away from “schizophrenia” or “feebleminded” as concepts and labels with which to recognize such children.

Kanner concluded his paper and outlined the criteria in recognising “autistic disturbances of affective contact” amongst children (p.242):

“The outstanding “pathognomic,” fundamental disorder is the children’s *inability to relate themselves* in the ordinary way to people and situations from the beginning of life. Their parents referred to them as having always been “self-sufficient”; “like in a shell”; “happiest when left alone”; “acting as if people weren’t there”; “perfectly oblivious to everything about him”; “giving the impression of silent wisdom”; “failing to develop the usual amount of social awareness”; “acting almost as if hypnotized.” This is not, as in schizophrenic children or adults, a departure from an initially present relationship; it is not a “withdrawal” from formerly existing participation. There is from the start an *extreme autistic aloneness* that, whenever possible, disregards, ignores, shuts out anything that comes to the child from the outside. Direct physical contact or such motion or noise as threatens to disrupt the aloneness is either treated “as if it weren’t there” or, if this is no longer sufficient, resented painfully as distressing interference.”

Therefore, for Kanner the core factor in recognising an ‘autistic’ child is that right from birth they do not relate in the usual – or the expected way – with people and the environment. He referred to this as “from the start an *extreme autistic aloneness*”, which for him is what differentiated ‘autistic’ children from schizophrenic children and adults. This is very much in line with what Ssucharewa (1926) and Asperger (1943) were putting forward. It is also a demonstration of how Kanner used a paradoxical lens of comparing and contrasting to recognise and label such children.

Some of the other behaviours that Kanner outlined are to do with the children’s communication abilities (verbal and non-verbal) as well as their cognitive abilities; he highlighted that despite the significant differences in the way in which such children use and do not use language, e.g. there being delayed echolalia, they have an excellent rote memory and are intelligent. Hence, Kanner attempted to provide as much of a rounded picture of the children as he could.

In the “Comment” section (pp.248-250) Kanner stipulated that the children did not fit the usual concept of schizophrenia and completed the paper with (p.250):

“We must, then, assume that these children have come into the world with innate inability to form the usual, biologically provided affective

contact with people, just as other children come into the world with innate physical or intellectual handicaps. If this assumption is correct, a further study of our children may help to furnish concrete criteria regarding the still diffuse notions about the constitutional components of emotional reactivity. For here we seem to have pure-culture examples of *inborn autistic disturbances of affective contact*.*"

Kanner exercised an embodied and non-embodied worldview and lens to establish what he deemed as the core factor of "*inborn autistic disturbances of affective contact*"; as being to do with an "*inability to relate themselves* in the ordinary way to people and situations from the beginning of life" (p.242). Which for him meant that these children had an inborn emotional difficulty(ies) and difference with creating and maintaining relationships or connections with people and their environment(s), leading to "extreme autistic aloneness" (p.242) and behaviours that were repetitive, "obsessive", focused more so on objects and non-spontaneous, with a dislike for intrusions. He used a paradoxical lens in (i) observing the children on an individual basis, e.g. a child having an excellent rote memory and not using language in the expected way, (ii) by comparing the children within the group being studied – looking for similarities and differences in traits, (iii) by comparing them with those who were deemed to be schizophrenic, and (iv) by comparing them with those who were not born with an 'autistic' or schizophrenic aspect to their being.

Kanner's desire to create some criteria in identifying such children seems to have arisen from wanting to differentiate them from those who were recognised as being schizophrenic as he felt that the developmental pathway of 'autistic' children was different right from birth. Therefore, he was attempting to create a new concept and criteria to establish this. It seems that he exercised a paradoxical and a dynamic way of thinking and researching so as to identify this mystery, or a not-known factor, regarding these children. He was also reflective to the degree of attempting to enable his way of thinking to be influenced and changed by such a group of children, in that he recognised them and attempted to formulate a new way of thinking about them. Which could be said to be reflective insofar as bringing forth new knowledge and enabling researchers to attempt to understand 'autistic' children via a new concept – as is also valid for Ssucharewa (1926) and Asperger (1943).

However, Kanner was not reflexive by questioning his own questions, assumptions, observations and practices and nor in studying how 'autistic' children experienced

the world. For example, he observed that they preferred to play with objects rather than socialise when entering the office, but did not ask the children how they felt whilst undergoing this activity(ies) or / and consider what implications this had for his own aim, methodology and methods of research. He had been reflective throughout the study and this paper (1943), though not entirely reflexive. Again, this may be a reflection of the then societal attitudes of not asking children about their inner lives, albeit some psychiatrists such as Carl Gustav Jung were doing so at the time. Kanner had also highlighted that all the children came from highly intelligent families, which in itself is likely to have led to a non-diverse group of 'autistic' children. Furthermore, one assumes that the families were aware enough, and also wealthy enough, to take their children to see a doctor and the observations were carried out in clinical settings – not the children's families' settings. These are factors that are likely to have affected the kinds of children Kanner ended up observing and what he observed, therefore, influencing his thinking and the criteria – aspects of his research he has not reflexively delved into. Although this is also applicable to Ssucharewa's (1926) and Asperger's (1943) findings and criteria.

Furthermore, it is noteworthy that Kanner worked very closely with two researchers, Anni Weiss (a psychologist) and Georg Frankl (a physician), both of whom had worked at the Curative Education Clinic in Vienna beside Asperger. They had immigrated to the United States as they were Jewish and their lives were in danger due to the rise of the Nazi party. Whilst working at the clinic in Vienna, Weiss and Frankl had published papers regarding 'autistic' children in 1934, 1935 and 1937, and after moving to the United States they got married and both worked with Kanner at Johns Hopkins' Harriet Lane Children's Home in Maryland (Sheffer, 2018). Interestingly, Asperger never seems to have referenced Weiss and Frankl's work (Sheffer, 2018) nor Ssucharewa's work at that (Wolff, 1996). On the other hand, Kanner did reference Weiss and Frankl's work (Sheffer, 2018). Therefore, it is of no surprise that Kanner and Asperger used the term 'autism' or came up with ideas regarding 'autistic' children that have overlaps, e.g. the notion that 'autistic' children are as so from birth / infancy.

The mainstream method of carrying out research in a logical positivist paradigm, of attaining observational data and projecting western academic concepts and language on to the findings so as to make meaning of the data, is also likely to have

influenced Kanner's findings and thinking. He seems to have exercised a reflective embodied and non-embodied paradoxical, dynamic and mysterious lens in an attempt to understand and make sense of what he deemed to be "autistic disturbances of affective contact" – which had been a mystery to him and to his colleagues in the field. However, he had not been reflexive in terms of seeking the children's meaning-making of their lived experiences and the implications of this for him as a researcher.

Having attempted to focus my phenomenological attitude on Dr. Leo Kanner's 1943 concept regarding what 'autism' is I shall now summarise this sub-section.

5.2.4. Summary of what is 'autism'? Focusing on the research of some of the pioneers

In summary, I have attempted to focus my reflexive embodied&non-embodied paradoxical, dynamic and mysterious self and lens (i.e. my phenomenological attitude) on how the pioneers seem to have created the concepts of "Schizoid personality disorders of childhood" (Ssucharewa, 1926 in Wolff, 1996; p.120) or "an autistic attitude" (Ssucharewa, 1926 in Wolff, 1996; p.129), "autistic psychopaths" (Asperger, 1943; p.84) and "inborn autistic disturbances of affective contact" (Kanner, 1943; p.250). Whereby they seem to have utilised an implicit reflective embodied and non-embodied paradoxical, dynamic and mysterious self and lens to recognise 'autistic' children and to create the label of "autism". Although all three highlighted that the main marker of such children was their preference for being alone and not seeking to socialise from birth, hence their use of the terms "autism" and "autistic". They implicitly focused on the physical features of the children, their behaviours and their interactions with their environment(s), i.e. the children's intersubjective ways of being, although have not been explicit and reflexive about the implications of this for themselves and their practice(s).

They accessed children of families who were aware enough and had enough money to access a doctor and observed them in clinical settings, which are all factors that are likely to have affected the kinds of children they observed and the kinds of behaviours they recorded. However, the family environment is usually the first environment which a baby enters and has her / his first experiences of life

(Bronfenbrenner, 1979), therefore, he / she is very much influenced by it. When researchers do not observe children in their familial context(s), i.e. usually their very first social setting(s), this is likely to lead to the omission of a significant amount of observations and insights – leading to a less rounded understanding of such children. What with the children being of a young age there is also the element of a lack of voice having been exercised by them (Waltz, 2005). However, all three researchers were able to create criteria by which to recognise these children, and so ‘autism’ as a concept and term arose from medical practitioners and was / is constructed by professionals looking at ‘autistic’ children from the outside, without attempting to understand the insider’s perspective (Williams, 1996).

Now I shall proceed to demonstrate how despite the core factor remaining the same within the later concepts and criteria to come, i.e. the “autism”, the constructs of ‘autism’ have been changing over the years.

5.3. WHAT IS ‘AUTISM’? FOCUSING ON THE DIFFERING AND CHANGING CONCEPTS

Since the early 1900s there have been further concepts regarding ‘autistic’ children and what the ‘cause(s)’ of their way(s) of being may be. In this sub-section I will focus on some of the theories in the field of ‘autism’ studies so as to demonstrate the dynamic element(s) of how there were, and are, differing and changing constructs regarding ‘autism’. I will use examples and direct quotes so as to further lay down the foundations for the rationale for the study herein.

5.3.1. ‘Autism’ in the 1950s

In 1959 Bruno Bettelheim, a social scientist who was working at the University of Chicago’s Orthogenic School and whose thinking was heavily influenced by Freudian psychology, published a paper entitled “Feral Children and Autistic Children”, so as to attempt to compare children found in the wild with ‘autistic’ children. He concluded that (p.467):

“To sum up: study of the so-called feral children, and comparison of them with known and well-observed wild autistic children, suggests strongly that their behaviour is due in large part, if not entirely, to extreme emotional isolation combined with utter destruction. It seems

to be the result of some persons' – usually their parents' – inhumanity and not the result, as was assumed, of animals' – particularly, wolves' humanity. To put it differently, feral children seem to be produced not when wolves behave like mothers but when mothers behave like non-humans. The conclusion tentatively forced on us is that, while there are no feral children, there are some very rare examples of feral mothers, of human beings who become feral to one of their children."

Bettelheim's conclusion seems to be in line with that of psychoanalytic theory, whereby the 'cause' of the 'autistic' child's 'feral' like behaviour is deemed to be a parent, i.e. the mother. Bettelheim was also a holocaust survivor and had written in such a way whereby he compared 'autistic' children to prisoners in holocaust camps during the Nazi era in Germany (e.g. Bettelheim's 1955 paper, "Childhood Schizophrenia"); this tone seems to be present here whereby he viewed the mothers of 'autistic' children as inhumane, i.e. the perpetrators. Bettelheim may well have had a point in terms of how the familial social environment may not have been as suitable for the 'autistic' child as could be, however, to use such powerful words to remonstrate mothers of 'autistic' children with such a sweeping statement is likely to have done more harm than good. What this demonstrates is a lack of self-reflexivity on the part of a researcher, whereby he did not reflect deeper into his own experiences and attempt to be more open to other kinds of thinking and use of language regarding 'autistic' people and their families. What it also highlights is that research that purely focuses on observed behaviour with the aim to generalize one's theories as far as possible, without introspection into the inner lives of human beings, is more prone to create theories that are more so reflections of researchers' projections.

During the same decade Eisenberg and Kanner had recommended taking up what could be viewed as an implicit intersubjective lens (1956; p.564):

"The dualistic view implicit in a rigid distinction between "organic" and "functional" is no longer tenable. The pharmacological production of psychosislike states stimulating certain features of schizophrenia (40, 41) – and the recent hint that analogue blockade will interfere with chemically induced "model psychoses" (42) – serves to reassert the obvious fact that biochemical change is accompanied by alterations in thought processes."

Therefore, they had highlighted that focusing on biological *and* psychological factors simultaneously would be the way forward (p.564):

“Early infantile autism is a total psychobiological disorder. What is needed is a comprehensive study of the dysfunction at each level of integration: biological, psychological, and social. The supposition of an innate difference in the autistic child will mean relatively little until we can specify the nature and meaning of that difference.”

It would seem that ‘autism’ was beginning to be viewed by these researchers in a manner whereby they were realizing the importance of both embodied (e.g. biological) and non-embodied (e.g. social / environmental) ways of being and were recommending taking up such a way of researching about ‘autistic’ people. Although it seems that the call for such a lens was within a logical positivist paradigm, therefore, leading to more research in the field that followed a similar pattern of conceptualising ‘autism’ in terms of ‘cause and effects’ and using the term ‘autism’ in dynamic ways.

5.3.2. ‘Autism’ in the 1960s

During the 1960s there began a move away from the label of ‘schizophrenia’ for ‘autistic’ children, whereby ‘autism’ began to be viewed as a developmental ‘disorder’ rather than a mental health ‘disorder’. Michael Rutter, a British psychiatrist, wrote a paper, “Concepts of Autism: A Review of Research”, in 1968 stating that (p.1):

“Psychotic or “schizophrenic” disorders in children have been recognized since the beginning of this century (Eisenberg, 1957), although it was not until the 1930’s that the topic began to arouse much interest (Potter, 1933; Bradley, 1941; Bender, 1947), and it is only with Kanner’s classical paper on infantile autism in 1943 that major differentiation *within* the overall group of children with so-called “childhood schizophrenia” was attempted. [.....] Kanner emphasized that the condition was first manifest in early infancy and concluded that in this respect autism differed from other cases of childhood schizophrenia. At that time, too, he put forward the view that autism represented an inborn disturbance of affective contact.”

Ssucharewa’s paper was published in 1926, Asperger’s paper too was published in 1943 like Kanner’s paper, although Ssucharewa and Asperger’s papers were not in English – as was Kanner’s. This highlights how the accessibility of articles and research influences and changes the lines of thinking in a field of study. It also

demonstrates how concepts can, and do, lead to changes many years after they come into being, e.g. Kanner's paper was published in 1943 and yet a move away from the use of the umbrella term of 'schizophrenia' only began in the 1960s.

Furthermore, Rutter (1968; p.4) pointed to a particular problem in the usage of the term 'autism' in the literature because it is used to "refer to a *syndrome* or "disease" (i.e. that described by Kanner using the term "infantile autism") and to a *symptom* (i.e. a particular kind of disturbance in inter-personal relationships). There is no entirely satisfactory resolution of this problem." Therefore, it would seem that because the 'cause(s)' of 'autism' was not, and still is not known, the use of the term 'autism' by researchers is also dynamic. It implies there is some kind of inherent difference in the 'autistic' person which also affects their social interactions and vice versa. My guess is that this may be to do with the concept of 'autism' being created via the means of observation(s), which is usually paradoxical by nature as demonstrated above, and therefore this has led to both ways of using the term 'autism' – as a 'syndrome' and as a 'symptom'.

Rutter concluded that (1968; p.21):

"Of all the hypotheses concerning the nature of autism, that which places the primary defect in terms of a language or coding problem appears most promising. It is suggested that many of the manifestations of autism are explicable in terms of cognitive and perceptual defects. This is an area of enquiry likely to reward further study."

Hence, Rutter's theorising of 'autism' leaned more so towards understanding 'autism' in terms of perception and cognition, which he deemed as being able to be measured via a focus on language. This is in line with the move away from the concept and label of 'schizophrenia'. However, it seems that research that focused on cognition and language with the exclusion of perception was more influential in the following decades, as follows.

5.3.3. 'Autism' in the 1970s

In 1979 Lorna Wing, a British psychiatrist, and Judith Gould, a British clinical psychologist, published a paper entitled "Severe Impairments of Social Interaction

and Associated Abnormalities in Children: Epidemiology and Classification” whereby they came to view ‘autism’ as being a continuum, manifesting to differing degrees along with other ‘disorders’, and attempted to create their own criteria for ‘autism’. This epidemiological research that was carried out in London, England, is known to be the foundation for their idea of ‘the triad of impairments’. Wing and Gould wrote (1979; p.11):

“Children with severe impairments of social interaction, abnormalities of language development involving both speech and gesture, and a behavioral repertoire consisting mainly of repetitive, stereotyped activities beginning from birth or within the first few years of life have been described by a number of writers. This pattern of impairments and behaviour problems has been variously (and unfortunately) termed *childhood psychosis, childhood autism, or childhood schizophrenia.*”

Therefore, “impairments of social interaction”, “abnormalities of language development” and repetitive stereotyped behaviour were the main three criteria by which they constructed their understanding of ‘autism’. As much as the theorising of ‘autism’ has been dynamic and continued to change, both in terms of the constructing of the concept(s) and the terms used, one can still see remnants of past research and theories, e.g. Ssucharewa’s (1926) paper had also mentioned repetitive stereotyped behaviour. It seems that the researchers have been observing similar kinds of children over the years and have been emphasising different factors as being a part of the construct(s) of ‘autism’.

During the 1960s and 1970s, what are termed as ‘disability movements’ in western countries began to take action with protests and legal lobbying. They challenged the power of the medical establishment(s), the use of language(s) that was / is used in disempowering ways, and they called for more positive discourse throughout society – language wise and practice wise (Oliver, 2013). However, despite this, research in general continued to be carried out with a medical lens regarding impairments (Pellicano, Dinsmore and Charman, 2014) rather than with a focus on differences, as illustrated below.

5.3.4. 'Autism' in the 1980s

In 1985 Simon Baron-Cohen, Alan M. Leslie and Uta Frith published a paper entitled "Does the autistic child have a "theory of mind"?"* They had drawn upon Premack and Woodruff's (1978) research regarding being able to "impute mental states to oneself and to others" (Baron-Cohen et al., 1985; p.39). How they carried out their research was by having three groups of children, twenty being 'autistic', fourteen children with Down's Syndrome and twenty-seven "clinically normal preschool children" (p.40), whereby they gave the children "Sally and Anne" (p.41) tests. This involved giving the children a scenario with two dolls, Sally and Anne, whereupon Sally placed a marble in a basket and walked out of the room. Anne then removed the marble and hid it in her box. Sally re-entered the room and the children were then asked "the Belief Question: "Where will Sally look for her marble?" (p.41), ""Where is the marble really?" (Reality Question)" (p.41) and ""Where was the marble in the beginning?" (Memory Question)" (p.41). This was repeated. After the two trials the result was that sixteen of the 'autistic' children did not pass the Belief Question, directly pointing to where the marble really was, whilst four did pass. The authors concluded that (p.43):

"Our results strongly support the hypothesis that autistic children as a group fail to employ a theory of mind."

The need to generalize one's findings seems to have led these researchers to ignore the fact that there were at least four 'autistic' children who actually were able to fulfil the task. Furthermore, one must also consider whether the other sixteen children understood the task(s), i.e. they may have been tested more so in relation to their understanding of the language that was spoken to them via the questions asked rather than understanding what was being asked of them per se. Simply put, the format of the delivery of the questions may not have been accessible for the sixteen 'autistic' children. Therefore, the logical positivist assumption and need to generalize can, and does, lead to stereotypical ways of thinking about 'autistic' people. Hence emerged the idea that 'autistic' children lacked a theory of mind, without any consideration for self-reflexivity on the part of the researchers as to whether they lacked a theory of mind regarding the 'autistic' children (Milton, 2012). What this also

highlights is a lack of recognition of our intersubjective and transactional ways of being as humans.

5.3.5. 'Autism' in the 1990s

In his paper "On the origins of self and the case of autism" (1990) Peter Hobson focused on 'autistic' children so as to attempt to understand what is meant by 'self'. He stated that (pp.177-178):

"I have argued that autistic children's awareness of themselves and other persons as subjects of experience, and ultimately their capacity to think of themselves as thinkers, is limited by disruption in their affectively patterned interpersonal relations. Their perceptually anchored understanding of affective-conative relatedness between people and the outside world is also deficient. Together, these impairments restrict the children's grasp of the manifold ways a person may "take" (construe) reality, and both be a self and relate to other selves. The fact that in spite of this they show little delay in evolving certain forms of self-experience seems to imply that not all senses of self entail recognition of others."

Therefore, it would seem that Hobson's understanding of 'autism' was / is along Kanner's (1943) line of thinking, in that 'autism' is to do with a "disruption" in the emotional life of the 'autistic' person and their ability to relate with other people. Although he added that the ability to think of oneself as a thinker was "limited" by this "disruption" and therefore had an impact on the way the 'autistic' child constructed an understanding of reality, a sense of 'self' and 'other' selves. One must, however, question whether 'autistic' children do not recognize others, in that are they actually not aware when others are present with them in the same environment? Or are they so emotionally aware of others' presence that they feel the need to pull away, and paradoxically, seem as though they are not aware of others? Nevertheless, Hobson's work has helped to open the way for research that has a focus on intersubjectivity and 'autistic' persons.

5.3.6. 'Autism' in the 2000s

In 2007 Markram, Rinaldi and Markram published a paper, "The Intense World Syndrome – an alternative hypothesis for autism"; they drew upon genetic and

neurological research to attempt to explain how and why 'autistic' people may experience the world in the manner they may do so (p.92):

“The *Intense World Syndrome* suggests that the autistic person is an individual with remarkable and far above average capabilities due to greatly enhanced perception, attention and memory. In fact it is this hyper-functionality, which could render the individual debilitated. This perspective of hyper-functionality offers new hope for pharmacological as well as behavioral treatments.”

Interestingly, this is a hypothesis that Asperger had put forward in 1938 during a lecture, although had not given it a particular name or label to it. Asperger had written the following regarding a ten year old boy he had observed at the clinic (Asperger, 1938; p.1315):

“It can also be expressed as follows: The difficulties with his relations to the world are the price he must pay for his special talent. What particularly stands out is also particularly vulnerable. We have to imagine: This man has fine sentient sense-organs, a fine differentiated brain. But because of this he is also sensitive, easily damaged and harmed by the effects of the environment.”

Despite Markram et al.'s paper being published in 2007 and utilising a different set of research and data, it would seem that they had made a very similar observation(s) and hypothesis to the one that Asperger had made in 1938. Hence, theorising about 'autism' and the construct of 'autism' seems to have been dynamic and changing in terms of the methods of research and data being used. However, paradoxically, some factors have remained the same regardless, e.g. in this case the observation and hypothesis of the sensitivity of the 'autistic' person within their given environment(s).

With the publishing of the fifth version of the Diagnostic and Statistical Manual of Mental Disorders (DSM-V) in 2013, the sensory ways of being of 'autistic' persons was included into what is now one of the main two manuals that are used by clinicians to recognize, or 'diagnose', 'autistic' people. The other manual is the International Statistical Classification of Diseases and Related Health Problems (ICD), of which the eleventh version was published in 2018 (ICD-11). The ICD is published by the World Health Organisation (WHO) and the DSM is published by the American Psychiatric Association (APA) – in itself demonstrating that the medical

establishment(s) has the final say in how 'autism' is theorised about and constructed. For example, under the sub-section of "Autism Spectrum Disorder", within the section entitled "Neurodevelopmental disorders" (DSM-V, 2013; p.50), the following is included (DSM-V, 2013; p.50, point B.4.):

"Hyper- or hyporeactivity to sensory input or unusual interest in sensory aspects of the environment (e.g. apparent indifference to pain / temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement)."

Although DSM-V now also includes three levels of "severity" (DSM-V, 2013; p.50) regarding support required. This is to do with the fact that the DSM is used by insurance companies in America to pay for health care for claimants (APA, 2018). There have been many terms used to identify 'autistic' people and this is still the case, e.g. in the ICD-11 "Autism spectrum disorder" is under the sub-section of "Neurodevelopmental disorders" and includes the term "Pervasive developmental delay" (WHO, 2018; online, chapter 6, section 6A02). Therefore, it would seem that the theorising of 'autism' and the constructing of it has been changing not only in terms of what the medical professionals have researched and concluded but also in terms of specific contextual requirements. For example, the APA decided to include levels of 'severity' so as to create pathways through which practical support can be paid for by insurance companies for those who are 'autistic' and living in America whereas the ICD-11 does not include such information. These manuals may well be useful for clinicians to recognise 'autistic' people as being so, however, they do not provide any substantial knowledge of the lived experiences and meaning-making of such persons.

So far I have exercised my phenomenological attitude on, with and through some of the kinds of influential concepts and criteria that have been created regarding 'autism', including how the term 'autism' is used; I shall now summarise this sub-section and move on to focusing on what is missing in the field.

5.3.7. Summary of what is ‘autism’? Focusing on the differing and changing concepts

‘Autism’ as a term and as a construct has been used in a dynamic manner since its first official use by Paul Eugen Bleuler in the early 1900s. It seems that from the medical point of view the core aspect of ‘autism’ remains the same, in that from childhood the individual behaves in a way that is seemingly inward oriented and prefers to isolate oneself; this as a state of being on the part of the ‘autistic’ individual has been a mystery to most researchers so far. The aspects of this way of being have been researched in different ways by researchers utilising different theoretical frameworks, research methodologies, methods and data, however, this has been so without a focus on what we can learn from the lived experiences of such persons in a self-reflexive manner.

5.4. FOCUSING ON WHAT IS MISSING IN THE CURRENT FIELD OF ‘AUTISM’ STUDIES: A RATIONALE FOR THE STUDY HEREIN

Here I put a case forward for concentrating on ‘autistic’ persons’ lived experiences by further focusing my phenomenological attitude on, in, with and through dialoguing with ‘autistic’ persons’ autobiographical narratives. This is so as to begin to focus on what is missing in the field of ‘autism’ studies in a self-reflexive manner, i.e. the lived experiences of ‘autistic’ persons over a lifespan within their family contexts – from their perspective.

5.4.1. Turning to the lived experience(s) of ‘autistic’ people in a reflexive manner

Dr. Damian Milton, an ‘autistic’ academic, highlighted that (2014b; p.7):

“In the history of autism studies, expertise has been claimed by many differing academic schools of thought, practitioners, parents, quacks and so on. Yet, the one voice that has been traditionally silenced within the field is that of autistic people themselves. Due to a lack of interactional expertise with autistic communities (Arnold, 2012b; Milton and Bracher, 2013), one could say a negative spiral has ensued. Consequently, autistic people have often become distrustful of

researchers and their aims and are frozen out of processes of knowledge production (Milton et al., 2012).”

Researchers have yet to seek the meaning-making of ‘autistic’ persons from the inside out and to create research methodologies and methods that are in line with such ways of being (Williams, 1996; Morris, 2008; Milton, 2012; Ridout, 2017). Considering that the first official autobiographical account of being an ‘autistic’ person was published by Temple Grandin in 1986, *Emergence: Labeled Autistic*, and many more have been published since (Goidsenhoven, 2017), researchers have yet to deeply dialogue with such narratives in an attempt to reflexively understand the inner lives and meaning-making of such persons.

Focusing on the inner lives of ‘autistic’ people by taking up phenomenology as a methodology may provide us with deeper insights regarding the behaviours that have been observed by medical professionals and have been termed as ‘autism’ (Zahavi and Parnas, 2003; Milton, 2012, 2014a, 2014b; Lawlor and Solomon, 2017). The need to want to be alone from infancy, the core aspect of ‘autism’ as defined by Ssucharewa (1926), Kanner (1943) and Asperger (1943), may well be explained by Christopher Goodchild’s lived experience and narrative (2009; pp.21-22):

“My earliest memories were of a world that felt totally overwhelming. Lights, sounds, movements and smells flooded into my senses, leaving me feeling distressed and anxious. For me it made perfect sense to remove myself from all social interaction. This way I felt safe from a world that was strange and alien to me, and the more I ventured out into the world the more I wanted to retreat from it.”

There is a very paradoxical nature of Christopher’s embodied and non-embodied lived experiences, i.e. as an infant he was so sensitive and connected to the environment that he felt the need to pull away – this is what may be interpreted by an onlooking researcher as ‘autism’.

Christopher explained the conflictual situation with his family in terms of his embodied and non-embodied meaning-making and their embodied and non-embodied meaning-making (Goodchild, 2009; p.21):

“When I was able to crawl I would struggle for dear life to be away from my family members, only to be picked up and returned to them. Over and over again this painful ritual was re-enacted, painful because being held felt like what some people experience when they scrape their

“fingernails down a blackboard. The more I resisted mother’s attempts to cuddle me, the more she persisted. I soon realised the wisdom that comes with acceptance and in the end gave in to my mother’s need to hold me, over my need to be away from her.”

Therefore, it would seem that there was a mystery, a not-knowing, regarding – and between – his family members’ embodied and non-embodied experiences and his embodied and non-embodied experiences as a baby. His family did not realize that their child was extremely sensitive to his environment and probably misinterpreted this as a rejection of them. Therefore, maybe they felt more of a need to be accepted by their child, continuing to pick him up and cuddle him, e.g. as his mother did. Whereas he felt overwhelmed by the experience(s) and therefore wanted to avoid social contact. One can then envisage how this kind of experience probably created and reinforced feelings of anxiety and trauma for Christopher whilst he was a baby and exacerbated his behaviour(s) in terms of attempting to be alone. This could explain why Kanner (1943; p.250) preferred to use the term “autistic disturbances of affective contact”, emphasising the emotional factor of the way of being that the children exhibited. Christopher’s example is what Milton refers to as the ‘double empathy problem’ (2014b; p.7):

“The somatic affordance of autistic and non-autistic dispositions may well create a large double-empathy problem (Milton, 2012b), where both have a difficulty in understanding the nuances of one another’s perception and sociality. To what extent can anyone immerse themselves in the language and culture of the other? At least some must be the answer, as autistic people are not ‘aliens’ despite the popular use of the term within autistic culture. Such an immersion can also be said to be the inspiration of approaches to education of autistic people that have a more child-led focus (Milton, 2012c).”

This highlights how important it is for researchers to be more self-reflexive and to develop a language that is consistent in its openness to the dialectic and circular (i) paradoxical, dynamic and mysterious nature of human experience (e.g. of oneself and that of the ‘other’) and to (ii) various ways of being and interpretations of human experience(s). The embodied and non-embodied self, as a living phenomenon in its own right as well as a concept(s), influences our ways of being. Furthermore, Milton (2014b) is calling for researchers to immerse ourselves in ‘autistic’ culture. One of

the ways in which this can be achieved is via reflexivity of, in, with and through 'autistic' persons' lived experiences and narratives.

A similar account has been given by Dr. Donna Williams, an 'autistic' academic and activist who passed away in 2017. In *Nobody Nowhere. The Extraordinary Autobiography of an Autistic*, she wrote (Williams, 1992; pp.128-131):

"The hypnotic fascination I had for the spots in the air left me with very little sensation of my own body except for the shock and repulsion of the invasion of physical closeness. Even the comfort I derived from being picked up by my grandmother was found, not in snuggling up to her, but in holding on to the chain around her neck or enmeshing my fingers in her crocheted cardigan.

There was something overwhelming about giving into a physical touch. It was the threat of losing all sense of separateness between myself and the other person. Like being eaten up, or drowned by a tidal wave, fear of touch was the same as fear of death."

Donna would lose all sense of her 'self' when being touched, so much so that this felt like death to her, as though she was being consumed by the presence of the 'other'. Meanwhile, family members' actions and reactions may not be appropriate, regardless of how much good intention there is / was. If the experience(s) becomes too painful for the 'autistic' person they may end up in a 'meltdown', e.g. feeling very anxious, frustrated, keeping away from people, refusing to enter a particular environment or attempting to exit out of the current one and behaving in ways that may be considered 'inappropriate' by family members or researchers. The above illustrates the differences in persons' embodied and non-embodied ways of being and perception interweaving with their lived experience(s), meaning-making and self-knowledge.

Olga Bogdashina (2012; p.7) highlights that 'autistic' people tend to have a 'gestalt perception' which then usually leads to mono-processing and peripheral perception as forms of avoiding sensory overload:

"They perceive everything without filtration and selection. This results in a paradoxical phenomenon: sensory information is received in infinite detail and holistically at the same time. It can be described as 'gestalt perception' – perception of the whole scene as a single entity with all the details perceived (but not processed) simultaneously."

That (Bogdashina, 2006; p.109):

“Consciously or unconsciously, they develop their own perceptual styles, in order to cope with unreliable and often painful perception [....] The most common perceptual styles in autism are: monoprocessing (Williams 1996) or monotropism (Lawson 2001) [and] peripheral perception.”

Hence, what seems to the onlooking researcher as a ‘self’ or ‘autism’ oriented way of being whereby an ‘autistic’ person may seem like they are in their own world could well be a way in which the ‘autistic’ person is attempting to cope within their environment. For example, they may be focusing on one particular object in a very deep manner so as to attempt to block out all other painful information coming in, i.e. they may be mono-processing / exercising monotropism. In addition, they may be avoiding eye contact but are actually observing what is going on in their environment through the means of peripheral perception – seeming as though they are not aware of what is occurring in the environment but are actually aware of what is occurring.

Williams continually reiterated that ‘autism’ ought to be understood in terms of how it is experienced, from the inside out. She wrote that (Williams, 1996; p.14):

“The assumption that those who seemed to be self-focused were actually in a ‘self-state’ seems to be a sweeping one. People can be intensely focused on their body parts or sensations or workings, specifically *because* they perceive them as foreign, incomprehensible, ever new and ‘other’ and generally not aware that these things are part of themselves. As a teenager, I spent many of my lunch breaks at my first secondary school trying to shake a hand off an arm without the perception that both were part of my body. I had spent a childhood trying to get away from my own body, finally accepting that the damned thing wasn’t going to stop making me aware of its clinging attachment to me.

I spent most of my life with a jumble of sounds going through my mind that were the regurgitation of sounds of the world around me and devoid of much that was generated by me.

I spent the largest percentage of my life trying to cope with what the world around me had bombarded me with, with little or no extra processing time for the luxury of having any conscious thoughts about that world. If anything, my ‘autism’, like that of so many others like me, was often an example not of a kind of ‘self-ism’ but of a kind of ‘other-ism’ where any conscious and conjoined or consistent sense of selfhood doesn’t come easily at all.

Whilst this little play on words might seem like an irrelevant load of hoo-ha, it has a point to it. That point is that right from the start, from the time someone came up with the word 'autism', the condition has been judged from the outside, by its appearances, and not from the inside according to how it is experienced. As we have seen, that has big implications for how people try to deal with the condition and big implications for 'success' or a lack of it."

Donna's extremely paradoxical experiences in terms of her embodied and non-embodied nature, i.e. as a teenager her not having a sense of owning an arm or hand but yet simultaneously acknowledging that it exists and trying to shake it off, and her connectedness with her environment(s) in such a way that she felt she was being bombarded by the world, led her to refer to this state of being as "a kind of 'other-ism'". This reported experience and her use of such a term is the opposite of the term that the psychiatrists gave, i.e. 'autism'. This has very significant implications for researchers in terms of reflexivity, research methodology, methods of research and how researchers create and use language. I hope that this study will enable me to at least begin to try and understand 'autism' in terms of how it is experienced – from the inside out. This is also a reason as to why I did not want to delve into literature or autobiographical writings of mothers and fathers of 'autistic' people. I wanted to try and begin to understand matters from 'autistic' persons' perspectives. This decision may seem too extreme. However, considering it is often the 'autistic' person's way of being that is not understood, as highlighted above, I felt more inclined to start with the voices and narratives of the very people themselves.

We as researchers have yet to deeply reflect in, on, with and through our embodied and non-embodied nature and consider the effect(s) upon research and how we ought to adjust our behaviour in line with our reflections – beginning with ourselves at the micro-level. In addition, we have yet to deeply dialogue with 'autistic' persons' embodied and non-embodied meaning-making in specific contexts over a lifespan and consider the possible implications of this for research methodology and methods. For example, Donna's behaviour of attempting to shake her hand off her arm during lunch breaks may well be interpreted by a non-'autistic' researcher as repetitive behaviour or / and self-stimulating behaviour, however, this interpretation does not give us an insight as to why Donna behaved the way she did. Whereas the

reported lived experience above gives one possible explanation as to why an 'autistic' person may carry out such behaviour. Waltz (2005; p.433) states that:

“Where medical literature attempts to define and thereby contain different ways of being, personal stories frequently contest such definitions, whilst simultaneously engaging with them through comparison and reference. These lived experiences of autism encourage the examination of assumptions about normality, impairment and difference that underlie the medical model of autism, and many foreground the issue of disablement. They also have the potential to guide actual practice: recent initiatives in health and social care policy have requested input from service users, and disability activists have requested control of the process itself in the form of ‘emancipatory research’ (Gilbert, 2004).”

Hence, a focus on, in, with and through the lived experiences of 'autistic' people via phenomenological research could help to answer the “Why?” questions regarding 'autistic' people and might lead to a deeper insight(s) into understanding and communicating with them (Zahavi and Parnas, 2003; Milton, 2012, 2014a, 2014b; Lawlor and Solomon, 2017). Further leading to (i) research questions that are more sensitive because they are embedded in the very lived experiences of 'autistic' people and (ii) to methodologies and methods that are more ethical. Therefore, creating knowledge that is more open to, and reflective of, the lived experience(s) of the 'other'.

In more recent times 'autistic' academics and activists have been taking up leading roles. For example, Jim Sinclair, an American 'autistic' person, worked with friends to set up Autism Network International in 1992 and has had a significant influence in what is now known as the 'autism rights movement'. His article 'Don't mourn for us' (Sinclair, 1993) was a call to the parents of 'autistic' people to accept their child for the unique being that they are rather than mourn for the 'normal child' that was 'lost'; in many ways it is also a call to society as a whole to do the same. Later in 2006, Ari Ne'eman, another American 'autistic' adult set up the Autistic Self Advocacy Network (ASAN), a national advocacy organization run by and for 'autistic' Americans; the organization focuses on highlighting the societal barriers for 'autistic' people and seeks to remove them. The term 'Nothing about us without us' is very visible on the homepage of ASAN's website (ASAN, 2019; online) and I have met several 'autistic' academics in the United Kingdom who use the term with regards to research.

In England, the Participatory Autism Research Collective (PARC) was set up at London Southbank University in 2015 by Prof. Nicola Martin and Dr. Damian Milton as a way to begin applying practices in line with 'nothing about us without us' within the field of 'autism' studies. According to Milton, Ridout, Kourti, Loomes and Martin (2019; p.82):

“PARC was set up with the purpose of bringing autistic people together, including scholars and activists (but not exclusively) with early career researchers and practitioners who work with autistic people, with the aim being to build a community where those who wished to see more significant involvement of autistic people in autism research could share knowledge and expertise.”

Therefore, the aim of the group was / is to create an inclusive academic ethos as well as to promote the inclusion of 'autistic' people in the creation of knowledge and the sharing of it, i.e. creating and carrying out participatory research designs.

Cornwall and Jewkes (1995; p.1668) state that participatory research is more of an attitude and an approach that is 'bottom up', i.e. working with the lived experiences of the person / community being studied, rather than a series of techniques:

“Participatory methodologies are often characterized as being reflexive, flexible and iterative, in contrast with the rigid linear designs of most conventional science [2, 3,13]. One of their key strengths is seen to reside in exploring local knowledge and perceptions. Some conventional research methodologies require researchers to continually adapt their approaches, learn cumulatively from their informants and use the categories or concepts informants provide them with.”

For a researcher with ethical anxieties attempting to learn of the 'insider's perspective' from 'autistic' people, this kind of approach was / is befitting for this study. Furthermore, PR (Participatory Research) tends to be better suited for research with 'autistic' people, or people who may be deemed as the 'other', due to the researcher sharing power in the process(es) throughout the study and being open to making changes as the study proceeds. This tends to lead to better suited research and practices in real-world situations and is therefore usually more ethical in nature (Nicolaidis, Raymaker, McDonald et al., 2015; Guldberg, Parsons, Porayska-Pomsta et al., 2017; Kosyvaki, 2017; Fletcher-Watson, Adams, Brook et al., 2019).

I have attended seminars and conferences organized and run by PARC whereby 'autistic' academics such as Wenn Lawson (formerly known as Wendy Lawson) has

spoken about what it was like for him to 'transition' from a woman to a man, and where Rod Morris, another 'autistic' academic, has promoted that professionals and families adapt a holistic viewpoint of 'autistic' people. The dialogues I have participated in during such events have helped me in developing my understanding and have also convinced me that participatory research is of utmost importance if (i) one seeks to be a reflexive researcher, and (ii) if one aims to create and develop research questions that are sensitive to, and reflective of, the experiences of the 'other'. I had initially wanted to work with 'autistic' academics and participants in person, as part of this research. However, being aware of what I was not aware of, e.g. knowing that 'autistic' people have different sensory ways of being yet not knowing what my standpoint was / is regarding this so as to develop an ethical research design, added to my need to pull back from active engagement with participants. I felt that I ought to develop my insight(s), and the way I could begin to do so was to sit down with a few 'autistic' writers' autobiographies and attempt to be reflexive regarding my understanding and assumptions and prepare sensitive questions. Simply put, in order to address my ethical anxieties, I had to develop my own standpoint and sensitise myself to the ways of 'autistic' people and their meaning-making before I could even begin to carry out research with them in person. The next chapter, *Chapter Six The Methods Process(es) and the Phenomenological Attitude*, shall illustrate how this was put into practice for the purposes of this study.

I shall now summarise this sub-section and proceed to the Conclusion of this chapter.

5.4.2. Summary of focusing on what is missing in the current field of 'autism' studies: a rationale for the study herein

I have demonstrated how my reflexive embodied&non-embodied paradoxical, dynamic mysterious self and lens (i.e. my phenomenological attitude) has enabled me to dialogue with some of the autobiographical narratives of 'autistic' persons in an attempt to bridge the observed phenomena regarding 'autistic' persons and the inner lived phenomena experienced by 'autistic' persons. It would seem that what is deemed to be 'autism' is usually a heightened experience(s) of the embodied and

non-embodied self – of ‘self’ and ‘other’ – for the ‘autistic’ person, leading to emotions of being overwhelmed to the degree of pulling away or keeping oneself to oneself, and to developing perceptual styles such as monoprocessing and peripheral perception – which are also coping strategies. Therefore, such bodily senses and perception(s) can, and do, affect an ‘autistic’ person’s experience of self as well as with ‘other’ people and the environment(s), and vice versa.

Exercising a phenomenological attitude to focus on the lived experiences of people on the ‘autism’ spectrum via the use of autobiographical accounts in family settings may enable a researcher to develop deeper insight into such persons’ ways of being. Leading to creating sensitive and more ethical research questions, research methodologies, methods and knowledge that are informed by ‘autistic’ persons’ perspectives right from the outset.

Other researchers might learn from this chapter by focusing on how I exercised my phenomenological attitude with regards to the literature in the field, how I questioned the assumptions made by past researchers and how I learned from them so as to lay down the foundations and rationale for this study. Utilizing such a phenomenological attitude may enable researchers in various fields to reflexively focus on, in, with and through the studies in their field(s) and become more consciously aware of the assumptions made. This in turn might lead to more reflexive and insightful ideas for further research. Families with an ‘autistic’ member and researchers in the field of ‘autism’ studies may be able to learn more about the kinds of research that have led to the creation of the concept now termed as ‘autism’. This may assist them in developing their insight(s) about how assumptions in research affect(s) them and their everyday activities within the family setting(s) – be it in the home setting or elsewhere, leading to more nuanced everyday understandings and practices. In other words, what would be deemed as participatory research with ‘autistic’ people and their families can flourish further.

5.5. CONCLUSION

I have illustrated how I have exercised a phenomenological attitude to focus on the research of the pioneers in the field of ‘autism’ studies. I focused on Ssucharewa (1926), Asperger (1943) and Kanner’s (1943) research to tease out how these

researchers seem to have utilised an implicit reflective (though not necessarily a reflexive) embodied and non-embodied paradoxical, dynamic and mysterious lens to observe 'autistic' children, therefore, creating the concepts and criteria by which to recognise an 'autistic' child as being so. I have discussed how their disciplines have shaped their theorising in terms of their methodology(ies) and methods of research, coupled with a lack of self-reflexivity and interest in the meaning-making and inner lives of 'autistic' people. This may in part be to do with the then culture of not asking children about their inner lives. In turn, this all led to the uptake of the term 'autism' from Bleuler (Asperger, 1943). Researching mainly about children in clinical settings has meant that adult 'autistic' persons have been ignored in terms of constructing a theory(ies) regarding 'autism' and in gaining an insight into such persons' lives over a lifespan in the family context – the family context usually being the first environment in experiencing the world (Bronfenbrenner, 1979). I have demonstrated how there has been a dynamic flow of research and concepts over the past decades, with differing and changing methodologies and methods of research, yet one aspect seems to remain the same – the observed behaviour termed as 'autism' since childhood.

Although what is missing in the field of 'autism' studies is the focusing of a phenomenological attitude upon, with and through the lived experiences of 'autistic' people over a lifespan within family contexts. Doing so can enable a researcher to (i) be self-reflexive and to question oneself and the research questions, and to (ii) create sensitive research questions right from the outset. This is likely to lead to the creation of knowledge that is more insightful and respectful of the 'other'. Hence, I do not adhere to a particular theory or ideology regarding 'autistic' people and am aiming to exercise a phenomenological attitude through my reflexive embodied and non-embodied paradoxical, dynamic, mysterious self and lens throughout this study and thesis so as to learn about the inner lives of 'autistic' people; the next chapter, *The Methods Process(es) and the Phenomenological Attitude* (Chapter Six), shall outline how I attempted to practically achieve this.

6. THE METHODS PROCESS(ES) AND THE PHENOMENOLOGICAL ATTITUDE

6.1. INTRODUCTION

Given that I seek to become more aware and conscious of the lived experiences of 'autistic' persons, without adhering to any particular theory(ies) regarding such persons, I gradually came to realise that the approach that was going to enable me to achieve this was to exercise a phenomenological attitude. This enabled me to reflexively question myself, the assumptions I was making about 'autistic' persons and my research questions before even setting off to interview such persons about their family lives for example. As Heidegger (1929 / 2013) states, we must be able to sense the presence of something so as to be able to ask the question(s). When we ask a new question we learn something new (Greenstein, 1988); different participatory research designs vary from the level of involvement from participants, however, participants can be involved right from the outset in creating and setting the research question(s) (Jivraj, Sacrey, Newton et al., 2014). According to Cornwall and Jewkes (1995; p.1671)

“Research activities are expanded to encompass performance, art and story-telling, as well as using more conventional methods such as focus group discussions, processes develop through praxis. Local people are involved in a process through which they are empowered to take charge of the research process and to organize to implement potential solutions or to take action on concerns.”

However, having anxieties about not knowing my own standpoint regarding what 'autism' is and also not being deeply aware of 'autistic' persons' inner ways of being, meant that I did not feel ready to approach 'autistic' people in person and ask them questions regarding their inner lives and spirituality. Therefore, I had to think deeply about what I was and am bringing to this study and this involved being reflexive regarding my thoughts and potential actions or / and non-actions.

Through the process(es) outlined in this chapter I was able to dialogue with the 'other' in me, acknowledging and exercising my reflexive embodied&non-embodied paradoxical, dynamic, mysterious self and lens as well as 'theirs' in a dialectic manner. This has enabled me to develop a certain way of sensing and an openness

of seeing and interpreting myself as well as the 'other', beginning with – and at – the micro-level. In addition, it has made me more conscious of what I was projecting on to, with and through my interpretations; which I have tried to be as explicit about as possible.

This chapter will initially provide a rationale for focusing my phenomenological attitude on, with and through (i) the autobiographical writings of 'autistic' persons and then with (ii) Interpretative Phenomenological Analysis (IPA) (Smith et al., 2009) – discussing the advantages and limitations. I will then proceed to provide a rationale for the use of IPA to analyse the autobiographical writings in line with my phenomenological attitude and then describe the three stages of analyses I carried out at the micro-level so as to achieve my aim(s) that is outlined in the *Introduction* chapter. An in-depth discussion of having worked with 'autistic' persons' autobiographies and IPA for exercising my phenomenological attitude will be provided in the final chapter of this thesis as this will be a more insightful task to undertake then.

Now I shall provide a rationale for focusing my phenomenological attitude on, with and through the autobiographical writings of 'autistic' persons.

6.2. A RATIONALE FOR MY PHENOMENOLOGICAL ATTITUDE AND 'AUTISTIC' PERSONS' AUTOBIOGRAPHIES

As a Turkish child who grew up in London I know what it means to experience communication difficulties and to be the 'other', although I am not 'autistic' and despite having worked with 'autistic' people in different roles and settings over many years, I had significant ethical anxieties about researching into their lives. I did not feel that I had the insider's perspective and this lack of knowledge was very likely to affect my understanding(s) of such persons as well as my assumptions and questions. Therefore, I felt the need to turn to their lived experiences. What with the lack of research into 'autistic' persons' inner lives and meaning-making, as discussed in Chapter Five, I was at a loss. Hence, the most suitable option I found was to turn to their autobiographical writings; exercising a phenomenological attitude with such data serves the purpose of questioning myself and my research questions. Therefore, leading to a more insightful approach, methods of research and sensitive

questions right from the outset – before even going out to, for example, interview participants, and so beginning at the micro-level. The decisions I made in the manner in which I approached ‘autistic’ persons’ autobiographies and the implications in terms of the ensuing decisions and actions I decided to undertake, e.g. the decisions that led me to take up IPA as a method of analysing the data, are discussed and outlined as follows.

6.2.1. A reflexive account of the context and ‘autistic’ persons’ autobiographies

Here I have focused my phenomenological attitude on, with and through the context in which ‘autistic’ persons’ autobiographies have emerged and how this is likely to have shaped the authors’ thinking. Therefore, creating and affecting the kind of narratives and data I have worked with and through. My explicit focus here is more so regarding being reflexive, however, aspects such as the embodied and non-embodied self, paradox, dynamics and mystery are still prevalent. I have later highlighted the implications of this in terms of the contextual information I have reported regarding the autobiographical writings I have analysed.

Marcus (2018; p.1) draws upon the Greek language to state that:

“The term ‘autobiography’ (coined at the close of the 18th century) breaks down into its component parts—‘auto’ (self), ‘bios’ (life), ‘graphein’ (writing). The element of writing or text is inscribed in the term itself. Language, as well as the workings of memory, shapes the past.”

Therefore, an ‘autobiography’ is usually a very personal account of one’s understanding of oneself, one’s life and meaning-making in a written format. I define ‘autobiography’ as a personal self-reflective account of one’s life; for the purposes of this study, I have decided to focus on such accounts that are in written formats. ‘Autistic’ persons’ autobiographies tend to be placed within a cultural and political milieu of the medical model of ‘disability’ as the term ‘autism’ itself is derived from the medical establishment (Rose, 2008). The discourse in much academic work regarding ‘autism’ is dominated by the medical model of disability and the language used is peppered with deficit terms such as ‘disorder’, ‘diagnosis’ and ‘impairment’ (Molloy and Vasil, 2002; Clarke and van Amerom, 2008).

In the last 25 years or so 'autistic' persons' stories and voices have been creating discourses that are critical of the status quo (Hacking, 2009a, 2009b; Davidson, 2008; Davidson and Henderson, 2010; Young, 2012). The very existence of such texts "radically destabilises the simple yet wide ranging DSM-IV diagnostic criteria for autistic conditions", and "rewording G. Thomas Couser slightly, autobiography lets impairment be represented as a fact, as a 'living condition', not as a trope or metaphor" (Rose, 2005; online). McGeer (2009) states that such narratives are avenues to challenging theories such as the lack of Theory of Mind (Baron-Cohen et al., 1985) and the Extreme Male Brain Theory (Baron-Cohen, 2002). Furthermore, she agrees with Hacking (2009a) in that there may be a cross-fertilization of ideas influencing such writings, both via 'autistic' authors and professional discourse(s), pointing out that 'autistic' persons' voices are limited by the dominant psychological experiences and language of the society from which they emerge. Therefore, working with 'autistic' persons' voices and autobiographical writings enables a critical thread to be woven into and throughout this research in terms of my approach, methods, content and the language used herein. Exercising a phenomenological attitude with autobiographical writings may enable a researcher to not only question oneself and one's assumptions but also give one the opportunity to create a way of seeing that may enable one to create thinking and language that are more open in terms of forming bridges of openness between oneself and the 'other'.

Furthermore, the use of language is changing due to the forming of an 'autistic' culture, e.g. some 'autistic' people refer to non-autistic people as 'Neuro-Typicals' (NTs). Waltz (2003) outlines that 'autistic' people are taking up ownership of a way of being that involves challenging the 'official' construct(s) of 'autism'. 'Autistic' people tend to "position autism as a culture, not a problem, in much the same way deaf culture has been constructed. They reculturise autism, exposing the epistemological impacts of dominant representations. These counter-representations also encourage examination of larger assumptions about normality, impairment, and difference" (Waltz, 2003; p.7). In addition, 'autistic' authors and activists call for researchers to listen to 'autistic' people and carry out research as co-researchers; this standpoint is further supported by the works of researchers such as Majia Holmer Nadesan (2005), Victoria McGeer (2009), Ian Hacking (2009a, 2009b), Chloe Silverman (2008) and Stuart Murray (2008). According to MacLeod et al. (2013; pp.2-3):

[A] “crossover exists within the field of autism research, in which a few authors and activists have become researchers (Dawson, Mottron, and Gernsbacher 2008; Lawson, 2009) or influenced the research agenda by originating theoretical ideas (Grandin, 2009; Sinclair 1993). However, this crossover is not yet having a perceptible influence upon the dominant autism research agenda and more work is needed to explore how individuals on the autism spectrum can become active participants in research that is relevant to their lives”.

Therefore highlighting the importance of, and the need for, a participatory research design(s); this ought to begin right from the initial stage of formulating research questions, for the kinds of questions we ask lead to the kinds of knowledge that emerge. This kind of approach may well be recognised as ‘autoethnography’, which has been used in the social sciences since the 1970s. Ellis, Adams and Bochner (2011; online) define it as:

“Autoethnography is an approach to research and writing that seeks to describe and systematically analyze (graphy) personal experience (auto) in order to understand cultural experience (ethno) (Ellis, 2004; Holman Jones, 2005). This approach challenges canonical ways of doing research and representing others (Spry, 2001) and treats research as a political, socially-just and socially-conscious act (Adams & Holman Jones, 2008). A researcher uses tenets of autobiography and ethnography to do and write autoethnography. Thus, as a method, autoethnography is both process and product. [1]”

My focus was / is to learn about the ‘insider’s perspective’ of being ‘autistic’, therefore, I did not delve into the political elements within the field of ‘autism’ studies so much. However, my turning to the lived experiences of ‘autistic’ people themselves could very well be viewed as a ‘political’ move in the direction of what I deem to be socially just and socially-conscious research. Furthermore, I have touched upon some of the cultural and political aspects via the literature I reviewed (please refer to Chapter Five for this). Hence, this study and thesis is “both process and product” that has led to an approach that “challenges canonical ways of doing research and representing others”; in this case with regards to oneself as a researcher and regarding knowledge that is being created within the field of ‘autism’ studies. Although I would add that the kind of study herein also brings the researcher to account, i.e. myself, for one’s representation of oneself as well – not just the ‘other’. Ellis et al. (2011; online) emphasise the reflexive standpoint a researcher must take and state that:

“Autoethnographers must not only use their methodological tools and research literature to analyze experience, but also must consider ways others may experience similar epiphanies; they must use personal experience to illustrate facets of cultural experience, and, in so doing, make characteristics of a culture familiar for insiders and outsiders. To accomplish this might require comparing and contrasting personal experience against existing research (Ronai, 1995, 1996), interviewing cultural members (Foster, 2006; Marvasti, 2006; Tillmann-Healy, 2001), and / or examining relevant cultural artifacts (Boylorn, 2008; Denzin, 2006). [9]”

Therefore, exercising a reflexive approach with autobiographies can enable a researcher to not only gain the ‘insider’s perspective’ but also to help build a cultural bridge(s), or / and, to identify the bridge(s) and strengthen it / them. For example, the insights and knowledge within this entire study and thesis, and especially in the next chapter (*The Findings and Discussion: Insights via the Phenomenological Attitude*), are an example of this process(es) being initiated. Hence, exercising one’s phenomenological attitude with ‘autistic’ persons’ autobiographies may help to pave the way for a new approach(es) of participatory research to develop.

With regards to memory and autobiographical writing, such reflective writings are very much influenced by an interplay of one’s cultural context / ‘cultural memory’ and one’s individual memory(ies), furthermore, one’s meaning-making can, and does, change over time (Marcus, 2018). ‘Autistic’ persons have existed beyond the emergence and use of the term ‘autism’ to refer to them, having been called other terms in the past, e.g. ‘fools’ and ‘idiots’ (Bogdashina, 2010). However, autobiographies written by such persons, that specifically use the term ‘autism’, began to be created in 1986 - the first by Temple Grandin (*Emergence: Labeled Autistic*). Hence, to a certain degree such reflective narratives are embedded in a historical context of a cultural memory(ies) that is unknown / is a mystery, in that there are likely to be authors who have written such accounts via their stories or / and may have been on the ‘autism’ spectrum themselves, but have not used the term ‘autism’ per se, e.g. Albert Camus’s (1942 / 2000) *The Outsider*. Exercising a phenomenological attitude enables one to be open to this aspect of ‘autistic’ autobiography(ies), acknowledging that memory(ies) can be retrieved and not retrieved and that the use – and non-use – of language changes accordingly, reflecting the dynamic and mysterious elements of human nature. Therefore,

exercising a phenomenological attitude is likely to enable one to explore this interplay(s) of 'autistic' persons' memories and use of language, as well as the cultural factors at a micro and macro-level.

More 'autistic' autobiographies are now emerging (Goidsenhoven, 2017), meaning that a new form of historical cultural memory(ies) and language(es) are being created by 'autistic' persons thanks to the use of the concept and term 'autism'. Therefore, one must also ask why this may be so. It may be partly due to the fact that the number of people being recognised as being 'autistic' is increasing (National Autistic Society, 2019) and is therefore leading to an increase in numbers of people who may potentially feel the need to want to write an autobiography. It may be partly due to the social movement of neurodiversity (Rose, 2008) and therefore 'autistic' people may feel more inclined to voice their worldview(s) via the means of autobiography. It may be that some 'autistic' persons want to carry out the endeavour of writing an autobiography for the purpose(es) of understanding oneself and one's life, i.e. for self-reflection and self-knowledge, and this may be a way of validating their reality(ies) and meaning-making. This in itself may serve a self-empowering purpose and enable them to exercise their voice in a way in which they may never have done so before. This may be intertwined with a need to be understood, to influence and change others' worldviews – and ultimately cultural and individual memories – especially of those who are not 'autistic'. Furthermore, the increase in such autobiographies may also be due to publishers such as Jessica Kingsley Publishers recognising a niche in the market and helping to bring such autobiographies into mainstream domains of public life. Although the role of editors and publishers also ought to be considered with regards to the creation of such autobiographies. Exercising a phenomenological attitude that does not pertain to any particular theory may help to illuminate these various factors and the possible effects they may have on the creation and dissemination of 'autistic' persons' autobiographies – i.e. the data for this study.

Therefore, in terms of reflexivity I have been mindful of the cultural contexts in which such autobiographies have been created, e.g. keeping in mind the effects of the medical community(ies) and the 'autistic' community(ies). I decided to select autobiographical writings in line with my definition (i.e. personal reflective accounts in the written format), continued to familiarise myself with relevant narratives,

language(s), and attempted to be reflexive of my own practice(s) and use of language(s). When focusing on the reported lived experiences of 'autistic' persons via their autobiographies I decided to provide the following contextual information regarding the writings I chose to work with:

- (i) Who wrote the autobiography(ies);
- (ii) Why they wrote it;
- (iii) A summary of what the narrative is about;
- (iv) Where the autobiography was written;
- (v) When the autobiography was written;
- (vi) How the text came into being.

Hence, exercising a phenomenological attitude can enable a researcher to be mindful of the cultural and individual influences that create and shape 'autistic' persons' autobiographies, being aware of the interplay of cultural memory(ies) and individual memory(ies) as well as the use and non-use of language. Focusing with, and on, contextual information regarding such narratives is one possible way in which one can begin to exercise a phenomenological attitude regarding the creation and dissemination of 'autistic' persons' autobiographies, especially in terms of being reflexive at the micro-level.

I have exercised my phenomenological attitude to provide a rationale for working with and through 'autistic' persons' autobiographies and the contexts in which they emerge. I shall now proceed to the embodied and non-embodied elements regarding such writings.

6.2.2. The embodied and non-embodied elements regarding 'autistic' persons' autobiographies

Here I have focused my phenomenological attitude on, with and through research regarding working with 'autistic' persons' lived experiences, highlighting more so the embodied and non-embodied elements of such writings. I have then gone on to outline the implications of this in terms of the decisions I made and the manner in which I approached such texts for the purpose(es) of analysis.

In *Concepts of Normality* Lawson states that (2008; p.15):

“Disability presents itself in a variety of ways, and for most of us living with disability, who we are is normal. For many people on the autism spectrum, which is certainly very disabling in a world that does not accept, value or accommodate ‘difference’, being handicapped is an everyday reality. This text argues for the right to exist as oneself, with or without disability; this should be part of ‘the norm’.”

Hence, the embodied and non-embodied self of ‘autistic’ persons ought to be recognised and worked with in its own right, as the norm for the individual and for the community. Society members, which includes researchers, ought to make changes so as to be open to such difference; “researchers should attend more to their own deficiencies than to the limitations of their informants” (Booth and Booth, 1996; p.67). Exercising a phenomenological attitude that focuses with, on and through the embodied and non-embodied self of ‘autistic’ persons via autobiographical writings can enable a researcher to begin to undertake this dialogue – that of one’s own embodiedness and non-embodiedness and that between oneself and the ‘other’s’ embodiedness and non-embodiedness.

The family environment is usually the first setting for social interaction(s) and one’s lived experiences are affected by one’s family (Bronfenbrenner, 1979). Therefore, one’s family members can also be viewed as embodied selves of one’s non-embodied self and vice versa; this is intersubjectivity – which I refer to as ‘inner&intersubjectivity’ – a more explicitly aligned term that epitomises the status quo. The double-empathy problem (Milton, 2014b; p.7) is a concept that implicitly relies on the notion of inner&intersubjectivity and highlights that “the somatic affordance of autistic and non-autistic dispositions may well create a large double-empathy problem (Milton, 2012), where both have a difficulty in understanding the nuances of one another’s perception and sociality”. Exercising a phenomenological attitude that explicitly focuses on the embodied and non-embodied self may well enable a researcher to be consciously aware of the double-empathy problem (Milton, 2012, 2014b) and to begin to work with this aspect(s) at an individual level, e.g. by questioning one’s own inner&intersubjective meaning-making, use of language, and creating terms that may be more in line with ‘autistic’ persons’ lived experiences. It may well also enable one to work with ‘autistic’ people and their families in a more harmonious manner in the future.

Being more aware of the kinds of familial dynamics reported by 'autistic' persons may help one to act as a bridge between the family members' embodied and non-embodied meaning-making and the 'autistic' person's. For example, Christopher Goodchild (2009) and Donna Williams (1992) both reported lived experiences with family members during infancy that were emotionally traumatic for them (please refer to Chapter Five, section 5.4.). Hence, exercising a phenomenological attitude may also enable one to create the space for a more consciously aware dialogue(s) to take place between the 'autistic' person and other family members.

The implications of these aspects has meant that I have had to create a way of approaching 'autistic' persons' autobiographical writings such that it enables me to acknowledge my limitations as a researcher and to be aware of my inner&intersubjective meaning-making as well as that of the 'other(s)', e.g. the implications of the double empathy problem (Milton, 2012, 2014b). Exercising a phenomenological attitude that includes the embodied and non-embodied elements regarding 'autistic' persons' lived experiences can enable a researcher to carry out this dialogue with, and of, the 'other' within oneself. Therefore, I decided to undertake this endeavour through the means of sitting down, reading 'autistic' persons' autobiographies and including questions regarding inner&intersubjectivity – which includes a focus on emotional connectedness and non-connectedness.

I have exercised my phenomenological attitude to provide a rationale for focusing on the embodied and non-embodied elements regarding 'autistic' persons' autobiographies and will now focus on the paradoxical elements.

6.2.3. The paradoxical elements of 'autistic' persons' autobiographies

Here I have focused my phenomenological attitude on, with and through 'autistic' persons' autobiographies so as to highlight and discuss the paradoxical elements and provide a rationale for this task in relation to their autobiographical writings; I have then outlined the implications of this.

Stories or narratives are the means by which we seek and make meaning and develop – and simultaneously possibly not develop – our understanding with regards to ourselves and the world (Bolton, 1999; Squire, 2008). According to Hacking

(2009a; p.1467) “Autism narrative is a new genre: not expert reports by clinicians or reflections by theorists, but the stories about people with autism, told by the people themselves, or their families, or by novelists, or by writers of stories for children”, they are enabling the development of describing “experience for which there is little pre-existing language”, and are providing an ‘insider’s’ account to some degree. Hence, the paradoxical nature of ‘autistic’ persons’ writings is that as much as they may, and do, use the term ‘autism’ as part of book titles etc. they are from the insiders’ perspectives – not from medical clinicians’ perspectives. Therefore, exercising a phenomenological attitude that brings to the fore the paradoxical elements with regards to their lived experiences and the language(s) they use, and do not use, may well enable one to gain an insight into how they make meaning.

The process(es) of publishing, e.g. having co-writers, as well as the interpretation(s) of each individual reader, leads to the mediating of all texts in some form or another (Waltz, 2005). Therefore, the text ought to be viewed and accepted as a constructed representation of the person’s story whilst simultaneously reflecting upon what I as a researcher and reader may be projecting on to, with and through the text; so there are two paradoxical elements at play.

One paradoxical element is that the text is not the actual lived experience of the ‘autistic’ person, it is a representation of it, although through this dualistic aspect there is a connection between the lived experience of the person and the text. Brown (2009; p.204) states that, “Looking closely at the autobiographical writings of people diagnosed with autism reveals a wealth of information about an autistic writer’s motivation, use of genre convention, point of view, representation of self, content selection, themes, metaphors and style”. My focus was / is more so on the persons’ lived experiences and their meaning-making process(es) so I did not want to carry out a literary style of dialogue or analysis. However, I was mindful of Brown’s (2009) assertion in relation to the text(s) as being a representational piece of work in its own right, and that it is influenced by the motivation(s) of the person who wrote it.

The second paradoxical element is that I have been interpreting ‘autistic’ persons’ interpretations of their lived experiences, leading to a double hermeneutic process of interpretation(s). Mitchell (2000; p.312) warns researchers regarding the construction and interpretation(s) of such representational texts; “Memoirs and autobiographical

tales of physical hardship and public ostracism appeal to the singularity of experience that appeases a reader's desire for the intimacy of confession and the narrative demand for individual exclusivity”, thereby somewhat ignoring the influence(s) of community and relationships. Paradoxically, reflective narratives in particular can enable empowerment through the validating and owning up to of one’s experiences through the sharing of one’s story; whereby similar reported experiences validate a persons’ lived experiences, and some readers may identify themselves as being say ‘autistic’ after reading such a text (Atkinson, 2004; Rose, 2008). This may possibly lead to a better understanding of oneself, which in turn may create and enhance a sense of belonging to a community (Atkinson, 2004; Rose, 2008). I have been mindful of the nature of such texts, whereby the influence(s) of people and one’s environment may be pointed at but not given more attention and detail in the work(s), and this is a part of the reason as to why I decided to select works that include reflections regarding family life. Whereby my focus was on the dynamic relationships and environments the person(s) was / is immersed in. Yet simultaneously such texts can act as resources of, and for, knowledge – not just for researchers but for ‘autistic’ people themselves and their families. Hence, there was a place for their use in the third stages of this research as vignettes.

Therefore, exercising a phenomenological attitude that consciously acknowledges the paradoxical nature of ‘autistic’ persons’ autobiographical texts, and one’s paradoxical endeavour in attempting to gain an understanding of their interpretations, may help to create a way of perceiving that which is also dynamic about their lived experiences. This can enable one to be open to many more potential ways of understanding.

The implications of exercising a phenomenological attitude that includes a focus on the paradoxical nature of ‘autistic’ persons’ autobiographical writings can enable a researcher to gain an insider’s paradoxical perspective(s) whilst simultaneously keeping in mind that one is also undertaking a paradoxical endeavour in terms of interpreting a constructed piece of text. The text is not the actual lived experience of the person who wrote it and therefore should not be approached with an assumption that it is. Therefore, a style of analysis that acknowledges this factor was required, which is a part of the reason why I turned to IPA as it acknowledges the double hermeneutic nature of this kind of endeavour; this shall be discussed in section 6.3.

A rationale for exercising my phenomenological attitude with 'autistic' persons' autobiographies and Interpretative Phenomenological Analysis (IPA).

I have exercised my phenomenological attitude to provide a rationale for focusing on the paradoxical elements regarding 'autistic' persons' autobiographies and will now focus on the dynamic elements.

6.2.4. The dynamic elements of 'autistic' persons' autobiographies

Here I have focused my phenomenological attitude on, with and through 'autistic' persons' autobiographical writings to highlight more so the dynamic elements. I later proceed to outline the implications of this in terms of the way I approached such writings and carried out the analyses.

One's meaning-making can, and does, change over time and so there is a dynamic element to the ways in which one can attempt to – or not – make sense of the world and interpret one's lived experience(s) (Romanyshyn, 2007). The autobiographical writings of 'autistic' persons in themselves are a 'snapshot' of their meaning-making at a given reflective period of their lives. However, the very nature of such reflective writings and meaning-making may give insights into how an 'autistic' person understood, and did not understand, their lived experience(s) as an infant, child, teenager and an adult. The gradual process of growing up, which in itself is a manifestation of one's embodied and non-embodied self in dynamic motion(s), can and does affect one's understanding and interpretation(s). Therefore, exercising a phenomenological attitude that includes a conscious attention to, and of, the dynamic nature of meaning-making within 'autistic' person's autobiographies may give deeper insights into the longitudinal aspects of their lived experiences and meaning-making, including meaning-making with family members.

Furthermore, regarding the dynamic element and meaning-making over time, Cortazzi (1993; p.85) states that:

[in] “their attempts to define narrative a number of literary theorists have suggested three necessary conditions or criteria. These are temporality, causation and human interest. The three are seen as combining to form a minimum plot structure.”

'Autistic' autobiography, or 'autiebiography' as Rose (2008) puts it, may not always benefit this traditional structure and therefore one ought to be flexible when attempting to define works by 'autistic' writers as autobiographical (Rose, 2005). Hence, for the purposes of this study, I decided to define 'autistic' autobiography as: written pieces of reflective narrative by 'autistic' persons attempting to construct an understanding and / or seeking meaning of, in, with and through their lived experiences.

The implication of this is that I decided to try and get hold of a variety of 'autistic' persons' autobiographical writings, including those who had written their books as adults and as teenagers, so as to acknowledge the differing, dynamic and longitudinal aspect of their lived experiences and meaning-making. I also decided that I would re-read the books I chose to analyse from the beginning to the end and focus on the dynamic nature of their meaning-making. This in turn led to my having to split the phases of research into three stages so as to be able to work with the amount of vast data. The stages will be outlined in sub-section 6.4. *How I exercised my phenomenological attitude for the purposes of this study: the three stages of this research.*

Now that I have exercised my phenomenological attitude of a dynamic element regarding the autobiographical writings of 'autistic' persons I will proceed to focus on the mysterious element.

6.2.5. The mysterious elements of 'autistic' persons' autobiographies

Here I have focused my phenomenological attitude on, with and through 'autistic' persons' autobiographies, highlighting more so the mysterious elements. I have then proceeded to outline the implications of this in terms of my decision-making in approaching the texts and the nature of the analyses.

The dynamic element of the lived experience also brings to consciousness the element that there is something about the lived experience that constantly escapes one's understanding (Romanyshyn, 2007; van Manen, 2014). Hence, it seems that there is an element that is not knowable or mysterious within phenomena (Merleau-Ponty, 1945 / 2013, 1964 / 1968) and this is what makes all beings unique (Shems&Rumi, 1263 / 2011). Furthermore, one can become even more consciously

aware of this mystery – or the unfathomable element – when facing the ‘other’ (Lévinas, 1961 / 1979). It is a mystery that can, and usually does, render language and meaning-making obsolete; this is why narratives and poetry seem to be the only kinds of written styles of text that can somewhat reflect the nuances of such a mysterious element of phenomena (Midgley, 2001) – though ultimately even these styles cannot suffice.

Nevertheless, working with ‘autistic’ persons’ autobiographies could help to unveil some of the unknown aspects about their lived experiences and meaning-making. Their reflective narratives could enable researchers, family members and other professionals to begin to ask and understand the “Why?” questions, e.g. the examples given in Chapter Five, section 5.4., from Christopher Goodchild and Donna Williams regarding why they wanted to pull away from their family members. Therefore, exercising a phenomenological attitude that consciously acknowledges the mysterious element of the lived experience could enable one to unveil some of the unknown aspects of ‘autistic’ persons’ ways of being whilst simultaneously accepting that their lived experience(s) cannot be understood or unveiled in its entirety – just as one cannot do so with one’s own lived experience(s).

The implication of this is that I am a unique being and so are the ‘autistic’ authors – including their families. I was mindful that each writer is an individual and therefore as much as I may gain certain insights I ought not to concretize my constructs and continuously attempt to keep an open mind to the meaning-making process(es) of each one. Evans (2002; p.21) states that:

“research is a social practice and that it is therefore both embedded and embodied. Thus one thing we can do in terms of becoming more aware of what we silently think is to recognize that research is not a technology but a practice, that it is not individualistic but social and that there are no universal methods to be applied.”

I therefore decided to be flexible in considering approaches and methods of research when carrying out this study. In order to acknowledge the mysterious and unique aspects of ‘autistic’ persons’ lived experiences I decided to choose a type of approach that acknowledges and practices in line with this aspect; this would be deemed as working with idiographic data and IPA is in line with it (Smith et al., 2009). Furthermore, IPA is of an inductive nature (Smith et al., 2009) and is a

suitable approach for analysing textual data to unveil the mystery(ies) – bringing forth new knowledge that was heretofore not known. This in turn led to my wanting to analyse three autobiographies in-depth so as to attempt to unveil some of the idiographic elements of ‘autistic’ persons’ lived experiences, which paradoxically led to recognising similarities between them – IPA enables one to focus on the similarities between people’s lived experiences as well (Smith et al., 2009). These will be discussed further in the next section, 6.3. *A rationale for exercising my phenomenological attitude with ‘autistic’ persons’ autobiographies and Interpretative Phenomenological Analysis (IPA).*

I have exercised my phenomenological attitude regarding the mysterious element of the lived experience and ‘autistic’ persons’ autobiographical writings. I shall now summarise this section.

6.2.6. Summary of a rationale for my phenomenological attitude and ‘autistic’ persons’ autobiographies

Thus far I have exercised my phenomenological attitude to discuss and highlight the decisions I made, the manner in which I approached the texts and the implications in terms of the way I chose to analyse them. Exercising my reflexive, embodied and non-embodied paradoxical, dynamic, mysterious self and lens has led to my creating a way of approaching ‘autistic’ persons’ autobiographical writings in a reflexive manner, hence my wanting to document the analyses and being able to ask the questions “What is self-knowledge? How does it develop?”, “What is meaning? How does it develop?” and “What is perception? How does it develop?”

Acknowledging the embodied and non-embodied element of the lived experience enabled me to recognise the influences of culture, the family unit, medical establishments and concepts, memory, language and the creation and prevalence of “autiebiography” (Rose, 2008; p.48). Therefore I was able to question myself at the micro-level and to create sensitive research questions that are sensitive to and reflective of the ‘other’s’ experience at the micro-level. Christopher Goodchild’s (2009) and Donna Williams’s (1992) narratives, along with Milton’s (2012, 2014b) double empathy problem theory, led to my concentrating on emotional connectedness&non-connectedness – an aspect of the embodied and non-

embodied self, hence arose the question about it for the analyses.

Consciously being aware of the paradoxical nature of the lived experience enabled me to recognise that the autobiographical texts are representations of people's lived experiences and I was interpreting the authors' interpretations. This made me that much more vigilant in terms of becoming aware of my assumptions, my use of language and their effects in my decision-making process(es). Acknowledging the dynamic element of the lived experience enabled me to choose a variety of autobiographical writings of a longitudinal span as I was focusing with, in and through the 'autistic' authors' meaning-making and its dynamic nature. It also enabled me to undergo three stages of data analyses so as to be able to fulfil the aim of this study.

Being aware of the mysterious element of the lived experience enabled me to recognise myself and the authors as unique beings, therefore, I did not – and do not – wish to concretize the ideas that have emerged throughout this study. This enabled me to analyse three autobiographies in-depth so as to bring forth the idiographic aspects of 'autistic' persons' lived experiences, which could help in beginning to answer some "Why?" questions regarding their ways of being and lived experiences.

In turn, this led to my taking up IPA. In that the researcher is (i) reflexive as much as possible whilst being conscious of the double-hermeneutic process(es) taking place when working with textual data; (ii) focuses on embodied and non-embodied aspects of the lived experience whilst bracketing and questioning oneself and one's questions; (iii) is able to focus on idiographic aspects of people's lived experiences – which in turn can also lead to seeing some of the similarities between people's lived experiences; and (iv) is inductive, enabling one to understand more about the 'other's' meaning-making and bring forth new insights and knowledge. Working with IPA also enabled me to ask questions regarding the paradoxical, dynamic and mysterious elements of the reported lived experiences by 'autistic' authors.

I have now summarised this section. The next two sections will further illuminate why and how I worked with IPA and 'autistic' persons' autobiographies.

6.3. A RATIONALE FOR EXERCISING MY PHENOMENOLOGICAL ATTITUDE WITH 'AUTISTIC' PERSONS' AUTOBIOGRAPHIES AND INTERPRETATIVE PHENOMENOLOGICAL ANALYSIS (IPA)

Here I have discussed why exercising my phenomenological attitude with 'autistic' person's autobiographies and IPA emerged in order to fulfil the aim of this study. I have initially introduced IPA, its aim and how it can be adapted in a flexible manner to analyse textual data. I have then discussed why I took up IPA as an approach through which I exercised my phenomenological attitude.

6.3.1. What is IPA?

IPA was developed in the early to mid-nineties by Jonathan Smith and colleagues in England working within the discipline of health psychology (Fade, 2004; Hefferon and Gil-Rodriguez, 2011). According to Smith et al. (2009; p.4):

“IPA has a short and long history. Its first real mark came with the publication of Jonathan Smith's (1996) paper in *Psychology and Health* which argued for an approach to psychology which was able to capture the experiential and qualitative, and which could still dialogue with mainstream psychology. An important aim at this point was to stake a claim for a qualitative approach centred in psychology, rather than importing one from different disciplines. The point here was not that there was anything wrong with other subject areas but to revive a more pluralistic psychology as envisaged by William James. Thus the argument is that psychology was, could and should be both experimental and experiential and recognizes the important, if suppressed, role for the experiential within the intellectual history of psychology.”

Therefore, Smith and his colleagues aimed to focus on bringing more of a balance to the kinds of knowledge being created within the field of psychology by focusing on the experiential nature of people's lived experiences. Furthermore, William James was a philosopher and a mystic who influenced Edmund Husserl, the philosopher who is regarded as being the founder of phenomenology (please refer to Chapter Three, section 3.2.), and whose works include *The Varieties of Religious Experience: A Study in Human Nature* (1901 – 1902 / 2000). In that, James very much concentrated on the inner lives and meaning-making of people. Therefore, the aim of IPA to focus on the experiential aspects of people's lives and to contribute to the balancing of knowledge in the field of psychology is in line with my aim to become

conscious of that which I am not conscious of and to contribute to balancing the kinds of knowledge within 'autism' studies.

The long history of IPA stems from its theoretical grounding, e.g. the philosophies of Edmund Husserl (1859-1938), Martin Heidegger (1889-1976), Maurice Merleau-Ponty (1908-1961), Jean Paul-Sartre (1905-1980), Friedrich Daniel Ernst Schleiermacher (1768-1834) and Hans-Georg Gadamer (1900s-2002). Therefore, IPA is an approach that is influenced by phenomenological, hermeneutical and ideographical philosophy(ies) and is a qualitative way of working with data (Smith et al. 2009; Finlay, 2011). Yardley (2000; p.215) states that:

“QMs [Qualitative Methods] have been associated in recent times with a renewed interest in culture and language. This has led to an intensive examination of the philosophical and socio-cultural foundations of concepts and procedures which have sometimes been employed in quantitative research with little explicit discussion of their origin, function and connotations.”

My philosophical assumption is that all research is qualitative in nature as there is the human gaze that is cast upon the phenomenon(mena) and is interpreting it with a certain kind(s) of perception(s) – as illustrated by the double-slit experiment in the field of physics (American Physical Society, 2008), whilst the researcher is often using different symbols to observe, record and represent such meaning(s). In that both 'object' and 'subject' are intricately intertwined, i.e. they are the embodied and non-embodied aspect(s) of the lived experience. As Smith et al. (2009; p.37) state, “without the phenomenology, there would be nothing to interpret; without the hermeneutics, the phenomenon would not be seen.”

Although I agree with Yardley (2000) in that (i) the philosophical and socio-cultural foundations of concepts and methods ought to be evaluated and; (ii) a reflexive discussion about the forming and development of concepts and procedures ought to be carried out and included in the research process(es) and report, hence my attempt to do so throughout this entire study. Therefore, working with qualitative methods of research, e.g. with textual data and IPA, along with a phenomenological attitude can enable the development of a method(s) of research that creates new ways of thinking / philosophy(ies) in carrying out research in the field of 'autism' studies.

Yardley (2000; p.219) states that there are four principles a researcher ought to put into practice when undertaking research:

“Table 1: Characteristics of good (qualitative) research

Essential qualities are shown in bold, with examples of the form each can take shown in italics.

Sensitivity to context

Theoretical; relevant literature; empirical data; sociocultural setting; participants’ perspectives; ethical issues.

Commitment and rigour

In-depth engagement with topic; methodological competence/skill; thorough data collection; depth / breadth of analysis.

Transparency and coherence

Clarity and power of description / argument; transparent methods and data presentation; fit between theory and method: reflexivity.

Impact and importance

Theoretical (enriching understanding); socio-cultural; practical (for community, policy makers, health workers).”

Therefore, I attempted to put the above guidelines into practice as much as possible. I was significantly concerned about developing more sensitivity to the context and about ethical practice(s). Hence, I carried out much reflexive endeavours, e.g. by (re-)reading material, carrying out self-dialogue – documenting my decisions, questioning my assumptions, carrying out dialogues with colleagues, diary work etc. in order to fathom the factors I was focusing on, with and through this research. I have dialogued more so with myself regarding my own being, nature and bias(es), dialogued more so with ‘autistic’ people regarding this study, (re-)read ‘autistic’ persons’ autobiographies, and have attempted to use and / or create language that portrays my understanding(s) as closely as it can; the three stages of this research demonstrate how I did this, as outlined in section 6.4. *How I exercised my phenomenological attitude for the purposes of this study: the three stages of this research.*

These examples illustrate my commitment and rigour to, with, and through this research. The methods that are proposed within this chapter, and the manner in which I worked with them for carrying out this study is illustrated by my commitment

to becoming sensitive to the context and exercising rigour in terms of data collection and analyses in, with, and through as ethical a manner as possible. In turn, the reflexive manner in which such methods were utilized fulfilled the principle of transparency and coherence as far as possible and has contributed to making an original and important contribution to the field.

Smith et al. (2009) do not provide a prescriptive method of how to carry out IPA research, outlining that the process(es) ought to be flexible in relation to the question(s) at hand and should also facilitate creative ways of researching. The following are the six key elements of IPA that illustrate how suitable it is in relation to the research aims and questions (Reid, Flowers and Larkin, 2005; p.20):

“IPA is an inductive approach (it is ‘bottom up’ rather than ‘top down’). It does not test hypotheses, and prior assumptions are avoided. IPA aims to capture and explore the meanings that participants assign to their experiences.

Participants are experts on their own experiences and can offer researchers an understanding of their thoughts, commitments and feelings through telling their own stories, in their own words, and in as much detail as possible. Participants are recruited because of their expertise in the phenomenon being explored (e.g. undergraduate psychology students are usually avoided).

Researchers reduce the complexity of experiential data through rigorous and systematic analysis. Analysis relies on the process of people making sense of the world and their experiences, firstly for the participant, and secondly for the analyst.

Analyses usually maintain some level of focus on what is distinct (i.e. idiographic study of persons), but will also attempt to balance this against an account of what is shared (i.e. commonalities across a group of participants).

A successful analysis is: interpretative (and thus subjective) so the results are not given the status of facts; transparent (grounded in example from the data) and plausible (to participants, co-analysts, supervisors, and general readers).

Researchers should reflect upon their role in the interpretative and collaborative nature of the IPA interview, data analysis and subsequent publication.”

Therefore, IPA is adaptable and one can work with written documents to carry out analyses according to one’s aim and questions. Now that I have briefly outlined what IPA is I shall draw upon the six key aspects of IPA research above to further discuss

why I chose IPA to exercise my phenomenological attitude with 'autistic' person's autobiographies.

6.3.2. Why I chose IPA to exercise my phenomenological attitude with 'autistic' persons' autobiographies

I chose IPA because of its emphasis on reflexivity, its focus on the lived experience and the embodied and non-embodied aspect of self, the influence of phenomenology whereby it is an approach that includes notions about paradox, change (dynamics) and that all is not known (mystery), its focus on meaning-making via the means of narrative and its flexible inductive nature. I shall now draw upon the six key aspects of IPA (above) to discuss and outline why I chose IPA to exercise my phenomenological attitude with 'autistic' persons' autobiographies.

This study is not that of a typical IPA style of research, in that IPA studies tend to be carried out with interviews and the data is transcribed and analysed in the form of text (Smith et al., 2009). However, Johanna Spiers and Jonothan Smith (2012) carried out an IPA analysis regarding the lived experiences of a person with End-Stage Renal Disease (ESRD) who had written about his experience using poetry. Furthermore, I had personally contacted Jonothan Smith and Michael Larkin to ask whether IPA could be adapted to work with autobiographies and both stated that this was possible (Smith, 2014 and Larkin, 2014 personal communication; Appendix 15). Therefore, IPA can be adapted to work with 'autistic' persons' autobiographical writings and my phenomenological attitude in order to gain an insight into their inner lives and meaning-making.

Exercising my phenomenological attitude by working with IPA and 'autistic' people's autobiographies enabled me to acknowledge the validity of 'autistic' persons' lived experiences, narratives and voices in their own right. This is partly due to the inductive nature of IPA and its aim to explore people's meaning-making and lived experiences. Smith et al. (2009; p.1) state that:

"IPA is a qualitative research approach committed to the examination of how people make sense of their major life experiences. IPA is phenomenological in that it is concerned with exploring experience in its own terms."

There is an attempt to accept one's lived experience as being valid in its own right and a focus on meaning-making. Thus they highlight that researchers who utilize IPA are encouraged to uptake, in part, an 'insider's perspective' (citing Conrad, 1987). This is very relevant when considering the nature of 'autistic' persons' lived experiences, for many people may have similar experiences but may not live them as intensely as 'autistic' people may and do, because 'autistic' persons' experiences tend to be explicitly phenomenological due to their hyper and hypo sensory abilities (Davidson and Smith, 2009; Duncan and Klinger, 2010; Young, 2012). Therefore, when considering the overall research aim and the explicitly phenomenological nature(s) of 'autistic' persons' lived experiences IPA became a suitable approach to work with. Exercising my phenomenological attitude has enabled me to adapt IPA in such a way for it to begin to serve as a bridge between the worldview(s) of 'autistic' persons and mine.

Exercising my phenomenological attitude via the adaptation and use of IPA with 'autistic' persons' autobiographies enabled me to unveil insights into the inner lives of 'autistic' people. Therefore also enabling me to dialogue with the 'other' in me. With regards to narratives, "IPA has a strong intellectual connection with various narrative analysis" and "is centrally concerned with meaning-making and the construction of a narrative is one way of meaning-making" (Smith et al., 2009; p.196). I did not want to delve into how structure(s) and discourse(s) are used to create such texts as my focus was / is more so on the content, i.e. the lived experience, although I am aware that the structure(s) and discourse(s) of narratives assist to create and affect the reader's interpretation(s), i.e. my reading and interpretation(s).

The autobiographies of 'autistic' writers "provide an invaluable yet underexplored qualitative resource for those interested in understanding "insider" accounts of ASD [Autistic Spectrum Disorder]" (Davidson and Smith, 2009; p.902). The works of authors such as Temple Grandin, Wendy Lawson, Jim Sinclair and Donna Williams, all of whom are 'autistic', illustrate that such "autobiographical writings suggest that autistic interactions with animals – and sometimes also what are inanimate aspects of the 'natural' environment – have profoundly emotional qualities of a kind more usually associated with social settings. This suggestion is conspicuously at odds with

widespread popular views [that autistic people are non-social], largely supported by clinical accounts” (Davidson and Smith, 2009; p.898). This highlights the need for researchers to accept autistic persons’ experiences and voices as being meaningful and qualitatively different in various contexts.

The ‘bracketing’ practice within IPA, whereby the researcher accepts the lived experience(s) of the ‘other’ as being valid in itself and attempts to place one’s biases aside whilst also being mindful of one’s own assumptions, is a practice of reflective thinking that attempts to enable one to learn deeper insights (Smith et al., 2009). Thus enabling me to practically dialogue with the ‘other’ in me by exercising my phenomenological attitude with ‘autistic’ persons’ autobiographies.

Spiers and Smith (2012; p.120) cited the work of Max van Manen (1997; p.6) who states that in “thoughtful phenomenological texts, the distinction between poetic and narrative is hard to draw” and they highlight that there is a link between poetry and phenomenology. Some of the autobiographies I have read are poetic in nature, e.g. Wendy Lawson’s (1998) *Life Behind Glass*, Donna Williams’s (1992) *Nobody Nowhere* and Christopher Goodchild’s (2009) *A Painful Gift*, and they also include poems within some of the chapters. Therefore, I am sensitive to the poetic language style(s) within texts that have been authored by ‘autistic’ people to make meaning of their lived experiences, which by my interpretation is due to their conscious awareness of the mysterious element in their lived experiences. This is because language in the form of poetry often attempts to express and reflect the intangible aspects of life (Midgley, 2001; van Manen, 2014). Hence, IPA is an approach that is useful for exercising a phenomenological attitude in analysing such texts.

I have attended training workshops for IPA (see Appendix 15), drawn upon Smith et al.’s (2009) handbook, *Interpretative Phenomenological Analysis: Theory, Method and Research*, and Spiers and Smith’s (2012) paper to carry out the analyses.

Spiers and Smith (2012; p.122) state that:

“The poems were approached in the way traditional IPA data would be. The first author read the poems again and again to familiarise herself with them. She then made initial notes relating to the descriptive, linguistic and conceptual elements of the texts, before grouping these observations in to sub-themes. The sub-groups were then grouped in to super-ordinate themes. The analysis process continued throughout the writing, and was checked and refined by the second author.”

They also inform the reader that they were in touch with the poet and sought his feedback regarding their interpretation(s). I have re-read the autobiographical texts that befit the criteria of selection (as outlined in the next section, 6.4.) and have also read certain chapters several times; this enabled me to refine my reflexive notes and questions. I did not contact the writers in relation to my interpretation because the aim of the analyses were not to form super-ordinate themes that are then validated by the writer, it was to enable me to develop my standpoint and create reflexive sensitive questions from the very lived experience(s) of 'autistic' people.

Phenomenological research is initiated by acknowledging that one needs to "understand a phenomenon from the point of view of the lived experience in order to understand the meaning of it" (Englander, 2012; p.16). As outlined in the previous chapters, 'autistic' persons voices are not as prevalent in research as they ought to be (MacLeod et al., 2013; Milton, 2014b; Ridout, 2017). Therefore, the use of IPA with 'autistic' persons' narratives is suitable for carrying out research with people whose voices and stories may not be listened to or / and heard (Squire, 2008; Reid et al., 2005). Furthermore, this has enabled me to learn about the idiographic aspects of 'autistic' people's lived experiences, which in turn also led me to notice some of the similarities between their lived experiences. Therefore, exercising my phenomenological attitude with IPA enabled me to focus with, in and through the lived experiences of 'autistic' people in terms of what seems to make their lived experiences unique and what seems to make them similar.

Exercising my phenomenological attitude via the adaptation and use of IPA with 'autistic' persons' autobiographies enabled me to carry out the analyses of stages two and three in a manner that enabled me to acknowledge the subjective and interpretative aspects of the analyses. This also enabled me to be as transparent and plausible as possible, e.g. by summarising autobiographies, creating tables of analyses and by creating vignette analyses. Smith and Osborn (2008; p.54) state that:

"IPA has a theoretical commitment to the person as a cognitive, linguistic, affective and physical being and assumes a chain of connection between people's talk and their thinking and emotional state. At the same time, IPA researchers realize this chain of connection is complicated – people struggle to express what they are

thinking and feeling, there may be reasons why they do not wish to self-disclose, and the researcher has to interpret people's mental and emotional state from what they say."

Therefore, a holistic worldview, whereby aspects of the embodied and non-embodied self, e.g. emotions and thought, are recognized as being interconnected, is taken up regarding the nature of being human and it is acknowledged that the researcher also acts as an interpreter of such experience(s). This is in line with the aim of this study in terms of my attempting to become consciously aware of that which I am not be aware of. Furthermore, it has enabled me to practice in line with the notion of the double-hermeneutic aspect of the analyses (Smith et al., 2009), in that my subjective understanding(s) is an interpretation(s) of the authors' interpretations of their lived experiences.

Nevertheless, consciously acknowledging this by exercising a phenomenological attitude with IPA and narratives has meant that I have been able to carry out rigorous and systematic analyses in a reflexive manner. This has enabled me to catch a 'snapshot' of some 'autistic' people's meaning-making of the world and their experiences – to a certain degree, and I have also been able to ask questions about the paradoxical, dynamic and mysterious elements of their lived experiences.

So far I have provided a rationale for why and how I exercised my phenomenological attitude with IPA and 'autistic' person's autobiographies. I shall now summarise this section.

6.3.3. Summary of a rationale for exercising my phenomenological attitude with 'autistic' persons' autobiographies and IPA

In summary, I exercised my phenomenological attitude by taking up and adapting IPA to analyse the autobiographical texts of some 'autistic' persons. The advantages of this have been to develop more of an 'insider's' view into the lived experiences of 'autistic' persons; to initiate and facilitate the process of questioning myself and my questions, thereby creating research questions that are reflective of and sensitive to the ways of the 'other'; to be able to reflect upon, with and through such experiences and consider the implications with regards to the approaches and methods

process(es) of undertaking this research; and to assist in the process(es) of developing my philosophical assumptions, standpoint and voice as a researcher.

I have worked with 'autistic' persons' writings for the status quo reasons, which has led to the creation and development of the methods of investigation herein. This in turn fed into other processes involved in writing this thesis, e.g. Chapters Four, Five, Six etc., and continued to help form a coherent piece of research as the study developed.

Therefore, IPA is an approach that is recognized as being of a qualitative nature and enables a researcher to work from the roots upwards; focusing on meaning-making whilst being flexible enough to focus with, on and through the embodied and non-embodied, paradoxical, dynamic and mysterious elements of participants' lived experiences. It also values the researcher's own interpretations whilst simultaneously emphasizing that the researcher uphold a reflexive standpoint all throughout the study as well as afterwards. This is in line with my aim in terms of exploring 'autistic' persons' meaning-making processes; valuing their lived experiences and stories whilst simultaneously being self-reflexive with, in and through my meaning-making throughout the study and hereafter. However, this approach, of working with autobiographies and IPA, has its limitations and I shall discuss this in the final chapter of this thesis (Chapter Eight).

Having summarised this section, I will now proceed to outline and illustrate how I exercised my phenomenological attitude for the purposes of this study.

6.4. HOW I EXERCISED MY PHENOMENOLOGICAL ATTITUDE FOR THE PURPOSES OF THIS STUDY: THE THREE STAGES OF THIS RESEARCH

The three stages of this research involved:

- (i) a pilot study that enabled me to create the selection criteria for the autobiographies and to further support the uptake of IPA as an approach to analyse the data (Appendix 1);
- (ii) analysing three autobiographies in-depth, especially so as to question myself and question my questions (Appendices 2, 3 and 4). This led to the creation of a *Table of Questions, Categories and Themes* (Appendix 13);

- (iii) vignette analyses that span from infancy to adulthood; these were also used for creating draft interview protocols for interviewing 'autistic' adults about their inner lives and family lives over a lifespan. Draft vignette protocols for interviewing a family member(s) have also been created. I added the questions that emerged during this stage to the *Table of Questions, Categories and Themes* (Appendix 13).

Therefore, exercising my phenomenological attitude with 'autistic' persons' autobiographies and IPA has enabled me to question myself and my questions as well as to bring forth new knowledge and create interview protocols for future research. The stages are outlined as follows and each stage has fed into the next stage. Furthermore, one can view all the methods of enquiry and analyses in Appendices 1 to 14 – including the references I drew upon within the analyses.

6.4.1. Stage one: the pilot study, selecting autobiographies, the stages of analyses and questions

Here I shall describe how I got hold of Christopher Goodchild's (2009) autobiography, *A Painful Gift: The Journey of a Soul with Autism*, which I then read through and wrote a summary of. This then helped in the process of developing the criteria of selecting autobiographies for analysis; please refer to Appendix 1 to view the summary.

Initially, in early 2012, I carried out searches on the internet with the term 'autism and spirituality', 'the inner lives of people with autism' and 'autobiographies by people on the autism spectrum'. I found a website on the internet with a list of books written by 'autistic' people and it is below:

<http://www.ont-autism.uoguelph.ca/books-by-ASD-authors.html>

The website was created by Amanda Melissa Baggs, who is an American 'autistic' person. The books listed were / are all in English, of which some were translated into English. I ordered a few that had a title with a feeling of focusing on the inner life and were written by females and males, e.g. Temple Grandin's *Emergence: Labeled Autistic* (1986) and Edgar Schneider's *Discovering My Autism: Apologia Pro Vita Sua (With Apologies to Cardinal Newman)* (1999). I also searched on online book stores

and bought books that 'autistic' academics recommended, e.g. William Stillman's *The Soul of Autism: Looking Beyond Labels to Unveil Spiritual Secrets of the Heart Savants* (2008) and *The Reason I Jump* by Naoki Higashida (2013). The next subsection, 6.4.1.1. *The autobiographies, stages of analyses and questions*, includes a list of the books I ordered and read. I came across Christopher Goodchild's (2009) autobiography on an online book store; the title grabbed my attention due to the use of the terms 'painful gift', 'journey', 'soul' and 'autism'. These terms were relevant in light of the nature of this study. I read a brief summary of what the book was / is about and then ordered it.

Christopher was adopted as a baby of six weeks by a family in north London. They were of a middle class background and as an infant he preferred to remain in his room due to painful sensory experiences, especially when interacting with family members. He realised he was / is 'autistic' at the age of forty-two and sought an official recognition of being 'autistic', i.e. a medical diagnosis. I chose Goodchild's (2009) autobiography because it moved me when I read it. Goodchild explicitly uses the story of HH. Jesus Christ as a lens and framework to make sense of his own experiences whereby he attains better self-realization and self-acceptance, illustrating the development of his perception(s) and meaning-making process(es). It captures the paradox(es), dynamic and the mystery(ies) of the lived experience of being human as well as being an 'autistic' one at that.

Furthermore, many of his descriptions are explicitly phenomenological in nature, in that some of the everyday things many people take for granted were / are experienced more intensely by him. The embodied and non-embodied elements of the lived experience are explicitly illustrated and emotional connectedness&non-connectedness in terms of learning and self-realization are explicitly outlined. He reflects on family life and family dynamics over a lifespan and also happens to use poetic language and quotes throughout the chapters in order to express himself.

After the summary was complete I re-read it and asked myself "Bearing in mind the overall research aim and the questions, what are the factors that I am looking for when selecting autobiographies to analyse?", and so I arrived at the following core criteria:

- (i) the author writes in the first-person and includes detailed reflections about

- their self-knowledge, learning and family life;
- (ii) the author's narrative illustrates the paradox(es), dynamics and the mystery(ies) of being an 'autistic' human being;
- (iii) the embodied and non-embodied aspects of self are explicitly illustrated, whereby emotional connectedness&non-connectedness in terms of learning and self-knowledge are outlined.

Therefore, the books did not have to be officially recognised as autobiographies. They simply had to be written in an autobiographical manner, i.e. self-reflective accounts of the person's lived experiences. Having exercised my phenomenological attitude and having undergone the pilot study enabled me to create the selection criteria; this in turn enabled me to seek and select the kinds of autobiographies I was looking for.

6.4.1.1. The autobiographies, stages of analyses and questions

The books that I read that are by 'autistic' persons, and that are autobiographical and / or include reflective stories of their own lived experiences are the following, in order of the publication year:

1. *Emergence: Labeled Autistic. A True Story*, by Temple Grandin and Margaret M. Scariano (non-'autistic' co-author), 1986. New York; Warner Books.
2. *Nobody Nowhere: The Extraordinary Autobiography of an Autistic*, by Donna Williams, 1992. New York; Times Books.
3. *Thinking in Pictures and Other Reports from My Life with Autism*, by Temple Grandin, 1995. New York; Vintage Books.
4. *Life Behind Glass: A Personal Account of Autism Spectrum Disorder*, by Wendy Lawson, 1998. Australia; Southern Cross University Press.
5. *Autism and Sensing: The Unlost Instinct*, by Donna Williams, 1998. London; Jessica Kingsley Publishers.
6. *Discovering My Autism: Apologia Pro Vita Sua (with Apologies to Cardinal*

- Newman*), by Edgar Schneider, 1999. London; Jessica Kingsley Publishers.
7. *Asperger Syndrome, the Universe and Everything*, by Kenneth Hall, 2001. London; Jessica Kingsley Publishers.
 8. *Glass Half-Empty, Glass Half-Full: How Asperger's Syndrome Changed My Life*, by Chris Mitchell, 2005. London; Lucky Duck.
 9. *Freaks, Geeks and Asperger Syndrome: A User Guide to Adolescence*, by Luke Jackson, 2002. London; Jessica Kingsley Publishers.
 10. *ASPoetry*, by Wendy Lawson, 2006. London; Jessica Kingsley Publishers.
 11. *Autism and the God Connection: Redefining the Autistic Experience Through Extraordinary Accounts of Spiritual Giftedness*, by William Stillman, 2006. Naperville, Illinois; Sourcebooks Inc.
 12. *Born on the Wrong Planet [second revised edition]*, by Erika Hammerschmidt, 2008. U.S.A; Autism Asperger Publishing Company.
 13. *The Soul of Autism: Looking Beyond Labels to Unveil Spiritual Secrets of the Heart Savants*, by William Stillman, 2008. U.S.A.; New Page Books.
 14. *A Painful Gift: The Journey of a Soul with Autism*, by Christopher Goodchild, 2009. UK, Darton; Longman and Todd Ltd.
 15. *Asperger's Syndrome and Mindfulness: Taking Refuge in the Buddha*, by Chris Mitchell, 2009. London; Jessica Kingsley Publishers.
 16. *Martian in the Playground, Understanding the Schoolchild with Asperger's Syndrome*, by Clare Sainsbury, 2009. London; SAGE.
 17. *The Reason I Jump*, by Naoki Higashida (translated by K.A. Yoshida and David Mitchell), 2013. London; Sceptre.

I stopped at seventeen books because I was aware that there was already a lot of data that I was likely to work with and I had to manage my time in order to be able to carry out this actual study. It may seem that the books are outdated, however, the lived experiences that 'autistic' persons report at the given time periods of their lives are the representations of their meaning-making during then and therefore valid in

their own right. Therefore, exercising my phenomenological attitude with 'autistic' persons' autobiographies enabled me to create the criteria of selection and to set two stages of analyses; this was so as to be able to achieve my research aim and to work with the vast amount of data effectively.

Firstly, I selected the following three autobiographies as they fit the selection criteria and I analysed them in-depth on an individual basis; I focused on how some 'autistic' people may, and do, use spirituality or / and religion to make meaning regarding their inner lives and lived experiences – drawing upon the idiosyncrasies and similarities over a lifespan:

1. *Autism and Sensing: The Unlost Instinct*, by Donna Williams, 1998.
 - (i) About the author: Donna was born in Australia and later moved to England in her mid-twenties. She realised that she may be 'autistic' in her early to mid-twenties and sought a medical diagnosis when living in London, England, at the age of twenty-eight. She later took up a name from her infancy years and called herself Polly Samuel. However, for the purposes of clarity this book and other books of hers included in this study shall use her then name when having published them, i.e. Donna Williams.
 - (ii) Where the autobiography / reflective text was written: This is not clearly stated in the book, however, Donna had moved to England at the age of twenty-six and the book was published in England, so one assumes that this book was written in England.
 - (iii) When the autobiography / reflective text was written: It was published in 1998 by Jessica Kingsley Publishers, London.
 - (iv) Why and how the text came into being: In the *Foreword* Donna outlines that her motive to write this text was to enlighten people with regards to accepting the different realities that exist. There is no co-author and no particular person is given an acknowledgment regarding the actual creation of the text, so I am assuming that she wrote it by herself and it was then submitted to the publishers for editing etc.

2. *Discovering My Autism: Apologia Pro Vita Sua (with Apologies to Cardinal Newman)*, by Edgar Schneider, 1999.

- (i) About the author: Edgar was born in America in the 1930s. In 1978 he had a breakdown at work. He states that this was due to an onset of Attention Deficit Disorder (ADD). He was initially diagnosed as being 'schizophrenic' by his doctors. Then in 1995 he himself realised he was / is 'autistic' upon having read an article written by Oliver Sacks. After which he sought a medical diagnosis of 'autism'. This occurred when he was well into his adult years, whereupon he had a family and children. He does not mention his age upon writing the autobiography, however, given the certain time periods he outlines I guess he was in his mid-sixties when he wrote it.
- (ii) Where the autobiography / reflective text was written: It was written in America.
- (iii) When the autobiography / reflective text was written: It was published in 1999 by Jessica Kingsley Publishers, London.
- (iv) Why and how the text came into being: In the *Prologue* Edgar outlines that he wrote this book because once he had learnt that he was / is 'autistic' it helped him to understand himself better; "it explained so many things about me that had previously been enigmas, even to myself" (p.9), and when he discussed this with the pastor of his church the pastor encouraged him to write an autobiography. He states that (p.9), "I have done just that, not only for those who might like to know me better, but also as catharsis for myself."

3. *Asperger's Syndrome and Mindfulness: Taking Refuge in the Buddha*, by Chris Mitchell, 2009.

- (i) About the author: Chris was born in England. After having a breakdown at university he was referred to an Educational Psychologist and at the age of twenty was recognised as being 'autistic'.
- (ii) Where the autobiography / reflective text was written: The book was published in England, though from Chris's story one learns that he was working on it on and off for some time between his travels.
- (iii) When the autobiography / reflective text was written: It was published in 2009 by Jessica Kingsley Publishers, London.
- (iv) Why and how the text came into being: Chris was encouraged to write this

book by Genevieve Edmonds, a consultant and writer in the field of 'autism' and was an adult recognized as being 'autistic'; she passed away in 2008.

The above authors have been explicit in relation to the spiritual or /and religious lenses they use to make meaning of their lives and have written these texts in the first person. I also did consider William Stillman's work, however, he writes from a professional point of view and includes some of his experiences in a manner that 'seeps' through the writing at certain times and is not as prominent in terms of his own experiences – it is not explicit enough. However, I accept that what he has written is likely to be meaningful for him and therefore he is likely to be expressing elements of his own experiences via the use of other persons' lived experiences and his professional accounts. I wanted to include writers' stories that are as explicit as possible, i.e. written in the first person, so as to gain as deep an understanding into such persons' lived experiences and meaning-making process(es) and their interpretations. This also enabled me to explicitly explore my own meaning-making process(es) and interpretations of 'spirituality' and 'religion', in turn enabling me to question myself and my questions in-depth and to create sensitive research questions.

Secondly, after analysing the above autobiographies I decided to focus more so on the family context over a lifespan, and my selection criteria became more specific for stage three of the analyses, as follows:

- (i) meaning-making in terms of the embodied and non-embodied aspect of self within a family setting, regardless of whether there is or is not an explicit reference to spirituality / religion etc. In that I will be imposing my interpretation upon the text in relation to the theoretical framework of this study, i.e. my phenomenological attitude;
- (ii) how the family worked with their inner&intersubjective ways of being together as a whole in the particular outlined narrative, i.e. how were paradox, dynamics and mystery prevalent in their experience(s) and which strategies helped to work with these elements and maintain communication and non-communication as well as understanding and

non-understanding;

- (iii) bear in mind inner&intersubjectivity and emotional connectedness and non-connectedness throughout;
- (iv) the lifespan vignettes ought to be regarding infancy, childhood, teenagehood and adulthood, with there being two vignettes per lifestage.

Therefore, the autobiographies from which I selected excerpts of lived experiences within the family setting did not have to have a spiritual or / and religious theme and are as follows:

1. *Emergence: Labeled Autistic. A True Story*, by Temple Grandin and Margaret M. Scariano (a non-‘autistic’ co-author), 1986.
 - (i) About the author: Temple was born in America in 1947. Due to her behaviour her family suspected that she had brain damage and her mother took her to a neurologist at the age of three to have her examined. She was given a diagnosis of brain damage and ‘autism’.
 - (ii) Where the autobiography / reflective text was written: America.
 - (iii) When the autobiography / reflective text was written: It was published in 1986 and this copy was printed in 1996. It was published by Grand Central Publishing, U.S.A.
 - (iv) Why and how the text came into being: Temple writes about her experiences and also includes research materials in the Appendices for parents, educators, and other professionals. Therefore, I am assuming that as much as this written work is a form of self-exploration it is also aimed at educating people.

2. *Born on the Wrong Planet [second revised edition]*, by Erika Hammerschmidt, 2008.
 - (i) About the author: Erika was born in America. Her parents realised she may be ‘autistic’ and she was officially recognised as being ‘autistic’ and as having Tourette’s syndrome at the age of eleven.
 - (ii) Where the autobiography / reflective text was written: America.

- (iii) When the autobiography / reflective text was written: It was published by AAPC, U.S.A.
- (iv) Why and how the text came into being: Erika always enjoyed writing and has a fascination with language (p.186), so she had wanted to pen down her life story, including details regarding also being 'autistic' (Asperger Syndrome) and having Tourette's.

3. *Nobody Nowhere: The Extraordinary Autobiography of an Autistic*, by Donna Williams, 1992.

- (i) About the author: Donna was born in Australia. She later moved to England in her mid-twenties. She realised that she may be 'autistic' in her early to mid-twenties and sought a medical diagnosis in London at the age of twenty-eight.
- (ii) Where the autobiography / reflective text was written: England.
- (iii) When the autobiography / reflective text was written: It was published by Jessica Kingsley Publishers, London.
- (iv) Why and how the text came into being: Donna wrote this autobiography so as to understand herself and life better, as well as to educate people who are non-'autistic' about an 'autistic' person's life.

4. *Freaks, Geeks and Asperger Syndrome: A User Guide to Adolescence*, by Luke Jackson, 2002.

- (i) About the author: Luke was born in England. He was officially recognised as being 'autistic' at the age of eight.
- (ii) Where the autobiography / reflective text was written: England.
- (iii) When the autobiography / reflective text was written: It was published in 2002 by Jessica Kingsley Publishers, London.
- (iv) Why and how the text came into being: Luke wrote this book as a guide for adolescents, including those who are not 'autistic', and also outlines that it is likely to be useful for families, educators and other professionals. At the time he was thirteen years old, was in a family of six other siblings, and they assisted with writing the book as well as drawing pictures for it – included in the book.

5. *Life Behind Glass: A Personal Account of Autism Spectrum Disorder*, by Wendy Lawson, 1998.

- (i) About the author: Wendy was born in Australia. She had been recognized as being 'autistic' in August 1994, at the age of forty-two.
- (ii) Where the autobiography / reflective text was written: Australia.
- (iii) When the autobiography / reflective text was written: Wendy wrote this book when she was forty-six years old. It was published in 1998 by Southern Cross University Press, Australia.
- (iv) Why and how the text came into being: On page ii, she states that she began to write this book 20 years ago (that would be in the 1970s), and proceeds to finally state (page iii) "I hope this book will turn the light on for you, and perhaps it will be another link in the chain towards greater understanding, acceptance and respect for those of us who are "different". Wendy is now known as Wenn Lawson, however, for the sake of clarity I shall refer to him as 'her' and as 'Wendy Lawson' – the name she used when writing the book.

6. *Glass Half-Empty, Half-Full: How Asperger's Syndrome Changed My Life*, by Chris Mitchell, 2005.

- (i) About the author: Chris was born in England. At the age of twenty he had a breakdown at university and was referred to an Educational Psychologist who officially recognised him as being 'autistic'.
- (ii) Where the autobiography / reflective text was written: England.
- (iii) When the autobiography / reflective text was written: It was published in 2005 by Lucky Duck, London.
- (iv) Why and how the text came into being: On page 3 the author states that "Being diagnosed with Asperger's syndrome at nearly 20 years old, I feel I have lived two separate lives. For this purpose, I feel that my life story needs two separate sections. Glass Half-Empty is about my life before diagnosis and Glass Half-Full is about my life after diagnosis. The intention of this book is to show how my life has changed since diagnosis, and above all, to recognize the positive

aspects of Asperger syndrome.”

7. *Discovering My Autism: Apologia Pro Vita Sua (with Apologies to Cardinal Newman)*, by Edgar Schneider, 1999.

For the contextual information regarding this author and book please refer to the section above regarding the individual analyses.

For the purposes of clarity, the following tables provide a summary of the list of ten autobiographies that I selected and worked with during stages two and three of the analyses.

Table 2: The autobiographies I analysed in-depth during stage two of the analyses

The autobiographies I worked with during stage two for the in-depth individual analyses, in order of the year of publication.
1. <i>Autism and Sensing: The Unlost Instinct</i> , by Donna Williams, 1998.
2. <i>Discovering My Autism: Apologia Pro Vita Sua (with Apologies to Cardinal Newman)</i> , by Edgar Schneider, 1999.
3. <i>Asperger's Syndrome and Mindfulness: Taking Refuge in the Buddha</i> , by Chris Mitchell, 2009.

Table 3: The autobiographies that I selected vignettes from during stage three of the analyses regarding the family context(s) over a lifespan

Lifespan period	The autobiographies from which I selected the vignettes for the family context analyses.	
Infancy	Vignette 1 from: <i>Emergence: Labeled Autistic. A True Story</i> , by Temple Grandin and Margaret M. Scariano (a non-‘autistic’ co-author), 1986.	Vignette 2 from: <i>Born on the Wrong Planet [second revised edition]</i> , by Erika Hammerschmidt, 2008.
Childhood	Vignette 3 from: <i>Freeks, Geeks and Asperger Syndrome: A User Guide to Adolescence</i> , by Luke Jackson, 2002.	Vignette 4 from: <i>Life Behind Glass, A Personal Account of Autism Spectrum Disorder</i> , by Wendy Lawson, 1998.
Teenagehood	Vignette 5 from: <i>Glass Half-Empty, Half-Full: How Asperger's Syndrome Changed My Life</i> , by Chris Mitchell, 2005.	Vignette 6 from: <i>Nobody Nowhere: The Extraordinary Autobiography of an Autistic</i> , by Donna Williams, 1992.
Adulthood	Vignette 7 from: <i>Discovering My Autism: Apologia Pro Vita Sua (with Apologies to Cardinal Newman)</i> , by Edgar Schneider, 1999.	Vignette 8 from: <i>Nobody Nowhere: The Extraordinary Autobiography of an Autistic</i> , by Donna Williams, 1992.

Questions were created to focus on the following aspects of the lived experience by analysing the narratives using them:

1. How did the 'autistic' person work with the paradox(es) of their lived experience? How did their family work with the paradox(es)?
2. How did the person work with the dynamic aspect of their lived experiences? How did their family work with this aspect?
3. How did the person work with the mysterious aspect of their lived experiences? How did their family work with this?

The following questions emerged from the above questions and were also used to analyse the autobiographies:

1. How do 'autistic' persons' make meaning? Especially in the family context? What seems to be the family's meaning-making process(es)? What is my meaning-making process(es)?
2. What are the implications for perception(s) and self-knowledge?
3. What are the implications for phenomenology as a methodology?
4. What are the implications for IPA as an approach and the methods involved?

Smith et al. (2009) focus more so on interview data, however, IPA can also be used with narratives. They also illustrate how to proceed with analysing data and how to write up the findings so that it is clear as to how one interpreted the data. I have taken up this approach and also created tables to demonstrate how the clusters and themes of questions emerged. I then treated the idiographic details as a means of questioning myself and my research questions and I created questions for future interview vignette protocols with 'autistic' persons and their family members. In turn, I became more comfortable with regards to adapting IPA for exercising my phenomenological attitude with 'autistic' persons' autobiographies, and more specific questions regarding working with narratives and IPA emerged:

1. How does one use autobiographical texts with IPA?
2. How does one use autobiographical texts in order to further become sensitive to the context and culture of 'autistic' persons and 'their' family life?
3. How does one create further research questions (e.g. for interviews) and develop one's standpoint(s) whilst analysing 'autistic' person's autobiographies with IPA?

I worked with the above questions by attempting to (re-)answer each of them per analysis. Furthermore, during and after each analysis of an autobiography or excerpt of narrative I reflected in, with and through the reported lived experiences; I created questions that enabled me to be reflexive about my worldview at the micro-level and also kept diaries throughout the whole study. I have drawn upon these in order to be able to carry out this study and incorporated questions, ideas and practices accordingly during each phase of this research.

Having outlined stage one of this research, I shall now proceed to the second stage of analysing three 'autistic' persons' autobiographies in-depth.

6.4.2. Stage two: analysing three 'autistic' persons' autobiographies in-depth

I selected three 'autistic' person's autobiographies that fulfilled the selection criteria and analysed them through and through to fathom their meaning-making so as to gain an overall sense of their lived experiences and to question myself and my research questions. In that, I was able to learn about the insider's perspective – to a certain degree. This enabled me to fathom my meaning-making as far as I could and to demonstrate it by reflexively creating questions – both for myself and for potential interview situations. Therefore enabling me to fulfil this study's research aim insofar as is possible.

During this process I read one book at a time with the research questions in mind. I summarised the chapters in each book and then created and worked with a table for analysing the narrative in more depth. The table was constructed of the set questions above to dialogue with the 'autistic' person's lived experiences as well as

illustrate how their works in turn led me to dialogue with the works of certain philosophers, poets, scientists, spiritual teachers etc. and to create questions. After all three books were analysed I took a break and then returned to the analyses (Appendices 2 to 4). For each individual author's analysis I re-read the summaries of the chapters several times whilst turning the statements into questions. Once this was achieved I then added these questions into a *Table of Questions, Categories and Themes* (Appendix 13). Therefore, a reflexive dialogue has taken place throughout and continues to do so.

6.4.2.1. A step-by-step example(s) of how I carried out an in-depth analysis of an autobiography regarding the individual

Below are step-by-step examples from Chris Mitchell's (2009) individual analysis (Appendix 2), illustrating how I exercised my phenomenological attitude. I summarised and interpreted the chapters and then reflected further and created sensitive questions regarding my worldview and that of the 'other', i.e. the 'autistic' author. Note, in Appendix 2 I have included images of a printed version of the analysis that I used to further reflect and create sensitive questions from the summaries of the chapters. The steps of analysis are as follows.

Step 1: I summarised the chapters as Figures 2 and 3 illustrate below. They are examples of how I carried out my style of 'line-by-line coding' as recommended in IPA (Smith et al., 2009).

Figure 2: Contextual information regarding the author and the book

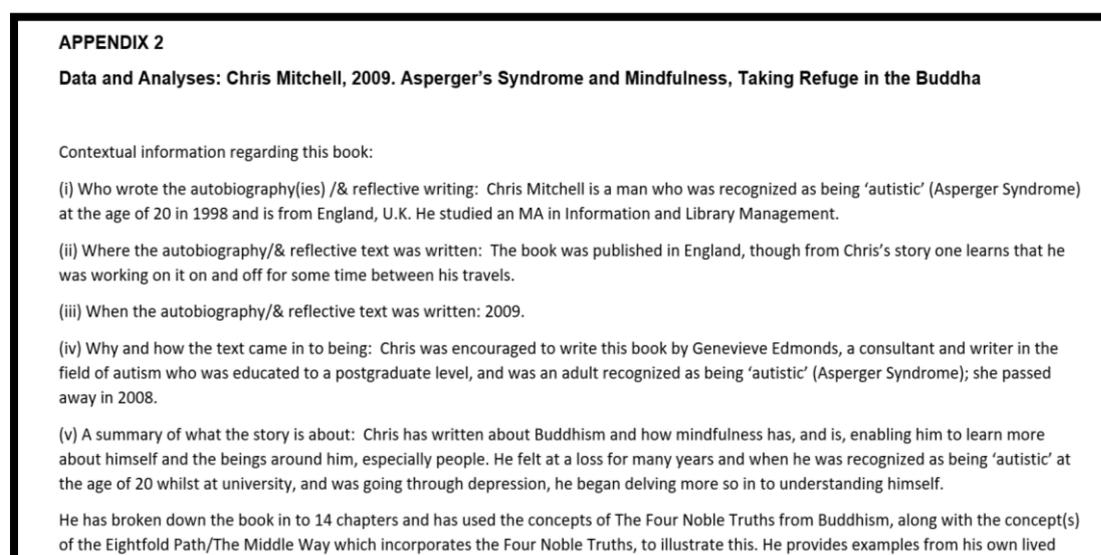
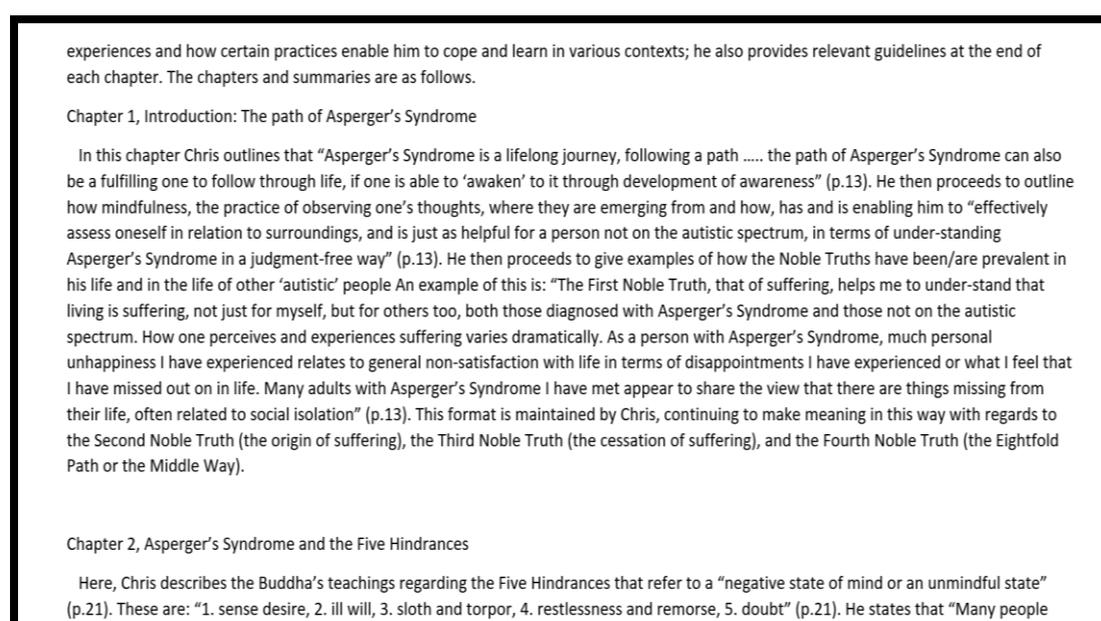


Figure 3: A summary of chapter 1 of the book, going on to chapter 2



I continued with this style of analysis until the last chapter.

Step 2: I had created a table of analysis that included my research questions, and Figure 4 (below) provides an example of it. Interpretative Phenomenological Analysis recommends creating a table of analysis to demonstrate the interpretation process(es).

Figure 4: An example of the table of analysis and my beginning to analyse the paradoxical elements of Chris's lived experience

How does Chris Mitchell use spirituality &/ religion to make meaning regarding his embodied&non-embodied life experiences?			
Question	Excerpt(s) from the Book	Researcher's Reflections and Notes	Ideas of Possible Questions for Interviews
1. How did the 'autistic' person make meaning of the paradox(es) of their lived experience? How did they practically deal with it?	"Being diagnosed with Asperger's Syndrome back in 1998, when I was 20 years old, was an immediate relief. Having had my diagnosis for almost ten years at the time of writing, I have found that beyond the impermanent nature of relief, Asperger's Syndrome is a lifelong journey, following a path. At times, this path can be difficult to negotiate, but with the right effort and through developing self-esteem, the path of Asperger's Syndrome can also be a fulfilling one to follow through life, if one is able to 'awaken' through development of awareness.	Chris is accepting more so that life changes and this in itself is adding to him working with the 'impermanent nature', i.e. paradoxes and motion/dynamics of life. The mystery of being 'autistic', that was recognized later in life, gave Chris relief; a recognition of an aspect of oneself enabled further development of self-understanding /&perception? He is using the notion of 'the path' from Buddhism to merge his understanding and non-understanding of self regarding being 'autistic'?	

The research question regarding how Chris uses spirituality or / and religion is at the top of the table as a reminder for me about what to focus on. Note that I have also focused on his embodied and non-embodied ways of being – this is drawn upon all throughout his and the other individuals' analyses. There are four columns. The far left column of the table includes the first question in exercising the phenomenological attitude and focusing on, in, with and through an example of Chris's lived experience that I felt was explicitly paradoxical. The second column from the left includes the actual excerpt of his lived experience and next to this column is the third column that includes my reflections and notes. The final column on the right side of the table is one for writing in possible ideas of questions for future interviews.

Step 3: The table continues in the same format with regards to the dynamic and mysterious aspects of Chris's lived experiences, as Figures 5 and 6 illustrate below.

Figure 5: An example of my beginning to analyse the dynamic aspect(s) of Chris's lived experiences

<p>2. How did the person make meaning of the dynamic aspect of their lived experience? How did they practically deal with it?</p>	<p>Anxiety and mind: "Anxiety is present in some shape or form almost every day in our lives. As a person with Asperger's Syndrome, I have experienced much difficulty in being able to cope with anxiety, to the extent that it has taken over my mind" (p.53) and "Looking back, the anxiety that plagued me during those years took control of me to the extent that it was even affecting the quality of my work. For often, when I felt that my mind was troubled by such uncertainty, it was so difficult for me to focus on the immediate task in hand. When having to try and balance these particular concerns, I often found that my mind ended up reacting to situations and in some cases certain people in a quite cynical way. This was where my inability to recognise</p>	<p>Anxiety can and does produce thoughts that overwhelm Chris, illustrating the thoughts&feelings in lived experiences as well as a concept (Mary Midgley's <i>Science and Poetry</i> comes to mind), and how these affect his everyday life – distancing him from the immediate tasks. Leading to negative thoughts&emotions regarding self and others, illustrating inner&intersubjectivity.</p> <p>Also illustrating how emotional&thought connectedness and non-connectedness affect learning and understanding regarding self, others and life.</p> <p>Making meaning with mind, body and actions – continual 're-aligning' with self? Continual reflexivity? This is also applicable</p>	
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Figure 6: An example of my beginning to analyse the mysterious aspect(s) of Chris's lived experiences

<p>3. How did the person make meaning of the mysterious aspect of their lived experiences? How did they practically deal with this?</p>	<p>Suffering and not knowing why in itself led to more suffering: "For me though, what I felt was suffering was remaining undiagnosed until I was 20 years old, often knowing I was different but not knowing of any reason as to why." (p.102).</p> <p>Facing and coping with suffering via reflection: "I feel from what I have learned that being aware of how Asperger's Syndrome affects a</p>	<p>"knowing I was different" & "not knowing of any reason as to why"; the known&mysterious(unknown) aspect of oneself and one's lived experiences cause pain. Self-knowledge in itself is paradoxical? Which leads to a self-understanding/flourishing in relation to being recognised as being 'autistic'? And continues via Chris's ongoing journey and path? A constant paradoxical dynamic flow of mystery revealing itself, leading one in to deeper depths of Self with Self?</p> <p>Shems&Rumi come to mind (in Fihi Ma Fih (1260 – 1273), "It is what it is"/The Discourses of Rumi, translated by A.J. Arberry, 1961 / 2000; p.37-38): "It is pain that guides us in every enterprise. Until there is an ache within, a passion and a yearning for that thing arising</p>	<p>When were you recognised as being 'autistic'? Whilst growing up did you feel different and not know why? Do you feel that you suffered during the years that you were not as aware of this aspect of yourself? What do you think suffering is?</p>
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These questions enabled me to exercise my phenomenological attitude with regards to the lived experiences of the 'other' in a reflexive manner. Enabling me to develop my insight(s) into their (i) meaning-making and (ii) my meaning-making of their meaning-making. Furthermore, the structure of the table has enabled me to be explicit and transparent about this process(es).

Step 4: I then moved on to focus on meaning-making, both with regards to myself and the ‘other’, and its implications for perception, self-knowledge, phenomenology, IPA and the research process(es) of this study; Figures 7, 8 and 9 demonstrate this below.

Figure 7: An example of the question regarding meaning-making

Questions and Reflective Notes Regarding the ‘Other’ and Myself	
1. How do ‘autistic’ persons’ make meaning? What is my meaning-making process(es)?	<p>Buddhism, goals, as a guideline of thinking, observing self, framework and concepts and moral guidelines... Merging with Asperger’s – a path/way – same in Buddhism. I am doing this as well – bridging aspects.</p> <p>Practices; mindfulness - Reflection – vepassana – autobio, the work he does.</p> <p>Bodily functions; anger, anxiety, food.</p> <p>Past experiences and memories; others, goes to a temple, food.</p> <p>Independence and interdependence; seeking to be economically independent and wants to feel less isolated, i.e. seeking a deeper sense of connectedness with the beings in life?</p> <p>What he has and does not have; i.e. a stable job makes him content, and simultaneously he does not want too many material belongings.</p> <p>Paradox; as described above.</p> <p>Dynamics; as described above.</p> <p>Mystery; as described above.</p> <p>This whole document illustrates my meaning-making, i.e. via the embodied&non-embodied Self (inner&intersubjectivity)</p>

Figure 8: An example of the questions regarding the implications of meaning-making for perception and self-knowledge as well as for phenomenology as a methodology

2. What are the implications for perception(s) and self-knowledge?	<p>Lived experiences are extremely important in our development of self-understanding. Yet, is there also something, that which is observing, that is not actually living (or not involved in) the moment by simply observing the moment itself? Death&life intertwined as one? Self-knowledge is present and simultaneously not present?</p> <p>Thoughts&emotions and self-understanding are very much intertwined; cognition and phenomenology?</p> <p>Observing Self; mindfulness and development of better understanding?</p>
3. What are the implications for phenomenology as a methodology?	<p>Phenomenology is very useful in terms of describing paradox and lived experiences, however, how does one work with the dynamic and mysterious nature of being in educational terms? Van Manen, 1990, and the four existential categories (p.102), as mentioned above in the table, may be useful for producing the interview protocols and may be aspects to focus on and through when working with families in the future.</p> <p>Phenomenological theory may well be developed further in terms of learning about the nature of self, and through self, by ‘autistic’ persons and ‘their’ lived experiences; this needs to be made that much more explicit. Jung, Romanyshyn and Shotter come to mind; maybe there is a place for a bridging of phenomenological theory and depth / analytical psychology? Mearleau-Ponty’s <i>The Visible and the Invisible</i> and learning come to mind.</p>

Figure 9: An example of the question regarding the implications of meaning-making for IPA and the overall research process(es)

<p>4. What are the implications for IPA as an approach and the methods involved?</p>	<p>IPA as a conceptual framework:</p> <p>William James’s influence in IPA is very useful.</p> <p>When thinking about William James, Chris’s writings as well as Donna Williams and her writings: how about ‘tools’ when exploring that which is not visible, the mysterious element of our being? A place for depth psychology, e.g. Jung, within phenomenology and IPA? I feel this bridge is already present in phenomenology and IPA via its use of persons’ lived experiences, however, maybe it is worth making it that much more explicit?</p> <p>IPA and methods:</p> <p>Bracketing is very useful in accepting people’s lived experiences as being valid in their own right. Maybe this is also a way of accepting the mysterious element in our lived experiences?</p> <p>More research required with IPA and reflective texts/autobiographies in themselves; sent Jonathan Smith as well as Michael Larkin e-mails (June 2014) asking for papers they may be aware of, they stated IPA could be utilized with autobiographical/reflective texts, though they are not aware of such papers. One paper, as outlined in the Methods section, by Spiers and Smith (2012) that utilizes IPA with poetic reflective writing has been</p>	
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These questions enabled me to be reflexive and become more sensitive about how the ‘autistic’ person’s meaning-making may be incorporated into the ways in which research is carried out; it also enabled me to reflect about, with, in and through my assumptions as a social scientist and what I am bringing to this study in terms of my projections and biases.

Step 5: I began to focus on Chris’s meaning-making in his family context(s) and how I was making meaning of this / these. This was not as in-depth as the vignette analyses to come, however, I wanted to begin to prepare for delving into the next stage. Figure 10 below shows this.

Figure 10: An example of the question regarding Chris’s meaning-making in the family context and my meaning-making of it

Questions and Reflective Notes Regarding the ‘Other’, the Family Context and Myself	
<p>How does this ‘autistic’ person make meaning? Especially in the family context? What seems to be the family’s meaning-making process(es)? What is my meaning-making process(es)?</p>	<p>Chris uses Buddhism and its teachings, the Four Noble Truths and the Eightfold Path, to make meaning of ‘autism’ as a way of being, living, as well as working with one’s suffering.</p> <p>Chris does not delve so much into his family’s meaning-making in terms of whether they practice Buddhism or not, however, he states that being able to like himself is also enabling him to see, feel and accept that he is valued by his family; as is in <i>Chapter 3, Starting with Who You Are: How the easiest person to like can be you</i>:</p> <p>He explains that in “Theravāda Buddhism though, the focus of who is the easiest person to like is oneself. Initially this may sound self-important or even egoistic, but the focus on liking oneself within the Theravāda tradition is more about finding the positive aspects and personal qualities one may have, that in some cases perhaps one wasn’t previously aware of, before applying these qualities to how they relate to others. This includes being able to take one’s frustrating experiences and curtail them in such a way that one can even see positive actions from where frustrations originate” (p.30). He then includes information about some of the frustrations that ‘autistic’ people can and do experience, e.g. struggling to achieve high grades in school, not being employed, and finding it difficult to make friends and form intimate relationships. He later states that meditation has enabled him to learn to like himself and “can be a route to self-confidence and, ultimately, personal happiness” (p.33). He also states that it has “enabled me to feel that who I am means much to those close to me, including my family, friends and people who feel my help has made a positive difference to their lives” (p.33).</p> <p>Furthermore, the non-recognition of an aspect of oneself can be confusing and frustrating for both Chris</p>

I then continued to ask the same questions regarding the implications of such meaning-making for perception, self-knowledge, phenomenology, IPA and the research approach of this study with the family context(s) in mind. Figures 11 and 12 illustrate this, as follows.

Figure 11: An example of the questions regarding the implications of meaning-making for perception and self-knowledge as well as for phenomenology as a methodology with the family context(s) in mind

<p>What are the implications for perception(s) and self-knowledge?</p>	<p>The implications are that one’s perception and self-knowledge can be ‘developed’ by:</p> <ul style="list-style-type: none"> - Self-reflection and meditation - Liking oneself, or by my terms, self-love - Intersubjectivity <p>Furthermore, as a researcher attempting to be as ethical as possible, do I have a duty to like myself and the ‘other’?</p>
<p>What are the implications for phenomenology as a methodology?</p>	<p>Self-love comes to mind</p> <p>Meaning-making ought to be focused on, with a more explicitly descriptive way of expression regarding interpretation and the sensory</p>

Figure 12: An example of the questions regarding the implications of meaning-making for IPA and how meaning-making, perception and self-knowledge may develop

What are the implications for IPA as an approach and the methods involved?	IPA: simply reflecting the emerging analysis process, for example: Certain readings come to mind as I proceed and therefore I include them in the table and illustrate how I dialogue with them Questions are arising in my mind as I proceed, hence the last column named 'Ideas of Possible Questions'
What is self-knowledge? How does it develop?	There is and is no such thing. We exist and do not exist simultaneously. It does not 'develop' as such, it is present and we are simply realizing it in becoming more consciously aware. Maybe I ought to stop using the term 'develop'?
What is meaning? How does it develop?	Meaning is God, "mâna Allah'dır" (Shems&Rumi in the Mesnevi/Mathnawi, 1263/2011; page 96) & meaning is also perception (p.79), and 'develops' by God playing backgammon with itself (Shems&Rumi, 1263 / 2011); inner&intersubjectivity and a continuous dance.
What is perception? How does it develop?	Perception? That which is paradoxical, dynamic and mysterious and is embodied and non-embodied, is magnifier and non-magnifier of experience. Pointing to meaning from 'within' and in the 'physical' realm. It develops by constantly merging with its true essence, in continual flux, being observed in, with and through awareness and then rolling back in to the depths from which it came from ... ?

During the stage of analysing the vignettes over a lifespan I drew upon these kinds of questions, reflections and thoughts to try and understand the 'autistic' person's worldview(s). It also enabled me to be more consciously aware of what I was bringing to the research as a person with my own worldview, interpretations and bias(es). The exploration of meaning-making within the family context(s) over a lifespan shall be illustrated further in the next sub-section, 6.4.3. *Stage three: analysing eight vignettes from 'autistic' persons' autobiographies in-depth.*

Step 6: The last section of the analyses during stage two was for me to be reflexive about the methods of this study; Figure 13 below is an example of this.

Figure 13: An example of my being reflexive regarding the methods of research I utilised for this study

1. How does one use narratives/autobiographical texts with IPA?
 - So far summarising the story and then asking the status quo phenomenological questions, simultaneously utilizing a table structure, is helping to use IPA with reflective writings.
2. How does one use autobiographical/reflective texts in order to further become sensitive to the context and culture of 'autistic' persons and 'their' family life?
 - As is illustrated above, reflective readings and questions that are arising from such interpretations are enabling me to become more sensitive to the context and culture of 'autistic' persons; this will hopefully happen more so with regards to the family when analysing the second set of excerpts of reflective texts.
3. How does one create further research questions (e.g. for interviews) and develop one's philosophical standpoint(s) whilst analysing 'autistic' person's autobiographies with IPA?
 - Asking questions regarding the 'other's' embodied&non-embodied lived experiences and my lived experiences is enabling me to create further questions for interviews whilst using IPA with the reflective writings of 'autistic' persons. Having engaged with the descriptive summaries of the chapters is also leading to the development of questions directly derived from my interpretations of the text; after having completed the table I have returned to the chapters and gone through them, coming up with questions that are directly linked to the statements and points made by the author, therefore developing both thematic and idiographic questions.

I later drew upon these kinds of questions to reflexively evaluate the strengths and limitations of this research and to write about it in the final chapter of this thesis.

Step 7: I then went on to analyse the second and third autobiographies. After a break I returned to the analyses, printed each one out, and I started reading through the summaries of the chapters of each autobiography in a reflexive manner. Whilst working with a hardcopy of an analysis I wrote down reflective notes on the actual hardcopy and also turned the statements into questions. Therefore, creating research questions that have helped to sensitise me further to 'autistic' person's ways of being and could also be used in future research. Figures 14 and 15 below show how I did this regarding Chris Mitchell's analysis.

Figure 14: The first example of an excerpt from the analysis of Chris Mitchell's book, illustrating how my reflections and research questions were emerging from them

Chris Mitchell, 2009. *Asperger's Syndrome and Mindfulness, Taking Refuge in the Buddha*

Contextual information regarding this book:

- (i) Who wrote the autobiography(ies) /& reflective writing: Chris Mitchell is a man who was recognized as being 'autistic' (Asperger Syndrome) at the age of 20 in 1998 and is from England, U.K. He studied an MA in Information and Library Management.
- (ii) Where the autobiography/& reflective text was written: The book was published in England, though from Chris's story one learns that he was working on it on and off for some time between his travels.
- (iii) When the autobiography/& reflective text was written: 2009.
- (iv) Why and how the text came in to being: Chris was encouraged to write this book by Genevieve Edmonds, a consultant and writer in the field of autism who was educated to a postgraduate level, and was an adult recognized as being 'autistic' (Asperger Syndrome); she passed away in 2008.
- (v) A summary of what the story is about: Chris has written about Buddhism and how mindfulness has, and is, enabling him to learn more about himself and the beings around him, especially people. He felt at a loss for many years and when he was recognized as being 'autistic' at the age of 20 whilst at university, and was going through depression, he began delving more so in to understanding himself.

He has broken down the book in to 14 chapters and has used the concepts of The Four Noble Truths from Buddhism, along with the concept(s) of the Eightfold Path/The Middle Way which incorporates the Four Noble Truths, to illustrate this. He provides examples from his own lived experiences and how certain practices enable him to cope and learn in various contexts; he also provides relevant guidelines at the end of each chapter. The chapters and summaries are as follows.

Chapter 1, Introduction: The path of Asperger's Syndrome

Handwritten notes:
 Why do people feel the need to reflect + write?
 How does their environment induce + encourage this process(es)?

Figure 15: The second example of an excerpt from the analysis of Chris Mitchell's book, illustrating how my reflections and research questions were emerging from them

In this chapter Chris outlines that "Asperger's Syndrome is a lifelong journey, following a path the path of Asperger's Syndrome can also be a fulfilling one to follow through life, if one is able to 'awaken' to it through development of awareness" (p.13). He then proceeds to outline how mindfulness, the practice of observing one's thoughts, where they are emerging from and how, has and is enabling him to "effectively assess oneself in relation to surroundings, and is just as helpful for a person not on the autistic spectrum, in terms of understanding Asperger's Syndrome in a judgment-free way" (p.13). He then proceeds to give examples of how the Noble Truths have been/are prevalent in his life and in the life of other 'autistic' people. An example of this is: "The First Noble Truth, that of suffering, helps me to understand that living is suffering, not just for myself, but for others too, both those diagnosed with Asperger's Syndrome and those not on the autistic spectrum. How one perceives and experiences suffering varies dramatically. As a person with Asperger's Syndrome, much personal unhappiness I have experienced relates to general non-satisfaction with life in terms of disappointments I have experienced or what I feel that I have missed out on in life. Many adults with Asperger's Syndrome I have met appear to share the view that there are things missing from their life, often related to social isolation" (p.13). This format is maintained by Chris with regards to the Second Noble Truth, the origin of suffering, the Third Noble Truth, cessation of suffering, and the Fourth Noble Truth, the Eightfold Path or the Middle Way.

Chapter 2, Asperger's Syndrome and the Five Hindrances

Here, Chris describes the Buddha's teachings regarding the Five Hindrances that refer to a "negative state of mind or an unmindful state" (p.21). These are: "1. sense desire, 2. ill will, 3. sloth and torpor, 4. restlessness and remorse, 5. doubt" (p.21). He states that "Many people with Asperger's Syndrome, including myself, often experience 'mental block-ages' in relation to frustration and anxiety, which often make such issues difficult to cope with, thus 'hindering' one's ability to cope effectively" (p.21) and proceeds to give examples with regards to each hindrance. For example, in the 'Sense desire' sub-section, he states that "For me, this hindrance often arises out of personal frustration through things being the way they are, in terms of thinking that 'as a person with Asperger's Syndrome, for what I have experienced in my life, I deserve to have it better'. In thinking along the lines of 'having it better', one may find oneself giving unwise attention to beautiful, often material, images and items, building up an image of 'how I should have it'" (p.22). He then describes how this sense also prevails in social contexts whereby he feels that people around him have moved on professionally and in their personal lives yet he cannot relate to this, therefore leaving him feeling as though he is "like a seed frozen in time" (p.22), socially isolated and feeling low in self-esteem.

Handwritten notes:
 Do you practice a particular religion? ~~and~~ what practices or rituals do you undertake? How do these practices make you feel?
 Do you feel you suffer? How do you cope?
 Do you feel socially isolated? How does this make you feel? How do you address this? (Cope?)
 What does your religion (or) spiritual beliefs teach about suffering?
 Do you have particular practices to address your suffering?
 How do you feel about yourself overall? Your level of self-esteem? Does your spiritual/religious beliefs play a role regarding your self-esteem?
 What are your practices? + How? (2)

Step 8: I then took the questions from the summaries of chapters, and the questions from the tables of analysis of the individual analyses, and incorporated them into the first part of an overall table referred to as the *Table of Questions, Categories and Themes* (Appendix 13). This enabled me to collect the questions per individual into one main document and work with the idiographic questions as well as the similar questions. Figure 16 illustrates this, as below.

Figure 16: An extract of the *Table of Questions, Categories and Themes* (Appendix 13) document for Chris’s individual analysis

Data and Analyses: Table of Questions, Categories and Themes from the Analyses of Autobiographies

The Individual Analyses

After reading through the autobiographies of three ‘autistic’ people and dialoguing with the texts by using Interpretive Phenomenological Analysis (IPA) as a framework for analyses (as previously demonstrated), I then re-reminded myself of what the purposes of this stage are; (i) to become more sensitive to ‘autistic’ people’s ways of being and (ii) to create relevant questions for possible future interviews with ‘autistic’ adults. Therefore, I re-read over the analyses so far and asked myself “What kinds of questions arise from what these people have written and what I have transcribed and worked with thus far?” Hence the following table; the questions arising from my descriptive engagement(s) with the chapters as well as the individual tables produced in the past analyses that focus on the questions regarding the authors’ embodied and non-embodied paradoxical, dynamic and mysterious lived experiences. The categories and themes that have emerged are as follows in the table.

Author and Book	Chapters and the Arising Questions	Categories	Themes	Further Reflections or / and Questions
Chris Mitchell, 2009. Asperger’s Syndrome and Mindfulness,	1: Do you practice a particular religion? What practices or rituals do you undertake? How do these practices make you feel? Do you feel you suffer?	Spirituality /& religion(s) Rituals and practices Effects of practices Suffering Beliefs about suffering	Spirituality /& religion	Why do people feel the need to reflect and write? How does their environment induce and encourage this process(es)?

The *Table of Questions, Categories and Themes* consists of five columns. The first column to the left of the table is for noting the author and book, the second column next to it on the right is for the summarised chapters and the arising questions (e.g. chapter one is written as ‘1.’ and the emerging questions from it are underneath it), the third column is for the categories that were forming thanks to the questions that were emerging and the fourth column is for the themes that are created thanks to the categories – IPA analysing practice is as so (Smith et al., 2009). The final column is for any further reflections and questions that may have emerged for me whilst creating and working with the *Table of Questions, Categories and Themes*; this was /

is my attempt to continue being reflexive. The *Table of Questions, Categories and Themes* also includes the questions regarding the paradoxical, dynamic and mysterious elements from the individual tables of analyses. Figures 17, 18 and 19 below show this regarding Chris Mitchell's individual analysis.

Figure 17: *The Table of Questions, Categories and Themes also including the questions regarding the paradoxical elements in Chris Mitchell's life*

From the Table of Analysis				
Paradox: If you do remember, how did you feel when you were recognized as being 'autistic'?	Recognition of also being 'autistic'	'Autism'		
Did your spiritual /& religious beliefs play a role in this process? How did your family or/and guardians behave?	Recognition of 'autism' and spirituality/&religion			
Did they hold spiritual /& religious beliefs about it?	Recognition of 'autism', spirituality/&religion and family			
How did it come in to play in your home life and/or when you were out with family/a guardian?				
Do you carry out any particular spiritual /& religious practices? How about in your everyday life? What are these?	Spiritual /& religious practices	Spirituality /& religion		
Do spiritual /& religious practices affect the quality of your life? The quality of your relationships? The quality of communication that takes	Spiritual /& religious practices and quality of life			

Figure 18: *The Table of Questions, Categories and Themes also including the questions regarding the dynamic elements in Chris Mitchell's life*

Dynamic(s): How do you cope with changes? Do your spiritual/&religious beliefs and/or practices play a role in this?	Changes in life and learning	Learning		How does the participant make meaning of the status quo elements (anxiety, mind, frustration and anger)? Is there a particular theme(s) or thread(s) that runs throughout their story(ies)? How is perception playing a role in their experiences? How are they illustrating self-knowledge and what role is this playing in their story(ies)? How might I do these things during
What kinds of situations make you feel happy? What kinds of situations make you feel content or and neutral? Is there something you remind yourself of/and do to feel like this? What do you learn about yourself? What do you learn about others' /& family members?	Happiness	Emotions		
Do you have hypersensitivities and hyposensitivities? How do you make sense of such abilities and their	Sensory abilities	The body and senses		

Figure 19: *The Table of Questions, Categories and Themes also including the questions regarding the mysterious elements in Chris Mitchell’s life*

	<p>Mystery: When were you recognised as being ‘autistic’? Whilst growing up did you feel different and not know why? Do you feel that you suffered during the years that you were not as aware of this aspect of yourself? What do you think suffering is?</p> <p>What do you do when you are in a confused state? How do you feel? How do you behave? Do your spiritual/&religious beliefs play a role in your decision-making? How?</p> <p>Have you been in a situation with a person whereby they apologised to you in a way that made you understand and forgive them? Do you use this kind of understanding with other people who may not have had the chance to do a similar thing or/and may be feel too embarrassed to do so?</p>	<p>Recognition of being ‘autistic’</p> <p>Suffering</p> <p>Confusion Confusion and learning</p> <p>Confusion, learning and spirituality /& religion</p> <p>Learning forgiveness with others</p> <p>Projecting forgiveness</p>	<p>‘Autism’</p> <p>Spirituality /& religion</p> <p>The body and senses</p> <p>Love</p>	<p>One way of working with the mystery of life, that can cause confusion, is to practice meditation and align more so with the observing self?</p> <p>Strengthening one’s alignment with the observing self so as to be better prepared with the mystery of life?</p>
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The *Table of Questions, Categories and Themes* then moves on to the next author, i.e. Edgar Schneider (1999); please refer to Appendix 13.

Hence, I proceeded to undergo steps one to eight with the other two individuals’ autobiographical writings and continued to work with the individual analyses and the *Table of Questions, Categories and Themes* (Appendix 13). This enabled me to recognise emerging categories and themes as well as idiosyncratic factors. Once the *Table of Questions, Categories and Themes* was completed for this stage I took a break and later focused on reflecting and writing about this process. Then I moved on to the third stage of enquiry.

6.4.3. Stage three: analysing eight vignettes from ‘autistic’ persons’ autobiographies in-depth

During this process I read the books one at a time with the research questions in mind and selected narratives set in the family context according to the more specific selection criteria regarding the family, as outlined earlier in section 6.4.1.1. of this chapter. I chose and analysed eight vignettes that fulfil the selection criteria, focusing on four phases of the ‘autistic’ persons’ lives so as to create and exercise a lifespan perspective regarding ‘autistic’ individuals within their family contexts. The phases covered were / are infancy (two vignettes, from birth to approximately five years old),

childhood (two vignettes, age six to approximately age twelve), teenagehood (two vignettes, age thirteen to approximately eighteen or nineteen) and adulthood (two vignettes, age nineteen or twenty onwards). For the infancy phase I selected a vignette from Temple Grandin (1986) and one from Erika Hammerschmidt (2008); for the childhood phase I selected a vignette from Luke Jackson (2002) and another from Wendy Lawson (1998); for the teenagehood stage I selected a vignette from Chris Mitchell (2005) and one from Donna Williams (1992); and for the adulthood phase I selected a vignette from Edgar Schneider (1999) and Donna Williams (1992). Therefore, I adapted and worked with a developmentally longitudinal lens regarding meaning-making and the family context and simultaneously demonstrated my ways of dialoguing with these texts. Please refer to Table 3 in section 6.4.1.1. for a summary of the vignettes I worked with.

After selecting the reported lived experiences I typed them up as vignettes in separate Microsoft Word documents – beginning with the ones from infancy; I read through all of them and began to type up questions. Once this was completed I took a break and then decided to analyse more in-depth ‘backwards’, beginning with adulthood vignettes as this is also how the books were written, in that the authors were reflecting over their past lived experiences to make meaning and to illustrate their worldview to readers. Thus I wanted to emulate and use this style of thinking and expression in the way in which I carried out the analyses in order to gain a deeper feeling for the process(es) they underwent as reflective beings. After this I returned to each vignette at different times and reflected over each one and analysed it that much more.

I analysed each vignette in-depth by using the table of analysis I had utilized for the previous set of analyses, focusing on the paradoxical, dynamic and mysterious aspects of the persons’ lived experiences, and continued to ask questions and demonstrate how I dialogued with the works of philosophers, poets, scientists, spiritual teachers etc. Once I had completed this task regarding all eight vignettes (Appendices 5 to 12) the questions that arose from the analyses were then added into the *Table of Questions, Categories and Themes* (Appendix 13). This has enabled me to gain a deeper insight into ‘autistic’ individuals’ life experiences and meaning-making in their family contexts and has also enabled me to illustrate my

interpretations and meaning-making regarding them in such contexts. Again, a reflexive and dialectic dialogue has taken place throughout and continues to do so.

Having already analysed three individuals' autobiographies in-depth had given me a lot of insight(s) into 'autistic' persons' ways of being, hence, this stage (three) enabled me to really home into certain experiences in the family context(s) during the authors' developmental phases. In terms of the data side of matters, this stage enabled me to practically work with the narratives in a way that was manageable and reduced my feelings of anxiety regarding the vast amount of data. Therefore, further helping me in fulfilling this study's research aim and in attempting to answer the research questions. What follows is a step-by-step example(s) of how I analysed a vignette regarding an 'autistic' person's experience in the family context during infancy, which was then repeated for all the following life phases and vignettes.

6.4.3.1. A step-by-step example(s) of how I analysed a vignette regarding the family context from an 'autistic' person's autobiography

Below is a step-by-step guide and example(s) regarding how I analysed Temple Grandin's (1986) experience in the family context during infancy (Appendix 5), which was then repeated for all the life phases and vignettes so as to create and exercise a lifespan perspective.

Step 1: I wrote the contextual information regarding the author and the book. Then I typed up the selected excerpt from the 'autistic' person's autobiography, as Figures 20 and 21 illustrate below.

Figure 20: An excerpt from Temple's vignette, illustrating how I copied and typed up the vignette from the book; part one

Data and Analyses: Family Vignette 1, Infancy. Temple Grandin, 1986. Emergence: Labeled Autistic

Contextual information regarding this book:

- (i) Who wrote the autobiography/& reflective text: Temple Grandin, with the assistance of Margaret M. Scariano
- (ii) Where the autobiography/& reflective text was written: It was published in California, U.S.A
- (iii) When the autobiography /& reflective text was written: It was published in 1986, and this copy was printed in 1996.
- (iv) Why and how the text came in to being:

Temple writes about her experiences and also includes research materials in the Appendices for parents, educators, and other professionals. Therefore, as much as this written work is a form of self-exploration it is also aimed at educating people.

Vignette from pages 15 – 16:

"Perhaps, because of my inability to communicate adequately and because of my "inner" world, the scenes of my childhood are vivid. Memories play like a movie on the big screen of my mind.

Mother, who was only nineteen when I was born, said she remembers me as a normal, healthy newborn with big blue eyes, a mass of downy brown hair, and a dimple in my chin. A quiet, "good" baby girl named Temple.

If I could remember those first days and weeks of life, would I have known I was on a fast slide slipping into an abyss of aloneness? Cut off by over-reactions or in-consistent reactions from my five senses? Would I have sensed the alienation I would experience because of brain damage suffered as an unborn child – the brain damage that would become apparent in life when that part of the damaged brain matured?

I was six months old when Mother noticed that I was no longer cuddly and that I stiffened up when she held me. When I was a few months older, Mother tried to gather me into her arms, and I clawed at her like a trapped animal. She has said she didn't understand my behavior and

Figure 21: An excerpt from Temple's vignette, illustrating how I copied and typed up the vignette from the book; part two

felt hurt by my hostile actions. She'd seen other babies cuddling and cooing in their mother's arms. What was *she* doing wrong? But she figured she was young and inexperienced. Having an autistic child was scary for her because she didn't know how to respond towards a baby who rejected her. Maybe my seeming re-jection was not unusual so she shoved her apprehension aside. After all, my health was good. I was alert, in-telligent, and well-coordinated. Since I was the first-born, Mother thought my withdrawal was probably normal, part of maturing and becoming independent.

This withdrawal from touch, so typical of autistic children, was followed in the next years by standard autistic behaviors: my fixation on spinning objects, my preference to be alone, destructive behavior, temper tan-trums, inability to speak, sensitivity to sudden noises, appearance of deafness, and my intense interest in odors.

I was a destructive child. I drew all over the walls – not once or twice – but any time I got my hands on a pencil or a crayon. I remember really "catching" it for peeing on the carpet. So the next time I had to go, instead of using the carpet, I put the long drape between my legs. I thought it would dry quickly and Mother wouldn't notice. Normal children use clay for modeling; I used my feces and then spread my creations all over the room. I chewed up puzzles and spit cardboard mush out on the floor. I had a violent temper, and when thwarted, I'd throw anything handy – a museum quality vase or left-over feces. I screamed continually, responded violently to noise and yet appeared deaf on some occasions.

At age three Mother took me to a neurologist to be examined because I did not act like the little girls next door. I was the first child in a family of four and none of my younger sisters or brothers behaved the way I did."

Step 2: I proceeded to type up the research question in seeking the 'other's' meaning-making as a reminder, with embodied and non-embodiedness in mind. I

created the table of analysis and began to ask the question regarding the paradoxical elements of Temple’s lived experience in the family context. Figure 22 below demonstrates this.

Figure 22: The table of analysis for Temple’s vignette regarding her experience in the family setting during infancy, with a focus on the paradoxical element(s)

How does Temple make meaning regarding her embodied&non-embodied life experiences as an infant?			
Question	Excerpt(s) from the Vignette	Researcher’s Reflections and Notes	Ideas of Possible Questions for Interviews
1. How did the ‘autistic’ person make meaning of the paradox(es) of their lived experience? How did they practically deal with it?	Perhaps, because of my inability to communicate adequately and because of my “inner” world, the scenes of my childhood are vivid. Memories play like a movie on the big screen of my mind.	<p>Temple makes meaning of the paradoxical aspect of her life, i.e. her lack of communication with others yet having vivid childhood memories, by highlighting this element(s) of her way of being.</p> <p>She can practically deal with this state of being by replaying her memories like a movie in her mind. She is likening her mind to a movie screen in order to illustrate this. This style of remembering memories could be interpreted as a means of self-storytelling. The entire book itself is a form of self-storytelling. Reflection as self-storytelling?</p> <p>Romanyshyn (2007, page 30) comes to mind: “The more we come to know, the more we come to know that we do not know. Jung</p>	<p>To ‘autistic’ person: Do you have any memories from infancy? Are they vivid memories or/and not so vivid?</p> <p>To parent(s): What was your child’s memory like during infancy? How did you feel about it?</p>

The table of analysis consists of four columns. The far left column of the table is for the ‘Question’, e.g. the question I sought to attempt to answer regarding, for example, the paradoxical element of Temple’s experience. The second column from the left is for the excerpt(s) from the vignette, enabling me to break down the vignette in such a way that I can reflexively dialogue with aspects of Temple’s experience; hence the third column is for my reflections and notes. The final column is for ideas of possible questions for interviews that have emerged from the specific excerpt of the vignette, and I have created such questions with two possible agents in mind – those directed towards the ‘autistic’ person and those directed towards the parent(s). Note, there are also some vignettes in the later phases of stage three that include siblings, and therefore there are also questions for them as well.

Step 3: I continued analysing with regards to the dynamic and mysterious aspects of Temple’s lived experience in the family context, as Figures 23 and 24 below illustrate.

Figure 23: Asking about the dynamic element(s) of Temple’s lived experience(s) during infancy

<p>2. How did the person make meaning of the dynamic aspect of their lived experience? How did they practically deal with it?</p>	<p>This withdrawal from touch, so typical of autistic children, was followed in the next years by standard autistic behaviors: my fixation on spinning objects, my preference to be alone, destructive behavior, temper tantrums, inability to speak, sensitivity to sudden noises, appearance of deafness, and my intense interest in odors.</p> <p>I was a destructive child. I drew all over the walls – not once or twice – but any time I got my hands on a pencil or a crayon. I remember really “catching” it for peeing on the carpet. So the next time I had to go, instead of using the carpet, I put the long drape between my legs. I thought it would dry quickly and Mother wouldn’t notice. Normal children use clay for modeling; I used my feces and then spread my creations all over the room. I chewed up puzzles and spit cardboard mush out on the floor. I had a violent temper, and when thwarted, I’d throw anything handy – a museum quality vase or left-over feces. I screamed continually, responded violently to noise and yet appeared deaf on some occasions.</p>	<p>Temple was finding it difficult to cope with her environment and the demands being made on her, e.g. withdrawal from touch as she was sensitive to being held.</p> <p>She preferred to be alone, exhibited what people saw as “destructive” behaviours, and had deep interests in elements in the environment. ‘Double empathy problem’ (Milton, 2012, 2014) comes to mind.</p> <p>She drew on the wall to express herself.</p> <p>It seems that she was frustrated and angry.</p> <p>She did not understand that the drapes were not to be used for peeing on. She behaved in ways that would be viewed by adults as ‘naughty’ or/and delinquent.</p> <p>I feel that these were all her ways of trying to communicate - including the ‘violent’ responses.</p> <p>Rosenberg’s <i>Living Nonviolent Communication</i> (2012, page viii): “I found that the following three factors are very important in understanding why some of us</p>	<p>To ‘autistic’ person: What kinds of sensory experiences did you have as an infant? E.g. regarding being touched, smells, objects etc.? Did you prefer to be alone? Did people think you were deaf?</p> <p>Did you draw over the walls as an infant? Did you pee or/and poo in places that your family did not want you to? How did your parents react to your behaviour? Say when being touched? When smelling things? When playing with certain objects?</p> <p>Were you frustrated or / and angry as an infant? Why? How?</p> <p>To parent(s): Did your child carry out behaviour as an infant that seemed like inappropriate behaviour? E.g. peeing on the carpet or</p>
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Figure 24: Asking about the mysterious element(s) of Temple’s lived experience(s) during infancy

<p>3. How did the person make meaning of the mysterious aspect of their lived experiences? How did they practically deal with this?</p>	<p>At age three Mother took me to a neurologist to be examined because I did not act like the little girls next door. I was the first child in a family of four and none of my younger sisters or brothers behaved the way I did.</p>	<p>When compared with other little girls and children of Temple’s age and under (i.e. when a paradoxical lens is used to view these infants), her mother recognizes more so that there is a mystery about her child’s behaviour. Her mother takes her to a professional to seek advice – with the hope of unravelling this mystery. A word(s) or/and label or/and conceptual construct is being sought to try and understand the mysteries of Temple as an infant.</p> <p>Lorna Wing in <i>The Autistic Spectrum</i> (1996; pages 189 – 190): “Another problem over the last three decades has been the influence of the school of thought that denies the reality of mental illness and disability and is opposed to ‘labelling’. Those who hold these views believe that giving a name to a condition is a self-fulfilling prophecy and harms the person concerned. In reality, having an accurate and detailed diagnosis as early as possible is the first crucial step for parents, enabling them to find information and help and giving access to services and the support found from meeting other parents in the same situation. [... ...]</p> <p>A full diagnostic evaluation involves taking a</p>	<p>To ‘autistic’ person: When did your parent(s) seek the advice of a medical professional in relation to you? Or/and when did you seek this kind of advice? How did this come about?</p> <p>To parent(s): When did you feel the need to seek professional medical advice regarding your child? How did this come about? How did you feel during the process(es) of your child being seen? How did you feel afterwards? How do you feel now?</p>
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Step 4: Then I spent some time reflecting and asked myself questions regarding the ‘autistic’ person, the family context and myself. Figure 25 below demonstrates how I did this with regards to the ‘autistic’ person’s meaning-making, the family members’ meaning-making and my meaning-making.

Figure 25: Questions and reflections regarding the ‘autistic’ person’s meaning-making, the family members’ meaning-making and my meaning-making

Questions and Reflective Notes Regarding the ‘Other’, the Family Context and Myself	
<p>How does this ‘autistic’ person make meaning? Especially in the family context? What seems to be the family’s meaning-making process(es)? What is my meaning-making process(es)?</p>	<p>As an infant Temple was making meaning via her embodied&non-embodied experiences, e.g. at 6 months she had begun to push her mother away (I assume this was due to sensory overload as she refers to this a little later on), being engrossed in spinning objects and odours, and I assume that she was also attempting to communicate with the tools that she had, e.g. carrying out what she terms as ‘destructive behaviour’ and drawing on the walls etc. She also preferred to be alone. Therefore, meaning-making can take many forms, which includes the family context in terms of family being present and not being present.</p> <p>Her mother’s meaning-making of this was that Temple was rejecting her and this led to her feeling hurt. Yet Temple refers to it as “my seeming rejection”, implying that physical distancing of oneself from one’s mother does not necessarily mean that one is rejecting their mother. Hence, it seems that it is more so a distancing (or rejection) from the type of physical interaction rather than a rejection of the parent. In this situation both the parent and child are exhibiting significantly varying degrees of embodied neurological sensory abilities, and what with the parent generalizing this in her mind to be rejection of herself, one can see how this may lead to further misunderstandings about the child and how to share love with her/&him. Therefore, their meaning-making was shrouded in mystery as well, in that both struggled to understand the other’s embodiedness. However, Temple is now able to shed some light upon it all, so it would also seem that meaning-making is an ongoing dynamic process which then changes as times goes by and information received from various sources, e.g. in this case it was via the comparison of Temple with other infants and her younger siblings and then from the neurologist, that all helped to uncover some of the mystery. Threads of meaning and meaning-making intertwining?</p>

I then proceeded to ask myself questions about the implications of such meaning-making for perception and self-knowledge, for phenomenology and for IPA. Figure 26 below illustrates this.

Figure 26: The implications of the ‘autistic’ person’s meaning-making, the family members’ meaning-making and my meaning-making for perception and self-knowledge, for phenomenology and for IPA

<p>What are the implications for perception(s) and self-knowledge?</p>	<p>Perception as the embodied&non-embodied self? Perception as relationship? Relationship as self-knowledge? Self-knowledge as perceptual relationship? Perceptual relationship as self-knowledge?</p>
<p>What are the implications for phenomenology as a methodology?</p>	<p>The implication for phenomenology as a methodology is that it should set out that researchers ought to be focused on exercising the phenomenological attitude along with the intention of seeking to come up with questions regarding ‘oneself’ and ‘one’s own’ story as well as regarding ‘others’ and ‘their’ stories – i.e. in my case it is to exercise reflexivity all the way throughout the actual PhD study and make it the very means of writing the thesis. Furthermore, the researcher should also attempt to consciously be aware of the relationship(s) that exists amidst the endeavour of the research process(es), i.e. how the initial research questions came up, how the researcher carried out a literature review, why and how the researcher took up phenomenology as a methodology and IPA as an approach, how the researcher came up with the criteria of selection for autobiographies and vignettes, how the researcher then analysed such works, how the researcher is writing about such findings, and what this means for phenomenology as well as IPA and the methods we use for research.</p>
<p>What are the implications for IPA as an approach and the methods involved?</p>	<p>The implications for IPA as an approach is that the embodied&non-embodied self also entails relationship; relationship with ‘oneself’, the ‘other’ and the given environmental context. Therefore, how can IPA analyses be carried out such that these three intertwining elements are explicitly acknowledged? ... Focusing on the embodied&non-embodied self along with focusing on the sub-interrelated aspects of paradox, dynamics and mystery may well be a way to achieve this. In addition, carrying out analyses with questions in mind rather than statements/categories/or themes in mind - at the beginning stage that is – may also be a useful phenomenological cognitive style to utilize when examining lived experiences.</p>

I also asked questions regarding the development of self-knowledge, meaning and perception in the context of Temple's vignette and Figure 27 below outlines this.

Figure 27: Questions regarding the development of self-knowledge, meaning and perception in the context of Temple's experience and vignette

What is self-knowledge? How does it develop?	Self-knowledge as being an element of relationship and relationships? Relationship and relationships as being an element of self-knowledge? Self-knowledge 'develops' in, as, with and through relationship and relationships? Or/and relationship 'develops' in, as, with and through self-knowledge? Or/and it develops in, as, with and through the moment and intertwining moments?
What is meaning? How does it develop?	Meaning as the interaction between 'oneself' and the 'other'? 'Oneself' and 'other' in, as, with and through paradoxical dynamic mysterious meaning? Meaning 'develops' as, with, in and through relationship?
What is perception? How does it develop?	Perception as relationship with one's body and non-body? Relationship with one's embodied&non-embodied self? Perception 'develops' in, as, with and through the presence of relationship with the 'other'? The 'other' and 'self' in a dynamic interaction within perception as relationship?

Step 5: I completed the analysis by asking myself questions regarding the methods in the context of Temple's vignette and Figure 28, as below, illustrates how I did this.

Figure 28: Questions regarding the methods in the context of Temple's experience and vignette

<p>The questions that have arisen regarding the methods so far are:</p> <ol style="list-style-type: none"> How does one use reflective texts/autobiographies, especially those by 'autistic' persons, with IPA? <ul style="list-style-type: none"> - By asking phenomenological questions; - Illustrating the interpretive process the researcher is undergoing by producing tables, as above, and using direct quotes and excerpts from 'autistic' persons' writings for this. Which in itself is a reflexive act(s); - Coming up with ideas of possible questions for interviews; - Taking up a developmental lens and working with vignettes that are to do with family members at different stages of the 'autistic' persons' development. How does one use autobiographical/reflective texts in order to further become sensitive to the context and culture of 'autistic' persons and 'their' family life? <ul style="list-style-type: none"> - Asking phenomenological questions that focus on the embodied&non-embodied self; - Keeping in mind the implications of such ways of being that I am learning about and coming up with ideas as I proceed; e.g. the ideas of possible interview questions are emerging from the narratives of the 'autistic' writers themselves; - Analysing vignettes that specifically focus on family contexts are also enabling me to become that much more sensitive. How does one create further research questions (e.g. for interviews) and develop one's philosophical standpoint(s) whilst analysing 'autistic' person's autobiographies with IPA? <ul style="list-style-type: none"> - Read the books, pick out a vignette for the relevant developmental stage that fulfils the selection criteria and type it up word for word from the book, ask the phenomenological questions, create the table and whilst doing so reflect and make notes; when ideas of possible questions for interviews come to mind note these down.

After having carried out steps one to five with all eight vignettes I took a break, reflected over the process(es) and wrote about it.

Step 6: I then returned to the vignette analyses and transferred the emerging questions from each table analysis (Appendices 5 to 12) into the second part of the *Table of Questions, Categories and Themes* (Appendix 13). Figure 29 below demonstrates how I did this regarding Temple’s analysis table (Appendix 5).

Figure 29: An example of the emerging questions from the table of analysis of Temple’s vignette (Appendix 5) transferred into the *Table of Questions, Categories and Themes* (Appendix 13)

<u>The Family Context</u>				
After reading through the autobiographies of three ‘autistic’ people and dialoguing with the texts by using Interpretive Phenomenological Analysis (IPA) as a framework for analyses (as previously demonstrated), I then moved on to select eight vignettes in the family context over a lifespan; two vignettes of a lived experience(s) as an infant, two for childhood, two for teenagehood and two for adulthood. I focused on the embodied and non-embodied paradoxical, dynamic and mysterious elements of their ways of being. Hence the following table consisting of the questions arising from my dialogue(s) with the vignettes and the categories and themes that have emerged, as follows.				
Vignette, Author, Book and Developmental Stage	Arising Questions From Vignette Table(s)	Categories	Themes	Reflective Questions and Notes
Vignette 1. Temple Grandin, 1986. Emergence: Labeled Austistic. Infancy.	Paradox: To ‘autistic’ member: Do you have any memories from infancy? Are they vivid memories or/and not so vivid? To parent(s): What was your child’s memory like during infancy? How	Memories and infancy Family and memory	Memory(ies)	

The second part of the *Table of Questions, Categories and Themes* (Appendix 13) consists of five columns – just as the first part does. The first column to the left is for noting the vignette, author, book and the developmental stage (e.g. infancy). The second column along is for the questions that emerged from the specific vignette’s table of analysis regarding the paradoxical, dynamic and mysterious elements of Temple’s infancy experience(s); this includes questions directed to the ‘autistic’ person and to the parent(s). The third column is for the categories that I created thanks to such questions. The fourth column is for the theme(s) that the categories form, and the fifth column is for my use in terms of any further reflective questions and notes I might have whilst undergoing this activity(ies).

Once the *Table of Questions, Categories and Themes* (Appendix 13) was completed for this stage I took a break and focused on reflecting and writing about and with this process; I have continued to re-write and re-work with such reflexive writings regarding stages one to three of this methods process(es). Furthermore, these processes, along with the advice given by my supervisors, has led to the creation of draft interview protocols for future research, as is set out in the final chapter '*Conclusion, the Phenomenological Attitude and Future Research*'; where I have worked with Temple Grandin's infancy vignette to illustrate this. Now I shall summarise this section.

6.4.4. Summary of how I exercised my phenomenological attitude for the purposes of this study: the three stages of this research

In summary, the research herein was carried out in three stages; the pilot, the in-depth autobiographical analyses of three 'autistic' individuals and the analyses of eight vignettes from 'autistic' persons' autobiographies that are of a lifespan longitudinal lens in family settings. This enabled me to question myself, my questions, to create new and sensitive questions for future research and to create and develop new approaches for researching one's own and 'autistic' people's self-knowledge, meaning-making and perception. The strength of this approach is that it enabled me to work with the very lived experiences and inner lives of 'autistic' people so as to further exercise and develop my phenomenological attitude. The main limitation could be the very subjective nature of this research – both with regards to me as a researcher and with regards to the nature of the data I have worked with (i.e. autobiographies that are subjective). However, this was my aim – to become more conscious of that which I am not conscious of. Hence, the very subjective nature of this research has enabled me to achieve this insofar as is possible through the means of language and academic rhetoric.

The stages of research have led to (i) the creation of a manner of reflexive research that is grounded in the very lived experiences of 'autistic' persons; (ii) in-depth analyses, dialogues and questioning processes with three 'autistic' individuals' lived experiences and meaning-making; (iii) the creation of eight vignette analyses that can be worked with for future research as interview protocols with 'autistic' adults

and family members (as will be outlined in the final chapter of this thesis); and (iv) a *Table of Questions, Categories and Themes* (Appendix 13) that can be worked with to develop one's insight(s) and knowledge as well as to follow up on the questions both in terms of future research and potential questions for interviews.

This kind of research contributes to the paradigm of participatory research by taking 'participation' into account right from the outset, therefore, the methods of investigation are also a finding. In that a researcher is constantly questioning oneself and status of power; opening oneself up to the 'other' in oneself right from the beginning stages; creating further questions for say potential interviews; whilst viewing the person on the 'autism' spectrum as a developing human being, in a family, and navigating within day-to-day social contexts over a lifespan. This has enabled me to consciously create and maintain space within my way of being and thinking so as to attend to the perspective(s) of the 'other' throughout.

This approach may enable families with 'autistic' people, other researchers and professionals to achieve a similar kind of openness to the 'other' in oneself. This in turn can inform one's own meaning-making and foster the process(es) of interactions that are more harmonious. For researchers, it can help in carrying out research that is sensitive to the ways of the 'other', leading to an openness and knowledge that emerges from the inner lives of 'autistic' people themselves, and that makes a meaningful contribution to their lives and to one's own.

Researchers in different fields who research the 'other' can adapt the step-by-step approach outlined in this chapter and use it for their own aims. This might enable them to become more insightful and to create sensitive research questions that are more reflective of the ways of the 'other'. Researchers in the field of 'autism' studies could also benefit in a similar manner by uptaking and exercising such a methods process(es). This is likely to lead to research that is more ethical. Families with an 'autistic' member may benefit from this methods process(es) and chapter in terms of future research that could emerge that involves questions and approaches that are more reflective of their ways of being, leading to more collaborative and meaningful participatory research designs. They might also benefit by becoming aware of the various possible kinds of research with narratives and may even be encouraged to write their own life stories – which in itself can be a self-empowering act.

Having summarised this section I shall proceed to conclude this chapter.

6.5. CONCLUSION

In conclusion, this chapter has connected the former chapters in terms of how they informed the methods process(es) and has also prepared the foundation for the next chapters. I have explicitly discussed and illustrated the links with my phenomenological attitude, 'autistic' person's autobiographies and the approach of analysis, i.e. IPA, providing a rationale(s) for working in such a manner. I have attempted to acknowledge my limitations as a researcher and have demonstrated continual reflexive thinking and behaviour at the micro-level throughout the methods and the analysis processes. This has led to the creation of an eighty-three page long *Table of Questions, Categories and Themes* (Appendix 13), which in itself illustrates the arduous dialogues I have undertaken with the narratives of 'autistic' persons and how my ethical anxieties have led to a certain kind of methodology and method(s) that is taking IPA as well as participatory research further. In that, the lived experiences of 'autistic' persons have informed this study right from the outset of the very creation of research questions – through the means of analysing autobiographical narratives. In addition, questions regarding my nature and questions regarding the nature of the 'other' have also led to the creation of potential interview questions, which are themselves embedded in 'autistic' persons' lived experiences, as has been demonstrated in this chapter. This whole methods process(es) is a finding in itself that has enabled me to become aware of my phenomenological attitude and has enhanced my phenomenological attitude by enabling me to exercise it throughout this entire study. These findings and methods will be discussed in the final chapter, including a discussion of working with 'autistic' persons' autobiographies and IPA for exercising my phenomenological attitude. Now I shall proceed to the *Findings and Discussion* chapter.

7. THE FINDINGS AND DISCUSSION: INSIGHTS VIA THE PHENOMENOLOGICAL ATTITUDE

7.1. INTRODUCTION

It was as I reached the end of the analysis stages that I became consciously aware that what I had been attempting to achieve all throughout this study was to exercise a phenomenological attitude and this in itself is a finding. My phenomenological attitude consists of two aspects. One, that I am a reflexive, paradoxical, dynamic and mysterious self, and two, considering this is what I believe to be what and who I am, this is also my lens and worldview for experiencing and interpreting the world – including this study. Hence my use of the term ‘my reflexive embodied and non-embodied paradoxical, dynamic and mysterious self and lens’ to define my phenomenological attitude (please refer to Chapters Two, Three and Four as to why and how this came to be so). It is my phenomenological attitude that has enabled me to address my ethical concerns by (i) explicitly illustrating what I may be projecting on to ‘autistic’ people’s lived experiences whilst also being as open as possible about this, and (ii) questioning myself, my questions and creating sensitive questions via the analyses. For it is when we ask a new question that we learn something new (Greenstein, 1988), therefore, leading to deeper insight(s) and knowledge regarding ‘autistic’ persons. Hence, the core original contribution of this study is that of an approach that can enable a researcher(s) to think deeply about the effects of the research process(es) and to develop sensitivity to the lived experiences of participants. Throughout the following section of this chapter I shall highlight the themes that have emerged and how they are connected. I shall also illustrate and discuss how the insights of the given theme(s) could lead to developing more suitable participatory research designs.

The main section of this chapter, 7.2. *Findings and discussion: my phenomenological attitude and insights into the inner lives of some ‘autistic’ people*, will outline and discuss some of the insights I have learned. In addition, throughout this chapter, I will demonstrate how my dialogues and analyses have enabled me to

draw from the narratives and lived experiences of 'autistic' people so as to write this chapter. I have included direct quotes from the autobiographies and analyses as these illustrate my dialogues and how I interpreted the data, leading to the findings. It will also enable the reader to gain further insight into why and how I did what I did and enable them to form their own opinions. One might find that this chapter raises more questions than conclusions and may feel as if it is work in progress; this is my aim, and I hope that mine and your insight is developed further thanks to it. Other researchers may learn from this approach and if they wish to they too may be able to undergo a similar process(es) in (i) developing their insight(s) so as to create more sensitive and meaningful participatory research designs, and (ii) learn how to draw from such insights to write their findings.

I have outlined the aims and structure of this chapter, now I shall proceed to the next section.

7.2. FINDINGS AND DISCUSSION: MY PHENOMENOLOGICAL ATTITUDE AND INSIGHTS INTO THE INNER LIVES OF SOME 'AUTISTIC' PEOPLE

The *Table of Questions, Categories and Themes* (Appendix 13) is a table that includes all the clusters of questions that emerged via the analyses throughout stages two and three; to learn about how it was created please refer to *Chapter Six, section 6.4. How I Exercised My Phenomenological Attitude For The Purposes Of This Study: The Three Stages Of This Research*. It is thanks to the creation of this table that I was able to continue my analyses to form categories and themes of insights as IPA recommends (Smith et al., 2009). However, in order to acknowledge and include idiographic data I also included themes that only came up once or twice.

7.2.1. The themes of insights that emerged from the analyses during stages two and three

During the individual analyses (stage two), the three autobiographies that were analysed were *Autism and Sensing: The Unlost Instinct* by Donna Williams (1998), *Discovering My Autism: Apologia Pro Vita Sua (with Apologies to Cardinal Newman)*

by Edgar Schneider (1999), and *Asperger's Syndrome and Mindfulness: Taking Refuge in the Buddha* by Chris Mitchell (2009). Some of the themes of insights that emerged from their narratives in *The Table of Questions, Categories and Themes* (Appendix 13) occurred frequently, e.g. 'The body and senses' and 'Autism', yet themes that were not so frequent have also been created, e.g. 'Altruism' and 'Finance'. There are thirty-five themes in total and it is noteworthy that these insights emerged due to the aim of this study. If the study had a different aim or / and was carried out by another researcher then the themes are likely to have been different.

I recommend trying to view the themes as being connected with each other, i.e. they are not concepts that are separate from one another, and some of the interlinking connections of the themes will be made explicit as I proceed throughout this chapter. This way both the common and idiographic factors have been acknowledged and included; please refer to *Table 4: Themes of the clusters of questions that emerged from the individual analyses during stage two*, below. For the purposes of clarity, the themes in the table are in an alphabetical numerical order, and the numbers in brackets next to the themes indicate how often their corresponding cluster of questions emerged during stage two of the analyses.

Table 4: Themes of the clusters of questions that emerged from the individual analyses during stage two

The themes				
1. Altruism (2)	8. Difference (1)	15. Isolation (2)	22. Mental health (3)	29. Self-love (10)
2. 'Autism' (16)	9. Emotions (21)	16. Language(s) (4)	23. Motivation(s) (1)	30. Sexuality (1)
3. Childhood (1)	10. Ethics (1)	17. Learning (7)	24. Other (1)	31. Spirituality /& religion (26)
4. Communication (5)	11. Exploration (7)	18. Life goals (4)	25. Play (4)	32. The body and senses (41)
5. Creativity (6)	12. Finance (1)	19. Love (6)	26. Professionals (1)	33. Valuing things (1)
6. Culture (3)	13. Food (2)	20. Medicine (1)	27. Relationships (9)	34. Vulnerability (1)
7. Death (3)	14. Identity (3)	21. Memory(ies) (1)	28. Self (2)	35. Work life (3)

The themes of clusters of questions that emerged whilst undergoing the analyses during stage three are in the next table, *Table 5: Themes of the clusters of questions that emerged from the lifespan family context(s) analyses during stage three.*

The following themes of insights emerged from the cluster of questions that were created during the analyses of the family context vignettes with a lifespan

perspective. For the purposes of clarity, the themes are in alphabetical order per vignette analysis, and the numbers in brackets next to the themes indicate how often their corresponding cluster of questions emerged. Please note, the vignettes were short excerpts from the autobiographies and were regarding different developmental phases of the given authors' lives, hence, many of the themes occur only once. Again, I recommend trying to view these themes as being connected with each other – at least within each given vignette analysis, and I shall highlight some of the interlinking themes as I proceed.

Table 5: Themes of the clusters of questions that emerged from the lifespan family context(s) analyses during stage three

The lifespan phase and family context(s)	The themes
Vignette 1: Infancy (Temple Grandin, 1986)	Communication and the senses (2) Emotions and infancy (1) Memory(ies) (1) Professionals (1) The senses and infancy (1) The senses and others' meaning-making (1)
Vignette 2: Infancy (Erika Hammerschmidt, 2008)	Communication tools (1) Communication tools and family (1) Creativity and family (1)
Vignette 3: Childhood (Luke Jackson, 2002)	Family communication (1) Family outings (1) Family outings and the senses (3) Family outings and the role(s) of parenting (1) Family and safety (2) Meditation and time (1)

	Sensory processing and family (1)
Vignette 4: Childhood (Wendy Lawson, 1998)	Family and secrets (1) Family (non-)communication (1) Family and safety (1) Learning, play and family (1)
Vignette 5: Teenagehood (Chris Mitchell, 2005)	Family and socializing (3) School life and socializing (1) Socializing (1)
Vignette 6: Teenagehood (Donna Williams, 1992)	Changes in identity (1) Identity (1) Family conflict (4) Family and socializing (3)
Vignette 7: Adulthood (Edgar Schneider, 1999)	Family bereavement (1) Family bereavement and self-awareness (1) The body senses and family bereavement (1)
Vignette 8: Adulthood (Donna Williams, 1992)	Emotions and coping strategies (1) Emotions and family (1) Family conflict (1) Family memories and self-recognition of being 'autistic' (1) Family and trauma (1) Memory(ies) and family (1) Objects in family setting (1) Personas (1) Self-recognition of being 'autistic' (2) Suffering (1)

In summary, there was a lot of data and analyses to work with, however, during stage two of the analyses a significant theme that emerged was 'The body and senses' (occurring forty-one times). Of which proprioception – the sense of ownership, or a lack of sense of ownership, of one's body (Sacks, 1985; Talay-Ongan and Wood, 2000), and 'autistic' persons' sensory ways of being emerged as categories worth delving into; note, these are what I deem to be an aspect of the embodied and non-embodied self. Therefore, throughout this chapter, I will highlight certain hyper and hypo sensory abilities of some 'autistic' people and how these seem to influence their meaning-making, self-knowledge (or awareness of self) and perception. The following section of this chapter, *7.2.2. Insight one: my phenomenological attitude and the embodied and non-embodied self at an individual level*, will initially demonstrate how exercising my phenomenological attitude led to insights into the lived experiences of some 'autistic' people by firstly focusing on the embodied and non-embodied self at an individual level. Section *7.2.3. Insight two: my phenomenological attitude and the embodied and non-embodied self at an interactional level over a lifespan*, will then focus on the embodied and non-embodied self at an interactional level over a lifespan within the family context(s). Although, these two are intertwined and I have merely focused more so on the individual level aspects first and later my focus has been more so on the interactional level aspects.

7.2.2. Insight one: my phenomenological attitude and the embodied and non-embodied self at an individual level

It would seem that due to 'autistic' persons' bodily senses and hyper and hypo sensory abilities (Talay-Ongan and Wood, 2000; Davidson and Smith, 2009; Bogdashina, 2012; DSM-V, 2013), their sense of embodiedness and non-embodiedness, perception, meaning-making and self-knowledge is very much influenced by such abilities. Proprioception may well be a significant factor in how such hyper and hypo sensory abilities may manifest for some 'autistic' people at the individual level. I will illustrate and discuss how my phenomenological attitude was exercised so as to further sensitise myself to the worldview(s) of the 'other' in terms of their individual meaning-making.

The following is an example of being hyper-sensitive to the colour of a pink billiard ball from Donna Williams, *Autism and Sensing: The Unlost Instinct* (1998; p.22):

“When I was about ten years old I used to have a certain colour billiard ball – a pink one. I used to spend around an hour with it before I could reach the point of resonance with it where I would merge with the colour. To anyone else this would have looked like someone ‘psychotic’ but if they’d known the physical alteration felt in that moment of becoming one with a colour some people would perhaps see it as far less crazy than other ways many people may have spent an hour of their lives at the same age.” (In Appendix 4; pp.389-390)

The full analysis is in Appendix 4 and Donna later proceeds to state that the feeling of merging is like knowing God (Williams, 1998; pp.57-58). I have drawn upon the analysis to write the following.

It would seem that Donna surrendered to and with the mystery, or the not-knowing nature, of her being as well as the object(s) in her environment and she enjoyed this. She recognizes that there is no ‘I’ or ‘object’ as she is merging with the colour of the ball. Merleau-Ponty (1945 / 1989, p.111) states that:

“The underlying question is whether there can in fact *be* such a realm of pure ideas, of thoughts lacking all temporality or contingency; whether there can be an absolute interiority in which consciousness is utterly transparent to itself so that nothing eludes its grasp.”

Has Donna answered this question with “Yes”? It is known that some people experience what is known as synaesthesia. This involves:

“a “union of the senses” whereby two or more of the five senses that are normally experienced separately are involuntarily and automatically joined together. Some synaesthetes experience colour when they hear sounds or read words. Others experience tastes, smells, shapes or touches in almost any combination. These sensations are automatic and cannot be turned on or off.” (UK Synaesthesia Association, 2019; online)

However, the state of being that Donna reports seems to go beyond synaesthesia. She experienced a bodily lived experience, in that she felt a physical alteration, whilst simultaneously being a non-embodied lived experience, in that she was merging with the colour pink; this in itself is a paradoxical and a dynamic experience. It may also point to the role her sense of proprioception was playing within such an

experience. Furthermore, regarding Merleau-Ponty's point, I may not be sure as to whether there is an absolute interiority in which consciousness is utterly transparent to itself, however, for the ten-year-old Donna this seems to have been her lived experience. Although, she does not mention having thoughts during such an experience.

Therefore, exercising a phenomenological attitude that focuses on the embodied AND non-embodied self of 'autistic' people may enable one to think in terms of 'and' rather than 'or', which in itself can enable one to become more consciously aware of the various intermingling aspects of the lived experience(s). In turn, by focusing with, through and on the paradoxical, dynamic and mysterious aspects of a person's lived experience(s) one can exercise thinking in terms of 'and', which can lead to rounded insights. Furthermore, dialoguing with the statement of, for example a philosopher, in the analysis process(es) may help to further engage with the person's (i.e. in this case Donna's) reported lived experience and help to create sensitive questions as findings that open up one's thinking further to the lived experience of the 'other'.

The following cluster of questions as findings emerged from the analysis of Donna's narrative and one can see how I interpreted her experience as being that of a meditative state (Appendix 4; pp.389-390):

“Do you find yourself naturally falling into a meditative state? Do you feel that you are merging with objects in the environment? What do you learn from this?”

This cluster of questions contributed to the creation of the theme 'Spirituality /& religion' in *The Table of Questions, Categories and Themes* (Appendix 13; p.559). Asking such questions, even if they are hypothetical, is the beginning of the process(es) of becoming more sensitive to the meaning-making and lived experiences of 'autistic' people in a more specific manner. So one's thinking style is further honed to be more open. The clusters of questions as findings are embedded in the narratives and I have found that even a short excerpt of a narrative usually incites several questions, therefore, a ripple effect can take place whereby a cluster of questions bloom. Hence, as this chapter proceeds you will see that the findings as questions are in clusters. A researcher who is seeking to design participatory research methods could draw upon this kind of approach so as to (i) develop one's own level of sensitivity to 'autistic' people's interpretations of their own lived

experiences in a spiritual / religious manner or / and (ii) delve into the meaning-making of the 'other' regarding their natural states of being. It can lead to creating research questions that are meaningful for 'autistic' people and that reflect their interests and not just merely the researcher's interests. Participatory research designs vary from the level of engagement with participants, although some involve participants right from the outset of creating research questions all the way to implementing the findings (Cornwall and Jewkes, 1995; Jivraj et al., 2014; Kossovaki, 2017). This approach of self-critical reflexive dialogue at the micro-level – before even setting out to dialogue with 'autistic' people – could lead to more thoughtful and sensitive approaches whilst 'in the field'; enabling a researcher to notice and interpret ways of being or / and nuances that one otherwise may not have noticed. In the long run, e.g. when working face-to-face with 'autistic' people and their families, this insight could lead to a certain kind of receptivity and harmonious dialogue for both the researcher and co-researcher / participant that otherwise may not have developed.

Donna's sense of proprioception, i.e. her sense of embodiedness and non-embodiedness, was not limited to 'subject' (i.e. herself) and 'object' (i.e. the pink ball) as being separate; for her she was very much one with the colour of the pink billiard ball. This has two implications for a researcher; firstly, this example and other such examples that follow provide a strong case for taking up an intersubjective lens that is in line with such ways of being when focusing on 'autistic' persons' lived experiences. Secondly, practicing in line with an intersubjective lens, whereby one exercises a reflexive standpoint of questioning oneself and thinking to create questions that are sensitive to, and reflective of, the 'other's' intersubjective lived experience(s) is crucial. Therefore, one is able to gain new insights thanks to creating new questions that are created via a more explicit intersubjective lens, and so one can think and behave in a more ethical manner.

The above is an example that I deem to be due to Donna's hyper-sensitivity. The next example is one that I view to be due to the 'autistic' person's hypo-sensitivity.

Edgar Schneider, in *Discovering My Autism, Apologia Pro Vita Sua (With Apologies to Cardinal Newman)* (1999), states that he can feel emotions through the means of art but cannot do so in the very moment with people despite wanting to. Please note, I view emotion(s) as being a sense. The following begins with his statement regarding his mother's death (Schneider, 1999; pp.51-52):

“My brother was devastated, even though we all saw her death coming. (He and I had even worked on the list of ‘things to do’ and on her obituary before she actually died; it was that imminent, but it did not occur precipitously.) Everyone else in the family, and friends also, expressed sorrow.

I felt nothing. I also felt that there was something wrong there. Somewhat sardonically, I said to my pastor (who had been a psychologist before becoming a priest), ‘There are all kinds of support groups for people who grieve, but nothing for people who should be grieving but don’t.’” (p.51)

“I feel nothing in real-life emotional situations. This is connected with that topic of feeling ‘emotion’ only through art.” (p.52)

“Real-life emotions appear to me to consist of things felt in an unexpressed manner, and with another person also feeling them, almost in the manner of sympathetic vibrations at a resonant frequency.” (p.52)

Later in the book, under the subtitle of ‘The Emotional Deficit’, Edgar states that (Schneider, 1999; p.94):

“When talking to people about autism, this aspect of it [what he refers to as ‘the emotional deficit’] has been the most difficult to put across. This is true even when it comes to people who are understanding, open-minded, and even sympathetic. I believe that it must be understood, for I have come to be of the opinion that it is the bedrock characteristic of autism.

This is not some personal hangup. I should like to refer back to my initial discovery and recall two important items. When I first saw that New Yorker article [by Oliver Sacks in January 1995], it was the sentence in the subtitle that caught my eye: ‘Can an artist make art without feeling it?’ When I wrote to Temple Grandin about my discovery, in her reply it was the emotional deficit that she identified as the hallmark of autism.

It has become my very strong belief that all other autistic traits can be explained in terms of it and, furthermore, it also explains why autistic people are often misdiagnosed with other psychological disabilities, since many outward symptoms are similar, but have different causes.” (p.94) (In Appendix 4; pp.343-344)

The full analysis is in Appendix 3 and I have drawn upon the analysis to write the following.

Seeing as 'autistic' people tend to have hyper and hypo sensitivities, they can also have hypoproprioception, the ability to feel less of a sense of ownership of one's body (Bogdashina, 2006, 2012). It seems that what Edgar is attempting to say is that he does and can feel emotion(s) in certain situations (e.g. through art, theatre etc.), and in other situations (e.g. his mother dying) he does not feel a sense of ownership of such emotions, and therefore he thinks that "I feel nothing in real-life emotional situations" (p.52). Could it be that the symbolism and creative energy involved in the arts may be the coping strategy through which he recognises, acknowledges and expresses his emotions? Is this an indirect, yet simultaneously a direct, way of attending to one's own pain and suffering? Furthermore, if real-life emotional situations are likely to overload one's sensory system, maybe the coping strategy is to distance oneself from such emotions during the very moment? If practiced since infancy maybe this becomes a natural way of being for the person and therefore the person ends up thinking that they have an 'emotional deficit' when it may be a bit more complex than that? Bogdashina (2012) highlights that 'autistic' people tend to have a 'gestalt perception' which then usually leads to mono-processing and peripheral perception as forms of avoiding sensory overload (please refer to section 5.4. of Chapter Five). Could it be that these coping strategies also affect one's sense of embodiedness and non-embodiedness?

On the other hand, Arthur Deikman (1982), an American psychiatrist, has written about the observing self; the aspect of one's self that is the witness and can enable one to experience emotions but not have a sense of ownership of them. Hence, are 'autistic' people's perceptual ways of being likely to be more so oriented around or / and from the observing self? Is hypoproprioception an indicator of this? Or is it more so to do with the possible effects of their coping strategies? I am not sure, it could be both, and these are possible ways to attempt to think about Edgar's experience(s).

The cluster of questions as findings that emerged from the analysis is as follows (Appendix 3; pp.342-344):

"When someone close to you died were you able to grieve? Feel sad and cry?
Did you compare your behaviour to a sibling's behaviour?"

Does art play a role in your emotional life? How do you feel around people who may be emotionally charged? How do you respond or / and not respond?

Do you think the most difficult things to explain and talk about with people are emotions?

Do you feel emotions? How do you cope with emotions? Do you have a sense of ownership of your emotions? Does your sense of ownership of emotions vary from situation to situation? For example, you may feel your pain and cry in one situation yet not feel pain or cry in another situation despite others doing so?"

These clusters of questions led to the creation of the themes 'Death' and 'Emotions' in *The Table of Questions, Categories and Themes* (Appendix 13; p.534). These kinds of questions may enable one to exercise an openness and an intersubjective lens that is in line with recognising 'autistic' people's 'gestalt perception' (Bogdashina, 2006, 2012), their hyper and hypo sensory abilities, their sense of embodiedness and non-embodiedness (proprioception) and the coping strategies they exercise in attempting to (or not) make meaning of their lived experiences. Being aware that 'death' and 'emotions' may be experienced in a different manner by an 'autistic' person could also enable a researcher, or a therapist working with such a person, to be more open to the meaning-making process(es) of an individual who feels AND does not feel in a way that is unique to them. Therefore, when one is attempting to carry out participatory research with 'autistic' people it is worth keeping in mind that they may express themselves in emotional or / and non-emotional ways that may not be considered the 'norm' by oneself as well as by societal attitudes. However, for some 'autistic' people such as Edgar, this is their norm. One could also encourage the use of art, whether this be painting, singing or drama etc., by 'autistic' co-researchers / participants and their families when carrying out research with them. This might help everyone involved in the research process(es) to access their emotions and to express them, therefore, creating a meaningful and therapeutic research approach.

According to Donna Williams, there is a sensory way of being and an interpretative way of being. She states that she relied on her sensory system more so, that she began to develop an interpretative style of thinking after the age of four and that she preferred and practiced using a sensory system. This is because she felt that the system of interpretation was unreliable. She states that (Williams, 1998; p.47):

“So although I eventually and progressively took interpretation on board, the system of interpretation remained alien and disconnected to my self-identity and ‘I’ (in the sense of mind-will-identity) relied upon, trusted and identified with the system of sensing rather than the system of interpretation. To my inner self and what I later distinguished as my ‘real self’, sensing was flawless but interpretation could make so many mistakes and was unreliable.” (In Appendix 4; p.359)

She later adds that language is systemised and “passed down rather than evolving from the sensory or emotional experiences they spring from” (Williams, 1998; p.115). She describes some of the sensory based language she uses, e.g. the term ‘degoitz’ for lemons or ‘lemon like’ experiences and the signing of pulling down one’s trousers for ‘toilet’. She further compares sensory and interpretative languages and states that both systems have their time and place and can be complimentary. Hence, she refers to people as moving in different sensory-perceptual and social worlds (Williams, 1998; p.117):

“Those who live primarily by the system of interpretation live, effectively, in the same physical world as those who are primarily sensory beings (in the sense of the earth or universe). However, they move in different sensory-perceptual and social worlds or ‘cultures’. Just as each can be ‘bilingual’ in terms of ‘language’, each could be ‘multicultural’, able to move between culture-worlds as needed and able to interpret for those more proficient in one system than the other.

The sensory based social system could be important for crossing boundaries to know the nature of something which cannot be fathomed with mind or through language. The interpretive-based social system could be important when subjectivity is required (which requires an intact sense of self).” (In Appendix 4; p.371)

Although, translation difficulties between sensory and interpretive ways of being can occur (Williams, 1998; p.129):

“Problems of interpretation between people using one system and those using the other are also likely to occur just as they currently do in bilingual or multicultural environments.

Taking a very simple everyday example. Two people are in a bathroom. As one picks up a fluffy towel after a bath, one may merely have perceived the object in its purely sensory form. At that moment, irrelevant of having interpreted the use of the object, reached for it purely for the sensory experience, wrapping him or herself up in the sensation, becoming part of it, it may not have been interpreted. The other, using interpretation may ask, ‘why are you covering yourself up?’ Unlike two languages using the same system, sensing and

interpretation have no direct translations. How would one set the other straight about these actions without stepping into the world of words, so irrelevant to the system of sensing? Though explanation may have no place or relevance in the system of sensing, according to the system of interpretation it would be rude not to answer. The person sensing may see there is a mistranslation and seek to set it right not by explaining but by touching the person with the towel, sharing the sensory experience. The person using the system of interpretation may have no idea why the person has appeared to have been so rude as not to have answered, even perhaps assuming this behaviour as some sort of strange, unexpected come-on. Yet by the system of sensing, the person already had answered in the action of sharing the sensory experience of the towel. Even in a society where all were proficient in both systems, society could become polarised, split between those who identified with, valued and more strongly relied on one system or another.” (In Appendix 4; pp.396-398)

The full analysis is in Appendix 4, however, I have drawn from it as follows.

This can be viewed as an example of what Milton (2012, 2014a, 2014b) outlines as being the ‘double empathy problem’ (please refer to section 5.4. of Chapter Five). I wonder whether a sense of a lack of embodiedness on the part of non-‘autistic’ people can lead to relying more so on an interpretative system? Maybe non-‘autistic’ researchers, families and other professionals ought to be more open to ways of communication that are more sensory-based, at least attempting to become more consciously ‘bilingual’ in terms of one’s own sensory and interpretative ways of being so as to be open to that of ‘autistic’ people’s ways of being? Furthermore, maybe non-‘autistic’ researchers are not able to recognise a sensory based style of communication and therefore label ‘autistic’ people as having ‘developmental delays’ when in fact they are just developing differently? Drawing from Donna’s narrative and Milton’s (2012, 2014a, 2014b) theory, it would seem that intersubjectivity not only has a ‘multicultural’ and a ‘double empathy’ aspect to it, but also a ‘multi-spatiality’ aspect to it. In that as an individual with a body one exhibits a certain kind of space, and as one proceeds through different environments and interacts (or not) with different people ‘shared’ spaces are formed and re-formed each time. Being aware of this may enable one to create a research approach(es) that seeks to acknowledge the ‘newness’ in each situation and study; exercising a phenomenological attitude may help in paving the way for this.

The cluster of questions as findings that emerged from analysing the above are:

“Have you had any experiences with a person whereby you were trying to explain something in a sensory way and they were reacting in a confused or / and negative manner? How did you feel? How did you cope? How did you react or / and not react?”

Have you had any experiences whereby you felt like you had answered a person’s question and yet they could not understand? How did you cope? Did you react or / and not react? How?” (Appendix 4; pp.397-398)

These clusters of questions led to the creation of the theme ‘Communication’ in *The Table of Questions, Categories and Themes* (Appendix 13; p.561-562). Asking questions like these can sensitise one further to the sensory and interpretative ways of communication. This will hopefully lead to participatory research approaches and behaviours that are in line with acknowledging sensory and interpretative ways of being and what is termed as the ‘double empathy problem’ (Milton, 2012, 2014a, 2014b). I shall demonstrate the usefulness of this kind of sensitivity regarding the family context in the next section, *7.2.3. Insight two: my phenomenological attitude and the embodied and non-embodied self at an interactional level over a lifespan.*

Now that I have discussed what I view as being the sense of embodiedness and non-embodiedness of Donna and Edgar, I will turn to Chris Mitchell’s account regarding what it was like for him to not be self-aware of being ‘autistic’.

Chris, in *Asperger’s Syndrome and Mindfulness: Taking Refuge in the Buddha* (2009) states that the difficulties he was having at university finally led to a breakdown and a recognition of being ‘autistic’ (Mitchell, 2009; p.102):

“For me though, what I felt was suffering was remaining undiagnosed until I was 20 years old, often knowing I was different but not knowing of any reason as to why.” (Appendix 2; pp.269-270)

The full analysis is in Appendix 2. I have drawn upon the analysis to write the following.

Knowing that he was / is different and not knowing why was a cause of suffering for Chris. It seems that the mysterious aspect(s) of oneself, i.e. not consciously being

aware of an aspect(s) of oneself, can cause pain. Although it can also gradually become consciously known due to certain life experiences, e.g. his breakdown and the recognition process(es) of being identified as being 'autistic'. Therefore, is self-knowledge in itself paradoxical? Does this lead to a self-understanding and flourishing in relation to being recognised as being 'autistic'? Additionally, does it continue via Chris's ongoing journey and path? Is there a constant paradoxical dynamic flow of mystery revealing itself, leading one into deeper depths of self in, with and through self? In *Fihi Ma Fih* (1260 – 1273) / *The Discourses of Rumi*, Shems&Rumi state that (in Arberry, 1961 / 2000; pp.37-38):

“It is pain that guides us in every enterprise. Until there is an ache within, a passion and a yearning for that thing arising within us, we will never strive to attain it. Without pain it remains beyond our reach, whether it is success in this world or salvation in the next, whether we aim at becoming a merchant or a king, a scientist or an astronomer. It was not until the pains of birth manifested in Mary that she made for the tree. Those pangs drove her to the tree, and the tree that was withered became fruitful. We are like that story of Mary in the Koran. Every one of us has a Jesus within, but until the pangs manifest, our Jesus is not born. If the pangs never come, then our child rejoins its origin by the same secret path through which it came, leaving us empty, without the birth of our true self.”

I am not insinuating that 'autistic' people are meant to suffer. I believe that many of us suffer in our own ways and to various degrees. In Chris's case what had been an aspect of his embodied and non-embodied way of being and had somewhat been obvious to him, i.e. knowing that he was different, had simultaneously evaded his self-knowledge or self-awareness until the age of twenty. It was the pressures of university life and his breakdown, i.e. the pangs of pain, which finally led to him becoming more conscious of that which he was not as conscious of, i.e. becoming more conscious of an aspect of his being was a kind of birth. What Chris and Shems&Rumi (1260 – 1273, in Arberry, 1961 / 2000) bring to light is an aspect that many human beings share. In that many of us suffer. This in itself is more than enough of a reason to attempt to be as ethical as possible when attempting to research the 'other', so that one further develops one's own self-knowledge / awareness of self and also assists the 'other' in doing so – if they wish for such help.

The cluster of questions as findings that emerged from Chris's piece of narrative are (Appendix 2; pp.269-270):

“When were you recognised as being ‘autistic’? Whilst growing up did you feel different and not know why? Do you feel that you suffered during the years that you were not as aware of this aspect of yourself? What do you think suffering is?”

These clusters of questions led to the creation of the themes ‘Autism’ and ‘Spirituality /& religion’ in *The Table of Questions, Categories and Themes* (Appendix 13; p.517). These kinds of questions open one’s thinking by acknowledging the ‘other’ as being human, in that one recognises that the ‘other’ also suffers just like oneself, and this might give a researcher more of a motive to carry out ethical research – this has certainly been the case with me. It could also help in bringing forth deeper insights regarding ‘autistic’ people that expresses the humanness of the diversity of being human. Leading to developing participatory research designs that acknowledge the uniqueness of each human being who is involved in the research by also focusing on, and highlighting, what would be deemed as ‘idiographic’ elements.

In summary, exercising a phenomenological attitude has enabled me to become more consciously aware of the embodiedness and non-embodiedness of ‘autistic’ people as well as my own. I think that proprioception, the ability to have a sense of ownership of one’s body – or a lack of it, may play a role in how ‘autistic’ people perceive the world in hyper and hypo sensitive states of being. It would seem that this can vary for the individual in their own right as well as between people. It may also change over time and in differing contexts. Dialoguing with the narratives of ‘autistic’ people, the works of previous authors, and creating questions from the very lived experiences of ‘autistic’ people can enable one to open one’s thinking further so as to become more sensitive of the ways of the ‘other’. It can also help to create sensitive questions that are in line with an intersubjective lens, therefore increasing the likelihood of gaining insights and knowledge that are / is ethical.

Other researchers in the field of ‘autism’ studies may benefit from exercising a phenomenological attitude in developing their insight(s) and knowledge regarding ‘autistic’ people’s meaning-making in the context of the specific area of research they have in mind. Families with an ‘autistic’ member could benefit from this study by being taught to carry out this approach and being encouraged to develop their insight(s) and knowledge(s) within their specific family context(s). In addition, researchers in other fields could also benefit from exercising a phenomenological

attitude in such a way to develop their insight(s) in their given fields and, if they wish, to write their findings by exercising a phenomenological attitude.

Having exercised my phenomenological attitude and discussed some of the insights of the embodied and non-embodied self with a focus that is more so on the individual level, I shall now focus more so on, with and through the embodied and non-embodied self at an interactional level over a lifespan.

7.2.3. Insight two: my phenomenological attitude and the embodied and non-embodied self at an interactional level over a lifespan

It would seem that the body, senses and proprioception plays a key role in 'autistic' people's sense of embodiedness and non-embodiedness, which in turn can influence their meaning-making and interaction styles. This is probably also the case with regards to people who may not be on the 'autism' spectrum. Here I continue to exercise a phenomenological attitude to draw upon the narratives of some 'autistic' people over a lifespan within the family context(s). Bogdashina's (2012) theory regarding 'autistic' people having more so of a gestalt perception and their coping strategies, e.g. mono-processing (Williams, 1996) or mono-tropism (Lawson, 2001), and Milton's (2012, 2014b) 'double empathy' problem theory, have been drawn upon to develop my insight further into the lived experiences of 'autistic' persons at an interactional level over a lifespan. I will demonstrate and discuss how my phenomenological attitude was exercised so as to further sensitise myself to the worldview(s) of the 'other' in terms of their meaning-making of interactions. Please note, due to the word count restriction, here I have chosen one vignette analysis per stage to write about. However, the same kind of process(es) could be carried out with the other vignettes to write about the insights learned from them.

7.2.3.1. Infancy

Temple Grandin in *Emergence: Labeled Autistic* (1986), the first officially recognised 'autistic' person's autobiography, states the following regarding her infancy years (Grandin, 1986; pp.15-16):

“This withdrawal from touch, so typical of autistic children, was followed in the next years by standard autistic behaviors: my fixation on spinning objects, my preference to be alone, destructive behavior, temper tantrums, inability to speak, sensitivity to sudden noises, appearance of deafness, and my intense interest in odors.

I was a destructive child. I drew all over the walls – not once or twice – but any time I got my hands on a pencil or a crayon. I remember really “catching” it for peeing on the carpet. So the next time I had to go, instead of using the carpet, I put the long drape between my legs. I thought it would dry quickly and Mother wouldn’t notice. Normal children use clay for modeling; I used my feces and then spread my creations all over the room. I chewed up puzzles and spit cardboard mush out on the floor. I had a violent temper, and when thwarted, I’d throw anything handy – a museum quality vase or left-over feces. I screamed continually, responded violently to noise and yet appeared deaf on some occasions.” (Appendix 5; pp.407-408)

The full analysis is in Appendix 5 and I have drawn upon the analysis to write the following.

Temple was finding it difficult to cope with her environment and the demands being made on her, e.g. withdrawal from touch as she was sensitive to being held. She preferred to be alone, exhibited what people saw as destructive behaviours and had deep interests in elements in the environment. She drew on the wall to express herself and it seems that she was frustrated and angry. She did not understand that the drapes were not to be used for peeing on and she behaved in ways that would be viewed by adults as naughty or / and delinquent. I feel that these were all her ways of trying to communicate – including the ‘violent’ responses. In *Living Nonviolent Communication*, Rosenberg (2012, page viii) states that:

“three factors are very important in understanding why some of us respond violently and some of us respond compassionately in similar situations:

The language that we have been educated to use;

How we have been taught to think and communicate;

The specific strategies we have learned to influence others and ourselves.”

Furthermore, he adds that (Rosenberg, 2012; p.2):

“The Nonviolent Communication practices that support conflict resolution involve expressing our needs;

sensing the needs of others, regardless of how others are expressing themselves;

checking to see whether needs are accurately being received;

providing the empathy people need in order to hear the needs of others; and

translating proposed solutions or strategies into positive action language.”

So how do we work with an infant who is explicitly in conflict with oneself and one’s environment? Especially when the infant has an embodied and non-embodied make-up that may influence language comprehension or / and behaviour comprehension in a significantly different manner and degree to other infants her age? How do we understand our needs in such a situation? How do we sense her needs in such a situation (regardless of how she may be expressing herself)? How do we check to see whether her and our needs are being accurately received? How do we exercise the empathy needed to hear her needs as well as ours? How can we translate proposed solutions or strategies into positive action language, especially with an infant who may not be so disposed to spoken language per se?

I do not know the answers to these reflective questions, however, maybe just being aware of these aspects of the infant’s ways of being and asking such reflective questions may enable parents and professionals to begin to work with the infant in a more harmonious manner. It may also lead to research approaches that are more sensitive to such a way of being – especially during infancy – and therefore more ethical as well.

The clusters of questions as findings that emerged from the analysis of this narrative is as follows (Appendix 5; pp.407-408):

“To ‘autistic’ person: What kinds of sensory experiences did you have as an infant? E.g. regarding being touched, smells, objects etc.? Did you prefer to be alone? Did people think you were deaf?

Did you draw over the walls as an infant? Did you pee or / and poo in places that your family did not want you to? How did your parents react to your behaviour? Say when being touched? When smelling things? When playing with certain objects?

Were you frustrated or / and angry as an infant? Why? How?

To parent(s): Did your child carry out behaviour as an infant that seemed like inappropriate behaviour? E.g. peeing on the carpet or wiping faeces over the room? How did this make you feel? How did you behave in relation to this kind of behaviour? How do you think your child felt?"

These clusters of questions led to the creation of the themes 'The senses and infancy', 'The senses and others' meaning-making', 'Communication and the senses' and 'Emotions and infancy' in *The Table of Questions, Categories and Themes* (Appendix 13; pp.563-564). Maybe it is questions such as the ones above that may help to begin to unveil some of the mystery or not-knowing of the "somatic affordance of autistic and non-autistic dispositions" that create a double empathy problem (Milton, 2012; p.7) during interactions? They might enable the exercising of insights and behaviour that are in line with an intersubjective lens whereby the 'other' is recognised, and treated as, an aspect of oneself. Therefore, leading to more sensitive ways of being for families with an 'autistic' member, researchers, other professionals etc. These kinds of questions also challenge the notion of 'autism' from the medical perspective, in that an entire group of people – be it the family or / and the researcher or / and any other professional – can acknowledge the possible meaning-making of the 'autistic' infant and recognise that it is not only the infant who is 'autistic'. In that non-'autistic' people also have a communication problem with regards to the 'autistic' person.

Therefore, as is in line with the tenet of ethics within participatory research (Cornwall and Jewkes, 1995), the family, researchers etc. can hold themselves / ourselves to account in a more insightful manner, whereby the infant is not looked upon as a separate being with her / his own issues or blamed for being so. Instead, the infant is perceived – and therefore treated – in a manner that means that the family, researchers etc. is / are able to exercise a social responsibility together with the infant. If a human being is treated as such from the beginning stages of life then their experience(s) of the world is / are likely to be less conflicted 'within', as an individual, and less conflictual 'without' at an interactional level. I also ought to highlight that focusing on the paradoxical, dynamic and mysterious aspects of 'autistic' persons' lived experiences has enabled me to create these kinds of clusters of questions and insights as findings. Hence, in order to develop more participatory research designs,

one could work with, in and through this kind of phenomenological attitude to enable oneself, families, other researchers, professionals etc. to also develop their insight(s) regarding 'autistic' people's inner lives and meaning-making.

7.2.3.2. Childhood

The following are excerpts from Luke Jackson's narrative in *Freaks, Geeks and Asperger Syndrome: A User Guide to Adolescence* (2002), where he has written about how his embodied and non-embodied sensory experiences influenced his experience of an outing to the beach with his family during childhood (Jackson, 2002; pp.63-66):

“As I walked and tolerated the disgusting feeling of wet sand between my toes, the attraction of the warm grass and the reed-type plants sticking out of the grass was too much for me and I turned and wandered to a particular big patch of grass, never giving anyone else a second thought.

One second, I was there, the next, poof – I was gone, or so it seemed to them. In actual fact, I was picking all the little seeds off this piece of grass and then trying to fold it and blow between it. Have you ever tried that? Be careful though, because grass is like paper and can cut you. If you get it right, it makes a really cool squealing noise. I never can quite manage it.

I often get engrossed in one thing or another and lose track of time. I think it's a pity that time exists at all, but then I suppose at least we know when to have meals. I can spend hours looking at the patterns and shapes in things around me. I carry in my head my own little show of patterns and prisms and shapes and colours. They intermingle with shapes from the outer world. It is very hard to explain, but maybe other AS [Asperger Syndrome] or autistic people understand. Strangely enough, as I get older I am more aware of time and space and people and less aware of my own little world. I think when I used to 'get lost' (I have put that in inverted commas because I only got lost in other people's eyes, I always knew where I was), I was in my own world quite a lot. Ben [his younger little brother who is also 'autistic'] is like that now.

After a little while, I decided to go back to Mum. I was told that it was a very long while, many hours actually, but I didn't realize that. One small problem with going back to Mum was that I didn't particularly know which way back was. I looked round for a while and finally saw a man walking along in the grass. He asked if I was lost. I explained that I wasn't lost but I didn't know where my Mum was and had he seen her.” (In Appendix 7, pp.431-433)

The full analysis is in Appendix 7 and I have drawn from it to write the following.

Luke was finding it difficult to walk on the wet sand due to sensory difficulties. Amidst this paradoxical experience, whereby he was struggling to tolerate the feeling of stepping on wet sand and the attraction of the warm grass – the play of opposites, Luke became dynamic by walking and tolerating the feeling of the wet sand to get to the grass and plants that appealed to him. This seems to be a familiar and soothing micro-context within a larger painful context for Luke, e.g. he is likely to have known what warm grass felt like from his experiences at home and therefore he sought to enter this soothing micro-context. He also attempts to relate with the reader by asking whether one has tried to blow between grass; highlighting what appeals to him about doing this, and gives advice that illustrates his caring side.

Luke then delves into how the dynamic acts he got involved in, i.e. playing with grass, led to him becoming so engrossed in it that he lost track of time. He provides a paradoxical account, in that he wishes time did not exist but simultaneously gives the positive side regarding knowing when to have meals. He describes a phenomenological way of being in relation to patterns, shapes etc. in his mind and how these also intermingle with shapes in the outer world. It is interesting that he takes a standpoint that strongly suggests that language is not always adequate to describe these kinds of experiences, and simultaneously he seems to validate his experiences by stating that maybe other people who are also 'autistic' understand. Possibly also implying that those who are not 'autistic' may struggle to understand this way of being?

The description of him 'getting lost', including the fact that he states he always knew where he was, suggests a meditative style of perception that others did not seem to recognize for what it was / is. Is this an example of the 'flow state'? Mihaly Csikszentmihalyi, an American-Hungarian psychiatrist, states the following regarding the flow state (in Nakamura and Csikszentmihalyi, 2014; pp.6-7):

"It seems that every time people enjoy what they are doing, or in any way transcend ordinary states of existence, they report specific changes in attentional processes. To be conscious of pleasurable experiences one must narrow the focus of attention exclusively on the stimuli involved. What we usually call "concentration" is this intensely focused attention on a narrow range of stimuli. It is a prerequisite for making love or

listening to music, for playing tennis, or working at the peak of one's capacity."

Could it be that what researchers observe and define as 'obsessive' or / and 'repetitive behaviour' regarding 'autistic' people (e.g. Ssucharewa, 1926; Kanner, 1943; Asperger, 1943; DSM-V, 2013; ICD-11, 2018) is actually a person in the flow state? Especially if they seem as though they are enjoying the moment for what it is. Or / and is this an example of mono-processing (Williams, 1996) and mono-tropism (Lawson, 2001), whereby the 'autistic' person has found a micro-context that has enabled them to focus on one thing (i.e. the grass) so as to cope with the sensory difficulties they are experiencing? Could it also possibly be a way of coping with the anxiety of being in a larger context that makes them feel uncomfortable?

During the time of 'getting lost' in his own world with the seeds and grass, Luke had not recognised the duration of the time he was gone. Martin Heidegger in *Being and Time* (1927 / 1962; p.245) states that:

"Our analysis of Dasein's disclosedness showed further that, with this disclosedness, Dasein, in its basic state of Being-in-the-world, has been revealed equiprimordially with regard to the world, Being-in, and the Self. Furthermore, in the factual disclosedness of the world, entities within-the-world are discovered too. This implies that the Being of these entities is always understood in a certain manner, even if it is not conceived in a way which is appropriately ontological. To be sure, the pre-ontological understanding of Being embraces all entities which are essentially disclosed in Dasein; but the understanding of Being has not yet articulated itself in a way which corresponds to the various modes of Being."

My background is not in academic philosophy and I may be misinterpreting the term 'Dasein', however, from what I can fathom from what Heidegger was attempting to state is that consciousness is intersubjective in itself; in that Being reveals itself to itself through itself. Furthermore, as consciousness reveals itself to itself through itself via entities, e.g. individuals, then such entities also discover themselves / ourselves. Although understanding is itself then shaped and affected by the very nature of the entity / individual through which Being is revealing itself to itself through itself. Consciousness or Being embraces all by revealing itself to itself through itself, but it would seem that Being in all its diverse modes cannot be understood.

Could it be that Luke was experiencing a flow state such that he had 'lost' understanding and was just simply being? Luke then highlights that the older he is getting the more he is becoming open to the outer world. So things can and do change – there is a dynamic element to his experiences and states of being. Although during his time at the beach he gradually got out of the state of being 'lost' in his experience(s) with the grass and sought his mother, who was looking for him along with his siblings and other people.

The clusters of questions that emerged from this narrative are as follows (Appendix 7; pp.431-433):

“To 'autistic' person: Whilst at the place of an outing what kinds of sensory experiences made you feel like not wanting to be there? Or / and not do certain kinds of activities there? Did you go off and do something by yourself? What was this? How did you feel whilst doing this? What did you learn?

Are there moments whereby you become engrossed in one thing or another for hours? For example, looking at patterns and shapes in things? Do you keep certain kinds of images / shapes / patterns / colours in your mind? Do they intermingle with shapes from the outer world? How does this make you feel? Do others say that you are in your own world a lot of the time? How do you respond?

Whilst on an outing, have you ever had your family or / and other people go looking for you because they thought you were lost? What were you doing at the time? When your family or / and other people found you what did they say? How did you respond? How did you feel?”

These clusters of questions led to the creation of the themes 'Family outings and the senses', 'Meditation and time' and 'Family and safety' in *The Table of Questions, Categories and Themes* (Appendix 13; pp.569-570). These kinds of questions can enable families, researchers and other professionals to be more mindful of the different kinds of attention or states of being that 'autistic' people can experience – especially during childhood, and how this / these influence communication(s). It can also enable an 'autistic' person as well as non-'autistic' researchers, family members etc. to think about their different styles of attention and become more self-aware and how their styles of attention may affect their interactions. Therefore, when attempting to create a participatory research design one ought to be mindful that the 'autistic' person may prefer to be in an environment(s) that is suitable and makes them feel

comfortable in terms of their sensory ways of being. Family members may also need to be made aware of this so that arrangements can be made, for example, within the home setting so as to accommodate the 'autistic' family member's sensory requirements and, for example, during the research process(es). Furthermore, when researching / working with the 'autistic' person it is worth keeping in mind that they may 'drift off' if they feel overwhelmed within the given environment, e.g. they may physically leave the room or / and divert their attention to an object that they can meditate with. This is fine and the person ought to be given the space and time they need in order to carry this out. It may also be their way of trying to communicate something through, so it is worth being reflexive as possible and changing one's behaviour as required.

Luke proceeded to state that (Jackson, 2002; pp.63-66):

"Meanwhile, Mum had got every single person on the beach looking for me. Coastguards, police, a pack of Brownies and every available person were all shouting my name over a loudspeaker. I didn't hear a thing! I have a strange kind of hearing and can only concentrate on listening to things if I know I am meant to. Distinguishing between background and foreground noise has always been a problem, so however loud they shouted I would have presumed that it was background noise. This is a difficulty of AS because I get told off so many times for being an ignorant pig when I genuinely do not recognize that I am being spoken to. Joe [another younger brother who is also 'autistic'] has this problem a lot, lot worse than I do.

I wasn't really looking for anyone when I was found. I just stumbled across them. It was very strange because my sisters and brothers were crying and Mum grabbed me and a big fuss was made over what seemed to me like nothing. Sometimes it is very hard to understand exactly what I have done wrong. If you are a parent and your child is like that, then make sure to explain to them very clearly." (In Appendix 7; pp.434-435)

It would seem that this is an embodied and non-embodied way of being that can be a mystery to others and for Luke, i.e. Luke's processing of incoming information via sounds and the way he distinguishes and does not distinguish between foreground and background noise. This led to his mum calling upon the assistance of several other people (other non-self-embodied embodied beings of his mother) on the beach to find him. He describes how this can lead to misunderstandings with others, in that they think that he ignores them on purpose, however, this is not the case. The

underlying thread here would seem to be that other people who do not have this kind of way of being do not understand his way of being and therefore project their own negative assumptions on to him, which are significantly rooted in their own embodied experiences. Luke then proceeds to further elaborate, and possibly further validate, his experience(s) by comparing himself with his younger 'autistic' brother Joe, in that Joe exhibits this way of being a lot more than Luke.

Luke practically dealt with this situation by stumbling upon his family whilst they were looking for him; it is a mystery to him as to why his family were sad and crying and he also did not understand what he had done 'wrong'. Therefore, he states that when this kind of thing happens people ought to practically and explicitly explain the situation. It seems that when a person has this kind of sensory way of being they require that the mystery, i.e. in this case the standpoints that have been taken up by family members during the event, ought to be openly unravelled and described. Hence, the embodied and non-embodied mysterious way of being he exhibits requires that much more of an open honest manner of communication(s) – this in itself could be viewed as a paradoxical relationship. It has implications for the family and for researchers / professionals in terms of how we ought to openly interact with 'autistic' people when carrying out activities or research with them.

The cluster of questions as findings that emerged from the analysis are (Appendix 7; pp.434-436):

“To parent(s) / guardian(s): Whilst on an outing, have you ever had to go looking for your 'autistic' child because you thought they were lost? What were you doing at the time when you realized they were gone? Who found them? When you found your child what did you say or / and do? How did they respond? How did you feel?

To sibling(s): Whilst on an outing, have you ever had to go looking for your sibling because you thought they were lost? What were you doing at the time when you realized they were gone? Who found your sibling? What did you say to them or / and do? How did they respond? How did you feel?

To 'autistic' person: What is your hearing like? What is it like trying to distinguish between foreground and background noise? Have you ever had any difficulties in doing so? Are there any experiences you have had with other people whereby it affected what happened, e.g. people thinking that you are lost, shouting out your name and looking for you, but you did not realize this was so and only found out later? Has anyone ever told you that you were ignoring them when they were

trying to get your attention by calling out your name or / and asking you to do something? How did you feel when they told you this? What did you think? What did you say to them or / and do? What did they say to you or / and do?

To parent(s) / guardian(s): If or when your 'autistic' child does anything you consider to be wrong, do you explicitly explain things to them and advise them on how you expect them to behave? What do you say or / and do?"

These clusters of questions led to the creation of the themes 'Family and safety', 'Sensory processing and family' and 'Family communication' in *The Table of Questions, Categories and Themes* (Appendix 13; pp.571-572). These kinds of questions could make researchers, 'autistic' people and their families, professionals etc. more consciously aware of the sensory influences of 'autistic' people's hearing, especially during childhood. It could help to decrease misunderstandings and also lead to more explicit communication that may be / are required in these kinds of social settings so as to help everyone involved to learn together in a meaningful manner. It could also help to create participatory research designs and therapeutic approaches that acknowledge such states of being and are in line with them. For example, during a research study, if an 'autistic' child does not respond to a question or task it may be that they could not differentiate between foreground and background noise. Therefore, not even knowing that they were being referred to let alone being asked to undergo an activity. It may then be worth working with some visual aids, e.g. a Tablet with visual pictures of tasks, to communicate with them and encourage the family to do the same.

7.2.3.3. Teenagehood

The following is an excerpt from Chris Mitchell's narrative, *Glass Half-Empty, Glass Half-Full* (2005). He has written about how his parents encouraged him to join a youth club when he was a teenager as he did not have any friends like his brother, sister and cousins did, and this was his experience(s) with fellow peers in and out of school (Mitchell, 2005; p.21):

"In the schoolyard, because the pupils are under the control of teachers and school rules, having to wear a uniform, it is often a case of having to find a way to exert superiority over others in the pecking

order. This can be ruthless and aggressive, especially when trying to prove themselves as the hardest or coolest kids in the school. I was particularly vulnerable to other pupils trying to exert such superiority over me. Joining Monkwearmouth Youth Club enabled me to see other kids my age away from the confines of school rules and school uniform.” (In Appendix 9; pp.451-452)

Chris makes meaning of his lived experience in the schoolyard and the youth club by comparing the two settings in terms of the types of systemized dynamics. Is this in itself a form of taking up a paradoxical lens to attempt to understand the dynamic and mysterious nature of one’s lived experiences (i.e. that which at the time he was not consciously aware of)? Furthermore, he has an understanding of the schoolyard whereby it is not necessarily a fun playful space, that it is prohibitive and kids attempt to form groups or / and hierarchies. This meant that Chris had experiences whereby he was not able to see other teenagers “away from the confines of school rules and school uniform”, possibly further adding to his sense of non-belonging and the negative dynamics surrounding why and how other kids behaved the way they did? However, participating in the youth group as well as being exposed to other kids in such a relaxed setting enabled him to see another side to his fellow pupils and enabled him to show another side of himself.

Ludwig Wittgenstein (1993, in Heaton, 2010; p.77) states that:

“The child learns to believe a host of things. I.e. it learns to act according to these beliefs. Bit by bit there forms a system of what is believed, and in that system some things stand unshakeably fast and some are more or less liable to shift. What stands fast does so, not because it is intrinsically obvious or convincing; it is rather held fast by what lies around it. (OC ¶144)”

It would seem that the social dynamics and structure(s) of being within one system, i.e. the school environment that lay around Chris, enabled him to develop experiences and beliefs that stand fast, e.g. being picked on by other teenagers his age and being reluctant to spend time with them. However, partaking within another system, i.e. the youth club and its social dynamics that lay around Chris, enabled him to have shifting experiences and beliefs about his fellow peers outside of the school environment. Encouraging ‘autistic’ children and teenagers to participate in different environments, especially environments that are geared towards enjoying an

activity(ies), may be a positive way to create and foster social interactions with peers.

The clusters of questions as findings that emerged from the analysis are as follows (Appendix 9; pp.451-452):

“To ‘autistic’ person: How was your school life like? How was it like in the playground? How were the other kids like towards you? How did this make you feel?

Did your parents encourage you to join any youth clubs outside of school? Did you ever compare this context to the school context regarding the social dynamics between yourself and other teenagers? What did you learn about yourself? What did you learn about others? What did you learn about social contexts?”

These clusters of questions led to the creation of the theme ‘School life and socializing’ in *The Table of Questions, Categories and Themes* (Appendix 13; p.576). Questions such as these can enable families, ‘autistic’ people themselves and researchers etc. to become more aware of the social dynamics of the environmental systems in which one navigates within. Therefore, the context may well be created by the embodied and non-embodied interactions of at least two agents or more, and simultaneously, the context can influence the embodied and non-embodied interactions of the agents involved. In addition, these kinds of questions help a researcher, ‘autistic’ people, their families etc. to (re-)remember and (re-)acknowledge the social context as a factor that influences social interactions. Therefore, not just simply focusing on the ‘autistic’ individual and their supposed ‘social deficiencies’ but also consciously looking at matters via an intersubjective lens that considers environmental factors and pressures. This in turn can lead to a participatory research design where the researcher and co-researchers consciously acknowledge the social context(s) in which the study is being carried out, being reflexive about the influences of the social dynamics we / they find ourselves / themselves in. Doing so will help in terms of fathoming how the knowledge that was created emerged and it will enable all concerned to exercise some level of reflexive accountability.

7.2.3.4. Adulthood

I will bring this section (7.2.) to an end with Donna Williams's lived experience in *Nobody Nowhere: The Extraordinary Autobiography of an Autistic* (1992). As an adult in her early to mid twenties she was seeking to understand why she was the way she was, trying to gather information from different sources such as her doctor, school and her aunt. This excerpt of Donna's narrative entails a return to her aunt's home to ask about her own behaviour as an infant and the possibility of her being 'autistic'. Her aunt begins to tell the story and it leads to Donna re-living the memory and moment with her mother when she was an infant (Williams, 1992; pp.128-131):

"I was back there. I could see my aunty across the room. I could hear the pleading tone in her voice and sensed danger. I was watching everything around me happen as though in slow motion, though still moving far too fast for me to be able to respond in time.

I looked up at the figure of my mother. I shot silent glances in the direction of the pleading voice from across the room [her aunt]. I looked down at the opened tin of cold spaghetti in front of me and was aware of the fork in my hand.

I had not heard the introduction: the threat of death against my spilling a single drop of food. I never connected the repeated slapping with the event. It was just something that came to me from out of the blue as a series of shocks.

I felt the dishcloth being forced into my mouth. It made me gag. I was choking as I vomited up against it.

The pleading voice was at war with the cutting snarl of my mother's voice. I glanced up at the black and white striped cord as though it was a snake. It began to whip my face. I could not cry, or speak, or scream. I looked at my aunty and collapsed on the cold smooth surface of the table in front of me and vomited through my nose. I thought I had drowned.

[As an adult with her aunt] There was a rising choke of vomit in my throat and a deafening scream inside my head that couldn't get out. Willie [one of Donna's personas] had asked why she [her aunt] had done nothing.

Without waiting for a reply, I went wandering down the hallway of my aunty's house like an automaton.

My cousin's room branched off to one side. I looked through the door. My cousin had been given the furniture from my old room as a child. There on my old bed was the same bedspread, with fine yellow flowers embroidered on it." (In Appendix 12; pp.492-493)

Donna's aunt's narrative pulls up an episodic memory that is dynamic as well as conflictual in nature and Donna relives the moment whereby her mother is about to attack her, remembering the can of spaghetti and the fork in her hand. Whilst reliving the moment via memory she is understanding the dynamic and mysterious element of this infancy experience, making the conscious connection between her mother's threat of spilling the food and the slaps – which she had not made before. Probably because at the time as an infant she did not understand what her mother was trying to communicate to her via spoken language.

Her aunt was trying to stop Donna's mother; there was a non-embodied embodied self (i.e. not Donna herself but her aunt) trying to protect her as another dynamic force. Donna's body as an infant practically dealt with the dynamic nature of this experience by becoming silent, physically collapsing, and finally vomiting through her nose. This memory in turn led to Donna as an adult re-experiencing the moment in a physical manner; I deem this to be trauma relived and may well be recognised as Post-traumatic Stress Disorder (PTSD). It also brings to light that there are aspects of one's lived experience(s) that may be processed (or re-processed) many years after the event, therefore, in a way, rendering time obsolete. This also provides a strong rationale to focus on the lived experiences of 'autistic' people over a lifespan, in that one is able to become conscious of the real consequences and effects of infancy / childhood trauma up to the ages of adulthood.

Furthermore, considering that 'autistic' persons are hypersensitive and hyposensitive in certain ways then how deeply or / and non-deeply is trauma experienced? What of post-traumatic stress? How do such persons cope with such experiences during the moment? And how do they cope with it once they begin to make sense of it years later as teenagers or adults? Donna as an adult seems to have practically dealt with it by seeking out more of her history and story, e.g. by visiting her aunt.

She confronts her aunt by asking her the question as to why she never did anything about the abuse she (Donna) experienced, though it seems that this was more of a rhetorical question as she does not wait to hear the answer. She walks into her cousin's room, which has some of her old childhood items in it, and seeing these objects probably affected her negatively because she proceeds to state that she then sat in her cousin's wardrobe for a while whilst curled up in a ball (Williams, 1992;

pp.130-131). Although this could also be viewed as a positive experience, in that she found solace in the darkness of the wardrobe. She later goes home and sits and rocks in her room for three days, carrying out this dynamic act so as to cope with her new understanding of herself – realising that she is ‘autistic’.

I do not condone Donna’s mother’s behaviour, however, given what she knew and did not know then it may have been her frustrated manner of trying to reach out to her child whom she struggled to understand. Paradoxically, it is often the very darkness through which one suffers that leads to one becoming more consciously aware of aspects of oneself and that of the ‘other’ (Shems&Rumi, 1263 / 2011; Jung, 1961 / 1995), i.e. re-living this trauma led to Donna finally learning that she is ‘autistic’ and why her mother had behaved the way she did.

The clusters of questions that emerged as findings are (Appendix 12; pp.492-493):

“To ‘autistic’ person: Whilst talking with family about your younger days are there any particular memories from certain periods of your life that struck you? For example a memory from your infancy years that made you realize something about yourself that you may have not realized before? How did you deal with this?

Before I go on to the following question, I remind you that you do not have to answer any of these questions if you do not wish to. Do you have any memories with your family whereby when you now look back at it and you think, “That was physical or / and emotional abuse?” How did you feel at the time? How did you deal with it? Was there anyone else who knew about it, e.g. an aunt or uncle? What did they do or / and not do? How does this make you feel now? How do you deal with it now? How do you think that family member felt at the time? How do you think they felt whilst telling you that information? How is your relationship now?

How do you define ‘trauma’? Have you ever had a traumatic experience as an infant? As a child? As a teenager? As an adult? Have any of these traumatic feelings come about again after you have remembered such moments? How did you feel? How did you cope with it or / and them?”

These clusters of questions led to the creation of the themes ‘Family memories and self-recognition of being ‘autistic’’, ‘Family conflict’ and ‘Family and trauma’ in *The Table of Questions, Categories and Themes* (Appendix 13; pp.586-588). Asking these kinds of questions can create and facilitate the process(es) of acknowledging the darkness or ‘shadow self’, e.g. aspects that one is not consciously aware of,

within oneself and within one's family dynamics. In doing so this may well enable transformations to take place that lead to harmonious interactions (Jung, 1961 / 1995; Hellinger and ten Hovel, 1999), and this is applicable for all concerned – the family, the 'autistic' person, researchers, professionals etc. The lived experiences of 'autistic' people ought to be dialogued with, especially those experiences that are deemed to be negative or abusive, so as to develop participatory research designs that acknowledge family trauma. When I read the excerpt of the narrative above I cried, and it is this emotional interaction with Donna's narrative that has enabled me to think of the real consequences of not being consciously aware.

If parents with 'autistic' children or professionals read the narratives of 'autistic' people, such as the examples set out in this chapter, it may help in them becoming more consciously aware of their child's / children's behaviour and may prevent the kind of lived experience Donna lived through as an infant and as an adult. Therefore, exercising a phenomenological attitude that focuses on the 'autistic' person's intersubjective ways of being at an interactional level with family members over a lifespan may enable researchers, families and other professionals to be more consciously aware of the real possible consequences of one's behaviour in the present. Hence, researchers can develop participatory research designs that involve taking the necessary preventative steps in the present – or behave in more consciously aware ways now – so as to help create and maintain a more understanding environment(s).

7.2.4. Summary of insights

It seems that at an individual level 'autistic' persons' embodied and non-embodied sense of self, in this case the body and senses, proprioception, and their hyper and hypo sensory abilities as well as their coping strategies, influence and shape their lived experiences. Leading to different ways of meaning-making, self-knowledge or self-awareness and perception. At an interactional level, it seems that due to different somatic ways of being and worldviews, there can be misunderstandings that take place between family members, peers, researchers etc. and 'autistic' people. A possible ethical way in which to develop insight and knowledge could be through exercising a phenomenological attitude with the narratives of 'autistic' people and

opening oneself to the 'other' in oneself, as has been demonstrated and discussed here. Furthermore, working with a lifespan perspective may enable one to develop the foresight to think and see possible consequences for adulthood. Utilising such a perspective may help families and researchers to become more consciously aware of the real consequences of one's lack of understanding. Therefore, one may be able to take action that is more harmonious with infants, children, teenagers and adults who are 'autistic' so as to create more suitable environments for both 'autistic' and non-'autistic' persons.

Researchers in the field of 'autism' studies, as well as those in other fields, may benefit from these insights by becoming aware of the kinds of knowledge that can emerge when one takes up a phenomenological attitude and exercises it throughout a study. In that, right from the outset one questions one's self and one's questions and begins to create sensitive questions; recognizing the significance of this might give them the motivation to take up a phenomenological attitude. Furthermore, they will have at least one methods process(es) – as outlined in Chapter Six, from which they can draw upon so as to fulfil such a task.

7.3. CONCLUSION

I have demonstrated how I exercised my phenomenological attitude to draw from the analyses and to write this chapter. Developing one's insight regarding the 'autistic' individual's meaning-making and then 'turning the glass ball around' and focusing on their meaning-making with family members has enabled me to become more comfortable in addressing my initial ethical dilemmas and anxieties. At least I have been able to fathom a way of carrying out research that has enabled me to acknowledge my biases and worldview in an open, explicit manner as far as is possible. This in itself is an original contribution to the field of 'autism' studies, in that other researchers with ethical dilemmas and anxieties could draw from this approach to attend to their specific research question(s). The main theme that emerged at the individual level was 'The body and senses', which I have discussed in-depth in the first section of this chapter in relation to proprioception, hyper and hypo sensory abilities and emotion. The second section enabled me to draw from the vignette analyses in-depth so as to help create a lifespan perspective of the kinds of lived

experiences 'autistic' people can, and do, experience at an interactional level within family settings. I have been able to learn a lot about the very human experiences such people have and I hope that the insights and knowledge outlined in this chapter will motivate families and researchers alike to seek to be more consciously aware of 'autistic' people's ways of being and one's own ways of being.

The next chapter will further discuss these findings and the methods process(es) in terms of future research that could be carried out in line with such insights.

8. 'CONCLUSION', THE PHENOMENOLOGICAL ATTITUDE AND FUTURE RESEARCH

8.1. INTRODUCTION

In this chapter I shall address the research aim and answer the research questions as far as I can in the initial section. I will highlight that working with a phenomenological attitude and approach can lead to new knowledge that contributes to the field of 'autism' studies in developing one's insight(s). It can also help in creating research questions that are sensitive to, and reflective of, the lived experiences and meaning-making of 'autistic' people, which is likely to be more ethical. In the second section I shall further discuss the findings, methods process(es) and working with autobiographies and IPA, highlighting how future research can be carried out.

8.2. 'CONCLUSIONS': THE PHENOMENOLOGICAL ATTITUDE, RESEARCH AIM AND QUESTIONS

I use the term 'Conclusions' in apostrophes here as a reminder to myself and the reader that the insights, theories and knowledge put forward in this chapter and throughout this thesis are concepts and ways of exploring. Therefore, they are not concrete and are dynamic in nature. I shall first address the research aim, then the research questions and then the underlying areas of interest, as outlined in the *Introduction* chapter.

My aim was to explore how a researcher with spiritual beliefs can carry out research that is as ethical as possible with a family with a member on the 'autism' spectrum who also practice spiritual beliefs so as to enhance self-knowledge for myself and for the family. I experienced significant ethical anxieties regarding my not being on the 'autism' spectrum and the biases I am likely to be bringing to this research, so I decided to take up a reflexive standpoint and be as explicit as possible about my worldview throughout the study. Hence, I ended up asking myself "What and who am I?" and this process(es) led to the creation of a standpoint that I refer to as 'my reflexive embodied and non-embodied paradoxical, dynamic, mysterious self

and lens' – what I see as also being my phenomenological attitude. I dialogued with the autobiographies of 'autistic' people and their lived experiences so as to sensitise myself to the 'insider's perspective' by creating questions that enabled me to develop my insight(s) and to create potential research questions for say interviewing 'autistic' adults and their families. Thanks to this study I have gotten to know myself better and I hope that the findings as research questions – those for my own thinking and those that could be included for interviews – have enabled me to begin to think and behave in a more ethical manner regarding 'autistic' people.

In addition, the approach of this study as a whole and the questions as findings could be used with families with an 'autistic' member so as to enable them to develop their insight(s) of self and the 'other'. Therefore, the aim of this study has been achieved insofar as developing an approach that has enabled me to address my ethical anxieties and it may be more suited to working with families with an 'autistic' member who hold spiritual or / and religious beliefs. However, I have come to realise that the approach could well be used with families who do not hold such beliefs. In that the narratives could be worked with in such a way that family members' worldviews are reflected upon, with, in and through, regarding their 'autistic' family member's lived experiences and vice versa. This in itself could lead to deeper insights and more understanding within the family setting(s).

It could also be put into practice by other researchers and professionals who work with such families, whereby some could even use the questions created in this study (i.e. the *Table of Questions, Categories and Themes* in Appendix 13) to draw from, reflect with, and work with so as to carry out further studies. Other researchers in other fields could also exercise a phenomenological attitude and carry out a similar approach(es) so as to sensitise themselves to the lived experiences of the 'other'. Therefore, there may be more to exercising a phenomenological attitude, and the findings of this study, than initially meets the eye. I shall now focus on the two main research questions of this study.

The two main research questions of this study were / are:

- (i) How do I as a researcher with spiritual or / and religious values attempt to be as ethical and reflexive as possible?
 - How do I make meaning?
 - How can I enhance my understanding of self?

- (ii) How do people on the 'autism' spectrum make meaning of their everyday life experiences with respect to their spirituality and in the family context?
 - How can this be worked with to enhance understanding within the family setting?

This led to three areas of interest for myself as a researcher and for the lived experiences reported by people on the 'autism' spectrum in the form of autobiographical writings: (i) what is self-knowledge? How does it develop?; (ii) what is meaning? How does it develop?; (iii) what is perception? How does it develop?

To answer the first main research question, I have found that explicitly taking up a 'reflexive, embodied and non-embodied, paradoxical, dynamic and mysterious self and lens' has enabled me to achieve five things. One, I have come to realise that this worldview and behaviour is my phenomenological attitude in action in the context of the research aim and questions herein. Two, it has enabled me to harmonize the Alevi in me with the social scientist in me. Three, it has also enabled me to focus on elements of the lived experience and reported phenomena of people on the 'autism' spectrum in a manner that has deepened my understanding and awareness of their inner lives and meaning-making. As much as my ethical anxieties have not been entirely put to rest, in that I accept that this study in its entirety is my interpretation of 'autistic' people and their families' ways of being, they have been significantly reduced. I have learned a way in which I can 'dance' with academic research questions in a harmonious manner. Therefore, overall, I have come to feel more at ease with the potential endeavour of carrying out interviews with people on the 'autism' spectrum and their families and with myself as a human being, an Alevi and a researcher. The fourth aspect is that this kind of research design takes

'participatory research' further. In that right from the outset – before even beginning to create interview protocols let alone starting to work with 'autistic' people and their families as co-researchers – the researcher begins to develop one's insight(s); creating questions that are sensitive to and reflective of the experiences of the 'other(s)'. The final and fifth aspect is that I have come to realise how much I make meaning thanks to my body and would go so far as to state that one's body is meaning itself. Therefore, I as a researcher with spiritual / religious values have attempted to be as ethical and reflexive as possible by exercising my phenomenological attitude all throughout this research and study, explicitly demonstrating how I make meaning (insofar as is possible) and how I have sought to understand my self by attempting to understand the 'other'.

To answer the second research question, it would seem that due to their heightened sensory abilities – whether this be hyper or / and hypo sensory abilities – people on the 'autism' spectrum can experience the world in a much more intense manner (Ssucharewa, 1926; Asperger, 1943; Williams, 1996; Markram et al., 2007; Bogdashina, 2010). This seems to affect their perception, meaning-making and self-knowledge in terms of their lived experiences, their spiritual beliefs as well as how they make meaning within their family context. Although, it would seem that their family members also approach them from their own embodied and non-embodied perceptual styles, meaning-making and self-knowledge, therefore leading to what Milton (2012, 2014a) refers to as the 'double empathy problem'.

Being consciously aware of these ways of being means that a researcher / practitioner ought to practice more so in line with an intersubjective lens that explicitly focuses on, in, with and through the embodied and non-embodied aspects of 'self' – both regarding oneself and the 'other'. Turning to the lived experiences of people on the 'autism' spectrum may well enable a researcher to develop this kind of insight and knowledge by creating further research questions, theorising methods, tools and theories that may be applicable in real world situations such as with a family with an 'autistic' member. What has been achieved with this study is only a drop in the ocean and there is scope for more research that adapts this kind of a phenomenological attitude and approach with narratives.

Furthermore, language plays a significant role in the ways we think and behave, therefore, we ought to apply the phenomenological attitude to our use of language as well in order to be open to 'autistic' persons' ways of being (e.g. using sensory based language) and to their families' – as has been attempted throughout this study and thesis. Therefore, 'autistic' people seem to make meaning of their everyday life experiences thanks to their body and senses, i.e. their embodied and non-embodied aspect(s) of self, and their understandings about their spirituality seem to be influenced by this – including within the family context. One way in which this might be worked with so as to enhance understanding within the family setting is by exercising a phenomenological attitude in order to create sensitive research questions and protocols for future research, e.g. a vignette protocol for interviewing an 'autistic' adult about their family life and another similar protocol directed towards a parent (please refer to section 8.3.1. of this chapter). This has been achieved thanks to undergoing the methods process(es), and specifically the third stage of analyses (please refer to Chapter Six, sub-section 6.4.3. *Stage three: analysing eight vignettes from 'autistic' persons' autobiographies in-depth*).

As for my three areas of interest, it would seem to me that self-knowledge, meaning and perception are all aspects of one's body. Like waves begin to form from the depths of the sea, gradually rise to the surface, dance in their grandeur and then 'return' to the depths, it would seem that the experiences of these elements of our ways of being and the concepts of 'self-knowledge', 'meaning' and 'perception' also do the same. I am finding them to be quite indistinguishable.

Now I shall proceed to discuss this study in terms of the findings and the methods process(es), and make specific recommendations for future research.

8.3. A DISCUSSION OF THIS STUDY AND RECOMMENDATIONS FOR FUTURE RESEARCH

Here I shall focus on discussing the findings in terms of the methods process(es); the first being with regards to my phenomenological attitude and the three stages of the methods process(es) and the second being with regards to my phenomenological attitude, working with autobiographies and Interpretative Phenomenological Analysis (IPA).

8.3.1. My phenomenological attitude, the methods process(es) and findings: limitations and future research

My ethical anxieties and limitations led me to take up a reflexive standpoint and to turn to the lived experiences of 'autistic' people. As mentioned before, the whole methods process(es) enabled me to address my anxieties and limitations insofar as is possible, and in itself is a finding. Therefore, Chapter Six *The Methods Process(es) and the Phenomenological Attitude* is an illustration of this finding. The approach that has been created and developed enabled me to exercise a phenomenological attitude and to also become consciously aware of my attempting to exercise a phenomenological attitude throughout this entire research and study – this may sound paradoxical, however, this is the way it occurred.

Here I have drawn from Chapter Six so as to continue and 'finalise' the discussion regarding the methods process(es), also including examples of potential vignette style interview protocols that can be used for interviews with 'autistic' adults and their families. Therefore, demonstrating how this methods process(es) can lead to the creation of sensitive questions for future research that enable a researcher to continue exercising a phenomenological attitude, and it may also help families and other professionals to adapt this kind of approach so as to develop a way of understanding that is suitable for them or / and the nature of their study(ies).

The whole three stages of the methods process(es) enabled me to exercise my phenomenological attitude and to develop new insights into the meaning-making of 'autistic' people (please refer to Chapter Seven). Stage one, whereby I analysed Christopher Goodchild's (2009) autobiography, enabled me to explore how I was dialoguing with an 'autistic' person's narrative and it gradually occurred to me that I wanted to draw from this to create the selection criteria – which I did. This meant that the selection criteria was heavily created by, and influenced by, Goodchild's (2009) narrative. One could state that this is a limitation, in that one subjective dialogue with one autobiography set the agenda for the entire set of narratives to be chosen for analysis. However, I deem this to be the strength of the study, in that from the very beginning a reflexive dialogue with the meaning-making of an 'autistic' person's story over a lifespan set off the rest of the processes of analyses. In addition, the pilot

study enabled me to set down the roots for the research and to become more comfortable in what I was attempting to achieve and how I was to proceed; I had begun to exercise my phenomenological attitude with regards to the data.

Stage two enabled me to build upon stage one; I was able to exercise my phenomenological attitude in terms of focusing on, with and through the individual narratives of three 'autistic' people in-depth, especially with regards to their inner lives and spirituality. This could be viewed as a disadvantage, in that there are many autobiographies written by people on the 'autism' spectrum and I chose a specific three. However, in light of the aims of this study, the selection criteria and the autobiographies I had access to, they were the three to be selected. This stage also enabled me to continue exercising my phenomenological attitude and helped in lessening my anxieties by learning more from, and about, the 'insider's perspective' (Conrad, 1987 in Smith et al., 2009) – which I drew from to write about the insights outlined and discussed in Chapter Seven.

Stage three enabled me to exercise my phenomenological attitude via a lifespan lens, with a particular focus on interactions with family members. I was able to draw from the narratives of several 'autistic' authors so as to analyse two vignettes per developmental stage, i.e. infancy, childhood, teenagehood and adulthood. This could be a limitation, in that I chose only two vignettes to analyse per life stage. However, given the in-depth nature of the analyses and the time I had to carry them out, this was the most suitable option at the time. The final steps in stage three enabled me to complete the *Table of Questions, Categories and Themes* (Appendix 13) and to also create draft vignette style interview protocols that can be worked with for future research. I still have ethical anxieties, however, I feel more confident in undertaking further research with 'autistic' adults and their families so as to (i) create and foster spaces to enhance mutual understanding and harmony and (ii) learn from such families to carry out research that is more meaningful for them, me and other professionals. I have drawn deeply from this stage to outline and discuss the insights in Chapter Seven and to create the draft vignette interview protocols included here; this has also enabled me to create the recommendations for future research in section 8.3.4. of this chapter. The following are examples of the potential interview protocols that were created thanks to stage three and are findings in themselves

(Figures 30 and 31); they were created whilst working with Temple Grandin's (1986) infancy vignette (Appendix 5). They can be used in further research by myself or / and other researchers in the field of 'autism' studies:

Figure 30: *An example, and a finding, of a potential interview protocol with an 'autistic' adult about their family life*

A Protocol Regarding Infancy and Family Life with an 'Autistic' Adult

Reminder: please note that if at any point you feel uncomfortable during this task(s) or / and do not wish to answer the question or questions then please inform me and I will respect your wishes and comply with them.

1. Please read the following short story from Temple Grandin's book, 'Emergence: Labeled Autistic' (1986), pages 15-16.

"Perhaps, because of my inability to communicate adequately and because of my "inner" world, the scenes of my childhood are vivid. Memories play like a movie on the big screen of my mind.

Mother, who was only nineteen when I was born, said she remembers me as a normal, healthy newborn with big blue eyes, a mass of downy brown hair, and a dimple in my chin. A quiet, "good" baby girl named Temple.

If I could remember those first days and weeks of life, would I have known I was on a fast slide slipping into an abyss of aloneness? Cut off by over-reactions or inconsistent reactions from my five senses? Would I have sensed the alienation I would experience because of brain damage suffered as an unborn child – the brain damage that would become apparent in life when that part of the damaged brain matured?

I was six months old when Mother noticed that I was no longer cuddly and that I stiffened up when she held me. When I was a few months older, Mother tried to gather me into her arms, and I clawed at her like a trapped animal. She has said she didn't understand my behavior and felt hurt by my hostile actions. She'd seen other babies cuddling and cooing in their mother's arms. What was *she* doing wrong? But she figured she was young and inexperienced. Having an autistic child was scary for her because she didn't know how to respond towards a baby who rejected her. Maybe my seeming rejection was not unusual so she shoved her apprehension aside.

After all, my health was good. I was alert, intelligent, and well-coordinated. Since I was the first-born, Mother thought my withdrawal was probably normal, part of maturing and becoming independent.

This withdrawal from touch, so typical of autistic children, was followed in the next years by standard autistic behaviors: my fixation on spinning objects, my preference to be alone, destructive behavior, temper tantrums, inability to speak, sensitivity to sudden noises, appearance of deafness, and my intense interest in odors.

I was a destructive child. I drew all over the walls – not once or twice – but any time I got my hands on a pencil or a crayon. I remember really “catching” it for peeing on the carpet. So the next time I had to go, instead of using the carpet, I put the long drape between my legs. I thought it would dry quickly and Mother wouldn’t notice. Normal children use clay for modeling; I used my feces and then spread my creations all over the room. I chewed up puzzles and spit cardboard mush out on the floor. I had a violent temper, and when thwarted, I’d throw anything handy – a museum quality vase or left-over feces. I screamed continually, responded violently to noise and yet appeared deaf on some occasions.

At age three Mother took me to a neurologist to be examined because I did not act like the little girls next door. I was the first child in a family of four and none of my younger sisters or brothers behaved the way I did.”

2. Questions.

Do you have any memories from infancy? Are they vivid memories or / and not so vivid?

What kinds of sensory experiences did you have as an infant? E.g. regarding being touched, smells, objects etc.? Did you prefer to be alone? Did people think you were deaf?

Did you draw over the walls as an infant? Did you pee or / and poo in places that your family did not want you to? How did your parents react to your behaviour? Say when being touched? When smelling things? When playing with certain objects?

Were you frustrated or / and angry as an infant? Why? How?

When did your parent(s) seek the advice of a medical professional in relation to you? Or / and when did you seek this kind of advice? How did this come about?

3. Contextual information regarding this book.

(i) Who wrote the autobiography or / and reflective text: Temple Grandin, with the assistance of Margaret M. Scariano.

(ii) Where the autobiography or / and reflective text was written: It was published in California, U.S.A.

(iii) When the autobiography or / and reflective text was written: It was published in 1986, and this copy was printed in 1996.

(iv) Why and how the text came into being:

Temple writes about her experiences and also includes research materials in the Appendices for parents, educators, and other professionals. Therefore, I am assuming that as much as this written work is a form of self-exploration, it is also aimed at educating people.

4. Guidance for the researcher / practitioner during the interview:

- Attempt to be open to the participant's own unique life story and meaning-making by taking up a reflexive standpoint;
- Encourage the participant to reflect and to tell their life story;
- Continually re-remember how the the participant's embodied and non-embodied paradoxical, dynamic and mysterious self may be creating and influencing the interview process(es);
- Continually re-remember how your own embodied and non-embodied paradoxical, dynamic and mysterious self may be creating and influencing the interview process(es);
- Try and co-create language with the participant that is meaningful for them and helps you and others to understand as much as possible;
- Near the end ask the participant if there is anything else they would change about this protocol or / and like to talk about;
- At the end ensure to give your contact details to the participant and remind them that they can contact you at any point.

After the interview, take a break and do something else.

Later, return to the recording of the interview and type it up. Proceed to analyse as outlined in Chapter Six of this

thesis. Be open to changing the protocol, interviewing and analysing styles if this is to help develop a better way of becoming sensitive to the lived experiences of the participants.

The above protocol could be used for interviewing adults who are 'autistic' so as to learn more about them and their lived experiences as an infant. Some might relate to Temple's experience (section 1. of the protocol) and some may not. However, because the text itself is taken from Temple's very narrative, i.e. it is not my interpretation, it may act as a 'mirror' for the person being interviewed and help to initiate and maintain a dialogue about their experiences during infancy. I myself have also thought about my own infancy when creating this protocol.

Furthermore, the questions in section 2. of the protocol – which emerged during the analysis of Temple's vignette (please refer to Chapter Six, section 6.4., and Appendix 5) – do not all have to be asked nor answered. They ought to be used like guidelines so as to acknowledge the unique life story and lived experiences of the person being interviewed. Working together as researcher and co-researcher (i.e. the participant) may enable both persons to learn more about themselves, each other and family dynamics. This in turn could lead to more self-aware thinking and behaviour(s) – both for the researcher and for the 'autistic' person. Therefore, reflexivity could be created and put into practice by both persons in a manner that is meaningful for both. The findings from this could then be fed into informing the educational practices of the co-researchers' families as well as other families with members who are 'autistic'. It could also inform methodologies and methods of research in the future.

The next example, and finding, was created with the same vignette but with questions intended for the parent(s) (please refer to Chapter Six, section 6.4., and Appendix 5), as follows.

Figure 31: An example, and a finding, of a potential interview protocol with a family member

A Protocol Regarding Infancy and Family Life with a Family Member

Reminder: please note that if at any point you feel uncomfortable during this task(s) or / and do not wish to answer the question or questions then please inform me and I will respect your wishes and do as you require.

1. Please read the following short story from Temple Grandin's book, 'Emergence: Labeled Autistic' (1986), pages 15-16.

"Perhaps, because of my inability to communicate adequately and because of my "inner" world, the scenes of my childhood are vivid. Memories play like a movie on the big screen of my mind.

Mother, who was only nineteen when I was born, said she remembers me as a normal, healthy newborn with big blue eyes, a mass of downy brown hair, and a dimple in my chin. A quiet, "good" baby girl named Temple.

If I could remember those first days and weeks of life, would I have known I was on a fast slide slipping into an abyss of aloneness? Cut off by over-reactions or inconsistent reactions from my five senses? Would I have sensed the alienation I would experience because of brain damage suffered as an unborn child – the brain damage that would become apparent in life when that part of the damaged brain matured?

I was six months old when Mother noticed that I was no longer cuddly and that I stiffened up when she held me. When I was a few months older, Mother tried to gather me into her arms, and I clawed at her like a trapped animal. She has said she didn't understand my behavior and felt hurt by my hostile actions. She'd seen other babies cuddling and cooing in their mother's arms. What was *she* doing wrong? But she figured she was young and inexperienced. Having an autistic child was scary for her because she didn't know how to respond towards a baby who rejected her. Maybe my seeming rejection was not unusual so she shoved her apprehension aside. After all, my health was good. I was alert, intelligent, and well-coordinated. Since I was the first-born, Mother thought my withdrawal was probably normal, part of maturing and becoming independent.

This withdrawal from touch, so typical of autistic children, was followed in the next years by standard autistic behaviors: my fixation

on spinning objects, my preference to be alone, destructive behavior, temper tantrums, inability to speak, sensitivity to sudden noises, appearance of deafness, and my intense interest in odors.

I was a destructive child. I drew all over the walls – not once or twice – but any time I got my hands on a pencil or a crayon. I remember really “catching” it for peeing on the carpet. So the next time I had to go, instead of using the carpet, I put the long drape between my legs. I thought it would dry quickly and Mother wouldn’t notice. Normal children use clay for modeling; I used my feces and then spread my creations all over the room. I chewed up puzzles and spit cardboard mush out on the floor. I had a violent temper, and when thwarted, I’d throw anything handy – a museum quality vase or left-over feces. I screamed continually, responded violently to noise and yet appeared deaf on some occasions.

At age three Mother took me to a neurologist to be examined because I did not act like the little girls next door. I was the first child in a family of four and none of my younger sisters or brothers behaved the way I did.”

2. Questions.

To parent(s):

What was your child’s memory like during infancy? How did you feel about it?

Did your child carry out behaviour as an infant that seemed like inappropriate behaviour? E.g. peeing on the carpet or wiping faeces over the room? How did this make you feel? How did you behave in relation to this kind of behaviour? How do you think your child felt?

When did you feel the need to seek professional medical advice regarding your child? How did this come about? How did you feel during the process(es) of your child being seen? How did you feel afterwards? How do you feel now?

3. Contextual information regarding this book:

(i) Who wrote the autobiography or / and reflective text: Temple Grandin, with the assistance of Margaret M. Scariano.

(ii) Where the autobiography or / and reflective text was written: It was published in California, U.S.A.

(iii) When the autobiography or / and reflective text was written: It was

published in 1986, and this copy was printed in 1996.

(iv) Why and how the text came into being:

Temple writes about her experiences and also includes research materials in the Appendices for parents, educators, and other professionals. Therefore, I am assuming that as much as this written work is a form of self-exploration, it is also aimed at educating people.

4. Guidance for the researcher / practitioner during the interview:
 - Attempt to be open to the participant's own unique life story and meaning-making by taking up a reflexive standpoint;
 - Encourage the participant to reflect and to tell their life story;
 - Continually re-remember how the the participant's embodied and non-embodied paradoxical, dynamic and mysterious self may be creating and influencing the interview process(es);
 - Continually re-remember how your own embodied and non-embodied paradoxical, dynamic and mysterious self may be creating and influencing the interview process(es);
 - Try and co-create language with the participant that is meaningful for them and helps you and others to understand as much as possible;
 - Near the end ask the participant if there is anything else they would change about this protocol or / and like to talk about;
 - At the end ensure to give your contact details to the participant and remind them that they can contact you at any point.

After the interview, take a break and do something else.

Later, return to the recording of the interview and type it up. Proceed to analyse as outlined in Chapter Six of this thesis. Be open to changing the protocol, interviewing and analysing styles if this is to help develop a better way of becoming sensitive to the lived experiences of the participants.

The above protocol could be used for interviewing the parents of 'autistic' people, some of whom themselves may be on the 'autism' spectrum. This could be carried out so as to learn more about them and their lived experiences with their 'autistic' family member. Some might see aspects of Temple's experience as an infant within

their own child and some may not; either way, the vignette may help to create more of an insight(s) about their daughter's or son's way(s) of experiencing the world. The questions in section 2. of the protocol, which were created during the analysis of Temple's vignette (please see Chapter Six, section 6.4.) and were / are intended for the parent(s) of the 'autistic' person, do not all have to be asked nor answered.

Just like the first version of this protocol (above), they ought to be used like guidelines in order to acknowledge the unique life story of the parent(s), their lived experiences and their family dynamics. Working together as co-researcher (i.e. the participant) and researcher could lead to both people learning more about themselves, each other and family dynamics. This might lead to the development of more self-aware thinking and behaviour(s) – both for the researcher and for the parent(s). Therefore, again, reflexivity could be created and exercised by both persons in a way that is meaningful for both. The findings could then inform the educational practices of families with infants, children, teenagers and adults who are 'autistic'; it can also help to develop methodologies and methods of research that are more sensitive and ethical in nature.

The protocols above are initial drafts and were created by working with Temple Grandin's family oriented vignette analysis and the clusters of questions that emerged from this. Hence the two sets of protocols; one for 'autistic' adults and one for family members – who were usually parents. This can be carried out with the rest of the vignette analyses of stage three of the methods process(es) so as to create interview protocols that cover a lifespan from infancy to adulthood. Such protocols could then be used – and adapted as required – to carry out future research with both 'autistic' adults and their families. Furthermore, 'autistic' academics can also be consulted and worked with so as to refine the protocols as required. Adults on the 'autism' spectrum are under-researched; only 7% of 'autism' research in the UK focuses on adults (Pellicano et al., 2014; Autistica, 2019). Therefore, these vignette style interview protocols could help with carrying out research in the community with 'autistic' adults and their families, also enabling them to reflect and exercise their voices in terms of their lived experiences and stories. In turn, this may lead to the process(es) of the research being both educational and therapeutic, e.g. narrative therapy is a way in which a person or / and a group of people can come together to explore 'self' and 'other' and to construct new ways in which to view oneself and the

'other' (Finlay, 2011; Herman, 2013). The insights learned by all concerned, including the researcher, can lead to more reflexive and sensitive approaches of self-exploration and participatory research that includes 'autistic' adults and their families as co-researchers.

The findings could be fed into approaches of research and family education programs that seek to help to create more understanding and harmony within such contexts. For example, the lifespan lens oriented protocols could benefit parents with an infant who is 'autistic' so as to try and develop a more informed and insightful understanding of 'autistic' people's ways of being and development. Therefore, leading them to be more reflexive regarding their parenting style(s) and how they may have to make changes to certain aspects of their behaviour (or / and not) as the years go by and their child gets older. While the same lifespan protocols may enable a parent with an 'autistic' adult to reflect over their parenting style(s) and re-evaluate the practices they have carried out over the years and how they may have to change – or / and not – how they have been parenting. Researchers can also learn from co-researchers, e.g. by creating research questions and protocols that reflect the interests of families with an 'autistic' member and by continuing to learn from them. Carrying out such participatory research that also involves 'autistic' academics could create insights and knowledge that help policy-makers as well, leading to the development of policies that are better suited for families with 'autistic' members. Therefore, working with lifespan vignette protocols in the future may be beneficial for all who are involved. In addition, researchers in other fields could well take up a similar task and carry out future research with those whom they consider to be the 'other'.

Stage three has helped in further exercising my phenomenological attitude and to create protocols with sensitive research questions for future research that could help 'autistic' adults, their families and other researchers etc. to also exercise a phenomenological attitude. Exercising such an attitude may help in being sensitive to the embodied and non-embodied lived experiences of 'autistic' people as well as non-'autistic' people, and may help to begin to address the 'double empathy' problem (Milton, 2012, 2014b). This could lead to more research that is meaningful for 'autistic' people and their families and therefore also more ethical in nature – examples of which have been provided above.

Hence, it would seem that the very approach of exercising a phenomenological attitude with 'autistic' persons' narratives, and encouraging all involved to try to do the same, may lead to more insight and harmony. It is known that narratives can be, and are, used for educational and therapeutic purposes by some 'autistic' people; the 'autistic' people mentioned throughout this thesis wrote their books for the purposes of self-exploration and also highlight writing such books for the purposes of educating others, e.g. Luke Jackson, Chris Mitchell, Edgar Schneider and Donna Williams.

However, exercising a phenomenological attitude or / and turning to the lived experiences of 'autistic' people via autobiographies may not be the intention for some other 'autistic' people, their families or / and nor for other researchers. This also may not be possible if an 'autistic' person does not read or write or is more of a non-verbal communicator. Although if the person communicates via signing, e.g. Makaton, then the vignette interview protocols could be translated and worked with in this way – making them accessible to such persons. Therefore, there are limits to this kind of research and I may be mistaken in making an assumption that others may want to be reflexive, or to exercise a phenomenological attitude, or that they may want to work with 'autistic' persons' autobiographies. However, if a researcher is keen on learning about the insider's perspective and wants to behave in as ethical a manner as possible, working with this kind of approach is one possible way forward.

In summary, the methods process(es) overall is a finding in itself and all three stages of the process(es) have helped with regards to exercising my phenomenological attitude right from the beginning and to continue to do so throughout this study. Thanks to carrying out the three stages I have been able to develop my insight(s) and knowledge regarding 'autistic' people as individuals and also as members of a family(ies) who grow and develop over a lifespan. The methods process(es) and stages could be criticized for being too subjective and limited in terms of (i) working with autobiographies as well as the (ii) number of autobiographies I have worked with, however, they have enabled me to learn more about 'autistic' people's inner lives and meaning-making.

This has helped in making me feel more comfortable about being uncomfortable whilst researching. In that exercising a phenomenological attitude is my way of

exercising what John Keats refers to as 'negative capability' (1817, in Hebron, 2014) – the ability to be comfortable with being uncomfortable or / and not knowing. Undergoing the three stages led to the creation of questions regarding what and who I am, and questions have also emerged regarding the nature of the 'other'. The emergence of an eighty three page long *Table of Questions, Categories and Themes* (Appendix 13) has helped in recording such questions and in writing this chapter.

It has also helped in my finding the thread for this thesis, or should I say that I am consciously recognising the thread of this thesis – i.e. my phenomenological attitude. The process has also led to the creation of draft vignette style interview protocols, which are themselves embedded in 'autistic' persons' lived experiences, as has been demonstrated in Chapter Six and this chapter. Hence, my ethical anxieties have led to the creation of a certain approach that is taking participatory research further by exercising a phenomenological attitude and by also taking into account the lived experiences of the 'other' right from the beginning stages of a study. Other researchers in the field of 'autism' studies, and those in other fields, could adapt such an approach for their own endeavour and this might benefit the persons and the families being researched in a meaningful and ethical manner. Therefore, I am developing my ability to ask new questions so as to learn something new whilst simultaneously accepting that I cannot know all and this is alright too.

Now I shall proceed to further discuss exercising my phenomenological attitude with the autobiographies of 'autistic' people and IPA.

8.3.2. My phenomenological attitude, autobiographies and IPA: the limitations of this study and future research

Working with the autobiographies of some 'autistic' people enabled me to turn to their lived experiences, meaning-making, self-knowledge and perception. Seeing as there is a dialectic connection between a study's main research question / aim(s) and the methods of investigation (van Manen, 1990), it was somewhat inevitable that the methods process(es) led to the kinds of findings that have emerged. In Chapter Six, sub-section 6.3.2. *Why I chose IPA to exercise my phenomenological attitude*

with 'autistic' persons' autobiographies, I have provided a rationale as to why I chose to work with 'autistic' persons' autobiographies and IPA. Here I shall further discuss the findings in the context of having worked with autobiographies and IPA.

Focusing with, on, in and through 'autistic' persons' autobiographies meant that I automatically honed into the topics that are their lived experiences and (I assume) were / are meaningful to them. Although, the autobiographies could well be limited and compromised in terms of being highly subjective, most of which have been created in western contexts by western 'autistic' people and having been written and edited for a public audience within a medical model context (Rose, 2005, 2008; McGeer, 2009). There are also implications in terms of the cultural psychological experiences, language and memory(ies) that one has been born into (Hacking, 2009a, 2009b) and one's embodied and non-embodied sensory abilities. Donna Williams states that she tended to use the term 'degoitz' to describe objects that had a sensory-emotional impact on her (Williams, 1998; pp.100-101):

“On the level of signing, there was an emotional experience that I called 'lemons'. In the language of interpretation this would have been something like 'sensation of acute and intense exposure anxiety resulting in an involuntary and instinctual aversion response, akin to sensations underlying so-called shyness or agoraphobia'. This experience was called lemons because that was the word used for a related sensation. If you ate lemons (which I did), the taste caused the same sort of involuntary and instinctual aversion response. And yet the sensation of lemons was defined not by the object of lemon, nor by its smell or its taste but by the physical reaction evoked by eating the thing with this name. This was also the same physical reaction evoked through being complimented or through conscious acknowledgement of having a great liking for another person and sometimes even just before one's own consciousness.” (In Appendix 4; p.368)

She then proceeds to state that 'autistic' people from different parts of the world use sensory ways of being to create sensory-based language which is / are similar. Therefore, maybe the very fact that the 'autistic' authors had to express themselves through a language and memory(ies) that is not very sensory-based, i.e. English, could well be a limitation regarding how far some of these writers could express themselves – both in their daily lives and in their writings. This affects the autobiographies I have worked with in terms of the limited manner in which

expression was possible and therefore skews the data and findings to a certain degree.

In addition, working with autobiographical data could be viewed as a disadvantage in that there are many 'autistic' people in the world who have their own unique worldviews and may not have written an autobiography – or I may not have access to these due to my being limited to the use of English and Turkish. Meaning that there is, or could well be, a vast amount of insight(s) and knowledge that is missing. However, this study is a beginning and there is still value in working with 'autistic' person's autobiographies; it has helped to begin to fill in the gap of knowledge regarding 'autistic' people's inner lives via a lifespan lens that also focuses on the family context(s), as outlined and discussed in Chapter Five, Chapter Seven and here in Chapter Eight. At least some 'autistic' people's human voices are expressed in this study to a certain degree – not with a distanced observer's language but through a dialogue(s) with the perspectives of the persons themselves in the forms of their narratives. This in itself invites the researcher / parent / professional to begin to view things from the human 'autistic' person's worldview. For example, my simply being aware that an 'autistic' person may be more prone to create and use sensory-based language has enabled me to be more conscious of such persons' ways of being as well as how this is likely to have affected the data that I have worked with, enabling me to be more aware and more realistic with regards to the insights and limitations of this study.

Working with such narratives could also enable 'autistic' people and their families to draw upon them as resources for becoming more self-aware and more knowledgeable about the environments in which they navigate. People's lived experiences and stories are powerful; they enable one to step into the shoes of the 'other', even if it is but for a brief moment (Romanyshyn, 2007; Meade, 2010; Herman, 2013; van Manen, 1990, 2014). Inevitably, one's outlook of – and on – life is affected, hopefully for the better. Furthermore, by working with such texts one can also develop one's insight into 'autistic' people's lives who may not be as verbal via spoken or / and written language. 'Autistic' people's life experiences and perspectives have played a very significant role in creating and leading the way forward for this research. Exercising a phenomenological attitude with the narratives

of 'autistic' people could enable more of such insights and knowledge to emerge, leading to more sensitive and ethical approaches of research, education and therapy.

Despite this study not being that of a traditional piece of IPA work, as is discussed in Chapter Six, taking up and adapting IPA to carry out the analyses has been very useful. It has enabled me to focus on, with, in and through 'autistic' persons' narratives and to exercise a phenomenological attitude. I was conscious of my interpreting nature and therefore I continued to exercise a reflexive standpoint throughout the analyses, which is a practice that IPA embraces and encourages via bracketing (Smith et al., 2009). Furthermore, I have been able to focus on elements of 'autistic' persons' lived experiences such as paradox, dynamics and mystery, and to acknowledge the embodied and non-embodied nature of myself as well as that of the 'other'; again, factors that IPA embraces due to the influence of phenomenology (Smith et al., 2009; Finlay, 2011). I was able to hone into the idiographic aspects of 'autistic' persons' lived experiences, e.g. through stage two of the methods process(es) whereby I carried out three individual analyses in-depth (Appendices 2 to 4), and have also been able to hone into the similarities, e.g. through the creation of the *Table of Questions, Categories and Themes* (Appendix 13).

This study can be criticized for its heavily subjective nature, on my part as a researcher as well as the data I have worked with, however, I have attempted to be as open and reflexive about this process(es) as possible, e.g. Chapter Six *The Methods Process(es) and the Phenomenological Attitude*. Interpretative Phenomenological Analysis acknowledges the double-hermeneutic factor in terms of interpretation (Smith et al., 2009), and being aware of this process(es) has enabled me to create the tables of analyses for three individuals, eight family vignettes and the *Table of Questions, Categories and Themes* (Appendix 13). Therefore, I have been as explicit as possible regarding my reflexive dialogues with 'autistic' persons' autobiographical writings. Other researchers could take up IPA in a similar way and work with it to analyse the autobiographical writings of people who may be considered as the 'other', enabling them to sensitise themselves to the ways of the 'other' and to create questions that reflect such ways of being.

8.3.3. Summary of a discussion of this study

In summary, I have been able to address my ethical anxieties by exercising my phenomenological attitude with 'autistic' persons' autobiographies and IPA. The three stages of inquiry have enabled me to achieve this in a gradual manner whereby I have felt more confident in becoming comfortable with my discomfort in approaching the unknown / mystery. The research approach herein, the data and findings are subjective, however, this approach has enabled me to establish my standpoint as a researcher in the field of 'autism' studies, i.e. that of exercising a phenomenological attitude, and to contribute to the field by creating another kind of approach of research and by bringing to light deeper insights into the inner lives of 'autistic' people.

This in turn has led to more sensitive and more ethical questions to emerge as findings in two ways. One, in terms of challenging my position of understanding and power, and two, by creating further research questions and vignette protocols from the very lived experiences and narratives of people on the 'autism' spectrum. Thereby beginning to address the call by academics (e.g. Williams, 1996; Morris, 2008; Milton, 2012; Ridout, 2017) to seek the perspectives of 'autistic' persons from the inside out and to create approaches of research that are in line with such ways of being. Thanks to this methods process(es) I have outlined and discussed the insights I have learned in Chapter Seven and have also discussed the limitations and strengths of this approach here.

Researchers in the field of 'autism' studies could learn and benefit from this chapter by seeing how future interview protocols can be created and worked with thanks to exercising a phenomenological attitude and using IPA and autobiographies. 'Autistic' people and their families might benefit from this chapter by being able to read and dialogue with the vignettes of the interview protocols and have meaningful discussions about it amongst themselves or / and with the researcher, therefore, leading to deeper insights and knowledge about each other's ways of being. Furthermore, future research could also be carried out with, for example, the vignette protocols that have been created – as outlined and discussed above, and the families may even be encouraged to write their own life stories.

8.3.4. Recommendations for future research and continuing to exercise a phenomenological attitude

I have drawn from the insights learned so far in Chapter 7, sections 7.2.2. and 7.2.3., to recommend the following guidelines for future research. This will enable myself, and other researchers who wish to take this approach up, to continue exercising a phenomenological attitude and design a participatory research study(ies) with families with 'autistic' members. One can attempt to be ethical by continuing to exercise a phenomenological attitude in 'the field' with practices that create and maintain what Yardley (2000) refers to as (i) sensitivity to context, (ii) commitment and rigour, (iii) transparency and coherence, and (iv) impact and importance. The following guidelines will help in fulfilling these principles:

- Be reflexive and question one's own embodied and non-embodied ways of being, thoughts, emotions and practices – first as a human being and then as a researcher. Make changes to one's practices at the micro-level as required. This will help to create and facilitate research designs that are more participatory and ethical.
- Be open to creating further research questions from the very lived experiences of 'autistic' people and their family members; encourage them to share their stories and express themselves in ways that they feel comfortable to do so. This should lead to research that is meaningful for the participants / co-researchers and for oneself as a researcher who is attempting to be sensitive and ethical.
- Involve 'autistic' academics in the research process(es) and seek their mentoring and advice regarding steps that one intends to take. This will help with monitoring one's insights and behaviours so as to maintain an ethical standpoint. It will also help with further developing one's insights and knowledge.
- Throughout the research process(es) continue to question one's own emotional ways of being and how societal norms affect this. Simultaneously, be open to the unique expressions of 'autistic' people and their families. This may involve utilising art for the purposes of better expression of emotions, especially styles of art that the participants / co-researchers are familiar with,

which is equally applicable to oneself as a researcher as well as with regards to the families. Putting this into practice will help to learn more about their inner emotional lives, as well as one's own inner emotional life.

- Acknowledge and re-remember that the 'other' is also a unique human being, and that they too suffer and feel pain, just like oneself. By consciously re-reminding oneself of this one can be mindful of the common humanity that one shares with one's fellow being(s). This will help in remaining motivated to behave in an ethical manner with the families and to continue exercising a reflexive intersubjective lens.
- Attempt to exercise social responsibility and accountability in the following ways:
 - Ensure that the environment in which the research is being carried out is sensory-friendly for the 'autistic' family member; include the family in this process(es) so that they too undergo the reflexivity process(es) regarding this factor.
 - Be open to using visual aids, e.g. a Tablet with visual pictures of tasks, so as to work with the 'autistic' person and their family. This should help with communicating with an 'autistic' person who finds it difficult to differentiate between background and foreground noise.
 - Attempt to include the whole family in the process(es) of being reflexive about their own practices; the draft protocol interviews above can help with this.
 - Try to communicate in a language that the 'autistic' person understands, e.g. attempt to make the implicit explicit. Remain open to sensory forms of expression and attempt to reciprocate communication via this kind of language. The family members may be aware of this and doing it already, so be open to learning from them as well.
 - Give the 'autistic' person time to process information and to respond. Whilst doing this try and be open to forms of communication that one may not be used to.
 - Acknowledge that the social context(s) affects the kinds of interactions one encounters. For example, each family is unique and each has their own values and family dynamics; one ought to seek to be aware of this

and how this is likely to affect the family's interactions and one's own interactions with the family.

- Seek to be consciously aware of family trauma, both for the 'autistic' person and their family members, and attempt to fathom how the 'shadow self' within the family constellation can be acknowledged and worked with. Be mindful that this will also involve 'shadow work' with oneself as a human being and as a researcher (Jung, 1961 / 1995; Hellinger and ten Hovel, 1999).

The above insights ought to be kept in mind whilst carrying out, for example, research with the vignette interview protocols above.

8.4. CONCLUSION

The insights and knowledge within this chapter make an original contribution to the field of 'autism' studies and is a beginning in attempting to fill the gap in knowledge regarding 'autistic' persons' inner lives, the family context(s) and their lifespan development(s). Due to my ethical anxieties my aim was to create a standpoint and an approach that is sensitive to the lived experiences of 'autistic' persons' right from the outset of questioning my assumptions and in creating sensitive research questions, which led to my exercising a phenomenological attitude. What has emerged due to exercising a phenomenological attitude is a certain way of focusing with, in and through the embodied and non-embodied experiences of the 'other' so as to develop insights into their meaning-making, self-knowledge and perceptual ways of being. This in turn also led to my questioning my embodied and non-embodied ways of being. Therefore, attempting to exercise a phenomenological attitude has enabled me to begin to address what other researchers in the past have not, i.e. that which is projected on to the 'autistic' person(s) by the researcher and not seeking to understand their meaning-making (please refer to Chapter Five for a discussion of this). Hence, I have been continually to-ing and fro-ing between the worldview of the 'other' in myself and my understanding of 'I'. It would seem that exercising a phenomenological attitude is one way in which a researcher can achieve a deeper level of sensitivity to the ways

of the 'other(s)' as well as oneself, and the findings here are not the be-all or the end of it all.

Putting into practice Yardley's (2000) four principles, as highlighted above (also see Chapter 6, section 6.3.), in turn creates and influences the validity of a study, the reliability of the findings and what may or may not be generalizable. In order to exercise the principles that Yardley (2000) recommends I have attempted to be as reflexive as possible throughout this research in order to develop my sensitivity to the context. I have rigorously dialogued with the narratives of 'autistic' people to question my assumptions and to create sensitive questions; I have presented at conferences and symposiums in a transparent and coherent manner, including those organised and attended by 'autistic' academics; I have dialogued with colleagues and friends on the 'autism' spectrum and parents and family members to rigorously reflect with, in and throughout the stages of this study and have attempted to fathom the importance and impact of this kind of study. I have also dialogued with my supervisors, colleagues who are not 'autistic' and my family and friends all throughout this research. This thesis and the approach of research herein demonstrates my having exercised the four principles, therefore, rendering this study valid, reliable and generalizable in its own right.

Regarding future research and the dissemination of these findings, the approach of this study could be utilised with 'autistic' adults and their families to carry out research that is hopefully more meaningful, therapeutic and educational, e.g. via the use of the vignette interview protocols. It could also be an approach that other researchers take up and adapt for their own endeavour when researching whom they consider to be the 'other'. Therefore, continuing to exercise a phenomenological attitude can be a way forward in carrying out future research.

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APPENDICES

APPENDIX 1

Stage 1: The Summary of A Painful Gift: The Journey of a Soul with Autism by Christopher Goodchild (2009)

I chose this autobiography because:

1. It moved me when I read it.
2. Goodchild explicitly uses the story of HH. Jesus Christ as a lens and framework to make sense of his own experiences whereby he attains better self-realization and self-acceptance, illustrating the development of his perception(s) and meaning-making process(es).
3. It captures the paradox(es) and the mystery(ies) of being human as well as being 'autistic', which are certain aspects of the dynamic Self. Furthermore, many of his descriptions are phenomenological in nature, in that some of the everyday things many people take for granted are experienced more intensely by him.
4. Inner&intersubjectivity are explicitly illustrated.
5. Emotional connectedness&non-connectedness in terms of learning and self-realization are explicitly illustrated.
6. He reflects on family life and family dynamics.
7. The embodied&non-embodied Self are also explicitly prevalent throughout.

This is not necessarily a criteria, however, I would also like to note that he uses poetic language and quotes poetry throughout the chapters in order to express himself.

The book is about Christopher's journey and how he comes to learn that he is 'autistic'. He uses the story of the final days of HH. Jesus Christ as a theme, consisting of the following chapters and structure:

Introduction

1. Condemned
2. Taking up the Cross
3. Falling Down
4. Mother
5. Being Helped

6. Tenderness
 7. Falling Again
 8. Women
 9. The Third Fall
 10. Being Stripped
 11. Crucifixion
 12. Death
 13. Lamentation
 14. Laid to Rest
 15. Resurrection
- Conclusion

He begins with outlining how he felt a need to be one with all things and to connect with them and yet simultaneously it was /& is these very things that also make him suffer, e.g. "It seemed mysterious to me then that the very things that brought me such joy would also bring me such pain. The sun and wind would bring blisters to my face, the may blossom would make my nose run and my eyes swell, and the kaleidoscope of colours would dazzle my eyes. It seemed I ached for what I could not bear." (p.15).

In the first chapter, *Condemned*, he describes how he was adopted at the age of six weeks and was brought up in North London in a middle-class family with a working-class background. He had /& has a sister who was also adopted. In this chapter he outlines how his sensory abilities and interactions with his family led to him feeling "distressed and anxious" (p.22). He therefore preferred to isolate himself in his room as this was his haven. He was condemned.

In the second chapter, *Taking Up the Cross*, he describes memories of school and family life whereby he found school "totally overwhelming" (p.27) and his home life was the same. "Social situations filled me with such intense anxiety, that I was totally unable to engage with an authentic sense of self, or participate most of the time without rigid control over my anxieties and behaviour." (p.28). He then proceeds to state how his mother saw him as being "mad, odd and disrespectful" (p.29) and how he had to conform to their expectations of the norm in order to "avoid being humiliated" (p.29). He reflects on such experiences and as a final statement in this chapter states that "I must have been so hard for my parents, for my actions seemed to imply I did not want to be with them. The truth was, I just did not know how to be with them." (p.32). He has illustrated how his family and the social context(s) were interacting with him and his bodily sensory make-up in such a way that he felt lost and mental health difficulties were beginning to develop. He had taken up the weight of the cross.

In the third chapter, *Falling Down*, he describes how mental health difficulties set in and he began to formulate scriptural behaviours and characters so as to utilize these/them in social contexts - he was becoming an actor. His sensory abilities enabled him to perceive and experience the world with and at a heightened level. Therefore, things that gave him pain were not just to do with him but also to do with simply witnessing others' behaviour. For example, he describes how his mother was brushing their pet dog and the dog was whimpering as she did so, and despite being mute "deep inside me I cried" (p.36). He formed a close relationship with the family dogs and felt that he could be his self with them. Simultaneously, he did not see a point in making friendships and therefore preferred to play alone. The more he conformed the more he fell apart within.

In *Mother* he describes how he wanted to be saved because people were taking advantage of him and/or bullying him. A profound example of this is when a psychiatric consultant sexually abused him over 2 years during the therapy sessions and he felt too frightened to say anything because he was afraid the doctor would label him as being mad and send him back in to the mental health hospital where they would make him take drugs like they did before. I was in tears as I read this chapter; who is really 'mad'? Foucault comes to mind, and as he implies in *Madness and Civilization (1964)*, it is the mad who label others as being mad. I realize that I too am committing the same mistake here – by viewing the consultant as being mad. Although, are we all not mad in some way or another? Goodchild proceeds to write in a forgiving tone, showing an understanding for why the doctor had done what he did, and feeling anger at the lack of understanding from his family for not standing by him. Therefore he is seeking Jesus and Mother Mary in particular to save him.

In *Being Helped* he describes how he met an Egyptian lady called Naomi and with whom he lived with for 3 years. The relationship exacerbated the difficulties he had and he suffered from "ongoing bouts of depression and nervous exhaustion" (p.54). This all led to him seeking a psychotherapist, and he found an elderly lady who was working as a Jungian therapist. She helped him, and then he worked with two more therapists who worked with those having gone through childhood trauma. In the meanwhile he also found his natural father, leading to further insights regarding himself; illustrating the mirror effect and the dynamic inner&intersubjective aspects of Self. He proceeded to meet siblings and also his natural mother. Meeting other family members, i.e. increasing one's community, enabled him to understand himself better and also reflects the inner&intersubjective dynamics taking place in his life, in turn developing his perception(s) of Self and meaning-making. Yes, he was being helped, and simultaneously, and I think more importantly, he was helping himself; he was putting in the effort, asking questions and seeking answers.

In *Tenderness* he explains how he became more understanding of himself, learned to forgive himself and others better and also took up the Alexander technique; "at the core of its teaching was a way of breaking free of our habitual reaction to stimuli, and learning a new approach to life by applying the Alexander technique principles of constructive conscious control." (p.62). Here the paradox(es) of the embodied&non-embodied Self are brought to light along with the mystery(ies) that brings up a yearning in him to be:

"Alexander work was invaluable in helping me restore my body and posture from the ravages of a life-time of stress. It transformed my skeleton from one which collapsed and bowed under the weight of enormous muscular tension, to one which my spine and posture were more naturally aligned. However, at the same time as the Alexander technique was helping me to release into life, I

was also unconsciously using the Alexander principles to conceal at great depth my expressions of anxiety concerning sensory and social difficulties. So although the work clearly gave me enormous benefits, I was also able to find even more ways of acting 'normal' or unaffected. Another persona.

O how I longed to be more at home in my bones and my being in the presence of another." (p.63)

The above also illustrates the want and need to be witnessed by another as one is. The nature of the kind of deep connection that one yearns for is implicit in the last statement, highlighting the inner&intersubjective yearning(s) and the people, and/or beings, we seek in our lives so as to mirror such yearning and fulfill it. Maybe the feeling and knowing of such interdependence with others also leads to our developing our humility and tenderness?

In *Falling Again* he states that "the world I had created and adapted for myself was one that had clearly passed its 'sell-by' date for me. My adapted self, although protecting me, was at the same time preventing me from moving on." (p. 67). The dilemma of wanting to be oneself, to realize oneself, and what others can and do expect of oneself is experienced by many people. Yet for 'autistic' persons it can be that much more exacerbated and intense? Therefore, paradoxically, enabling a greater potential to arise for self-development? As the author states, "A Painful Gift"..? Christopher continues with the Alexander technique sessions and also joins other self-help support groups.

In *Women* he outlines that home life and many social situations were like war zones for him. This is a man seeking peace. He then proceeds to state that "I learned empathy from being able to move beyond the intellectualisation of my feelings, and into learning to feel the feelings through the shattering and yet transformative process of grieving." (p.73). He was asking questions about God and how he could integrate his political stance with his interest in such a being, especially after "exploring Eastern paths and disciplines, which were so compatible with the principles underpinning the Alexander technique, I felt a 'great hunger'. I saw this 'great hunger' as a desire for God." (p.74). Don't many of us desire this? Whether we consciously &/ sub-consciously and or unconsciously are aware of it, is this not why we wake up every morning and live and experience? He then states that after having read Tolstoy's *Government is Violence* his heart was set on fire, for "when I contemplated the story of Christ taking on the Empire, simply dressed and riding on a donkey, armed with nothing but tenderness and love, I fell in love with Jesus." (p.75). He gains meaning from identifying with a man who was vulnerable and tender and yet whose message of love has survived throughout the centuries. Simultaneously, the heart being on fire means that energy has been set off, therefore turning points during self-realization can be spontaneous at times? Does this all in itself illustrate that (i) he is not alone with his suffering? (ii) as much as his story is unique simultaneously it is not because HH. Jesus also lived through the same kinds of experiences? (iii) Jesus and his story give Goodchild hope? Therefore, Goodchild joined the Catholic Worker movement who worked with the poor and the marginalised. This brings to mind a saying I came across, "When you are going through tough times help others". Assisting and helping others enables us to learn more about ourselves as we learn better from the ones we are assisting, therefore, they have actually helped us as well. Hence, a teacher is a pupil and a pupil is a teacher. It is an ongoing circle(s) of inner&intersubjectivity, just as HH. Christ was surrounded by those, i.e. the women, who reflected his inner grief I guess.

The *Third Fall* describes how Christopher went on to learn and teach the Alexander Technique. He therefore started to use his learning about himself to assist others, which in turn added to the meaning in his life: "It was a real gift to be able to work at long last, and to know I had a skill I was good at. The wonderful thing was that I realised I could truly shine and be totally present in myself with another person within the highly structured and time-disciplined environment that a one-to-one teaching session offered, in complete contrast to the difficulties I always experienced whenever I was in a group situation, when my calm and contemplative exterior concealed an inner turmoil. At last my quality of presence was the same on the inside as it appeared on the surface." (p.80). Goodchild enters a relationship again and moves out of London to be with a lady and her two children. However, "Within a couple of weeks I was having panic attacks and felt emotionally and physically exhausted... The enormity of change was all too much for me to bear... I felt deeply ashamed of my inability to manage myself well regarding the anxiety associated with her children, and felt very alone." (p.84). A professional role requires some level of distance with the person(s) one is working with, yet an intimate relationship is not as such. So it seems that as much as Christopher was able to be himself in a professional role he was still finding it difficult to be himself in an intimate relationship.

In *Being Stripped* he outlines the birth of his son with Sarah, despite difficulties with their relationship, and states that this was the best moment of his life. Yet he found it very difficult to cope with the demands of having a baby. His routine was in chaos, he felt inadequate when others held his son, Daniel, because they looked so natural doing so, and he was paranoid that someone may steal him. Therefore, he decided to move out and continued to work, especially becoming interested in meditation.

In *Crucifixion* the love for his son conquers his Self. Christopher states:

"My usual way of coping, whenever situations became too difficult for me, was to walk away quietly, but for the first time in my life I found myself in a painful situation I couldn't walk away from. Because I felt such great love for Daniel, this time I couldn't pull back and turn away - I was 'nailed' and I couldn't break away. What was worse, although I loved him more than anything else in the world, the deep feeling of at-oneness whilst being in his company caused such awful intrusive thoughts and awkwardness, it felt like some strange kind of 'empathic backlash' and as such, it felt as if nails were being driven in to my very being. It would be understandable to see such difficulties purely in the context of Daniel's innocence and tenderness unlocking my vulnerability, my resistance to this experience of intimacy coming in the form of these awful thoughts when I was spending time with him and when we were playing together. However, after all my years of psychotherapy, something still seemed terribly amiss which I couldn't account for. This mystery was killing me. I felt as if I was being crucified." (p.93).

What the above illustrates is an extension of the Self, both in terms of physically having a son and in terms of the psychological implications it has for oneself, for his son is holding up a very intimate mirror for him merely by existing - an embodied&non-embodied Self. Such a mirror was also pointing towards a mystery, something which Christopher is yet to understand.

In *Death* he recounts experiences with his son whereby he feels "that my best times were my worst times? Not knowing why this was, made life unbearable and unendurable." (p.101- 102). He begins to consider suicide again.

Lamentation describes how he started to isolate himself from family and friends, re-live negative thoughts in his mind, and would also cut himself. He states "That I might really be mad was the thing that terrified me more than anything else." (p.109). As much as it can, and does, cause us pain and much grief, the thing we fear is usually the thing we need to work with and attend to.

Laid to Rest explains how he planned his suicide and wrote a letter for his son. He then prayed to St. Theresa and the next day went to visit his son for what he thought was the last time. When returning from seeing Daniel:

"Whilst on the train home I found myself engaging in an exercise I learned on my spiritual direction course, which involved the process of spontaneous drawing and discernment. I felt such deep relief to be away from the intensity of despair. I wrote on a big piece of paper, 'Where is God when I am with Daniel?' I sat in silence for a minute or two and what had somehow evaded me all my life was dramatically revealed to me in that moment.

What I drew revealed to me that I had autism. The picture of me with Daniel. I drew a stick man, representing myself, encircled by several lines which were symbolic of walls. My head was surrounded by circles too, next to which I wrote, 'Not a halo, but a loop for hell. [...] However, what was deeply revealing for me were the sharp lines that I drew radiating out from Daniel towards my heart. These lines I interpreted at first as sparks, and then it hit me that in fact they represented a force, and that this force radiating from Daniel was his beams of love for me. The flood of feeling from Daniel was like an assault which produces a profound emotional reaction in me, the intensity of which I am unable to express. So the 'loop of hell' was a neurological reaction to an empathic flow of energy." (p.117).

WOWWWWWWWWWWWWWWWWWWWWWWWWW!!! And no, he does not commit suicide.

It is known that some 'autistic' people can, and do, experience others' emotions at a heightened level. This emotional connectedness between Christopher and his son was also the reason as to why he sought to disconnect. A reflection of the dynamics between beings and Love/God? Whereby we accept and not accept a Love/God? The paradoxical relationship between belief and doubt in motion? Which in turn is constantly creating mystery as well as becoming enveloped in, with and through it? Furthermore, inner&intersubjectivity, as well as the embodied&non-embodied Self, are also brought into light here.

Resurrection outlines how Goodchild sought a diagnosis, or shall I say a route of recognition, regarding being 'autistic'. Stating that "it is my son who has taken me out of the comfort zone and into the world." (p.124).

In the *Conclusion* a beautiful quote from William Blake is used and this is how I would like to end this summary (p.129):

"... We are put on earth a little space

That we may learn to bear the beams of love."

APPENDIX 2

Data and Analyses: Chris Mitchell, 2009. Asperger's Syndrome and Mindfulness, Taking Refuge in the Buddha

Contextual information regarding this book:

(i) Who wrote the autobiography(ies) /& reflective writing: Chris Mitchell is a man who was recognized as being 'autistic' (Asperger Syndrome) at the age of 20 in 1998 and is from England, U.K. He studied an MA in Information and Library Management.

(ii) Where the autobiography/& reflective text was written: The book was published in England, though from Chris's story one learns that he was working on it on and off for some time between his travels.

(iii) When the autobiography/& reflective text was written: 2009.

(iv) Why and how the text came in to being: Chris was encouraged to write this book by Genevieve Edmonds, a consultant and writer in the field of autism who was educated to a postgraduate level, and was an adult recognized as being 'autistic' (Asperger Syndrome); she passed away in 2008.

(v) A summary of what the story is about: Chris has written about Buddhism and how mindfulness has, and is, enabling him to learn more about himself and the beings around him, especially people. He felt at a loss for many years and when he was recognized as being 'autistic' at the age of 20 whilst at university, and was going through depression, he began delving more so in to understanding himself.

He has broken down the book in to 14 chapters and has used the concepts of The Four Noble Truths from Buddhism, along with the concept(s) of the Eightfold Path/The Middle Way which incorporates the Four Noble Truths, to illustrate this. He provides examples from his own lived experiences and how certain practices enable him to cope and learn in various contexts; he also provides relevant guidelines at the end of each chapter. The chapters and summaries are as follows.

Chapter 1, Introduction: The path of Asperger's Syndrome

In this chapter Chris outlines that "Asperger's Syndrome is a lifelong journey, following a path the path of Asperger's Syndrome can also be a fulfilling one to follow through life, if one is able to 'awaken' to it through development of awareness" (p.13). He then proceeds to outline

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how mindfulness, the practice of observing one's thoughts, where they are emerging from and how, has and is enabling him to "effectively assess oneself in relation to surroundings, and is just as helpful for a person not on the autistic spectrum, in terms of understanding Asperger's Syndrome in a judgment-free way" (p.13). He then proceeds to give examples of how the Noble Truths have been/are prevalent in his life and in the life of other 'autistic' people. An example of this is: "The First Noble Truth, that of suffering, helps me to understand that living is suffering, not just for myself, but for others too, both those diagnosed with Asperger's Syndrome and those not on the autistic spectrum. How one perceives and experiences suffering varies dramatically. As a person with Asperger's Syndrome, much personal unhappiness I have experienced relates to general non-satisfaction with life in terms of disappointments I have experienced or what I feel that I have missed out on in life. Many adults with Asperger's Syndrome I have met appear to share the view that there are things missing from their life, often related to social isolation" (p.13). This format is maintained by Chris, continuing to make meaning in this way with regards to the Second Noble Truth (the origin of suffering), the Third Noble Truth (the cessation of suffering), and the Fourth Noble Truth (the Eightfold Path or the Middle Way).

Chapter 2, Asperger's Syndrome and the Five Hindrances

Here, Chris describes the Buddha's teachings regarding the Five Hindrances that refer to a "negative state of mind or an unmindful state" (p.21). These are: "1. sense desire, 2. ill will, 3. sloth and torpor, 4. restlessness and remorse, 5. doubt" (p.21). He states that "Many people with Asperger's Syndrome, including myself, often experience 'mental block-ages' in relation to frustration and anxiety, which often make such issues difficult to cope with, thus 'hindering' one's ability to cope effectively" (p.21) and proceeds to give examples with regards to each hindrance. For example, in the 'Sense desire' sub-section, he states that "For me, this hindrance often arises out of personal frustration through things being the way they are, in terms of thinking that 'as a person with Asperger's Syndrome, for what I have experienced in my life, I deserve to have it better'. In thinking along the lines of 'having it better', one may find oneself giving unwise attention to beautiful, often material, images and items, building up an image of 'how I should have it'" (p.22). He then describes how this sense also prevails in social contexts whereby he feels that people around him have moved on professionally and in their personal lives yet he cannot relate to this, therefore leaving him feeling as though he is "like a seed frozen in time" (p.22), socially isolated and feeling low in self-esteem.

Chapter 3, Starting with Who You Are: How the easiest person to like can be you

In this chapter Chris states that one can end up hating oneself and therefore focuses on building up one's self-esteem, i.e. believing more in

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oneself and doubting less, and provides advice to non-'autistic' persons in working with 'autistic' persons with regards to building up self-esteem. He explains that in "Theravāda Buddhism though, the focus of who is the easiest person to like is oneself. Initially this may sound self-important or even egoistic, but the focus on liking oneself within the Theravāda tradition is more about finding the positive aspects and personal qualities one may have, that in some cases perhaps one wasn't previously aware of, before applying these qualities to how they relate to others. This includes being able to take one's frustrating experiences and curtail them in such a way that one can even see positive actions from where frustrations originate" (p.30). He then includes information about some of the frustrations that 'autistic' people can and do experience, e.g. struggling to achieve high grades in school, not being employed, and finding it difficult to make friends and form intimate relationships. He later states that meditation has enabled him to learn to like himself and "can be a route to self-confidence and, ultimately, personal happiness" (p.33). He also states that it has "enabled me to feel that who I am means much to those close to me, including my family, friends and people who feel my help has made a positive difference to their lives" (p.33).

Chapter 4, Seeing the Truth: How to control mind proliferation and see others as they really are

Chris outlines that in Buddhism mind proliferation is referred to as "Papañca" (p.37), whereby the mind 'proliferates' thoughts, just like the ears hear or eyes see without effort, which in turn can lead to "various concepts that one may take delight in and cling onto thus taking them to be true" (p.37). He describes how whilst at university he became fixated with Marxism and how that had led to him developing a rigid line of thinking; "What I didn't realise though was that developing an identity for yourself, especially if politically or religiously motivated in a fundamental way, can be isolating" (p.38). He provides further examples of what he refers to as "fixations" (p.38) and, according to the situation, promotes a flexible line of thinking. He states, "The increased self-awareness that I have developed from mind cultivation through meditation and experience of different cultures has helped me understand that all individuals have their own views and opinions, with it being more apparent in some than others" (p.39). Hence, he has also developed further insight in to how individuals can experience mind proliferation and how this can, and does, affect behaviour. This in turn has enabled him to develop a deeper a sense of self; "One doesn't see who he or she really is when accepting others' opinions of who they are" (p.40), "One has to be careful using labels to set them apart from one another, as this can again result in divisions, which inevitably lead to conflict" (p.41) and "Through mind proliferation, we don't often see ourselves as we really are, and don't often see others as they really are" (p.42). Therefore, he promotes having both 'autistic' and non-'autistic' friends so as to develop one's identities and so as not to experience the hindrance of ill-will.

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Chapter 5, Gaining Insight from Those Around Me: How insight can strengthen one's awareness

In this chapter Chris outlines how being recognized as having Asperger's Syndrome and reviewing his life so that he could write his life story (*Glass Half Empty, Half-Full*, 2005) has enabled him to develop a deeper insight in to the ways that he was treated in his younger years by family, peers and teachers. He states that what he felt needed to be understood is the "confusion that can result from growing up with undiagnosed Asperger's Syndrome. People around a person with undiagnosed Asperger's Syndrome, including members of their family, can experience frustration when they try so many different ideas to help the person develop social and independent skills with the best of intentions but have negative results" (p.46). He then advocates recognition of 'autistic' traits at a young age and relevant educational arrangements. He states that forgiveness can be difficult, however, he is finding that a way to achieve this is to look at people in the context of the present rather than the past, which he feels that in turn enables people from his past to see him as he is now. For example, "One of my former teachers, after reading my auto-biography, said that he often got very angry and frustrated with himself for not being able to get through to me. After finding that he felt this way about me as his pupil, I realised that other teachers I had, as well as college/university lecturers and student colleagues, may well have experienced similar frustrations and confusions about me" (p.47). He then outlines how being recognized as being 'autistic' at university enabled his peers to get in touch with him and say how they felt guilty about some of the ways they had treated him; "In this way, a person who doesn't have Asperger's Syndrome can find out something about him- or herself through the way they relate to a person with Asperger's Syndrome, in terms of how they treat different people as individuals" (p.47). Chris also outlines how the competitive nature of educational life and workplaces sadly lead to bullying and belittling, and that how his values are not based on such success and status as he finds it too "stressful to manage in terms of anxiety, which is why I am generally happy just being content with a stable life" (p.49). Insight oriented meditation techniques are also useful "to think more flexibly in the sense of being able to collect my thoughts when responding to others as well as being able to recognise the second hindrance of ill-will and how to under-mine it more effectively" (p.49).

Chapter 6, Worrying in an Anxiety-driven World: How to curb tendency to worry through curtailing stress and anxiety

Chris highlights that anxiety is present in all our lives and then explains how anxiety affects him and takes over his mind; "I can hear playbacks in my mind, almost like having a tape recorder inside my head. For me this is often difficult to curtail. In this case, the fourth hindrance of restlessness and worry represents the interference that leads to such difficulties" (p.53). He has experienced much anxiety "relating to educational and social issues" (p.53); that despite his age he was not mentally ready for the school environment, and that the constant testing

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of children in schools creates competitive and negative atmospheres whereby "one can feel very vulnerable, especially a person with Asperger's Syndrome" (p.54). Such environments can, and do foster, bullying, emotional issues and depression amongst young persons, and these aspects also prevail in adult life due to the competitive nature of work environments. Having short-term contracts to work by created a lot of anxiety for Chris, whereby he experienced "mental overload" (p.55). He became very cynical; "This was where my inability to recognise the fourth hindrance of restlessness and worry verged into the second hindrance of ill-will towards myself and others" (p.55). He finds that "Samatha meditation" (p.57) has enabled him to "retain a calm state of mind" (p.57) and that "I find that generally stepping back from it all through meditation or undertaking a physical activity (e.g. walking) or even doing a routine job (e.g. washing the dishes, vacuuming) helps to put such feelings aside so that I can handle them appropriately when I need to" (p.57).

Chapter 7, Curtailing Feelings of Anger and Frustration: How to control and respond to anger effectively

This chapter focuses on how anxieties lead to frustration and anger. Chris states that job interviews and comments that people sometimes make can make him very angry, which can lead to the second hindrance of ill-will towards oneself as well as others. Chris later provides an example of how being rejected from jobs, especially ones that he may really want, "can be soul-destroying" (p.63); "I have found that the more frustrated and angrier that it has made me, the more it has detached my mind from my body, in that the mind loses much bodily control, including control of the nervous system, leading to tension and shaking. When my mind is elsewhere, I can lose both awareness and control over the body in the sense that I find myself thinking about something different to what I am supposed to be doing, such as putting in the wrong ingredients when cooking" (p.63). He then states that anger can lead to shutting oneself off from other people and that one can become very selective with one's thoughts so as to make oneself feel as though one is completely in the right. The circular inner&intersubjective element of such feelings and their effects are outlined by Chris as follows, "Looking back, it was like me wielding a sword with a blade on each end in terms of the anger I was experiencing. The blade on the end nearest to those I was angry with was distancing them from me, whilst the blade facing me was emotionally hurting me further" (p.65). He then outlines that a useful strategy to utilize is to vent such anger behind closed doors and that expressing anger in a constructive way is useful, suggesting that one ought to also take up responsibility for the situation and avoid entirely blaming the other person – as recommended by a Buddhist monk in Northumberland. Chris then provides further advice, e.g. doing something that is not related to what made one angry and then "reviewing the circumstances concerned with a clearer mind" (p.68).

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Chapter 8, Discipline and Routine: How to maintain discipline within routine, including managing changes

Chris outlines that he struggled with the lack of structure at university, especially in his final year and the 6 months for which he was a research assistant, and he developed unhealthy habits such as not eating proper meals and snacking on crisps and biscuits; "My mind had become so full of anxiety to the extent that I often didn't realise I was hungry and lost a lot of weight as a result" (p.70). He then proceeds to describe how the very routine of setting aside time every day for meditation in itself provides structure; "The practice itself I feel has given me the discipline to maintain a routine in which I am comfortable, which reduces my anxiety levels. [...] Such input can then be transferred to other situations where right effort and concentration is needed, from very simple tasks such as copy-typing a letter to completing a long-term project" (p.71). Chris then points to the 5 precepts from Buddhism with regards to self-conduct, e.g. "1. abstaining from injury to living beings" (p.71) and "2. abstaining from taking what is not given" (p.71), as guidelines that he uses and adapts according to his daily living pattern and environments. He proceeds to include information about managing his finances in a disciplined manner and asserts that self-discipline "can be a useful tool in terms of controlling such cravings [regarding excess alcohol and drug use]" (p.73) and includes information about how spending some time in a Buddhist monastery in Northumberland enabled him to "realise the value of being open to different food than I may otherwise choose, helping me to become used to a varied and disciplined diet" (p.74). Chris then describes how meditation has helped him physically in remaining still and calm when required (p.75), and that recognizing the "impermanence in our lives" (p.76) and preparing for change(s) whenever possible has also helped him to cope with anxieties regarding change, e.g. "Where possible, try to adapt a routine you feel most comfortable in to different environments, especially if you are changing jobs" (p.77).

Chapter 9, Developing Tolerance: How to develop acceptance of and openness towards others without resorting to naivety

Chris states that "holding on to a view or opinion can be the root of conflict" (p.79) and can lead to divisions amongst people. He outlines that "One of the uplifting joys I have experienced meeting many other individuals diagnosed with Asperger's Syndrome is finding that all people on the autistic spectrum are different. Though in some cases we share some similarities, no two of us are the same" (p.79). He proceeds to state that some 'autistic' people want a cure for 'autism', yet he himself would not, despite this he feels that if there ever was a cure he would rather that such persons have access to it – illustrating his openness to others' desires (p.80). Chris highlights a Buddhist monk's teachings in relation to us all being "a product of our 'cultural conditioning', in terms of different values we are brought up with. To go beyond it can take a determined effort, but through development of effective tolerance, one can become 'awakened' rather than 'conditioned'" (p.81). He then outlines how 'autistic' people can be less likely to be conditioned due to such cultural values being invisible and unwritten,

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therefore being missed by 'autistic' people – hence an advantage of being 'autistic'. Simultaneously, he describes how this can also be a disadvantage, in that when an 'autistic' person is not aware of such unseen cultural values they may, and do, become confused as to why people behave the way they do. Chris later outlines how meeting different people who have also been discriminated against can lead to seeing them as they are rather than from a conditioned perspective (p.84), that exposing oneself to different cultures (p.84) and practicing loving-kindness (Mettā) meditation (p.85) also helps in developing understanding.

Chapter 10, Measuring Success and Goal-setting: How to measure success realistically and achieve without distancing ourselves from truth

Chris states that cultural conditioning can also affect one's view of what success is and that "One of the most important things I feel I have learned since my diagnosis is not to live up to anybody's expectations but my own, and to ensure avoidance of extreme disappointment where possible, by keeping my hopes and expectations realistic" (p.89). Buddhism focuses on happiness and material wealth comes and goes, especially in light of death, whereby "material possessions are no longer of use to us" (p.90). Going through suffering can mean that one feels that one deserves "a better future than others because of what one has previously suffered" (p.91). He feels that it is this line of thinking that led him to distance himself from reality (p.91) and create false unrealistic hopes (p.92), which in turn can lead to ill-will and envy. He brings to the fore Buddha's teachings regarding the "five component parts, or 'Khandas', of sensory perception that contribute to such irrational distractions" (p.92), e.g. "1. rūpa – physical phenomena", "2. vedanā – feelings of pleasure, pain or indifference" and "3. saññā – concepts, labels and allusions", and states that "Through recognising the Khandas, I have found that the more one wants things to be the way they want them to be, the more this can expose one to dukkhā [suffering]" (p.93). Chris then describes his attitude of trying to measure his personal happiness in the long run rather than in short-term material gains, seeing the positive aspects in all his actions as well as in mistakes, and setting realistic goals so as to avoid the hindrance of sloth and torpor (p.94 – p.95).

Chapter 11, Facing and Coping with Suffering; How to manage feelings of suffering (dukkhā) through reflection

Suffering arises in not being able to accept things as they are, "often because we want things to be a particular way" (p.101). Chris details how being aware of being 'autistic' has helped him to adapt to different environments and that writing his autobiography (Mitchell 2005) "was almost like an extended Vipassanā practice in the sense that writing it involved gathering and reviewing some of the most difficult periods in my life" (p.103). He goes on to highlight that by balancing the difficult times with the happy times enabled him to accept that "suffering is

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impermanent, and that to some extent it helps to remember how one may have learned through such experiences, without becoming attached to them to the extent that one finds themselves living with the effects of such times rather than letting them go through moving on. This can also help one relate to others who experience similar difficulties, as well as one's own development of effective coping strategies" (p.103). Therefore, acknowledging the roots of suffering can enable one to learn and develop. Using the Vipassanā practice, Chris has come to realize that the social isolation and asking oneself " 'why me and not anybody else' " (p.104) led to much suffering, yet he now recognizes that there were other people going through the same thing, and he got involved in an e-mailing group list called "Autuniv-1" and met others in the same situation. Therefore, he states, "My own ways of dealing with suffering, I feel, have had effects on others in terms of finding meaning in suffering" (p.105). He then highlights that dukkhā (suffering) has enabled him to find out the truth about himself, e.g. being 'autistic', and that it has also brought the Asperger community together; "The ability of dukkhā to bring together the Asperger community to provide one another with insight, I feel, can, despite what those who have experienced it have been through, be the meaning of suffering for many people with Asperger's Syndrome" (p.106). He also states that dukkhā can also bring together people who are not 'autistic' (p.108). According to Chris, "Vipassanā practice has enabled me to both welcome dukkhā and find meaning in it, and, perhaps most importantly, to recognise it" (p.108); hence, self-reflection has enabled him to develop his perception and understanding of himself and the beings around him.

Chapter 12, Finding Balance in Mindfulness and Concentration: How to take responsibility of one's own world and recognise the worlds others live within

In this chapter Chris outlines how "Many textbooks and guidance literature, when describing the conditions of autism and Asperger's Syndrome, often describe people on the autism spectrum as 'living in their own world'. Though this is largely true, the teachings within Buddhism suggest that *all* individuals live in their own world, a creation of the mind, largely perceiving their surroundings through the perspective of the self" (p.113). Therefore, Chris is amalgamating a concept with regards to himself as an 'autistic' person with a concept from Buddhism that is that much more encompassing and inclusive with regards to *all* humans. He then continues to promote going beyond one's comfort zone(s) (p.114) and that there are many strengths to being 'autistic', e.g. remarkable art work, deep concentration etc. (p.115). He also states that "Concentration is also a necessary tool for meditation, particularly for noticing and adjusting to different stages during meditation practice, while memory is a necessary tool for chanting in terms of being able to retain different chants recited during practice" (p.115). Though he also states that it is these kinds of strengths that can also "cut one diagnosed with the condition off from their surroundings" (p.115). Hence, Chris is suggesting that 'autistic' persons have a meditative style(s) of being? He further outlines how meditation

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has enabled him to “develop more mind flexibility” (p.116) and that as much as routines are useful it also helps to do things differently so as to remain mindful of the moment itself (p.117) and avoid the hindrance of sloth and torpor; he has been applying these principles in his own life, e.g. taking a different route when driving to work (p.118).

Chapter 13, Overcoming the Hindrances: How a person with Asperger's Syndrome can overcome difficulties associated with the Five Hindrances through recognition of the Five Spiritual Faculties

Chris outlines how The Five Spiritual practices as described by the Buddha, 1. trustful confidence and faith, 2. mental strength, vigour and energy, 3. mindfulness, 4. concentration and mental unification, and 5. wisdom (on page 123), are useful in coping with various pleasant and unpleasant experiences. He provides examples of each, e.g. for trustful confidence and faith he states that “The neutrality that I have experienced during practice of loving-kindness (Mettā) meditation has enabled me, when feeling angry towards others, to concentrate anger, and to recognise acting on one's anger outside meditation. This has helped me to put behind me much agitation from past instances of bullying and ill-will that I have experienced as a person with Asperger's Syndrome, to the point where I understand other reasons for their actions towards me and do not lay blame” (p.124).

Chapter 14, Epilogue: University reunion

In this chapter Chris outlines the reunion between he and former university peers. He initially does not want to attend as he is reluctant to see some people who treated him negatively, however, due to his belief in seeing people as they are now he replies to the e-mail invitation and is encouraged by the peer who sent it to attend, and he does. Attending the event made him realise how people can change over time, including himself, and he felt that “what was perhaps even nice was how we were all happy for one another in regards to how our futures had turned out since university” (p.131).

How does Chris Mitchell use spirituality &/ religion to make meaning regarding his embodied&non-embodied life experiences?

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Question	Excerpt(s) from the Book	Researcher's Reflections and Notes	Ideas of Possible Questions for Interviews
<p>1. How did the 'autistic' person make meaning of the paradox(es) of their lived experience? How did they practically deal with it?</p>	<p>"Being diagnosed with Asperger's Syndrome back in 1998, when I was 20 years old, was an immediate relief. Having had my diagnosis for almost ten years at the time of writing, I have found that beyond the impermanent nature of relief, Asperger's Syndrome is a lifelong journey, following a path. At times, this path can be difficult to negotiate, but with the right effort and through developing self-esteem, the path of Asperger's Syndrome can also be a fulfilling one to follow through life, if one is able to 'awaken' through development of awareness.</p> <p>Mindfulness is a technique, or state of mind, where one becomes intentionally aware of their way of thoughts, including being aware of how different thoughts arise, which provides for open, non-judgemental thought[...] is helpful for a person</p>	<p>Chris is accepting more so that life changes and this in itself is adding to him working with the 'impermanent nature', i.e. paradoxes and motion/dynamics of life.</p> <p>The mystery of being 'autistic', that was recognized later in life, gave Chris relief; a recognition of an aspect of oneself enabled further development of self-understanding /&perception? He is using the notion of 'the path' from Buddhism to merge his understanding and non-understanding of self regarding being 'autistic'?</p> <p>He feels a need to develop his perception due to the nature of his lived experiences. Hence, mindfulness is practiced so as to be in tune with the environment.</p>	<p>If you do remember, how did you feel when you were recognized as being 'autistic'? Did your spiritual/&religious beliefs play a role in this process? How did your family</p>

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	<p>with Asperger’s Syndrome, in terms of being able to effectively assess oneself in relation to one’s surroundings, and is just as helpful for a person not on the autistic spectrum, in terms of understanding Asperger’s Syndrome in a judgement-free way.” (p.13)</p>	<p>Inner&intersubjectivity; becoming more sensitive to his own being is enabling him to become more sensitive and in tune with the outer physical environment/being(s) – paradoxical and dynamic in itself.</p> <p>Mindfulness is effective for all in terms of developing perception; mindfulness as a bridge between ‘self’ and ‘others’? Mindfulness: can be practiced within a family setting?</p> <p>Lévinas (1961/1979, p.36): “The alterity, the radical heterogeneity of the other, is possible only if the</p>	<p>or/and guardians behave? Did they hold spiritual/&religious beliefs about it? How did it come in to play in your home life and/or when you were out with family/a guardian?</p> <p>Do you carry out any particular spiritual/&religious practices? How about in your everyday life? What are these?</p> <p>Do spiritual/&religious practices affect the quality of your life? The quality of your relationships? The quality of communication that takes place between yourself and people or/and other beings? How?</p>
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		<p>other is other with respect to a term whose essence is to remain at the point of departure, to serve as <i>entry</i> in to the relation, to be the same not relatively but absolutely. <i>A term can remain absolutely at the point of departure of relationship only as I.</i></p> <p>To be I is over and beyond any individuation that can be derived from a system of references, to have identity as one's content. The I is not a being that always remains the same, but is the being whose existing consists in identifying itself, in recovering its identity throughout all that happens to it. It is the primal identity, the primordial work of identification. [.....] The I that thinks hearkens to itself thinking or takes fright before its depths and is to itself an other.... faced with this alterity the I is the same, merges with itself, is incapable of apostasy with regard to this surprising "self"."</p>	<p>When you say "I" what kinds of thoughts come to mind with regards to the meaning of "I"? When you say "you" what kinds of thought come in to mind with regards to the meaning of "you"? How about the meaning and/or definition of "we"?</p>
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<p>2. How did the person make meaning of the dynamic aspect of their lived experience? How did they practically deal with it?</p>	<p>Anxiety and mind: "Anxiety is present in some shape or form almost every day in our lives. As a person with Asperger's Syndrome, I have experienced much difficulty in being able to cope with anxiety, to the extent that it has taken over my mind" (p.53) and "Looking back, the anxiety that plagued me during those years took control of me to the extent that it was even affecting the quality of my work. For often, when I felt that my mind was troubled by such uncertainty, it was so difficult for me to focus on the immediate task in hand. When having to try and balance these particular concerns, I often found that my mind ended up reacting to situations and in some cases certain people in a quite cynical way. This was where my inability to recognise the fourth hindrance of restlessness and worry verged into the second hindrance of ill-will towards myself and others" (p.55).</p>	<p>Anxiety can and does produce thoughts that overwhelm Chris, illustrating the thoughts&feelings in lived experiences as well as a concept (Mary Midgley's <i>Science and Poetry</i> comes to mind), and how these affect his everyday life – distancing him from the immediate tasks. Leading to negative thoughts&emotions regarding self and others, illustrating inner&intersubjectivity.</p> <p>Also illustrating how emotional&thought connectedness and non-connectedness affect learning and understanding regarding self, others and life.</p> <p>Making meaning with mind, body and actions – continual 're-aligning' with self? Continual reflexivity? This is also applicable to the next excerpt from Chris regarding frustration, anger, his mind, body and actions which are in motion in a 'confused' manner.</p>	
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	<p>When feeling frustration and anger due to not having got a job from an interview(s): "I have found that the more frustrated and angrier that it has made me, the more it has detached my mind from my body, in that the mind loses much bodily control, including control of the nervous system, leading to tension and shaking. When my mind is elsewhere, I can lose both awareness and control over the body in the sense that I find myself thinking about something different to what I am supposed to be doing, such as putting in the wrong ingredients when cooking" (p.63).</p> <p>Action: "I find that generally stepping back from it all through meditation or undertaking a physical activity (e.g. walking) or even doing a routine job (e.g. washing the dishes, vacuuming) helps to put such feelings aside so that I can handle them appropriately when I need to" (p.57).</p>	<p>Merleau-Ponty (1964/1968; p.9): "it is not entirely my body that perceives: I know only that it can prevent me from perceiving, that I cannot perceive without its permission; the moment perception comes my body effaces itself before it and never does the perception grasp the body in the act of perceiving.* If my left hand is touching my right hand, and if I should suddenly wish to apprehend with my right hand the work of my left hand as it touches, this reflection of the body upon itself always miscarries at the last moment: the moment I feel my left hand with my right hand, I correspondingly cease touching my right hand with my left hand. But this last-minute failure does not drain all truth from that presentiment I had of being able to touch myself touching: my body does not perceive, but it is as if it were built around the perception that dawns through it; through its whole internal arrangement, its</p>	
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		<p>sensory-motor circuits, the return ways that control and release movements, it is, as it were, prepared for a self-perception, even though it is never itself that is perceived nor itself that perceives. Before the science of the body (which involves the relation with the other) the experience of my flesh as gangue of my perception has taught me that perception does not come to birth just anywhere, that it emerges in the recess of a body.”</p> <p>Chris reminds himself that the anger is impermanent and distances himself from the cause of it, addressing it behind closed doors; aligning the angry aspect of his self with the observing self? Arthur Deikman's "The Observing Self" comes to mind. Chris's course of action is dynamic; flowing with the dynamics in an 'indirect' manner (e.g. doing something with one's body to keep one's mind otherwise occupied) in order to</p>	<p>How do you cope with changes? Do your spiritual/&religious beliefs and/or practices play a role in this? What kinds of situations make you feel happy? What kinds of situations make you feel content or and neutral? Is</p>
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		<p>gain a <i>sense</i> of stability? This is paradoxical: movement and state of calmness are inter-related. Delving in, to, through a sense of mystery (e.g. taking mind off the actual matter at hand) in order to work with the dynamics? Coping and learning with mystery? He is developing more of an attitude of accepting that things change; in itself leads to accepting that we cannot know how all things will turn out to be, i.e. accepting of mysterious nature of our lived experience.</p> <p>van Manen may be of use regarding categorising the reflective aspects of my, as well as participants', lived experiences (1990; p. 101): "Lifeworld Existentials as Guides to Reflection</p> <p>There are four existentials that may prove especially helpful as guides for reflection in the research process: <i>lived space</i> (spatiality), <i>lived body</i> (corporeality), <i>lived time</i> (temporality), and <i>lived human</i></p>	<p>there something you remind yourself of/and do to feel like this? What do you learn about yourself? What do you learn about your body? What do you learn about others' /& family members? Do you have hypersensitivities and hyposensitivities? How do you make sense of such abilities and their effects? Do you use spirituality /& religion to make sense of such abilities? What do you learn about others? What do you learn about their bodies? What do you learn about life? What kinds of situations make you feel anxious? How do you cope with them? What kinds of situations make you feel angry? What do you learn about yourself? What do you learn about your body? Hyper and hypo sensitivities? Meaning-making regarding, and/or with, such abilities? What do you learn about others? What do you learn</p>
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		<p><i>relation</i> (relationality or communality).” Something to think about... ?</p> <p>For myself to consider: How does participant make meaning of the status quo elements (anxiety, mind, frustration and anger)? Is there a particular theme(s) or thread(s) that runs throughout their story(ies)? How is perception playing a role in their experiences? How are they illustrating self-knowledge and what role is this playing in their story(ies)? How am I doing these things during the interview(s) and afterwards?</p>	<p>about their bodies? What do you learn about life?</p>
<p>3. How did the person make meaning of the mysterious</p>	<p>Suffering and not knowing why in itself led to more suffering: “For me though, what I felt was suffering was remaining undiagnosed until I</p>	<p>“knowing I was different” & “not knowing of any reason as to why”; the known&mysterious(unknown) aspect of oneself and one’s lived experiences cause pain. Self-</p>	<p>When were you recognised as being ‘autistic’? Whilst growing up did you feel different and not know why? Do you feel that you suffered during the years</p>

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<p>aspect of their lived experiences? How did they practically deal with this?</p>	<p>was 20 years old, often knowing I was different but not knowing of any reason as to why." (p.102).</p> <p>Facing and coping with suffering via reflection: "I feel from what I have learned that being aware of how Asperger's Syndrome affects a person can enable one to put their diagnosis into the context of different surroundings and situations they may find themselves in. In turn, this can help explain different mind states, positive and negative, that one may be subject to in different situations" (p.103), "Writing my autobiography (Mitchell 2005), when I look back</p>	<p>knowledge in itself is paradoxical? Which leads to a self-understanding/flourishing in relation to being recognised as being 'autistic'? And continues via Chris's ongoing journey and path? A constant paradoxical dynamic flow of mystery revealing itself, leading one in to deeper depths of Self with Self?</p> <p>Shems&Rumi come to mind (in Fihi Ma Fih (1260 – 1273), "It is what it is"/The Discourses of Rumi, translated by A.J. Arberry, 1961 / 2000; p.37-38): "It is pain that guides us in every enterprise. Until there is an ache within, a passion and a yearning for that thing arising within us, we will never strive to attain it. Without pain it remains beyond our reach, whether it is success in this world or salvation in the next, whether we aim at becoming a merchant or a king, a scientist or an astronomer. It was not until the pains of birth manifested in Mary that she made for the tree. Those pangs drove her to the tree, and the tree that was withered became fruitful.</p>	<p>that you were not as aware of this aspect of yourself? What do you think suffering is?</p>
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	<p>now, was almost like an extended Vipassanā practice [a meditation practice that is aimed at seeing things as they really are] in the sense that writing it involved gathering and reviewing some of the most difficult periods in my life” (p.103), and Chapter 14: reunion with colleagues as being the epilogue; “One of the themes that this book has covered is being able to see people from one’s past as they are now, including those that one has experienced friction and conflict with. A concept in Buddhism that hasn’t been covered in this book though is the notion of Karma. Karma, meaning ‘action’ in Pāli, is often applied to future results of past actions, including how false or malicious actions can result in suffering. As I have discussed much in this work, actions by or towards a person with Asperger’s Syndrome, especially undiagnosed Asperger’s Syndrome, that have negative effects can result from things being tried to the best of intentions but</p>	<p>We are like that story of Mary in the Koran. Every one of us has a Jesus within, but until the pangs manifest, our Jesus is not born. If the pangs never come, then our child rejoins its origin by the same secret path through which it came, leaving us empty, without the birth of our true self.”</p> <p>Constantly practicing this accepting of paradox, dynamics and mystery, which are all intertwined. In itself leading to development, or re-alignment, of the reality(ies) that which is ‘in’ our depths and ‘outside’ of it?</p> <p>Regarding Chris writing his autobiography, van Manen (1990 p.127) comes to mind: “To write is to measure our thoughtfulness” – Chris is practicing reflexivity and phenomenology.</p> <p>Chris is using the notion of Karma regarding accepting the mysterious nature of one’s lived experiences with others and practicing forgiveness.</p>	
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	<p>having reverse effects or simply through misunderstanding. In this case, Karma can help one atone for past actions.</p> <p>To give an idea of how these themes can apply effectively to situations where one meets people from their past, I have taken my university reunion (from my undergraduate years) as an example" (p.129).</p> <p>'Returning' and facing others by using a former teacher's statement and empathy: "Thinking of what one of my former primary school teachers had said of how he often felt frustrated with himself, more so than with me, wondering what to do to 'get through to me', this insight enabled me to realise that there was a similarity in this sense with my former undergraduate colleagues" (p.130).</p>	<p>Chris is projecting the understanding and empathy he developed for his former teacher on to his fellow former university peers. The acceptance of the confusion/mystery of the reality(ies) that was lived between them in itself enables further empathy and compassion to be exercised. A revelation of mystery in to understanding (i.e. what his teacher told him) enables the resolving and empathy development with others he lived similar kinds of confusion/mystery with; Chris is willing to work with</p>	<p>What do you do when you are in a confused state? How do you feel? How do you behave? Do your spiritual/&religious beliefs play a role in your decision-making? How?</p> <p>Have you been in a situation with a person whereby they apologised to you in a way that made you understand and forgive them? Do you use this kind of understanding with other people who may not have had the chance to do a similar</p>
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	<p>Seeking balance: “the teachings within Buddhism suggest that all individuals live in their own world, a creation of the mind, largely perceiving their surroundings through the perspective of the self” (p.113).</p> <p>“Mindfulness is not developed overnight. It can take months or even years of right effort and concentration to cultivate the mind. But if one is willing to put in the time, potential benefits of mindfulness include: [...]” (p.119)</p> <p>Overcoming the Hindrances: “Throughout this book, I have discussed bringing in qualities I feel I have experienced during meditation practice, including calmness, insightfulness, empathy and general neutrality, into different life</p>	<p>the mystery of life and try again by agreeing to attend the reunion.</p> <p>William Blake (1790) comes to mind: “If the doors of perception were cleansed every thing would appear to man as it is, Infinite. For man has closed himself up, till he sees all things thro' narrow chinks of his cavern.” How does one achieve this? One method is self-reflection/meditation?</p>	<p>thing or/and maybe feel too embarrassed to do so?</p> <p>Have you been in a situation whereby you were interpreting things in one way and the other person was interpreting them in a different way? How did you work with this? Did your spiritual/&religious beliefs come in to play? How?</p>
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	<p>situations [...]through qualities of the cultivated mind, to recognise and balance what the Buddha described as the Five Spiritual Faculties.” (p.123).</p> <p>Measuring success and goal-setting: “not to live up to anybody’s expectations but my own” (p.89), “Within Buddhist values, the ethos is on happiness and, above all, contentment rather than ‘success’ (p.90), “Through recognising the Khandas [sensory perception that contribute to irrational distractions], I have found that the more one wants things to be the way they want them to be, the more this can expose one to dukkhā” (p.93), and “Goal-setting, if done realistically while applying the patience to see it through can also be a motivating force, thus avoiding being affected by the hindrance of sloth and torpor” (p.95).</p>	<p>One way of working with the mystery of life, that can cause confusion, is to practice meditation and align more so with the observing self?</p> <p>Strengthening one’s alignment with the observing self so as to be better prepared with the mystery of life?</p> <p>Accepting one’s own expectations and reality(ies) as being worthy of living in line with, and placing one’s wellbeing and happiness at the top of one’s priorities so as to work with the mystery of life.</p> <p>Achievable goals; less stress and suffering and more satisfaction with one’s life. Working with the mystery of life in terms of explicitly establishing a goal(s) and working towards it and with it – in itself leading to being content. Lévinas (1961/1979; p.115): “Happiness is accomplishment: it exists in a soul satisfied and not in a soul that has extirpated its needs, a</p>	<p>How do you decide your goals in life? Do your spiritual/&religious beliefs influence such decisions? Do your bodily abilities play a role in such decision making? Does your family life influence such decision making? What is your main goal in life? Are there particular things you do in order to achieve such a goal?</p>
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	<p>Discipline and routine: “The depression that I experienced prior to my diagnosis of Asperger’s Syndrome in 1998 was, now I feel, partly the result of loss of self-discipline, which then led to a loss of routine in which I felt comfortable. When losing routine, I found myself developing some unhealthy habits” (p.69), “One of the many benefits I feel I have gained from meditation practice and belief is that it has given me routine in terms of setting aside time each day to practise. The practice itself I feel has given me the discipline to maintain a routine in which I am comfortable, which reduces my anxiety levels” (p.71), “The Buddha’s teachings suggest that one of the sources of dukkhā relates to the impermanence in our lives. Something that I have found today’s highly competitive job market, is that even a permanent</p>	<p>castrated soul. And because life is happiness it is personal.”</p> <p>Forming routine behaviour and thoughts is a way of working with the mystery of life; making one’s life predictable in certain respects. Explicitly making a routine of self-reflection, meditation, a part of one’s routine is another way of working with the mystery. The meditation itself helping to lessen anxiety – becoming more comfortable with the uncomfortable – which is usually a product of the more so mysterious element of one’s lived experiences.</p>	
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	<p>post isn't entirely secure.... Having been affected by this in recent years working in local government.... I have found it helpful to, where possible, anticipate where change may occur, so that I can prepare for it" (p.76).</p> <p>Developing tolerance: "It is known that many adults with Asperger's Syndrome still suffer from the effects of bullying they experienced in the schoolyard, and some even have been treated with similar therapies to those used to treat Vietnam war veterans. Practice of Mettā [loving-kindness meditation] encourages one to extend their range of benevolence to even those that one finds they may have disliked or even found despicable, so that one finds compassion. Where I have found compassion in relation to the bullying that I suffered during my school days is through understanding that those who bullied me in the schoolyard</p>	<p>Accepting that things change and that it is better to be prepared for change and actually preparing; working with mystery. John Keates's 'negative capability' comes to mind and so does 'the phenomenological attitude'.</p> <p>Mystery revealing itself; the individual is placed in a position whereby he has to work with it in some way or another. He considers that there are other reasons why they acted the way they did and this enables him to take it less personally and use a more widened perspective of the dynamics that were prevalent between himself and former peers. It is maybe this to-ing and fro-ing of thoughts&feelings in itself that enables mystery and forgiveness to flourish? van Manen (1990; p.105): "As we meet the other we are able to develop a conversational relation which allows us to transcend ourselves. In a large existential</p>	<p>How do you feel about your work? Do you consider aspects to do with your bodily functioning (e.g. hyper and hypo sensitivities) when applying for jobs? How did you end up doing your line of work? Do your spiritual/&religious beliefs influence your choice of work /& the amount of work you do? How do you cope with changes in the working environment?</p>
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	<p>perhaps didn’t know any better, and it could be that now they are older, wherever they are, they perhaps feel a little guilty, like some of my former university colleagues said they felt after they found out I had been diagnosed with Asperger’s Syndrome” (p.85).</p>	<p>sense human beings have searched in this experience of the other, the communal, the social for a sense of purpose in life, meaningfulness, grounds for living, as in the religious experience of the absolute Other, God.” Relationship(s) and communication, and its prevalence in meaning-making? Merleau-Ponty (1945/1989; p.102): “I am essentially open; I am open to my own past and to other people, I exist with others in a common world in which my experience interweaves with theirs” ... (p.103:) “my body is always perspectival – I never have an all-encompassing hold on the world; there is therefore room for other incarnate subjectivities, and their points of view complement my own. Their body expresses their intentions and I perceive those intentions with my own body; insofar as my body takes up the other’s intentions, there is an internal relation between our bodies”.</p>	
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		<p>Everything that we experience is done so via perception? Our body is and is not perception? And it is constantly reflecting (Merleau-Ponty, 1964/1968)? Therefore being aware of this reflexive state and re-aligning with it enables us to gain a sense of stability and vibrate with the mystery of our beingness in a more harmonious manner? Mystery holds meaning. Paradox creates confusion and dynamics, which in themselves lead to seeking meaning, which the seeking in itself could be said to also be the meaning. The aim is to recognize the process(es) as so?</p>	<p>You do not have to answer this question if you do not want to... how do you feel about your body? How do you feel about your hypersensitivities? How do you feel about your hyposensitivities? How about your family's understanding and/or non-understanding of these aspects of your body? Are there aspects of yourself that you feel are present that you may not be able to put in to or express in words? Do you believe in intuition? How do you feel about it? Do you feel that you use your intuition much? How do you use it? How not? Does your family know about these factors? How do/did they respond?</p>
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Questions and Reflective Notes Regarding the 'Other' and Myself		
<p>1. How do 'autistic' persons' make meaning? What is my meaning-making process(es)?</p>	<p>Buddhism, goals, as a guideline of thinking, observing self, framework and concepts and moral guidelines... Merging with Asperger's – a path/way – same in Buddhism. I am doing this as well – bridging aspects.</p> <p>Practices; mindfulness - Reflection – vepassana – autobio, the work he does.</p> <p>Bodily functions; anger, anxiety, food.</p> <p>Past experiences and memories; others, goes to a temple, food.</p> <p>Independence and interdependence; seeking to be economically independent and wants to feel less isolated, i.e. seeking a deeper sense of connectedness with the beings in life?</p> <p>What he has and does not have; i.e. a stable job makes him content, and simultaneously he does not want too many material belongings.</p> <p>Paradox; as described above.</p> <p>Dynamics; as described above.</p> <p>Mystery; as described above.</p> <p>This whole document illustrates my meaning-making, i.e. via the embodied&non-embodied Self (inner&intersubjectivity).</p>	

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<p>2. What are the implications for perception(s) and self-knowledge?</p>	<p>Lived experiences are extremely important in our development of self-understanding. Yet, is there also something, that which is observing, that is not actually living (or not involved in) the moment by simply observing the moment itself? Death&life intertwined as one? Self-knowledge is present and simultaneously not present?</p> <p>Thoughts&emotions and self-understanding are very much intertwined; cognition and phenomenology?</p> <p>Observing Self; mindfulness and development of better understanding?</p>	
<p>3. What are the implications for phenomenology as a methodology?</p>	<p>Phenomenology is very useful in terms of describing paradox and lived experiences, however, how does one work with the dynamic and mysterious nature of being in educational terms? Van Manen, 1990, and the four existential categories (p.102), as mentioned above in the table, may be useful for producing the interview protocols and may be aspects to focus on and through when working with families in the future.</p> <p>Phenomenological theory may well be developed further in terms of learning about the nature of self, and through self, by 'autistic' persons and 'their' lived experiences; this needs to be made that much more explicit. Jung, Romanyshyn and Shotter come to mind; maybe there is a place for a bridging of phenomenological theory and depth / analytical psychology? Mearleau-Ponty's <i>The Visible and the Invisible</i> and learning come to mind.</p>	
<p>4. What are the implications for IPA as an approach and</p>	<p>IPA as a conceptual framework:</p> <p>William James's influence in IPA is very useful.</p> <p>When thinking about William James, Chris's writings as well as Donna Williams and her writings: how about 'tools' when exploring that which is</p>	

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<p>the methods involved?</p>	<p>not visible, the mysterious element of our being? A place for depth psychology, e.g. Jung, within phenomenology and IPA? I feel this bridge is already present in phenomenology and IPA via its use of persons' lived experiences, however, maybe it is worth making it that much more explicit?</p> <p>IPA and methods:</p> <p>Bracketing is very useful in accepting people's lived experiences as being valid in their own right. Maybe this is also a way of accepting the mysterious element in our lived experiences?</p> <p>More research required with IPA and reflective texts/autobiographies in themselves; sent Jonathan Smith as well as Michael Larkin e-mails (June 2014) asking for papers they may be aware of, they stated IPA could be utilized with autobiographical/reflective texts, though they are not aware of such papers. One paper, as outlined in the Methods section, by Spiers and Smith (2012) that utilizes IPA with poetic reflective writing has been useful, van Manen's (1990) writings are becoming more useful, and so has the table structure used herein thanks to Smith et al. (2009).</p>	
<p>Questions and Reflective Notes Regarding the 'Other', the Family Context and Myself</p>		

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<p>How does this 'autistic' person make meaning? Especially in the family context? What seems to be the family's meaning-making process(es)? What is my meaning-making process(es)?</p>	<p>Chris uses Buddhism and its teachings, the Four Noble Truths and the Eightfold Path, to make meaning of 'autism' as a way of being, living, as well as working with one's suffering.</p> <p>Chris does not delve so much into his family's meaning-making in terms of whether they practice Buddhism or not, however, he states that being able to like himself is also enabling him to see, feel and accept that he is valued by his family; as is in <i>Chapter 3, Starting with Who You Are: How the easiest person to like can be you:</i></p> <p>He explains that in "Theravāda Buddhism though, the focus of who is the easiest person to like is oneself. Initially this may sound self-important or even egoistic, but the focus on liking oneself within the Theravāda tradition is more about finding the positive aspects and personal qualities one may have, that in some cases perhaps one wasn't previously aware of, before applying these qualities to how they relate to others. This includes being able to take one's frustrating experiences and curtail them in such a way that one can even see positive actions from where frustrations originate" (p.30). He then includes information about some of the frustrations that 'autistic' people can and do experience, e.g. struggling to achieve high grades in school, not being employed, and finding it difficult to make friends and form intimate relationships. He later states that meditation has enabled him to learn to like himself and "can be a route to self-confidence and, ultimately, personal happiness" (p.33). He also states that it has "enabled me to feel that who I am means much to those close to me, including my family, friends and people who feel my help has made a positive difference to their lives" (p.33).</p> <p>Furthermore, the non-recognition of an aspect of oneself can be confusing and frustrating for both Chris and his family. Though practicing forgiveness, self-reflection, and focusing on living in the now is enabling Chris to have more understanding, and I assume, more harmony with his family and friends. As is outlined in <i>Chapter 5, Gaining Insight from Those Around Me: How insight can strengthen one's awareness:</i></p> <p>Chris outlines how being recognized as having Asperger's Syndrome and reviewing his life so that he could write his life story (<i>Glass Half Empty, Half-Full, 2005</i>) has enabled him to develop a deeper insight in to the ways that he was treated in his younger years by family, peers and teachers. He states that what he felt needed to be understood is the "confusion that can result from growing up with undiagnosed Asperger's</p>
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	<p>Syndrome. People around a person with undiagnosed Asperger’s Syndrome, including members of their family, can experience frustration when they try so many different ideas to help the person develop social and independent skills with the best of intentions but have negative results” (p.46). He then advocates recognition of ‘autistic’ traits at a young age and relevant educational arrangements. He states that forgiveness can be difficult, however, he is finding that a way to achieve this is to look at people in the context of the present rather than the past, which he feels that in turn enables people from his past to see him as he is now.</p> <p>My meaning-making process is as the above outlines; in that Chris is treating being ‘autistic’ as a ‘way’/’path(s)’, which from what I’m aware of about Buddhism is a common term that is used to refer to one’s life and life journey(s).</p>
<p>What are the implications for perception(s) and self-knowledge?</p>	<p>The implications are that one’s perception and self-knowledge can be ‘developed’ by:</p> <ul style="list-style-type: none"> - Self-reflection and meditation - Liking oneself, or by my terms, self-love - Intersubjectivity <p>Furthermore, as a researcher attempting to be as ethical as possible, do I have a duty to like myself and the ‘other’?</p>
<p>What are the implications for phenomenology as a methodology?</p>	<p>Self-love comes to mind</p> <p>Meaning-making ought to be focused on, with a more explicitly descriptive way of expression regarding interpretation and the sensory</p>

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<p>What are the implications for IPA as an approach and the methods involved?</p>	<p>IPA: simply reflecting the emerging analysis process, for example:</p> <p>Certain readings come to mind as I proceed and therefore I include them in the table and illustrate how I dialogue with them</p> <p>Questions are arising in my mind as I proceed, hence the last column named 'Ideas of Possible Questions'</p>
<p>What is self-knowledge? How does it develop?</p>	<p>There is and is no such thing.</p> <p>We exist and do not exist simultaneously.</p> <p>It does not 'develop' as such, it is present and we are simply realizing it in becoming more consciously aware. Maybe I ought to stop using the term 'develop'?</p>
<p>What is meaning? How does it develop?</p>	<p>Meaning is God, "mâna Allah'dır" (Shems&Rumi in the Mesnevi/Mathnawi, 1263/2011; page 96) & meaning is also perception (p.79), and 'develops' by God playing backgammon with itself (Shems&Rumi, 1263 / 2011); inner&intersubjectivity and a continuous dance.</p>
<p>What is perception? How does it develop?</p>	<p>Perception? That which is paradoxical, dynamic and mysterious and is embodied and non-embodied, is magnifier and non-magnifier of experience. Pointing to meaning from 'within' and in the 'physical' realm. It develops by constantly merging with its true essence, in continual flux, being observed in, with and through awareness and then rolling back in to the depths from which it came from ... ?</p>

The questions that have arisen regarding the methods so far are:

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1. How does one use narratives/autobiographical texts with IPA?

- So far summarising the story and then asking the status quo phenomenological questions, simultaneously utilizing a table structure, is helping to use IPA with reflective writings.

2. How does one use autobiographical/reflective texts in order to further become sensitive to the context and culture of 'autistic' persons and 'their' family life?

- As is illustrated above, reflective readings and questions that are arising from such interpretations are enabling me to become more sensitive to the context and culture of 'autistic' persons; this will hopefully happen more so with regards to the family when analysing the second set of excerpts of reflective texts.

3. How does one create further research questions (e.g. for interviews) and develop one's philosophical standpoint(s) whilst analysing 'autistic' person's autobiographies with IPA?

- Asking questions regarding the 'other's' embodied&non-embodied lived experiences and my lived experiences is enabling me to create further questions for interviews whilst using IPA with the reflective writings of 'autistic' persons. Having engaged with the descriptive summaries of the chapters is also leading to the development of questions directly derived from my interpretations of the text; after having completed the table I have returned to the chapters and gone through them, coming up with questions that are directly linked to the statements and points made by the author, therefore developing both thematic and idiographic questions.

Chris Mitchell, 2009. Asperger's Syndrome and Mindfulness, Taking Refuge in the Buddha: Reflective Questions and Creating Sensitive Questions

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Contextual information regarding this book:

(i) Who wrote the autobiography(ies) /& reflective writing: Chris Mitchell is a man who was recognized as being 'autistic' (Asperger Syndrome) at the age of 20 in 1998 and is from England, U.K. He studied an MA in Information and Library Management.

(ii) Where the autobiography/& reflective text was written: The book was published in England, though from Chris's story one learns that he was working on it on and off for some time between his travels.

(iii) When the autobiography/& reflective text was written: 2009.

(iv) Why and how the text came in to being: Chris was encouraged to write this book by Genevieve Edmonds, a consultant and writer in the field of autism who was educated to a postgraduate level, and was an adult recognized as being 'autistic' (Asperger Syndrome); she passed away in 2008.

(v) A summary of what the story is about: Chris has written about Buddhism and how mindfulness has, and is, enabling him to learn more about himself and the beings around him, especially people. He felt at a loss for many years and when he was recognized as being 'autistic' at the age of 20 whilst at university, and was going through depression, he began delving more so in to understanding himself.

He has broken down the book in to 14 chapters and has used the concepts of The Four Noble Truths from Buddhism, along with the concept(s) of the Eightfold Path/The Middle Way which incorporates the Four Noble Truths, to illustrate this. He provides examples from his own lived experiences and how certain practices enable him to cope and learn in various contexts; he also provides relevant guidelines at the end of each chapter. The chapters and summaries are as follows.

Chapter 1, Introduction: The path of Asperger's Syndrome

Why do people feel the need to reflect + write?
How does their environment induce + encourage this process(es)?

(1)

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Do you practice a particular religion? ~~and~~ what practices or rituals do you undertake? How do these practices make you feel?

In this chapter Chris outlines that "Asperger's Syndrome is a lifelong journey, following a path the path of Asperger's Syndrome can also be a fulfilling one to follow through life, if one is able to 'awaken' to it through development of awareness" (p.13). He then proceeds to outline how mindfulness, the practice of observing one's thoughts, where they are emerging from and how, has and is enabling him to "effectively assess oneself in relation to surroundings, and is just as helpful for a person not on the autistic spectrum, in terms of understanding Asperger's Syndrome in a judgment-free way" (p.13). He then proceeds to give examples of how the Noble Truths have been/are prevalent in his life and in the life of other 'autistic' people An example of this is: "The First Noble Truth, that of suffering, helps me to understand that living is suffering, not just for myself, but for others too, both those diagnosed with Asperger's Syndrome and those not on the autistic spectrum. How one perceives and experiences suffering varies dramatically. As a person with Asperger's Syndrome, much personal unhappiness I have experienced relates to general non-satisfaction with life in terms of disappointments I have experienced or what I feel that I have missed out on in life. Many adults with Asperger's Syndrome I have met appear to share the view that there are things missing from their life, often related to social isolation" (p.13). This format is maintained by Chris with regards to the Second Noble Truth, the origin of suffering, the Third Noble Truth, cessation of suffering, and the Fourth Noble Truth, the Eightfold Path or the Middle Way.

Do you feel socially isolated? How does this make you feel? How do you address this? (and cope?) your religion (or/and spiritual beliefs) teach about suffering?

Chapter 2, Asperger's Syndrome and the Five Hindrances

Here, Chris describes the Buddha's teachings regarding the Five Hindrances that refer to a "negative state of mind or an unmindful state" (p.21). These are: "1. sense desire, 2. ill will, 3. sloth and torpor, 4. restlessness and remorse, 5. doubt" (p.21). He states that "Many people with Asperger's Syndrome, including myself, often experience 'mental block-ages' in relation to frustration and anxiety, which often make such issues difficult to cope with, thus 'hindering' one's ability to cope effectively" (p.21) and proceeds to give examples with regards to each hindrance. For example, in the 'Sense desire' sub-section, he states that "For me, this hindrance often arises out of personal frustration through things being the way they are, in terms of thinking that 'as a person with Asperger's Syndrome, for what I have experienced in my life, I deserve to have it better'. In thinking along the lines of 'having it better', one may find oneself giving unwise attention to beautiful, often material, images and items, building up an image of 'how I should have it'" (p.22). He then describes how this sense also prevails in social contexts whereby he feels that people around him have moved on professionally and in their personal lives yet he cannot relate to this, therefore leaving him feeling as though he is "like a seed frozen in time" (p.22), socially isolated and feeling low in self-esteem.

How do you feel about yourself overall? What are your practices? + How? (2)

Do you have particular practices to address your suffering?

Do you feel you suffer? How do you cope?

Do you feel you suffer? How do you cope?

Do you feel you suffer? How do you cope?

If or when you are feeling low in self-esteem how do you want to address this? Do you have any practices which you feel help to address your feeling this way?

Chapter 3, Starting with Who You Are: How the easiest person to like can be you

In this chapter Chris states that one can end up hating oneself and therefore focuses on building up one's self-esteem, i.e. believing more in oneself and doubting less, and provides advice to non-'autistic' persons in working with 'autistic' persons with regards to building up self-esteem. He explains that in "Theravāda Buddhism though, the focus of who is the easiest person to like is oneself. Initially this may sound self-important or even egoistic, but the focus on liking oneself within the Theravāda tradition is more about finding the positive aspects and personal qualities one may have, that in some cases perhaps one wasn't previously aware of, before applying these qualities to how they relate to others. This includes being able to take one's frustrating experiences and curtail them in such a way that one can even see positive actions from where frustrations originate" (p.30). He then includes information about some of the frustrations that 'autistic' people can and do experience, e.g. struggling to achieve high grades in school, not being employed, and finding it difficult to make friends and form intimate relationships. He later states that meditation has enabled him to learn to like himself and "can be a route to self-confidence and, ultimately, personal happiness" (p.33). He also states that it has "enabled me to feel that who I am means much to those close to me, including my family, friends and people who feel my help has made a positive difference to their lives" (p.33).

Chapter 4, Seeing the Truth: How to control mind proliferation and see others as they really are

Chris outlines that in Buddhism mind proliferation is referred to as "Papañca" (p.37), whereby the mind 'proliferates' thoughts, just like the ears hear or eyes see without effort, which in turn can lead to "various concepts that one may take delight in and cling onto thus taking them to be true" (p.37). He describes how whilst at university he became fixated with Marxism and how that had led to him developing a rigid line of thinking; "What I didn't realise though was that developing an identity for yourself, especially if politically or religiously motivated in a fundamental way, can be isolating" (p.38). He provides further examples of what he refers to as "fixations" (p.38) and, according to the situation, promotes a flexible line of thinking. He states, "The increased self-awareness that I have developed from mind cultivation through meditation and experience of different cultures has helped me understand that all individuals have their own views and opinions, with it being more apparent in some than others" (p.39). Hence, he has also developed further insight in to how individuals can experience mind proliferation and how this can, and does, affect behaviour. This in turn has enabled him to develop a deeper a sense of self; "One doesn't see who he or she really is when accepting others' opinions of who they are" (p.40), "One has to be careful using labels to set them apart from one

Do you like yourself? How? Factors? How not?

What are your positive traits? What things do you enjoy?

What are the relationships in your life like? With family? Friends? Allies? Partners? Negatives? Neutral?

Are there particular thoughts that proliferate in your mind? How do address them? How do you learn with 3rd act?

Are you a flexible thinker? How? - situations?

What do you think are others' opinions of you? Family? Friends? Allies? How does this make you feel?

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another, as this can again result in divisions, which inevitably lead to conflict" (p.41) and "Through mind proliferation, we don't often see ourselves as we really are, and don't often see others as they really are" (p.42). Therefore, he promotes having both 'autistic' and non-'autistic' friends so as to develop one's identities and so as not to experience the hindrance of ill-will.

↳ What is your friend circle like? 'Autistic' and non-'autistic'?

Chapter 5, Gaining Insight from Those Around Me: How insight can strengthen one's awareness

In this chapter Chris outlines how being recognized as having Asperger's Syndrome and reviewing his life so that he could write his life story (*Glass Half Empty, Half-Full*, 2005) has enabled him to develop a deeper insight in to the ways that he was treated in his younger years by family, peers and teachers. He states that what he felt needed to be understood is the "confusion that can result from growing up with undiagnosed Asperger's Syndrome. People around a person with undiagnosed Asperger's Syndrome, including members of their family, can experience frustration when they try so many different ideas to help the person develop social and independent skills with the best of intentions but have negative results" (p.46). He then advocates recognition of 'autistic' traits at a young age and relevant educational arrangements. He states that forgiveness can be difficult, however, he is finding that a way to achieve this is to look at people in the context of the present rather than the past, which he feels that in turn enables people from his past to see him as he is now. For example, "One of my former teachers, after reading my auto-biography, said that he often got very angry and frustrated with himself for not being able to get through to me. After finding that he felt this way about me as his pupil, I realised that other teachers I had, as well as college/university lecturers and student colleagues, may well have experienced similar frustrations and confusions about me" (p.47). He then outlines how being recognized as being 'autistic' at university enabled his peers to get in touch with him and say how they felt guilty about some of the ways they had treated him; "In this way, a person who doesn't have Asperger's Syndrome can find out something about him- or herself through the way they relate to a person with Asperger's Syndrome, in terms of how they treat different people as individuals" (p.47). Chris also outlines how the competitive nature of educational life and workplaces sadly lead to bullying and belittling, and that how his values are not based on such success and status as he finds it too "stressful to manage in terms of anxiety, which is why I am generally happy just being content with a stable life" (p.49). Insight meditation techniques are also useful "to think more flexibly in the sense of being able to collect my thoughts when responding to others as well as being able to recognise the second hindrance of ill-will and how to undermine it more effectively" (p.49).

↳ How do you feel in school your home life? School? Workplace? Any stressors? How did/do you cope? Do your spiritual/religious values play a role?

When were you recognized as being 'autistic'? How did you feel? How did your family feel? How did your friends feel? Teachers? Colleagues? (4)

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Do you get anxious at times? What causes this? How do you cope?

Chapter 6, Worrying in an Anxiety-driven World: How to curb tendency to worry through curtailing stress and anxiety

Chris highlights that anxiety is present in all our lives and then explains how anxiety affects him and takes over his mind; "I can hear playbacks in my mind, almost like having a tape recorder inside my head. For me this is often difficult to curtail. In this case, the fourth hindrance of restlessness and worry represents the interference that leads to such difficulties" (p.53). He has experienced much anxiety "relating to educational and social issues" (p.53); that despite his age he was not mentally ready for the school environment, and that the constant testing of children in schools creates competitive and negative atmospheres whereby "one can feel very vulnerable, especially a person with Asperger's Syndrome" (p.54). Such environments can, and do foster, bullying, emotional issues and depression amongst young persons, and these aspects also prevail in adult life due to the competitive nature of work environments. Having short-term contracts to work by created a lot of anxiety for Chris, whereby he experienced "mental overload" (p.55). He became very cynical; "This was where my inability to recognise the fourth hindrance of restlessness and worry verged into the second hindrance of ill-will towards myself and others" (p.55). He finds that "Samatha meditation" (p.57) has enabled him to "retain a calm state of mind" (p.57) and that "I find that generally stepping back from it all through meditation or undertaking a physical activity (e.g. walking) or even doing a routine job (e.g. washing the dishes, vacuuming) helps to put such feelings aside so that I can handle them appropriately when I need to" (p.57).

Do certain environments affect your anxiety levels? Which environments? How?

Do you feel angry at times? What causes this? How do you cope with anger? Any spiritual/religious practices?

Chapter 7, Curtailing Feelings of Anger and Frustration: How to control and respond to anger effectively

This chapter focuses on how anxieties lead to frustration and anger. Chris states that job interviews and comments that people sometimes make can make him very angry, which can lead to the second hindrance of ill-will towards oneself as well as others. Chris later provides an example of how being rejected from jobs, especially ones that he may really really want, "can be soul-destroying" (p.63); "I have found that the more frustrated and angrier that it has made me, the more it has detached my mind from my body, in that the mind loses much bodily control, including control of the nervous system, leading to tension and shaking. When my mind is elsewhere, I can lose both awareness and control over the body in the sense that I find myself thinking about something different to what I am supposed to be doing, such as putting in the wrong ingredients when cooking" (p.63). He then states that anger can lead to shutting oneself off from other people and that one can become very selective with one's thoughts so as to make oneself feel as though one is completely in the right. The circular inner&intersubjective element of such feelings and their effects are outlined by Chris as follows, "Looking back, it was like me wielding a sword

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with a blade on each end in terms of the anger I was experiencing. The blade on the end nearest to those I was angry with was distancing them from me, whilst the blade facing me was emotionally hurting me further" (p.65). He then outlines that a useful strategy to utilize is to vent such anger behind closed doors and that expressing anger in a constructive way is useful, suggesting that one ought to also take up responsibility for the situation and avoid entirely blaming the other person – as recommended by a Buddhist monk in Northumberland. Chris then provides further advice, e.g. doing something that is not related to what made one angry and then "reviewing the circumstances concerned with a clearer mind" (p.68)

Is your eating ^{habit} affected by anxiety? Is there another term you'd prefer to use to describe 'anxiety'?

Chapter 8, Discipline and Routine: How to maintain discipline within routine, including managing changes

Chris outlines that he struggled with the lack of structure at university, especially in his final year and the 6 months for which he was a research assistant, and he developed unhealthy habits such as not eating proper meals and snacking on crisps and biscuits; "My mind had become so full of anxiety to the extent that I often didn't realise I was hungry and lost a lot of weight as a result" (p.70). He then proceeds to describe how the very routine of setting aside time every day for meditation in itself provides structure; "The practice itself I feel has given me the discipline to maintain a routine in which I am comfortable, which reduces my anxiety levels Such input can then be transferred to other situations where right effort and concentration is needed, from very simple tasks such as copy-typing a letter to completing a long-term project" (p.71). Chris then points to the 5 precepts from Buddhism with regards to self-conduct, e.g. "1. abstaining from injury to living beings" (p.71) and "2. abstaining from taking what is not given" (p.71), as guidelines that he uses and adapts according to his daily living pattern and environments. He proceeds to include information about managing his finances in a disciplined manner and asserts that self-discipline "can be a useful tool in terms of controlling such cravings [regarding excess alcohol and drug use]" (p.73) and includes information about how spending some time in a Buddhist monastery in Northumberland enabled him to "realise the value of being open to different food than I may otherwise choose, helping me to become used to a varied and disciplined diet" (p.74). Chris then describes how meditation has helped him physically in remaining still and calm when required (p.75), and that recognizing the "impermanence in our lives" (p.76) and preparing for change(s) whenever possible has also helped him to cope with anxieties regarding change, e.g. "Where possible, try to adapt a routine you feel most comfortable in to different environments, especially if you are changing jobs" (p.77).

How do you feel about money?
How do you manage your money/finances?

What kinds of food do you eat?
Do your spiritual/religious values play a role?

→ How do you vent your anger?
Do you have any hobbies?
Do you talk through with the person(s) that contributed to your anger?
Ⓞ

Do you know other 'autistic' people? Any anomalies? Spiritual / religious anomalies? How about with non-'autistic' people?

Chapter 9, Developing Tolerance: How to develop acceptance of and openness towards others without resorting to naivety

Chris states that "holding on to a view or opinion can be the root of conflict" (p.79) and can lead to divisions amongst people. He outlines that "One of the uplifting joys I have experienced meeting many other individuals diagnosed with Asperger's Syndrome is finding that all people on the autistic spectrum are different. Though in some cases we share some similarities, no two of us are the same" (p.79). He proceeds to state that some 'autistic' people want a cure for 'autism', yet he himself would not, despite this he feels that if there ever was a cure he would rather that such persons have access to it – illustrating his tolerance (p.80). Chris highlights a Buddhist monk's teachings in relation to us all being "a product of our 'cultural conditioning', in terms of different values we are brought up with. To go beyond it can take a determined effort, but through development of effective tolerance, one can become 'awakened' rather than 'conditioned'" (p.81). He then outlines how 'autistic' people can be less likely to be conditioned due to such cultural values being invisible and unwritten, therefore being missed by 'autistic' people – hence an advantage of being 'autistic'. Simultaneously, he describes how this can also be a disadvantage, in that when an 'autistic' person is not aware of such unseen cultural values they may, and do, become confused as to why people behave the way they do. Chris later outlines how meeting different people who have also been discriminated against can lead to seeing them as they are rather than from a conditioned perspective (p.84), that exposing oneself to different cultures (p.84) and practicing loving-kindness (Mettā) meditation (p.85) also helps in developing understanding.

How do you feel about also being autistic?

Are there any advantages / abilities that 'autistic' people may have that non-'autistic' people may have difficulty with?

Are there any advantages that 'autistic' people may have that non-'autistic' people may have difficulty with? How about in relation to spiritual life / religion?

Chapter 10, Measuring Success and Goal-setting: How to measure success realistically and achieve without distancing ourselves from truth

Chris states that cultural conditioning can also affect one's view of what success is and that "One of the most important things I feel I have learned since my diagnosis is not to live up to anybody's expectations but my own, and to ensure avoidance of extreme disappointment where possible, by keeping my hopes and expectations realistic" (p.89). Buddhism focuses on happiness and material wealth comes and goes, especially in light of death, whereby "material possessions are no longer of use to us" (p.90). Going through suffering can mean that one feels that one deserves "a better future than others because of what one has previously suffered" (p.91). He feels that it is this line of thinking that led him to distance himself from reality (p.91) and create false unrealistic hopes (p.92), which in turn can lead to ill-will and envy. He brings to the fore Buddha's teachings regarding the "five component parts, or 'Khandas', of sensory perception that contribute to such irrational distractions" (p.92), e.g. "1. rūpa – physical phenomena", "2. vedanā – feelings of pleasure, pain or indifference" and "3. saññā – concepts,

same question re: negatives?

Do you travel? How do you feel about that culture?

What do you expect for yourself? your goals? Do others influence what you expect of yourself? Do your sensory abilities influence your expectations? Goals?

→ what are the things in your life that you easily accept?
what are the things you find difficulty in accepting?

labels and allusions", and states that "Through recognising the Khandas, I have found that the more one wants things to be the way they want them to be, the more this can expose one to dukkhā [suffering]" (p.93). Chris then describes his attitude of trying to measure his personal happiness in the long run rather than in short-term material gains, seeing the positive aspects in all his actions as well as in mistakes, and setting realistic goals so as to avoid the hindrance of sloth and torpor (p.94 – p.95).

Chapter 11, Facing and Coping with Suffering; How to manage feelings of suffering (dukkhā) through reflection

Has being recognized as also being 'autistic' influenced your ability to accept + not accept certain things in your life?

Do you reflect about your life experiences? Do you think about them?

Suffering arises in not being able to accept things as they are, "often because we want things to be a particular way" (p.101). Chris details how being aware of being 'autistic' has helped him to adapt to different environments and that writing his autobiography (Mitchell 2005) "was almost like an extended Vipassanā practice in the sense that writing it involved gathering and reviewing some of the most difficult periods in my life" (p.103). He goes on to highlight that by balancing the difficult times with the happy times enabled him to accept that "suffering is impermanent, and that to some extent it helps to remember how one may have learned through such experiences, without becoming attached to them to the extent that one finds themselves living with the effects of such times rather than letting them go through moving on. This can also help one relate to others who experience similar difficulties, as well as one's own development of effective coping strategies" (p.103). Therefore, acknowledging the roots of suffering can enable one to learn and develop. Using the Vipassanā practice, Chris has come to realize that the social isolation and asking oneself "why me and not anybody else" (p.104) led to much suffering, yet he now recognizes that there were other people going through the same thing, and he got involved in a e-mailing list called "Autuniv-1" and met others in the same situation. Therefore, he states, "My own ways of dealing with suffering, I feel, have had effects on others in terms of finding meaning in suffering" (p.105). He then highlights that dukkhā (suffering) has enabled him to find out the truth about himself, e.g. being 'autistic', and that it has also brought the Asperger community together; "The ability of dukkhā to bring together the Asperger community to provide one another with insight, I feel, can, despite what those who have experienced it have been through, be the meaning of suffering for many people with Asperger's Syndrome" (p.106). He also states that it can dukkhā can also bring together people who are not 'autistic' (p.108). According to Chris, "Vipassanā practice has enabled me to both welcome dukkhā and find meaning in it, and, perhaps most importantly, to recognise it" (p.108); hence, self-reflection has enabled him to develop his perception and understanding of himself and the beings around him.

what, if any, have your moments of suffering enabled you to learn about yourself? others? environment?

Do you meditate? How does this make you feel? Do you meditate with others? How do you meditate? How often? Does also being autistic influence this at all?

Chapter 12, Finding Balance in Mindfulness and Concentration: How to take responsibility of one's own world and recognise the worlds other live within

In this chapter Chris outlines how "Many textbooks and guidance literature, when describing the conditions of autism and Asperger's Syndrome, often describe people on the autism spectrum as 'living in their own world'. Though this is largely true, the teachings within Buddhism suggest that *all* individuals live in their own world, a creation of the mind, largely perceiving their surroundings through the perspective of the self" (p.113). Therefore, Chris is amalgamating a concept with regards to himself as an 'autistic' person with a concept from Buddhism that is that much more encompassing and inclusive with regards to *all* humans. He then continues to promote going beyond one's comfort zone(s) (p.114) and that there are many strengths to being 'autistic', e.g. remarkable art work, deep concentration etc. (p.115). He also states that "Concentration is also a necessary tool for meditation, particularly for noticing and adjusting to different stages during meditation practice, while memory is a necessary tool for chanting in terms of being able to retain different chants recited during practice" (p.115). Though he also states that it is these kinds of strengths that can also "cut one diagnosed with the condition off from their surroundings" (p.115). Hence, Chris is suggesting that 'autistic' persons have a meditative style(s) of being? He further outlines how meditation has enabled him to "develop more mind flexibility" (p.116) and that as much as routines are useful it also helps to do things differently so as to remain mindful of the moment itself (p.117) and avoid the hindrance of sloth and torpor; he has been applying these principles in his own life, e.g. taking a different route when driving to work (p.118).

Chapter 13, Overcoming the Hindrances: How a person with Asperger's Syndrome can overcome difficulties associated with the Five Hindrances through recognition of the Five Spiritual Faculties

Chris outlines how The Five Spiritual practices as described by the Buddha, 1. trustful confidence and faith, 2. mental strength, vigour and energy, 3. mindfulness, 4. concentration and mental unification, and 5. wisdom (on page 123), are useful in coping with various pleasant and unpleasant experiences. He provides examples of each, e.g. for trustful confidence and faith he states that "The neutrality that I have experienced during practice of loving-kindness (Mettā) meditation has enabled me, when feeling angry towards others, to concentrate anger, and to recognise acting on one's anger outside meditation. This has helped me to put behind me much agitation from past instances of bullying and ill-will that I have experienced as a person with Asperger's Syndrome, to the point where I understand other reasons for their

When I say 'love', what comes to mind and/or body?
Do you meditate with 'love' in mind & body?
Do you love yourself? Do you love others?

what does your religious/spiritual beliefs state about love?
(?)

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actions towards me and do not lay blame" (p.124).

Chapter 14, Epilogue: University reunion

In this chapter Chris outlines the reunion between he and former university peers. He initially does not want to attend as he is reluctant to see some people who treated him negatively, however, due to his belief in seeing people as they are now he replies to the e-mail invitation and is encouraged by the peer who sent it to attend, and he does. Attending the event made him realise how people can change over time, including himself, and he felt that "what was perhaps even nice was how we were all happy for one another in regards to how our futures had turned out since university" (p.131).

→ what comes to mind / Body when I say "forgiveness"?
 Do you practice forgiveness?
 What are your spiritual beliefs about (or and religious) this?
 → Do you practice living in the here + now?
 How?

How does Chris Mitchell use spirituality &/ religion to make meaning regarding his embodied&non-embodied life experiences?

Question	Excerpt(s) from the Book	Researcher's Reflections and Notes	Ideas of Possible Questions for Interviews
1. How did the 'autistic' person make meaning of the paradox(es) of their lived experience? How did they practically deal with it?	"Being diagnosed with Asperger's Syndrome back in 1998, when I was 20 years old, was an immediate relief. Having had my diagnosis for almost ten years at the time of writing, I have found that beyond the impermanent nature of relief, Asperger's Syndrome is a lifelong journey, following a path. At times, this path can be difficult to negotiate, but with the right effort and through developing self-	Chris is accepting more so that life changes and this in itself is adding to him working with the 'impermanent nature', i.e. paradoxes and motion/dynamics of life. The mystery of being 'autistic', that was recognized later in life, gave Chris relief; a recognition of an aspect of oneself enabled further development of self-understanding	

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	<p>esteem, the path of Asperger's Syndrome can also be a fulfilling one to follow through life, if one is able to 'awaken' through development of awareness.</p> <p>Mindfulness is a technique, or state of mind, where one becomes intentionally aware of their way of thoughts, including being aware of how different thoughts arise, which provides for open, non-judgemental thought[...] is helpful for a person with Asperger's Syndrome, in terms of being able to effectively assess oneself in relation to one's surroundings, and is just as helpful for a person not on the autistic spectrum, in terms of understanding Asperger's Syndrome in a judgement-free way." (p.13)</p>	<p>/&perception? He is using the notion of 'the path' from Buddhism to merge his understanding and non-understanding of self regarding being 'autistic'?</p> <p>He feels a need to develop his perception due to the nature of his lived experiences. Hence, mindfulness is practiced so as to be in tune with the environment.</p> <p>Inner&intersubjectivity; becoming more sensitive to his own being is enabling him to become more sensitive and in tune with the outer physical environment/being(s) – paradoxical and dynamic in itself.</p>	<p>If you do remember, how did you feel when you were recognized as being 'autistic'? Did your spiritual/&religious beliefs play a role in this process? How did your family or/and guardians behave? Did they hold spiritual/&religious beliefs about it? How did it come in to play in your home life and/or when you were out with family/a guardian?</p> <p>Do you carry out any particular spiritual/&religious practices? How about in your everyday life? What are these?</p> <p>Do spiritual/&religious practices affect the quality of your life? The quality of your</p>
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		<p>Mindfulness is effective for all in terms of developing perception; mindfulness as a bridge between 'self' and 'others'? Mindfulness: can be practiced within a family setting?</p> <p>Lévinas (1961/1979, p.36): "The alterity, the radical heterogeneity of the other, is possible only if the other is other with respect to a term whose essence is to remain at the point of departure, to serve as <i>entry</i> in to the relation, to be the same not relatively but absolutely. <i>A term can remain absolutely at the point of departure of relationship only as I.</i></p> <p>To be I is over and beyond any individuation that can be derived from a system of references, to have identity as one's content. The I is not a being that always remains the same, but is the being whose existing consists in identifying itself,</p>	<p>relationships? The quality of communication that takes place between yourself and people or/and other beings? How?</p> <p>When you say "I" what kinds of thoughts come to mind with regards to the meaning of "I"? When you say "you" what kinds of thought come in to mind with regards to the meaning of "you"? How about the meaning and/or definition of "we"?</p>
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		<p>in recovering its identity throughout all that happens to it. It is the primal identity, the primordial work of identification. [.....] The I that thinks hearkens to itself thinking or takes fright before its depths and is to itself an other.... faced with this alterity the I is the same, merges with itself, is incapable of apostasy with regard to this surprising "self"."</p>	
<p>2. How did the person make meaning of the dynamic aspect of their lived experience? How did they practically deal with it?</p>	<p>Anxiety and mind: "Anxiety is present in some shape or form almost every day in our lives. As a person with Asperger's Syndrome, I have experienced much difficulty in being able to cope with anxiety, to the extent that it has taken over my mind" (p.53) and "Looking back, the anxiety that plagued me during those years took control of me to the extent that it was even affecting the quality of my work. For often, when I felt that my mind was troubled by such uncertainty, it was so difficult for me to focus on the</p>	<p>Anxiety can and does produce thoughts that overwhelm Chris, illustrating the thoughts&feelings in lived experiences as well as a concept (Mary Midgley's <i>Science and Poetry</i> comes to mind), and how these affect his everyday life – distancing him from the immediate tasks. Leading to negative thoughts&emotions regarding self and others, illustrating inner&intersubjectivity.</p> <p>Also illustrating how emotional&thought connectedness</p>	

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	<p>immediate task in hand. When having to try and balance these particular concerns, I often found that my mind ended up reacting to situations and in some cases certain people in a quite cynical way. This was where my inability to recognise the fourth hindrance of restlessness and worry verged into the second hindrance of ill-will towards myself and others" (p.55).</p> <p>When feeling frustration and anger due to not having got a job from an interview(s): "I have found that the more frustrated and angrier that it has made me, the more it has detached my mind from my body, in that the mind loses much bodily control, including control of the nervous system, leading to tension and shaking. When my mind is elsewhere, I can lose both awareness and control over the body in the sense that I find myself thinking about something different to what I am supposed to be doing, such as putting in the wrong</p>	<p>and non-connectedness affect learning and understanding regarding self, others and life.</p> <p>Making meaning with mind, body and actions – continual 're-aligning' with self? Continual reflexivity? This is also applicable to the next excerpt from Chris regarding frustration, anger, his mind, body and actions which are in motion in a 'confused' manner. Merleau-Ponty (1964/1968; p.9): "it is not entirely my body that perceives: I know only that it can prevent me from perceiving, that I cannot perceive without its permission; the moment perception comes my body effaces itself before it and never does the perception grasp the body in the act of perceiving.* If my left hand is touching my right hand, and if I should suddenly wish to apprehend with my right hand the work of my left hand as it touches, this reflection of the body upon itself always miscarries at the last</p>	
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	<p>ingredients when cooking" (p.63).</p> <p>Action: "I find that generally stepping back from it all through meditation or undertaking a physical activity (e.g. walking) or even doing a routine job (e.g. washing the dishes, vacuuming) helps to put such feelings aside so that I can handle them appropriately when I need to" (p.57).</p>	<p>moment: the moment I feel my left hand with my right hand, I correspondingly cease touching my right hand with my left hand. But this last-minute failure does not drain all truth from that presentiment I had of being able to touch myself touching: my body does not perceive, but it is as if it were built around the perception that dawns through it; through its whole internal arrangement, its sensory-motor circuits, the return ways that control and release movements, it is, as it were, prepared for a self-perception, even though it is never itself that is perceived nor itself that perceives. Before the science of the body (which involves the relation with the other) the experience of my flesh as gangue of my perception has taught me that perception does not come to birth just anywhere, that it emerges in the recess of a body."</p> <p>Chris reminds himself that the</p>	
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		<p>anger is impermanent and distances himself from the cause of it, addressing it behind closed doors; aligning the angry aspect of his self with the observing self? Arthur Deikman's "The Observing Self" comes to mind. Chris's course of action is dynamic; flowing with the dynamics in an 'indirect' manner (e.g. doing something with one's body to keep one's mind otherwise occupied) in order to gain a <i>sense</i> of stability? This is paradoxical: movement and state of calmness are inter-related. Delving in, to, through a sense of mystery (e.g. taking mind off the actual matter at hand) in order to work with the dynamics? Coping and learning with mystery? He is developing more of an attitude of accepting that things change; in itself leads to accepting that we cannot know how all things will turn out to be, i.e. accepting of mysterious nature of our lived experience.</p>	<p>How do you cope with changes? Do your spiritual/&religious beliefs and/or practices play a role in this? What kinds of situations make you feel happy? What kinds of situations make you feel content or and neutral? Is there something you remind yourself of/and do to feel like this? What do you learn about yourself? What do you learn about your body? What do you learn about others' /& family members? Do you have hypersensitivities and hyposensitivities? How do you make sense of such abilities and their effects? Do you use spirituality /& religion to make sense of such abilities? What do you learn about others? What do you learn about their bodies? What do you learn about life? What kinds of</p>
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		<p>van Manen may be of use regarding categorising the reflective aspects of my, as well as participants', lived experiences (1990; p. 101): "Lifeworld Existentials as Guides to Reflection</p> <p>There are four existentials that may prove especially helpful as guides for reflection in the research process: <i>lived space</i> (spatiality), <i>lived body</i> (corporeality), <i>lived time</i> (temporality), and <i>lived human relation</i> (relationality or communality)." Something to think about... ?</p> <p>For myself to consider: How does participant make meaning of the status quo elements (anxiety, mind, frustration and anger)? Is there a particular theme(s) or thread(s) that runs throughout their story(ies)? How is perception playing a role in their experiences? How are they illustrating self-knowledge and what role is this</p>	<p>situations make you feel anxious? How do you cope with them? What kinds of situations make you feel angry? What do you learn about yourself? What do you learn about your body? Hyper and hypo sensitivities? Meaning-making regarding, and/or with, such abilities? What do you learn about others? What do you learn about their bodies? What do you learn about life?</p>
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		playing in their story(ies)? How am I doing these things during the interview(s) and afterwards?	
3. How did the person make meaning of the mysterious aspect of their lived experiences? How did they practically deal with this?	<p>Suffering and not knowing why in itself led to more suffering: "For me though, what I felt was suffering was remaining undiagnosed until I was 20 years old, often knowing I was different but not knowing of any reason as to why." (p.102).</p> <p>Facing and coping with suffering via reflection: "I feel from what I have learned that being aware of how Asperger's Syndrome affects a</p>	<p>"knowing I was different" & "not knowing of any reason as to why"; the known&mysterious(unknown) aspect of oneself and one's lived experiences cause pain. Self-knowledge in itself is paradoxical? Which leads to a self-understanding/flourishing in relation to being recognised as being 'autistic'? And continues via Chris's ongoing journey and path? A constant paradoxical dynamic flow of mystery revealing itself, leading one in to deeper depths of Self with Self?</p> <p>Shems&Rumi come to mind (in Fihi Ma Fihi (1260 – 1273), "It is what it is"/The Discourses of Rumi, translated by A.J. Arberry, 1961 / 2000; p.37-38): "It is pain that guides us in every enterprise. Until there is an ache within, a passion and a yearning for that thing arising</p>	<p>When were you recognised as being 'autistic'? Whilst growing up did you feel different and not know why? Do you feel that you suffered during the years that you were not as aware of this aspect of yourself? What do you think suffering is?</p>

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<p>person can enable one to put their diagnosis into the context of different surroundings and situations they may find themselves in. In turn, this can help explain different mind states, positive and negative, that one may be subject to in different situations" (p.103), "Writing my autobiography (Mitchell 2005), when I look back now, was almost like an extended Vipassanā practice [a meditation practice that is aimed at seeing things as they really are] in the sense that writing it involved gathering and reviewing some of the most difficult periods in my life" (p.103), and Chapter 14: reunion with colleagues as being the epilogue; "One of the themes that this book has covered is being able to see people from one's past as they are now, including those that one has experienced friction and conflict with. A concept in Buddhism that hasn't been covered in this book though is the notion of Karma. Karma, meaning 'action' in Pāli, is</p>	<p>within us, we will never strive to attain it. Without pain it remains beyond our reach, whether it is success in this world or salvation in the next, whether we aim at becoming a merchant or a king, a scientist or an astronomer. It was not until the pains of birth manifested in Mary that she made for the tree. Those pangs drove her to the tree, and the tree that was withered became fruitful. We are like that story of Mary in the Koran. Every one of us has a Jesus within, but until the pangs manifest, our Jesus is not born. If the pangs never come, then our child rejoins its origin by the same secret path through which it came, leaving us empty, without the birth of our true self."</p> <p>Constantly practicing this accepting of paradox, dynamics and mystery, which are all intertwined. In itself leading to development, or re-alignment, of the reality(ies) that which is 'in' our depths and 'outside' of it?</p>	
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	<p>often applied to future results of past actions, including how false or malicious actions can result in suffering. As I have discussed much in this work, actions by or towards a person with Asperger's Syndrome, especially undiagnosed Asperger's Syndrome, that have negative effects can result from things being tried to the best of intentions but having reverse effects or simply through misunderstanding. In this case, Karma can help one atone for past actions.</p> <p>To give an idea of how these themes can apply effectively to situations where one meets people from their past, I have taken my university reunion (from my undergraduate years) as an example" (p.129).</p> <p>'Returning' and facing others by using a former teacher's statement and empathy: "Thinking of what one of my former primary school teachers had said of how he often felt frustrated with himself, more so</p>	<p>Regarding Chris writing his autobiography, van Manen (1990 p.127) comes to mind: "To write is to measure our thoughtfulness" – Chris is practicing reflexivity and phenomenology.</p> <p>Chris is using the notion of Karma regarding accepting the mysterious nature of one's lived experiences with others and practicing forgiveness.</p> <p>Chris is projecting the understanding and empathy he developed for his former teacher on to his fellow former university peers. The acceptance of the</p>	<p>What do you do when you are in a confused state? How do you feel? How do you behave? Do your spiritual/&religious beliefs play a role in your decision-making? How?</p>
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	<p>than with me, wondering what to do to 'get through to me', this insight enabled me to realise that there was a similarity in this sense with my former undergraduate colleagues" (p.130).</p> <p>Seeking balance: "the teachings within Buddhism suggest that all individuals live in their own world, a creation of the mind, largely perceiving their surroundings through the perspective of the self" (p.113).</p> <p>"Mindfulness is not developed overnight. It can take months or even years of right effort and concentration to cultivate the mind. But if one is willing to put in the</p>	<p>confusion/mystery of the reality(ies) that was lived between them in itself enables further empathy and compassion to be exercised. A revelation of mystery in to understanding (i.e. what his teacher told him) enables the resolving and empathy development with others he lived similar kinds of confusion/mystery with; Chris is willing to work with the mystery of life and try again by agreeing to attend the reunion.</p> <p>William Blake (1790) comes to mind: "If the doors of perception were cleansed every thing would</p>	<p>Have you been in a situation with a person whereby they apologised to you in a way that made you understand and forgive them? Do you use this kind of understanding with other people who may not have had the chance to do a similar thing or/and maybe feel too embarrassed to do so?</p> <p>Have you been in a situation whereby you were interpreting things in one way and the other person was interpreting them in a different way? How did you</p>
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	<p>time, potential benefits of mindfulness include: [...] ” (p.119)</p> <p>Overcoming the Hindrances: “Throughout this book, I have discussed bringing in qualities I feel I have experienced during meditation practice, including calmness, insightfulness, empathy and general neutrality, into different life situations [...]through qualities of the cultivated mind, to recognise and balance what the Buddha described as the Five Spiritual Faculties.” (p.123).</p> <p>Measuring success and goal-setting: “not to live up to anybody’s expectations but my own” (p.89), “Within Buddhist values, the ethos is on happiness and, above all, contentment rather than ‘success’ (p.90), “Through recognising the Khandas [sensory perception that contribute to irrational distractions], I have found that the more one wants things to be the way they want them to be, the more this can expose one to dukkhā” (p.93), and</p>	<p>appear to man as it is, Infinite. For man has closed himself up, till he sees all things thro' narrow chinks of his cavern.” How does one achieve this? One method is self-reflection/meditation?</p> <p>One way of working with the mystery of life, that can cause confusion, is to practice meditation and align more so with the observing self?</p> <p>Strengthening one’s alignment with the observing self so as to be better prepared with the mystery of life?</p> <p>Accepting one’s own expectations and reality(ies) as being worthy of living in line with, and placing one’s wellbeing and happiness at the top of one’s priorities so as to work with the mystery of life.</p> <p>Achievable goals; less stress and suffering and more satisfaction</p>	<p>work with this? Did your spiritual/&religious beliefs come in to play? How?</p> <p>How do you decide your goals in life? Do your</p>
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	<p>"Goal-setting, if done realistically while applying the patience to see it through can also be a motivating force, thus avoiding being affected by the hindrance of sloth and torpor" (p.95).</p> <p>Discipline and routine: "The depression that I experienced prior to my diagnosis of Asperger's Syndrome in 1998 was, now I feel, partly the result of loss of self-discipline, which then led to a loss of routine in which I felt comfortable. When losing routine, I found myself developing some unhealthy habits" (p.69), "One of the many benefits I feel I have gained from meditation practice and belief is that it has given me routine in terms of setting aside time each day to practise. The</p>	<p>with one's life. Working with the mystery of life in terms of explicitly establishing a goal(s) and working towards it and with it – in itself leading to being content. Lévinas (1961/1979; p.115): "Happiness is accomplishment: it exists in a soul satisfied and not in a soul that has extirpated its needs, a castrated soul. And because life is happiness it is personal."</p> <p>Forming routine behaviour and thoughts is a way of working with the mystery of life; making one's life predictable in certain respects. Explicitly making a routine of self-reflection, meditation, a part of one's routine is another way of working with the mystery. The meditation itself helping to lessen anxiety – becoming more comfortable with the uncomfortable – which is usually a product of the more so mysterious element of one's lived experiences.</p>	<p>spiritual/&religious beliefs influence such decisions? Do your bodily abilities play a role in such decision making? Does your family life influence such decision making? What is your main goal in life? Are there particular things you do in order to achieve such a goal?</p>
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	<p>practice itself I feel has given me the discipline to maintain a routine in which I am comfortable, which reduces my anxiety levels" (p.71), "The Buddha's teachings suggest that one of the sources of dukkhā relates to the impermanence in our lives. Something that I have found today's highly competitive job market, is that even a permanent post isn't entirely secure.... Having been affected by this in recent years working in local government.... I have found it helpful to, where possible, anticipate where change may occur, so that I can prepare for it" (p.76).</p> <p>Developing tolerance: "It is known that many adults with Asperger's Syndrome still suffer from the effects of bullying they experienced in the schoolyard, and some even have been treated with similar therapies to those used to treat Vietnam war veterans. Practice of Mettā [loving-kindness meditation]</p>	<p>Accepting that things change and that it is better to be prepared for change and actually preparing; working with mystery. John Keates's 'negative capability' comes to mind and so does 'the phenomenological attitude'.</p> <p>Mystery revealing itself; the individual is placed in a position whereby he has to work with it in some way or another. He considers that there are other reasons why they acted the way they did and this enables him to take it less personally and use a more widened perspective of the dynamics that were prevalent between himself and former peers. It is maybe this</p>	<p>How do you feel about your work? Do you consider aspects to do with your bodily functioning (e.g. hyper and hypo sensitivities) when applying for jobs? How did you end up doing your line of work? Do your spiritual/&religious beliefs influence your choice of</p>
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	<p>encourages one to extend their range of benevolence to even those that one finds they may have disliked or even found despicable, so that one finds compassion. Where I have found compassion in relation to the bullying that I suffered during my school days is through understanding that those who bullied me in the schoolyard perhaps didn't know any better, and it could be that now they are older, wherever they are, they perhaps feel a little guilty, like some of my former university colleagues said they felt after they found out I had been diagnosed with Asperger's Syndrome" (p.85).</p>	<p>to-ing and fro-ing of thoughts&feelings in itself that enables mystery and forgiveness to flourish? van Manen (1990; p.105): "As we meet the other we are able to develop a conversational relation which allows us to transcend ourselves. In a large existential sense human beings have searched in this experience of the other, the communal, the social for a sense of purpose in life, meaningfulness, grounds for living, as in the religious experience of the absolute Other, God." Relationship(s) and communication, and its prevalence in meaning-making? Merleau-Ponty (1945/1989; p.102): "I am essentially open; I am open to my own past and to other people, I exist with others in a common world in which my experience interweaves with theirs" ... (p.103:) "my body is always perspectival – I never have an all-encompassing hold on the world; there is therefore room for other incarnate subjectivities, and their</p>	<p>work /& the amount of work you do? How do you cope with changes in the working environment?</p>
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		<p>points of view complement my own. Their body expresses their intentions and I perceive those intentions with my own body; insofar as my body takes up the other's intentions, there is an internal relation between our bodies".</p> <p>Everything that we experience is done so via perception? Our body is and is not perception? And it is constantly reflecting (Merleau-Ponty, 1964/1968)? Therefore being aware of this reflexive state and re-aligning with it enables us to gain a sense of stability and vibrate with the mystery of our beingness in a more harmonious manner? Mystery holds meaning. Paradox creates confusion and dynamics, which in themselves lead to seeking meaning, which the seeking in itself could be said to also be the meaning. The aim is to recognize the process(es) as so?</p>	<p>You do not have to answer this question if you do not want to... how do you feel about your body? How do you feel about your hypersensitivities? How do you feel about your hyposensitivities? How about your family's understanding and/or non-understanding of these aspects of your body? Are there aspects of yourself that you feel are present that you may not be able to put in to or express in words? Do you believe in intuition? How do you feel about it? Do you feel that you use your intuition much? How do you use it? How not? Does your family know about these factors? How do/did they respond?</p>
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Questions and Reflective Notes Regarding the 'Other' and Myself	
<p>1. How do 'autistic' persons' make meaning? What is my meaning-making process(es)?</p>	<p>Buddhism, goals, as a guideline of thinking, observing self, framework and concepts and moral guidelines... Merging with Asperger's – a path/way – same in Buddhism. I am doing this as well – bridging aspects.</p> <p>Practices; mindfulness - Reflection – vepassana – autobio, the work he does.</p> <p>Bodily functions; anger, anxiety, food.</p> <p>Past experiences and memories; others, goes to a temple, food.</p> <p>Independence and interdependence; seeking to be economically independent and wants to feel less isolated, i.e. seeking a deeper sense of connectedness with the beings in life?</p> <p>What he has and does not have; i.e. a stable job makes him content, and simultaneously he does not want too many material belongings.</p> <p>Paradox; as described above.</p> <p>Dynamics; as described above.</p> <p>Mystery; as described above.</p> <p>This whole document illustrates my meaning making, i.e. via the embodied&non-embodied Self (inner&intersubjectivity).</p>

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<p>2. What are the implications for perception(s) and self-knowledge?</p>	<p>Lived experiences are extremely important in our development of self-understanding. Yet, is there also something, that which is observing, that is not actually living (or not involved in) the moment by simply observing the moment itself? Death&life intertwined as one? Self-knowledge is present and simultaneously not present?</p> <p>Thoughts&emotions and self-understanding are very much intertwined; cognition and phenomenology?</p> <p>Observing Self; mindfulness and development of better understanding?</p>	
<p>3. What are the implications for phenomenology as a methodology?</p>	<p>Phenomenology is very useful in terms of describing paradox and lived experiences, however, how does one work with the dynamic and mysterious nature of being in educational terms? Van Manen, 1990, and the four existential categories (p.102), as mentioned above in the table, may be useful for producing the interview protocols and may be aspects to focus on and through when working with families in the future.</p> <p>Phenomenological theory may well be developed further in terms of learning about the nature of self, and through self, by 'autistic' persons and 'their' lived experiences; this needs to be made that much more explicit. Jung, Romanyshyn and Shotter come to mind; maybe there is a place for a bridging of phenomenological theory and depth / analytical psychology? Mearleau-Ponty's <i>The Visible and the Invisible</i> and learning come to mind.</p>	
<p>4. What are the implications</p>	<p>IPA as a conceptual framework:</p> <p>William James's influence in IPA is very useful.</p>	



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<p>for IPA as an approach and the methods involved?</p>	<p>When thinking about William James, Chris's writings as well as Donna Williams and her writings: how about 'tools' when exploring that which is not visible, the mysterious element of our being? A place for depth psychology, e.g. Jung, within phenomenology and IPA? I feel this bridge is already present in phenomenology and IPA via its use of persons' lived experiences, however, maybe it is worth making it that much more explicit?</p> <p>IPA and methods:</p> <p>Bracketing is very useful in accepting people's lived experiences as being valid in their own right. Maybe this is also a way of accepting the mysterious element in our lived experiences?</p> <p>More research required with IPA and reflective texts/autobiographies in themselves; sent Jonathan Smith as well as Michael Larkin e-mails (June 2014) asking for papers they may be aware of, they stated IPA could be utilized with autobiographical/reflective texts, though they are not aware of such papers. One paper, as outlined in the Methods section, by Spiers and Smith (2012) that utilizes IPA with poetic reflective writing has been useful, van Manen's (1990) writings are becoming more useful, and so has the table structure used herein thanks to Smith et al. (2009).</p>	
<p>Questions and Reflective Notes Regarding the 'Other', the Family Context and Myself</p>		
<p>How does this 'autistic' person make meaning? Especially in the family context?</p>	<p>Chris uses Buddhism and its teachings, the Four Noble Truths and the Eightfold Path, to make meaning of 'autism' as a way of being, living, as well as working with one's suffering.</p> <p>Chris does not delve so much into his family's meaning-making in terms of whether they practice Buddhism or not, however, he states that being able to like himself is also enabling him to see, feel and</p>	

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<p>What seems to be the family's meaning-making process(es)? What is my meaning-making process(es)?</p>	<p>accept that he is valued by his family; as is in <i>Chapter 3, Starting with Who You Are: How the easiest person to like can be you:</i></p> <p>He explains that in "Theravāda Buddhism though, the focus of who is the easiest person to like is oneself. Initially this may sound self-important or even egoistic, but the focus on liking oneself within the Theravāda tradition is more about finding the positive aspects and personal qualities one may have, that in some cases perhaps one wasn't previously aware of, before applying these qualities to how they relate to others. This includes being able to take one's frustrating experiences and curtail them in such a way that one can even see positive actions from where frustrations originate" (p.30). He then includes information about some of the frustrations that 'autistic' people can and do experience, e.g. struggling to achieve high grades in school, not being employed, and finding it difficult to make friends and form intimate relationships. He later states that meditation has enabled him to learn to like himself and "can be a route to self-confidence and, ultimately, personal happiness" (p.33). He also states that it has "enabled me to feel that who I am means much to those close to me, including my family, friends and people who feel my help has made a positive difference to their lives" (p.33).</p> <p>Furthermore, the non-recognition of an aspect of oneself can be confusing and frustrating for both Chris and his family. Though practicing forgiveness, self-reflection, and focusing on living in the now is enabling Chris to have more understanding, and I assume, more harmony with his family and friends. As is outlined in <i>Chapter 5, Gaining Insight from Those Around Me: How insight can strengthen one's awareness:</i></p> <p>Chris outlines how being recognized as having Asperger's Syndrome and reviewing his life so that he could write his life story (<i>Glass Half Empty, Half-Full</i>, 2005) has enabled him to develop a deeper insight in to the ways that he was treated in his younger years by family, peers and teachers. He states that what he felt needed to be understood is the "confusion that can result from growing up with undiagnosed Asperger's Syndrome. People around a person with undiagnosed Asperger's Syndrome, including members of their family, can experience frustration when they try so many different ideas to help the person develop social and independent skills with the best of intentions but have negative results" (p.46). He then advocates recognition of 'autistic' traits at a young age and relevant educational arrangements. He states that</p>
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	<p>forgiveness can be difficult, however, he is finding that a way to achieve this is to look at people in the context of the present rather than the past, which he feels that in turn enables people from his past to see him as he is now.</p> <p>My meaning-making process is as the above outlines; in that Chris is treating being 'autistic' as a 'way'/'path(s)', which from what I'm aware of about Buddhism is a common term that is used to refer to one's life and life journey(s).</p>
<p>What are the implications for perception(s) and self-knowledge?</p>	<p>The implications are that one's perception and self-knowledge can be 'developed' by:</p> <ul style="list-style-type: none"> - Self-reflection and meditation - Liking oneself, or by my terms, self-love - Intersubjectivity <p>Furthermore, as a researcher attempting to be as ethical as possible, do I have a duty to like myself and the 'other'?</p>
<p>What are the implications for phenomenology as a methodology?</p>	<p>Self-love comes to mind</p> <p>Meaning-making ought to be focused on, with a more explicitly descriptive way of expression regarding interpretation and the sensory</p>
<p>What are the implications for IPA as an approach and</p>	<p>IPA: simply reflecting the emerging analysis process, for example:</p> <p>Certain readings come to mind as I proceed and therefore I include them in the table and illustrate how I</p>

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the methods involved?	dialogue with them Questions are arising in my mind as I proceed, hence the last column named 'Ideas of Possible Questions'
What is self-knowledge? How does it develop?	There is and is no such thing. We exist and do not exist simultaneously. It does not 'develop' as such, it is present and we are simply realizing it in becoming more consciously aware. Maybe I ought to stop using the term 'develop'?
What is meaning? How does it develop?	Meaning is God, "mâna Allah'dir" (Shems&Rumi in the Mesnevi/Mathnawi, 1263/2011; page 96) & meaning is also perception (p.79), and 'develops' by God playing backgammon with itself (Shems&Rumi, 1263 / 2011); inner&intersubjectivity and a continuous dance.
What is perception? How does it develop?	Perception? That which is paradoxical, dynamic and mysterious and is embodied and non-embodied, is magnifier and non-magnifier of experience. Pointing to meaning from 'within' and in the 'physical' realm. It develops by constantly merging with its true essence, in continual flux, being observed in, with and through awareness and then rolling back in to the depths from which it came from ... ?

The questions that have arisen regarding the methods so far are:

1. How does one use narratives/autobiographical texts with IPA?

- So far summarising the story and then asking the status quo phenomenological questions, simultaneously utilizing a table structure, is helping to use IPA with reflective writings.

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2. How does one use autobiographical/reflective texts in order to further become sensitive to the context and culture of 'autistic' persons and 'their' family life?

- As is illustrated above, reflective readings and questions that are arising from such interpretations are enabling me to become more sensitive to the context and culture of 'autistic' persons; this will hopefully happen more so with regards to the family when analysing the second set of excerpts of reflective texts.

3. How does one create further research questions (e.g. for interviews) and develop one's philosophical standpoint(s) whilst analysing 'autistic' person's autobiographies with IPA?

- Asking questions regarding the 'other's' embodied&non-embodied lived experiences and my lived experiences is enabling me to create further questions for interviews whilst using IPA with the reflective writings of 'autistic' persons. Having engaged with the descriptive summaries of the chapters is also leading to the development of questions directly derived from my interpretations of the text; after having completed the table I have returned to the chapters and gone through them, coming up with questions that are directly linked to the statements and points made by the author, therefore developing both thematic and idiographic questions.

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APPENDIX 3

Data and Analyses: Edgar Schneider, 1999. Discovering My Autism, Apologia Pro Vita Sua (With Apologies to Cardinal Newman)

Contextual information regarding this book:

(i) Who wrote the autobiography/& reflective text: Edgar Schneider

(ii) Where the autobiography/& reflective text was written: America

(iii) When the autobiography /& reflective text was written: It was published in 1999

(iv) Why and how the text came in to being:

In the *Prologue*, which is a page long, Edgar outlines that he wrote this book because once he had learnt that he is 'autistic' it "explained so many things about me that had previously been enigmas, even to myself" (p.9), and when he discussed this with the pastor of his church the pastor encouraged him to write an autobiography. He states that (p.9):

"I have done just that, not only for those who might like to know me better, but also as catharsis for myself.

I should like to start with a past incident that could be said to have marked the onset of this process of self-revelation. It took place at the time at which the classical epic poems began their stories: the 'middle of things'."

He then proceeds on to the next chapter, "The Determining Time Period".

(v) A summary of what the story is about:

Chapter 1: The Determining Time Period

In June 1978 Edgar was living in New York and suffered a nervous breakdown. Looking back he states that this was the onset of ADD (Attention Deficit Disorder) and that this was not recognized as so. His workplace also did not recognize this as the onset of a disability and he felt pressurised to come up with the goods as he had three children in school and his wife needed an operation. He did not want to change his workplace as

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when entering a new job his wife's pre-existing condition would not have been included in the medical benefits. A month in to having difficulties at work he looked into seeing a psychiatrist, however, there were no appointments available before the workplace's "shaping up or shipping out" (p.12) deadline. It all became too much for him and his wife ended up submitting him to a crisis centre at a nearby hospital, whereby he was appointed a psychiatrist. He took medication and gradually increased his working hours, until the doctor did not feel he had to see him anymore. He was doing well at work until a few months in he started to have difficulties with short-term memory and concentration. The new manager noticed this, they had a talk, and in the summer of 1979 he contacted his psychiatrist once more. His psychiatrist had thought that the previous incident had been more so to do with the circumstances, though in this case he was surprised as things were okay in Edgar's life. Edgar states, "I can only guess that, just as internists call anything they cannot pinpoint a virus (if there is a fever) or an allergy (if there isn't one), psychiatrists would call someone schizophrenic when they do not know what else to call him." (p.13). He then outlines that he possessed a "number of unconventional personality characteristics" (p.13) which make him come across as eccentric, and these did not help matters. Proceeding to state that (p.13), "Yet, although schizophrenics are eccentric, a person can be eccentric without being schizophrenic. This is a subtlety seemingly lost on many people, professionals in the field not excepted." The medication that he was taking also had side effects on his thought processes and made him come across as illogical. "Eccentric, tangential, illogical, and hallucinatory: this added up to schizophrenia" (p.14).

Chapter 2: Aftermath

He tried to work for a couple of years. Though his work was negatively affected by the effects of the medication he was taking. So after a series of meetings with the manager, the company doctor and his doctor he was "persuaded to be placed on the corporation's medical disability retirement program" (p.15). His doctor tried various medications, including Loxatane (which was not improving things), Lithium (which made him suicidal), MAO (monoamine oxidase) and Xanax (an anti-anxiety drug). He also had electric shock therapy; this did not go well. Xanax actually exacerbated his anxiety; on the few occasions he took it (December 1982 and July 1983) it led to severe psychotic episodes whereby his wife had to call the police. After the second occurrence he was submitted to the hospital and the diagnosis of schizophrenia was confirmed. He was put on Navane and another medication that helps to counter the side effects of Navane. He and his doctor had a disagreement over the care plan and he parted ways with this doctor.

Chapter 3: Resolution, of a Sort

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He went from one psychiatrist to another at the county mental health clinic, and when he moved to South Florida in July 1992 he got a new psychiatrist who stated that he disagreed with the use of Navane and the Cogentin (side medication) that comes with it as it turns people into zombies. In December 1992 he was moved on to Depakote, a mood stabilizer, and Buspar, an anti-anxiety drug. “Those lost intellectual and aesthetic faculties returned [...] I have since done a great deal of writing [...] I have gone back in to artsy photography, and I have sung with three concert choruses” (p.18). He feels that had he stayed on Navane he would not have been able to write this autobiography.

Chapter 4: Suspicions

During the years of psychiatric sessions and so on there was only one professional who suspected that Edgar may not actually be schizophrenic, plus “a number of confirmed schizophrenics” (p.19) that he knew. A professional with a Master of Social Work (MSW) stated that there were three things that made him question; (i) that Edgar was not divorced from reality, (ii) that he did not hear voices that told him to do things, and (iii) that he was not delusional, in that he did not *believe* that he was the mathematician or opera singer he fantasized about being. Edgar then outlines another three factors that he noticed; (i) his thought processes were not chaotic, (ii) he was not ruled by his emotions, and that (iii) he is generally not a grim person, unlike most individuals with schizophrenia. Edgar asked the MSW what he thought the actual factor might be, and the MSW stated he did not know, though after a year he stated that it was probably schizophrenia, “because, I am sure, he, like everyone else, did not know what else to call it” (p.21).

Chapter 5: A Revelation

Edgar did not question the label of schizophrenia until the spring of 1995, whilst his current doctor was not comfortable with this label as he referred to him as being “*atypical*” (p.22). Edgar read an article by Oliver Sacks, a neurological psychologist, in the New Yorker, entitled ‘Prodigies’ (January 9th, 1995), which was about ‘autistic’ savants. What had caught Edgar’s attention was the question “ ‘Can an artist make art without feeling it?’ ” (p.22). Which he then proceeds to explain and answer by stating, “ ‘ Since expressing emotion is what art is all about, can one express emotion through words and pictures, even emotion of great depth, without feeling it?’ The answer, judging from my own life is: ‘You had better believe it!’ ” (p.22). He saw much of himself in this article and took it to his doctor; after 3 months of talking it over they both agreed that for 16 years he had been misrecognized as being schizophrenic.

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Chapter 6: Recap of a Terrible Period

Here Edgar reflects on the past 16 years of his life, whereby he recounts that the medication that was given to him was not effective and had unfortunate side effects, that we was given electric shock therapy that also did not work, and “was considered by most as being unstable, unpredictable, possibly dangerous; if you will: ‘crazy’, someone who had to be put under some kind of control, chemically if not physically” (p.23). He outlines that his 3 children worried about inheriting “something awful which would come out in their early forties” (p.23) and he also worried that his descendants may become schizophrenic. The worst thing was that he felt he had lost his rationality, which is something he treasures highly, yet simultaneously still did have his rationality and so had full awareness of what he thought was happening. The irony! He states that (p.23 – 24) “My current doctor told me that whatever evidence exists that autism might be inherited indicates that it is a recessive trait so that my kids would, at most, be carriers. But even this might be a cause for needless worry. One area of agreement seems to be that autism is developed during the formative stages of the nervous system. This means that any ailments, which can cause neurological damage and that take place during those early years, could be the culprit, without having to have any genetic predisposition.” Edgar proceeds to outline that when he was 2 and a half years old he was bitten by a rabid dog and had to take a series of Pasteur injections, whilst when he was about 3 or 4 years old he came down with pertussis and scarlet fever, and that from what he has been told it could be a combination or any of these factors which “impeded proper neurological development or damaged what had already developed” (p.24). His mum had also told him that up until the age of 4 he had been an outgoing and playful child, and he became “withdrawn, uncommunicative, and solitary” (p.24). He believes that “this coincided with the onset of my autism” (p.24). He is thinking about ‘autism’ via the interaction of biological and environmental factors: “I have come to strongly doubt that autism is inherited in the sense of there being an ‘autism’ gene. Perhaps there could be said to be an indirect genetic component, in the form of an inherited susceptibility to the neurological assaults that cause autism” (p.24). He completes this chapter by asserting that such a neurological history may be the reason why he is constantly manic, that this causes him little concern whilst others may have to have small doses of him, and that thanks to this he gains a lot of joy out of living, bad and good.

Chapter 7: Correlating My Past Life

He uses Oliver Sacks’s article to point out factors with regards to his own life. He feels that since childhood he has had problems with emotion; “It seems that, just as some people have an important physical component missing (eyes, limbs, etc.), I have an important component of the human psyche missing: the ability to connect emotionally with other human beings” (p.25), referring to himself as an “emotional idiot”, and that in psychology the term “emotional deficit” is used. He is not devoid of emotion, however he feels that he lacks “the emotions that enable people

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to ‘connect’ with the emotions of other people” (p.25). He experiences the “‘survival’ emotions: fear and anger” (p.25), though these tend to be solitary and usually happen when he feels his space is intruded, so when he invites a person in things are okay. This can lead to behaviour that may seem as being obsessive-compulsive, though not in the strict technical sense that he does things repetitiously. His biggest fear is uncertainty. He is not a savant, and he is a part of a group called HFA, High Functioning Autism, and that people like him who have “normal communication capabilities are said to have AS” (p.26), Asperger’s Syndrome; “What we all share, of course, is the emotional deficit” (p.26). He states that he can express emotion through art and literature, including opera, “but not in direct communication with other people’s feelings” (p.26), and that he still cannot understand how non-‘autistic’ people can do this; “It is not that I am totally unfeeling, but that I just cannot ‘read other people’s signals’. I have no built-in signal decoder” (p.26). He has been criticized for intellectualizing problems. He may come over as being overly suspicious, however, this is more so due to his wariness about understanding people’s intentions. Furthermore, he completely trusts people who are upfront with him. He highlights that when the other person can put their feelings in to words these become thoughts and ideas in Edgar’s mind, and these he can deal very well with. In addition, the lack of emotional connection can be useful during conversations whereby a friend may seek his counsel and Edgar will not bring his own emotional baggage into the dialogue, so the friend is likely to receive sound advice. Stating that the “autistic person might appear to others to be distant and unsympathetic. (I have, no doubt, I appeared that way to many.) This, however, is not the case. He must be allowed to consider the problems and feelings of others with the tools that he has at his disposal, often in abundance” (p.27). Connecting with the article’s subtitle, he states that he is able to recount and tell classic love stories with great emotion and that people are very much moved by it, however, he is not able to do this with real people – something which his wife pointed out by asking him why this was so. He did not know what to tell her as he did not know. Edgar states that “For all of our life together, my wife complained about an ‘emotional wall’ that she said that I had around me. Considering what I know now, a more fitting metaphor would be a ‘dry hole’. A wall can be either knocked down by one outside, or pulled down by the one inside. Nothing thirst-quenching can ever be sucked out of a dry hole” (p.28).

Chapter 8: An Interesting Aside

Edgar outlines how three of his favourite composers, Richard Wagner, Anton Bruckner and Richard Strauss, and their lives illustrate how one can “express emotion through art when one does not feel such emotion” (p.29); for example, “One was Richard Wagner. His music dramas bristle with lofty, idealistic principles and tender, caring emotions. Yet in my view he was a totally unprincipled wretch who shamelessly used others, even those who virtually worshipped him and his music” (p.29). He also mentions Albert Einstein and Bertrand Russell as men who achieved great things in their respective fields yet “failed in every attempt that they made to try to form a close personal relationship” (p.30).

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Chapter 9: My Tastes

Edgar discusses music, art and literature here. He lists his favourite composers, e.g. Bach and Mozart, delves in to music from the Renaissance and Baroque periods, and dismisses “Rococo as the decadence of the Baroque” (p.31). He was not interested in music of any kind before the age of 12, however, when he was 12 (in 1944) he heard a piece of opera by Wagner on the radio and then soon afterwards heard another piece by Wagner. At the age of 14 a friend introduced him to Italian and French opera music; he muses about Italian opera, what he likes and dislikes. He learnt to play the piano, also using books from the library. He would sing for himself, and when he was a first year undergraduate a friend of his at the New York City music school said that he had a good voice and that he should train it. The school had scholarships and his friend talked to a tutor who gave Edgar an audition; he was given a scholarship and “studied voice for three and a half years” (p.34) until he graduated from College and was drafted into the army. He did not sing much until 1964, whereby he joined a local Church choir thanks to a neighbour, and from then on he decided that he would always make sure to sing in a choir. He states, “As to Church choirs, because the main interest in doing that was musical rather than religious, I restricted myself to groups that sang music that I liked and considered a challenge” (p.34). He feels that his tastes in art are unorthodox, e.g. Henry Tanner, Jose Orozco and Salvador Dali. He delves in to more about Dali and highlights that a reproduction of *The Sacrament of the Last Supper* hangs on the living room wall. Picasso’s and Michelangelo’s works are also mentioned, whilst “Impressionist works are pleasant enough, but to my taste, tend all to look alike. I’m hard put to see where the Expressionist school gets its name” (p.35). Moving on to literature, he outlines that “while I do have an extensive aesthetic sensitivity, it is with ideas that I have my greatest facility. These are not unrelated, which is why the authors whose ideas impress me the most (even when I disagree with them) are the ones whose works appear to have the greatest beauty of style” (p.35). He mentions Shaw and Wilde as two of his favourite writers, and that whilst at College his friends introduced him to the poetry of Gerard Manley Hopkins, answering some of his questions about religion. This criticism of Dickens is interesting in that it gives the reader a clue about Edgar’s beliefs about social reform: “There are a number of lionized authors whose supposed genius escapes me totally. Dickens wrote one great novel: *A Tale of Two Cities*. He was supposed to be a great exponent of social reform, but his solution to the poverty problem seems to be: for each poor person, find a rich benefactor or a long-lost rich relative” (p.36). More works by other authors are outlined and discussed to various degrees. He completes this chapter by asserting that one ought to familiarize oneself with the works themselves before reading criticisms or commentary about them: “When I was an undergraduate, I was discussing something with a professor whose specialty was medieval history. Another student came by and, after joining the conversation, asked what was a good book to read to find out about St Paul. The professor said, ‘Why don’t you read his letters?’” (p.42).

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Chapter 10: What I Mean by the Word 'Love'

Edgar prefers Greek as the language for discussing love, referring to the three words of *philos*, *agape* and *eros*: "Their meanings can be summed up as: love from the head, love from the heart, and love from the sex hormones. Looking back, the only one of which I was ever capable was *philos*. For all of my life, even when I came to be quite fond of someone, it was an intellectual appreciation of that person rather than one that was 'heartfelt'" (p.43). He proceeds to describe how he experiences his sexuality, stating that for example whilst being with a woman he has aesthetic fantasies of her during the moment(s), and this is what makes it pleasurable. He defines 'relationship' as: "any interaction between two people. This can range from a casual acquaintance to a committed marriage" (p.45).

Chapter 11: A Missing Faculty

Edgar refers to Olive Sacks's *An Anthropologist on Mars*, and compares himself to the blind man who had developed his other senses and was able to function well, however, when the man was given sight via a medical procedure he was psychologically disoriented. Edgar states that "Analogously, I seem to have compensated (some say I have over-compensated) for my emotional deficit by developing my intellectual and aesthetic sensibilities" (p.46). He proceeds to state, "It makes me wonder whether or not I would even want to be given the capability to feel the emotions others feel if my other faculties were to suffer as a result" (p.46).

Chapter 12: The Perilous Characteristics

He describes how two aspects of being 'autistic' can have their advantages and disadvantages and have played a significant role in his life; "having a very high pain threshold and being blasé about physical dangers" (p.48). For example, in 1968 he had locked himself out of the house, so without stopping to think he shoved the heel of his hand through the glass pane of the door. A piece of the glass cut right through his forearm, all the way to the bone. He had not felt anything and only noticed when he saw all the blood gushing out on the door. "Even then, I felt neither fear nor panic" (p.48).

Chapter 13: Can 'Heartless' Pity be Real?

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For all of his adolescent and adult life he has been socially conscious, however, this was not because he identified with the people he was trying to help, but more so out of “an intellectual conviction that this was morally right” (p.49). He feels he cannot ‘suffer with’ a person via the heart.

Chapter 14: Grief

He has never felt grief or a sense of loss. When his mother died in October 1994 everyone in his family expressed sorrow, however, he felt nothing. He said to a priest, “There are all kinds of support groups for people who grieve, but nothing for people who should be grieving but don’t” (p.51). He mentions that one of his daughter’s cats had passed away and that the remaining cat in the house was clearly grieving, and he could not help but think that “a cat, the most independent of God’s creatures, can grieve, but I cannot” (p.52). The irony is that he becomes very emotional and weepy when watching an operatic drama, “Yet, as noted above, I feel nothing in real-life emotional situations. This is connected with that topic of feeling ‘emotion’ on through art” (p.52). Moving on to state that, “Real-life emotions appear to me to consist of things felt in an unexpressed manner, and with another person also feeling them, almost in the manner of sympathetic vibrations at a resonant frequency” (p.52).

Chapter 15: Death and the Afterlife

Edgar believes in an afterlife. Death: “occurs when the laws of biology and chemistry come together to cause cessation of all functions of the body. (Given that, everyone has to die sometime of something.)” (p.53). Afterlife: “means that there is a part of one’s essence that survives death, and that this includes a continued consciousness of one’s existence” (p.54). His belief in the “existence of a supreme intelligence (or, if you will, a God) is based on scientific factors” (p.54). He then describes the often paradoxical ways in which people think and behave; that people who define themselves as believers and believing in an afterlife act as though there is no such thing, e.g. they are afraid of death and behave in ways that seem as though the deceased has gone to an ultimate destruction, whilst people who define themselves as non-believers act as if an afterlife does exist, e.g. atheists who ask their family and friends not to pray for them once they pass away, pointing out that if death is death and there is no afterlife what does it matter if they do or don’t pray for them?

Chapter 16: Solitude and Loneliness

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Edgar states that he has “never felt lonely or a need for what could be called ‘the warmth of another human being’, even a loving woman, or a good friend of either sex” (p.57), though he does enjoy the company of those whom he can have an interesting and stimulating conversation with. Regardless of where he is he can maintain solitude. He has never felt an emotional void that needed to be filled by another person and he has never taken up such a role in someone else’s life; he refers to himself as someone who is kind and a ‘loner’.

Chapter 17: Learning

Here he outlines how the “penchant for solitude manifested itself even when I started school” (p.58) and goes on to state that “My teachers were at a loss to explain why it was that, although I appeared to do no work in the classroom (because I did not interact with my classroom environment), tests showed that I had both absorbed and mastered the material” (p.58). He has been referred to as a ‘walking encyclopaedia’ and has a love of learning.

“Most autistic people have severe communication difficulties. This would indicate that they do not have the kind of communication channels possessed by most people, which is why they demonstrate learning difficulties when taught by conventional methods. It may be that autistic *savants* and high functioning autistics have extraordinary channels. (*Extra*, is the Latin preposition for ‘outside’. As a result, that word ‘extraordinary’ must be taken in the literal sense: ‘outside’ the ordinary.)

I get the impression that little study has been done on this. Consequently, having only this smallest intuitive grasp of how I learn, I am extremely hard put to explain the process to others. I have suggested this hypothesis (of extraordinary communication channels) to a number of professionals in the field. One did tell me that this approach is being taken with a view to explaining parapsychology” (p.59).

Is he suggesting that there is an intuitive element to learning? What is to be said about the concept of ‘tabula rasa’?

He proceeds to state that the “Bible says we cannot enter Heaven unless we come as little children” and gives his interpretation of this; “Is there another facet to being ‘childlike’? The answer is ‘yes’. There is another trait that kids have that they lose all too soon: an insatiable curiosity, coupled with great joy in learning something new, or finding the answer to a question that has been hanging fire for a while”. Later stressing that the ability to wonder ought not to be lost.

Chapter 18: Values that were Manifested During Military Service

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As an enlisted man he did not want to be a follower and felt uncomfortable in his roles. He ended up in a role whereby he was the FDC, Fire-Director and Computer, for an 81mm mortar platoon, which meant that he made the transformations from the FO's (Forward Observer's) corrections to those required by the guns, and to issue fire commands to the guns. This meant that he had a unique skill whereby everyone on the team, regardless of rank, were dependent on his expertise for the platoon's effectiveness. He was a one-man band working in a solitary manner, which suited him fine, though he felt that he was becoming vain and glorifying in it, therefore leading to a lack of job satisfaction.

Chapter 19: Interactions with Others

When it came to the time for him to be discharged from the army he had decided that seeing as he was neither a follower or a leader he would like to be an expert at something. This way he would not be a follower in terms of taking orders, and neither would he be a leader, in that he would simply give advice to people for achieving their objectives. He therefore returned to College and graduated in physics and mathematics. By this time he had also decided that he was never going to be able to make sense of human behaviour so it was worth sticking to a course and role that did not involve this so much. Edgar feels he is capable of giving love to people in the right conditions, however, he does not seem to be able to accept it: "For this reason, if I do connect with another person, it is because we have a compatibility, and not in order to fill some emotional need. (I often refer to the latter as 'feeding on someone emotionally'. This may seem harsh, however, this is the way I see it.)" (p.63). He likens himself to a cat, in that his favour is given freely, with no possessiveness, because he wants to, not because he has to or needs to do so. Since he does not cling on to a relationship his attachments can be easily alienated, and because he does not give the other person the feeling of being 'needed' this also affects his relationships, which he has been informed is an important thing for most people, who would otherwise feel insecure. He has never felt insulted by anyone and his feelings are not easily hurt. He remembers negative experiences, however, he was indifferent to them whilst living such moments. His step-father had referred to him as excess baggage and punished him physically and verbally at times, especially during the period in which his mother was not well, though he does not have any traumatic feelings or memories that come up. He had been taunted at school by the other kids, yet this made no difference as he had always been a loner, and during his adolescent years he never followed the crowd, preferring the company of adults. He has always shrugged his shoulders and let things be. Reflecting on his youth now he feels proud of himself. Though because it is difficult for him to be insulted it can be difficult for him to anticipate the possible hurts of others, and this is something he works at. Finally, he states that, "How should I like people to be toward me in this regard? Don't be polite; be candid" (p.67).

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Chapter 20: Art as an Early Outlet

The main person in the article by Oliver Sacks had an aptitude for art from a young age, and so did / does Edgar. He would draw things “rather realistically with minute detail” (p.68), did not prefer paint brushes at school because they did not enable him to paint such detail, so preferred pencil or pen, and he states that, “I am physically sensitive to small differences in color, but I am indifferent to it aesthetically” (p.68).

Chapter 21: Religion

He refers to Temple Grandin’s autobiography, *Thinking in Pictures*, and states that “her religious beliefs have evolved into those that are based on logic rather than faith and appear to stem, in an *ad hoc* manner, from addressing specific questions” (p.70). His family were all atheists and as an adult he converted to Roman Catholicism. There are two reasons for this:

“The first is the discovery I made at that time that, far from being, of their own essence, tolerant and open-minded, non-believers can be just as dogmatic, self-righteous, guilt-peddling, and judgemental as the most hard-shell religious fundamentalists.

The second involves the fact that, from the time that I became politically aware (at the age of twelve) I have had a social conscience. It occurred to me that this social conscience was resting on shifting sand unless it depended on objective truth and an ethical system that had a basis other than whose ox is being gored” (p.70).

By the time he was an undergraduate in College he had decided “that Catholicism had the ideal mix: orthodox and rational in its theology, but liberal and progressive in its teachings on social and economic matters” (p.71), also highlighting that the ethical system set by the Church has a great position regarding conflict resolution and peace, which significantly appealed to him. Furthermore, God sent prophets to people so that “His will be known” (p.72), it was not direct communication, and he refers to this as a mechanism of “working for people through people” (p.72), which is acknowledged in the sacraments carried out in the Catholic Church. It’s interesting that this aspect of God, as well as the recognition of it by the Church, appeals to him, a man who finds it difficult to directly communicate with people especially when emotion is involved. A sense of belonging partly due to this? There is also an acknowledgement of the embodied&non-embodied self, i.e. God working in us and through us. He does not believe and/or practice everything put forward by the Church, and outlines that his belief in Catholicism does not have any emotional underpinnings, it is totally intellectual in its nature. “My religious faith, I guess, I could say, is not a gift from God, as so many people say: it is a gift I gave to myself. In line with this, I have never felt the emotional exhilaration that people must feel when they have a ‘religious experience’. This is true even when I receive the sacraments. The only thing that has deeply moved me is the *reasonableness* of it all ” (p.73). “I realize that

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all of this might cause me to run afoul of what St Paul said about the agape kind of love in I Corinthians 13:2.⁹ This is to say that, without it, knowledge and conviction just do not amount to anything. But, as I said above, that happens to be the way I am” (p.73).

Chapter 22: Disclaimers about Religion

Edgar became a Catholic because those “things that attracted me to the Church were its ‘teachings’, which is the essence of the Church. The day-to-day visible practices are the institutional church, composed of fallible human beings” (p.75). He describes how things such as paedophilia and workers building churches not being paid decent wages are things that have been distasteful, however, he has been active in addressing changes in the Church as well as pushing the Church to contribute to social changes in society.

Chapter 23: A Perhaps Dangerous Characteristic

Autistic people can, and do, turn their anger on themselves, hence why one sometimes sees some persons with helmets. A year before his nervous breakdown he was having a shouting match with his family and then ended up cutting his forearm. Everyone took it to be a suicide attempt, however, he did not want to die. “When my anger boiled over, I turned it against myself” (p.78). Therefore, Edgar states that it may be better for an autistic person to live alone, or if he is living with people he should be given all the space he needs, and is this not what cat lovers do for their feline friends?

Chapter 24: The Upshot of this Self-Discovery

He felt liberated when he found out that he is autistic. “Far from being disturbed by these insights, this self-knowledge has enabled me to accept myself to a degree that I never have before” (p.79). Edgar states that autistic people will want to control their space and so on, however, they are not likely to be manipulative because this means getting inside people’s emotions, and for such persons this is difficult to do. An autistic person is also less likely to be manipulated because of the same reason, in that “he does not have emotions for another person to get into” (p.80), i.e. two characteristics of his are that he is not competitive and is not ambition-driven. “I have always found competition, confrontation, and other such ‘power games’ to be extremely distasteful, engaging in them only under the most extreme necessity. [...] The way that I function may be incomprehensible to most people, but it never ceases to mystify me that other people do these things for enjoyment” (p.81). He enjoys

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card games that require honesty.

Chapter 25: Is a Future Close Relationship Possible?

Here Edgar gives details of how a blind man and his sighted wife can work together in the home setting to have a successful relationship, and simultaneously compare this with an autistic man and his wife as he proceeds, e.g. the blind man may require everything to be left where he places them and therefore his wife should not move things without verbally informing him of this, likewise, an autistic man may require the same kind of adjustment so that the uncertainty is reduced and he is able to carry out his routine in a non-interrupted manner. If they have children she is likely to have to teach the kids the same kinds of knowledge and skills whilst also ensuring that the father is included in the upbringing of the children. A difference may be that a blind man may be able to pick up on his wife's emotions whereas the autistic man may require his wife to explain her emotions in words to him whilst being as explicit as possible. When such couples work together in an understanding manner they can complete each other in terms of their limitations and strengths.

Chapter 26: Waxing Philosophical about 'Love' Among the Non-Autistic

He explains how from an autistic person's point of view the relations between men and women appear to be. He feels that women who have been attracted to him always had a list of things they wanted to change about him, i.e. they could not accept him as he is, implying that women do this with men. That there are women who keep on returning to men who hurt them emotionally and physically because he says he loves her. Why should one die for love? Surely love ought to make one feel like living. 'Agape' and 'eros' represent different ideas, that most people struggle to understand the difference between the two, and most do not even consider the 'philos' kind of love.

Chapter 27: The Emotional Deficit

Edgar believes that the bedrock characteristic of autism is an emotional deficit and that all other autistic traits can be explained in terms of this; it also explains why autistic people are usually "misdiagnosed with other psychological disabilities, since many outward symptoms are similar, but have different causes" (p.94). He states that it is difficult for an NT (Neuro-Typical) person to understand this, for example, such a person can place a blinder over their eyes in order to understand what being blind is like. However, how can they turn off their emotions? Whenever

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he asks himself this question there is a silence and the implied answer is 'Nothing'. A comparison and an explanation regarding a schizophrenic person and an autistic person is carried out. "If by observing the way we operate, we come across as, if not from outer space, at least a different species, it is quite understandable. An appropriate Biblical quotation is Isaiah 55:8 'For my thoughts are not your thoughts, nor are your ways my ways'" (p.99).

Chapter 28: Self-Compensating?

Here Edgar describes how the traits of being autistic can be disadvantageous and advantageous. He refers to a media story about a 10 year old autistic boy he wandered into some swamps and his family and the authorities found him a few days later. He is likely to have wandered in due to being curious, and because of his (i) lack of fear of physical danger and (ii) high pain threshold, he is likely to have not considered the possible dangers in the swamps. However, these are also the very abilities that are likely to have helped him to survive, e.g. if he came across a crocodile he is not likely to have shown fear and the animal is likely to have left him alone because of this. So what disturbed the parents is not likely to have bothered the boy at all. This phenomenon manifests itself in various ways in social situations. For example, people like to discuss relationships, yet Edgar excludes himself from such conversations because he feels he struggles to pick up on the emotional factors regarding relationships, though will do so when or if the conversations are more so from an ethical point of view. He did not join the Church for a sense of belonging, and therefore wherever he goes to mass he does not feel out of place. He is content with solitude, while he thinks that a lot of neurotypical people struggle with being an outsider. He has always lived according to his values; for example, despite his family being atheists he always questioned this and finally chose Catholicism as a religion. Neurotypical people's emotions are persistent, whereas his are situational and he does not carry grudges for anyone. He believes that autistic people appear to have lost intuitive emotions, but retained the survival ones, and hypothesizes that the brain may have two emotion centers; the intuitive center would be vulnerable and the survival would be protected. By comparing autistic and non-autistic ways of being he has come to the conclusion that as much as nature may have taken something from him when he was a child he has also gained from it. He has understood more so what life is like for non-autistic people, and this has helped him to understand and accept himself more so, as well as accept NT persons as they are. Rudyard Kipling is quoted: "If you can trust yourself when all men doubt you, But make allowance for their doubting too" (p.104). The only thing he does fear is uncertainty, though the "fact that, for most of my life, I was able to endure the fear that was fed by this uncertainty, perhaps might indicate that I did have sources of strength within me for which I have not heretofore given myself sufficient credit" (p.105).

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Chapter 29: Our Own Country

The title of this chapter is from an internet forum for autistic people, and the message thread(s) entitled with this was about how such people feel like outsiders, which the author wanted to incorporate here. He has always felt like an outsider and even when he was not consciously aware of it others made it clear to him that this was so. Though at the time he did not know the reason for this and did not have the faintest notion that they were different. He likens this to a classical song called *The Wanderer* and that in a poem by Schmidt von Lübeck, the singer cries for where his beloved country may be, where everyone speaks his language. Edgar feels that he has somehow managed to function in society and has also adapted to it; this was thanks to the Cold War, whereby people like him with computer and maths knowledge, were sought after. This is what enabled him to be an outsider without being an outcast. The discovery of being autistic has led him to confront his limitations “while remaining cognizant of my abilities. One result is that I have, ironically, become much more of an extrovert than I had before. I found a greater ease in dealing with people, because I knew how I was *not* able to interact with them.

The Bible⁷ says that the truth will make you free; it does not say that it will make you happy. However, if you really are free, you can make your own happiness” (p.110).

He further outlines how having purpose to one’s life is the most important thing, referring to the works carried out by Mother Theresa, and that by leaving their luxury filled lives seekers such as Gautama Siddhartha (Buddha) and Giovanni Bernadone (St. Francis of Assisi) illustrated that one only needs so much in order to live a meaningful life.

“I know that my differences cannot be papered over; I have had to deal with them as best as I could, mostly in ignorance of what those differences were. Perhaps, instead of dwelling on similarities, people should be asking themselves: ‘What is wrong with being different?’” (p.113).

Chapter 30: Retrospect

Edgar states that if he had these insights into his life from the time of his youth he would not have married and possibly not had more than a casual date. He may well have tried to become a scholar-priest, meaning that he would have kept to himself, and this kind of lifestyle may have been better suited to his way of being, e.g. he always found it easy to be alone, even when surrounded by people, so he had (has) much practice in this way of being.

“What I wrote earlier, about *philos* being the only kind of love of which I am capable, bears strongly on the last points. Even if I should become,

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given my limitations, quite fond of a woman, ‘I love you with my whole head’, probably would not come across as very romantic. Yet, in Greek, ‘Se phileo’² can be said by a cerebral person, with all the intensity an emotional person uses to say, ‘Se agapao’.³ Perhaps even more” (p.114).

He feels that his biggest failure is to not be able to give “at least one woman happiness with my constant, close companionship over the long haul” (p.115).

Chapter 31: What I have Tried to do Here

He has tried to explain what being autistic is like. That he would like this self-explanation to reach parents, mental health professionals and educators.

“My intent was to explain how things are perceived and how opinions are formed by the autistic mind. In particular, how such perceptions and opinions can take place independent of any intuitive emotions. ¹

I wrote, at the beginning, that I wanted others to know me better. Other than having made such an easy swipe of the title from the autobiography of Cardinal Newman, the word *apologia* has a special significance. In a technical sense, it is Latin for defence of what one has done or said. Indeed, the dialogue of Plato in which Socrates defends himself before the Athenian court is called the *Apology*.

Yet, Socrates did not feel that he needed to either defend himself or apologize for what he had said. Instead, he tried to *explain* to the people of Athens what he was all about. I hope that I have had more success than he had. ²”

He feels that autism is a misunderstood disability, that the use of the term ‘autism spectrum’ implies variation, and he strongly believes that the common trait is the emotional deficit.

Chapter 32: Conclusion

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Looking at himself as “being autistic was a big surprise” (p.118), that one usually thinks of autistic persons as being non-verbal and when thinking of savants one may think of Raymond from the film *Rainman*, who had to be led around.

“Under no circumstances do people usually think of the autistic as being articulate.

I guess that I do have to thank God for the many high functioning gifts that I do have. Otherwise, I might have been like the autistic types I described just above” (p.118).

He also felt that due to being autistic he had missed out on possible pleasurable experiences during his adolescence, however, a lady reminded him that he was also spared a lot of pain.

Chapter 33: Epilogue

Edgar states that, “I have written earlier about how the discovery of my autism has improved my quality of life by enabling me to both understand myself and to explain myself to others, who, for the most part, have accepted me as I have been able to accept myself (once they had been able to absorb certain concepts which, before, had been totally foreign to them” (p.119). The icing on the cake has been that he has been able to help others, e.g. parents to understand their autistic children’s behaviour. Furthermore, it appeared to him that “the lion’s share of research is geared toward helping children learn, with not much going into helping parents understand what is going on inside their children” and this “is where an autistic person who can communicate could be quite valuable” (p.121). Temple Grandin has written that her faith is based on logic and he does the same, seeking for rational answers to his questions; “In fact, the closest verbal concept of God that I have ever had was given by the medium in a motion picture *Poltergeist*: a great light in which is contained the answer to any question you might ever want to ask” (p.123). He proceeds to outline how things with his choir singing worked out such that it did not coincide with the parents’ group meetings, and brings the book to a close with (p.125):

“These things do keep, in the back of my mind, the thought that, for all of my rationality, God likes to remind me, every so often, that He sometimes does move in mysterious ways.

Isn’t that a frightening thought?”

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How does Edgar Schneider use spirituality &/ religion to make meaning regarding his embodied&non-embodied life experiences?

Question	Excerpt(s) from the Book	Researcher's Reflections and Notes	Ideas of Possible Questions for Interviews
<p>1. How did the 'autistic' person make meaning of the paradox(es) of their lived experience? How did they practically deal with it?</p>	<p>[The practical process(es) of how Edgar learns is paradoxical]</p> <p>“Earlier, I wrote about how I would not take part in the classroom work, but would absorb the material being taught. A few understanding teachers, realizing this, let me sit in the back of the class and draw pictures” (p.69)</p>	<p>Is there really such a thing as 'tabula rasa'? Yes and no</p> <p>Mystery in the sense that it is not and is present; unfolding taking place so as to reveal it. Intuition and Arthur Deikman (1982) come to mind.</p> <p>Acknowledged his own learning process and did not get engaged in the lesson, therefore, paradoxically, learning. Drawing whilst he did so; the act of drawing and self-reflection? Lévinas (1961 / 1979; p.113): “Happiness is a condition for activity, if activity means a commencement occurring in duration, which nevertheless is continuous. Action implies being, to be sure, but it marks a beginning and an end in an anonymous being – where end and beginning have no meaning.”</p> <p>Some of the other people, e.g. teachers, acknowledged this paradox and made the necessary adjustment to facilitate the</p>	<p>How did you learn at home? Did this change over time?</p> <p>What kinds of methods and strategies used by your family were useful? What was not as useful?</p> <p>How did you learn at school? Did this change over time? What kinds of methods and strategies used by your teachers were useful? What was not as useful?</p> <p>Was there any other place or/and kind of situation you preferred to learn in? Why? Is this still the case?</p>

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		<p>process(es).</p> <p>Maybe the teacher’s role is to help to re-discover the knowledge, e.g. according to Michael Angelo the sculpture <i>David</i> was already present in the block of stone and all it needed was for the chipping away to take place, and maybe this is what teachers actually do – illustrate how to chip away?</p> <p>Van Manen (1990, p.6): “Especially where I meet the other person in his or her weakness, I experience the undeniable presence of loving responsibility: a child who calls upon me may claim me in a way that leaves me no choice.”</p> <p>How about a child whereby the call is made in such a way that they require physical distance?</p>	
<p>2. How did the person make meaning of the dynamic aspect of their lived experience? How did they</p>	<p>[He refers to three types of love, philo, agape and eros, and states that he is more of a <i>philo</i> kind of person and his intellect, along with art, is what he uses for coping with changes]</p>	<p>Lévinas (1961/1979; p.114): “Plato speaks of the soul that feasts on truths.¹” May be worth reading some of Plato’s work?</p>	<p>What is your definition of love? Do you believe in the 3 types of love? Philo, Agape</p>

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<p>practically deal with it?</p>	<p>“Their meanings can be summed up as: love from the head, love from the heart, and love from the sex hormones. Looking back, the only one of which I was ever capable was <i>philos</i>. For all of my life, even when I came to be quite fond of someone, it was an intellectual appreciation of that person rather than one that was ‘heartfelt’ ” (p.43).</p> <p>One of the practical ways he dealt with this is by having aesthetic fantasies about a woman during the act of making love:</p> <p>“This is not to say that I have never had a pleasurable experience with a real woman whom I have found to be attractive, in the sense I have described above. It is just that, as I now recall, in order for the experience to be pleasurable, I had to invent a rather interesting mechanism, in other words, aesthetic fantasizing about her during that time.” (page 44)</p>	<p>Lévinas (1961/1979; p.130): “What the subject contains represented is also what supports and nourishes its activity as a subject.”</p> <p>Lévinas (1961/1979, p.140): “The sensible world, overflowing the freedom of representation, does not betoken the failure of freedom, but the enjoyment of a world, a world “for me” which already contents me. The elements do not receive man as a land of exile, humiliating and limiting his freedom.”</p> <p>One’s representational world, or/and imagination, is a lived experience in its own right... also based in the elements of being and a phenomenon to its own? The term ‘an individual and multiple realities’ comes to mind, as well as the question “Is this a coping strategy to work with the sensory information coming in and to make meaning of it such that the intellect is aroused, and because the person identifies more so, or is located more</p>	<p>and Eros? Do you feel that you love more so in a <i>philos</i> kind of way?</p> <p>These questions may be too personal so I will re-remind the person that they do not have to answer them:</p> <p>How do you feel or/and think during the act of physically making love with someone? Do you fantasize about the person during the moment of making love? Do you think of various forms of art/theatre etc. whilst making love?</p>
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	<p>[Used intellectual abilities for becoming a computer technician who was indispensable]</p> <p>“Similar to the idea of being a ‘loner’ is the notion of not being a ‘team player’. This explains many of the successes and failures that I have had in my life.</p> <p>I served in the army for about three and a half years, starting in October 1954. I spent one and a half years as an enlisted man and two years as an officer. I remember that, as an enlisted man, I decided I did not want to be a follower. After I became an officer, I realized I was equally uncomfortable being a leader. I felt extremely vulnerable in either role.</p> <p>Considering what I have written, in a later section, about being neither competitive or ambitious, the most rewarding assignment that I had in the army was not as an officer, but the last one that I held as an enlisted man.</p>	<p>so, in the intellectual world, is stimulated and aroused, i.e. philos love?”</p> <p>Merleau-Ponty (1945/1989; p.7):</p> <p>“The appeals to association and memory presuppose the present recognition of a figure; consequently, association and memory cannot serve as explanatory principles in the analysis of perception.” Why do I feel the need to place this comment here? Do Edgar’s memories of this job, written herein (including the entire book) mean that they cannot be used as explanatory principles of perception and therefore cannot be analysed?</p>	<p>Have you had, got a job you</p>
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	<p>I was fire-director and computer (FDC) for an 81mm mortar platoon. The significance of this bears some explanation.</p> <p>Heavy, high-trajectory weapons, such as these, are usually placed toward the rear, where they cannot see the target area. There is a forward observer (FO) who can see the target, but is generally looking at it from a completely different direction than the one from which the guns face the target. Consequently, any changes ordered by the FO, in range and direction, for the purpose of adjusting fire on the target, will be irrelevant to the changes the guns have to make.</p> <p>My job was to make the necessary transformations from the FO's corrections to those required by the guns, and to issue fire commands to the guns.</p> <p>I was outranked in that platoon by the platoon leader (an officer), the platoon sergeant, the gun crew commanders, and even some members of the gun crews themselves. That did not bother me in the slightest because, in that organization, I possessed a unique skill, and everybody, from the platoon leader on down, depended on my</p>		<p>enjoy very much? What is it about this job that makes you feel good?</p>
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	expertise for that unit’s effectiveness.” (p.61)		
3. How did the person make meaning of the mysterious aspect of their lived experiences? How did they practically deal with this?	<p>[He suffers a nervous breakdown at work in June 1978]</p> <p>“It may very well have been the onset of an attention deficit disorder (ADD). They are just now discovering that this condition can arise in adults, and not, as they had thought previously, only in children. Of course, at that time, nobody had any inkling that this might be the case.” (p.11)</p> <p>[Early spring of 1995, he recognizes that he is not schizophrenic after all]</p> <p>“I read an article by Oliver Sacks called ‘Prodigies’ that aroused in me the great possibility that, for sixteen years, all of the professionals who had been treating me were dead wrong!” (p.22)</p>	<p>He acknowledged that (i) things were not going well at work in terms of his concentration and productivity, and his body illustrated this pressure through a nervous breakdown, and (ii) he did not know what was going on. He sought professional advice, was in hospital; it was thought that it was the family circumstances, then schizophrenia with anxiety for 16 years, and finally it was realized that it was ‘autism’ and ADD.</p> <p>Edgar’s revelation of understanding that he is ‘autistic’ arose from having read an article by Oliver Sacks regarding ‘autistic’ savants. He then uses this article throughout the autobiography to bring to the fore aspects of his lived experiences, especially regarding being able to enjoy and express art without it requiring any emotional capability of his own. This in itself is a paradox and a mystery.</p>	<p>When were you recognized as being ‘autistic’? How did it come about? What were your thoughts at the time of that period? How did you feel? How have your thoughts changed? How have your feelings changed? Or remained the same?</p> <p>Did you read any materials that were useful for you in recognizing yourself as being ‘autistic’? Or are there any particular resources you recommend? How did you come across them? What did you think when you read them? How did you feel</p>

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	<p>[He cannot make sense of love, it is a mystery and gives an example of an experience with his mother when he was fourteen years old]</p> <p>“At one point my mother, exasperated at me, said “You know what the trouble with you is? You don’t know how to love! You need to learn how to love!’ I was taken aback totally. I hadn’t the faintest notion what she meant. I still don’t.” (page 43)</p> <p>[He could not feel grief when his mother died]</p> <p>“My brother was devastated, even though we all saw her death coming. (He and I had even worked on the list of ‘things to do’ and on her</p>	<p>Knowledge derived from another source; enabled him to reflect and see aspects of himself, leading to a discussion with his doctor for 3 months, and finalized that he is ‘autistic’.</p> <p>Shems&Rumi (1263/2011, p.88):</p> <p>“Yokluk âlemi, pek geniş ve hudutsuz bir âlemdir.” Translation: “The realm of nothingness is a very wide realm without boundaries [infinite].” Do any of us really know how to love? Is it not a case whereby we are always attempting to love rather than knowing entirely what it is to love? And if there is a nothingness or / and an emptiness with regards to not being able to love in a way that is expected and taken as the norm by others, does this actually mean that one does not love?</p> <p>Seeing as ‘autistic’ people tend to have hyper and hypo sensitivities, and some also have</p>	<p>when you read them?</p> <p>Have you had anyone tell you that you do not know how to love?</p> <p>When someone close to you died were you able to grieve? Feel sad and cry?</p>
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	<p>obituary before she actually died; it was that imminent, but it did not occur precipitously.) Everyone else in the family, and friends also, expressed sorrow.</p> <p>I felt nothing. I also felt that there was something wrong there. Somewhat sardonically, I said to my pastor (who had been a psychologist before becoming a priest), ‘There are all kinds of support groups for people who grieve, but nothing for people who should be grieving but don’t.’” (p.51)</p> <p>“Yet, as noted above, I feel nothing in real-life emotional situations. This is connected with that topic of feeling ‘emotion’ only through art.” (p.52).</p> <p>“Real-life emotions appear to me to consist of things felt in an unexpressed manner, and with another person also feeling them, almost in the manner of sympathetic vibrations at a resonant frequency.” (p.52)</p> <p>“The Emotional Deficit</p> <p>When talking to people about autism, this aspect of it has been the most difficult to put across. This is true even when it comes to people who are understanding, open-minded,</p>	<p>hypo-proprioception (Bogdashina, 2013), maybe what Edgar is attempting to say is that he does and can feel emotion(s) at certain times and in certain situations (e.g. with art, theatre etc.), and in other situations (e.g. his mother dying) he does not feel a sense of ownership of such emotions and therefore thinks that “I feel nothing in real-life emotional situations” (p.52). Whereas the symbolism and creative energy involved in the arts may be the very vent through which he recognises, acknowledges and expresses his emotions? An indirect, yet simultaneously direct, way of attending to one’s own pain and suffering? Plus, if real-life emotional situations are likely to overload one’s sensory system maybe the coping strategy is to distance oneself from such emotions? If practiced since infancy maybe this becomes a natural way of being for the person and therefore the person ends up thinking that they have an ‘emotional deficit’ when it may be more complex than that?</p> <p>Note, the ‘observing self’ comes to mind (Arthur Deikman, 1982), in that one may experience emotions but may not necessarily have a sense of ownership of such emotions.</p>	<p>Did you compare your behaviour to a sibling’s behaviour?</p> <p>Does art play a role in your emotional life? How do you feel around people who may be emotionally charged? How do you respond or/and not respond?</p> <p>Do you think the most difficult thing to explain and talk about with people are emotions?</p> <p>Do you feel emotions? How do you cope with emotions? Do you have a sense of</p>
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	<p>and even sympathetic. I believe that it must be understood, for I have come to be of the opinion that it is the bedrock characteristic of autism.</p> <p>This is not some personal hangup. I should like to refer back to my initial discovery and recall two important items. When I first saw that <i>New Yorker</i> article, it was the sentence in the subtitle that caught my eye: ‘Can an artist make art without feeling it?’ When I wrote to Temple Grandin about my discovery, in her reply it was the emotional deficit that she identified as the hallmark of autism.</p> <p>It has become my very strong belief that all other autistic traits can be explained in terms of it and, furthermore, it also explains why autistic people are often misdiagnosed with other psychological disabilities, since many outward symptoms are similar, but have different causes.” (page 94)</p> <p>[Furthermore, his meaning-making is such that he states that he has a different learning style and thinks that most ‘autistic’ people’s learning style(s) is/are not recognized]</p>	<p>Are ‘autistic’ people’s perceptual ways of being likely to be more so oriented around or/and from the observing self? For example, hypo-proprioception, a lack of sense of ownership of one’s body, may in itself be an indicator of this... ?</p> <p>Merleau-Ponty (1964/1968, p.110): “We are no doubt using essences in order to establish and state this; the necessity of this conclusion is a necessity of essence. But it</p>	<p>ownership of your emotions? Does your sense of ownership of emotions vary from situation to situation? For example, you may feel your pain and cry in one situation yet not feel pain or cry in another situation despite others doing so?</p> <p>Are there any particular writings or/and books or/and articles that made you feel like you were reading about yourself? How did you feel? Did they help in learning more about yourself? How? How not? Do you think the cornerstone of ‘autism’ is an emotional deficit?</p> <p>Do you have a sense of ownership of your body? How do you experience your body? Sensory wise, are you sensitive to certain things? Sensory wise, are you not</p>
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	<p>“Most autistic people have severe communication difficulties. This would indicate that they do not have the kind of communication channels possessed by most people, which is why they demonstrate learning difficulties when taught by conventional methods. It may be that autistic <i>savants</i> and high functioning autistics have extraordinary channels. (<i>Extra</i> is the Latin preposition for ‘outside’. As a result, that word ‘extraordinary’ must be taken in the literal sense: ‘outside’ the ordinary.)</p> <p>I get the impression that little study has been done on this. Consequently, having only this small intuitive grasp of how I learn, I am extremely hard put to explain the process to others. I have suggested this hypothesis (of extraordinary communication channels) to a number of professionals in the field. One did tell me that this approach is being taken with a view to explaining parapsychology.” (page 59)</p>	<p>only crosses over the limits of one thought and imposes itself upon all, it indeed only survives my own intuition of the moment and is valid for me as a durable truth because my own experience interconnects within itself and connects with that of the others by opening upon one sole world, by inscribing itself in one sole Being.”</p> <p>Intuition is intertwined with inner&innersubjectivity and the embodied&&non-embodied s(S)elf?</p> <p>Van Manen (1990, p.17):</p> <p>“So to believe in the power of thinking is also to acknowledge that it is the complexity and mystery of life that calls for thinking in the first place. Human life needs knowledge, reflection, and thought to make itself knowable to itself, including its complex and ultimately mysterious nature. It is a naïve rationalism that believes that the phenomena of life can be made intellectually crystal clear or theoretically perfectly transparent. That is why a human science that tries to do justice to the full range of human experience cannot operate with a concept of rationality that is restricted to a formal intellectualist</p>	<p>sensitive to things?</p> <p>Do you think some non-verbal ‘autistic’ people have other means or and channels of communication?</p> <p>Do you believe that people learn intuitively, especially ‘autistic’ people? Or and learn to rely more so on their intuition to learn?</p>
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		interpretation of human reason.” Language and everything written is an approximation? Implications for this study?	
Questions and Reflective Notes Regarding the ‘Other’ and Myself			

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<p>1. How do 'autistic' persons' make meaning? What is my meaning-making process(es)?</p>	<p>Edgar has various life experiences to make meaning of his way of being and seeing the world. A very significant moment was the moment he read Oliver Sacks's article about creating art without feeling emotion as he resonated with this. Which finally led him to become more aware of the 'autistic' aspect of his way of being. Another example of this is his mother's death and him feeling as though he could grieve despite wanting to.</p> <p>He states that he drew upon his own internal ethics to become a Catholic. The family he was born into were atheists.</p> <p>How I have made meaning of his experiences and interpreted his text is as this analysis as a whole illustrates. I have read books (e.g. by Olga Bogdashina) and articles (e.g. Talay-Ongan and Wood, 2000) regarding 'autistic' people's embodied and non-embodied ways of being, i.e. senses, and my guess is that proprioception may play a significant role in 'autistic' persons' ways of being.</p> <p>Paradox; as described above.</p> <p>Dynamics; as described above.</p> <p>Mystery; as described above.</p>
<p>2. What are the implications for</p>	<p>Proprioception may play a significant role in terms of how one perceives and experiences the world. This in turn may affect</p>

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<p>perception(s) and self-knowledge?</p>	<p>their self-knowledge. Considering the mind and emotions are senses, I wonder if the self-knowledge in itself is also sense?</p>
<p>3. What are the implications for phenomenology as a methodology?</p>	<p>It would seem that one can know the world insofar as one is able to experience a sense of embodiedness and non-embodiedness, however, sensing seems to be nuanced at the individual level – and between individuals. Time may even play a role here. Phenomenology as a methodology ought not to make any specific assumptions regarding the body, senses and how one experiences the world. Bracketing is useful and I intend to continue to try putting it into practice via the analyses.</p>
<p>4. What are the implications for IPA as an approach and the methods involved?</p>	<p>Implications for IPA: very similar to the reflective commentary above in point 3 regarding phenomenology. In terms of setting out and structuring analyses, it is worth keeping in mind to ensure to have reflexive descriptions and columns throughout all the tables created and used. A final table that gathers the reflexive questions regarding paradox, dynamics and mystery may well be useful.</p>
<p>Questions and Reflective Notes Regarding the ‘Other’, the Family Context and Myself</p>	
<p>How does this ‘autistic’ person make meaning? Especially in the family context? What seems to be the family’s</p>	<p>Edgar makes meaning with regards to being ‘autistic’ by stating that an emotional deficit is the cornerstone of ‘autism’ and that he loves more so in a <i>philos</i> kind of manner, with the mind. Regarding his family, he states that he was born into an atheist family, thereby suggesting that religion /& spirituality was not used as a form of meaning-making in their household. He took up Catholicism in adult life. As for his wife and children, he does not refer to their religious/&spiritual beliefs in an explicit manner.</p>

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<p>meaning-making process(es)? What is my meaning-making process(es)?</p>	<p>My meaning-making process is as above.</p>
<p>What are the implications for perception(s) and self-knowledge?</p>	<p>Self-knowledge and the mind. Maybe we ought to view the mind as a sense? Is the brain 'mind'? Or/and is 'mind' an extension of the brain? Or/and is 'mind' interlinked with proprioception as well as the 'other' senses, e.g. eyes? Something to be said about synaesthesia. I think everyone has this ability, some more or/and less than others' ability(ies). That a person can identify with a sense, i.e. the mind, and views themselves as being loving via this sense is a notion I am becoming more familiar and comfortable with.</p>
<p>What are the implications for phenomenology as a methodology?</p>	<p>Bracketing is crucial, in that every individual is different in experiencing and interpreting the world from and with various degrees. Kaleidoscopes come to mind. We are all different unique kaleidoscopes: our bodies act as so for, with and to the light&darkness that make us so. How does a researcher continuously acknowledge differences? Emmanuel Lévinas and the notion of the face of the 'other' comes to mind, whereby simply by looking into the face of the 'other' we are invited to perceive an aspect of ourselves, and there is a mystery of each face. What role does the face(s) have to play in the research process(es)? How is it known? Lévinas (<i>Humanism of the Other</i>, translated by Nidra Poller, University of Illinois Press, Chicago, 2003, p.5): "The Other who faces me is not included in the totality of being that is expressed. He arises behind all collection of being, as the one to whom I express what I express. I find myself facing the Other. He is neither a cultural signification nor a simply given. He is, primordially, sense because he lends it to expression itself, because only through him can a phenomenon such as signification introduce itself, of itself, into being."</p>

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	<p>And:</p> <p>“But the epiphany of the Other bears its own significance, independent of the signification received from the world. The Other not only comes to us from a context but signifies by itself, without that mediation. The cultural signification that is in a way revealed, reveals, horizontally; reveals itself from the historical world to which it belongs; and, as phenomenology expresses it, reveals the horizon of this world. This mundane signification is disturbed and upset by another presence, abstract (or more exactly, absolute), non-integrated in the world. That presence consists in coming to us, making an entry. Which can be stated thus: the phenomenon that is the apparition of the Other is also face; or again (to show this entry at every instant new in the immanence and essential historicity of the phenomenon), the epiphany of the face is visitation. Whereas the phenomenon is already, on whatever score, image, captive manifestation of its mute plastic form, the epiphany of the face is alive. Its life consists in undoing the form where every being [étant], when it enters into immanence—that is, when it exposes itself as theme—is already dissimulated.”</p> <p>Shall think about this...</p>
<p>What are the implications for IPA as an approach and the methods involved?</p>	<p>Illustrate how we as researchers bracket our beliefs or/and world experiences so as to create a space for the participant(s) and their world views.</p>
<p>What is self-knowledge? How does it develop?</p>	<p>Self knows itself.</p> <p>Self unfolds like a lotus flower (Halil Gibran).</p> <p>Self is paradoxical, dynamic and mysterious.</p> <p>Our interpretations regarding ourselves via our senses influence our becoming and vice versa. Our senses are us and</p>

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	simultaneously not us.
What is meaning? How does it develop?	Meaning is intertwined with bodily experiences and people assign different terms, languages and concepts that are approximations of representing the persons' understanding of self.
What is perception? How does it develop?	Perception is that which one identifies as being linked to a sense and uses the most frequently.

The questions that have arisen regarding the methods so far are:

1. How does one use reflective texts/autobiographies, especially those by 'autistic' persons, with IPA?

- Meaning-making and the use of concepts, e.g. *philos*, *eros* and *agape*; a form of IPA that focuses more so on how people use intellect for demonstrating their love? Conceptualizing cognition&emotion?

2. How does one use autobiographical/reflective texts in order to further become sensitive to the context and culture of 'autistic' persons and 'their' family life?

- Bracketing; Edgar's way of being has confronted me with some lived experiences that I find difficult to relate to, e.g. being more of a *philos* kind of person, though simultaneously can relate with in certain respects, e.g. having a deep appreciation for poetry etc., so I have had to use the method of bracketing in a flexible manner. This in turn has reminded me (i) not to generalize concepts, (ii) to exercise a nuanced and idiographic understanding, and (iii) make sure that my writing reflects this. These are aspects of bracketing.

3. How does one create further research questions (e.g. for interviews) and develop one's philosophical standpoint(s) whilst analysing 'autistic' person's autobiographies with IPA?

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- Questioning my own assumptions, e.g. what is love? Is there 3 types of love or more or less? Can a person really not feel any emotion during the actual moments of interaction with others? Yet can express it through art and simultaneously not feel it as such? Or maybe a person can feel the emotion passing through them though not be or become attached to it? No or/and lack of ownership of emotion? Thought&emotion and emotion&thought? Connectedness and non-connectedness? Learning?
- What does IPA actually have to say about love, thought and emotion?

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APPENDIX 4

Data and Analyses: Donna Williams, 1998. Autism and Sensing, The Unlost Instinct

Contextual information regarding this book:

(i) Who wrote the autobiography/& reflective text: Donna Williams

(ii) Where the autobiography/& reflective text was written: This is not clearly stated in the book, however, Donna had moved to England at the age of 26 and the book was published in England, so one assumes that this book was written in England.

(iii) When the autobiography /& reflective text was written: It was published in 1998.

(iv) Why and how the text came in to being:

In the Foreword of the book Donna states that, “When conveyed, a good autobiography gets beyond the surface to that place where realities, experiences, are captured by others – self in other and other in self. I hope that, though not an autobiography, this book has some of this” (p.9). Her motive to write this text was to enlighten people with regards to accepting the different realities that exist. There is no co-author and no particular person is given an acknowledgment regarding the actual producing of the text, so I am assuming that she wrote it and it was then submitted to the publishers for editing etc.

(v) A summary of what the story is about:

Foreword

Donna outlines the reason for creating this text (as above), and in this section she also states that autism is a label that is applied to outer behaviours and is not focused on the inner realities of the individual.

Introduction:

Donna states that people often live in the world of 'appear' (page 11), as in certain expectations people feel that have to be lived up to, and

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some live in the world of 'be', as in such people do not know of or/and do not care for living up to the ways of appearance. She describes "Be" (page 12) as a natural way of living and being oneself, which is mainly achieved through the sensing body, and provides a case for a phenomenological way of being and looking at the world. She advocates the returning to the lived experiences in themselves.

Chapter 1: Origins

Here Donna outlines that people live in a variety of realms, on page 13 she states that:

"You probably take it for granted that when you experience yourself, you can also at the same time also experience the room you are in, the object you are holding or the person you are with. Most people live in a world in which they can simultaneously experience 'self' and 'other'. Yet at times people lose track of where they are or who they are with or that they are even in company.

At that moment when you look up, embarrassed, to realise you'd started picking your nose without the awareness you weren't alone, you'd slipped out of gear, slipped into the mode of *all self, no other*.

Everyone has had the experience of being so caught up in awareness of another person, a captivating object, an overwhelming surrounding, that you can't remember what you thought or felt or why you were there. You'd slipped into the mode of *all other, no self*. There are moments when you realise you were lost in a limbo, unaware of yourself or anything beyond your-self. This is the state of *no self, no other*."

The "all self, no other" is the one she most identifies with as this is the one she feels comfortable with. Donna then outlines three ways of being in the world, (i) via "The Sensory" (page 15) during early to mid-childhood, (ii) "The Literal[...]" (page 16) during mid to late childhood, and (iii) "[...] and the Significant" (page 17) at the age of 32.

She states that most people interpret their experiences and therefore miss out on the actual beauty and art of the phenomenon they are experiencing, hence, she prefers the sensory way of being. On page 15 she states that:

"Recently, having moved out of this sensory I looked up at a huge over-head chandelier and the drug-like addictive effect such an experience once had on me. When asked about it, I recalled experiences like it as 'merging with God' because I would resonate with the sensory nature of the object with such an absolute purity and loss of self that it was like an overwhelming passion into which you merge and become part of the beauty itself. It was the ultimate in belonging and 'company'. The feeling was completely compelling and addictive and by comparison the call of the world of interpretation seemed pale, weak, insignificant, foreign and of little reward."

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Chapter 2: Who's Me?

Donna states that we are more than our senses and yet "Still, it is so easy to confuse 'self' with 'the mechanics of perception or cognition'; our systems.

Ultimately, the self existed before its separability from everything external to it; all entities progressively considered 'other'. Self existed before its various phases of relationship to body or mind and its eventual identification of these. Self existed before the formation of expressed personality or the impact of environment.

Self is essentially none and all of these things simultaneously and yet is, ultimately, a greater force than all of the things with which self is identified; systems, personality, environment, body.

Asked, who am I, my reply is, 'I am a self in the becoming'." (page 19)

She asserts that we all "began in the sensory" (page 19) and provides an example of how she had a doll's house and yet she did not know the significance of the objects and the purposes they served because she experienced them more so through her senses. In the sub-section *Losing One's Mind* (page 20):

"I was given a doll's house when I was seven. I love 'it' – the bright red smooth glossy contoured triangular form with the great rih-rih noise made by running the back of the hand over the plastic hollow form which was 'the roof' and the smooth woody tock-tock, slot together hard square white surfaces which were the walls and the collection of plastic chewable forms of various colours, contours and pliability which were the dolls and furniture. I spent my time disassembling the component parts to create the perfection of unmuddied water. The roof, walls, furniture and dolls were kept separate. Later, I used the walls to keep various categories of furniture separate and the dolls all stayed in one category separate from the furniture. Only once I'd unmuddied all the forms could I explore the various structured ways in which the forms could justifiably become muddied according to purpose." She refers to this process as "unmuddied waters" (page 20) and has illustrated the importance and development of perception(s).

Mind is defined as (page 21): "Mind itself, the move from preconsciousness into consciousness, provides the greatest tool with which to filter the flood of 'non-relevant' information that would otherwise make simultaneous genius and fool of us all."

In the sub-section '*Disability?*' she describes disability (page 21): "Many people with developmental disabilities live in the sensory, struggling for

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the literal and among them are some, often unrecognised, great artists and poets. Others, affected less extremely live in the literal, struggling for the significant and among these people are some with quite pure mathematical thinking, inventors and, sometimes, involuntary comedians.”

Donna’s resonating with a pink ball (page 22):

“When I was about ten years old I used to have a certain colour billiard ball – a pink one. I used to spend around an hour with it before I could reach the point of resonance with it where I would merge with the colour. To anyone else this would have looked like someone ‘psychotic’ but if they’d known the physical alteration felt in that moment of becoming one with a colour some people would perhaps see it as far less crazy than other ways many people may have spent an hour of their lives at the same age.”

Under the sub-section *Body?* she outlines that when thinking about ‘self’ one may think of the mind, the body, feelings, and the very life experiences we live, and the last two sentences are (page 23): “But, before the time of interpretation, identifying and knowing was not about the interpretation of mind. It was about the resonance of ‘will’.”

For Donna self and body are intertwined, innerintersubjectivity comes to mind here.

Chapter 3: The Essence of ‘Social’

Will existed before notion and the concept of the other (page 25):

“Before mind was even a notion, before hierarchy and the discrimination born of it, there was will; the realm of selfless-self. In the time before mind, there was no simultaneous sense of self and other.”

Under the sub-section *‘No Self, No Other’* she describes how things can be experienced as energy and that one can also be experienced as energy by the surrounding environment. Again, highlighting an innerintersubjective way of being and perceiving the world.

On page 26 she refers to us having ‘shadow senses’:

“Before we learned to use our physical-body senses with intention, we were still able to see, hear, feel with ‘shadow senses’. Some people blind from birth, for example, can get about without some of the aids used by those who came to rely on their physical eyes. Some amputees can still feel the pain or itch in a limb that has been cut off. The ‘body’ is more than a physical form. It is an energy form, generally, but not necessarily, contained and expressed through a physical form.”

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Until the age of 7 she believed that she could walk through walls, and at the age of three she had started having out of body experiences and would respond to people's wants before they voiced it; this surprised people and she learned to wait for them to ask via speech so as not to frighten people (page 27). She states that this is why some autistic people feel no need to articulate or talk, assuming that others can also use these mechanisms; these mechanisms are within us all, just not used as much by most people and therefore like an "unworked muscle" (page 28).

Between the ages of 2 and 5 she would leave her body and felt no sense of self most of the time (page 27). Under sub-section *All Self, No Other; All Other, No Self* (p.28): when being given something she did not recognise it to be given by an 'other' and implies 'Why should I say "thank you" or "please" (page 28) to me?' This raises questions regarding the beingness of self and how people learn, and do not learn, social norms.

In the sub-section *Simultaneous Self-Other* (page 30):

"I could hear a sound and physically sense the tactile nature of the object, look at it and sense the sound that would come from it or exactly how it would catch or refract light".

She completes this chapter with the line (p.31):

"'In my end is my beginning', wrote T.S. Eliot."

Chapter 4: The Everything of Nothing

Donna states that her ability to interpret was impaired (page 33): "Up to the age of four, I sensed according to pattern and shifts in pattern. My ability to interpret what I saw was impaired because I took each fragment in without understanding its meaning in the context of its surroundings."

She then proceeds to outline the dynamic nature of self (page 33): "I couldn't consistently process the meaning of my own body messages if I was focusing in on something with my eyes or ears. I didn't know myself in relation to other people because when I focused on processing information about 'other', I lost 'self', and when I focused on 'self', I lost 'other'. I could either express something in action or make some meaning of some of the information coming in but not both at once. So crossing the room to do something meant I'd probably lose the experience of walking even though my body did it. Speaking, I'd lose the meaning of my own sounds whilst moving. The deaf-blind may have lost their senses; I had my senses but had lost the sense. I was meaning deaf, meaning blind; interpretation and the realm of mind wasn't a reliable or consistent system for me. I remained reliant far longer than most people on an earlier system: the system of sensing." Proprioception comes to mind here.

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However, she feels that if most people lived from the state of sensing then there would be no need for a system of interpretation like the one devised by religion(s) and the sciences (page 34, sub-section *Being Trained Out of Sensing*): “Had the system of sensing not become so globally redundant in adults, religion, the concepts of life and death, of physics and science, of language and of the social would not be the black and white ‘realities’ they are perceived to be.”

Donna describes having un-intentional out of body experiences, e.g. when she left a house she used to live in and two years later came across the person who had bought it, she was told that it was like she [Donna] never left the house (page 35). An interesting line (page 35): “This mind versus will, intention versus resonance, interpretation versus sensing, appear versus be, is all strange language to most people.” The terms ‘confusion(s)’ and ‘paradox(es)’ come to mind.

There is a fear about talking about these kinds of experiences as people have stereotypical views and are afraid to engage with these topics (page 36): “Just as ‘will’ could join with body or not, ‘will’ could join with all sorts other things. ‘Will’ could sense the wall or the surface, texture and density of material without looking at it with physical eyes or touching it with physical hands or tasting it with a physical tongue or tapping it to hear its sound. It was as though some part of ‘me’, of my ‘being’ could see without my eyes, hear without my ears, touch without my hands and feel bodily without my body making direct physical contact. It was as though ‘I’ had two sets of senses, the physical ones, and non-physical ones which some people have termed ‘shadow senses’.”

Resonance is (page 37): “I have vague recollections of being able to sense the surfaces around me. I have a sketchy sense of having been able to sense the wall and changes in its structure where some parts were more solid than others. I re-call sensing this without looking or using touch, changes such as where a door or window broke up or changed continuity. I recall a sort of ‘resonance’ with matter, a kind of non-physical ‘body mapping’.”

On pages 38 – 39 information is given as to how consciousness and pre-consciousness affected her body: “For someone like me who found the constant shifts disturbing and alienating to my sense of cohesion and sense of self, I fought for that cohesion as a matter of soul survival.” (page 39)

She was ashamed of her creativity as she felt frightened of it and that it was emerging from a shallow person, yet she was writing deep rich poetry and creating deeply meaningful paintings – she was so ashamed that she burned much of it (page 39).

She feared her feelings and didn’t acknowledge them as being directly hers (page 40).

Page 41: Donna describes how people have senses of de ja vu, and how people’s energy(ies) can influence each other: “Trust and closeness are

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more likely to provoke 'resonance' in people who have some warmth and 'open-ness'. The purely empathic person may resonate easily with energies which are like its own, whether strangers or not."

Pages 41- 42: Sensory perception enables a person to take in everything whilst not judging it. Therefore, the "constant insistent one-sided emphasis on 'paying attention', seeing 'daydreaming' as a waste of time, the emphasis on 'look at me when I'm speaking to you' may be eroding the sacred within us all" (page 42).

Page 43: "I didn't 'learn' with any conscious application how to sculpt, yet as soon as I began, I could sculpt with a lot of skill, producing as my third piece of work after six weeks of sculpting, a detailed life sized nude which later got cast in bronze. I did not paint in the art classes at school, yet when as an adult, I did finally dare to use colour and brushes, the works I produced were like those of an artist who'd been painting for years. I didn't study how to write and had barely handed in any expressive written work other than purely academic replies to set topics. Yet when I sat down to type out the story of my life, both my first and second instalments became international best-sellers, not after trying for the right publisher, but seemingly 'by chance'. [She then outlines creativity regarding playing the piano, singing and writing poetry.] These skills have been labelled 'savant skills', said to affect around ten percent of people with 'autism' while the majority of 'savants' have autism. Yet these labels tell nothing of the mechanics of these skills and the question is not so much why some have got them but why they retained them where others let them go before ever discovering they had them." Will, intuition and creativity come to mind here.

Page 44: Donna describes how she would merge with the wind, colours and shapes through her sensory experiences, as though they were a part of each other; this was achieved without the mind and its interruptions. She also merged with a man (page 45) who was like her, sensing him from the inside out, and he was able to feel her as so. "Sensing, by contrast, involved establishing familiarity from the inside-out and was a purer system that involved none of the distortions of constructed mind-self or discrimination between what the constructed mind-self considered worth knowing and what it did not."

Pages 46 – 47: She relied on her sensory system, practiced using this a lot as she felt the system of interpretation was unreliable, and could tell things from the energy of patterns and motions in her environment. "So although I eventually and progressively took interpretation on board, the system of interpretation remained alien and disconnected to my self-identity and 'I' (in the sense of mind-will-identity) relied upon, trusted and identified with the system of sensing rather than the system of interpretation. To my inner self and what I later distinguished as my 'real self', sensing was flawless but interpretation could make so many mistakes and was unreliable." (page 47)

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Chapter 5: The Mechanics of Sensing

In the sub-section *Body Connectedness* (page 49): she suspects that “before the body is even fully formed and before the senses have become physically-based senses, that non-physical senses are at work. It is interesting that Webster’s dictionary not just defines the word incarnation as ‘embodiment in flesh’ but also as ‘to put an idea into concrete form’ and it is true that we are born into our bodies before we are born into the world and perhaps our conception is more than just an act of biochemistry. Perhaps our conception is a free [page 50] floating idea of our potential existence brought eventually into concrete form. Certainly, spiritualists would insist that people can have sex but for a life to be conceived and continue fully into its (next) incarnation the energy form that will be that life has been drawn to or willed existence in that particular form. In this sense it is perhaps not that we have been conceived by our parents but that we conceived of our own potential existence which was drawn or willed into physical concrete form.”

Page 50: “Some of us are born before our physical birth, some of us take a long time after birth to be born fully into our bodies, our minds, our emotions.” We will ourselves into existence and are simultaneously willed into existence?

An indecisive will?: “An indecisive will may have been drawn fiercely to life and avoidance of it.” (page 52) This is how Donna tries to make sense of how will and body may be connected and simultaneously not so connected, whereby when will is resistant to life it may manifest information processing problems.

She could see and sense via her senses to the point that nothing could shock her (page 53): “I began using non-physical senses to make sense of my environment. I could see but it did not naturally occur to me to look. It didn’t naturally occur to me because I experienced no need to look. Nothing could shock me because no interpretation was happening, no judgement and no thought.” Maybe this is also why some ‘autistic’ people do not make eye contact when communicating at times? ‘Bodily sensory overload’ may also simultaneously be another form of retrieving and processing the information given off by environmental stimuli?

Page 53: “As far as I was concerned, my body was welcome as a sensory tool, but as a body with a competing will of its own, it was like a leech that happened to be there by coincidence but wouldn’t take the hint and couldn’t be gotten rid of. It was my first known enemy.” A conflictual relationship with one’s body, whereby the body is accepted as oneself and is also not.

Chapter 6: In Resonance

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During the ages of 3 or 4 years Donna begins to reach out to objects, using touch and taste, though for example she touches wood and loses the sense of her hand whilst simultaneously feeling the texture of the wood, which she refers to as being 'mono'. A form of 'limb loss'? Fluctuating perceptions&body&energy(ies)? Proprioception also comes to mind again. Pages 55 – 56:

“I moved from becoming one with matter ('resonance') to using touch. Instead of merely 'taking on' the things around me in a sort of merging, I now began reaching out to them physically as separate entities.

My developmental condition affected how I processed sensory information. I wasn't able to filter incoming information properly so I was being sensorily flooded by it. The capacity to filter information requires some progressively accumulated sense of relative and personal significance and it is from this development of hierarchy that I think a sort of meta-self, some sort of pseudo-self or false self, is gradually born from mind.

Without this filtering, I was flooded and this led to a range of involuntary adaptations, one of which I call being 'mono'.

What being mono meant was that even though I'd progressed beyond mere mergence with things in my environment, I still had big restrictions in being able to process information produced from the outside and the in-side at the same time. This meant that I could feel the texture of the wood, for example, but in taking the action physically to do so I would have no sense of my own hand. I could also switch channels and feel my own hand but would lose sensation of what my hand was in contact with.”

She also refers to objects that reach into oneself and brings this into focus by providing a possible explanation for people with ADD (Attention Deficit Disorder). Page 57:

“Unable to filter out un-wanted, or unnecessary information adequately, people with ADD are 'grabbed' by sensory experiences that come to them rather than the other way around. It is probably no coincidence that people with ADD often have considerable difficulty holding onto a thought or carrying out a complex, decisive and intentional action.

Even emotional connection or symbolism doesn't figure in the 'call' of these things, this sense of 'other' that jumps in. Experiences of resonance may be disciplined but they don't start that way. They start out (and probably almost always remain) entirely indiscriminate.

Yet, for this resonance to be possible don't we require some inherent map within us? Don't we need some physical-based experience that would map within us the sense of hugeness or tininess, the sense of something being paper-thin or light or heavy or substantial, or the sense of some-thing able to give way without effort or be unable to be budged? If not, how can we sense experiences we have no concept for? The answer is that we require concepts in order to interpret and understand but we do not re-quire concepts in order to sense or experience. It is

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through the *interpretation* of what we sense or experience that concepts evolve.

'Complete' resonance is like knowing 'God' (page 57-58): "One could ask, what is the experience of merging, of resonance, worth if there is none of the reflection or consciousness that comes with bringing a conscious simultaneous sense of self to the experience?"

Certainly, I cannot talk of these times as 'deep experiences' in the usual cognitive sense of the phrase and yet these experience remain the deepest experiences possible. Perhaps only in death will I ever again know what it is to lose myself so wholly in the experience of something 'other', without sense of time or space, with no past, and no future and no here. There is no deeper experience than the total encapsulation of self within an experience until one *is* indistinguishable from the experience. It is like knowing 'God'.

Ask those who have ever flown, like butterflies, into the consuming flame of a deep and burning love with an insatiable hunger to merge. [.....] Perhaps it is not that one's 'selfhood' becomes extinguished but that one's separateness, one's separability, becomes extinguished." The dynamic self and the ever-changing being?

She outlines the difference between sympathy and empathy, whereby the former involves a simultaneous sense of self and 'other', and the latter involves feeling for the 'other' as though one was/is that person (page 59).

As a young child she would merge with people who walked into her room and as they left the room the part of her that identified with them would also leave the room, until her body called her back and she experienced a sharp perceptual shift, surprised to find herself back in her own body (page 60). It may be worth looking into works regarding out-of-body experiences (O.B.E.s)?

Donna goes on to describe how she has a 'feel' for places and that dogs, cats and horses also have this ability (page 61): "Non-physically based sensing, though it requires a body, probably mostly uses what might be called 'spirit' and it is my feeling that this is what eventually evolves into what people know as emotions.

People can learn to display mind-driven, pseudo-emotions and defend them as though they are real. In some people, mind has come to rule so much that felt emotion becomes redundant, replaced by the performance of pseudo-emotions. In others, emotion is at the heart of a still existent spirituality. The movement from non-physically based sensing to physically-based sensing is essentially a movement from reliance upon spirit and emotion to reliance upon the integration of spirit and body."

She began exploring the environment with her non-physical senses and then moved on to exploring it with her physical senses, whilst not being consciously aware of the context(s) in which her explorations were taking place (page 62). She asserts that the conscious mind is not the only

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way to take in information and that the preconscious state takes things in indirectly, and it is not that she was under-developed but simply that she became “differently developed” (page 63).

In the sub-section *Sensing the Nature of People* she states that “Some animals seem to ‘know’ before they even smell another creature” (p.64), that she believes they sense what she has come to call ‘edges’ and that people also have ‘edges’. She has a poem entitled ‘Edges’ on pages 64 – 65 that describes the types of edges and people, e.g. “Fluffy edged people make me squirm like a worm Hard edged people you can lean on Sharp edged people, they are crisp....” etc. After the poem she continues to describe such persons in more detail.

Chapter 7: Giving Self a Chance to Answer

Donna states that people tend to confuse thinking and sensing, and yet “Sensing comes from a time before mind. It has nothing to do with suspicion. Suspicion comes from learning, learning which has come from the interpretation and storage of interaction patterns [...] Sensing does not question, it does: “It just follows what its instinct tells it, a gut feeling, something sensed before the mental learning of everyday life even starts.” (page 73)

Through mock emotion(s) and expression(s) we acquire a pseudo-self (page 75): “Then someone acquires and adheres to an extensive and pervasive repertoire of mock-emotion and mock-expression, the person actually develops a pseudo-self. All of these are like invisible walls which close out or restrict the system of sensing and internal felt ‘dialogue’ with one’s own soul (not to be confused with thought).”

She then proceeds to outline that this is self-masochistic and it’s like people tying up their soul(s) in a straightjacket, “gagging it, dehumanising it, devaluing it, ignoring it but visiting it every so often to stick a pin in it” (page 75). In that people attempt to control experiences and fear emotions and experiences that are raw and that reveal how they truly feel. The “greatest madness of this is that the ‘natural’ response is then to fight these off like the enemy” (page 75). Therefore, people ought to give up the necessity to confirm everything with the mind and trust in the knowledge of the body, for “the body senses the ‘feel’ of something, its pattern or the relative symmetry or asymmetry between ‘appears’ and ‘be’” (page 75).

Her soul gave birth to her mind: “My soul, the capacity to sense, gave birth to my mind, not the other way round” (page 76).

Inner + outer + mind: “One may sense an inner at-traction towards what one’s mind is repelled by” (page 76). Emotion is therefore the realm of unknown knowing. “The mind speaks in accessible thought and can answer questions. The emotions speak in evoked triggerable reaction and

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respond not to questions but to statements” (page 77).

Donna completes this chapter with: “The system of sensing is a thing of purity and vulnerability which should be respected. In the right hands, it can be a tool with which to free those who for one reason or another are effectively imprisoned within themselves” (page 78).

Chapter 8: The Getting of ‘Clever’

Donna states that it was not within a few days of birth that the transition from the system of sensing to interpretation took place for her, it began to happen when she was 3 years old (page 79). Therefore, the difficulty with regards to language for her was that most words do not relate to their sensory experience (page 80): “The word ‘cat’ says nothing of the sound that comes from the thing when stroked, the noise it makes or the tactile sensation felt when stroking it. I had developed two words for the sensory experience of ‘cat’. One was ‘foosh’ which defined it by the sound made by your hand over the fur when stroking the creature. The other was ‘brook’ (with a rolled ‘r’) which defined it by the noise which came out of the creature when it was stroked.”

She asked objects their name by the interaction(s) she had with them (page 80): “If you asked me the name of something within the system of sensing I’d tell you to ask it. You wouldn’t do so in words, you’d ask it through the interaction between it and your body and it will tell you its ‘name’.” Sensory exploration is beyond the mental, it is an instinctive way of being curious and learning about the environment, exploring with one’s body and sensation(s) (page 81). Note, ‘intuition’ comes to mind here.

We should let life speak to us (page 82): “The mind learns to judge and discriminate and in that process we lose a certain freedom; the freedom to let life speak to us in its enormity and its own language.” As humans have developed, we have passed our interpretive minds on to new generations and this has led to more complex knowledge and ways of interpretation, including language (visual and physical), morality and social convention, forming interpretive cultural structures.

Chapter 9: ‘Seeing Ghosts’

At the age of 6 Donna had an experience whereby she decided to trust her sensory system: “I was walking down the street with my mother. I had a distinct sensing about which way to do something which was coming up. I could read the ‘feel’ of this, almost like it sat upon the air and this ‘feel’ instinctually told me that to do this thing in this way ‘fitted’. Then I used my mind to judge whether this was the best thing or not, the

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best way to do this thing. Using logic, it came to the conclusion that this sensed way as not the best way and that instead another way should be used. I felt convinced by this logic, and unable to see beyond it mentally, I went with the way it dictated. The result was that this way was not the best way after all and did not work out. At this I cursed myself for trusting in this new system – this system of interpretation, this ‘logic’ – and vowed I’d stick by ‘my own system’, that of sensing.” As Donna got older she too participated in the conditioned ways of being and “stored learned roles” (page 85). However, by the time she was 13 years old she was depressed and distressed by all this and the way people ignored their real self (page 86): “The pattern of their real self in the every form of expression contrasted sharply and with great clarity as an entirely different system to what they put on and the two stood out in clashing contrast as clearly as if they had been painted one black, one orange or had they been distinctly clashing notes. To relax and know it was safe to be my real self, I needed others to be willing and able to drop their bullshit too.

To my horror, when challenged to drop these facades, I found people defended them fiercely as though these were their ‘real’ selves.”

Note, this reminds be about the term ‘aspects of self’, and stories of (i) the emperor’s clothes and (ii) Nasreddin hoja’s coat.

According to Donna these people had the blessing of ignorance, and as her ex-husband put it, “it was as though I was ‘talking to ghosts’” (page 88). She therefore felt alienated by the lack of validation, and also a de-valuing, of her reality(ies) and this meant that it “out my real self into what felt like exile and it necessitated the need to ‘visit myself’” (page 89). She felt comfortable and at home in the company of herself, and she enjoyed the enriching experiences she had here. Therefore, her body was experiencing life without the mind narrowing such experiences (page 89).

When she was 16 years old, she “gave in to the pressure of a world which seemed only to want my mind-self and I stopped visiting my self. The result was acute anxiety, panic attacks and depression. I had the constant sense that I’d lost something. I felt somehow ‘disconnected’ and found life to be flat and without hope; an endless play of scenarios I had no feeling for. After six months, I couldn’t stand it any longer. Whether I was considered mad, weird, disturbed or not, I went back to visiting my self.

I began to stand in front of the mirror, staring into my eyes and looking for the real me looking back. At first, I couldn’t see the real me at all, not in any gesture, not even in my eyes. I whispered my name to my reflection, trying to call me out but it was as though my real self no longer trusted the mind-self to which it had conceded. My real self had been discarded, made redundant, ignored by the mind-self and it no longer trusted it. In just six months I’d succeeded in losing my soul just as others had.

I was lucky that I didn’t stay in that state.”

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Chapter 10: War or Growth?

Donna points to the role that self-reflection plays in our ways of being: “Conscious awareness is the start of reflection and choice. It is through re-flection that we form a concept of self and identity and gradually ac-knowledge and come to terms with our separateness from all around us.” (page 91). She then proceeds to describe how emotion, interpretation and consciousness play a role in a child’s development (pages 91 – 92): “Emotional hypersensitivity or exposure anxiety can be a natural stage for most children and the support of their environment together with their own repertoire of deflective and avoidance strategies probably protects them in getting through this and no long-term harm is done to their development.

Sometimes, a child going through this may not have the resources to cope. If the capacity to perceive or interpret is impaired, then even in a supportive environment, reassuring tones of voice, words, gestures or facial expressions may not be able to be consistently or cohesively interpreted with meaning. Expression may convey nothing, or worse, be sensed as clashing with the actual feeling of tension, annoyance or anxiety that is sensed as happening. Here the support that environment offers may be intangible, incomprehensible, imperceivable, confusing and even disturbing. The result may be that as conscious awareness dawns, such a child may be left too rawly exposed and, in effect, be unable to feel supported no matter how present that displayed support may be.” There are advantages to being able to interpret, and Donna “spent the first three decades of my life swinging between war and growth. Step by step, sometimes gradually, sometimes suddenly, a range of my own development blocks (biochemical, metabolic, perceptual, cognitive, emotional, psychological) were unblocked enough to free up development. With this came eventual trust of the system of interpretation and of mind and of my own separateness as I distinguished between boundaries of self and other. That brought with it the beginnings of expression through social interaction and communication with others. Without properly making that transition, I may still be staring at a pink billiard ball, resonating with the colour in the absence of any concept of what I was staring at or its use, attempting to feel the bliss of ‘becoming one’ with it. Without properly making that transition, you wouldn’t be reading this book I’ve now written and you would never know the system that was once in yourself which got left behind in a time before you identified yourself with it and probably before you can even remember.” (Page 93)

Chemistry and Motivation: Her body acts as a “measuring instrument” (page 95) and despite her sensing changes this may not always necessarily lead to action(s). *Sensation and Motivation*: She believes that thought and emotion are separable systems, although they “become integrated, even fixedly integrated with development as one progresses from sensing to interpretation” (page 95). *Thought and Motivation* (page 96): “An experience may be stored without interpretation, purely on the level of impression. That impression may, on the most basic level, be a mapping

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of edges. [...] Without interpretation, there is still experience". Therefore, despite thought being a form of interpretation, it is not needed in order to experience? Yes and no.

Chapter 11: Blah Blah and Ideas

A descriptive, explicitly phenomenological extract of the experience and the concept of a 'door' (page 97): "Concepts begin to be born when the sensation or image of a sensory experience becomes stored and is later recalled as a prompt. It is stored first, not in mind, but on the level of impulse; a kind of 'body mapped' imprint.

Imagine that, without yet having developed interpretation as a consistent system, I came across what you'd know as a 'door'. I may sense its nature through my body without even touching nor looking at it, and simply through 'resonance' may feel its lack of permeability and not attempt to walk through it. I may sense the shallowness of its depth and the release of this sense of density into open space on the other side. If I'd moved into physically-based sensing, I may test the nature of what happens to be a 'door' by tapping the panelling and the sonic feedback this gave me might confirm or deny what I already sense. Having had such an experience several times, this experience may then become linked to similar sensory experiences and further sensory exploration such as texture, smell or visual impression may further help categorise such 'door' experiences. Later, a similar sensing of a similar pattern regarding sensed permeability, sensed density or the sensed release of this density into open space on the other side may trigger not thought, but a recall of the body mapped impulse to test this sensing by tapping. On a more complex level, the sensing of the 'door' through smell may trigger the body mapped impulse of an earlier further exploration using texture, taste or visual mapping.

It is only later that one moves from nature to function of what is sensed." Donna then highlights that she used to swing the living room door repetitively as it was like a magic trick, and she did this over several years. She found dropping objects through space to be an amazing experience and would repeat such behaviour (page 98). Eating was such that she felt she had a hole in her face and whatever she placed in it was experienced via its texture and taste (page 98): "I'd grasped the sensation of textures going into a hole in my face that is called 'eating' and whilst it seems such an unnatural thing to do without actually having sought the experience, I did learn the pattern of eating what was put in front of me. Without the discrimination that comes of interpretation, one gets the nature of the experience without the function. I went about playing with this 'trick', putting all sorts of things into that hole in my face – sand, dirt, paper, cardboard [... etc.]" . On page 99 she outlines her hierarchy, stating that on "a sensory level, nature comes first, pattern comes second and function comes last".

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She tended to use the term 'degoitz' to describe objects that had a sensory-emotional impact on her and certain experiences are like lemons (page 100 - 101): "On the level of signing, there was an emotional experience that I called 'lemons'. In the language of interpretation this would have been something like 'sensation of acute and intense exposure anxiety resulting in an involuntary and instinctual aversion response, akin to sensations underlying so-called shyness or agoraphobia'. This experience was called lemons because that was the word used for a related sensation. If you ate lemons (which I did), the taste caused the same sort of involuntary and instinctual aversion response. And yet the sensation of lemons was defined not by the object of a lemon, nor by its smell or its taste but by the physical reaction evoked by eating the thing with this name. This was also the same physical reaction evoked through being complimented or through conscious acknowledgement of having a great liking for another person and sometimes even just before one's own consciousness." 'Autistic' people from different parts of the world use sensory ways of being to produce sensory-based language which are similar (page 102).

Chapter 12: Progress?

Sub-section *From the Sensory to the Literal* (page 103): "Identity is one of the reasons why one lets go of an earlier stage. Another is the capacity to trust and become familiar with the next stage. [...] Working with the will and getting will to trust the mind is something much harder to tackle. The mind is reasoned with consciously. The path to the will, however, is an indirectly confrontational one. The home of will exists in a place before the dawning of consciousness and it is only there that it is to be met and gradually helped to edge its way progressively towards trust and daring to connect with consciousness." Within the same sub-section (page 104): "Within the system of sensing, familiarity is a matter of empathy and empathy is a matter of resonance and mergence. By contrast, the system of interpretation requires the maintenance of separateness and the mechanism of 'reflection' which springs from these encounters." This raises questions for this research; what is self-reflection or/and reflexivity?

Sub-section *From Sensing to Personal Significance*, according to Donna "Sensing is about what is" (page 104). Page 105: "The sensing person may not bother with the meaning, purpose or function of people, creatures, places or things (even body) within the environment just as the literal person may not bother, nor even conceive, of the hierarchy, game playing and image making of the person who lives in the world of personal and relative significance." She then proceeds to highlight that (page 106): "The mind concept of self (and other) now is likely to not just be a representation of what is but of what one wishes or fears oneself (or others) to be. Misunderstanding may be born of a literal mind but madness is the stuff of false self. Development may have its costs as balance becomes an increasingly precarious task."

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Chapter 13: Beyond an Exchange of Cultures

Donna refers to different ways of being and likens these to the merging of cultures. Page 107: “At every level, the sensing creature is different from the interpretive one.

The interpretive creature, particularly humans, have come to rely pre-dominantly and primarily on vision or hearing. The sensing creature, human or otherwise, may use senses more flexibly, relying on non-physical sensing, body-mapping, touch, sonics and smell.”

The sensing person, and relying upon different forms of will (page 108): “Reliance upon different forms of consciousness also has implications for the concept of ‘social’. The person functioning on preconscious autopilot is governed by the will. The person functioning on a conscious level is governed by the mind. [...] After all, ‘I’ is a concept of mind, not of will. Will is the ‘it’, well before the time of ‘I’. When the ‘it’ expresses something, there is no sense of choice.”

On page 109 she illustrates how one may not have a sense of ownership of one’s body: “In a preconscious state, body may be experienced neither as part of self nor part of ‘I’. Expression through body in gear on preconscious autopilot, may mean that if the ‘I’ of mind even coexists at this stage, body may well be experienced as a separate entity from ‘I’; a tool used by ‘it’. Consider this in the context of social touching where interpretive people seek to share ‘I’ with one another through physical contact. Consider this in the context of personal and emotional response to the physical pain, cold or discomfort of the body and all the social behaviours and expression considered ‘normal’ associated with such sensations. Sure, the sensations may be felt, but uninterpreted and, moreover, devoid of personal interpretation, even the concept that one should care what happens to ‘body’ may be an extremely foreign concept.”

Imagination is a tricky topic (page 110), especially in relation to persons whose actions are more so governed by a sensory way of being or/and will /& a preconscious state. The information may remain separate in one’s mind as the ability to interpret and make meaning may not be exercised as heavily.

Page 110: “Existence is about experience and it is about what is foreground and what is background and just how foreground or background something is.”

Dishonesty: lying is not about lying itself, it is about mind’s denial of the will, dishonesty from self. Pages 110 – 111: “Dishonesty is not just about lying, it is about mind’s denial of the will. If I convince myself I feel something, even conjure up the pseudo emotion and follow it through in a logical assumption of action expression, then I am dishonest. If I listen to mind about my surroundings, judging them to be safe when my soul (if not already stifled to the point of being so background as to no longer be experienced) on a feeling level attempts to tell my mind otherwise,

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this is dishonesty.

Society appears to promote honesty but most of its structures rely on dishonesty. Dishonesty is not just from others but from oneself.”

She refers to herself as becoming bilingual with both sensory and interpretive systems (page 111). She further states that (page 111): “It is a difficult life when someone stands before you expressing the emotions their mind expects them to have about something when the ‘be’ (what’s between the lines) shouts out the opposite feeling to what is expected or being portrayed. All the more shocking, when, in empathy for the soul being sold out, one makes the sell-out clear only to be laughed at, shouted down or ignored! [...] The sensory being, who has acquired the system of interpretation as a secondary language, may buy into the appear. Yet, unlike the interpretive, he or she may be unable to become convinced that this is self.” She then outlines how people’s understanding of God is also very much in line with their sensory way of being (page 112): “It is, perhaps, no coincidence, that their concept of ‘God’ bears such a similarity to their own sensory being, left behind for most, too long ago to re-member. These people may actually be reaching, not outside of themselves as they believe, but for their own souls from which they’ve become estranged.”

She asserts that as a sensory being her soul is her God (page 113): “To the sensory being, the nearest concept to ‘God’ may be one’s own soul. Resonance is the empathic mechanism through which the sensory being feels the soul (of ‘God’ in all things). If what the sensory being feels is energy, then it is energy that is encapsulated within various bodies but also energy which exudes beyond it into the feel of a room. It is carried in the wind and an ocean tide. It is carried in the earth and in every rock.” Further stating that being this way leads to a sensory person not being afraid of death or physical danger. She describes how she wanted to fly (page 113): “I had wanted to fly for so long, as long as I could remember. Even in my early teens, I wanted to jump from the top of a building in order to fly. My theory was simple. I couldn’t fly because my body wouldn’t leave me. If I could make it leave me, make it detach, I could fly and be free in a way I felt I never could be in life. I did not feel I was being suicidal because I didn’t identify with my body. I wasn’t thinking of killing myself. I wasn’t thinking of an end to experience. I left my body in sleep and for periods throughout the day so I simply wanted to retain the state, not be dragged back to body. At various times when friends experienced me in this state I was thought of as disturbed, suicidal. Yet I was always happy in this state, as happy as anyone standing at the gates to potential heaven might be. I knew about death and suicide. That was about tragedy and sadness and about killing one’s self. Death was about an end to experience. This was not about suicide and death. I knew my self would be freed, not ended.”

Chapter 14: Multiplicity

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In the sub-section *Languages*, Donna describes how language is systemised and “passed down rather than evolving from the sensory or emotional experiences they spring from” (page 115). She describes some of the sensory based language she uses, e.g. the signing of pulling down one’s trousers for ‘toilet’.

Sensory and interpretive languages are further compared and both systems have their time and place (page 116): “It takes humility, intuition and pragmatism to see that both the language of interpretation and the sensory-based language of the soul could have their time and place as complementary systems.”

Under the sub-section ‘*Culture*’, she refers to people as moving in different sensory-perceptual worlds (page 117): “Those who live primarily by the system of interpretation live, effectively, in the same physical world as those who are primarily sensory beings (in the sense of the earth or universe). However, they move in different sensory-perceptual and social worlds or ‘cultures’. Just as each can be ‘bilingual’ in terms of ‘language’, each could be ‘multicultural’, able to move between culture-worlds as needed and able to interpret for those more proficient in one system than the other.

The sensory based social system could be important for crossing boundaries to know the nature of something which cannot be fathomed with mind or through language. The interpretive-based social system could be important when subjectivity is required (which requires an intact sense of self).”

Identity is how we view ourselves in relation to others, and the “system of interpretation involves retaining one’s separateness from others whilst having a simultaneous sense of self and other. It is this simultaneous sense of self and other which is necessary to being able to compare or contrast ourselves with others, whether objects, creatures or human-creatures. To those who live primarily by the system of interpretation, identity is an important concept but also leads to a feeling of alienation from others” (page 118). Her aim is to live in balance with these systems (page 119). Seeking a balance of the embodied&non-embodied self?

Chapter 15: Psychic?

Sensing is not of the mind (page 121): “The term ‘psychic’ is one that provokes a lot of different reactions; awe, disbelief, fear. There are those who confuse the mind-based capacity to analyse or ‘psyche someone out’ with being psychic. There are those who confuse wishful thinking and imagination with intuition. Anyone can use the word ‘sense’ when what they really mean is ‘think’, ‘believe’, ‘imagine’ or ‘wish’. But all of these things are of the mind. Sensing, however, is not.

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When someone truly senses something, it also has nothing to do with false self. It involves no necessary connection with the personal significance or relative significance. It involves none of the discrimination of mind in terms of hierarchy. The mundane is equally as likely to be sensed as the catastrophic.” Donna then proceeds to state that this kind of sensing and knowing is more of a matter of energy and cannot be traced to an experience of mind via the physical senses.

‘Evil’ is described (page 123): “ ‘Evil’, too, is just a form of energy, embodied on a material form or not. It is merely an unhealthy, negative, repelling, stagnant and often destructive energy. This type of energy can be sensed by someone whose energy boundaries are open just as ‘good’ (healthy, positive, attracting, flowing, and constructive) energy can be sensed.” She feels that sensory beings are less likely to be drawn to ‘evil’.

Chapter 16: Why Nobody’s Talking

Being simple can mean being “purer, with greater clarity, greater focus, poise and balance” (page 125); we should not be ashamed of being like animals (page 125 - 126). “The system of sensing has long been enshrouded in words linking it with images of Ouija boards, crystal balls, palmistry, tarot cards and the mythology of demons, angels and fairy folk. It is portrayed as ‘other worldly’. Actually, it is very much an integral and interconnected part of this world in its most holistic sense. Far from being unhealthy, used in a balanced integrated way the system of sensing could be the answer to so much of the spiritual cancer that eats away at the life force of so many people.” In order for this to take place people have to have the discipline to let go of the mind (page 127).

Within the sub-section *Translation Problems* (page 129), Donna states that there are likely to be problems of interpretation between people who are using their sensory system and those using their interpretive system, “just as they currently do in bilingual or multicultural environments” (page 129). Although, unlike “two languages using the same system, sensing and interpretation have no direct translations” (page 129).

Under the sub-section *‘Normality’, ‘Reality’ and ‘Humanness’* (page 130) she states that our recognition of our inner&intersubjective way(s) of being would lead to a perceptual and social reformation: “Our whole idea of perceptual and social reality would become reformed if it was no longer assumed that things are experienced only from without rather than within.” Going on to promote a sensory way of being (page 130): “It is possibly true that as one becomes cut off from the belonging, equality and empathic empathy that comes of the system of sensing, one is perhaps cut off from the experience of what is so enigmatically labelled ‘God’. Yet humans continue to pride themselves on their cleverness, on mind. When they speak of animals being without soul, perhaps they, themselves, no longer can tell the difference between mind and soul, or don’t dare to, or perhaps to do so has simply become progressively ever more convenient.”

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Chapter 17: Imagine

It takes courage to be vulnerable (page 131): “It takes courageous daring to be vulnerable and open to mergence. It takes enormous skill to be directed by the purity of will devoid of mind and mind’s learning. It takes a very big person to be humble enough to let go of the rigidity of defensiveness, hierarchy and superiority. It takes an adventurer to find belonging among that perceived from the outside as ‘different’.”

We ought to accept ‘difference’ (page 131): “Many fear what is different and fear creates rigidity. The avoidance of experience is the avoidance of growth. It is stagnation. It is death within life. To the Xenophobes among and within us all, we’d probably make a good start to accept that there are ‘aliens’ among us. My advice is, get used to it.”

How does Donna Williams use spirituality &/ religion to make meaning regarding her embodied&non-embodied life experiences?

Question	Excerpt(s) from the Book	Researcher’s Reflections and Notes	Ideas of Possible Questions for Interviews
1. How did the ‘autistic’ person make meaning of the paradox(es) of	In chapter 6, Resonance (pages 55-56): “My developmental condition affected how I processed sensory information. I wasn’t able to filter incoming information properly so I was being sensorily flooded by it. The capacity	Donna makes meaning of the paradoxical nature of her lived experiences via the use of her body, e.g. hands to face, and with objects in the environment, e.g. hand to wood; simultaneously she also outlines how her	What were your experiences of your body as a child like? As a young person? As a young adult? Now?

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<p>their lived experience? How did they practically deal with it?</p>	<p>to filter information requires some progressively accumulated sense of relative and personal significance and it is from this development of hierarchy that I think a sort of meta-self, some sort of pseudo-self or false self, is gradually born from mind.</p> <p>Without this filtering, I was flooded and this led to a range of involuntary adaptations, one of which I call being 'mono'.</p> <p>What being mono meant was that even though I'd progressed beyond mere mergence with things in my environment, I still had big restrictions in being able to process information produced from the outside and the in-side at the same time. This meant that I could feel the texture of the wood, for example, but in taking the action physically to do so I would have no sense of my own hand. I could also switch channels and feel my own hand but would lose sensation of what my hand was in contact with. This also applied to my own body parts. If I touched my own face with my hand, I could feel the texture of my face <i>or</i> the effect of upon my hand, but not both at the same time. I was either in a constant state of jolting perceptual shifts or I remained on one sensory channel or the</p>	<p>perceptual experiences are intertwined with these. Therefore, a practical means of dealing with this is to (i) acknowledge the fluctuating nature of her experience(s) and (ii) pay attention to the various forms of perception taking place one at a time – 'mono'.</p> <p>Note that she also makes meaning by contrasting this with a false self that is born from mind, not the sensory way of being. Is she treating the mind as a sense in itself? One which we have come to identify with, or become attached to, more so than the bodily & sensory ways of our being?</p> <p>Whilst she describes the experience of 'mono' one can understand the inner&intersubjective ways of her being; maybe I ought to use the term 'innerintersubjective' or 'innerinterperceptual'? When considering the dynamic aspects of her experience(s), maybe proprioception itself ought to be treated as a fluctuating sense? This in itself has affected her understanding of self, in that she had no sense of self – there was no 'I'. Although when re-counting this is she not exercising a sense of 'I'? Is "I" a sense that we practice?</p>	<p>Did you have any favourite objects? What kinds of objects did you enjoy touching? What was it about this experience that made you want to do so? How about objects you didn't/don't like touching? Why did you not like touching them/it? What was it about this experience that made you feel like that?</p> <p>What do you think of when I say the word "mind"? "Brain"?</p> <p>When I say the word "self" what do you think of? What is your understanding of "self"? Or/and do you prefer using other terms and words? Have you thought about the word "I"? What can this mean when you use it?</p>
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	<p>other. It became far more natural to me to explore the textures of things using physical-based senses, but without being able to process my own body sensations in relation to these textures it was still, perceptually, as though either 'I' did not exist and other things did or they existed and 'I' did not.</p> <p>Perhaps it was this very perceptual condition, this 'mono' state, that stopped my original non-physically based sensing from becoming a redundant system as it might have been with anyone else who had more usual perceptual development. It could, however, be argued the other way. Perhaps, having lived for at least three years strongly exercising the use of non-physically based senses that required no simultaneous sense of 'self' and 'other', the various brain connections necessary for this perceptual development didn't happen and were perhaps even replaced by other functions.</p> <p>To resonate with an object or surface takes no trying. Trying is an act of mind and mind is consciousness, firmly consciousness, and this is to have a conscious 'sense of self'. To merge with an object is to become it and one cannot do that with an intact sense of separate</p>	<p>One that is used at times and then let go of? (Depending on the context)</p> <p>Donna is trying to make meaning of her sensory way of being by explaining that her interactions with the environment were not through a perceptual lens of separation, but more so through oneness with the surrounding environment. She then hypothesizes that maybe the very exercising of this perceptual style is why her brain developed the way it did. There is a circular aspect to this description, as she is highlighting that her practicing the 'mono' perceptual style is likely to have influenced her biological brain development, and simultaneously, her perceptual style already existed as so.</p> <p>She refers to resonance, a form of merging with the energies of objects (and people, animals, plants etc.) in the environment which she practiced a lot as a child; highlighting that one ought to put aside the</p>	<p>What kinds of perceptual styles did you practice as a child? For example, did you prefer to lower your eyes and listen to people? What kinds of perceptual styles did you use as a young person? What kinds of perceptual styles did you use as a young adult? What kinds of perceptual styles do you use now? How do you think these may have affected you?</p> <p>Do you meditate? Do you use any objects whilst doing so? How do you feel whilst</p>
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	<p>simultaneous existence.”</p>	<p>sense of self of the conscious mind so as to experience the object or surface as it actually is. This practice in itself is paradoxical, in that she is in her body, and she is able to concentrate on and with objects such that she is one with the object. Merleau-Ponty (1964 / 1968, p. 114): “The things – here, there, now, then – are no longer in themselves, in their own place, in their own time; they exist only at the end of those rays of spatiality and of temporality emitted in the secrecy of my flesh. And their solidity is not that of a pure object which the mind soars over; I experience their solidity from within insofar as I am among them and insofar they communicate through me as a sentient thing.”</p> <p>Through her meaning-making and this practical strategy of merging, is she pointing to moving to a state of being beyond paradox via the use of paradox? Using a sense of self that is non-existent&/non-existence&/emptiness? Is this way of being a sense in itself? Is this no-self&no-sense? This reminds me of Shems&Mevlana’s statement (1263/2011, page 135): “Allah’ı candan gönülden istiyorsan varlıktan yokluğa dön. Bu</p>	<p>meditating? How do you feel after meditation? What do you learn? Do you apply any of this in your home life? Or/and daily life? How?</p>
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		<p>yokluk gelir yeridir; ondan kaçınma. Bu varlık da çok olsun az olsun, gider yeridir!": "If you want God deeply from within your heart and soul then turn away from that which exists to that which does not, to nothingness. This nothingness is where all things are, where they come from, and is a place of fortune and income; do not run away from it. As for this existence, whether it is a lot or little, is a place of expenditure!"</p>	
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<p>2. How did the person make meaning of the dynamic aspect of their lived experience? How did they practically deal with it?</p>	<p>Donna states that her ability to interpret was impaired (page 33): "Up to the age of four, I sensed according to pattern and shifts in pattern. My ability to interpret what I saw was impaired because I took each fragment in without understanding its meaning in the context of its surroundings."</p>	<p>"Dynamic self and mystery" comes to mind Lévinas (1961/1979, p.55): "The conscious being may very well involve something unconscious and implicit, and one may denounce as much as one likes its freedom as already chained to an ignored determinism; ignorance here is a detachment, incomparable to the self-ignorance in which things lie. It is founded in the interiority of psychism; it is positive in the enjoyment of itself. The imprisoned being, ignorant of its prison, is at home with itself. Its power for</p>	<p>What was your experience of the world as a child like? As a teenager? As an adult? [sensory wise?] How did you cope with changes? Do you think that you have a sensory way of being as well as an interpretative way of being?</p>
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	<p>She then proceeds to outline the dynamic nature of self (page 33): “I couldn’t consistently process the meaning of my own body messages if I was focusing in on something with my eyes or ears. I didn’t know myself in relation to other people because when I focused processing information about ‘other’, I lost ‘self’, and when I focused on ‘self’, I lost ‘other’. I could either express something in action or make some meaning of some of the information coming in but not both at once. So crossing the room to do something meant I’d probably lose the experience of walking even though my body did it. Speaking, I’d lose the meaning of my own sounds whilst moving. The deaf-blind may have lost their senses; I had my senses but had lost the sense. I was meaning deaf, meaning blind; interpretation and the realm of mind wasn’t a reliable or consistent system for me. I remained reliant far longer than most people</p>	<p>illusion – if illusion there was – constitutes its separation.”</p> <p>The body as a reflective instrument? Merleau-Ponty (1964 / 1968, p.9):</p> <p>“No doubt, it is not entirely my body that perceives: I know only that it can prevent me from perceiving, that I cannot perceive without its permission; the moment perception comes my body effaces itself before it and never does the perception grasp the body in the act of perceiving.* If my left hand is touching my right hand, and if I should suddenly wish to apprehend with my right hand the work of my left hand as it touches, this reflection of the body itself always miscarries at the last moment: the moment I feel my left hand with my right hand, I correspondingly cease touching my right hand with my left hand. But this last-minute failure does not drain all truth from that presentiment I had of being able to touch myself touching: my body does not perceive,</p>	<p>Have you had experiences whereby you felt confused by the sensory information coming into your body? Did you lose a sense of ownership of your body or and body parts at times?</p> <p>How do you sense? How do you sense yourself? How do you sense your surroundings? Does this change as you go from one activity to another? When did you develop a sense of being separate</p>
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	<p>on an earlier system: the system of sensing.”</p>	<p>but it is as if it were built around the perception that dawns through it; through its whole internal arrangement, its sensory-motor circuits, the return ways that control and release movements, it is, as it were, prepared for a self-perception, even though it is never itself that is perceived nor itself that perceives. Before the science of the body (which involves the relation with the other) the experience of my flesh as gangue of my perception has taught me that perception does not come to birth just anywhere, that it emerges in the recess of a body. The other men who see “as we do,” whom we see seeing and who see us seeing, present us with but an amplification of the same paradox.”</p> <p>Merleau-Ponty (1945 / 1989, p.66):</p> <p>“As soon as we relinquish our stubborn adherence to the Cartesian idea of the body and reconsider the lived body itself, we are compelled to acknowledge ‘an ambiguous mode of existing’ which overturns the traditional subject-object or mind-body categories. We must then discard the idea of causal connections among bodily functions on</p>	<p>from other people? Does your sense of ‘self’ change as you interact with others? Does your sense of ownership or/and non-ownership of your body change as you interact with others? How? Does your sense of ownership or/and non-ownership of your body change as you enter different environments? How? Do you prefer a sensory way of being rather than an interpretative way of being? When did you being to interpret your surroundings, e.g. assign a word to an object in your environment?</p>
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		<p>the one hand, and between the body and the 'external world' on the other. In place of such connections, we will be prompted to recognize fundamental relations of mutual implication having their roots in that central phenomenon of incarnate signification which the phenomenological description has brought to light. Mind or thought and body are themselves abstract moments of this central phenomenon. In abandoning the traditional procedure of detaching mind from body and subject from object, we reinstate the embodied subject as one who is 'never hermetically sealed' but rather, always ready intentionally related to the world in some measure. Consequently, the rediscovery of incarnate subjectivity will lead us to revise as well our conception of the sensible world as a whole."</p> <p>So what are the implications for researchers and research? Max van Manen may have an answer:</p> <p>Van Manen (1990, p.20):</p> <p>"Those entering the field of human science research may need to realize that the very meanings of "knowledge", "science",</p>	
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		<p>“theory” and “research” are based upon different assumptions. In this text we do not maintain the view held by traditional experimental or behavioural science where research is that inductive investigative process that produces empirical generalizations which are then formulated or built into theories. Neither is theorizing equated with a process of deductive or speculative reasoning done by philosophers or theoretical scientists. Rather, research and theorizing are often seen to be interchangeable concepts for that process of reflecting on lived experience that is involved in the various human science activities.”</p> <p>A human body acts as a kaleidoscope? The light and nothingness we are made of comes into being via such frequencies that our atoms have ‘properties’ that make us look ‘black’, ‘white’, with ‘blue eyes’, ‘brown eyes’, sense in an endless manner of holistic ways etc.?</p> <p>Synaesthesia comes to mind; we all do this in some way, however with some people this is more pronounced and therefore there is more of a conscious awareness of it?</p>	
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	<p>Chapter 12, Progress? (p.103): “From the Sensory to the Literal As one moves from non-physical-based sensing to physical based sensing, the earlier stage can still remain. Identity is one of the reasons why one lets go of an earlier stage. Another is the capacity to trust and become familiar with the next stage”</p> <p>“Working with the will and getting the will to trust the mind is something altogether different and much harder to tackle. The mind is reasoned with consciously. The path to will, however, is an indirectly confrontational one. The home of will exists in a place before the dawning of conscious-ness and it is only there that it is to be met and gradually helped to</p>	<p>Question that comes up in my mind: Identity is also reflection, as well as a construct of reflection? So as our reflections change so do we..?</p> <p>Van Manen (1990, p.29): “Significantly, Heidegger talked about phenomenological reflection as following certain paths, “woodpaths,” towards a “clearing” where something could be shown, revealed, or clarified in its essential nature. However, the paths (methods) cannot be determined by fixed signposts. They need to be discovered or invented as a response to the question at hand.”</p> <p>Lévinas (1961/1979, p.53): “The idea of Infinity implies the separation of same with regard to the other, but this separation cannot rest on an opposition to the other which would be purely antithetical. Thesis and antithesis, in repelling one another, call for one another. They appear in</p>	<p>How did you explore your environment as an infant? As a child? Teenager? Adult? How did you feel?</p> <p>Do you think that as you got older you moved from a non-physical way of sensing to a physically based way of sensing? Do you think the earlier stage can still remain? Are your lived experiences in line with this? Why do you think</p>
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	<p>edge its way progressively towards trust and daring to connect with consciousness.</p> <p>If the path from sensing to interpretation goes smoothly, the first steps are in moving from sensory mapping to the mapping of pattern to ascertaining the nature of something or someone by pattern. From there, one can come to map not only nature but function and purpose or even a range of functions or purposes.”</p> <p>(pages 104 – 105):</p> <p>“From Sensing to Personal Significance</p> <p>Sensing is about what is.” ... “The sensing person may not bother with the meaning, purpose or function of people, creatures, places or things (even body) within the environment just as the literal person may not bother, nor even conceive, of the hierarchy, game playing and image making of the person who lives in the world of personal and relative significance.”</p>	<p>opposition to a synoptic gaze that encompasses them; they already form a totality which, by integrating the metaphysical transcendence expressed by the idea of infinity, relativizes it. An absolute transcendence has to be produced as non-integrateable.”</p> <p>Merleau-Ponty (1964 / 1968, p128 – 129):</p> <p>“But already when I say “what do I know?” in the course of a phrase,¹¹ another sort of question arises: for it extends to the idea of knowing itself; it invokes some intelligible place where the facts, examples, ideas I lack, should be found; it intimates that the interrogative is not a mode derived by inversion or by reversal of the indicative and of the positive, is neither an affirmation nor a negation veiled or expected, but an original manner of aiming at something, as it were a <i>question-knowing</i>, which by principle no statement or “answer” can go beyond and which perhaps therefore is the proper mode of our relationship with Being, as though it were the mute or reticent interlocutor of our questions. “What do I know?” is not only</p>	<p>that you let go of the earlier stage? Are you able to trust the next stage? Do you think identity has anything to do with this?</p> <p>Do you believe in a will? What is your definition of ‘will’? What do you think will is? Do you think will and mind are separate? What is your understanding of ‘mind’? Do you make a conscious effort to listen to the will? How?</p> <p>Do you think that your development has involved moving from the sensory to the interpretative way of being? Do you think you have or had a sensory</p>
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		<p>“what is knowing?” and not only “who am I?” but finally: “what is there?” and even: “what is the <i>there</i> is?” These questions call not for the exhibiting of something said which would put an end to them, but for the disclosure of a Being that is not posited because it has no need to be, because it is silently behind all our affirmations, negations, and even behind all formulated questions, not that it is a matter of forgetting them in its silence, not that it is a matter of imprisoning it in our chatter, but because philosophy is the reconversion of silence and speech into one another: “It is the experience... still mute which we are concerned with leading to the pure expression of its own meaning.”¹² [Note, this quote is from Husserl, 1947 (French translation) /1960 (English translation)]</p> <p>Merleau-Ponty (1945 / 1989, p.8):</p> <p>“By returning to phenomena, we discover ‘a whole already pregnant with an irreducible meaning’; and it is this whole, rather than the alleged sensations and memories, which forms the ‘basic layer’ of all experience.”</p>	<p>way of mapping your environment or/and others’ behaviour? Do you feel other beings’ energy(ies)? Do you sense patterns and shifts? Do you think that you moved away from this way of mapping to an interpretative way of mapping that involves looking at patterns of events in the environment or/and with people so as to understand them?</p> <p>What are the things that are personally significant to you? As a child? Teenager? Adult?</p>
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	<p>Chapter 13, Beyond an Exchange of Cultures (page 107):</p> <p>“The difference between sensing and interpretation would seem broadly to encompass what gets called a ‘culture’; a shared way of relating, communicating and ideas or concepts, a way of identifying oneself. But this difference makes for more than ‘cultural’ exchange too, for cultural exchange relies on swapping tools of interpretation within the same system.”</p> <p>(page 110-111:)</p> <p>“Dishonesty is not just about lying, it is about the mind’s denial of the will [.....] Dishonesty is not just from others but from oneself. [.....] Having lost sensing, most people use the ‘appear’ as foreground information. To the sensory being, the ‘be’ is the foreground regardless of the degree to which one is</p>	<p>Shems&Rumi (1263 / 2011, p.135, translated and interpreted as): All that exists comes into being from that which is invisible; the unseen is more real than that which is seen.</p> <p>Here Donna is referring to ways of being as a culture and that ‘autistic’ people’s way of being is different from that of the non-‘autistic’ person in terms of developing an interpretative way of being significantly later in life and being more grounded in their sensory way of being.</p>	<p>What is your definition of</p>
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	<p>socially trained and pressured to respond to the 'appear' as though, falsely, it was the 'be'. I used to go around unable to perceive 'appear' because it was so background that only the 'be' stood out. The 'appear' would strike out like an unannounced phantom from no-where. Later, I became 'bilingual' in acquiring and becoming reasonably able to use the system of interpretation as well as the system of sensing. [.....]</p> <p>It is a difficult life when someone stands before you expressing the emotions their mind expects them to have about something when the 'be' (what's between the lines) shouts out the opposite feeling to what is expected or being portrayed. All the more shocking, when, in empathy for the soul being sold out, one makes the sell-out clear only to be laughed at, shouted down or ignored! [.....]</p> <p>The sensory being, who has acquired the system of interpretation as a second language, may buy into the appear. Yet, unlike the interpretive, he or she may be unable to become convinced that this is self."</p> <p>Chapter 14, Multiplicity (p.119): "Those who have acquired a muti-identity, are</p>	<p>Merleau-Ponty (1945/1989, p.118): "we are our body... by thus remaking contact with the body and with the world, we shall also rediscover ourself"</p> <p>"Our perception of the world and of ourselves is fraught with ambiguity; yet not only are we open to illusion and to truth about the world and about ourselves, but we can and do distinguish truth from illusion in both cases by the kind of 'hold' which we have on the respective phenomena."</p> <p>We all are also confused as we are in dynamic motion, moving between ways of being, though 'autistic' people are more consciously aware of this confusion? And if they make a conscious decision to stick to a way of being that is more sensory oriented because it is not so confusing and develop this perceptual style and way of being further, then no wonder that they become more confused by other people's ways of being that are not as consciously sensory based as theirs?</p> <p>Shems&Rumi (1263 / 2011, p.404, translated and interpreted): Sell your mind and</p>	<p>'culture'? Do you think 'autistic' people have a different way of living? A different culture? Is there 'autistic' language? Do you think there is an inter-exchange of languages?</p> <p>Do you think that 'autistic' and non-'autistic' people have a shared way of relating and communicating? How? Why?</p> <p>What do you think honesty is? What do you think dishonesty is? Do you think many people behave in ways that do not reflect they ways they actually feel or/and want to be?</p>
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	<p>able to move between the system of sensing and the system of interpretation, may strike the best balance. Such people would be able to be functionally able, secure in his or her independence yet able to seek assistance, capable of deep true empathy, less prone to insecurity, loneliness and addictive behaviours and yet capable of both feeling and responding to these things in others.”</p>	<p>intelligence, buy wonder - ‘sell your cleverness / reason and buy bewilderment’ is another version of this quote. It seems that Shems&Rumi are recommending that we let go of the rational mind and develop a more sensory connected way of being? An intuitive way of being?</p>	<p>Would you say that you are bilingual in terms of having a sensory way of being and an interpretative way of being and that you use both ways of being in your life? Have you had any times whereby you could sense that a person was feeling one way and yet was acting in a different way to how they were actually feeling? How did this make you feel? How did you respond or/and not respond?</p> <p>Do you think you have multiple identities? For example, a sensory and an interpretative way of perceiving the world? Or</p>
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			<p>any other terms you may want to use? Do you feel that you can move between the sensory and the interpretative ways of being? Would you refer to this as having a multi-identity? Or would you prefer to use a different term(s)? What are the positive aspects of being like this? Do you feel more comfortable as a sensory being than an interpretative being?</p>
<p>3. How did the person make meaning of the mysterious aspect of their lived experiences? How did they practically deal with this?</p>	<p>Donna was given a wall hanging, she did not understand its meaning, it was a mystery, so she practically had to dis-assemble the object and its parts so as to understand (page 20):</p> <p>“recently, in Italy, after speaking at a conference for the Lion’s club, I was given a wall hanging. It had a gold fringe along the bottom of it and brocade running around the side boundaries. Through the top was a metal rod with detachable ends which ran through a</p>	<p>The wall hanging was a mystery to Donna as she did not understand the purpose or meaning of it, i.e. she did not know what it was, therefore, she took action to understand by dis-mantling the object into its smaller parts.</p> <p>Van Manen (1990, p.72):</p> <p>“educators have a professional interest in (auto)biographies because from descriptions of lives of individuals they are able to learn</p>	

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	<p>satin piece of multi-coloured fabric upon which was some writing and some kind of picture. I took the wall hanging gratefully and disassembled it very quickly, removing the brocade and the fringe, unscrewing the detachable ends from the metal rod running through the top and taking the rod out of the hemline of the fabric. Having separated all the categories, having un-muddied all the waters, I had now turned this collection into something pure and attractive, useful and non-distracting. It was only then that I could clearly see the use of the metal rod and its detachable ends, the use of the fringe and brocade as 'decoration' and, to my surprise, the writing and the picture on the satin now made sense in relation to each other. The writing referred to the picture, describing the place in the mountains portrayed in the satin drawing. It had looked as if I'd destroyed the gift. Only in its dis-assembly was I able to fully perceive what I'd been given."</p> <p>Donna naturally meditated upon, with and through particular objects in her environment as she enjoyed this (page 22):</p>	<p>about the nature of educational experiences and individual developments. [...]</p> <p>It is not unusual for biographic texts to contain rich ore of lived-experience descriptions for phenomenological analysis or for converting into anecdote or story. So, while biography is oriented to individual or private meaning, phenomenology is oriented to existential meaning."</p> <p>She surrenders to and with the mystery of her being as well as the object(s) in her environment; she is enjoying the mystery, whereby she recognizes that there is no 'I' or</p>	<p>Did or/and do you dismantle objects to understand their purpose? As a child? Teenager? Adult?</p> <p>Do you find yourself naturally falling into a meditative state? Do you feel that you are merging</p>
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	<p>“When I was about ten years old I used to have a certain colour billiard ball – a pink one. I used to spend around an hour with it before I could reach the point of resonance with it where I would merge with the colour. To anyone else this would have looked like someone ‘psychotic’ but if they’d known the physical alteration felt in that moment of becoming one with a colour some people would perhaps see it as far less crazy than other ways many people may have spent an hour of their lives at the same age.”</p> <p>She works with the mystery of one’s being by recognizing that there are many ways of knowing, including with one’s body and intuition(s).</p> <p>On page 26 she refers to us having ‘shadow senses’, on page 27 she refers to the inner&intersubjective ways of communication that take place that seem to be a mystery to most people yet everyday events for her, and</p>	<p>the ‘other’ as she is merging with the colour of the ball. Merleau-Ponty (1945 / 1989, p.111):</p> <p>“The underlying question is whether there can in fact <i>be</i> such a realm of pure ideas, of thoughts lacking all temporality or contingency; whether there can be an absolute interiority in which consciousness is utterly transparent to itself so that nothing eludes its grasp.” Has Donna answered this question with “Yes”?</p> <p>Plus, what to say of synaesthesia?</p> <p>Intuition itself can be mysterious in its very nature, e.g. sometimes very obvious and clear through say an intense ‘gut feeling’ about something or/and silent in its ways yet simultaneously present. Donna is referring to an intuitive way of being and that she totally trusts this way of being when making decisions</p>	<p>with objects in the environment? What do you learn from this?</p> <p>Do you feel that you perceive through senses that are not visible? For example, such as intuition? Have you had any experiences whereby</p>
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	<p>on page 85 she refers to an intuitive experience and how she decided to always trust her intuition:</p> <p>“Before we learned to use our physical-body senses with intention, we were still able to see, hear, feel with ‘shadow senses’. Some people blind from birth, for example, can get about without some of the aids used by those who came to rely on their physical eyes. Some amputees can still feel the pain or itch in a limb that has been cut off. The ‘body’ is more than a physical form. It is an energy form, generally, but not necessarily, contained and expressed through a physical form.” (page 26)</p>	<p>Intuition and will</p> <p>Merleau-Ponty (1964/1968, p.180):</p> <p>“One always talks of the problem of “the other”, of “intersubjectivity,” etc.</p> <p>In fact what has to be understood is, beyond the “persons,” the existentials according to which we comprehend them, and which are the sedimented meaning of all our voluntary and involuntary experiences. This unconscious is to be sought not at the bottom of ourselves, behind the back of our “consciousness,” but in front of us, as articulations of our field. It is “unconscious” by the fact that it is not an <i>object</i>, but it is that through which objects are possible, it is the constellation wherein our future is read --It is between them as the interval of the trees between the trees, or as their common level.”</p> <p>Merleau-Ponty (1964 / 1968, p.229):</p> <p>“Principle: not to consider the invisible as an <i>other visible</i> “possible,” or a “possible” visible for an other: that would be to destroy the inner framework that joins us to it. Moreover since this “other” would “see” it – or this “other world” it would constitute would</p>	<p>you decided to trust your intuition more than your mind? What is your definition of ‘intuition’? What is your definition of ‘will’? Can you please describe a lived experience whereby you used your intuition? Can you please describe a lived experience whereby you used your will or/and whereby will used you? What do you think the body is? How do you feel in your body? If you can describe it, what is your lived experience(s) of your body?</p>
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	<p>She responded to people without verbal communication: "I also remember responding to people's call by coming into the room, sometimes answering their request by going and getting what they'd wanted. People had seemed surprised at these behaviours because they hadn't spoken the requests. It didn't occur to me that I hadn't been verbally called or asked or that I was busy with things of my own at the time. At these times, I suppose, I was 'out of my mind'." (page 27)</p>	<p>necessarily be connected to our own, the true possibility would necessarily reappear within this connection - - The invisible is <i>there</i> without being an <i>object</i>, it is pure transcendence, without an ontic mask. And the "visibles" them-selves, in the last analysis, they too are only centred on a nucleus of absence - - ."</p> <p>Inner&intersubjectivity, telepathy and intuitive communication comes to mind.</p> <p>Shems&Rumi (1263 / 2011; p.347): "... gönülden gönüle pencere vardır!" There is a window that exists between hearts [or / and heart to heart]!</p> <p>Merleau-Ponty (1945 / 1989, p. 61):</p> <p>"The speaker feels the need to speak without knowing exactly what he will say, and the listener takes up this intention by adjusting his own being to the speaker's style of being-in-the-world. Expression and comprehension are achieved through the body first and foremost; any intellectual clarification comes later. Communication thus understood is no</p>	<p>Do you sometimes know things before people have uttered a word?</p> <p>Have you sometimes acted according to a person's request despite the fact that they may not have said anything via speech or external body language? How did</p>
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	<p>At the age of 6 Donna had an experience whereby she decided to trust her sensory system (page 85): "I was walking down the street with my mother. I had a distinct sensing about which way to do something which was coming up. I could read the 'feel' of this, almost like it sat upon the air and this 'feel' instinctually told me that to do this thing in this</p>	<p>more mysterious than is the perception of objects, for in both cases we experience a 'bodily presence' which is prior to any scientific conception of the event."</p> <p>Merleau-Ponty (1964 / 1968, p.137 - 138):</p> <p>"the body belongs to the order of the things as the world is universal flesh. One should not even say, as we did a moment ago, that the body is made up of two leaves, of which the one, that of the "sensible," is bound up with the rest of the world. There are not in it two leaves or two layers; fundamentally it is neither thing seen only nor seer only, it is Visibility sometimes wandering and sometimes reassembled."</p> <p>She decided to trust her senses; living in the now? Phenomenological awareness?</p> <p>Knowing before the mind knows; using senses.</p>	<p>others respond?</p> <p>Do you think that you</p>
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	<p>way 'fitted'. Then I used my mind to judge whether this was the best thing or not, the best way to do this thing. Using logic, it came to the conclusion that this sensed way as not the best way and that instead another way should be used. I felt convinced by this logic, and unable to see beyond it mentally, I went with the way it dictated. The result was that this way was not the best way after all and did not work out. At this I cursed myself for trusting in this new system – this system of interpretation, this 'logic' – and vowed I'd stick by 'my own system', that of sensing." (page 85)</p> <p>The door is sensed, though is not known to her in terms of a concept as yet, e.g. a door, and is a mystery; she copes and learns in practical ways by exploring via her senses and by swinging the door:</p> <p>"Concepts begin to be born when the sensation or image of a sensory experience becomes stored and is later recalled as a prompt. It is stored first, not in mind, but on the level of impulse; a kind of 'body mapped' imprint.</p> <p>Imagine that, without yet having developed</p>	<p>Merleau-Ponty (1964 / 1968, p.7) describes a similar phenomenon: "Now that I have in perception the thing itself, and not a representation, I will only add that the thing is at the end of my gaze, and in general, at the end of my exploration. Without assuming anything from what the science of the body of the other can teach me, I must acknowledge that the table before me sustains a singular relation with my eyes and my body: I see it only if it is within their radius of action; above</p>	<p>experience life in a deep way to the point that you are constantly pulled in to the here and now?</p> <p>Have you had any experiences that led you to make a decision about trusting your body and senses more than your mind? Do you trust your senses and your body more than you trust your mind? Have you experienced anything in particular that made you resort to making such a decision?</p> <p>What were your experiences of objects like as a child? As a teenager? As an adult?</p> <p>How did you play and</p>
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	<p>interpretation as a consistent system, I came across what you'd know as a 'door'. I may sense its nature through my body without even touching nor at it, and simply through 'resonance' may feel its lack of permeability and not attempt to walk through it. I may sense the shallowness of its depth and the release of this sense of density into open space on the other side. If I'd moved into physically-based sensing, I may test the nature of what happens to be a 'door' by tapping the panelling and the sonic feedback this gave me might confirm or deny what I already sense. Having had such an experience several times, this experience may then become linked to similar sensory experiences and further sensory exploration such as texture, smell or visual impression may further help categorise such 'door' experiences. Later, a similar sensing of a similar pattern regarding sensed permeability, sensed density or the sensed release of this density into open space on the other side may trigger not thought, but a recall of the body mapped impulse to test this sensing by tapping. On a more complex level, the sensing of the 'door' through smell may trigger the body mapped impulse of an earlier further exploration using texture, taste or</p>	<p>it there is the dark mass of my forehead, beneath it the more indecisive contour of my cheeks – both of these visible at the limit and capable of hiding the face, as if my vision of the world itself were formed from a certain point of the world. What is more, my movements and the movements of my eyes make the world vibrate – as one rocks a dolmen with one's finger without disturbing its fundamental solidity. With each flutter of my eye-lashes a curtain lowers and rises, though I do not think for an instant of imputing this eclipse to the things themselves; with each movement of my eyes that sweep the space before me the things suffer a brief torsion, which I also ascribe to myself; and when I walk on the street with eyes fixed on the horizon of the houses, the whole of the setting near at hand quivers with each footfall on the asphalt, then settles down in its place. I would express what takes place badly indeed in saying that here a "subjective component" or a "corporeal constituent" comes to cover over the things themselves: it is not a matter of another layer or a veil that would have come to pose itself between them and me. The stirring of the "appearance" does not disrupt the evidence</p>	<p>engage with these objects as a child? As an adult?</p> <p>How did you remember what the objects were during your childhood? Teenage life? Adult life?</p>
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	<p>visual mapping.</p> <p>It is only later that one moves from nature to function of what is sensed. This is where one goes from 'door' as a sensory impression to the response of 'door' to action upon it. Such an action may be very confusing on a sensory level. On a sensory level, one can understand relative permeability or density but what is dense is not expected to move in response to impact and yet the door, sensed as dense, gives way under impact – a most curious and irreconcilable experience. I remember my own repetitive swinging of the loungeroom door for several years. I think it was something of a magic trick to me.” (page 97 - 98)</p> <p>Donna refers to translation problems between the sensory and interpretive ways of being:</p> <p>“Problems of interpretation between people using one system and those using the other are also likely to occur just as they currently do in bilingual or multicultural environments.</p>	<p>of the thing – any more than monocular images interfere when my two eyes operate in synergy.”</p> <p>Does this also mean that Donna is more prone to traumatic ways of experiencing the world?</p>	<p>How did you learn about the purpose of or/and function of objects? Could you feel the objects without touching them with your body parts? How do you remember objects? When you think about say a door, how is it represented in your mind?</p>
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	<p>Taking a very simple everyday example. Two people are in a bathroom. As one picks up a fluffy towel after a bath, one may merely have perceived the object in its purely sensory form. At that moment, irrelevant of having interpreted the use of the object, reached for it purely for the sensory experience, wrapping him or herself up in the sensation, becoming part of it, it may not have been interpreted. The other, using interpretation may ask, 'why are you covering yourself up?' Unlike two languages using the same system, sensing and interpretation have no direct translations. How would one set the other straight about these actions without stepping into the world of words, so irrelevant to the system of sensing? Though explanation may have no place or relevance in the system of sensing, according to the system of interpretation it would be rude not to answer. The person sensing may see there is a mistranslation and seek to set it right not by ex-plaining but by touching the person with the towel, sharing the sensory experience. The person using the system of interpretation may have no idea why the person has appeared to have been so rude as not to have answered, even perhaps assuming this behaviour as some sort of strange, un-</p>	<p>Page 119, 129 in Donna's book: multiplicity and translation problems, mystery, conflict and function come to mind.</p> <p>Milton's (2012) paper: double empathy problem. HP: and double spatiality?</p> <p>Non-'autistic' researchers may not recognise a sensory style of communication – viewing 'autistic' person as having a 'developmental' delay.... ?</p>	<p>Have you had any experiences with a person whereby you were trying to explain something in a sensory way and they were reacting in a confused or/and negative manner? How did you feel? How did you cope? How did you react or / and not react?</p>
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	<p>expected come-on. Yet by the system of sensing, the person already had answered in the action of sharing the sensory experience of the towel. Even in a society where all were proficient in both systems, society could become polarised, split between those who identified with, valued and more strongly relied on one system or another." (page 129)</p>		<p>Have you had any experiences whereby you felt like you had answered a person's question and yet they could not understand? How did you cope? Did you react or/and not react? How?</p>
<p>Questions and Reflective Notes Regarding the 'Other' and Myself</p>			

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<p>1. How do 'autistic' persons' make meaning? What is my meaning-making process(es)?</p>	<p>Donna makes meaning via her senses and what I deem to be her intuition, e.g. 'will'. She highlights that she has learned to navigate in the world in two ways; the sensory and the interpretative. So her meaning-making is very much created and shaped by this. Although she makes it clear that she prefers the sensory way of being as it is a more reliable way of navigating in environments. What struck me was the sensory style of language that she describes, especially when communicating with another person, e.g. regarding the towel, which is an example of what Milton (2012) would describe as the 'double empathy' problem'.</p> <p>This whole document illustrates my meaning-making:</p> <p>Paradox; as described above.</p> <p>Dynamics; as described above.</p> <p>Mystery; as described above.</p>
<p>2. What are the implications for perception(s)</p>	<p>Perception may be created and influenced by both sensory and interpretative ways of being, which in turn may influence how a person is able to – or / and not – make sense of their lived experiences.</p>

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and self-knowledge?	
3. What are the implications for phenomenology as a methodology?	<p>Question: what are the implications for phenomenology as a methodology when considering Donna's sensory and interpretative ways of being?</p> <p>Are descriptive styles of phenomenological research more suited to understanding 'autistic' persons' ways of being?</p>
4. What are the implications for IPA as an approach and the methods involved?	<p>Again, is a more descriptive style of IPA more suited to researching into the lived experiences of 'autistic' people?</p>
<p>Questions and Reflective Notes Regarding the 'Other', the Family Context and Myself</p>	
<p>How does this 'autistic' person make meaning? Especially in the family context? What seems to be the family's meaning-making process(es)?</p>	<p>Donna makes meaning by referring to her embodied and non-embodied experiences, whereby she states that she is bilingual because she has a sensory way of being and an interpretative way of being which developed more so in her early 30s.</p> <p>Regarding her family, she does not write about their meaning-making or how they treated her. Having read her other book, the initial autobiography entitled <i>Nobody Nowhere</i> (first published in 1991), she does write a lot about her experiences with her family, though again, she does not outline their explicit spiritual/&religious beliefs&/non-beliefs or practices. In the current text, she describes her experiences in relation to self, no-self, objects, space(s), events, friends, guests in her home etc.</p>

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<p>What is my meaning-making process(es)?</p>	<p>My meaning-making process is as outlined above.</p>
<p>What are the implications for perception(s) and self-knowledge?</p>	<p>Perception entails the embodied sensory way of being as well as the interpretative way of being, which is non-embodied yet influenced by the body, thereby leading to self-knowledge. Embodied&non-embodied self-knowledge leading to embodied&non-embodied self-knowledge; circular dynamic process(es).</p>
<p>What are the implications for phenomenology as a methodology?</p>	<p>Phenomenology's focus on the body and the senses is very useful. I am becoming more and more mindful of the sensory ways of being and interpretative ways of being; making this element explicit in my thinking and writing is important, thereby also consciously creating a gap for the mystery that exists in the lived experiences as well as in the writing. Maybe I also ought to use a visual means to illustrate this? For example, in the written text have spaces and gaps to remind the reader to (i) acknowledge the mysterious element, (ii) 'see' it, (iii) be reminded of it, therefore also adding to the exercising of a reflective manner of reading? Max Van Manen clearly has a role to play here.</p>

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<p>What are the implications for IPA as an approach and the methods involved?</p>	<p>IPA ought to take more of a questioning standpoint, especially throughout the analyses.</p> <p>One can use question marks when categorising and theming so as to continue creating 'gaps' in the mind, with the use of these visual cues. This method is in line with bracketing and developing the phenomenological attitude.</p>
<p>What is self-knowledge? How does it develop?</p>	<p>Self-knowledge: Self-awareness of itself.</p> <p>Does it develop?</p>
<p>What is meaning? How does it develop?</p>	<p>Meaning is laden with many experiences, embodied and non-embodied.</p> <p>It 'develops' with mystery, yet simultaneously, it is clear and visible to itself.</p>
<p>What is perception? How does it develop?</p>	<p>Perception is the dance of and between the embodied and non-embodied self? All aspects melding into and with each other?</p> <p>'Develops' via sensory and environmental experiential elements?</p>

The questions that have arisen regarding the methods so far are:

1. How does one use reflective texts/autobiographies, especially those by 'autistic' persons, with IPA?

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- By asking phenomenological questions;
- Illustrating the interpretive process the researcher is undergoing by summarizing chapters and producing tables, and using direct quotes and excerpts from 'autistic' persons' writings for this, as above. Which in itself is a reflexive act(s);
- Coming up with ideas of possible questions for interviews.

2. How does one use autobiographical/reflective texts in order to further become sensitive to the context and culture of 'autistic' persons and 'their' family life?

- Asking phenomenological questions that focus on the embodied&non-embodied self;
- Keeping in mind the implications of such ways of being that I am learning about and coming up with ideas as I proceed; e.g. the ideas of possible interview questions are emerging from the narratives of the 'autistic' writer(s).

3. How does one create further research questions (e.g. for interviews) and develop one's philosophical standpoint(s) whilst analysing 'autistic' person's autobiographies with IPA?

- Read the book, summarize it, ask the phenomenological questions and produce the table, answer the questions by selecting detailed first-hand experiential stories from the 'autistic' writer(s), whilst doing so reflect upon the excerpts and make notes, and when ideas of possible questions for interviews come to mind note these down.
- Be, and remain, open to the story of the 'other' by reading it and dialoguing with it in such a questioning manner that one's worldview is challenged and possibly changed.
- Use IPA as flexibly as the research questions and narratives require, further acting as a bridge for 'autistic' thought and philosophy to shape the methodology of analyses and questions derived from therein.

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APPENDIX 5

Data and Analyses: Family Vignette 1, Infancy. Temple Grandin, 1986. Emergence: Labeled Autistic

Contextual information regarding this book:

(i) Who wrote the autobiography/& reflective text: Temple Grandin, with the assistance of Margaret M. Scariano

(ii) Where the autobiography/& reflective text was written: It was published in California, U.S.A

(iii) When the autobiography /& reflective text was written: It was published in 1986, and this copy was printed in 1996.

(iv) Why and how the text came in to being:

Temple writes about her experiences and also includes research materials in the Appendices for parents, educators, and other professionals. Therefore, as much as this written work is a form of self-exploration it is also aimed at educating people.

Vignette from pages 15 – 16:

“Perhaps, because of my inability to communicate adequately and because of my “inner” world, the scenes of my childhood are vivid. Memories play like a movie on the big screen of my mind.

Mother, who was only nineteen when I was born, said she remembers me as a normal, healthy newborn with big blue eyes, a mass of downy brown hair, and a dimple in my chin. A quiet, “good” baby girl named Temple.

If I could remember those first days and weeks of life, would I have known I was on a fast slide slipping into an abyss of aloneness? Cut off by over-reactions or in-consistent reactions from my five senses? Would I have sensed the alienation I would experience because of brain damage suffered as an unborn child – the brain damage that would become apparent in life when that part of the damaged brain matured?

I was six months old when Mother noticed that I was no longer cuddly and that I stiffened up when she held me. When I was a few months older, Mother tried to gather me into her arms, and I clawed at her like a trapped animal. She has said she didn’t understand my behavior and

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felt hurt by my hostile actions. She'd seen other babies cuddling and cooing in their mother's arms. What was *she* doing wrong? But she figured she was young and inexperienced. Having an autistic child was scary for her because she didn't know how to respond towards a baby who rejected her. Maybe my seeming re-jection was not unusual so she shoved her apprehension aside. After all, my health was good. I was alert, in-telligent, and well-coordinated. Since I was the first-born, Mother thought my withdrawal was probably normal, part of maturing and becoming independent.

This withdrawal from touch, so typical of autistic children, was followed in the next years by standard autistic behaviors: my fixation on spinning objects, my preference to be alone, destructive behavior, temper tan-trums, inability to speak, sensitivity to sudden noises, appearance of deafness, and my intense interest in odors.

I was a destructive child. I drew all over the walls – not once or twice – but any time I got my hands on a pencil or a crayon. I remember really “catching” it for peeing on the carpet. So the next time I had to go, instead of using the carpet, I put the long drape between my legs. I thought it would dry quickly and Mother wouldn't notice. Normal children use clay for modeling; I used my feces and then spread my creations all over the room. I chewed up puzzles and spit cardboard mush out on the floor. I had a violent temper, and when thwarted, I'd throw anything handy – a museum quality vase or left-over feces. I screamed continually, responded violently to noise and yet appeared deaf on some occasions.

At age three Mother took me to a neurologist to be examined because I did not act like the little girls next door. I was the first child in a family of four and none of my younger sisters or brothers behaved the way I did.”

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How does Temple make meaning regarding her embodied&non-embodied life experiences as an infant?

Question	Excerpt(s) from the Vignette	Researcher's Reflections and Notes	Ideas of Possible Questions for Interviews
<p>1. How did the 'autistic' person make meaning of the paradox(es) of their lived experience? How did they practically deal with it?</p>	<p>Perhaps, because of my inability to communicate adequately and because of my "inner" world, the scenes of my childhood are vivid. Memories play like a movie on the big screen of my mind.</p>	<p>Temple makes meaning of the paradoxical aspect of her life, i.e. her lack of communication with others yet having vivid childhood memories, by highlighting this element(s) of her way of being.</p> <p>She can practically deal with this state of being by replaying her memories like a movie in her mind. She is likening her mind to a movie screen in order to illustrate this. This style of remembering memories could be interpreted as a means of self-storytelling. The entire book itself is a form of self-storytelling. Reflection as self-storytelling?</p> <p>Romanyshyn (2007, page 30) comes to mind: "The more we come to know, the more we come to know that we do not know. Jung makes this prologue to <i>Memories, Dreams and Reflections</i> when he says, "We are a psychic process which we do not control, or only partly direct." Because of this fact he adds, "Consequently, we cannot have any</p>	<p>To 'autistic' person: Do you have any memories from infancy? Are they vivid memories or/and not so vivid?</p> <p>To parent(s): What was your child's memory like during infancy? How did you feel about it?</p>

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		<p>final judgement about ourselves or our lives.” A researcher who would keep soul in mind has to attend, as I said in the Introduction to this book, to feeling mourning for what is left behind in his or her ways of knowing and expressing and remembering soul.” I would add that this is equally applicable to the ‘autistic’ person as a researcher, i.e. as a being making meaning, as well as to me as a researcher.</p>	
<p>2. How did the person make meaning of the dynamic aspect of their lived experience? How did they practically deal with it?</p>	<p>This withdrawal from touch, so typical of autistic children, was followed in the next years by standard autistic behaviors: my fixation on spinning objects, my preference to be alone, destructive behavior, temper tantrums, inability to speak, sensitivity to sudden noises, appearance of deafness, and my intense interest in odors.</p> <p>I was a destructive child. I drew all over the walls – not once or twice – but any time I got my hands on a pencil or a crayon. I remember really “catching” it for peeing on the carpet. So the next time I had to go, instead of using the carpet, I put the long drape between my</p>	<p>Temple was finding it difficult to cope with her environment and the demands being made on her, e.g. withdrawal from touch as she was sensitive to being held.</p> <p>She preferred to be alone, exhibited what people saw as “destructive” behaviours, and had deep interests in elements in the environment. ‘Double empathy problem’ (Milton, 2012, 2014) comes to mind.</p> <p>She drew on the wall to express herself.</p> <p>It seems that she was frustrated and angry.</p> <p>She did not understand that the drapes were</p>	<p>To ‘autistic’ person: What kinds of sensory experiences did you have as an infant? E.g. regarding being touched, smells, objects etc.? Did you prefer to be alone? Did people think you were deaf?</p> <p>Did you draw over the walls as an infant? Did you pee or/and poo in places that your family did not want you to? How did your parents react to your behaviour? Say</p>

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	<p>legs. I thought it would dry quickly and Mother wouldn't notice. Normal children use clay for modeling; I used my feces and then spread my creations all over the room. I chewed up puzzles and spit cardboard mush out on the floor. I had a violent temper, and when thwarted, I'd throw anything handy – a museum quality vase or left-over feces. I screamed continually, responded violently to noise and yet appeared deaf on some occasions.</p>	<p>not to be used for peeing on. She behaved in ways that would be viewed by adults as 'naughty' or/and delinquent.</p> <p>I feel that these were all her ways of trying to communicate - including the 'violent' responses.</p> <p>Rosenberg's <i>Living Nonviolent Communication</i> (2012, page viii): "I found that the following three factors are very important in understanding why some of us respond violently and some of us respond compassionately in similar situations:</p> <ul style="list-style-type: none"> • The language that we have been educated to use • How we have been taught to think and communicate • The specific strategies we have learned to influence others and ourselves" <p>And on page 2 Rosenberg's (2012) book: "The Nonviolent Communication practices that support conflict resolution involve</p> <ol style="list-style-type: none"> 1. expressing our needs; 	<p>when being touched? When smelling things? When playing with certain objects?</p> <p>Were you frustrated or / and angry as an infant? Why? How?</p> <p>To parent(s): Did your child carry out behaviour as an infant that seemed like inappropriate behaviour? E.g. peeing on the carpet or wiping faeces over the room? How did this make you feel? How did you behave in relation to this kind of behaviour? How do you think your child felt?</p>
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		<ol style="list-style-type: none"> 2. sensing the needs of others, regardless of how others are expressing themselves; 3. checking to see whether needs are accurately being received; 4. providing the empathy people need in order to hear the needs of others; and 5. translating proposed solutions or strategies into positive action language. “ <p>So how do we work with an infant who is explicitly in conflict with oneself and environment? Especially when the infant has a neural make-up that may influence language comprehension or/and behaviour comprehension in a significantly different manner and degree to other infants her age? How do we understand our needs in such a situation? How do we sense her needs in such a situation (regardless of how she may be expressing herself)? How do we check to see whether her, and our, needs are being accurately received? How do we exercise the empathy needed to hear her needs as well as ours? How can we translate proposed solutions or strategies into positive action language, especially with an infant who may</p>	
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		not be so disposed to spoken language per se?	
<p>3. How did the person make meaning of the mysterious aspect of their lived experiences? How did they practically deal with this?</p>	<p>At age three Mother took me to a neurologist to be examined because I did not act like the little girls next door. I was the first child in a family of four and none of my younger sisters or brothers behaved the way I did.</p>	<p>When compared with other little girls and children of Temple’s age and under (i.e. when a paradoxical lens is used to view these infants), her mother recognizes more so that there is a mystery about her child’s behaviour. Her mother takes her to a professional to seek advice – with the hope of unravelling this mystery. A word(s) or/and label or/and conceptual construct is being sought to try and understand the mysteries of Temple as an infant.</p> <p>Lorna Wing in <i>The Autistic Spectrum</i> (1996; pages 189 – 190): “Another problem over the last three decades has been the influence of the school of thought that denies the reality of mental illness and disability and is opposed to ‘labelling’. Those who hold these views believe that giving a name to a condition is a self-fulfilling prophesy and harms the person concerned. In reality, having an accurate and detailed diagnosis as early as possible is the first crucial step for parents, enabling them to find information and help</p>	<p>To ‘autistic’ person: When did your parent(s) seek the advice of a medical professional in relation to you? Or/and when did you seek this kind of advice? How did this come about?</p> <p>To parent(s): When did you feel the need to seek professional medical advice regarding your child? How did this come about? How did you feel during the process(es) of your child being seen? How did you feel afterwards? How do you feel now?</p>

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		<p>and giving access to services and the support found from meeting other parents in the same situation. [... ...]</p> <p>A full diagnostic evaluation involves taking a detailed develop-mental history, psychological assessment, observation of behaviour, examination for any additional medical or psychiatric conditions or disabilities, including impairments of hearing or vision and investigations to try and establish the original cause.”</p> <p>I have not been present during such a recognition process(es) so I cannot write from first-hand experience. Though I have spoken with families who have been through such a process and have had parents tell me that their child was recognized as being ‘different’ by relatives and they had recommended that the parents seek professional advice. I have also spoken with some ‘autistic’ adults who have been recognized as being ‘autistic’ in their 20s or 30s; one told me she felt relieved, another told me that he felt depressed and continued to be depressed for years, another told me that it simply confirmed what he had felt all is life – that he is different. I agree with Wing</p>	
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		<p>(1996) in that recognition of ‘autism’ is required, however, simultaneously, recognition of the individual human being and their unique developmental path ought to come first before imposing expectations and non-expectations in relation to the person. In other words, the recognition of an aspect of the person’s way of being, e.g. ‘autism’, should not be used to justify all of their behaviour; factors such as the environment should also be brought into perspective when attempting to understand the person.</p>	
<p>Questions and Reflective Notes Regarding the ‘Other’, the Family Context and Myself</p>			
<p>How does this ‘autistic’ person make meaning? Especially in the family context? What seems to be the family’s meaning-making process(es)? What is my</p>	<p>As an infant Temple was making meaning via her embodied&non-embodied experiences, e.g. at 6 months she had begun to push her mother away (I assume this was due to sensory overload as she refers to this a little later on), being engrossed in spinning objects and odours, and I assume that she was also attempting to communicate with the tools that she had, e.g. carrying out what she terms as ‘destructive behaviour’ and drawing on the walls etc. She also preferred to be alone. Therefore, meaning-making can take many forms, which includes the family context in terms of family being present and not being present.</p> <p>Her mother’s meaning-making of this was that Temple was rejecting her and this led to her feeling hurt. Yet Temple refers to it as “my seeming rejection”, implying that physical distancing of oneself from one’s mother does not necessarily mean that one is rejecting their mother. Hence, it seems that it is more so a distancing (or rejection) from the type of physical interaction rather than a rejection of the parent. In this situation both the parent and child are exhibiting significantly varying degrees of</p>		

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<p>meaning-making process(es)?</p>	<p>embodied neurological sensory abilities, and what with the parent generalizing this in her mind to be rejection of herself, one can see how this may lead to further misunderstandings about the child and how to share love with her/&him. Therefore, their meaning-making was shrouded in mystery as well, in that both struggled to understand the other's embodiedness. However, Temple is now able to shed some light upon it all, so it would also seem that meaning-making is an ongoing dynamic process which then changes as times goes by and information received from various sources, e.g. in this case it was via the comparison of Temple with other infants and her younger siblings and then from the neurologist, that all helped to uncover some of the mystery. Threads of meaning and meaning-making intertwining?</p>
<p>What are the implications for perception(s) and self-knowledge?</p>	<p>Perception as the embodied&non-embodied self? Perception as relationship? Relationship as self-knowledge? Self-knowledge as perceptual relationship? Perceptual relationship as self-knowledge?</p>
<p>What are the implications for phenomenology as a methodology?</p>	<p>The implication for phenomenology as a methodology is that it should set out that researchers ought to be focused on exercising the phenomenological attitude along with the intention of seeking to come up with questions regarding 'oneself' and 'one's own' story as well as regarding 'others' and 'their' stories – i.e. in my case it is to exercise reflexivity all the way throughout the actual PhD study and make it the very means of writing the thesis. Furthermore, the researcher should also attempt to consciously be aware of the relationship(s) that exists amidst the endeavour of the research process(es), i.e. how the initial research questions came up, how the researcher carried out a literature review, why and how the researcher took up phenomenology as a methodology and IPA as an approach, how the researcher came up with the criteria of selection for autobiographies and vignettes, how the researcher then analysed such works, how the researcher is writing about such findings, and what this means for phenomenology as well as IPA and the methods we use for research.</p>
<p>What are the implications for</p>	<p>The implications for IPA as an approach is that the embodied&non-embodied self also entails relationship; relationship with 'oneself', the 'other' and the given environmental context. Therefore, how can IPA analyses be carried out such that these three</p>

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<p>IPA as an approach and the methods involved?</p>	<p>intertwining elements are explicitly acknowledged? ... Focusing on the embodied&non-embodied self along with focusing on the sub-interrelated aspects of paradox, dynamics and mystery may well be a way to achieve this. In addition, carrying out analyses with questions in mind rather than statements/categories/or themes in mind - at the beginning stage that is – may also be a useful phenomenological cognitive style to utilize when examining lived experiences.</p>
<p>What is self-knowledge? How does it develop?</p>	<p>Self-knowledge as being an element of relationship and relationships? Relationship and relationships as being an element of self-knowledge?</p> <p>Self-knowledge ‘develops’ in, as, with and through relationship and relationships? Or/and relationship ‘develops’ in, as, with and through self-knowledge? Or/and it develops in, as, with and through the moment and intertwining moments?</p>
<p>What is meaning? How does it develop?</p>	<p>Meaning as the interaction between ‘oneself’ and the ‘other’? ‘Oneself’ and ‘other’ in, as, with and through paradoxical dynamic mysterious meaning?</p> <p>Meaning ‘develops’ as, with, in and through relationship?</p>
<p>What is perception? How does it develop?</p>	<p>Perception as relationship with one’s body and non-body? Relationship with one’s embodied&non-embodied self?</p> <p>Perception ‘develops’ in, as, with and through the presence of relationship with the ‘other’? The ‘other’ and ‘self’ in a dynamic interaction within perception as relationship?</p>

The questions that have arisen regarding the methods so far are:

1. How does one use reflective texts/autobiographies, especially those by ‘autistic’ persons, with IPA?

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- By asking phenomenological questions;
- Illustrating the interpretive process the researcher is undergoing by producing tables, as above, and using direct quotes and excerpts from 'autistic' persons' writings for this. Which in itself is a reflexive act(s);
- Coming up with ideas of possible questions for interviews;
- Taking up a developmental lens and working with vignettes that are to do with family members at different stages of the 'autistic' persons' development.

2. How does one use autobiographical/reflective texts in order to further become sensitive to the context and culture of 'autistic' persons and 'their' family life?

- Asking phenomenological questions that focus on the embodied&non-embodied self;
- Keeping in mind the implications of such ways of being that I am learning about and coming up with ideas as I proceed; e.g. the ideas of possible interview questions are emerging from the narratives of the 'autistic' writers themselves;
- Analysing vignettes that specifically focus on family contexts are also enabling me to become that much more sensitive.

3. How does one create further research questions (e.g. for interviews) and develop one's philosophical standpoint(s) whilst analysing 'autistic' person's autobiographies with IPA?

- Read the books, pick out a vignette for the relevant developmental stage that fulfils the selection criteria and type it up word for word from the book, ask the phenomenological questions, create the table and whilst doing so reflect and make notes; when ideas of possible questions for interviews come to mind note these down.

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APPENDIX 6

Data and Analyses: Family Vignette 2, Infancy. Erika Hammerschmidt, 2008. Born on the Wrong Planet

Contextual information regarding this book:

(i) Who wrote the autobiography/& reflective text: Erika Hammerschmidt

(ii) Where the autobiography/& reflective text was written: It was written in Minneapolis, Minnesota, and published in Kansas, U.S.A. by the Autism Asperger Publishing Company (AAPC)

(iii) When the autobiography /& reflective text was written: It was published in 2008.

(iv) Why and how the text came in to being:

Erika always enjoyed writing and has a fascination with language (p.186), so she had wanted to pen down her life story, including details regarding also being 'autistic' (Asperger Syndrome) and having Tourette's.

How does Erika make meaning regarding her embodied&non-embodied life experiences as an infant?

Vignette from page 27:

“Mom and Dad have always supported me in my struggle to come to terms with my Asperger Syndrome, and perhaps they sensed that writing and other forms of artwork play a large role in this struggle. I have learned to understand the rest of the world by writing about it, and when I have been unable to understand it, I have taken refuge in other worlds I've created through writing, painting and drawing. I cannot remember a time when my creative urges were not met.

I demanded entire reams of paper for drawing, from the age of two. At that time, my pictures were nothing but shapeless scribbles, but I always got as much paper as I wanted. I remember it well: perfectly white paper in packages of three hundred sheets, enfolded in brown wrapping with the name “Quill” and a picture of a feather pen.

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Later I started wanting blank books to write in, and my parents bought me those, too. The books were always the kind with a binding like real hardcover books, sometimes with a beautiful pattern on the front and back covers, sometimes with a picture on the front. I especially liked the extra-small ones.

Sometimes I filled them to the last page with stories from my imagination; sometimes I only got about halfway through the book with writing, and filled the rest with drawings. Once I took scissors to a book and painstakingly cut a rectangle out of the center of each page so that when the book was closed, there was a secret empty space inside it where I could hide small treasures. If my parents saw any of my uses of blank books as wasteful, they kept it to themselves.”

Question	Excerpt(s) from the Vignette	Researcher’s Reflections and Notes	Ideas of Possible Questions for Interviews
<p>1. How did the ‘autistic’ person make meaning of the paradox(es) of their lived experience? How did they practically deal with it?</p>	<p>I demanded entire reams of paper for drawing, from the age of two. At that time, my pictures were nothing but shapeless scribbles, but I always got as much paper as I wanted. I remember it well: perfectly white paper in packages of three hundred sheets, enfolded in brown wrapping with the name “Quill” and a picture of a feather pen.</p>	<p>It would seem that Erica’s attempts to make meaning(s) of her life was passionately put into practice by drawing etc. Paradoxically, she became more of a reflective artist/&thinker/&writer – i.e. that much more of a social scientist – from childhood onwards. Van Manen (1990, p.125 – 126) states that: “Writing fixes thought on paper. It externalizes what in some sense is internal; it distances us from our immediate lived involvements with the things of our world. As we stare at the paper, and stare at what we have written, our objectified thinking now stares back at us. Thus, writing creates the</p>	<p>To ‘autistic’ person: When you were an infant, did you draw things? Do you remember what they were? Did your parents encourage you to draw or/and write or/and take up other creative activities?</p> <p>To parent(s): Did your child draw or/and write or carry out any other creative activities as an infant? How did you react to this? Why?</p>

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		<p>reflective cognitive stance that generally characterizes the theoretic attitude in the social sciences. The object of human science research is essentially a linguistic project: to make some aspect of our lived world, of our lived experience, reflectively understandable and intelligible. Researchers recognize this linguistic nature of research in the imperative reminder: “Write!” Human science research requires a commitment to write. But writing for a human science researcher is not just a supplementary activity. The imperative “Write!”, as Barthes put it, “is intended to recall ‘research’ to its epistemological condition: whatever it seeks, it must not forget its nature as language – and it is this which ultimately makes an encounter with writing inevitable” (Barthes, 1986, p.316).</p> <p>For Barthes, research does not merely involve writing; research is the work of writing – writing is its very essence (1986, p.316).”</p>	
<p>2. How did the person make meaning of the</p>	<p>Later I started wanting blank books to write in, and my parents bought me those, too. The books were always the kind with a binding like</p>	<p>She made meaning of, and enacted, her dynamic nature via her creativity. She did this by writing, drawing, using books in ways that</p>	<p>To ‘autistic’ person: How did you use the books or other creative tools you may have</p>

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<p>dynamic aspect of their lived experience? How did they practically deal with it?</p>	<p>real hardcover books, sometimes with a beautiful pattern on the front and back covers, sometimes with a picture on the front. I especially liked the extra-small ones.</p> <p>Sometimes I filled them to the last page with stories from my imagination; sometimes I only got about halfway through the book with writing, and filled the rest with drawings. Once I took scissors to a book and painstakingly cut a rectangle out of the center of each page so that when the book was closed, there was a secret empty space inside it where I could hide small treasures. If my parents saw any of my uses of blank books as wasteful, they kept it to themselves.</p>	<p>they were not initially intended to be used, e.g. cutting into and through the middle of a book's pages.</p> <p>Primo Levi (1975/1985, p.232 – 233): "It is that which at this instant, issuing out of a labyrinthine tangle of yeses and nos, makes my hand run along a certain path on the paper, mark it with these volutes that are signs: a double snap, up and down, between two levels of energy, guides this hand of mine to impress on the paper this dot, here, this one."</p> <p>Erika practically dealt with her dynamic nature in the above way.</p>	<p>been given as an infant? Did you draw, write, paint etc.?</p> <p>To parent(s): How did your infant use the creative tools you got them? Did they draw /& write /& cut say the paper you gave them? What did they draw /& paint /& write /& etc.? Why do you think they did this?</p>
<p>3. How did the person make meaning of the mysterious aspect of their lived experiences? How did they practically deal</p>	<p>Mom and Dad have always supported me in my struggle to come to terms with my Asperger Syndrome, and perhaps they sensed that writing and other forms of artwork play a large role in this struggle. I have learned to understand the rest of the world by writing about it, and when I have been unable to understand it, I have taken refuge in other worlds I've created through writing, painting</p>	<p>Erika outlines how writing has enabled her to express herself; the paradox is that the mystery she struggled to understand or/and verbalise she was able to pen on paper. Writing about events in one's life is usually a reflective act to some degree or another, though I wonder if she simply described the events or/and wrote about them with a particular emotion(s) or/and thread leading</p>	<p>To 'autistic' person: How did your parents behave in relation to your creative activities as an infant? Why do you think they reacted like that?</p> <p>To parents: What do you think your infant learned</p>

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<p>with this?</p>	<p>and drawing. I cannot remember a time when my creative urges were not met.</p>	<p>the story(ies)?</p> <p>As she highlights, she also used her imagination to make meaning of the events in her life. This spurred her creative nature and her parents facilitated this. They practically dealt with the mysterious as well as the paradoxical nature of Erika's way of being by recognizing it and supplying her with the necessary materials to write, draw, paint etc. This way Erika herself was also able to further develop coping strategies regarding her own mysterious nature. Therefore, this inner&intersubjective transactional way of being exercised by the whole family enabled all involved to practically work with the mysterious nature of the whole situation, e.g. a child struggling to understand aspects of her life and the parents are struggling to understand her, so creative tools are called upon and utilized to work with the mystery(ies) of life.</p>	<p>whilst undertaking drawing or/and writing etc.? What do you think you learned whilst they were doing this? How did you behave in relation to this?</p>
<p>Questions and Reflective Notes Regarding the 'Other', the Family Context and Myself</p>			

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<p>How does this 'autistic' person make meaning? Especially in the family context? What seems to be the family's meaning-making process(es)? What is my meaning-making process(es)?</p>	<p>Erika makes meaning via the art of writing. She is aware that her parents, i.e. her non-self-embodied embodied-self(ves), recognized that this was a meaningful way of being for her and therefore they fostered this kind of behaviour.</p> <p>Her parents' meaning-making seems to be that they validated her meaning-making and encouraged her to continue writing, e.g. by buying her paper etc.</p> <p>My meaning-making process(es) herein is that I am further recognizing and accepting the value of writing . It is a form of self-witnessing. Validating one's own ways of being as well as meaning-making; a reflective mirror that is held up by us upon us. Storytelling is a chemical endeavour, whereby the word is also light; this idea came to me thanks to Wes Jamroz's book 'Shakespeare's Sequel to Rumi's Teaching' (2015). It then reminded me of the phrase "In the beginning was the Word, and the Word was with God, and the Word was God" (King James Bible, John, 1:1).</p>
<p>What are the implications for perception(s) and self-knowledge?</p>	<p>By the means of writing, which in itself is an activity undertaken via the actions of the body, Erika was able to 'develop' her perception or/and understanding of her embodied and non-embodied experiences further – self-knowledge. Therefore, yet again, Merleau-Ponty's (1945 / 1989; 1964/1968) assertion in relation to perception and body being intertwined comes to the fore. As Thomas Stearns Eliot states (1940), "In my beginning is my end". Erika's writings begin from within, i.e. a need to want to understand, and the circular reflective process(es) of writing seems to end within her as well. What is writing? Is it another illustration of the relationship(s) that we have with ourselves? Threads of reflected perception(s) that 'extend beyond the body' continually bridging, un-bridging and re-bridging realities that fluctuate in a dynamic manner? Arising from the mystery of perception and flowing to the fore and returning like waves to the abyss from which they arose? – Is this what we refer to as 'self-knowledge'?</p>
<p>What are the</p>	<p>It would seem that the implication for phenomenology is that we have to acknowledge the fluid nature of the threads of</p>

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<p>implications for phenomenology as a methodology?</p>	<p>energy/light that is present within the very word. This must also be brought into consideration when focusing on the phenomenological nature of autobiographies written by people, including those who are 'autistic'. The implication for self-knowledge may well be that the word is in itself a story of light, and when sentences are constructed constellations of light are formed and threads become intertwined via the means of writing? Therefore further reflecting light from within and upon our within? And hence, perception is further 'developed'?</p> <p>A researcher ought to be reflexive about this element. One should consider autobiographical writing in this way in order to acknowledge and validate the very art that these particular 'autistic' people have used in an attempt to (i) understand themselves and life better, (ii) to share their stories, and to (iii) educate the reader. What is education? Do we actually know the essence of how we learn? Yes, there are various theories regarding learning styles and reading etc., but HOW do we actually learn? Are we not continuously re-uncovering that which is already present within?</p>
<p>What are the implications for IPA as an approach and the methods involved?</p>	<p>The narrative element of IPA has become that much more of a focus for this researcher and the study at hand. Therefore, the implication seems to be that the importance of the word and the ways in which it is used and not used ought to be brought to the fore, in that the manner(s) in which meaning-making, perception, body, self-knowledge and writing are all intertwined together ought to be explicitly reflected upon, with, in and through. Therefore, maybe an aspect of the non-embodied self is the actual story of the person and the book is a representation of it in the form of an object. Yet 'subject', i.e. the individual, and 'object', i.e. their story in the form of a book, are one. Carl Jung's 'Man and His Symbols' (1964/1997) comes to mind here - the autobiographical book as a symbol? The symbol as an 'extension' of the embodied self? Words as symbols? Symbols as words that carry light? Maybe when utilizing IPA and narratives in such a way to analyse the autobiographies of 'autistic' people regarding the embodied&non-embodied self one also ought to consider not only the word as light but also as a symbol? Therefore, maybe there also ought to be an exploration of IPA, narrative analysis, Jungian/ Analytical psychology and autobiography?</p>
<p>What is self-knowledge? How does it develop?</p>	<p>Self-knowledge is one's narrative? It 'develops', or is unravelled and ravelled and re-unravelled continuously, via writing or/and recounting one's story or/and via exercising self-reflection? The human being as a story and narrative in itself? That our genes carry thousands of stories that have influenced our own DNA and environments? That the human being is a source of self-knowledge and is also self-knowledge?</p>

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<p>What is meaning? How does it develop?</p>	<p>Meaning as the embodied&non-embodied self? Meaning as the very act and art of writing? Meaning as self-reflection? Meaning as recognizing and validating one's own meaning-making (e.g. drawing and writing)? Meaning as having such a recognition and validation process being recognized and being validated by one's parents (e.g. the provision of paper)? Meaning as a way of being?</p> <p>Maybe meaning 'develops', or in other words is unravelled and ravelled continuously, via the recognition and validation of one's bodily preference for a certain kind of meaning-making, which in turn can be further 'developed' by the affirming gaze/perception and actions of one's parents? In that one's reality(ies) is(are) consciously acknowledged by one's parents and therefore their gaze/perception influences the child's own gaze/perception regarding their meaning-making in a nourishing manner?</p>
<p>What is perception? How does it develop?</p>	<p>Perception is also story? Perception is one's narrative? One's body as perception and perception as one's body? Perception as the embodied&non-embodied self? Merleau-Ponty (1964/1968) highlights that essentially there is no 'subject' or 'object', that both are in relationship. This also leads to recognizing the importance of one's gaze and how this influences us and the events in our lives. Perception 'develops' as our story 'develops'? Perception 'develops' as our story is continually unravelled, ravelled and re-unravelled? Perception 'develops' as our bodies continue to transform over the years?</p>

The questions that have arisen regarding the methods so far are:

1. How does one use reflective texts/autobiographies, especially those by 'autistic' persons, with IPA?

- By asking phenomenological questions;

- Illustrating the interpretive process the researcher is undergoing by producing tables, as above, and using direct quotes and excerpts from 'autistic' persons' writings for this. Which in itself is a reflexive act(s);

- Coming up with ideas of possible questions for interviews;

-Taking up a developmental lens and working with vignettes that are to do with family members at different stages of the 'autistic' persons'

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development;

- This particular vignette has also brought to the fore the importance of creativity, drawing and writing in the process(es) of developing as a human being.

2. How does one use autobiographical/reflective texts in order to further become sensitive to the context and culture of 'autistic' persons and 'their' family life?

- Asking phenomenological questions that focus on the embodied&non-embodied self;

- Keeping in mind the implications of such ways of being that I am learning about and coming up with ideas as I proceed; e.g. the ideas of possible interview questions are emerging from the narratives of the 'autistic' writer(s).

- Analysing vignettes that specifically focus on family contexts are also enabling me to become that much more sensitive.

- The importance of creativity in this narrative is enabling me to be that much more sensitive about the creative nature of this study and thesis, e.g. I have become a lot more aware of my writing style(s) and the perceptual embodied&non-embodied ways of interpreting that I am exercising – as shown above by the nature of the questions that are arising;

- IPA and narrative analysis that focuses more so on the lived experience have shared objectives, and the nature of this vignette in terms of creativity, drawing, writing etc. illustrates the significance of this form of self-exploration and meaning-making – which becomes even more valuable and useful when one's family members validate it.

3. How does one create further research questions (e.g. for interviews) and develop one's philosophical standpoint(s) whilst analysing 'autistic' person's autobiographies with IPA?

- Read the books, pick out a vignette for the relevant developmental stage that fits the selection criteria and type it up word for word from the book, ask the phenomenological questions, create the table and whilst doing so reflect and make notes; when ideas of possible questions for interviews come to mind note these down.

APPENDIX 7

Data and Analyses: Family Vignette 3, Childhood. Luke Jackson, 2002. Freaks, Geeks and Asperger Syndrome. A User Guide to Adolescence

Contextual information regarding this book:

- (i) Who wrote the autobiography/& reflective text: Luke Jackson
- (ii) Where the autobiography/& reflective text was written: England
- (iii) When the autobiography /& reflective text was written: It was published in 2002 in London
- (iv) Why and how the text came in to being:

Luke has written this as a guide for adolescents, including those who are not 'autistic', and also outlines that it is likely to be useful for families, educators and other professionals. At the time he was 13 years old, was in a family of 6 other siblings, and they assisted with writing the book as well as drawing pictures for it – included in the book.

Vignette from pages 63 - 66:

"A Tiptoe Down Memory Lane

Are you sitting comfortably? Then I will begin! (My Grandad always says that, apparently it comes from a very old children's programme.)

One day we decided to go out. It was a boiling hot day so Mum had decided that we should go to St. Anne's beach. I hated beaches and sand and sun and water, even more than I do now, so it just was not my idea of a good time! As usual though, the majority ruled and off we went (even though I think all will agree that I put up a good fight).

When we got there, Mum carried me down across the sandhills on her back so that I didn't have to get my feet sandy or wet and settled me down on a towel – still moaning I hasten to add! My sisters were as usual, very scornful and bad tempered about the fact that I hated this so much. In my opinion they are freaks for liking this kind of stuff.

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Once on the beach, my sisters soon ran off to get muddy and sticky and wet (and they say I am weird!) and left me sitting on a towel working out bits of mental arithmetic to keep myself occupied. Mum was busy with Joe who was only four and very little but she interspersed this with the occasional 'Go and play with your sisters, Luke' or 'Just give it a go, you may like it'. I sat and thought 'Yeah, about as much as reclining in a vat full of acid', but eventually I dutifully got up and wandered in the direction of my sisters, trying to tiptoe to avoid as much of the sand as possible, whilst casting mournful faces at a smiling applauding Mum.

As I walked and tolerated the disgusting feeling of wet sand between my toes, the attraction of the warm grass and the reed-type plants sticking out of the grass was too much for me and I turned and wandered to a particular big patch of grass, never giving anyone else a second thought.

One second, I was there, the next, poof – I was gone, or so it seemed to them. In actual fact, I was picking all the little seeds off this piece of grass and then trying to fold it and blow between it. Have you ever tried that? Be careful though, because grass is like paper and can cut you. If you get it right, it makes a really cool squealing noise. I never can quite manage it.

I often get engrossed in one thing or another and lose track of time. I think it's a pity that time exists at all, but then I suppose at least we know when to have meals. I can spend hours looking at the patterns and shapes in things around me. I carry in my head my own little show of patterns and prisms and shapes and colours. They intermingle with shapes from the outer world. It is very hard to explain, but maybe other AS or autistic people understand. Strangely enough, as I get older I am more aware of time and space and people and less aware of my own little world. I think when I used to 'get lost' (I have put that in inverted commas because I only got lost in other people's eyes, I always knew where I was), I was in my own world quite a lot. Ben [his younger little brother who is also 'autistic'] is like that now.

After a little while, I decided to go back to Mum. I was told that it was a very long while, many hours actually, but I didn't realize that. One small problem with going back to Mum was that I didn't particularly know which way back was. I looked round for a while and finally saw a man walking along in the grass. He asked if I was lost. I explained that I wasn't lost but I didn't know where my Mum was and had he seen her. I explained that she had curly hair and pink lipstick and the last time I saw her she was sat on a pyramid. Looking back on it now, I suppose he was very puzzled. We were in St Anne's, not Egypt! The pyramid is a big, sloping stone wall with two faces, which look like that of a pyramid. It did to me anyway, but apparently not to others!

Meanwhile, Mum had got every single person on the beach looking for me. Coastguards, police, a pack of Brownies and every available person were all shouting my name over a loudspeaker. I didn't hear a thing! I have a strange kind of hearing and can only concentrate on listening to things if I know I am meant to. Distinguishing between background and foreground noise has always been a problem, so however

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loud they shouted I would have presumed that it was background noise. This is a difficulty of AS because I get told off so many times for being an ignorant pig when I genuinely do not recognize that I am being spoken to. Joe [another younger brother] has this problem a lot, lot worse than I do.

I wasn't really looking for anyone when I was found. I just stumbled across them. It was very strange because my sisters and brothers were crying and Mum grabbed me and a big fuss was made over what seemed to me like nothing. Sometimes it is very hard to understand exactly what I have done wrong. If you are a parent and your child is like that, then make sure to explain to them very clearly."

How does Luke make meaning regarding his embodied&non-embodied life experience with family as a child?

Question	Excerpt(s) from the Vignette	Researcher's Reflections and Notes	Ideas of Possible Questions for Interviews
<p>1. How did the 'autistic' person make meaning of the paradox(es) of their lived experience? How did they practically deal with it?</p>	<p>One day we decided to go out. It was a boiling hot day so Mum had decided that we should go to St. Anne's beach. I hated beaches and sand and sun and water, even more than I do now, so it just was not my idea of a good time! As usual though, the majority ruled and off we went (even though I think all will agree that I put up a good fight).</p>	<p>Luke makes meaning of the paradox(es) of this situation by outlining how he does not like going to the beach due to his overwhelming sensory experiences whilst there, yet paradoxically the majority of his family enjoy the experience. His own embodied way of being and former experience(es) at the beach led to him taking up an opposite standpoint to most of his family members, however, due to the majority's embodied ways of being not being like his, this led to the family going to the beach. Therefore, despite his efforts to not go he had to. Is the majority's vote</p>	<p>To 'autistic' person: When you were a child, did your family want to go to certain places that you did not want to go to? For example, the beach? How was the decision made? For example, was it a case of votes for and against the type of trip or was it otherwise? How about trips to places you enjoyed going to? How was the decision made regarding these?</p> <p>To parent(s)/guardian(s): What</p>

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	<p>When we got there, Mum carried me down across the sandhills on her back so that I didn't have to get my feet sandy or wet and settled me down on a towel – still moaning I hasten to add! My sisters were as usual, very scornful and bad tempered about the fact that I hated this so much. In my opinion they are freaks for liking this kind of stuff.</p>	<p>always the right vote? What to say of the minority's vote? If it is a 7 people versus 2 people vote what makes the 2 votes any less valid than the 7? Though one could also look at this in the sense that family life was/is preparing Luke well for living in a society that holds up this kind of way of being.</p> <p>Luke's mother knew about his sensory experiences and that Luke did not like the beach due to this, therefore, she tried to ameliorate the negative feelings of such an experience by carrying him on her back and setting him down on a towel. There is an inner&interplay amongst mother and son in terms of trying to work in harmony in a context that has created anxieties for both; an emotional connectedness&non-</p>	<p>kinds of outings or trips did you go out on with your child(ren)? E.g. the beach? How was the decision made? What kinds of things did you consider before going?</p> <p>To siblings: What kinds of outings or trips did you go out on as child(ren)? E.g. the beach? How was the decision made? How did you feel regarding your 'autistic' sibling's preferences?</p> <p>To 'autistic' person: When you got to the place did your parents/guardians make any adjustments in consideration of your sensory abilities? How did you feel? What were your siblings' reactions like towards you? What did you think about their behaviour?</p> <p>To parent(s)/guardian(s): What kinds of things did you keep in</p>
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	<p>Once on the beach, my sisters soon ran off to get muddy and sticky and wet (and they say I am weird!) and left me sitting on a towel working out bits of mental arithmetic to keep myself occupied. Mum was busy with Joe who was only about four and very little but she interspersed this with the occasional 'Go and play with your sisters, Luke' or 'Just give it a go, you may like it'. I sat and thought 'Yeah, about as much as reclining in a vat full of acid', but eventually I dutifully got up and wandered in the direction of my sisters, trying to tiptoe to avoid as much of the sand as possible, whilst</p>	<p>connectedness is coming to the fore that much more as each tries to accommodate their bodily preferences in a given space. The mother behaves as a non-self-embodied embodied self for Luke and he also behaves the same way for her as she carries him, and an object is used, i.e. a towel, to try and cater for Luke's bodily preference(s).</p> <p>Luke compares his sisters' reactions with his own. Is it comparison that acknowledges difference, or in other words the paradoxical ways of our being(s), which in turn leads to a better establishment of self? As well as a better understanding of self?</p> <p>Luke does not seem to have much to preoccupy his mind and attention apart from mental arithmetics, and in the meanwhile his mother is attending to his younger brother. Simultaneously she encourages him to go and play with his siblings; it seems that he feels a sense of</p>	<p>mind or and do whilst at the place? How did you feel?</p> <p>To sibling(s): When you got to the place of your outing, what did you do? What did your 'autistic' sibling do? How did you feel about this? What did you think?</p> <p>To 'autistic' person: How did your siblings behave at the place you were visiting? What did they enjoy? What did they not enjoy? What did you think about this? What were you doing or and not doing?</p> <p>Did your parent(s)/guardian(s) give you any activities to do whilst there? For example, a board game? Or and did they tell you to go and spend time</p>
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	<p>casting mournful faces at a smiling applauding Mum.</p>	<p>duty to do as asked. Their paradoxical interaction, i.e. an applauding mother and a mournful faced son, illustrates the ambiguity in the situation. Luke's embodied experience of the situation is painful but yet he is trying to fulfil his mother's wish, and it seems that despite knowing about Luke's embodied way of being his mother is trying to get him used to the beach and to playing with his siblings in such a context, hence she is congratulating him. Is there an ethical concern here? What his mother has done seems to be the kind of thing a parent would do to try and encourage their child to do something they may be hesitant about. However, in this case the hesitance is not purely due to a matter of having feelings of doubt or nervousness, the hesitance is due to having a neural make-up that makes the child that much more sensitive to water and sand, which is painful for the child and in itself may also likely induce nervousness. If the child's bodily ways of being are considered and taken into account at one stage of the situation, e.g. to enter the beach and sit down, but then they are ignored in terms of encouraging him to go and play in a painful context with siblings,</p>	<p>with your siblings? What was your reaction? Did you have any younger siblings that your parent(s)/guardian(s) was attending to during the outing? What did you think of this at the time?</p> <p>To parent(s)/guardian(s): Whilst at the outing place, what did your 'autistic' child do or and not do? How did you respond? Did you try and encourage them to spend time with their sibling(s)? Did you have any other children to take care of at the time?</p>
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		<p>then is this likely to lead to more confusions for the child in the long run? In that the parent makes adjustments to their behaviour in so far as it suits them, however, once the child is in the very context they struggle to navigate in they are no longer assisted by the parent to say go and play with their siblings? Simultaneously one could also look at this paradoxical experience(s) and situation in the sense that this is a challenge for Luke that is pushing his limits and enabling him to develop more independent coping skills.</p>	
<p>2. How did the person make meaning of the dynamic aspect of their lived experience? How did they practically deal with it?</p>	<p>As I walked and tolerated the disgusting feeling of wet sand between my toes, the attraction of the warm grass and the reed-type plants sticking out of the grass was too much for me and I turned and wandered to a particular big patch of grass, never giving anyone else a second thought.</p> <p>One second, I was there, the next, poof – I was gone, or so it seemed to them. In actual fact, I was picking all the little seeds off this piece of grass and then trying to fold it and blow between it. Have you ever tried that?</p>	<p>Amidst the paradoxical experience(s) Luke becomes dynamic by walking and tolerating the feeling of the wet sand. As he does so he sees some plants and grass that appeal to him. A familiar and soothing micro-context within a larger painful context?</p> <p>It seems that he is making meaning of the dynamic aspect of his lived experience by engaging with an element of the larger context that feels comfortable for him. He also attempts to relate with the reader by</p>	<p>To ‘autistic’ person: Whilst at the place of an outing what kinds of sensory experiences made you feel like not wanting to be there? Or and not do certain kinds of activities there? Did you go off and do something by yourself? What was this? How did you feel whilst doing this? What did you learn?</p>

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	<p>Be careful though, because grass is like paper and can cut you. If you get it right, it makes a really cool squealing noise. I never can quite manage it.</p> <p>I often get engrossed in one thing or another and lose track of time. I think it's a pity that time exists at all, but then I suppose at least we know when to have meals. I can spend hours looking at the patterns and shapes in things around me. I carry in my head my own little show of patterns and prisms and shapes and colours. They intermingle with shapes from the outer world. It is very hard to explain, but maybe other AS or autistic people understand. Strangely enough, as I get older I am more aware of time and space and people and less aware of my own little world. I think when I used to 'get lost' (I have put that in inverted commas because I only got lost in other people's eyes, I always knew where I was), I was in my own world quite a lot. Ben [his younger little brother who is also 'autistic'] is like that now.</p> <p>After a little while, I decided to go back to Mum. I was told that it was a very long while, many hours actually, but I didn't realize that.</p>	<p>asking whether one has tried to blow between grass, highlights what appeals to him about doing this, and gives advice that illustrates his caring side.</p> <p>Luke then delves into how the dynamic acts he gets involved in and with lead to him becoming so engrossed in it that he loses track of time. He provides a paradoxical account, in that he wishes time did not exist, but simultaneously gives the positive side regarding knowing when to have meals. He describes a phenomenological way of being in relation to patterns, shapes etc. in his mind and how these also intermingle with shapes in the outer world. It is interesting that he takes a standpoint that strongly suggests that language is not always adequate to describe these kinds of experiences, and simultaneously he seems to validate his experiences by stating that maybe other people who are also 'autistic' understand. The description of him 'getting lost', including the fact that he states he always knew where he was, suggests a meditative style of perception that others did not seem to recognize for what it was/is? Is this an example of the 'flow</p>	<p>Are there moments whereby you become engrossed in one thing or another for hours? For example, looking at patterns and shapes in things? Do you keep certain kinds of images/shapes/patterns/colours in your mind? Do they intermingle with shapes from the outer world? How does this make you feel? Do others say that you are in your own world a lot of the time? How do you respond?</p> <p>To 'autistic' person: Whilst on an outing, have you ever had your family or and other people</p>
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	<p>One small problem with going back to Mum was that I didn't particularly know which way back was. I looked round for a while and finally saw a man walking along in the grass. He asked if I was lost. I explained that I wasn't lost but I didn't know where my Mum was and had he seen her.</p>	<p>state'? Though simultaneously, he highlights that the older he is getting the more he is becoming open to the outer world, and compares himself with his younger brother to further illustrate his point.</p> <p>During this time of 'getting lost' in his own world with the seeds and grass Luke had not recognised the duration of the time he was gone. Martin Heidegger's <i>Being and Time</i> (1927 / 1962; p.245) comes to mind here:</p> <p>"Our analysis of Dasein's disclosedness showed further that, with this disclosedness, Dasein, in its basic state of Being-in-the-world, has been revealed equiprimordially with regard to the world, Being-in, and the Self. Furthermore, in the factual disclosedness of the world, entities within-the-world are discovered too. This implies that the Being of these entities is always understood in a certain manner, even if it is not conceived in a way which is appropriately ontological. To be sure, the pre-ontological understanding of Being embraces all entities which are essentially disclosed in Dasein; but the understanding</p>	<p>go looking for you because they thought you were lost? What were you doing at the time? When your family or and other people found you what did they say? How did you respond? How did you feel?</p>
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		<p>of Being has not yet articulated itself in a way which corresponds to the various modes of Being.”</p>	
<p>3. How did the person make meaning of the mysterious aspect of their lived experiences? How did they practically deal with this?</p>	<p>Meanwhile, Mum had got every single person on the beach looking for me. Coastguards, police, a pack of Brownies and every available person were all shouting my name over a loudspeaker. I didn't hear a thing! I have a strange kind of hearing and can only concentrate on listening to things if I know I am meant to. Distinguishing between background and foreground noise has always been a problem, so however loud they shouted I would have presumed that it was background noise. This is a difficulty of AS because I get told off so many times for being an ignorant pig when I genuinely do not recognize that I am being spoken to. Joe [another younger brother] has this problem a lot, lot worse than I do.</p> <p>I wasn't really looking for anyone when I was found. I just stumbled across them. It was</p>	<p>An embodied way of being that can be a mystery to others and to and for Luke: Luke's processing of incoming information via sounds, i.e. the way he distinguishes and does not distinguish between foreground and background noise. This led to his mum calling upon the assistance of several other people, i.e. other non-self-embodied embodied beings, on the beach to find him. He describes how this can lead to misunderstandings with others, in that they think that he ignores them on purpose, however, this is not the case. The underlying thread here would seem to be that other people who do not have this kind of way of being do not understand his way of being and therefore project their own negative assumptions on to him, which are significantly rooted in their own embodied experiences. Luke then proceeds to further elaborate, and possibly further validate (?), his experience(s) by comparing himself with his younger brother Joe, in that Joe exhibits</p>	<p>To parent(s)/guardian(s): Whilst on an outing, have you ever had to go looking for your 'autistic' child because you thought they were lost? What were you doing at the time when you realized they were gone? Who found them? When you found your child what did you say or and do? How did they respond? How did you feel?</p> <p>To sibling(s): Whilst on an outing, have you ever had to go looking for your sibling because you thought they were lost? What were you doing at the time when you realized they were gone? Who found your sibling? What did you say to them or and do? How did they respond? How did you feel?</p>

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	<p>very strange because my sisters and brothers were crying and Mum grabbed me and a big fuss was made over what seemed to me like nothing. Sometimes it is very hard to understand exactly what I have done wrong. If you are a parent and your child is like that, then make sure to explain to them very clearly.</p>	<p>this way of being a lot more than Luke.</p> <p>Luke practically dealt with this situation by stumbling upon his family whilst they were looking for him; it is a mystery to him as to why his family were sad and crying and he also did not understand what he had done 'wrong'. Therefore, he states that when this kind of thing happens people ought to practically and explicitly explain the situation. It seems that when a person has this kind of sensory way of being they require that the mystery, i.e. in this case the standpoints that have been taken up by family members during the event, ought to be openly unravelled and described. Hence, the embodied mysterious way of being he exhibits requires that much more of an open honest manner of communication(s), which in itself could be viewed as a paradoxical relationship.</p>	<p>To 'autistic' person: What is your hearing like? What is it like trying to distinguish between foreground and background noise? Have you ever had any difficulties in doing so? Are there any experiences you have had with other people whereby it affected what happened, e.g. people thinking that you are lost, shouting out your name and looking for you, but you did not realize this was so and only found out later? Has anyone ever told you that you were ignoring them when they were trying to get your attention by calling out your name or and asking you to do something? How did you feel when they told you this? What did you think? What did you say to them or and do? What did they say to you or and do?</p>
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			<p>To parent(s)/guardian(s): If or when your 'autistic' child does anything you consider to be wrong, do you explicitly explain things to them and advise them on how you expect them to behave? What do you say or and do?</p>
<p>Questions and Reflective Notes Regarding the 'Other', the Family Context and Myself</p>			
<p>How does this 'autistic' person make meaning? Especially in the family context? What seems to be the family's meaning-making process(es)? What is my meaning-making process(es)?</p>	<p>Luke is making meaning via his embodied&non-embodied self. His meaning-making in this situation is very much based on the interaction(s) that is taking place between his body's sensory neural make-up, the wants of his family members, the beach, his seeking of a comfortable sub-environment on the beach (i.e. the grass), and then delving into a playful meditative state within this environment to the extent that he is not aware of time etc. Therefore time also loses its meaning.</p> <p>The family's meaning-making is also via their embodied&non-embodied self. They feel the beach is a place of pleasure and play, therefore, a voting system is applied whereby they do go to the beach. Different members participate in sub-different forms of meaning-making, i.e. his mother tends to the care of his younger brother on the beach whilst his siblings go off and play. It seems that everyone becomes absorbed in what they are doing to the point that they do not see Luke going into the grassy patch on the beach. An absorption in one form of meaning-making activity to the point that another form of meaning-making activity is no longer conscious to the perceiver(s)? When they do become aware of Luke's non-visibility then they go about seeking him – meaning-making and seeking? Shems&Rumi (1263/2011) state something along the lines of what you seek is seeking you. Meaning-making as an intention of seeking? Meaning as seeking? And seeking as meaning?</p> <p>The other family members' meaning-making is that they have lost Luke but Luke's meaning-making is that he was not lost. What seems as paradoxical ways of meaning-making.</p>		

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	<p>My meaning-making process(es) is as outlined.</p>
<p>What are the implications for perception(s) and self-knowledge?</p>	<p>The implications for perception(s) and self-knowledge is that our perceptions are influenced by our embodied&non-embodied self and so we should always attempt to live the moment for what it is and try to describe it by the actual happenings and non-happenings rather than imposing our representational self-knowledge upon what we have perceived. This may be difficult to do as what is being called for is a style of interpretation that attempts to be formed more so in, with, through and from that particular moment(s) rather than from past historical events in one’s own lived experiences. This is likely to be challenging for any person attempting to do so as it also means having to exercise the phenomenological attitude to a depth whereby one’s own reality(ies) is challenged and opened up for further exploration and expansion.</p>
<p>What are the implications for phenomenology as a methodology?</p>	<p>Merleau-Ponty’s philosophy of phenomenology is crucial as a methodology; that we as researchers ought to attempt to perceive and think beyond the dualism of empiricism and intellectualism, in that one’s body and flesh is intertwined with all that is visible and invisible, so we have to continually return to the things themselves. Therefore, I am also developing a feeling that families with ‘autistic’ members may benefit from exercising this style of attempting to understand their familial situations.</p>
<p>What are the implications for IPA as an approach and the methods involved?</p>	<p>The implications for IPA may be that a more descriptive style of interpretation is required for analysing people’s lived experiences, e.g. after reading Luke’s vignette above I could have written “Luke’s mother was so preoccupied with her younger ‘autistic’ child that she neglected her older ‘autistic’ child and he got lost”. However, as I have been analysing these texts I am having to understand and re-understand more so that the meanings that we project on to ‘others’ and their situations usually hinders our development of understanding as well as places them in a negative light to the point that it blocks the flow of learning for ‘both’ parties. Therefore, I chose to write about it as “Different members participate in sub-different forms of meaning-making, i.e. his mother tends to the care of his younger brother on the beach whilst his siblings go off and play. It seems that everyone becomes absorbed in what they are doing to the point that they do not see Luke going into the grassy</p>

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	patch on the beach. An absorption in one form of meaning-making activity to the point that another form of meaning-making activity is no longer conscious to the perceiver(s)?" – an illustration of how I am attempting to move with and beyond dualistic thinking and language?
What is self-knowledge? How does it develop?	Self-knowledge as self&other knowledge? Or/and self-knowledge as self&other&environment knowledge? It 'develops' in, as, with, and through the interaction, or in other words the dynamics, of self-other-environment?
What is meaning? How does it develop?	Meaning as self&other&environment knowledge? Self&other&environment knowledge as meaning? Self&other&environment as the embodied&non-embodied self? The embodied&non-embodied self as knowledge? Knowledge as the embodied&non-embodied self? Meaning 'develops' in, with, as and through meaning?
What is perception? How does it develop?	Perception as time? Perception as no time? Perception 'develops' as concepts regarding time meet through the lived experience in, with, as and through the dynamics of self&other&environment? The lived experience as the non-existence of time?

The questions that have arisen regarding the methods so far are:

1. How does one use reflective texts/autobiographies, especially those by 'autistic' persons, with IPA?

- By asking phenomenological questions;

- Illustrating the interpretive process the researcher is undergoing by producing tables, as above, and using direct quotes and excerpts from 'autistic' persons' writings for this. Which in itself is a reflexive act(s);

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- Coming up with ideas of possible questions for interviews;

- Taking up a developmental lens and working vignettes that are to do with family members at different stages of the 'autistic' persons' development.

- This particular vignette has brought to the fore the importance of the phenomenological attitude.

2. How does one use autobiographical/reflective texts in order to further become sensitive to the context and culture of 'autistic' persons and 'their' family life?

- Asking phenomenological questions that focus on the embodied&non-embodied self;

- Keeping in mind the implications of such ways of being that I am learning about and coming up with ideas as I proceed; e.g. the ideas of possible interview questions are emerging from the narratives of the 'autistic' writer(s);

- Analysing vignettes that specifically focus on family contexts are also enabling me to become that much more sensitive;

- The phenomenological attitude is crucial and family members can, and do, exercise this pedagogical way of being with 'autistic' family members.

3. How does one create further research questions (e.g. for interviews) and develop one's philosophical standpoint(s) whilst analysing 'autistic' person's autobiographies with IPA?

- Read the books, pick out a vignette for the relevant developmental stage that fits the selection criteria and type it up word for word from the book. Ask the phenomenological questions, create the table and whilst doing so reflect and make notes; when ideas of possible questions for interviews come to mind note these down.

APPENDIX 8

Data and Analyses: Family Vignette 4, Childhood. Wendy Lawson, 1998. Life Behind Glass. A Personal Account of Autism Spectrum Disorder

Contextual information regarding this book:

(i) Who wrote the autobiography/& reflective text: Wendy Lawson

(ii) Where the autobiography/& reflective text was written: Australia

(iii) When the autobiography /& reflective text was written: It was published in 1998 in Lismore, Australia

(iv) Why and how the text came in to being:

Wendy wrote this book when she was 46 years old. She had been recognized as being 'autistic' in August 1994, at the age of 42. On page ii, she states that she began to write this book 20 years ago, and proceeds to finally state (page iii) "I hope this book will turn the light on for you, and perhaps it will be another link in the chain towards greater understanding, acceptance and respect for those of us who are "different"."

Vignette from pages 31 - 32:

"Mostly, I learnt things by actually doing them. When I received my new red bicycle I already knew how to ride it. I had taught myself how to ride by practising on mother's bike (against her knowledge, of course).

One afternoon the bicycle and I went for a long ride. We were following a big double-decker red bus and as it turned at a T-junction, so did we. I forgot to look and see if any more traffic was coming before I turned; I was just intent on following the big red bus. A car coming in the opposite direction hit me at around 30 miles per hour.

My bike went one direction and I went another. After flying through the air a short distance, I fell and landed on the kerb of the pavement, momentarily knocking myself out. At the hospital they said I had a nasty bump on my head, but I was fine to go home. My bicycle was not so lucky and I never saw it again.

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I do not remember my parents being angry with me over the incident with my bicycle. They did not sit me down to talk about the rules of the road. It just became yet another incident that was not talked about, and for my ninth birthday, I was given a colouring book and a pack of crayons.

When my bicycle did not return from the hospital I truly assumed it had been kept away from me so that I could not break it again. It was a form of punishment because I had been bad. My parents' lack of explanation only reinforced my belief about myself and withdrawal into my own world appeared to be the only thing to do."

How does Wendy make meaning regarding her embodied&non-embodied life experience with family as a child?

Question	Excerpt(s) from the Vignette	Researcher's Reflections and Notes	Ideas of Possible Questions for Interviews
<p>1. How did the 'autistic' person make meaning of the paradox(es) of their lived experience? How did they practically deal with it?</p>	<p>Mostly, I learnt things by actually doing them. When I received my new red bicycle I already knew how to ride it. I had taught myself how to ride by practising on mother's bike (against her knowledge, of course).</p>	<p>The paradox is that she was not allowed to ride her mother's bike but she did so in order to learn. Wendy learns well by doing; a kinaesthetic learner. Is it that the knowledge and ability to ride a bike were already present within her and Wendy simply had to try in order to realize this? So when we 'learn' is it simply an unfolding of a knowledge and way of being that is already present within?</p> <p>She practically dealt with this paradox by becoming dynamic, i.e. riding her mother's bike whilst not being allowed to do so.</p>	<p>To 'autistic' person: How did you learn as a child? E.g by doing things? What kinds of toys did you have? Did you ride a bike? Did you use your parents' items at all? E.g. riding their bike without their knowledge? Why did you do this?</p> <p>To parent(s)/guardian(s): Did your child prefer to use any of your items at all? E.g. a bicycle? Which ones? How?</p>

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			<p>Why do you think this was? How did you behave in relation to this? How did you feel?</p>
<p>2. How did the person make meaning of the dynamic aspect of their lived experience? How did they practically deal with it?</p>	<p>One afternoon the bicycle and I went for a long ride. We were following a big double-decker red bus and as it turned at a T-junction, so did we. I forgot to look and see if any more traffic was coming before I turned; I was just intent on following the big red bus. A car coming in the opposite direction hit me at around 30 miles per hour.</p> <p>My bike went one direction and I went another. After flying through the air a short distance, I fell and landed on the kerb of the pavement, momentarily knocking myself out. At the hospital they said I had a nasty bump on my head, but I was fine to go home. My bicycle was not so lucky and I never saw it again.</p>	<p>She wanted to create and participate in the dynamic act of riding a bike. She was riding behind a bus, and as it and she were turning round a corner a car hit her.</p> <p>She flew through the air and was knocked unconscious, she was then taken to the hospital.</p> <p>The bike was gone. Her parents practically dealt with the dynamics of the situation by eliminating the bike from Wendy's field of existence? Parents working/cooperating with the dynamic aspect of life to fulfil/&create a</p>	<p>To 'autistic' person: During childhood, did you do anything that you preferred to keep to yourself and not tell your parents? E.g. going for a long ride on your bicycle without your parents knowing about this? What did you do? How did this make you feel? What did you think about it whilst doing it? Did you ever end up in hospital because of doing something like this? How did your parent(s)/guardian(s) respond? What did you think about it all?</p>

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		mystery in Wendy's life?	To parent(s)/guardian(s): During childhood, did your ['autistic'] child do anything you were not aware of at the time which you then later found out about and disapproved of? E.g. going for a long bicycle ride behind a bus? How did this make you feel when you found out about it? What did you do or/and not do when you found out about it? Did your child ever end up in hospital because of doing something like this? How did you respond?
3. How did the person make meaning of the mysterious aspect of their lived experiences? How did they practically deal	I do not remember my parents being angry with me over the incident with my bicycle. They did not sit me down to talk about the rules of the road. It just became yet another incident that was not talked about, and for my ninth birthday, I was given a colouring book and a pack of crayons. When my bicycle did not return from the	The mysterious element is that it was not explained to her. Therefore, Wendy's meaning-making was left with a gap(s) of mystery(ies)? Her family practically dealt with it by giving her a colouring book and a pack of crayons rather than a new bike. Wendy never seeing the bike again is a mystery? Therefore, is a	To 'autistic' person: As a child, did you live any moments with family whereby you did something and an item or/and toy was taken away from you by your parents?? E.g. a bike? Did you understand why this was done? Were you told

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<p>with this?</p>	<p>hospital I truly assumed it had been kept away from me so that I could not break it again. It was a form of punishment because I had been bad. My parents' lack of explanation only reinforced my belief about myself and withdrawal into my own world appeared to be the only thing to do.</p>	<p>perceived gap of an object's presence, i.e. a mystery, replaced by the introduction of a new object(s) into the child's field of existence? Thus an attempt to acknowledge a mystery and simultaneously close it off?</p> <p>Wendy is attempting to make meaning of the situation by assuming that this was done as a form of punishment. Due to a lack of open dialogue with Wendy, i.e. the creation of a mystery, she is then left to make meaning of her behaviour in a framework that makes her feel negative about herself, which in turn leads her to further withdraw into herself. Mystery leads to further mystery at the time? Or/and now that she is looking back at the experience the mystery has led to further understanding about herself?</p>	<p>why? Did you ask why? If not, how did you feel about the event(s)? What did you think?</p> <p>To parent(s)/guardian(s): When your offspring was a child, did you live through any moments whereby you had to take an item away from them because you were worried about their safety? E.g. a bike? Did your child ask why you did this? Did you explain why you did this? How did they react and or not react? How did you feel about this? What did you think? Did you do anything regarding the event(s) afterwards? E.g. buy them another item/toy etc.?</p>
<p>Questions and Reflective Notes Regarding the 'Other', the Family Context and Myself</p>			

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<p>How does this 'autistic' person make meaning? Especially in the family context? What seems to be the family's meaning-making process(es)? What is my meaning-making process(es)?</p>	<p>Wendy makes meaning by describing an event regarding her ability to ride a bike, highlighting that she learned to ride a bike without the active affirming encouragement of her parents (i.e. riding her mother's bike without her permission). Therefore, it would seem that the active non-encouragement of learning a particular skill can also be a source of motivation for learning and practicing that particular skill. Her parents later acknowledged this want of hers and bought her a bicycle, i.e. finally affirming Wendy's want to ride a bicycle. However, after she had the accident the bike was gone and her parents did not buy her a new one, and she was left in a midst of not understanding why this was all so – i.e. a lack of meaning. Although can a lack of meaning also be a form of meaning-making as well as meaning?</p> <p>My meaning-making is described as such here.</p>
<p>What are the implications for perception(s) and self-knowledge?</p>	<p>Perception and self-knowledge as an active dynamic event/process(es)?</p>
<p>What are the implications for phenomenology as a</p>	<p>Phenomenological writing ought to be fluent and fluid in order to reflect and represent the fluid nature of our lived experiences? Thereby creating and maintaining a phenomenological attitude that is actively exercised and present throughout not just say the methodology chapter of a thesis but is the very thesis?</p>

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methodology?	
What are the implications for IPA as an approach and the methods involved?	IPA with autobiographical writings can open one's thinking to the lived experience(s) of meaning-making between the 'autistic' person and other members of their family – who may or may not be 'autistic'. The double-hermeneutic factor ought to be considered. In addition, a researcher working with IPA ought to be open to creating new language and terms that make the implicit as explicit as possible.
What is self-knowledge? How does it develop?	Self-knowledge as the dynamic self? Self-knowledge as a moment? Self-knowledge as moments connecting with moments in an ongoing process(es)? Self-knowledge and as a lack of self-knowledge? Self-knowledge as no knowledge? Self-knowledge as a mystery? Self-knowledge 'develops' in, as, with and through the dynamic nature of our lived experiences and moments?
What is meaning? How does it develop?	Meaning as one being aware of the meaning(s) one gives to events that have unfolded; meaning as being aware of the meaning(s) that 'others' give to events that have unfolded? Meaning as mystery? Meaning 'develops' in, as, with and through the events that are threaded together in our lives as time goes on?
What is perception? How does it develop?	Perception as dynamic lived experiences? And perception as mystery? Perception as a meeting point of different perceptions? E.g. Wendy's viewpoint and her parent's viewpoint? – Maybe this is one way in which perception 'develops'? Whereby Wendy is left to try and fathom why the bicycle was gone and whereby her parents are likely to have assumed that she would naturally make the connection and did not feel the need to explicitly explain why it was gone.

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The questions that have arisen regarding the methods so far are:

1. How does one use reflective texts/autobiographies, especially those by 'autistic' persons, with IPA?

- By asking phenomenological questions;
- Illustrating the interpretive process the researcher is undergoing by producing tables, as above, and using direct quotes and excerpts from 'autistic' persons' writings for this. Which in itself is a reflexive act(s);
- Coming up with ideas of possible questions for interviews;
- Taking up a developmental lens and working vignettes that are to do with family members at different stages of the 'autistic' persons' development.
- This particular vignette has brought to the fore the importance of explicit communication.

2. How does one use autobiographical/reflective texts in order to further become sensitive to the context and culture of 'autistic' persons and 'their' family life?

- Asking phenomenological questions that focus on the embodied&non-embodied self;
- Keeping in mind the implications of such ways of being that I am learning about and coming up with ideas as I proceed; e.g. the ideas of possible interview questions are emerging from the narratives of the 'autistic' writer(s);
- Analysing vignettes that specifically focus on family contexts are also enabling me to become that much more sensitive.
- 'Autistic' children can, and do, things that non-'autistic' children do, e.g. riding their parents' bike without permission. When accidents or/and other 'mishaps' take place other family members ought to (i) communicate and (ii) be explicit when communicating their worries about safety etc. to the 'autistic' child.

3. How does one create further research questions (e.g. for interviews) and develop one's philosophical standpoint(s) whilst analysing 'autistic' person's autobiographies with IPA?

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- Read the books, pick out a vignette for the relevant developmental stage that fulfils the selection criteria and type it up word for word from the book. Ask the phenomenological questions, create the table and whilst doing so reflect and make notes; when ideas of possible questions for interviews come to mind note these down.

Appendix 9. Chris Mitchell, 2005. Glass Half Empty Glass Half Full

APPENDIX 9

Data and Analyses: Family Vignette 5, Teenagehood. Chris Mitchell, 2005. Glass Half Empty Glass Half Full

Contextual information regarding this book:

- (i) Who wrote the autobiography/& reflective text: Chris Mitchell
- (ii) Where the autobiography/& reflective text was written: United Kingdom
- (iii) When the autobiography /& reflective text was written: It was published in 2005
- (iv) Why and how the text came in to being:

On page 3 the author states that “Being diagnosed with Asperger’s syndrome at nearly 20 years old, I feel I have lived two separate lives. For this purpose, I feel that my life story needs two separate sections. Glass Half-Empty is about my life before diagnosis and Glass Half-Full is about my life after diagnosis. The intention of this books is to show how my life has changed since diagnosis, and above all, to recognize the positive aspects of Asperger syndrome.”

Vignette from pages 20 - 21:

[During Secondary School years]

“Frustrations in social life

Back at home, my parents were becoming increasingly concerned about me spending too much time to myself in my room or watching television. They were especially worried that I didn’t have much scope in which to develop social skills. My brother and sister, meanwhile, appeared to have many friends round or were often round at a friend’s house. My cousins, each time we went around to see them, also appeared to be with friends most of their time. In this sense, I was ‘the odd one out’ as I stayed put most of my time. The longer this went on, the more my parents even ‘forced’ me to invite friends round for a game of snooker (we used to have a snooker table), often not realising why I wasn’t prepared to. In one instance, they even forced me to ring a friend, not realising I didn’t particularly like using the telephone, and stood over me when I made the call. It was only made worse when they kept on at me to speak properly and use the appropriate telephone manner.

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So that I would be around other pupils outside school hours, my parents suggested joining Monkwearmouth Youth Club. At first, I was slightly reluctant to go, as I would come across other kids who had been mean to me in the schoolyard, but when I found out about the activities that I could do, such as swimming, skiing and so on. I decided to give it a try.

In the schoolyard, because the pupils are under the control of teachers and school rules, having to wear a uniform, it is often a case of having to find a way to exert superiority over others in the pecking order. This can be ruthless and aggressive, especially when trying to prove themselves as the hardest or coolest kids in the school. I was particularly vulnerable to other pupils trying to exert such superiority over me. Joining Monkwearmouth Youth Club enabled me to see other kids my age away from the confines of school rules and school uniform.”

How does Chris make meaning regarding his embodied&non-embodied life experiences as a teenager?

Question	Excerpt(s) from the Vignette	Researcher’s Reflections and Notes	Ideas of Possible Questions for Interviews
<p>1. How did the ‘autistic’ person make meaning of the paradox(es) of their lived experience? How did they practically deal with it?</p>	<p>Back at home, my parents were becoming increasingly concerned about me spending too much time to myself in my room or watching television. They were especially worried that I didn’t have much scope in which to develop social skills. My brother and sister, meanwhile, appeared to have many friends round or were often round at a friend’s house. My cousins, each time we went around to see them, also appeared to be with friends most of their time. In this sense, I was ‘the odd one out’ as I stayed put most of my time. The longer this went on, the more my parents even ‘forced’</p>	<p>Chris makes meaning of this paradoxical experience by describing how his parents were comparing his social life and abilities to that of his siblings and cousins, in that they had friends and were spending time with them but Chris preferred to spend time alone or watch TV. He also states that they did not understand why he was behaving as such, a mystery to all concerned, but were trying to get Chris to fit in to the social dynamics of being a teenager by asking people to come round to play snooker. Chris seems to have felt intimidated by this, in that he felt</p>	<p>To ‘autistic’ person: How was your teenage life like? Did you socialize with kids your age? How (not)? Did your parents have concerns about your social life? Did they tell you? How? Did they try to get you to spend time with other teens? How? How did this make you feel? Did you have any reservations about this? Why?</p>

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	<p>me to invite friends round for a game of snooker (we used to have a snooker table), often not realising why I wasn't prepared to. In one instance, they even forced me to ring a friend, not realising I didn't particularly like using the telephone, and stood over me when I made the call. It was only made worse when they kept on at me to speak properly and use the appropriate telephone manner.</p>	<p>"forced", and this was further added to by his parents' insistence regarding social norms, e.g. speaking and manner wise. I guess this also further created and added to Chris's feelings of being misunderstood as well as maybe led to anxiety?</p> <p>Chris practically dealt with the situation by adhering to his parents' wishes.</p> <p>His parents had noticed that Chris was not creating and partaking in the kinds of social activities that their other children and family members of a similar age were doing so, and felt he ought to. Hence, they wanted him to do so and strongly encouraged him.</p> <p>Lévinas (1961/1979, p.212): "Everything that takes place here "between us" concerns everyone, the face that looks at it places itself in the full light of the public order, even if I draw back from it to seek with the interlocutor the complicity of a private relation and a clandestinity."</p>	<p>To parents/&guardians: Did/do you have any concerns about your offspring during their teenage years in terms of socializing? Why? Did you try to do anything about this? What did you do or / and not do? How did you feel whilst doing or/and not doing this? What was your daughter's/&son's reaction(s)? How did they feel about it?</p>
<p>2. How did the person make</p>	<p>In the schoolyard, because the pupils are under the control of teachers and school rules, having</p>	<p>Chris makes meaning of his lived experience in the schoolyard and the youth club by</p>	<p>To 'autistic' person: How was your school life like?</p>

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<p>meaning of the dynamic aspect of their lived experience? How did they practically deal with it?</p>	<p>to wear a uniform, it is often a case of having to find a way to exert superiority over others in the pecking order. This can be ruthless and aggressive, especially when trying to prove themselves as the hardest or coolest kids in the school. I was particularly vulnerable to other pupils trying to exert such superiority over me. Joining Monkwearmouth Youth Club enabled me to see other kids my age away from the confines of school rules and school uniform.</p>	<p>comparing the two settings in terms of the types of systemized dynamics. Is this in itself a form of taking up a paradoxical lens to attempt to understand the dynamic and mysterious nature of one's lived experiences?</p> <p>Furthermore, he has an understanding of the schoolyard whereby it is not necessarily a fun playful space, that it is prohibitive and kids attempt to form groups or/and hierarchies. This meant that Chris had experiences whereby at the time he was not able to see other teenagers "away from the confines of school rules and school uniform", possibly further adding to his sense of non-belonging and the negative dynamics surrounding why and how other kids behaved the way did?</p> <p>However, participating in the youth group as well as being exposed to other kids in such a relaxed setting enabled him to see another side to his fellow pupils as well as enabled him to show another side of himself. Ludwig Wittgenstein in Heaton (2010, p.77) comes to mind here: "The child learns to believe a host of things. I.e. it learns to act according to these beliefs. Bit by bit there forms a system of what is believed, and in that system some</p>	<p>How was it like in the playground? How were the other kids like towards you? How did this make you feel?</p> <p>Did your parents encourage you to join any youth clubs outside of school? Did you ever compare this context to the school context regarding the social dynamics between yourself and other teenagers? What did you learn about yourself? What did you learn about others? What did you learn about social contexts?</p>
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		<p>things stand unshakeably fast and some are more or less liable to shift. What stands fast does so, not because it is intrinsically obvious or convincing; it is rather held fast by what lies around it. (OC ¶144)”</p>	
<p>3. How did the person make meaning of the mysterious aspect of their lived experiences? How did they practically deal with this?</p>	<p>So that I would be around other pupils outside school hours, my parents suggested joining Monkwearmouth Youth Club. At first, I was slightly reluctant to go, as I would come across other kids who had been mean to me in the schoolyard, but when I found out about the activities that I could do, such as swimming, skiing and so on. I decided to give it a try.</p>	<p>Chris was made aware by his parents that he could participate in a youth club with other pupils. They were worried about him not socializing with other kids and wanted to assist Chris in doing so. Although he worried about this unbeknown dynamic setting in relation to being treated negatively by other kids he took a liking for the club due to the activities themselves. I assume these were dynamic activities that Chris already enjoyed and therefore was pulled in to the club by them, e.g. swimming and skiing. I also assume that he felt good and confident whilst undergoing such activities and this may have also added to his wanting to join the club, in that he could be and show another side of him to his fellow pupils which he had not been able to show before? A mysterious element coming into being?</p> <p>Chris practically dealt with the possible</p>	<p>To ‘autistic’ person: Did your parents /& guardians encourage you to take up any after school activities, e.g. going to a youth club? How did this make you feel? How did you react? Did you do more research about the club before making a decision? What did you do or/and not do at the club? How did you feel?</p> <p>To parents/&guardians: How did you convince your son/&daughter to take up a social activity(ies) after school? Or did they take it up on their own accord? How did this make you feel? How did they feel about</p>

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		<p>mysterious experience(s) put forward by his parents by researching into the activities at the club and by actually attending the youth club. Furthermore, he makes meaning of his schoolyard experiences by comparing it to his youth club experiences and coming to further understanding(s) about fellow teenagers and how social environments influence human behaviour.</p> <p>Merleau-Ponty (1964 / 1968, p.151): “With the first vision, the first contact, the first pleasure, there is initiation, that is, not the positing of a content, but the opening of a dimension that can never again be closed, the establishment of a level in terms of which every other experience will henceforth be situated. The idea is this level, this dimension. It is therefore not a <i>de facto</i> invisible, like an object hidden behind another, and not an absolute invisible, which would have nothing to do with the visible. Rather, it is the invisible <i>of</i> this world which inhabits this world, sustains it, and renders it visible, its own and interior possibility, the Being of this being.”</p>	<p>this? What happened thereafter?</p>
<p>Questions and Reflective Notes Regarding the ‘Other’, the Family Context and Myself</p>			

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<p>How does this 'autistic' person make meaning? Especially in the family context? What seems to be the family's meaning-making process(es)? What is my meaning-making process(es)?</p>	<p>Chris is making meaning by comparing his social way of being with that of his cousins and siblings. From Chris's perspective, this is also how his parents were making meaning and were therefore attempting to assist him in developing a social circle of friends. Inner&intersubjectivity in action?</p> <p>My meaning-making is as outlined.</p>
<p>What are the implications for perception(s) and self-knowledge?</p>	<p>The implication for perception(s) and self-knowledge is that maybe we ought to be perceiving everything in terms of relationship? Therefore taking up an interactionist lens? An interactionist lens whereby perception, self-knowledge and meaning-making are fused and amalgamated as one, and then de-fused and re-worked with, in a constant ongoing dynamic chemical interaction(s)?</p>
<p>What are the implications for phenomenology as a</p>	<p>The implications for phenomenology as a methodology would seem to be that when considering the family context(s) there are moments that are shared between nuclear as well as extended family members whereby it leads to an intention being set to create a phenomenon with regards to say creating a circle of friends. Therefore, maybe phenomenology ought to also focus on family phenomena and intention setting?</p>

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methodology?	Furthermore, inner&intersubjectivity seems to be that much more explicit and present during moments with family, therefore, this is leading this researcher to be that much more aware of this, and that such a lens ought to be exercised that much more when analysing vignettes of family contexts?
What are the implications for IPA as an approach and the methods involved?	IPA as incorporating inner&intersubjectivity? Il et, the embodied&non-embodied self? An interactionist lens that seeks to interpret via a relation based perception? The method(s) being such that one seeks to perceive by focusing on the paradox, dynamics and mystery of the reported lived experiences in the vignette(s) whilst simultaneously exercising a reflexive standpoint?
What is self-knowledge? How does it develop?	Self-knowledge as 'self&other(s)' and 'other&self' knowledge(s)? Self-knowledge 'develops' via that which exists and occurs between self&other(s)? Self-knowledge as that which is the ' <i>betweenness</i> '? Self-knowledge as relationship(s)?
What is meaning? How does it develop?	Meaning as 'self&other' and 'other&self'? Meaning as that which is the ' <i>betweenness</i> '? Meaning as relationship(s)? Meaning as 'developing' as it desires? As it desires in, as, with and through the ' <i>betweenness</i> '?
What is perception? How does it develop?	Perception as the ' <i>betweenness</i> '? Perception 'develops' in, as, with and through the ' <i>betweenness</i> '?

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The questions that have arisen regarding the methods so far are:

1. How does one use reflective texts/autobiographies, especially those by 'autistic' persons, with IPA?

- By asking phenomenological questions;
- Illustrating the interpretive process the researcher is undergoing by producing tables, as above, and using direct quotes and excerpts from 'autistic' persons' writings for this. Which in itself is a reflexive act(s);
- Coming up with ideas of possible questions for interviews;
- Taking up a developmental lens and working vignettes that are to do with family members at different stages of the 'autistic' persons' development;
- This particular vignette has brought to the fore the importance of assisting 'autistic' teenagers to explore different environments, especially outside of school with fellow peers.

2. How does one use autobiographical/reflective texts in order to further become sensitive to the context and culture of 'autistic' persons and 'their' family life?

- Asking phenomenological questions that focus on the embodied&non-embodied self;
- Keeping in mind the implications of such ways of being that I am learning about and coming up with ideas as I proceed; e.g. the ideas of possible interview questions are emerging from the narratives of the 'autistic' writer(s);
- Analysing vignettes that specifically focus on family contexts are also enabling me to become that much more sensitive;
- Parents' assistance can be crucial in facilitating the process(es) of the teenager participating in activities they enjoy with others their own age. This may initially raise anxieties for the teenager, especially if he feels pressurised by his parents, however, when the teenager and the parents do research beforehand and acknowledge the teenager's potential anxieties the teenager may be willing to try out activities he enjoys in a new environment.

3. How does one create further research questions (e.g. for interviews) and develop one's philosophical standpoint(s) whilst analysing 'autistic'

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person's autobiographies with IPA?

- Read the books, pick out a vignette for the relevant developmental stage that fulfils the selection criteria and type it up word for word from the book. Ask the phenomenological questions, create the table and whilst doing so reflect and make notes; when ideas of possible questions for interviews come to mind note these down.

APPENDIX 10

Data and Analyses: Family Vignette 6, Teenagehood. Donna Williams, 1992. Nobody Nowhere. The Extraordinary Autobiography of An Autistic

Contextual information regarding this book:

- (i) Who wrote the autobiography/& reflective text: Donna Williams
- (ii) Where the autobiography/& reflective text was written: United Kingdom
- (iii) When the autobiography /& reflective text was written: It was published in 1992
- (iv) Why and how the text came in to being:

Donna wrote this autobiography so as to understand herself and life better, as well as to educate people who are non-‘autistic’ about an ‘autistic’ person’s life.

Vignette from pages 53 – 54:

“I WAS TWELVE, and my mother and older brother had embarked on a new campaign of systematically teasing me. It began with them asking each other “What did she say?” at which the other would reply: “Don’t listen to her; she’s wonking again.”

They had thought up a new name for me. I was now “a blonk.” This meant that I was a moron. My older brother, secure in the knowledge that I dared not fight back against my mother’s “pride and joy,” would bring his face close up to mine, tilting his head from side to side as I did, and announce, “Wonk, wonk, blonk, blonk.” His proximity deeply disturbed me, but now so did his words. Perhaps this was because he had invaded my personal space by put-ting his face so close to mine as he said this. Perhaps it was the way he mirrored my habit of tilting my head from one side to the other when I was trying to understand someone, or the fact that he had employed my tactics of creating “special” words.

Regardless of how, he had made me relate to what he had said; visibly the words had stung. My brother and mother, having got a reaction, hurtfully persisted as I viciously retorted with “I’m not mad!” till I finally gave up entirely.

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My mother said that I had changed when I was twelve. Never before had I had to fight so strongly for the comforts of my own world. “The world” still seemed like either a battlefield or stage, but I was forced to keep trying “to play the game,” if for no other reason than to survive. I would have been happy to “let go” and retreat into my own world if not for my belief that my mother and older brother seemed to thrive on my strangeness and inability to cope. My hatred and my sense of injustice were my driving force to prove them wrong. At the same time, my fear of feeling kept calling me back into myself. Both drives were intense and had a shattering impact, both on the real “feeling me” within and the characters whom I threw at those who tried to reach me.”

[Note, Donna had created personas such as Willie and Carol to cope with the outside world]

How does Donna make meaning regarding her embodied&non-embodied life experiences as a teenager?

Question	Excerpt(s) from the Vignette	Researcher’s Reflections and Notes	Ideas of Possible Questions for Interviews
<p>1. How did the ‘autistic’ person make meaning of the paradox(es) of their lived experience? How did they practically deal with it?</p>	<p>My mother said that I had changed when I was twelve. Never before had I had to fight so strongly for the comforts of my own world. “The world” still seemed like either a battlefield or stage, but I was forced to keep trying “to play the game,” if for no other reason than to survive. I would have been happy to “let go” and retreat into my own world if not for my belief that my mother and older brother seemed to thrive on my strangeness and inability to cope. My hatred and my sense of injustice were my driving force to prove them wrong. At the same time,</p>	<p>Donna makes meaning of this experience by explicitly outlining the paradoxical element(s) of it. The paradox is that a part of Donna did not want to engage with the world as this led to feelings that she struggled to work with, yet simultaneously, the sense of injustice she felt was what led to, and added to, her fighting with her mother and brother during her teenage life. This also led to her creating personality characters to deal with the social world. I guess many of us do this to some degree, whereby we place a mask on our faces and try to not feel things that make us</p>	<p>To ‘autistic’ person: Did you change in any way during your teenage years? Did your parent(s)/guardian(s) say that you had changed? How? How did you feel about this? How did you respond to them?</p> <p>How did you feel about yourself during teenage life? What was your feeling like about the world? Why did</p>

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	<p>my fear of feeling kept calling me back into myself. Both drives were intense and had a shattering impact, both on the real “feeling me” within and the characters whom I threw at those who tried to reach me.</p>	<p>feel threatened or/and avoid focusing on such experiences that make us feel vulnerable or/and confused or/and require a potential change(s)? If one knows the social rules and norms that are required in that particular situation(s) then one may play the role of the character very well, and if others are also reluctant to acknowledge the reality(ies) of the situation then they may be all too accepting of the masked persona/character.... ? However, if or/and when a person struggles to do this because of their embodied&non-embodied ways of being, is it ethical to try and place them in a position whereby they are expected to put on a mask and behave in conditioned ways of being?</p> <p>Simultaneously, was it that her mother and brother picked on her because they did not understand her way of being and mockery was one of the ways in which they could engage and dialogue with her? Was it also a way of trying to exercise a sense of humour to deal with a person whose mere existence made them feel vulnerable and challenged their reality(ies)? Sometimes people do try to laugh about things that give them much pain</p>	<p>you feel like this? How did you behave during this time? Did you create characters in your mind to then cope with situations with family members? How did your family members behave towards you? How did this make you feel?</p> <p>To parent(s)/guardian(s): Do you think that your [‘autistic’] child changed in any way during teenagehood? How did you feel? How did you respond to them? How did their siblings respond? How did you deal with this situation?</p> <p>To sibling(s): Do you think that your [‘autistic’] sibling changed in any way during teenagehood? How did this make you feel? How did you respond? How did they respond? How did your</p>
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		<p>and sorrow. Or/and were there characteristics in Donna that her mother or brother recognized in themselves but were reluctant to acknowledge, therefore, maybe, treating Donna as a scapegoat? Blaming her and focusing on her 'inabilities' rather than their own?</p> <p>Donna practically dealt with the situation by arguing and fighting with these two family members, and she created personas to cope with social communication.</p>	<p>parent(s)/guardian(s) respond?</p>
<p>2. How did the person make meaning of the dynamic aspect of their lived experience? How did they practically deal with it?</p>	<p>They had thought up a new name for me. I was now "a blonk." This meant that I was a moron. My older brother, secure in the knowledge that I dared not fight back against my mother's "pride and joy," would bring his face close up to mine, tilting his head from side to side as I did, and announce, "Wonk, wonk, blonk, blonk." His proximity deeply disturbed me, but now so did his words. Perhaps this was because he had invaded my personal space by putting his face so close to mine as he said this. Perhaps it was the way he mirrored my habit of tilting my head from one side to the other when I was trying to</p>	<p>Donna makes meaning of the dynamic aspect of this lived experience by comparing herself to her brother whilst focusing on her mother's filial preferences and the behaviour he was able to exercise towards Donna because of this, which in turn made Donna feel helpless.</p> <p>The term 'blonk' was a way of othering Donna and re-affirming the mother and son's relationship?</p> <p>Donna had to practically deal with physically threatening behaviour by giving in. Furthermore, the fact that her brother had</p>	<p>To 'autistic' person: Did your family members give you a nickname at all? What was it? How did this nickname make you feel? Were there any moments whereby one of your parent(s)/guardian(s) sided with your sibling(s) and used this or/and another nickname in a way that made you feel negative? How did you respond? Did you ever argue or/and physically fight with</p>

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	<p>understand someone, or the fact that he had employed my tactics of creating “special” words.</p> <p>Regardless of how, he had made me relate to what he had said; visibly the words had stung. My brother and mother, having got a reaction, hurtfully persisted as I viciously retorted with “I’m not mad!” till I finally gave up entirely.</p>	<p>been able to make her relate is what made her feel pain?</p> <p>She had to fight for her sense of self. Giving up on trying to make her family understand that she is not mad? Having to learn that she had to validate her lived experiences regardless? Yet simultaneously being very experientially aware of this mystery via the feelings of injustice?</p> <p>Maybe this was one of the only ways that her brother felt like he could reach out to Donna? That he could have some sort of dialogue with her by mimicking her behaviour and the way she made up words for things? Yet done with anger and frustration towards his sister due to her seemingly distanced ways of being?</p>	<p>your sibling(s) or/and parent/guardian? How did this make you feel? What did you learn or/and not learn about yourself and your family members?</p> <p>Did you ever have to state or/and shout “I’m not mad(!)” to family members? What kind of events led to the occurrence of this? And after you stated/&shouted this term, how did they respond? How did this make you feel? What did you do or/and not do?</p> <p>To parent(s)/guardian(s): Did you or/and any other family members give your ‘autistic’ child a nickname at all? What was it? How did using this nickname make you feel? Were there any moments whereby you or/and another member of</p>
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			<p>your family used this nickname in a negative way towards your teenager? How did they respond? Did you or/and another member of your family ever argue or/and physically fight with your 'autistic' teenager? How did this make you feel? What did you learn or/and not learn about yourself and your family members?</p> <p>Did you ever hear your 'autistic' teenager state or/and shout "I'm not mad(!)"? What kind of events led to the occurrence of this? How did this make you feel? What did you do or/and not do?</p> <p>To sibling(s): Did you or/and any other family members give your 'autistic' sibling a nickname at all? What was it? How did using this</p>
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			<p>nickname make you feel? Were there any moments whereby you or/and another member of your family used this nickname in a negative way towards your sibling? How did your sibling respond? Did you or/and another member of your family ever argue or/and physically fight with your 'autistic' sibling? How did this make you feel? What did you learn or/and not learn about yourself and your family members?</p> <p>Did you ever hear your 'autistic' sibling state or/and shout "I'm not mad(!)"? What kind of events led to the occurrence of this? How did this make you feel? What did you do or/and not do?</p>
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<p>3. How did the person make meaning of the mysterious aspect of their lived experiences? How did they practically deal with this?</p>	<p>I WAS TWELVE, and my mother and older brother had embarked on a new campaign of systematically teasing me. It began with them asking each other “What did she say?” at which the other would reply: “Don’t listen to her; she’s wonking again.”</p>	<p>Donna makes meaning of the mystery of her mother and brother’s behaviour by describing how they teamed up and treated her in a negative way.</p> <p>She practically deals with the situation itself by trying to fight but then feels she has to give up and does so. Furthermore, the fact that she has written about it and is recounting it in her autobiography could also be viewed as a manner in which she is practically dealing with this experience; wanting to highlight her point of view and how she experienced such moments, explaining things from her embodied&non-embodied standpoint. Does this make her as well as the potential reader in her mind, as well as the actual reader such as myself, a witness? Whether it is read or not the fact that she has placed this on paper for herself is a form of self-witnessing and validation of her experience(s)? Regardless of whether I as the reader understand or not, the fact that I have read this has made me a witness? What to say of the gaze and mystery? Shems&Rumi (1263/2011, p.336): [Translated] “Those who come across suffering and are to be wiped</p>	<p>To ‘autistic’ person: Have you been teased by any family members? Have they done so together? How did they do so? How did you respond or/and not respond? What did they say or do in return?</p> <p>To parent(s)/guardian(s): Have you ever teased your ‘autistic’ teenager? How? Did you do tease them alongside another child/teenager of yours or anyone else? Why did you do so? How did your ‘autistic’ teenager respond? How did this make you feel? What did you learn or and not learn about your child/children?</p> <p>To sibling(s): Have you ever</p>
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		<p>clean like a mirror is to be cleaned, yet run, confuse and surprise me indeed. Love is similar to a [court] case, and to suffer is like [being] a witness. If you do not have a witness you cannot win the case!</p> <p>When the official requests a witness from you do not feel hurt by this. Kiss the snake so as to get hold of the treasure!"</p> <p>Regarding her family members: Ignoring her? Not validating her reality(ies)? Not listening to her? Further creating and adding to her sense of loneliness, sense of rejection, sense of pain, and sense of suffering? Is it easier to do this than to acknowledge one's own limitations and vulnerabilities as well? Is the mystery and a lack of understanding of a family member, i.e. Donna, frightening? Why? How? If there is a fear then does this fear manifest in situations such as the one described by Donna here?</p>	<p>teased your 'autistic' sibling? How? Did you do tease them alongside your parent(s)/guardian(s) or anyone else? Why did you do so? How did your 'autistic' sibling respond? How did this make you feel? What did you learn or and not learn about your sibling?</p>
<p>Questions and Reflective Notes Regarding the 'Other', the Family Context and Myself</p>			

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<p>How does this 'autistic' person make meaning? Especially in the family context? What seems to be the family's meaning-making process(es)? What is my meaning-making process(es)?</p>	<p>Donna is making meaning by outlining a conflictual element of the relationship(s) she had with her brother and mother.</p> <p>The other two family members seem to be making meaning of Donna's way of being by using a malicious sense of humour to highlight that neither of them understand what she is meaning. Therefore, the presence of non-meaning for both of them is a shared form of meaning-making which is then imposed upon Donna's meaning-making.</p> <p>My meaning-making is as above and herein.</p>
<p>What are the implications for perception(s) and self-knowledge?</p>	<p>The implications for perception(s) and self-knowledge is that as much as one may be embedded in a particular form(s) of perceptual way of being one also ought to be aware that self-knowledge of such a way of being may not be <i>realized</i> to the degree whereby one is able to work with others' ways of being in a harmonious manner – hence a conflict of meaning(s) and meaning-making(s).</p>

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<p>What are the implications for phenomenology as a methodology?</p>	<p>The implications for phenomenology as a methodology is that family situations that involve a very explicit form(s) of conflictual phenomena could be viewed as a clash of meaning-making(s), or in other words, an example of how the dynamic aspect of the embodied&non-embodied self comes into being.</p>
<p>What are the implications for IPA as an approach and the methods involved?</p>	<p>The implications for IPA is that when analysing family vignettes IPA should also utilize a lens of focusing on the dynamics of family relationships by focusing on meaning-making(s) and conflict. Maybe the researcher ought to incorporate the works of psychologists who focus on conflict resolution? E.g. Marshall Rosenberg’s work and methods in relation to non-violent communication? Actually, if one returns to the core of this study, how about non-violent research that informs non-violent methods of research? Wittgenstein stated that the philosophical question is also a therapeutic question (Heaton, 2010). Therefore, it seems natural that such a standpoint and methodology then ought to lead to a therapeutic form of research methods for all concerned? Hence, in the long run, hopefully, both myself as a researcher and the participants ought to benefit from the study?</p>
<p>What is self-knowledge? How does it develop?</p>	<p>Self-knowledge as the absence of knowledge regarding the ‘other’? Self-knowledge ‘develops’ via the dynamic conflictual nature of lived experiences; reflecting with them and acting accordingly?</p>
<p>What is meaning? How does it develop?</p>	<p>Meaning as non-meaning? Meaning as conflict? Conflict as meaning? Meaning ‘develops’ in, as, with and through an absence of meaning and the presence of conflict?</p>
<p>What is perception?</p>	<p>Perception as the dynamic self?</p>

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How does it develop?	Perception 'develops' in, as, with and through the dynamic aspect of self?
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The questions that have arisen regarding the methods so far are:

1. How does one use reflective texts/autobiographies, especially those by 'autistic' persons, with IPA?

- By asking phenomenological questions;
- Illustrating the interpretive process the researcher is undergoing by producing tables, as above, and using direct quotes and excerpts from 'autistic' persons' writings for this. Which in itself is a reflexive act(s);
- Coming up with ideas of possible questions for interviews;
- Taking up a developmental lens and working vignettes that are to do with family members at different stages of the 'autistic' persons' development;
- This particular vignette has brought to the fore the element of conflictual communication.

2. How does one use autobiographical/reflective texts in order to further become sensitive to the context and culture of 'autistic' persons and 'their' family life?

- Asking phenomenological questions that focus on the embodied&non-embodied self;
- Keeping in mind the implications of such ways of being that I am learning about and coming up with ideas as I proceed; e.g. the ideas of possible interview questions are emerging from the narratives of the 'autistic' writer(s);
- Analysing vignettes that specifically focus on family contexts are also enabling me to become that much more sensitive;
- As sad as it is, sometimes conflictual communication takes place between one's sibling and a parent due to the mystery that surrounds their

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ways of being. This can be in the form of nicknames that are meant to insult the 'autistic' member of the family.

3. How does one create further research questions (e.g. for interviews) and develop one's philosophical standpoint(s) whilst analysing 'autistic' person's autobiographies with IPA?

- Read the books, pick out a vignette for the relevant developmental stage that fulfils the selection criteria and type it up word for word from the book. Ask the phenomenological questions, produce the table and whilst doing so reflect and make notes; when ideas of possible questions for interviews come to mind note these down.

APPENDIX 11

Data and Analyses: Family Vignette 7, Adulthood. Edgar Schneider, 1999. Discovering My Autism, Apologia Pro Vita Sua (With Apologies to Cardinal Newman)

Contextual information regarding this book:

- (i) Who wrote the autobiography/& reflective text: Edgar Schneider
- (ii) Where the autobiography/& reflective text was written: America
- (iii) When the autobiography /& reflective text was written: It was published in 1999
- (iv) Why and how the text came in to being:

After realizing that he is also 'autistic' Edgar relayed his story to the pastor in his church, who encouraged him to write his story. On page 9 he states that "I have done just that, not only for those who might like to know me better, but also as catharsis for myself."

Vignette from pages 51 - 52:

"Grief

Love, in the *agape* sense, is not only emotion for which I seem to have no capacity. One rather fundamental emotion felt by people is grief when someone close is lost, either through death or permanent departure for a far-off place. Never in my life have I ever felt grief, or even a sense of loss.

This was brought out in very high relief to me when my mother died in October 1994. My brother was devastated, even though we all saw her death coming. (He and I had even worked on the list of 'things to do' and on her obituary before she actually died; it was that imminent, but it did not occur precipitously.) Everyone else in the family, and friends also, expressed sorrow.

I felt nothing. I also felt that there was something wrong there. Somewhat sardonically, I said to my pastor (who had been a psychologist before becoming a priest), 'There are all kinds of support groups for people who grieve, but nothing for people who should be grieving but don't.'

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This was before I even dreamed of myself as being autistic. When I read the remark, quoted in the New Yorker article ‘Prodigies’ by Oliver Sacks, of that 15-year-old boy who had just lost his mother (January 9, 1995, page 51, last column), I searched back as far as I could remember, even to early childhood, and noted that my reaction to my mother’s death was no isolated case.

It was not limited to family members, but also to close friends. There were two people who went out of their way to help me when I was in dire straits. They had no obligation to help me and, in some ways, could have caused problems for themselves by doing so. I remember feeling no pain of loss when told of their deaths (in one case, it was quite sudden and he was young). Any sorrow I felt was purely intellectual.

In March 1996, [I] spent some time, in solitude, at my daughter’s home, taking care of her house and her cat while she and her family were on vacation. (The cat and I became good buddies.) My daughter had just had to have her other cat euthanized. That remaining cat was obviously grieving for her longtime companion. I could not help but think that a cat, the most independent of God’s creatures, can grieve, but I cannot.

I am, though, able to intellectually appreciate the grief of another. At one time, I saw an old man lamenting the recent death of his wife. I thought about how there must have been a great deal of love to produce that much grief. Not being able to feel what he felt, I was at a loss as to what to say to him. But, then, so was everybody else.

The irony of this is that I can get all weepy at the tear-jerker endings of operas such as La Traviata, La Boheme, or Madame Butterfly, or novels such as Dracula. (Yes, I actually have read that book.) Yet, as noted above, I feel nothing in real-life emotional situations. This is connected with that topic of feeling ‘emotion’ only through art.”

How does Edgar make meaning regarding his embodied&non-embodied life experiences as a child?

Question	Excerpt(s) from the Vignette	Researcher’s Reflections and Notes	Ideas of Possible Questions for Interviews
1. How did the ‘autistic’ person make meaning of the	The irony of this is that I can get all weepy at the tear-jerker endings of operas such as La Traviata, La Boheme, or Madame Butterfly, or novels such as Dracula. (Yes, I actually have	The paradox is that Edgar can feel emotion through the means of art and symbolism, however, he does not report doing so in the actual moment with family, friends and	To ‘autistic’ person: How do you experience emotion(s)? E.g. say when a family member dies? Do you feel

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<p>paradox(es) of their lived experience? How did they practically deal with it?</p>	<p>read that book.) Yet, as noted above, I feel nothing in real-life emotional situations. This is connected with that topic of feeling ‘emotion’ only through art.</p>	<p>others. He practically deals with this paradox by being engrossed in art and opera, and furthermore, this is a significant factor as to how he came to recognize himself as being ‘autistic’.</p> <p>Merleau-Ponty (1964/1968, p.11) is useful here both in relation to Edgar’s view(s) and my view of his view(s): “But at the very moment that I think I share the life of another, I am rejoining it only in its ends, its exterior poles. It is in the world that we communicate, through what, in our life, is articulate. It is from this lawn before me that I think I can catch sight of the impact of the green on the vision of another, it is through the music that I enter into his musical emotion, it is the thing itself that opens unto me the access to the private world of another. But the thing itself, we have seen, is always for me the thing that I see. The intervention of the other does not resolve the internal paradox of my perception: it adds to it this other enigma: of the propagation of my own most secret life in another – another enigma, but yet the same one, since, from all the evidence, it is only through the world that I can leave myself. It</p>	<p>emotions right there and then during the actual event you are living through? Does any form of art play a role in your experience of emotion(s)?</p>
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		<p>is therefore indeed true that the “private worlds” communicate, that each of them is given to its incumbent as a variant of one common world. The communication makes us the witnesses of one sole world, as the synergy of our eyes suspends them on one unique thing. But in both cases, the certitude, entirely irresistible as it may be, remains absolutely obscure; we can live it, we can neither think it neither formulate it nor set it up in theses. Every attempt at elucidation brings us back to the dilemmas.”</p>	
<p>2. How did the person make meaning of the dynamic aspect of their lived experience? How did they practically deal with it?</p>	<p>This was brought out in very high relief to me when my mother died in October 1994. My brother was devastated, even though we all saw her death coming. (He and I had even worked on the list of ‘things to do’ and on her obituary before she actually died; it was that imminent, but it did not occur precipitously.) Everyone else in the family, and friends also, expressed sorrow.</p> <p>I felt nothing. I also felt that there was something wrong there. Somewhat sardonically, I said to my pastor (who had been a psychologist before becoming a priest),</p>	<p>Edgar’s brother was devastated when their mother died. Seeing as they knew she was dying maybe Edgar had enough time to acknowledge and accept this situation? Maybe his grieving had taken place during this time? Developing such a perception may have been the way he practically dealt with the dynamic changing nature of life?</p> <p>Another way he practically dealt with his mother’s death is by seeing his pastor and having a discussion about it. Furthermore, seeing as Edgar makes this kind of statement</p>	<p>To ‘autistic’ person: Have any members of your family died? Especially say someone such as your mother or father? How did you view this? How did you behave during that time? How did you practically deal with it? Did you feel you could grieve? Do you have any siblings? How did they view it? How did they behave? How did they deal with it? Did you find yourself</p>

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	<p>'There are all kinds of support groups for people who grieve, but nothing for people who should be grieving but don't.'</p>	<p>to the pastor about support groups, maybe it illustrates that a part of the way he was practically dealing with his mother's death is by comparing himself with his brother?</p> <p>Lévinas (1961 / 1979, p.214): "Human fraternity has then two aspects: it involves individualities whose logical status is not reducible to the status of ultimate differences in a genus, for their singularity consists in each referring to itself. (An individual having a common genus with another individual would not be removed enough from it.) On the other hand, it involves the commonness of a father, as though the commonness of race would not bring together enough. Society must be a fraternal community to be commensurate with the straightforwardness, the primary proximity, in which the face presents itself to my welcome. Monotheism signifies this human kinship, this idea of a human race that refers back to the approach of the Other in the face, in a dimension of height, in responsibility for oneself and for the Other."</p>	<p>comparing your reaction to the event with other family members' reactions? Was there anything in particular that struck you?</p> <p>To sibling(s): How did you respond to your family member passing away? How did your 'autistic' family member respond? At the time, did you find yourself comparing your reaction to theirs? What was this like?</p>
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<p>3. How did the person make meaning of the mysterious aspect of their lived experiences? How did they practically deal with this?</p>	<p>This was before I even dreamed of myself as being autistic. When I read the remark, quoted in the New Yorker article ‘Prodigies’ by Oliver Sacks, of that 15-year-old boy who had just lost his mother (January 9, 1995, page 51, last column), I searched back as far as I could remember, even to early childhood, and noted that my reaction to my mother’s death was no isolated case.</p> <p>It was not limited to family members, but also to close friends. There were two people who went out of their way to help me when I was in dire straits. They had no obligation to help me and, in some ways, could have caused problems for themselves by doing so. I remember feeling no pain of loss when told of their deaths (in on case, it was quite sudden and he was young). Any sorrow I felt was purely intellectual.</p> <p>In March 1996, [I] spent some time, in solitude, at my daughter’s home, taking care of her house and her cat while she and her family were on vacation. (The cat and I became good buddies.) My daughter had just had to have her other cat euthanized. That</p>	<p>Edgar had not known or/and not had a particular word to describe his ‘autistic’ way of being, therefore, this aspect of himself was a mystery to himself. It was through reading the article about certain ‘autistic’ people that he recognized elements of himself – a way of having learned and practically dealt with an aspect of himself. He was then able to reflect over his life and see how he had not felt sorrow over his mother’s or his close friends’ deaths.</p> <p>I wonder about the intermingling of body, proprioception and perception here. If one’s biological make-up is such that one has hypo and hyper sensitivities then can it be that as much as the body might be living through sorrow maybe the <i>sense of ownership</i> of sorrow is not registered or/and not registered as much? [Hypo-sensitivity in action?] Or / and if added to this is a perceptual way of being whereby one has come to accept suffering as a norm in life then maybe they might not actually have any feelings of sorrow of a loved one’s death? In that, if one has come to genuinely realize and accept that death is part of the natural way</p>	<p>To ‘autistic’ person: Did the passing away of this family member lead to a new kind of self-awareness? How did you practically deal with this self-awareness?</p> <p>To ‘autistic’ person: Have you had any close friends pass away? How was this experience for you? How did you cope with it?</p> <p>To ‘autistic’ person: Did or/and do you have any animals in your family? As part of your family? Have you ever compared yourself</p>
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	<p>remaining cat was obviously grieving for her longtime companion. I could not help but think that a cat, the most independent of God's creatures, can grieve, but I cannot.</p>	<p>of life in all its depth then maybe there is nothing wrong in not feeling sorrow? This might be a way(s) that perception, bodily senses and proprioception are intermingling? Furthermore, there are cultures whereby they celebrate a persons' death, e.g. the Aborigines have a feast, sing and dance and in Madagascar they have a celebration of turning the bones once every 5 or 7 years. This is all in recognition of the soul moving on and honouring death. Mevlana Celalleddin Rumi even referred to his death as his wedding night and requested that people celebrate with music and dance and laughter as it was him finally becoming one with his Beloved/God. Therefore, it is not always necessary to feel sorrow over a person's death, especially considering that there are people who request that everyone be joyous for them during their funeral.</p> <p>Though Edgar even compares himself to his daughter's cat and that it was able to mourn and he was not able to do so. Is this a self-imposed expectation? In that he ought to mourn? Or maybe he was mourning in his own way but did not recognize it to be so? Seeing aspects of oneself by observing the</p>	<p>to an animal or animals? What kinds of situations led to you to do this? How did you compare yourself to it or and them? How did this feel for you? Did you become more aware of any particular thing(s) regarding yourself?</p> <p>To the child of 'autistic' person: Have you ever asked your mother/father ['autistic' parent] to take care of any animals of yours whilst you were away? What had happened while you were away? Did your parent talk about how the animal(s) behaved? Was there anything that they had learned about themselves or/and the animal(s)? What did you think about this? How did you feel?</p>
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		<p>'Other' in the form of an animal's expression(s)? Could it be that for Edgar the very yearning to mourn in itself is a form of mourning? It seems that the intention to mourn is there.</p> <p>Shems&Rumi (1263 / 2011, pages 392 - 393): the body as being composed and consisting of soil, and that soil being in a paradoxical conflict with itself, whereby the soil looks bland on the outside yet is made of pearls within:</p> <p>[Translated] "Because the soil looks black and dusty but within it lye forms of light. Its outer face is in a conflict with its inner face... its inner face is like a pearl, its outer face looks like a rock. The outer states "This is all we are"... the inner states "Be careful, look carefully at the front and back of this work"!</p> <p>1010. The outer doubts by stating "We have nothing within us"... the inner states "Wait a moment, let us show you our truth". The outer and the inner are in a war... and because the inner is patient with the outer it is bequeathed with the help of Allah. Thus it is that we take from this face that is half-done and make forms with it such that its</p>	
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		<p>hidden smiles manifest into openly being so. Because the outer [form] of the soil is due to suffering and its cries, but within it are hundreds of thousands of smiles. Those things that are hidden, we bring them out into the open... We are constantly taking these hidden things out of traps!”</p> <p>Maybe Shems&Rumi’s description above describes the process(es) which Edgar has just lived through in relation to his embodied&non-embodied experience regarding grief? Maybe he was in a conflict with wanting to grieve as this is what he saw on the outer and he too wanted to display this on his outer face? However, it seems his inner being was not feeling that this was the case and thus the war raged between the outer and inner faces of his body? Yet it was also thanks to this and having read an article by Oliver Sacks that he came to realize an aspect of his self, in that he may well be ‘autistic’; the hidden thing(s) being taken out of the trap(s)? Thus the suffering leading to a (re-)realization about himself and an acceptance of this; hundreds of thousands of hidden smiles being brought out into the open?</p>	
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<p>Questions and Reflective Notes Regarding the ‘Other’, the Family Context and Myself</p>	
<p>How does this ‘autistic’ person make meaning? Especially in the family context? What seems to be the family’s meaning-making process(es)? What is my meaning-making process(es)?</p>	<p>Edgar is making meaning thanks to having read an article that resonated with him a lot and raised a question in his mind about him being ‘autistic’. He refers to his embodied experiences in terms of the manner in which he feels emotion via art but not through the very lived experience, e.g. his mother and two friends passing away and him not grieving. Regarding the family context, when his mother passed away his brother grieved for her yet Edgar feels that he did not or/and could not. Therefore, he also seems to be making meaning regarding his embodied experience(s) by comparing it to his brother’s displayed embodied experience. It seems that the family’s meaning-making during the mother’s passing away was one of sadness and grief, yet Edgar felt that he could not or/and did not participate in this experience, and therefore has a chat with the pastor about a support group for people who should be grieving but do not. Edgar seeks the guidance of a spiritual teacher in order to acknowledge his own experience in relation his family’s experience, and is also attempting to be open about his experience so as to better understand his situation, inclusive of inviting the pastor’s meaning-making in order to possibly shed more light upon his experience(s). There is also the role of animals in the family which influence Edgar’s meaning-making; e.g. the cat that was mourning for its fellow feline that passed away. From the manner in which he has written about this, it seems that he feels himself to be inadequate whilst comparing himself to the cat, although simultaneously, one could also interpret this as him being even more independent than a cat to the point that he is not even able to grieve.</p> <p>My meaning-making is above.</p>
<p>What are the implications for perception(s) and self-knowledge?</p>	<p>The implications for perception(s) and self-knowledge is that we have to validate our own perceptual bodily experiences and non-experiences, even when others’ behaviour and feelings may be in seeming contrast to our behaviour and feelings – this is also how self-knowledge ‘develops’? The honouring of one’s own reality(ies). Maybe the observing self, i.e. the witness in oneself, has a role to play in the ‘development’ of perception(s) and self-knowledge?</p>
<p>What are the implications for</p>	<p>The implications for phenomenology as a methodology is that maybe the phenomenological attitude also ought to take into account the observing self? The element of ourselves that witnesses all, despite our sense of ownership or/and non-ownership</p>

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phenomenology as a methodology?	of our feelings regarding our lived experiences.
What are the implications for IPA as an approach and the methods involved?	<p>The implications for IPA are that when the researcher reads about a phenomenon whereby the researcher’s meaning-making, i.e. interpretation, is somewhat different to the writer’s then this ought to be explicitly explored. For example, in this case one of my interpretations is that Edgar is likely to have been experiencing grief; however, it may be that he does not have as much of a <i>sense of ownership</i> of this grief during the moment of the lived experience(s) itself.</p> <p>The implications for the methods involved are that reflexivity is crucial and the researcher ought to write reflexively about the analyses that one has carried out and is continuing to carry out.</p>
What is self-knowledge? How does it develop?	<p>Self-knowledge is partly to do with reflecting over one’s lived experiences, embodied and non-embodied, including that of reflecting over others’ lived experiences and how this is integrated and not integrated into one’s own sense of self.</p> <p>It ‘develops’ in various ways, e.g. via reading an article that one sees aspects of oneself in, in the family context as well as in times of when the family is in a particular transitional period, e.g. a loved one passing away.</p>
What is meaning? How does it develop?	<p>Meaning is that which the person(s) sees in one’s lived experiences and that which one validates, and possibly also does not validate?</p> <p>The validating and non-validating of one’s lived experience(s) can also lead to the development and non-development of meaning and meaning-making?</p>
What is perception? How does it develop?	<p>Perception is that which is experienced, witnessed and validated and not validated; the paradoxical, dynamic and mysterious self.</p> <p>It develops through the paradoxical and dynamic lived experience(s)? Yet simultaneously, the mystery that is present in the lived embodied&non-embodied experience(s) is already present and already ‘knows’ that which develops and does not develop? As similar to what Halil Cibran/Kahlil Gibran (1929 / 2011; page 96) states, “The soul walks not upon a line, neither</p>

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	does it grow like a reed. The soul unfolds itself, like a lotus of countless petals”; revealing itself with, in, to and through itself? Concentric circles come to mind here.
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The questions that have arisen regarding the methods so far are:

1. How does one use reflective texts/autobiographies, especially those by ‘autistic’ persons, with IPA?

- By asking phenomenological questions;
- Illustrating the interpretive process the researcher is undergoing by producing tables, as above, and using direct quotes and excerpts from ‘autistic’ persons’ writings for this. Which in itself is a reflexive act(s);
- Coming up with ideas of possible questions for interviews;
- Taking up a developmental lens and working vignettes that are to do with family members at different stages of the ‘autistic’ persons’ development;
- This particular vignette has brought to the fore the element of feelings during important family events, e.g. a death in the family.

2. How does one use autobiographical/reflective texts in order to further become sensitive to the context and culture of ‘autistic’ persons and ‘their’ family life?

- Asking phenomenological questions that focus on the embodied&non-embodied self;
- Keeping in mind the implications of such ways of being that I am learning about and coming up with ideas as I proceed; e.g. the ideas of possible interview questions are emerging from the narratives of the ‘autistic’ writer(s);
- Analysing vignettes that specifically focus on family contexts are also enabling me to become that much more sensitive;
- An ‘autistic’ adult may compare his behaviour to that of his brother during the process(es) of bereavement. Family members can include animals, and an ‘autistic’ adult may compare himself to a cat when focusing on bereavement.

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3. How does one create further research questions (e.g. for interviews) and develop one's philosophical standpoint(s) whilst analysing 'autistic' person's autobiographies with IPA?

- Read the books, pick out a vignette for the relevant developmental stage that fulfils the criteria and type it up word for word from the book. Ask the phenomenological questions, produce the table and whilst doing so reflect and make notes; when ideas of possible questions for interviews come to mind note these down.

APPENDIX 12

Data and Analyses: Family Vignette 8, Adulthood. Donna Williams, 1992. Nobody Nowhere. The Extraordinary Autobiography of An Autistic

Contextual information regarding this book:

- (i) Who wrote the autobiography/& reflective text: Donna Williams
- (ii) Where the autobiography/& reflective text was written: United Kingdom
- (iii) When the autobiography /& reflective text was written: It was published in 1992
- (iv) Why and how the text came in to being:

Donna wrote this autobiography so as to understand herself and life better, as well as to educate people who are non-‘autistic’ about an ‘autistic’ person’s life.

Vignette from page 128 - 131:

“I WENT TO see the doctors who had seen me as a child. I wanted to hear what was on my medical records. I also went to the primary school I had attended and stood at the foot of the tiny staircase that led to the Psych and Guidance room – an attic that the school now no longer used. I visited my first high school, from which I had disappeared on my trip to the country. Finally I went to see an aunt who had been a regular visitor to the house during my early childhood.

My aunty was surprised to see me. It was the first time I’d visited her in about six years. She had always been very fond of me.

I told her that I had found out that my birth certificate was not a copy of the original; that it was a “second schedule” and that the registrar had told me to go and ask my parents to give me the answers to why this was so. I felt that here was a good place to start.

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I had once been told that my aunty's little girl had over-heard a conversation between her parents about how I could have been her sister. I told my aunty that the adoption agency had identified my certificate as an adoption certificate, and I wanted to know why. I grilled her for the answers.

My aunty told me the story behind my mother's never-ending threats to put me in a children's home. My aunty and my uncle had discussed the possibility of adopting me. I had, however, been put into my grandparents' care by my father, and as my grandparents lived in a shack in our back-yard, I remained at home. Upon the death of my grand-mother, my parents once again became my full custodians.

I looked at my aunty and wondered what it might have been like growing up with her, with a little sister instead of a little brother. Still, I wouldn't have swapped my early experiences with my little brother for the world.

My aunty was cornered. She told me everything she could remember from the moment I was born.

When it came to everything that was wrong with me – my not speaking to people, my aversion to closeness, my pre-occupation with the unreachable world within my own mind – to her it was simple: my mother had caused it.

There was much that justified this opinion, but Willie [one of the personas that Donna had created in her mind to cope with the world] examined what she said from an objective observer's point of view.

I had not linked the tragedy of what she had seen with the pleasant, beautiful, and hypnotic experiences of mere color, sensation, and sound that had held me spellbound until I was about three and a half. I had been unaware of the pain of sores from unchanged diapers or my mother's neglect or brutality until I became aware of people's efforts at getting my attention.

The hypnotic fascination I had for the spots in the air left me with very little sensation of my own body except for the shock and repulsion of the invasion of physical closeness. Even the comfort I derived from being picked up by my grandmother was found, not in snuggling up to her, but in holding on to the chain around her neck or enmeshing my fingers in her crocheted cardigan.

There was something overwhelming about giving into a physical touch. It was the threat of losing all sense of separateness between myself and the other person. Like being eaten up, or drowned by a tidal wave, fear of touch was the same as fear of death.

My aunty had recalled many memories of my child-hood, but none had really struck a chord. Willie stood there remembering many of these, but did so without any feeling for the self who had experienced them. Then, as my aunty recalled an event when I was three, it triggered something, and my mind replayed it in all its vividness and horror.

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I was back there. I could see my aunty across the room. I could hear the pleading tone in her voice and sensed danger. I was watching everything around me happen as though in slow motion, though still moving far too fast for me to be able to respond in time.

I looked up at the figure of my mother. I shot silent glances in the direction of the pleading voice from across the room. I looked down at the opened tin of cold spaghetti in front of me and was aware of the fork in my hand.

I had not heard the introduction: the threat of death against my spilling a single drop of food. I never connected the repeated slapping with the event. It was just something that came to me from out of the blue as a series of shocks.

I felt the dishcloth being forced into my mouth. It made me gag. I was choking as I vomited up against it.

The pleading voice was at war with the cutting snarl of my mother's voice. I glanced up at the black and white striped cord as though it was a snake. It began to whip my face. I could not cry, or speak, or scream. I looked at my aunty and col-lapsed on the cold smooth surface of the table in front of me and vomited through my nose. I thought I had drowned.

There was a rising choke of vomit in my throat and a deafening scream inside my head that couldn't get out. Wil-lie had asked why she had done nothing.

Without waiting for a reply, I went wandering down the hallway of my aunty's house like an automaton.

My cousin's room branched off to one side. I looked through the door. My cousin had been given the furniture from my old room as a child. There on my old bed was the same bedspread, with fine yellow flowers embroidered on it.

The bed was white and curved and smooth, and I could remember tracing its shape with my hand over and over. I could remember biting into the wood and feeling it give way with a fine crackling sound as the paint chipped away. Against another wall was the matching dressing table. Its three folding mirrors seemed to have captured the ghost of Carol [another persona that Donna had created to cope with the world], who had stood in front of it many times, whispering the name Donna and trying to feel it.

The mirror seemed to call me. I approached it and looked deeply into the eyes of the girl looking back. Willie was gone.

Against the other wall was the wardrobe – the wardrobe in which Carol had left me behind. I held my breath in front of it. I ran my finger along the pattern of the wardrobe door's handle. I was afraid and felt as though I was being swept up in a sort of magic. The magic of childhood. I opened the door and got in. In the darkness, closing the door behind me, I sat down and curled up in a ball.

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After a while I got out of the cupboard and left the room in a hurry. I left my aunty's house like a cornered rat that had suddenly found a way out. I had begun to touch upon the answers to what was missing. I went home, curled up in a ball, and rocked for three days."

How does Donna make meaning regarding her embodied&non-embodied life experiences as a child?

Question	Excerpt(s) from the Vignette	Researcher's Reflections and Notes	Ideas of Possible Questions for Interviews
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<p>1. How did the 'autistic' person make meaning of the paradox(es) of their lived experience? How did they practically deal with it?</p>	<p>I had not linked the tragedy of what she had seen with the pleasant, beautiful, and hypnotic experiences of mere color, sensation, and sound that had held me spellbound until I was about three and a half. I had been unaware of the pain of sores from unchanged diapers or my mother's neglect or brutality until I became aware of people's efforts at getting my attention.</p> <p>The hypnotic fascination I had for the spots in the air left me with very little sensation of my own body except for the shock and repulsion of the invasion of physical closeness. Even the comfort I derived from being picked up by my grandmother was found, not in snuggling up to her, but in holding on to the chain around her neck or enmeshing my fingers in her crocheted cardigan.</p> <p>There was something overwhelming about giving into a physical touch. It was the threat of losing all sense of separateness between myself and the other person. Like being eaten up, or drowned by a tidal wave, fear of touch was the same as fear of death.</p>	<p>As an adult Donna recognizes the paradox of her lived experiences as an infant, which in itself is also paradoxical because she is now an adult reflecting over her infancy and seeing and understanding things she had not seen and understood then in this kind of way, e.g. making the link between her lived experiences and others' actions.</p> <p>As an infant Donna's experiencing of her environment was so beautiful and serene, full of pleasure, simultaneously it was also this that contributed to her not noticing the pain she was also experiencing.</p> <p>Maybe 'autistic' people who are hypersensitive to others' touch need to focus more so on objects in order to cope with physical closeness?</p> <p>The human touch and a sense of self?</p> <p>Wittgenstein (1953/1986; p. 56): "Let us imagine the following: The surfaces of the things around us (stones, plants, etc.) have patches and regions which produce pain in our skin when we touch them. (Perhaps through the chemical composition of these surfaces. But we need not know that.) In this</p>	<p>To 'autistic' person: How did you come to know you are 'autistic'? Who told you? What did you do or/and not do when you found out? Did you speak about it with family members? Did you ask them questions about your life in your younger years? What did you ask?</p> <p>Did you reflect over your life? Did some things that were a mystery to you become understandable? What were they? What kinds of memories arose? Do your memories include your physical interactions with family members or/and objects? Infancy memories? Childhood memories? Teenagehood memories? Memories during adulthood? How did you feel? How did you deal with such memories? How did</p>
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		<p>case we should speak of pain-patches on the leaf of a particular plant just as at present we speak of red patches. I am supposing that it is useful to us to notice these patches and their shapes; that we can infer important properties of the objects from them.</p> <p>313. I can exhibit pain, as I exhibit red, and as I exhibit straight and crooked and trees and stones.—That is what we call "exhibiting".</p> <p>314. It shews a fundamental misunderstanding, if I am inclined to study the headache I have now in order to get clear about the philosophical problem of sensation.</p> <p>315. Could someone understand the word "pain", who had never felt pain?—Is experience to teach me whether this is so or not?— And if we say "A man could not imagine pain without having sometime felt it"—how do we know? How can it be decided whether it is true?"</p> <p>Lévinas (1961/1979, p.115): "The soul is not, as in Plato, what "has the</p>	<p>you deal with such feelings?</p> <p>To 'autistic' person: What is your definition of 'pain'? How do you experience pain? How do you cope with pain? Do you think that others experience pain like you do? What makes you think that? How? Why?</p>
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		<p>care of inanimate being everywhere”⁷; it to be sure dwells in what is not itself, but it acquires its own identity by this dwelling in the “other” (and not logically by opposition to the other).”</p> <p>Donna practically deals with this understanding by re-living a moment with her mum and aunt, and then proceeds to seek the physical items (as below), then runs out of her aunt’s home. The paradox is that by facing and coming to terms with an aspect of her truth she had to run away from the physical items and people that reminded her of that moment and also witnessed it with her.</p>	
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<p>2. How did the person make meaning of the dynamic aspect of their lived experience? How did they practically deal with it?</p>	<p>I was back there. I could see my aunty across the room. I could hear the pleading tone in her voice and sensed danger. I was watching everything around me happen as though in slow motion, though still moving far too fast for me to be able to respond in time.</p> <p>I looked up at the figure of my mother. I shot silent glances in the direction of the pleading voice from across the room. I looked down at the opened tin of cold spaghetti in front of me and was aware of the fork in my hand.</p> <p>I had not heard the introduction: the threat of death against my spilling a single drop of food. I never connected the repeated slapping with the event. It was just something that came to me from out of the blue as a series of shocks.</p> <p>I felt the dishcloth being forced into my mouth. It made me gag. I was choking as I vomited up against it.</p> <p>The pleading voice was at war with the cutting snarl of my mother's voice. I glanced up at the black and white striped cord as though it was a snake. It began to whip my face. I could not cry, or speak, or scream. I</p>	<p>Donna's aunt's story pulls up an episodic memory that is dynamic as well as conflictual in nature.</p> <p>Donna is reliving the moment whereby her mother is about to attack her, remembering the can of spaghetti and the fork in her hand.</p> <p>Whilst reliving the moment via memory she is understanding the dynamic and mysterious element of this infancy experience, making the connection between her mother's threat and the slaps.</p> <p>Reading this literally made me cry.</p> <p>Her aunt was trying to stop her mum; there was a non-embodied embodied self (i.e. not Donna herself but her aunt) trying to protect her as another dynamic force. Donna's body practically dealt with the dynamic nature of this experience by becoming silent, physically collapsing, and finally vomiting through her</p>	<p>To 'autistic' person: Whilst talking with family about your younger days are there any particular memories from certain periods of your life that struck you? For example a memory from your infancy years that made you realize something about yourself that you may have not realized before? How did you deal with this?</p> <p>Before I go on to the following question, I remind you that you do not have to answer any of these questions if you do not wish to. Do you have any memories with your family whereby when you now look back at it and you think, "That was physical or/and emotional abuse?" How did you feel at the time? How did you deal with it? Was</p>
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	<p>looked at my aunty and col-lapsed on the cold smooth surface of the table in front of me and vomited through my nose. I thought I had drowned.</p> <p>There was a rising choke of vomit in my throat and a deafening scream inside my head that couldn't get out. Wil-lie [one of Donna's personas] had asked why she had done nothing.</p> <p>Without waiting for a reply, I went wandering down the hallway of my aunty's house like an automaton.</p> <p>My cousin's room branched off to one side. I looked through the door. My cousin had been given the furniture from my old room as a child. There on my old bed was the same bedspread, with fine yellow flowers embroidered on it.</p> <p>The bed was white and curved and smooth, and I could remember tracing its shape with my hand over and over. I could remember biting into the wood and feeling it give way with a fine crackling sound as the paint chipped away. Against another wall was the matching dressing table. Its three folding mirrors seemed to have captured the ghost of</p>	<p>nose.</p> <p>This memory in turn leads to Donna as an adult re-experiencing the moment in a physical manner. This is trauma relived. If 'autistic' persons are hypersensitive and hyposensitive in certain ways then how deeply or/and non-deeply is trauma experienced? What of post-traumatic stress? How do such persons cope with such experiences during the moment? And how do they cope with it once they begin to make sense of it years later as teenagers or adults?</p> <p>One way Donna practically dealt with it by seeking out more of her history and story, e.g. by visiting her aunt. She confronts her aunt by asking her the question as to why she never did anything about it, though it seems that this was more of a statement as she does not wait to listen to the answer.</p> <p>She walks to her cousin's room and sees her furniture, leading to further memories of her younger days in her room.</p> <p>Donna is reflecting with and over such memories and the struggle of trying to see herself as she is, as Donna.</p>	<p>there anyone else who knew about it, e.g. an aunt or uncle? What did they do or/and not do? How does this make you feel now? How do you deal with it now? How do you think that family member felt at the time? How do you think they felt whilst telling you that information? How is your relationship now?</p> <p>How do you define 'trauma'? Have you ever had a traumatic experience as an infant? As a child? As a teenager? As an adult? Have any of these traumatic feelings come about again after you have remembered such moments? How did you feel? How did you cope with it or/and them?</p> <p>Did you seek out any of your old items after having realized an aspect of yourself? E.g. that you might</p>
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	<p>Carol [another persona that Donna had created to cope with the world], who had stood in front of it many times, whispering the name Donna and trying to feel it.</p> <p>The mirror seemed to call me. I approached it and looked deeply into the eyes of the girl looking back. Willie was gone.</p> <p>Against the other wall was the wardrobe – the wardrobe in which Carol had left me behind. I held my breath in front of it. I ran my finger along the pattern of the wardrobe door’s handle. I was afraid and felt as though I was being swept up in a sort of magic. The magic of childhood. I opened the door and got in. In the darkness, closing the door behind me, I sat down and curled up in a ball.</p> <p>After a while I got out of the cupboard and left the room in a hurry. I left my aunty’s house like a cornered rat that had suddenly found a way out. I had begun to touch upon the answers to what was missing. I went home, curled up in a ball, and rocked for three days.</p>	<p>Standing in front of the mirror she can see herself as Donna.</p> <p>She then sits in the darkness of her former wardrobe so as to acknowledge, accept and live her vulnerability, “curled up in a ball”.</p> <p>The time spent in darkness with her vulnerability paradoxically led to her running away from her aunt’s house in a more enlightened manner; this all in itself is dynamic. Donna practically dealt with it all by being dynamic as well, e.g. seeking her cousin’s room, sitting in the wardrobe, running out of the house, going home and rocking for three days with what she had somewhat known for years but was now realizing as she was making the connections between her lived experiences and why they had and were taking place. The mystery was</p>	<p>be / are ‘autistic’? How did the item(s) make you feel?</p> <p>Are there any personas that you have created in your mind to deal with social contexts, e.g. with family or friends? Do these personas have names? What are they? Why did you choose these names? Which particular contexts or/and with whom do you use these personas? How does this make you feel?</p> <p>When feeling emotionally charged up do you rock or/and do any other particular activity to calm down? Do you rock or/and do any other particular activity when thinking through things deeply? What kinds of things have made you do this in the past? How about what kinds of things that family may have said or did that make you feel like</p>
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		<p>unravelling. This brings to mind the following by Arberry and Rumi.</p> <p>A.J. Arberry (2000, page XV):</p> <p>“Rumi was never general in his discussions, he always spoke to specific situations. He addressed the particular beliefs and conflicts of those around him, and he was a witness and spokesman for The Way as it was manifesting in his day. And still his words can teach us now.” What are the implications of this kind of phenomenological attitude and research methods utilizing narratives? How can it be practiced and incorporated into research?</p> <p>Memory and language clearly play a role in this excerpt of the vignette. Hagberg (2008; p.143): [using Dostoevsky’s writing about an underground man’s writing about his job] “He is positioned not as the sole owner of a hermetically sealed point of consciousness, but rather as a mind: (1) positioned in relation to a remembered past that is not given transparently and immediately in introspection but rather one with a problematic significance that he must <i>work out</i>; (2) positioned with an ironic distance</p>	<p>say rocking?</p>
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		<p>from his present self; and (3) positioned in relation to his present sentences as they appear not with immediate inward transparency, but rather with a layered complexity that belies the simple notion that the autobiographical or self-descriptive sentence stands in a one-to-one relation to a mental state only contingently expressed in language.”</p> <p>Regarding objects and the mind, Merleau-Ponty (1945 / 1989; p. 23) comes to mind: “Objects are not mere projections or constructions of our minds; rather, they are objects to be encountered or discovered. In short, they are things offering a certain resistance to our touch and a depth to our gaze.”</p> <p>Regarding the dynamics of the embodied and non-embodied self as well as memory, Merleau-Ponty (1964 / 1968) is useful here (pages 114 – 115): “The space, the time of things are shreds of himself, of his own spatialization, of his own temporalization, are no longer a multiplicity of individuals synchronically and diachronically distributed, but a relief of the simultaneous and of the successive, a spatial and temporal pulp where</p>	
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		<p>the individuals are formed by differentiation. The things – here, there, now, then – are no longer in themselves, in their own place, in their own time; they exist only at the end of those rays of spatiality and of temporality emitted in the secrecy of my flesh. And their solidity is not that of a pure object which the mind soars over; I experience their solidity from within insofar as I am among them and insofar as they communicate through me as a sentient thing. Like the memory screen of the psychoanalysts, the present, the visible counts so much for me and has an absolute prestige for me only by reason of this immense latent content of the past, the future, and the elsewhere, which it announces and which it conceals. There is therefore no need to add to the multiplicity of spatio-temporal atoms a transversal dimension of essences – what there is is a whole architecture, a whole complex of phenomena “in tiers,” a whole series of “levels of being,”¹ which are differentiated by the coiling up of the visible and the universal over a certain visible wherein it is redoubled and inscribed. Fact and essence can no longer be distinguished, not because, mixed up in our experience, they in their purity would be inaccessible and</p>	
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		<p>would subsist as limit-ideas beyond our experience, but because – Being no longer being <i>before me</i>, but surrounding me and in a sense traversing me, and my vision of Being not forming itself from elsewhere, but from the midst of Being – the alleged facts, the spatio-temporal individuals, are from the first mounted on the axes, the pivots, the dimensions, the generality of my body, and the ideas are therefore already encrusted in its joints. There is no emplacement of space and time that would not be variant of the others, as they are of it; there is no [page 115] individual that would not be representative of a species or of a family of beings, would not have, would not be certain style, a certain manner of managing the domain of space and time over which it has competency, of pronouncing, of articulating that domain, of radiating about a wholly virtual center - in short, a certain manner of being, in the active sense, a certain <i>Wesen</i>, in the sense that, says Heidegger, this word has when used as a verb.²</p> <p>In short, there is no essence, no idea, that does not adhere to a domain of history and of geography. Not that it is <i>confined</i> there and</p>	
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		<p>inaccessible for the others, but because, like that of nature, the space or time of culture is not surveyable from above, and because the communication from one constituted culture to another occurs through the wild region wherein they all have originated. Where in all this is the essence? Where is the existence? Where is the <i>Sosein</i>, where the <i>Sein</i>? We never have before us pure individuals, indivisible glaciers of beings, nor essences without place and without date. Not that they exist elsewhere, beyond our grasp, but because we are experiences, that is, thoughts that feel behind themselves the weight of the space, the very Being they think, and which therefore do not hold under their gaze a serial space and time nor the pure idea of series, but have about themselves a time and a space that exist by piling up, by proliferation, by encroachment, by promiscuity – a perpetual pregnancy, perpetual parturition, generativity and generality, brute essence and brute existence, which are the nodes and antinodes of the same ontological vibration.”</p>	
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<p>3. How did the person make meaning of the mysterious aspect of their lived experiences? How did they practically deal with this?</p>	<p>I WENT TO see the doctors who had seen me as a child. I wanted to hear what was on my medical records. I also went to the primary school I had attended and stood at the foot of the tiny staircase that led to the Psych and Guidance room – an attic that the school now no longer used. I visited my first high school, from which I had disappeared on my trip to the country. Finally I went to see an aunt who had been a regular visitor to the house during my early childhood.</p>	<p>[Donna had been undergoing psychotherapy with a counsellor, Mary, whilst she was in her early 20s for two years. She began to have nightmares again and was trying to make sense of her lived experiences and why she felt she was different.] Donna was mystified and was struggling to understand, therefore she practically began to thoroughly investigate her history from early childhood onwards, e.g. via her medical records, her schools, and then finally a family member, her aunt.</p> <p>Michael Inwood (2000, p.42 – 43) regarding the disabling mood of thinking in, with and through mystery by giving examples of John Bunyan and linking it to Heidegger’s thinking. This mood then leads to understanding:</p> <p>Page 42: [John Bunyan sits in the street and muses over his own disabling mood] “Oh, how happy now was every creature over I for they stood fast, and kept their station. But I was gone and lost.” [In <i>Grace Abounding</i>]</p> <p>Page 43: [Inward continues] “Is it right, in any case, to call Bunyan’s mood disabling? While it lasts it prevents us from making shoes,</p>	<p>To ‘autistic’ person: When were you recognized as being ‘autistic’? Or/and when did you first think that you may be ‘autistic’? How did you practically deal with this? Did you talk with family about it? What was it like? Did you ask your doctor for your medical history and talk it over with them? What was it like? Did you go back to your old schools and talk to members of staff? What was it like?</p> <p>Is there anything in particular that made you physically or/and emotionally react to what they shared with you? What did they say? What happened to you at that moment or/and later?</p>
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		<p>writing books, from engaging in either the humdrum routine of life or in making crucial decisions. [...] For, Heidegger believes, moods such as this reveal things that we are usually unaware of. They light up the world and our being in the world in a way that everyday business does not. The craftsman catches a glimpse of his world, of the worldly character of his world, when he finds a tool missing; he notices the whole in conspicuously absent part. But a mood such as Bunyan's discloses the world more forcibly and memorably; it reveals the worldliness of the world and, by contrast, the everyday unobtrusiveness of the world. Heidegger believes that such moods (or at least less extreme cases such as boredom and <i>Angst</i>) are a vital source of insight for the philosopher. But they are not of course the exclusive preserve of the philosopher. Unphilosophical, everyday Dasein is prone to them too, and so moods play a part in Heidegger's attempt to explain Dasein becomes a philosopher.</p> <p>Moods alone, however, do not disclose the world. For this we need understanding."</p>	
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	<p>My aunty was surprised to see me. It was the first time I'd visited her in about six years. She had always been very fond of me.</p> <p>My aunty had recalled many memories of my childhood, but none had really struck a chord. Willie stood there remembering many of these, but did so without any feeling for the self who had experienced them. Then, as my aunty recalled an event when I was three, it triggered something, and my mind replayed it in all its vividness and horror.</p>	<p>Her aunt is a family member who felt positive toward Donna since childhood and Donna knows this.</p> <p>Merleau-Ponty (1964 / 1968, p.193): "It is already the flesh of things that speaks to us of our own flesh, and that speaks to us of the flesh of the other - - My "look" is one of those givens of the "sensible," of the brute and primordial world, that defies the analysis into being and nothingness, into existence as consciousness and existence as a thing, and requires a complete reconstruction of philosophy. The analytics of being and nothingness at the same time discloses and masks this order: it discloses it as a menace on nothingness and of nothingness on being, it masks it because the entity and the negentity remain in principle isolable.</p> <p>Lévinas (1961 / 1979, p.204): "Signification is the Infinite, but infinity does not present itself to a transcendental thought, nor even to meaningful activity, but presents itself in the</p>	<p>To 'autistic' person: Do you have any relatives who were positive towards you? How did they treat you that made you feel like this?</p> <p>Is there a particular family member or members who shared information with you about your childhood? How did this feel? What did it make you think about? Did you have any involuntary physical or/and emotional reactions to what they shared with you? How did you deal with this?</p>
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		<p>Other; the Other faces me and puts me in question and <i>obliges</i> me by his essence qua infinity. That “something” we call signification arises in being with language because the essence of language is the relation with the Other. This relation is not added to the interior monologue – be it Merleau-Ponty’s “corporeal intentionality” – like an address added to the fabricated object one puts in the mailbox; the welcoming of the being that appears in the face, the ethical event of sociality, already commands inward discourse. And the epiphany that is produced as a face is not constituted as are all other beings, precisely because it “reveals” infinity. Signification is infinity, that is, the Other. The intelligible is not a concept, but an intelligence.”</p>	
<p>Questions and Reflective Notes Regarding the ‘Other’, the Family Context and Myself</p>			
<p>How does this ‘autistic’ person make meaning? Especially in the family context? What seems to be the family’s</p>	<p>Donna makes meaning by seeking historical knowledge via others, e.g. her aunt, who is another aspect of oneself, and asks about her childhood. During the dialogue she is realizing an aspect of herself via the bridging up of a memory from infancy through a physically lived involuntary reaction, i.e. the vomit coming up. Is this a form of post-traumatic stress disorder? Whereby it had been lived and experienced but had yet to be acknowledged by the person in a meaning-making and meaning-understood manner? It is the mystery of meaning that led her to seek knowledge in order to make meaning, and she did so.</p> <p>She becomes dynamic and seeks the objects that were and are a part of her space. Sitting in her wardrobe; understanding</p>		

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<p>meaning-making process(es)? What is my meaning-making process(es)?</p>	<p>and meaning-making taking place with and in darkness – it epitomizes the whole process(es) with her family?</p> <p>She then becomes dynamic again and runs out of the house; a running away from the meaning she has come to make and realize? Then rocks at home for three days to work with such meaning; an intense embodied response to the meanings and emotions she had begun to make and understand?</p> <p>Regarding her aunt, maybe she too wanted and needed a moment like the one described above to face and realize elements of her being? Maybe in the long run this moment was a cathartic one for both concerned? St. Augustine’s words come to mind here: The truth is like a lion, it doesn’t need defending. Let it loose, it will defend itself.</p> <p>My meaning-making of the process is by utilizing the lens of the paradoxical dynamic mysterious self to view the situation and fathom how one element(s) of Donna’s being in the family context connects with and flows another element(s) of her paradoxical dynamic mysterious self. Furthermore, as above, certain sayings from past philosophers /& saints /& teachers /& poets /& scientists have also come to mind during the analysis process(es) and hence are included.</p>
<p>What are the implications for perception(s) and self-knowledge?</p>	<p>Perception is embodied&non-embodied. Dialogue and communication, whether it be via physical contact or/and via the spoken word or not, it is constantly embedded in our ways of being, whether we understand them via the sense of the mind or not. The body registers everything in energy form so perception is constantly paradoxical, dynamic and mysterious, yet there is an aspect that perceives and knows itself regardless?</p>
<p>What are the implications for phenomenology as a methodology?</p>	<p>The phenomenological attitude is CRUCIAL. Even one vignette can enable us to develop our insights into the lived experiences of ‘autistic’ persons.</p> <p>When considering the family and how the embodied&non-embodied self is coming into being via the organisms concerned maybe we ought to bring in some views from resonance research, e.g. Rupert Sheldrake’s and HeartMath’s research?</p>
<p>What are the implications for</p>	<p>IPA provides a useful flexible framework for analysing such vignettes. However, it needs to focus on and develop methods by which the phenomenological attitude is put at the fore of it. Reflexivity definitely helps in this process, however, from what I</p>

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<p>IPA as an approach and the methods involved?</p>	<p>am fathoming so far (i) the engaging in lived experiences before even producing interview questions, (ii) along with the three questions of, and focusing on, the paradoxical, dynamic and mysterious self, and (iii) asking the questions regarding self-knowledge, meaning-making and perception regarding both the writings and myself as the researcher, is helping to achieve this. Which in turn is helping to sensitize me as the researcher to this 'autistic' person's way of being and the kind of family context in which they navigated, in turn leading to questions about her lived experiences as well as what we perceive to be reality(ies). Therefore, I as a researcher am not only a researcher but also a pupil and an amateur philosopher.</p>
<p>What is self-knowledge? How does it develop?</p>	<p>Self-knowledge is part and parcel of all that is and is not. It develops via our interactions with family and others, and simultaneously, it knows itself and does not develop as such.</p>
<p>What is meaning? How does it develop?</p>	<p>Meaning in this case is the uniting of an aspect of oneself with another aspect of oneself, and this is how it is developed. Again, meaning knows itself anyway and so simultaneously it does not develop as such. I remember reading something about a Buddhist Zen monk's phrase as mentioned in Elizabeth Gilbert's <i>Eat Pray Love</i>: it is not the seed that grows into a tree, but the tree that is already present in the seed that pulls the seed into becoming a tree.</p>
<p>What is perception? How does it develop?</p>	<p>Perception is a gaze, the way one feels in one's skin and the way one simply <i>is</i> in the world. The place(s) with and from where one navigates in the world. Sometimes the sense of the mind has to acknowledge what has been lived and perceived in a magnified manner, i.e. make the lived experience conscious to the perceiver, and the body assists with this process. Therefore, perception can be developed via the sharing of historical events with family members and this in turn can assist all concerned to develop their perception. Simultaneously, perception is everything and nothing.</p>

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The questions that have arisen regarding the methods so far are:

1. How does one use reflective texts/autobiographies, especially those by 'autistic' persons, with IPA?

- By asking phenomenological questions;
- Illustrating the interpretive process the researcher is undergoing by producing tables, as above, and using direct quotes and excerpts from 'autistic' persons' writings for this. Which in itself is a reflexive act(s);
- Coming up with ideas of possible questions for interviews;
- Taking up a developmental lens and working vignettes that are to do with family members at different stages of the 'autistic' persons' development;
- This particular vignette has brought to the fore the element of memory(ies) and sharing family memory(ies) in the form of stories in order to try and understand oneself better.

2. How does one use autobiographical/reflective texts in order to further become sensitive to the context and culture of 'autistic' persons and 'their' family life?

- Asking phenomenological questions that focus on the embodied&non-embodied self;
- Keeping in mind the implications of such ways of being that I am learning about and coming up with ideas as I proceed; e.g. the ideas of possible interview questions are emerging from the narratives of the 'autistic' writer(s);
- Analysing vignettes that specifically focus on family contexts are also enabling me to become that much more sensitive;
- An 'autistic' adult can carry out more research about her past as a form of self-exploration and seek the help of family members, e.g. an aunt, as well as non-family members, e.g. professionals in the school she attended, to try and make meaning and sense of aspects of herself. This in turn can lead to a deeper understanding of oneself and yet simultaneously can bring up traumatic memories from the past that have to be re-acknowledged, made sense with in a different way, and to work with – both in an embodied&non-embodied manner.

3. How does one create further research questions (e.g. for interviews) and develop one's philosophical standpoint(s) whilst analysing 'autistic' person's autobiographies with IPA?

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- Read the books, pick out a vignette for the relevant developmental stage that fulfils the selection criteria and type it up word for word from the book, ask the phenomenological questions, create the table and whilst doing so reflect and make notes; when ideas of possible questions for interviews come to mind note these down.
- By focusing on the very lived experience(s).

APPENDIX 13

Data and Analyses: Table of Questions, Categories and Themes from the Analyses of Autobiographies

The Individual Analyses

After reading through the autobiographies of three ‘autistic’ people and dialoguing with the texts by using Interpretive Phenomenological Analysis (IPA) as a framework for analyses (as previously demonstrated), I then re-reminded myself of what the purposes of this stage are; (i) to become more sensitive to ‘autistic’ people’s ways of being and (ii) to create relevant questions for possible future interviews with ‘autistic’ adults. Therefore, I re-read over the analyses so far and asked myself “What kinds of questions arise from what these people have written and what I have transcribed and worked with thus far?” Hence the following table; the questions arising from my descriptive engagement(s) with the chapters as well as the individual tables produced in the past analyses that focus on the questions regarding the authors’ embodied and non-embodied paradoxical, dynamic and mysterious lived experiences. The categories and themes that have emerged are as follows in the table.

Author and Book	Chapters and the Arising Questions	Categories	Themes	Further Reflections or / and Questions
Chris Mitchell, 2009. Asperger’s Syndrome and Mindfulness,	1: Do you practice a particular religion? What practices or rituals do you undertake? How do these practices make you feel? Do you feel you suffer?	Spirituality /& religion(s) Rituals and practices Effects of practices Suffering	Spirituality /& religion	Why do people feel the need to reflect and write? How does their environment induce and encourage this process(es)?

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<p>Taking Refuge in the Buddha</p>	<p>What does your religion /and spiritual belief system teach/state about suffering? Do you have particular practices that address your suffering? What are these practices? How?</p> <p>Do you feel socially isolated? How does this make you feel? How do you address this or/and cope?</p> <p>2: How do you feel about yourself overall? Your level of self-esteem? Do your spiritual/&religious beliefs play a role regarding your self-esteem?</p> <p>3: If or when you are feeling low in self-esteem how do you work with this? Do you have any practices which you feel help to address your feeling this way? Do you like yourself? How? Practices? How not? What are your positive traits? What things do you enjoy?</p>	<p>Beliefs about suffering</p> <p>Rituals/& practices addressing suffering</p> <p>Social isolation Effects of social isolation Coping with isolation</p> <p>Self-love</p> <p>Self-love and spirituality/&religion</p> <p>Practices to address a low level of self-love</p> <p>Self-love Practices of self-love and non-practices</p>	<p>Isolation</p> <p>Self-love</p>	
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	<p>What are the relationships in your life like? With say family? Friends? Colleagues? Positives? Negatives? Neutral?</p> <p>4: Are there particular thoughts that proliferate in your mind? How do you address them? How do you learn with this and act?</p> <p>Are you a flexible thinker? How? Situations?</p> <p>What do you think are others' opinions of you? Family? Friends? Colleagues? How does this make you feel?</p> <p>What is your friend circle like? 'Autistic' and non-'autistic'?</p> <p>5: When were you recognized as being 'autistic'? How did you feel? How did your family feel? How did your friends feel? Teachers?</p>	<p>Relationships</p> <p>Mind</p> <p>Practices for calming the mind</p> <p>Mind</p> <p>Mind and situations</p> <p>Relationships</p> <p>Effects of relationships</p> <p>Relationships</p> <p>Neurodiversity and relationships</p> <p>Recognition of 'autism'</p> <p>Effects of recognition of 'autism'</p> <p>Effects of recognition of 'autism' and relationships</p>	<p>Relationships</p> <p>The body and senses</p> <p>Relationships</p> <p>'Autism'</p>	
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	<p>Colleagues?</p> <p>How do/did you feel in your home life? School? Workplace? Any stressors? How did/do you cope? Do your spiritual/&religious values play a role?</p> <p>6: Do you get anxious at times? What causes this? How do you cope?</p> <p>Do certain environments affect your anxiety levels? Which environments? How?</p> <p>7: Do you feel angry at times? What causes this? How do you cope with anger? Any spiritual/&religious practices?</p> <p>How do you vent your anger? Do you have any hobbies? Do you talk it through with the person(s) that contributed to your anger?</p>	<p>Relationships and different contexts</p> <p>Spirituality/&religion, relationships and contexts</p> <p>Anxiety Causes of anxiety Coping with anxiety</p> <p>Anxiety and different contexts</p> <p>Anger</p> <p>Coping with anger Spiritual/&religious practices addressing anger Coping with anger Relaxation practices Addressing anger and relationships</p>	<p>Relationships</p> <p>Emotions</p>	
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	<p>8: Is your eating habit(s) affected by anxiety? Is there another term you'd prefer to use to describe anxiety? How do you feel about money? How do you manage your money/finances?</p> <p>What kinds of food do you eat? Do your spiritual/&religious values play a role?</p> <p>9: Do you know other 'autistic' people? Any commonalities? Spiritual/&religious commonalities? How about with non-'autistic' people?</p> <p>How do you feel about also being 'autistic'? Are there any advantages/abilities that 'autistic' people or you, may have that non-'autistic' people may have difficulty with? How about in relation to spirituality /& religion? Are there any limitations or disadvantages that an 'autistic'</p>	<p>Eating and anxiety</p> <p>Constructing 'anxiety'</p> <p>Material wealth Handling material wealth</p> <p>Food preferences Spirituality/&religion(s) and food preferences</p> <p>Relationships and neurodiversity Spirituality/&religion(s) and neurodiversity</p> <p>Emotion and recognizing 'autistic' aspect(s) of self</p> <p>'Autistic' aspects of self</p> <p>'Autistic' aspects of self and spirituality /& religion</p>	<p>Finance</p> <p>Food</p> <p>Relationships</p> <p>'Autism'</p>	
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	<p>person may have that a non- 'autistic' person may not have? How about in relation to spirituality /& religion?</p> <p>Do you travel? How did you feel in that (those) culture(s)?</p> <p>10: What do you expect from yourself? Your goals? Do others influence what you expect of yourself? Do your sensory abilities influence your expectations? Goals?</p> <p>11: Has being recognized as also being 'autistic' influenced your ability to accept and not accept certain things in your life?</p> <p>Do you reflect about your life experiences? Do you write about them?</p> <p>What, if any, have your moments of suffering enabled you to learn</p>	<p>Exploration of the world</p> <p>Self-expectations and goals Self-expectations and goals and others Self-expectations and goals in relation to sensory abilities</p> <p>Recognition of being 'autistic' and self-love</p> <p>Self-reflection</p> <p>Self-reflection and writing</p> <p>Suffering and learning</p>	<p>Exploration</p> <p>Life goals</p> <p>'Autism'</p> <p>Spirituality /& religion</p>	
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	<p>about yourself? Others? The environment?</p> <p>12: Do you meditate? How does this make you feel? Do you meditate with others? How do you meditate? How often? Does also being 'autistic' influence this at all?</p> <p>13: When I say "love" what comes to mind or and body? Do you meditate with "love" in mind or and body? Do you love yourself? Do you love others? What does your religion/&spiritual beliefs state about love?</p> <p>What comes to mind or and body when I say "forgiveness"? Do you practice forgiveness? What are your spiritual/&religious beliefs about this?</p> <p>14: Do you practice living in the here and Now?</p>	<p>Self-reflection and meditation</p> <p>Love</p> <p>Meditation and love</p> <p>Self-love</p> <p>Love and spirituality/&religion</p> <p>Forgiveness</p> <p>Love and spirituality/&religion</p> <p>Living in the now</p>	<p>Love</p>	
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	How?			
From the Table of Analysis				
	<p>Paradox: If you do remember, how did you feel when you were recognized as being 'autistic'?</p> <p>Did your spiritual /& religious beliefs play a role in this process? How did your family or/and guardians behave?</p> <p>Did they hold spiritual /& religious beliefs about it?</p> <p>How did it come in to play in your home life and/or when you were out with family/a guardian?</p> <p>Do you carry out any particular spiritual /& religious practices? How about in your everyday life? What are these?</p> <p>Do spiritual /& religious practices affect the quality of your life? The quality of your relationships? The quality of communication that takes</p>	<p>Recognition of also being 'autistic'</p> <p>Recognition of 'autism' and spirituality/&religion</p> <p>Recognition of 'autism', spirituality/&religion and family</p> <p>Spiritual /& religious practices</p> <p>Spiritual /& religious practices and quality of life</p>	<p>'Autism'</p> <p>Spirituality /& religion</p>	

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	<p>place between yourself and people or/and other beings? How?</p> <p>When you say “I” what kinds of thoughts come to mind with regards to the meaning of “I”? When you say “you” what kinds of thought come in to mind with regards to the meaning of “you”? How about the meaning and/or definition of “we”?</p> <p>Dynamic(s): How do you cope with changes? Do your spiritual/&religious beliefs and/or practices play a role in this?</p> <p>What kinds of situations make you feel happy? What kinds of situations make you feel content or and neutral? Is there something you remind yourself of/and do to feel like this? What do you learn about yourself? What do you learn about your body? What do you learn about others’ /& family members?</p> <p>Do you have hypersensitivities and hyposensitivities? How do you make sense of such abilities and their</p>	<p>Identity</p> <p>Changes in life and learning</p> <p>Happiness</p> <p>Sensory abilities</p>	<p>Identity</p> <p>Learning</p> <p>Emotions</p> <p>The body and senses</p>	<p>How does the participant make meaning of the status quo elements (anxiety, mind, frustration and anger)? Is there a particular theme(s) or thread(s) that runs throughout their story(ies)? How is perception playing a role in their experiences? How are they illustrating self-knowledge and what role is this playing in their story(ies)? How might I</p>
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	<p>effects? Do you use spirituality /& religion to make sense of such abilities? What do you learn about others? What do you learn about their bodies? What do you learn about life?</p> <p>What kinds of situations make you feel anxious? How do you cope with them?</p> <p>What kinds of situations make you feel angry? What do you learn about yourself? What do you learn about your body? Hyper and hypo sensitivities? Meaning-making regarding, and/or with, such abilities? What do you learn about others? What do you learn about their bodies? What do you learn about life?</p> <p>Mystery: When were you recognised as being 'autistic'? Whilst growing up did you feel different and not know why? Do you feel that you suffered during the years that you were not as aware of this aspect of yourself? What do you think suffering is?</p>	<p>Sensory abilities and spirituality /& religion</p> <p>Anxiety Anxiety and learning</p> <p>Anger Anger and learning</p> <p>Anger, learning and sensory abilities</p> <p>Recognition of being 'autistic'</p> <p>Suffering</p>	<p>Emotions</p> <p>'Autism'</p> <p>Spirituality /& religion</p>	<p>do these things during the interview(s) and afterwards?</p>
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	<p>What do you do when you are in a confused state? How do you feel? How do you behave? Do your spiritual/&religious beliefs play a role in your decision-making? How?</p> <p>Have you been in a situation with a person whereby they apologised to you in a way that made you understand and forgive them? Do you use this kind of understanding with other people who may not have had the chance to do a similar thing or/and may be feel too embarrassed to do so?</p> <p>Have you been in a situation whereby you were interpreting things in one way and the other person was interpreting them in a different way? How did you work with this? Did your spiritual/&religious beliefs come in to play? How?</p> <p>How do you decide your goals in life? Do your spiritual/&religious beliefs influence such decisions? Do</p>	<p>Confusion Confusion and learning</p> <p>Confusion, learning and spirituality /& religion</p> <p>Learning forgiveness with others</p> <p>Projecting forgiveness</p> <p>Confusion, learning and coping</p> <p>Confusion, learning and spirituality/&religion</p> <p>Decision-making, self-expectations and goals</p>	<p>The body and senses</p> <p>Love</p> <p>The body and senses</p> <p>Life goals</p>	<p>One way of working with the mystery of life, that can cause confusion, is to practice meditation and align more so with the observing self?</p> <p>Strengthening one's alignment with the observing self so as to be better prepared with the mystery of life?</p>
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	<p>your bodily abilities play a role in such decision making? Does your family life influence such decision making? What is your main goal in life? Are there particular things you do in order to achieve such a goal?</p> <p>How do you feel about your work? Do you consider aspects to do with your bodily functioning (e.g. hyper and hypo sensitivities) when applying for jobs? How did you end up doing your line of work? Do your spiritual/&religious beliefs influence your choice of work /& the amount of work you do? How do you cope with changes in the working environment?</p> <p>You do not have to answer this question if you do not want to... how do you feel about your body? How do you feel about your hypersensitivities? How do you feel about your hyposensitivities? How about your family's understanding and/or non-understanding of these aspects of your body?</p>	<p>Decision-making, self-expectations, goals and spirituality/&religion Self-expectations, goals and family</p> <p>Work life Sensory abilities and choice of jobs</p> <p>Work and spirituality/&religion</p> <p>Work, changes and learning</p> <p>Body and self-love</p>	<p>Work life</p> <p>Self-love</p>	
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	<p>Are there aspects of yourself that you feel are present that you may not be able to put in to or express in words? Do you believe in intuition? How do you feel about it? Do you feel that you use your intuition much? How do you use it? How not? Does your family know about these factors? How do/did they respond?</p>	<p>Body and non-visible senses</p> <p>Intuition</p> <p>Family, non-visible senses and intuition</p>	<p>The body and senses</p>	
<p>Edgar Schneider, 1999. Discovering My Autism, Apologia Pro Vita Sua (With Apologies to Cardinal Newman)</p>	<p>1: Apart from 'autism', are you recognized as being any other way, e.g. Attention Deficit Disorder (ADD)? When were you recognized as being 'autistic', with ADD etc.? How did you feel? Had you felt 'different' before then and could not understand what? Did you receive any advice or support from work? Family? School? Doctors? How was your mental health as a child? Teenager? Adult?</p>	<p>Other neurological aspects of self</p> <p>Recognition of 'autism'</p> <p>Recognition of 'autism' and others</p> <p>Mental health or/and self-love</p>	<p>The body and senses</p> <p>'Autism'</p> <p>Mental health</p>	

Appendix 13. Data and Analyses: Table of Questions, Categories and Themes from the Analyses of Autobiographies

	<p>2: Did you feel people were understanding? How? Were you given any medication(s)? How did this affect you? Your life? Did you find any professionals as being helpful? For example, a doctor?</p> <p>3: Have you been mis-recognized as being schizophrenic or with any other mental health difficulty?</p> <p>4: Did you / do you research about 'autistic' people? Does this help you to understand yourself better?</p> <p>5: Have you questioned any of the labels stated to recognize an aspect of your being? Have you or and do you read any articles, books etc. that help you to understand yourself better?</p> <p>Do you make art?</p>	<p>Others' understanding</p> <p>Medication</p> <p>Experiences with professionals</p> <p>Misrecognitions of aspects of self</p> <p>Researching about other 'autistic' people</p> <p>Questioning labels</p> <p>Creativity Creativity and emotion</p>	<p>Medicine</p> <p>Professionals</p> <p>'Autism'</p> <p>Creativity</p>	
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Appendix 13. Data and Analyses: Table of Questions, Categories and Themes from the Analyses of Autobiographies

	<p>Do you think it is possible to express emotion without feeling it?</p> <p>6: Have others questioned your sanity? How did your family behave after the 'autistic', ADD traits etc. were recognized?</p> <p>How do you feel about being 'autistic'? Do you think about your children, grandchildren etc.? Do you ask the question "Why and how am I 'autistic'?"</p> <p>7: Do you think you have a difficulty in emotionally connecting with other human beings? What is your experience of emotion? What is your definition or and understanding of emotion?</p> <p>What is your biggest fear?</p>	<p>Self-belief and others Family's recognition of an aspect of one's self Self-recognition of 'autism'</p> <p>Identity formation</p> <p>Emotions and others</p> <p>Experiencing emotion Understanding of emotion</p> <p>Fear</p>	<p>Self-love</p> <p>'Autism'</p> <p>Identity</p> <p>Emotions</p>	
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Appendix 13. Data and Analyses: Table of Questions, Categories and Themes from the Analyses of Autobiographies

	<p>Do you prefer to use the term 'Asperger's' or another term to describe being 'autistic'?</p> <p>Do you feel you can register or and understand your own feelings? Others' feelings?</p> <p>When you give advice to others how do you feel? How do you feel about the quality of your advice and what may be unique about it?</p> <p>Have you ever had a person tell you that you lack emotion? How did you feel? Respond?</p> <p>8: Are there any particular artists or and poets or and musicians whose works or and lives you admire? Why?</p> <p>9: Do you enjoy music? When did you begin to enjoy it? What kind of music did you enjoy as a child?</p>	<p>'Autism' or any other preferred term(s)</p> <p>Recognizing one's emotions Recognizing others' emotions Helping others</p> <p>Emotions</p> <p>Admiration for creativity</p> <p>Enjoying creativity</p>	<p>'Autism'</p> <p>Emotions</p> <p>Altruism</p> <p>Emotions</p> <p>Creativity</p>	
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Appendix 13. Data and Analyses: Table of Questions, Categories and Themes from the Analyses of Autobiographies

	<p>Teenager? Adulthood? Do you sing? Have you sung for spiritual/&religious institutions?</p> <p>Are there any particular artists' works you enjoy looking at or and have in your home? Why?</p> <p>Do you have any favourite writers?</p> <p>What are your social values, e.g. say regarding how society ought to be governed?</p> <p>Do you read about the lives of, or and works of, saints, gurus etc.?</p> <p>10: What is your understanding / definition of "love"? Do you think there are three types? Philos, agape and eros? More / less?</p> <p>What is your understanding / definition of "relationship"?</p>	<p>Creativity and spirituality /& religion</p> <p>Admiration for creativity</p> <p>Admiration for creativity</p> <p>Social values</p> <p>Reading about explicitly spiritual /& religious people</p> <p>Understanding of love</p> <p>Understanding of relationship</p>	<p>Ethics</p> <p>Spirituality /& religion</p> <p>Love</p> <p>Relationships</p>	
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Appendix 13. Data and Analyses: Table of Questions, Categories and Themes from the Analyses of Autobiographies

	<p>What is your understanding / definition of “sexuality”?</p> <p>11: Do you feel that you have an emotional deficit? Or any other deficit? Do you feel you compensate for this in other ways?</p> <p>12: Do you have a high or low pain threshold? Example?</p> <p>13: Would you say your moral beliefs are more so based on your feelings than your intellect? Or and both? Examples from your experiences?</p> <p>14: Have you had any close family or and pets die? How did you feel? Do you feel a sense of ownership of your emotions?</p> <p>15: Do you believe in an afterlife? What do you think death is?</p>	<p>Understanding of sexuality</p> <p>Emotions</p> <p>Emotion and compensating behaviour?</p> <p>Pain threshold; hyper/hypo sensitivity?</p> <p>Moral beliefs, emotions and intellect</p> <p>Death and emotion</p> <p>Death</p>	<p>Sexuality</p> <p>Emotions</p> <p>The body and senses</p> <p>Emotions</p> <p>Death</p>	
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Appendix 13. Data and Analyses: Table of Questions, Categories and Themes from the Analyses of Autobiographies

	<p>What is your understanding of “God”? What is your understanding influenced by? Experiences or and people or and religion or and science?</p> <p>16: Do you feel lonely at times? Do you seek the warmth of another human being? Whose company do you enjoy? Why?</p> <p>17: How do you learn? As a child? Teenager? Adult?</p> <p>Do you enjoy being alone or and in solitude?</p> <p>Did you enjoy school? What was life like in school? How did you learn the materials? Do you feel you learn in ways that are not recognized by others? Or and yourself?</p>	<p>Understanding of God</p> <p>Loneliness Seeking companionship</p> <p>The company of others</p> <p>Learning styles</p> <p>Emotion and solitude</p> <p>School</p> <p>Learning in school</p>	<p>Spirituality /& religion</p> <p>Emotions Relationships</p> <p>Learning</p> <p>Isolation</p> <p>Learning</p>	
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	<p>Do you think intuition plays a role in your learning?</p> <p>Would you say you have childlike qualities? What are they? Do these influence your learning?</p> <p>18: What have you worked as? Still work as? What were jobs like? Are like? Do you prefer certain roles to others? Why?</p> <p>19: Do you think being 'autistic' has influenced your career choices?</p> <p>Would you say that a lot of people are emotionally needy?</p> <p>Do you feel insulted at times? Are your feelings easily hurt?</p> <p>Have you experienced any trauma? Do you still experience any trauma?</p> <p>Have you been picked on or and bullied by people? How did you respond?</p>	<p>Intuition and learning</p> <p>Learning and childlike qualities</p> <p>Jobs /& career(s)</p> <p>Jobs/&career(s) and being 'autistic'</p> <p>Emotions and people</p> <p>Emotion and others</p> <p>Experiencing trauma</p> <p>Others and bullying</p>	<p>Work life</p> <p>Emotions</p>	
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Appendix 13. Data and Analyses: Table of Questions, Categories and Themes from the Analyses of Autobiographies

	<p>Do your spiritual/&religious beliefs and practices play a role?</p> <p>Would you say you followed the crowd at school? Or were you a loner?</p> <p>As a child or and teenager did you prefer the company of adults?</p> <p>20: Do you, or did you, do any art or creative works? How do you go about it? How do you prepare? How do you make it? What is it about the process that you enjoy? Do you like adding detail?</p> <p>21: Do your family have spiritual/&religious values? Have you taken up any of this? Why do you believe or and do not believe or and doubt? Are you a member of a spiritual/&religious organisation? What do you enjoy about it? What do you not enjoy?</p>	<p>Others, bullying and spiritual/& religious practices School life and others</p> <p>The company of adults</p> <p>Creating art</p> <p>Spiritual /& religious belief system and family</p>	<p>Relationships</p> <p>Creativity</p> <p>Spirituality /& religion</p>	
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	<p>Do you believe that we can or cannot have a personal relationship with God?</p> <p>22: Does your religious/&spiritual organisation represent and practice your values in any way?</p> <p>23: What makes you angry? How do you cope with it? Do your spiritual /& religious values and practices play a role? How do others respond, e.g. family?</p> <p>24: How did you feel when you were recognized as being 'autistic'? How do you feel now?</p> <p>How do you feel about competition? How do you feel about confrontation?</p> <p>Do you play card games, board games etc.? What do you enjoy about them?</p>	<p>Understanding of how to be with God</p> <p>Spiritual/&religious organisation and practices</p> <p>Anger</p> <p>Anger and spirituality /& religion</p> <p>Recognizing being 'autistic'</p> <p>Competitive ways of being Confrontational ways of being</p> <p>Preferred games</p>	<p>Emotions</p> <p>'Autism'</p> <p>Culture</p> <p>Play</p>	
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	<p>25: Are you in a relationship with a partner? Do you feel your partner makes adjustments and vice versa for you both to get along? What kinds of adjustments do you both make? Do you have children? How do you feel about parenting?</p> <p>26: How do you feel about the processes / dynamics couples go through in exercising love? Your own experience(s)?</p> <p>27: Do you think you have an emotional 'deficit', as believed by some 'autistic' persons? Why? How?</p> <p>28: What are the 'autistic' traits in yourself that you feel are beneficial? How about traits that are not as beneficial? Examples?</p>	<p>Relationships with a significant other</p> <p>Experiencing a relationship with a significant other</p> <p>Relationships and children</p> <p>Understanding of relationships with a significant other</p> <p>Experiencing a relationship with a significant other</p> <p>Understanding of self and emotion</p> <p>Recognising 'autistic' aspects of self</p>	<p>Relationships</p> <p>Emotions</p> <p>'Autism'</p>	
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Appendix 13. Data and Analyses: Table of Questions, Categories and Themes from the Analyses of Autobiographies

	Do your emotions play a role in your participating in spiritual/&religious activities?	Emotions and spirituality /& religion	Emotions	
	Do you have any favourite poems or and poets? Why?	Admiration for creativity	Creativity	
	Do you feel you have strengths that you may have ignored, or not accepted as much, until now?	Recognition of aspects of self	Identity	
	29: Do you feel like an outsider? Does language play a role here?	Feeling different Feeling different and language	Emotions	
	When you recognized yourself as being 'autistic' how did you proceed thereafter? What have you learned about yourself?	The ongoing process(es) of recognizing oneself as being 'autistic'	'Autism'	
	Are you happy? What makes you happy?	Happiness	Emotions	
	Do you view yourself as being 'different'? How do you feel about this?	Feeling different		
	30: What is your biggest success?	Success	Life goals	

Appendix 13. Data and Analyses: Table of Questions, Categories and Themes from the Analyses of Autobiographies

	<p>Failure?</p> <p>31: Do you prefer to use the term 'autism spectrum' or any other term(s)? Why?</p> <p>32: Was it a surprise to also see yourself as being 'autistic'?</p> <p>33: Do you feel that being 'autistic' is helping you to help others? How?</p> <p>Are your spiritual /& religious beliefs and practices based on logical rational views? How? How not?</p>	<p>Language and preferred use of term(s) to describe 'autism'</p> <p>Recognising oneself as being 'autistic'</p> <p>Being 'autistic' and helping others</p> <p>Spiritual /& religious beliefs and practices</p>	<p>'Autism'</p> <p>Altruism</p> <p>Spirituality /& religion</p>	
From the Table of Analysis				

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	<p>Paradox:</p> <p>How did you learn at home? Did this change over time? What kinds of methods and strategies used by your family were useful? What was not as useful? How did you learn at school? Did this change over time? What kinds of methods and strategies used by your teachers were useful? What was not as useful? Was there any other place or/and kind of situation you preferred to learn in? Why? Is this still the case?</p> <p>Dynamic(s):</p> <p>What is your definition of “love”? Do you believe in the three types of love, agape, eros and philos? Do you feel you love more so in a philos kind of way?</p> <p>How do you feel about work life?</p> <p>Have you got, or had, a job you enjoy very much? What is it about this job that makes you feel good?</p>	<p>Learning and family context(s)</p> <p>Learning and school context(s)</p> <p>Other preferred learning context(s)</p> <p>Understanding of love</p> <p>Job /& Career</p>	<p>Learning</p> <p>Love</p> <p>Work life</p>	
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	<p>Mystery: When were you recognized as being 'autistic'? How did it come about? What were your thoughts at the time of that period? How did you feel? How have your thoughts changed? How have your feelings changed? Or remained the same?</p> <p>Did you read any materials that were useful for you in recognizing yourself as being 'autistic'? Or are there any particular resources you recommend? How did you come across them? What did you think when you read them? How did you feel when you read them?</p> <p>Have you had anyone tell you that you do not know how to love?</p> <p>When someone close to you died were you able to grieve? Feel sad and cry? Does art play a role in your emotion life?</p> <p>How do you feel around people who may be emotionally charged? How</p>	<p>Recognition of being 'autistic'</p> <p>Researching about being 'autistic'</p> <p>Knowing how to love</p> <p>Bereavement and death</p> <p>Emotion and others</p>	<p>'Autism'</p> <p>Love</p> <p>Death</p> <p>Emotions</p>	
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	<p>do you respond or and not respond?</p> <p>Do you think the most difficult thing to explain and talk about with people are emotions?</p> <p>Are there any particular writings or and books that made you feel like you were reading about yourself? How did you feel? Did they help in learning more about yourself? How?</p> <p>Do you think that the cornerstone of 'autism' is an emotional deficit?</p> <p>Do you think some non-verbal 'autistic' people have other means or and channels of communication?</p> <p>Do you believe that people learn intuitively, especially 'autistic' people? Or and learn to rely more so on their intuition to learn?</p>	<p>Emotions and communicating about emotions</p> <p>Researching about being 'autistic'</p> <p>Emotion and being 'autistic'</p> <p>Understanding of the forms of communication</p> <p>Learning and intuition</p>	<p>'Autism'</p> <p>Communication</p> <p>Learning</p>	
<p>Donna Williams, 1998. Autism</p>	<p>Foreward:</p>			

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<p>and Sensing, The Unlost Instinct</p>	<p>When I say “self” what comes to mind or and body? When I say “other” what comes to mind or and body? When I say “autism” what comes to mind or and body?</p> <p>Introduction:</p> <p>What are your expectations or and goals from/of yourself? Do others influence your expectations or and behaviour? Do you feel that people are true to themselves?</p> <p>1: When you come across another person how do you feel? Another being? For example an animal, plants etc.? When you walk into a room how do you feel? A room full of people?</p> <p>Do your sensory perceptions, e.g. via the eyes or ears or intuition, play a role in your everyday way of being? How?</p>	<p>The self The other ‘Autism’</p> <p>Self-expectations and goals Self-expectations, goals and others Honesty / self-love?</p> <p>Being with others</p> <p>Sensory abilities and one’s everyday way of being / one’s culture? Sensory abilities and creativity</p> <p>Energy(ies) and resonance</p>	<p>Self Other ‘Autism’</p> <p>Life goals</p> <p>Relationships</p> <p>The body and senses</p> <p>Spirituality /& religion</p>	
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	<p>Do they influence your creativity? Or when choosing art/music etc.? How?</p> <p>Do you feel that you resonate, or in other words connect, with objects or and people in the environment? How? How do you feel?</p> <p>Do you feel that you interpret things in the environment? In that your mind perceives things but you do not physically feel those things? What is it like compared to resonating with them?</p> <p>2: What is your experience of “self”? What is your understanding or definition of “self”?</p> <p>When you were a child did you have any favourite toys? How did you play with these? How did you feel? Do you still use these or do similar things?</p>	<p>Interpretation / mind and the environment</p> <p>Sensory and interpretive ways of being</p> <p>Experiencing self Understanding of self</p> <p>Toys and playing</p> <p>Toys and their purpose(s)</p>	<p>The body and senses</p> <p>Self</p> <p>Play</p>	
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	<p>When playing with toys did you feel the need to break them into smaller parts? Why did you do this? Did you know the purpose of a toy when it was given to you? How did you know? Not know?</p> <p>What is your experience of “mind”? What is your understanding or definition of “mind”?</p> <p>Do you understand things literally when you are spoken to? When you read?</p> <p>Do you “merge” with things in the environment at an energetic level? Do you meditate? How? What are your family members’ reactions? Friends? Colleagues?</p> <p>What is your experience of “will”? What is your understanding or definition of “will”?</p> <p>3: Do you think that there is a realm of selfless-self? Whereby there is</p>	<p>Experiencing mind Understanding of mind</p> <p>Literal understanding(s)</p> <p>Energy(ies) and resonance</p> <p>Meditation</p> <p>Meditation and others</p> <p>Experience of will Understanding of will</p> <p>Selfless self? Nothingness?</p> <p>Experience, energy and perception</p>	<p>The body and senses</p> <p>Spirituality /& religion</p>	
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	<p>no sense of self and other? No mind?</p> <p>Can you experience things as energy? Or and do you use another term to describe how you perceive your environment? Do you think the body is also an energy form?</p> <p>Have you had any experiences that may be considered as out of body experiences? Have you had any experiences that may be considered as telepathic communication?</p> <p>As a child, how did you experience objects when you touched them? Teenager? Adult? /Now?</p> <p>How did you experience sounds as a child? Teenager? Now?</p> <p>How did you experience light as a child? Teenager? Now?</p> <p>Do you read poetry?</p>	<p>Body and energy</p> <p>Out of body experiences</p> <p>Telepathic communication</p> <p>Experiencing objects and touching</p> <p>Experiencing sound</p> <p>Experiencing light</p> <p>Poetry and creativity</p>	<p>The body and senses</p> <p>Creativity</p>	
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	<p>Why do you like that/those poem(s)? Do you write poetry?</p> <p>4. Donna Williams states that up until the age of 4 she perceived the world more so through her senses; what were your experiences of the world like? Donna Williams states that she took everything in without putting it into context, i.e. she did not interpret so much; what were your experiences like?</p> <p>Do you have a sense of ownership of your body? Does this fluctuate according to the environment? Time? Space(s)? Anything else?</p> <p>Do you think language does or does not accurately portray how you experience the world? Do you create your own words to describe such experiences? What are they?</p> <p>Do you end up feeling things in the environment without intending to</p>	<p>Sensory way of being</p> <p>Sensory intake of environmental stimuli/information</p> <p>Proprioception</p> <p>Proprioception and change</p> <p>Language and representation(s) of experience</p> <p>Resonance or/and sensing</p>	<p>The body and senses</p> <p>The body and senses</p> <p>Language(s)</p> <p>Spirituality /& religion</p>	
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	<p>do so? How did / does this make you feel?</p> <p>Do you think we have non-visible senses? For example like 'shadow senses' or intuition(s)?</p> <p>Do you resonate or and merge with objects? How does this make you feel?</p> <p>Do you do any creative things? For example paint, write etc.? How did you get into doing this? How does it make you feel? Do you share them with others?</p> <p>Can you sense other people's energy(ies)? How do you respond?</p> <p>Do you feel that others understand your sensory ways of being? How does this make you feel?</p> <p>Are there things you learn very easily and master?</p> <p>Do you believe in intuition? What is/are your intuitive experiences like? What is your definition or</p>	<p>Non-visible senses</p> <p>Intuition</p> <p>Resonance</p> <p>Creativite works</p> <p>Creativity and self-esteem / self-love</p> <p>Resonance</p> <p>Sensory abilities and others</p> <p>Learning</p> <p>Learning and intuition</p>	<p>The body and senses</p> <p>Creativity</p> <p>Spiritual /& religion</p> <p>The body and senses</p> <p>Learning</p>	
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	<p>understanding of intuition? Do you use it? How?</p> <p>Have you ever merged energetically with a person?</p> <p>Do you rely more so on your senses than interpretation?</p> <p>5: How do you feel about the notion that we as energetic beings have willed ourselves into a human body / incarnation?</p> <p>Do you have any thoughts about will and the body?</p> <p>Do you prefer to focus on your sensory information when communicating with a person? Do make, or do not make, eye contact when communicating?</p> <p>Do you have sensory overload(s) at all? What are they? When? Where? During childhood? Teenage life? Adult life?</p>	<p>Resonance and people</p> <p>Sensory and interpretive ways of being</p> <p>Will and incarnation</p> <p>Will and the body</p> <p>Sensory abilities and communication</p> <p>Sensory perceptual styles and communication</p> <p>Sensory processing</p>	<p>Spiritual /& religion</p> <p>The body and senses</p> <p>Spirituality /& religion</p> <p>The body and senses</p>	
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	<p>How did you feel about your body as a child? At peace? Conflict? Both? As a teenager? Adult?</p> <p>6: Have there been times whereby you touched an object and felt the texture of the object whilst simultaneously losing the sense of your hand? How did you cope with this?</p> <p>If you remember, how did you process incoming information as a child? Teenager? Adult?</p> <p>Do you sometimes feel like you have been 'grabbed' by an object? Or sound? Light? Texture? Smell?</p> <p>When you resonate with an object(s) how does it feel?</p> <p>What is / are your experiences of emotion like? When you experience an emotion where in your body do you feel it?</p>	<p>Body and self-love</p> <p>Sensory processing, the body and proprioception</p> <p>Learning, sensory processing, the body and proprioception</p> <p>Involuntary resonance</p> <p>Resonance with an object</p> <p>Experiences of emotion</p> <p>Emotion and the body</p>	<p>Self-love</p> <p>The body and senses</p> <p>Spiritual /& religion</p> <p>Emotions</p>	
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	<p>For example when you feel happy? Sad? Angry? Confused? Anxious? What is your definition or and understanding of emotion?</p> <p>Do you consider your emotions to be a part of your spiritual life? If yes, how do you acknowledge this? What are your beliefs? Practices?</p> <p>When you were a child did you explore more so with your physical body, e.g. touching things, or via resonance?</p> <p>Do you get a certain type of feeling when you meet someone and have a clue of what kind of person they are likely to be?</p> <p>7: What is your definition of 'learning'?</p> <p>Do you feel that people have pseudo-selves? Including 'autistic' people?</p>	<p>Understanding of emotion</p> <p>Emotions and spirituality /& religion</p> <p>Emotions and practices</p> <p>Exploring the world and the body</p> <p>Emotion, intuition and other people</p> <p>What is learning</p> <p>Self-honesty / self-love</p>	<p>Exploration</p> <p>Emotions</p> <p>Learning</p> <p>Love</p>	
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	<p>Do you feel people ignore their sensory ways of being? For example, ignoring one's emotions? Including 'autistic' people?</p>	<p>Sensory ways of being and self-honesty</p>	<p>The body and senses</p>	
	<p>Do you trust in the knowledge of your body? Especially your sensory information? Do you think others trust in the knowledge of their body? Including 'autistic' people?</p>	<p>The body's knowing and knowledge</p>	<p>The body and senses</p>	
	<p>Do you think the soul comes first or the mind? Or both at the same time?</p>	<p>Soul and mind</p>	<p>Spirituality /& religion</p>	
	<p>Do you think emotion is the realm of unknown knowing?</p>	<p>What is emotion?</p>	<p>Emotions</p>	
	<p>8: Did you understand language as a child? Teenager? Adult? How did you learn language? What was easy? What was difficult? How can language and its use be improved? Do you relate language to your sensory experiences?</p>	<p>Understanding language Learning language Improvements for language Sensory abilities and language</p>	<p>Language(s)</p>	

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	<p>Do you like to interact with objects in the environment to find out what they are? What they do? As a child? Teenager? Adult?</p> <p>Do you think that life has its own language that speaks to us? Do you think we have complex interpretive cultural structures due to the use of language? How do you feel about this?</p> <p>9: Do you differentiate between your sensory and interpretive abilities? Do you trust one system more than the other? Examples? Have you been depressed at all? What made you feel like this?</p> <p>What kinds of moments make you feel like you can be your real self? (If this is applicable) Have you ever had depression or any other difficulties due to feeling as though you could not be yourself? (If applicable) How did / do you cope? Do your spiritual/&religious beliefs play a role?</p>	<p>Exploring the world and objects</p> <p>Will and life's language</p> <p>The complexity of language and cultural structures</p> <p>Sensory and interpretive ways of being Trusting the sensory or/and the interpretive way(s) of being Depression</p> <p>Self-honesty / self-love</p> <p>Depression</p> <p>Coping and learning with depression</p>	<p>Exploration</p> <p>Spirituality /& religion</p> <p>Language(s)</p> <p>The body and senses</p> <p>Mental health</p> <p>Self-love</p> <p>Mental health</p>	
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	<p>When you stand in front of a mirror do you feel that you see the real you? Do you feel content?</p> <p>10: What were your childhood experiences like? At home? When did you feel supported? When did you not feel supported?</p> <p>When I say “self-development” what comes to mind? How do you feel about your development? Childhood? Teenager? Adulthood so far?</p> <p>What kinds of things motivated you as a child? Teenager? Adulthood?</p> <p>11:</p>	<p>Viewing oneself and self-love</p> <p>Childhood experiences</p> <p>Self-development/self-love</p> <p>Motivation(s)</p>	<p>Self-love</p> <p>Childhood</p> <p>Self-love</p> <p>Motivation(s)</p>	
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	<p>Do you think that a concept of an experience is different to the actual experience? Example?</p> <p>Have you had any experiences whereby you could sense and feel the depth of an object and its other properties?</p> <p>Did you repeatedly play with certain objects as a child? Teenager? Adult? How did this make you feel?</p> <p>What was eating like for you as a child? Teenager? Adulthood?</p> <p>As a child did you have certain sounds or and words to describe sensory experiences? Teenage hood? Adulthood?</p> <p>12: Do you self-reflect? What do you do? How do you feel whilst doing this?</p>	<p>Experience and the concept of experience</p> <p>Experience and resonance</p> <p>Repetitive play</p> <p>Eating</p> <p>Sensory experiences, sounds and language</p> <p>Self-reflection</p>	<p>The body and senses</p> <p>Play</p> <p>Food</p> <p>The body and senses</p> <p>Spirituality /& religion</p>	
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	<p>What does self-reflection mean to you? Advantages? Disadvantages?</p> <p>Do you feel you have to balance your sensory way of being with your interpretive way of being?</p> <p>13: Do you think animals have a better sensory system than we do? In that they are more consciously aware of it?</p> <p>What is your understanding of consciousness? How do you experience it? Has this changed or and is changing over time?</p> <p>What do you think “will” is?</p> <p>Do you feel a sense of ownership of your body? Has this changed over time? Contexts?</p>	<p>Sensory and interpretive ways of being</p> <p>Animals and sensory ways of being</p> <p>Understanding of consciousness</p> <p>Understanding of ‘will’</p> <p>Proprioception</p>	<p>The body and senses</p> <p>Spirituality /& religion</p> <p>The body and senses</p>	
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	<p>What does “imagination” mean to you? What kinds of things do you imagine?</p>	<p>Imagination</p>	<p>The body and senses</p>	
	<p>What do you think “existence” is?</p>	<p>Existence</p>	<p>Spirituality /& religion</p>	
	<p>What do you think “dishonesty” is? What do you think “self-denial” is? What are your feelings about society and honesty?</p>	<p>Dishonesty Self-denial Society and honesty</p>	<p>Self-love</p>	
	<p>Do you use both sensory and interpretive styles of ways of being?</p>	<p>Sensory and interpretive ways of being</p>	<p>The body and senses</p>	
	<p>Do you sometimes feel people do not talk or and behave as they really wish to? How do you sense this? How does it make you feel? If you do believe or and use the term “soul”, what is your definition of it?</p>	<p>Self-honesty and people</p>	<p>Self-love</p>	
	<p>Do you think people understand or and misunderstand your sensory ways of being?</p>	<p>Understanding of soul</p>	<p>Spirituality /& religion</p>	
	<p>Do you think people understand or and misunderstand your sensory ways of being?</p>	<p>Sensory ways of being and others</p>	<p>The body and senses</p>	
	<p>What is your understanding or and definition of death?</p>	<p>Understanding of death</p>	<p>Death</p>	

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	<p>14: Which languages do you speak? How do you feel about it / them? Do your sensory abilities play a role in the language you use?</p> <p>What is your definition/understanding of “culture”?</p> <p>What is your definition/understanding of the term “interpretation”?</p>	<p>Use of language(s)</p> <p>Sensory ways of being and language(s)</p> <p>Understanding of culture</p> <p>Understanding of interpretation</p>	<p>Language(es)</p> <p>The body and senses</p> <p>Culture</p> <p>The body and senses</p>	
	<p>15: What does “sensory” mean to you? Your definition(s)?</p> <p>What does the term “evil” mean to you? Definition(s)?</p>	<p>Understanding of ‘sensory’</p> <p>Evil</p>	<p>The body and senses</p> <p>Spirituality /& religion</p>	
	<p>16: Do you think that the spiritual and material worlds are interconnected?</p>	<p>Spirituality and the material world</p>	<p>Spirituality /& religion</p>	

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	<p>Do you sometimes feel like you are using a different language other people?</p> <p>Do you think that people who are more sensory oriented with their perception(s) are more consciously aware of God?</p> <p>17: Do you feel vulnerable at times? What makes you feel like this?</p> <p>Did you feel “different” as a child? Teenager? Adult life?</p>	<p>Language and other people</p> <p>Sensory perception, consciousness and God</p> <p>Feelings of vulnerability</p> <p>Feeling different</p>	<p>Language(s)</p> <p>The body and senses</p> <p>Vulnerability</p> <p>Difference</p>	
From the Table of Analysis				
	<p>Paradox: What were your experiences of your body as a child like? As a young person? As a young adult? Now?</p> <p>Did you have any favourite objects? What kinds of objects did you enjoy touching? What was it about this experience that made you want to</p>	<p>Experiencing one’s body</p> <p>Experiencing objects and touching</p>	<p>The body and senses</p>	

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	<p>do so? How about objects you didn't/don't like touching? Why did you not like touching them/it? What was it about this experience that made you feel like that?</p> <p>What do you think of when I say the word "mind"? "Brain"?</p> <p>When I say the word "self" what do you think of? What is your understanding of "self"? Or/and do you prefer using other terms and words? Have you thought about the word "I"? What can this mean when you use it?</p> <p>What kinds of perceptual styles did you practice as a child? For example, did you prefer to lower your eyes and listen to people? What kinds of perceptual styles did you use as a young person? What kinds of perceptual styles did you use as a young adult? What kinds of perceptual styles do you use now? How do you think these may have affected you?</p>	<p>Mind</p> <p>Understanding of self</p> <p>Sensory perceptual styles</p>	<p>The body and senses</p> <p>Spirituality /& religion</p> <p>The body and senses</p>	
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	<p>Do you meditate? Do you use any objects whilst doing so? How do you feel whilst meditating? How do you feel after meditation? What do you learn? Do you apply any of this in your home life? Or/and daily life? How?</p> <p>Dynamic(s): What was your experience of the world as a child like? As a teenager? As an adult? [sensory wise?] How did you cope with changes? Do you think that you have a sensory way of being as well as an interpretative way of being?</p> <p>Have you had experiences whereby you felt confused by the sensory information coming into your body? Did you lose a sense of ownership of your body or and body parts at times? How do you sense? How do you sense yourself? How do you sense your surroundings? Does this change as you go from one activity to another? When did you develop a sense of being separate from</p>	<p>Meditation Meditation practices</p> <p>Experiencing the world</p> <p>Experiencing changes</p> <p>Confusion and the senses</p> <p>Proprioception</p> <p>Sensing Sensing whilst interacting</p> <p>Senses of separateness</p> <p>Sense of self and interaction</p>	<p>Spirituality /& religion</p> <p>Exploration</p> <p>The body and senses</p>	
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	<p>other people? Does your sense of 'self' change as you interact with others? Does your sense of ownership or/and non-ownership of your body change as you interact with others? How? Does your sense of ownership or/and non-ownership of your body change as you enter different environments? How? Do you prefer a sensory way of being rather than an interpretative way of being? When did you begin to interpret your surroundings, e.g. assign a word to an object in your environment?</p> <p>How did you explore your environment as an infant? As a child? Teenager? Adult? How did you feel?</p> <p>Do you think that as you got older you moved from a non-physical way of sensing to a physically based way of sensing? Do you think the earlier stage can still remain? Are your lived experiences in line with this? Why do you think that you let go of</p>	<p>Proprioception and interacting with people</p> <p>Proprioception and interacting with environment</p> <p>Identity and senses</p> <p>Identification and interpretation</p> <p>Exploring the world</p> <p>Exploring and aging</p>	<p>Exploration</p> <p>Exploration</p>	
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	<p>the earlier stage? Are you able to trust the next stage? Do you think identity has anything to do with this?</p> <p>Do you believe in a will? What is your definition of 'will'? What do you think will is? Do you think will and mind are separate? What is your understanding of 'mind'? Do you make a conscious effort to listen to the will? How?</p> <p>Do you think that your development has involved moving from the sensory to the interpretative way of being? Do you think you have or had a sensory way of mapping your environment or/and others' behaviour? Do you feel other beings' energy(ies)? Do you sense patterns and shifts? Do you think that you moved away from this way of mapping to an interpretative way of mapping that involves looking at patterns of events in the</p>	<p>Will</p> <p>Ways of being and aging</p> <p>Sensing and the environment</p> <p>Energy(ies), resonance and changes</p>	<p>Spirituality /& religion</p> <p>The body and senses</p> <p>Spiritual /& religion</p>	
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	<p>environment or/and with people so as to understand them?</p> <p>What are the things that are personally significant to you? As a child? Teenager? Adult?</p> <p>What is your definition of 'culture'? Do you think 'autistic' people have a different way of living? A different culture? Is there 'autistic' language? Do you think there is an inter-exchange of languages?</p> <p>Do you think that 'autistic' and non-'autistic' people have a shared way of relating and communicating? How? Why?</p> <p>What do you think honesty is? What do you think dishonesty is? Do you think many people behave in ways that do not reflect they ways they actually feel or/and want to be?</p> <p>Would you say that you are bilingual in terms of having a</p>	<p>Things of value and significance</p> <p>Understanding of culture</p> <p>A bridge of communication?</p> <p>Honesty Dishonesty</p> <p>Sensory and interpretive ways of being</p>	<p>Valuing things</p> <p>Culture</p> <p>Communication</p> <p>Self-love</p> <p>The body and senses</p>	
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	<p>sensory way of being and an interpretative way of being and that you use both ways of being in your life? Have you had any times whereby you could sense that a person was feeling one way and yet was acting in a different way to how they were actually feeling? How did this make you feel? How did you respond or/and not respond?</p> <p>Do you think you have multiple identities? For example, a sensory and an interpretative way of perceiving the world? Or any other terms you may want to use? Do you feel that you can move between the sensory and the interpretative ways of being? Would you refer to this as having a multi-identity? Or would you prefer to use a different term(s)? What are the positive aspects of being like this? Do you feel more comfortable as a sensory being than an interpretative being?</p> <p>Mystery:</p>	<p>Sensory and interpretive ways of being and others</p> <p>Identity(ies), the body and ways of being</p>		
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	<p>Did or/and do you dismantle objects to understand their purpose? As a child? Teenager? Adult?</p> <p>Do you find yourself naturally falling into a meditative state? Do you feel that you are merging with objects in the environment? What do you learn from this?</p> <p>Do you feel that you perceive through senses that are not visible? For example, such as intuition? Have you had any experiences whereby you decided to trust your intuition more than your mind? What is your definition of 'intuition'? What is your definition of 'will'? Can you please describe a lived experience whereby you used your intuition? Can you please describe a lived experience whereby you used your will or/and whereby will used you? What do you think the body is? How do you feel in your body? If you can describe it, what is</p>	<p>Exploring the world – objects</p> <p>Meditation</p> <p>Meditation and resonance</p> <p>Meditation, resonance and learning</p> <p>Non-visible senses</p> <p>Intuition</p> <p>Understanding of 'will'</p>	<p>Exploration</p> <p>Spirituality /& religion</p> <p>The body and senses</p> <p>Spirituality /& religion</p>	
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	<p>your lived experience(s) of your body?</p> <p>Do you sometimes know things before people have uttered a word?</p> <p>Have you sometimes acted according to a person's request despite the fact that they may not have said anything via speech or external body language? How did others respond?</p> <p>Do you think that you experience life in a deep way to the point that you are constantly pulled in to the here and now?</p> <p>Have you had any experiences that led you to make a decision about trusting your body and senses more than your mind? Do you trust your senses and your body more than you trust your mind? Have you experienced anything in particular that made you resort to making such a decision?</p>	<p>Understanding and lived experience of one's body</p> <p>Telepathy</p> <p>Telepathy and others</p> <p>Living in the now</p> <p>Senses, intuition and the mind</p>	<p>Communication</p> <p>Spirituality /& religion</p> <p>The body and senses</p>	
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	<p>What were your experiences of objects like as a child? As a teenager? As an adult?</p> <p>How did you play and engage with these objects as a child? As an adult?</p> <p>How did you remember what the objects were during your childhood? Teenage life? Adult life?</p> <p>How did you learn about the purpose of or/and function of objects? Could you feel the objects without touching them with your body parts? How do you remember objects? When you think about say a door, how is it represented in your mind?</p> <p>Have you had any experiences with a person whereby you were trying to explain something in a sensory way and they were reacting in a</p>	<p>Experiencing objects</p> <p>Playing with objects</p> <p>Memory and purpose(s) of objects</p> <p>Resonance</p> <p>Sensory and interpretive ways of being and others</p>	<p>The body and senses</p> <p>Play</p> <p>Memory(ies)</p> <p>Spirituality /& religion</p> <p>Communication</p>	
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	<p>confused or/and negative manner? How did you feel? How did you cope? How did you react or/and not react?</p> <p>Have you had any experiences whereby you felt like you had answered a person's question and yet they could not understand? How did you cope? Did you react or/and not react? How?</p>	<p>Confusion during communication</p>	<p>Communication</p>	
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The Family Context

After reading through the autobiographies of three 'autistic' people and dialoguing with the texts by using Interpretive Phenomenological Analysis (IPA) as a framework for analyses (as previously demonstrated), I then moved on to select eight vignettes in the family context over a lifespan; two vignettes of a lived experience(s) as an infant, two for childhood, two for teenagehood and two for adulthood. I focused on the embodied and non-embodied paradoxical, dynamic and mysterious elements of their ways of being. Hence the following table consisting of the questions arising from my dialogue(s) with the vignettes and the categories and themes that have emerged, as follows.

Vignette, Author, Book and Developmental Stage	Arising Questions From Vignette Table(s)	Categories	Themes	Reflective Questions and Notes
Vignette 1. Temple Grandin, 1986. Emergence: Labeled Autistic. Infancy.	<p>Paradox: To 'autistic' member: Do you have any memories from infancy? Are they vivid memories or/and not so vivid?</p> <p>To parent(s): What was your child's memory like during infancy? How did you feel about it?</p> <p>Dynamics: To 'autistic' member: What kinds of sensory experiences did you have as an infant? E.g. regarding being</p>	<p>Memories and infancy</p> <p>Family and memory</p> <p>Sensory experiences and infancy</p>	<p>Memory(ies)</p> <p>The senses and infancy</p>	

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	<p>touched, smells, objects etc.? Did you prefer to be alone? Did people think you were deaf?</p> <p>Did you draw over the walls as an infant? Did you pee or/and poo in places that your family did not want you to? How did your parents react to your behaviour? Say when being touched? When smelling things? When playing with certain objects?</p> <p>Were you frustrated or/and angry as an infant? Why? How?</p> <p>To parent(s): Did your child carry out behaviour as an infant that seemed like inappropriate behaviour? E.g. peeing on the carpet or wiping faeces over the room? How did this make you feel? How did you behave in relation to this this kind of behaviour? How do you think your child felt?</p> <p>Mystery: To 'autistic' member: When did your parent(s) seek the advice of a medical professional in relation to</p>	<p>Others' interpretation of their sensory experiences</p> <p>Creativity and communication Bodily excretion and communication</p> <p>Sensory experiences and family</p> <p>Feelings and infancy</p> <p>Family, bodily excretion and communication</p> <p>Seeking professional advice</p>	<p>The senses and others' meaning-making</p> <p>Communication and the senses</p> <p>Emotions and infancy</p> <p>Communication and the senses</p> <p>Professionals</p>	
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	<p>you? Or/and when did you seek this kind of advice? How did this come about?</p> <p>To parent(s): When did you feel the need to seek professional medical advice regarding your child? How did this come about? How did you feel during the process(es) of your child being seen? How did you feel afterwards? How do you feel now?</p>	<p>Family seeking professional advice</p>		
<p>Vignette 2. Erika Hammerschmidt, 2008. Born on the Wrong Planet. Infancy.</p>	<p>Paradox:</p> <p>To 'autistic' member: When you were an infant, did you draw things? Do you remember what they were? Did your parents encourage you to draw or/and write or/and take up other creative activities?</p> <p>To parent(s): Did your child draw or/and write or carry out any other creative activities as an infant? How did you react to this? Why?</p> <p>Dynamics:</p>	<p>Creativity and infancy</p> <p>Creativity and family</p> <p>Creativity and family</p>	<p>Creativity and family</p>	

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	<p>To 'autistic' member: How did you use the books or other creative tools you may have been given as an infant? Did you draw, write, paint etc.?</p> <p>To parent(s): How did your infant use the creative tools you got them? Did they draw /& write /& cut say the paper you gave them? What did they draw /& paint /& write /& etc.? Why do you think they did this?</p> <p>Mystery:</p> <p>To 'autistic' member: How did your parents behave in relation to your creative activities as an infant? Why do you think they reacted like that?</p> <p>To parents: What do you think your infant learned whilst undertaking drawing or/and writing etc.? What do you think you learned whilst they were doing this? How did you behave in relation to this?</p>	<p>Creativity and tools of explanation</p> <p>Creativity, tools of expression and the family</p> <p>Creativity and family</p> <p>Creativity and family</p>	<p>Communication tools</p> <p>Communication tools and family</p> <p>Creativity and family</p>	
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<p>Vignette 3. Luke Jackson, 2002. Freaks, Geeks and Asperger Syndrome. A User Guide to Adolescence. Childhood.</p>	<p>Paradox: To 'autistic' member: When you were a child, did your family want to go to certain places that you did not want to go to? For example, the beach? How was the decision made? For example, was it a case of votes for and against the type of trip or was it otherwise? How about trips to places you enjoyed going to? How was the decision made regarding these?</p> <p>To parent(s)/guardian(s): What kinds of outings or trips did you go out on with your child(ren)? E.g. the beach? How was the decision made? What kinds of things did you consider before going?</p> <p>To siblings: What kinds of outings or trips did you go out on as child(ren)? E.g. the beach? How was the decision made? How did you feel regarding your 'autistic' sibling's preferences?</p> <p>To 'autistic' member: When you got</p>	<p>Childhood and family outings</p>	<p>Family outings</p>	
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	<p>For example, a board game? Or and did they tell you to go and spend time with your siblings? What was your reaction? Did you have any younger siblings that your parent(s)/guardian(s) was attending to during the outing? What did you think of this at the time?</p> <p>To parent(s)/guardian(s): Whilst at the outing place, what did your 'autistic' child do or and not do? How did you respond? Did you try and encourage them to spend time with their sibling(s)? Did you have any other children to take care of at the time?</p> <p>Dynamics: To 'autistic' member: Whilst at the place of the outing what kinds of sensory experiences made you feel like not wanting to be there? Or and not do certain kinds of activities there? Did you go off and do something by yourself? What was this? How did you feel whilst doing this? What did you learn?</p>	<p>Activities undertaken during family outing(s)</p> <p>Family outing and parental responsibilities</p> <p>Family outing and sensory experiences</p>	<p>Family outings and the role(s) of parenting</p> <p>Family outings and the senses</p>	
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	<p>To 'autistic' member: Are there moments whereby you become engrossed in one thing or another for hours? For example, looking at patterns and shapes in things? Do you keep certain kinds of images/shapes/patterns/colours in your mind? Do they intermingle with shapes from the outer world? How does this make you feel? Do others say that you are in your own world a lot of the time? How do you respond?</p> <p>Whilst on an outing, have you ever had your family or and other people go looking for you because they thought you were lost? What were you doing at the time? When your family or and other people found you what did they say? How did you respond? How did you feel?</p> <p>Mystery: To parent(s)/guardian(s): Whilst on</p>	<p>Meditative activities and time</p> <p>Family outings and safety</p> <p>Family outings and (non-) interpretations of safety</p>	<p>Meditation and time</p> <p>Family and safety</p>	
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	<p>an outing, have you ever had to go looking for your 'autistic' child because you thought they were lost? What were you doing at the time when you realized they were gone? Who found them? When you found your child what did you say or and do? How did they respond? How did you feel?</p> <p>To sibling(s): Whilst on an outing, have you ever had to go looking for your sibling because you thought they were lost? What were you doing at the time when you realized they were gone? Who found your sibling? What did you say to them or and do? How did they respond? How did you feel?</p> <p>To 'autistic' member: What is your hearing like? What is it like trying to distinguish between foreground and background noise? Have you ever had any difficulties in doing so? Are there any experiences you have had with other people whereby it</p>	<p>Family outing, safety and (non-)interpretations of safety</p> <p>Hearing abilities</p> <p>Hearing abilities, family and others</p> <p>Hearing abilities, family and others' interpretations</p>	<p>Family and safety</p> <p>Sensory processing and family</p>	
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Appendix 13. Data and Analyses: Table of Questions, Categories and Themes from the Analyses of Autobiographies

	<p>affected what happened, e.g. people thinking that you are lost, shouting out your name and looking for you, but you did not realize this was so and only found out later? Has anyone ever told you that you were ignoring them when they were trying to get your attention by calling out your name or and asking you to do something? How did you feel when they told you this? What did you think? What did you say to them or and do? What did they say to you or and do?</p> <p>To parent(s)/guardian(s): If or when your 'autistic' child does anything you consider to be wrong, do you explicitly explain things to them and advise them on how you expect them to behave? What do you say or and do?</p>	<p>(Non-)Explicit communication in family</p>	<p>Family communication</p>	
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Appendix 13. Data and Analyses: Table of Questions, Categories and Themes from the Analyses of Autobiographies

<p>Vignette 4. Wendy Lawson, 1998. Life Behind Glass. A Personal Account of Autism Spectrum Disorder. Childhood.</p>	<p>Paradox: To 'autistic' member: How did you learn as a child? E.g by doing things? What kinds of toys did you have? Did you ride a bike? Did you use your parents' items at all? E.g. riding their bike without their knowledge? Why did you do this?</p> <p>To parent(s)/guardian(s): Did your child prefer to use any of your items at all? E.g. a bicycle? Which ones? How? Why do you think this was? How did you behave in relation to this? How did you feel?</p> <p>Dynamics: To 'autistic' member: During childhood, did you do anything that you preferred to keep to yourself and not tell your parents? E.g. going for a long ride on your bicycle without your parents knowing about this? What did you do? How did this make you feel? What did you think about it whilst doing it? Did you ever end up in hospital because of doing</p>	<p>Learning as a child Learning and play</p> <p>Family items and play</p> <p>Childhood and secrets</p>	<p>Learning, play and family</p> <p>Family and secrets</p>	
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Appendix 13. Data and Analyses: Table of Questions, Categories and Themes from the Analyses of Autobiographies

	<p>something like this? How did your parent(s)/guardian(s) respond? What did you think about it all?</p> <p>To parent(s): During childhood, did your ['autistic'] child do anything you were not aware of at the time which you then later found out about and disapproved of? E.g. going for a long bicycle ride behind a bus? How did this make you feel when you found out about it? What did you do or/and not do when you found out about it? Did your child ever end up in hospital because of doing something like this? How did you respond?</p> <p>Mystery: To 'autistic' member: As a child, did you live any moments with family whereby you did something and an item or/and toy was taken away from you by your parents?? E.g. a bike? Did you understand why this was done? Were you told why? Did you ask why? If not, what did you feel about the event(s)? What did</p>	<p>Childhood, secrets and consequences</p> <p>Family, childhood and secrets</p> <p>Family, childhood, secrets and consequences</p> <p>Childhood, the removal of certain items and safety</p>	<p>Family (non-)communication</p> <p>Family and safety</p>	
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Appendix 13. Data and Analyses: Table of Questions, Categories and Themes from the Analyses of Autobiographies

	<p>you think?</p> <p>To parent(s)/guardian(s): When your offspring was a child, did you live through any moments whereby you had to take an item away from them because you were worried about their safety? E.g. a bike? Did your child answer why you did this? Did you explain why you did this? How did they react and or not react? How did you feel about this? What did you think? Did you do anything regarding the event(s) afterwards? E.g. buy them another item/toy etc.?</p>	<p>Family, the removal of certain items and safety</p>		
<p>Vignette 5. Chris Mitchell, 2005. Glass Half Empty Glass Half Full. Teenagehood.</p>	<p>Paradox: To 'autistic' member: How was your teenage life like? Did you socialize with kids your age? How (not)? Did you parents have concerns about your social life? Did they tell you? How? Did they try to get you to spend time with other teens? How? How did this make you feel? Did you have any reservations about this? Why?</p> <p>To parents/&guardians: Did/do you</p>	<p>Teenagehood and socializing with peers</p>	<p>Socializing</p>	

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<p>Vignette 6. Donna Williams, 1992. Nobody Nowhere. The Extraordinary Autobiography of An Autistic. Teenagehood.</p>	<p>Paradox: To 'autistic' member: Did you change in any way during your teenage years? Did your parent(s)/guardian(s) say that you had changed? How? How did you feel about this? How did you respond to them?</p> <p>How did you feel about yourself during teenage life? What was your feeling like about the world? Why did you feel like this? How did you behave during this time? Did you create characters in your mind to then cope with situations with family members? How did your family members behave towards you? How did this make you feel?</p> <p>To parent(s)/guardian(s): Do you think that your ['autistic'] child changed in in any way during teenagehood? How did you feel? How did you respond to them? How did their siblings respond? How did you deal with this situation?</p>	<p>Teenagehood and changes in self</p> <p>Teenagehood and feelings about self and life</p> <p>Teenagehood and social coping strategies</p> <p>Family and changes with 'autistic' teenager</p>	<p>Changes in identity</p> <p>Identity</p> <p>Family and socializing</p> <p>Family and socializing</p>	
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Appendix 13. Data and Analyses: Table of Questions, Categories and Themes from the Analyses of Autobiographies

	<p>To sibling(s): Do you think that your ['autistic'] sibling changed in any way during teenagehood? How did this make you feel? How did you respond? How did they respond? How did your parent(s)/guardian(s) respond?</p> <p>Dynamics: To 'autistic' member: Did your family members give you a nickname at all? What was it? How did this nickname make you feel? Were there any moments whereby one of your parent(s)/guardian(s) sided with your sibling(s) and used this or/and another nickname in a way that made you feel negative? How did you respond? Did you ever argue or/and physically fight with your sibling(s) or/and parent/guardian? How did this make you feel? What did you learn or/and not learn about yourself and your family members?</p> <p>Did you ever have to state or/and</p>	<p>Family, teenagehood and siblings</p> <p>Family and nicknames</p> <p>Teenagehood and family conflict</p>	<p>Family and socializing</p> <p>Family conflict</p>	
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	<p>shout “I’m not mad(!)” to family members? What kind of events led to the occurrence of this? And after you stated/&shouted this term, how did they respond? How did this make you feel? What did you do or/and not do?</p> <p>To parent(s)/guardian(s): Did you or/and any other family members give your ‘autistic’ child a nickname at all? What was it? How did using this nickname make you feel? Were there any moments whereby you or/and another member of your family used this nickname in a negative way towards your teenager? How did they respond? Did you or/and another member of your family ever argue or/and physically fight with your ‘autistic’ teenager? How did this make you feel? What did you learn or/and not learn about yourself and your family members?</p> <p>Did you ever hear your ‘autistic’</p>	<p>Family and the use of the term “mad”</p> <p>Family and the use of a nickname for ‘autistic’ person</p> <p>Family conflict</p>	<p>Family conflict</p>	
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	<p>teenager state or/and shout “I’m not mad(!)”? What kind of events led to the occurrence of this? How did this make you feel? What did you do or/and not do?</p> <p>To sibling(s): Did you or/and any other family members give your ‘autistic’ sibling a nickname at all? What was it? How did using this nickname make you feel? Were there any moments whereby you or/and another member of your family used this nickname in a negative way towards your sibling? How did your sibling respond? Did you or/and another member of your family ever argue or/and physically fight with your ‘autistic’ sibling? How did this make you feel? What did you learn or/and not learn about yourself and your family members?</p> <p>Did you ever hear your ‘autistic’ sibling state or/and shout “I’m not mad(!)”? What kind of events led to the occurrence of this? How did this</p>	<p>Family and the use of the term “mad”</p> <p>Siblings and the use of nicknames</p>	<p>Family conflict</p>	
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	<p>else? Why did you do so? How did your 'autistic' sibling respond? How did this make you feel? What did you learn or and not learn about your sibling?</p>			
<p>Vignette 7. Edgar Schneider, 1999. Discovering My Autism, Apologia Pro Vita Sua (With Apologies to Cardinal Newman). Adulthood.</p>	<p>Paradox: To 'autistic' member: Have any members of your family died? Especially say someone such as your mother or father? How did you view this? How did you behave during that time? How did you practically deal with it? Did you feel you could grieve? Do you have any siblings? How did they view it? How did they behave? How did they deal with it? Did you find yourself comparing your reaction to the event with other family members' reactions? Was there anything in particular that struck you?</p> <p>Dynamics: To 'autistic' member: Have you had any members of family pass away? Die? How was this experience for</p>	<p>Adulthood, family and experiences regarding death</p>	<p>The body senses and family bereavement</p>	

Appendix 13. Data and Analyses: Table of Questions, Categories and Themes from the Analyses of Autobiographies

	<p>you? Do you have siblings? How did they respond to this event? At the time, did you compare your reaction with theirs? What was this like?</p> <p>To sibling(s): How did you respond to your family member passing away? How did your 'autistic' family member respond? At the time, did you find yourself comparing your reaction to theirs? What was this like?</p> <p>Mystery:</p> <p>To 'autistic' member: Did the passing away of this family member lead to a new kind of self-awareness? How did you practically deal with this self-awareness?</p> <p>Have you had any close friends pass away? How was this experience for you? How did you cope with it?</p> <p>Did or/and do you have any animals</p>	<p>Family, death and self-awareness</p> <p>Death and coping strategies</p>	<p>Family bereavement and self-awareness</p> <p>Family bereavement</p>	
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	<p>in your family? As part of your family? Have you ever compared yourself to an animal or animals? What kinds of situations led to you to do this? How did you compare yourself to it or and them? How did this feel for you? Did you become more aware of any particular thing(s) regarding yourself?</p>	<p>Family, including animal members, and self-awareness</p>		
<p>Vignette 8. Donna Williams, 1992. Nobody Nowhere. The Extraordinary Autobiography of An Autistic. Adulthood.</p>	<p>Paradox: To 'autistic' member: How did you come to know you are 'autistic'? Who told you? What did you do or/and not do when you found out? Did you speak about it with family members? Did you ask them questions about your life in your younger years? What did you ask? Did you reflect over your life? Did some things that were a mystery to you become understandable? What were they? What kinds of memories arose? Do your memories include your physical interactions with family members or/and objects? Infancy memories? Childhood</p>	<p>Adulthood and recognizing an aspect of self Recognition of 'autism' and self-reflection</p>	<p>Self-recognition of being 'autistic'</p>	

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	<p>them?</p> <p>Did you seek out any of your old items after having realized an aspect of yourself? E.g. that you might be or are 'autistic'? How did the item(s) make you feel?</p> <p>Are there any personas that you have created in your mind to deal with social contexts, e.g. with family or friends? Do these personas have names? What are they? Why did you choose these names? Which particular contexts or/and with whom do you use these personas? How does this make you feel?</p> <p>When feeling emotionally charged up do you rock or/and do any other particular activity to calm down? Do you rock or/and do any other particular activity when thinking through things deeply? What kinds of things have made you do this in the past? How about what kinds of things that family may have said or done that make you feel like say rocking?</p>	<p>Objects and self-reflection</p> <p>Personas and social contexts</p> <p>Emotion(s) and the body</p> <p>Family, emotion(s) and the body</p>	<p>Objects in family setting</p> <p>Personas</p> <p>Emotions and coping strategies</p> <p>Emotions and family</p>	
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	<p>Mystery:</p> <p>To 'autistic' member: When were you recognized as being 'autistic'? Or/and when did you first think that you may be 'autistic'? How did you practically deal with this? Did you talk with family about it? What was it like? Did you ask your doctor for your medical history and talk it over with them? What was it like? Did you go back to your old schools and talk to members of staff? What was it like?</p> <p>Is there anything in particular that made you physically or/and emotionally react to what they shared with you? What did they say? What happened to you at that moment or/and later?</p> <p>Do you have any relatives who were positive towards you? How did they treat you that made you feel like</p>	<p>Recognition of 'autism'</p> <p>Re-visiting and reflection(s) people, environments and aspects of self</p> <p>Family and positive experiences</p> <p>Family and childhood reflections</p>	<p>Self-recognition of being 'autistic'</p> <p>Memory(ies) and family</p>	
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	<p>this?</p> <p>Is there a particular family member or members who shared information with you about your childhood? How did this feel? What did it make you think about? Did you have any involuntary physical or/and emotional reactions to what they shared with you? How did you deal with this?</p>			
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A List of the Themes from the *Table of Questions, Categories and Themes*

After having completed creating the themes within the table above, I returned to the column of ‘Themes’ and collated them together as follows.

Themes: Individual Analyses

Some of the themes are common, e.g. ‘Autism’ and ‘The body and senses’, and some others are not, e.g. ‘Altruism’ and ‘Sexuality’. This way, both the common and idiographic factors are included. Please do keep in mind that these themes emerged due to the

Appendix 13. Data and Analyses: Table of Questions, Categories and Themes from the Analyses of Autobiographies

aim of this study. If this study had a different aim then the themes are likely to have been different. They are as follows in alphabetical order and the numbers in brackets next to the themes indicate how often they came up or / and not.

Altruism (2)

'Autism' (16)

Childhood (1)

Communication (5)

Creativity (6)

Culture (3)

Death (3)

Difference (1)

Emotions (21)

Ethics (1)

Exploration (7)

Finance (1)

Food (2)

Identity (3)

Isolation (2)

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Language(s) (4)

Learning (7)

Life goals (4)

Love (6)

Medicine (1)

Memory(ies) (1)

Mental health (3)

Motivation(s) (1)

Other (1)

Play (4)

Professionals (1)

Relationships (9)

Self (2)

Self-love (10)

Sexuality (1)

Spirituality /& religion (26)

The body and senses (41)

Valuing things (1)

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Vulnerability (1)

Work life (3)

Themes: Family Analyses

These themes are from the vignettes, which are short excerpts from the autobiographies, hence many of the themes occur only once. They are as follows in the life-span order.

Vignette 1: Infancy (Temple Grandin, 1986):

Communication and the senses (2)

Emotions and infancy (1)

Memory(ies) (1)

Professionals (1)

The senses and infancy (1)

The senses and others' meaning-making (1)

Vignette 2: Infancy (Erika Hammerschmidt, 2008)

Communication tools (1)

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Communication tools and family (1)

Creativity and family (1)

Vignette 3: Childhood (Luke Jackson, 2002)

Family communication (1)

Family outings (1)

Family outings and the senses (3)

Family outings and the role(s) of parenting (1)

Family and safety (2)

Meditation and time (1)

Sensory processing and family (1)

Vignette 4: Childhood (Wendy Lawson, 1998)

Family and secrets (1)

Family (non-)communication (1)

Family and safety (1)

Learning, play and family (1)

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Vignette 5: Teenagehood (Chris Mitchell, 2005)

Family and socializing (3)

School life and socializing (1)

Socializing (1)

Vignette 6: Teenagehood (Donna Williams, 1992)

Changes in identity (1)

Identity (1)

Family conflict (4)

Family and socializing (3)

Vignette 7: Adulthood (Edgar Schneider, 1999)

Family bereavement (1)

Family bereavement and self-awareness (1)

The body senses and family bereavement (1)

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Vignette 8: Adulthood (Donna Williams, 1992)

Emotions and coping strategies (1)

Emotions and family (1)

Family conflict (1)

Family memories and self-recognition of being 'autistic' (1)

Family and trauma (1)

Memory(ies) and family (1)

Objects in family setting (1)

Personas (1)

Self-recognition of being 'autistic' (2)

Suffering (1)

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APPENDIX 14

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Appendix 15. Email Correspondences Regarding Interpretative
Phenomenological Analysis

APPENDIX 15

Email Correspondences Regarding Interpretative Phenomenological Analysis

From: Marie-Anne James [Email address]
Sent: 23 October 2014 14:58
To: Hayrunisa Pelge [Email address]
Subject: Introduction to IPA Workshop Receipt

Dear Hayrunisa

Introduction to IPA Workshop
Saturday 25th and Sunday 26th October 2014
Derbyshire House, St Chad Street, London. WC1H 8AG
T:0203 5880200

On behalf of the organising committee, I am delighted to confirm your registration at the above event.

Please find attached confirmation of your registration fees. A map is attached and the address is: **Derbyshire House, St Chad Street, London. WC1H 8AG**

The closest station is Kings Cross and will take just 1 minute to walk

Outline for the two days

Day One

9am Registration

9.30-11.15 Introduction to the day and situating IPA and its theoretical underpinnings

11.15-11.30 Break

11.30-1.00 Situating IPA and its theoretical underpinnings

1.00-1.45 Lunch (not provided)

1.45-2.15 IPA study design: developing an IPA research question and data collection methods

2.15-3.15 IPA study design: constructing a suitable interview schedule and interviewing guidance

3.15-3.30 Break

3.30-4.30 Interviewing practical exercises

4.30-5pm Questions, plenary and close

Day Two

10.00-11.15 Data analysis in IPA including exploratory coding and emergent theme practical exercise

11.15-11.30 Break

11.30-1.00 Data analysis in IPA

1.00-1.45 Lunch (not provided)

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1.45-2.45 Developing your analysis and writing up your IPA

2.45-3.30 Comparison of IPA to other qualitative methods

3.30-3.45 Break

3.45-4.30 Quality in IPA

4.30 - 5.00 Plenary and close

Accommodation

There are 13 recommended places to stay within a 15 minutes walk from ST CHADS STREET:

[Great Northern Hotel](#) (3 minutes)

[St. Pancras Renaissance London Hotel](#) (4 minutes)

[Pullman London St Pancras](#) (6 minutes)

[Studios2Let Apartments Cartwright Gardens](#) (7 minutes)

[Holiday Inn London Kings Cross - Bloomsbury](#) (8 minutes)

[Ambassadors Bloomsbury Hotel](#) (8 minutes)

[Holiday Inn London Bloomsbury](#) (9 minutes)

[Hilton London Euston Hotel](#) (9 minutes)

[Hotel Russell London](#) (10 minutes)

[ibis London Euston St Pancras](#) (12 minutes)

[Mercure London Bloomsbury](#) (12 minutes)

[Bloomsbury Park Hotel London](#) (12 minutes)

[DoubleTree by Hilton London - West End](#) (13 minutes)

Please note we are not making recommendations on the quality and facilities of the hotels listed.

WiFi

Wifi is available throughout the venue and you will find the internet code on the back of the meeting room door.

If I can be of further assistance, please do not hesitate to contact me at londonipatraining@eyas.co.uk or call the conference team on 01243 775561.

[Further useful information is available on the London IPA Training website www.londonipatraining.co.uk](http://www.londonipatraining.co.uk)

Kind regards

Marie-Anne

Marie-Anne James

Managing Director

Eyas Limited

Conference & Event Management

[Telephone number]

[Email address]

[Website address]

Appendix 15. Email Correspondences Regarding Interpretative Phenomenological Analysis

From: Hayrunisa Pelge

Sent: 25 June 2014 10:40

To: Michael Larkin

Subject: RE: Request: IPA and Autobiographies?

Hi Michael,

Thank you.

Had tried the group and there was one paper in particular with regards to IPA and poetry that was useful, hence, I thought I'd also try yourself and Jonathan personally. Have found some more useful articles since I e-mailed yourselves.

Take care,

Hayrunisa

Hayrunisa Pelge

MPhil/PhD Education Researcher

University of Birmingham

School of Education

Edgbaston

Birmingham

England

B15 2TT

[Email address]

From: Michael Larkin

Sent: 24 June 2014 23:29

To: Hayrunisa Pelge

Subject: RE: Request: IPA and Autobiographies?

Hi

I don't, but why not try the Yahoo Group?

Michael

From: Hayrunisa Pelge

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Sent: 23 June 2014 15:59

To: Michael Larkin

Subject: Request: IPA and Autobiographies?

Dear Michael,

Hope you are well.

I am wondering if you know of any research and/or guiding texts that specifically utilize IPA with autobiographies... ?

Hope you can help...

Take care,

Hayrunisa

Hayrunisa Pelge

MPhil/PhD Education Researcher

University of Birmingham

School of Education

Edgbaston

Birmingham

England

B15 2TT

[Email address]

From: Jonathan A Smith [Email address]

Sent: 26 June 2014 13:28

To: Hayrunisa Pelge

Subject: RE: Request: Paper(s)

Ok good

jonathan

-----Original Message-----

From: Hayrunisa Pelge [Email address]

Sent: 24 June 2014 14:12

To: Jonathan A Smith

Subject: RE: Request: Paper(s)

Dear Jonathan,

Thank you for the advice and I shall make more of your point when it

Appendix 15. Email Correspondences Regarding Interpretative Phenomenological Analysis

comes to the Discussion section.

I read a paper of yours with regards to using IPA and autobiographical poetry (Spiers and Smith, 2012) and have found it very useful, thank you for that.

Take care,

Hayrunisa

Hayrunisa Pelge

MPhil/PhD Education Researcher

University of Birmingham

School of Education

Edgbaston

Birmingham

England

B15 2TT

[Email address]

From: Jonathan A Smith [Email address]

Sent: 23 June 2014 20:46

To: Hayrunisa Pelge

Subject: RE: Request: Paper(s)

Dear Hayrunisa

I don't, I'm afraid. It's an interesting thing to think of doing. Of course you need to take into account that an autobiography is at least, in part, a self-conscious production with an audience in mind- but I think it should be possible to incorporate that as part of the analysis.

Best wishes

Jonathan

-----Original Message-----

From: Hayrunisa Pelge [Email address]

Sent: 23 June 2014 16:07

To: Jonathan A Smith

Subject: Request: Paper(s)

Appendix 15. Email Correspondences Regarding Interpretative Phenomenological Analysis

Dear Jonathan,

Hope you are well.

I am wondering if you have any research and/or guiding texts that specifically utilize IPA with autobiographies... ?

Hope you can help...

Take care,

Hayrunisa

Hayrunisa Pelge

MPhil/PhD Education Researcher

University of Birmingham

School of Education

Edgbaston

Birmingham

England

B15 2TT

[Email address]

----- Forwarded message -----

From: **James Huff** [Email address]

Date: Sat, Mar 1, 2014 at 7:05 PM

Subject: Re: [IPANALYSIS] IPA and Autobiographical Texts?

To: IPANALYSIS@yahoogroups.com

Hello Hayrunisa -

Regarding your first questions, you might find the following article from Johanna Spiers and Jonathan Smith to be helpful:

Spiers J & Smith, JA (2012) Using autobiographical poetry as data to investigate the experience of living with end-stage renal disease: An interpretative phenomenological analysis. *Creative Approaches to Research*, 5 (2), 119-140.

Cheers,

James Huff

Appendix 15. Email Correspondences Regarding Interpretative Phenomenological Analysis

Ph.D. Candidate
School of Engineering Education
Purdue University
Instructor Harding University
Dept of Engineering and Physics

On Sat, Mar 1, 2014 at 8:29 AM, Hayrunisa Pelge [Email address] wrote:

Dear all,

Hope you are well.

I am wondering if you know of:

1. Any guidelines /& books /& articles /& research regarding using IPA with autobiographical texts..?
2. Any researchers who have used IPA with 'autistic' persons' autobiographies?

Hope you can help...

Take care,

Hayrunisa
Hayrunisa Pelge
MPhil./PhD Education Researcher
University of Birmingham
Shool of Education
Edgbaston
Birmingham
B15 2TT
[Email address]

From: Hayrunisa Pelge

Sent: 10 April 2013 15:17

To: Michael Larkin

Subject: RE: Question: IPA Workshop?

Dear Michael,

That's great! The 17th of May is indeed a Friday, and yes, I'd be very happy to attend it, thank you.

Best wishes,

Hayrunisa

Hayrunisa Pelge

Appendix 15. Email Correspondences Regarding Interpretative Phenomenological Analysis

MPhil/PhD Education Researcher

University of Birmingham

School of Education

Edgbaston

Birmingham

England

B15 2TT

[E-mail address]

From: Michael Larkin

Sent: 09 April 2013 22:05

To: Hayrunisa Pelge

Subject: RE: Question: IPA Workshop?

Hi

I'm running an internal event at Birmingham in May - I don't have my diary in front of me, but I think it's the 17th [if that's a Friday, that'll be it]. I can fit one more in, if you'd like to attend - best wishes -

Michael

From: Hayrunisa Pelge

Sent: 09 April 2013 12:52

To: Michael Larkin

Subject: Question: IPA Workshop?

Dear Dr. Larkin,

Hope you are well.

I am looking in to possibly using IPA for and with my research and have come across a workshop that you'll be carrying out in Manchester. I've registered for the event and am wondering if you are &/ will be holding such a session(s) at our university?

Best wishes,

Hayrunisa

Hayrunisa Pelge

MPhil/PhD Education Researcher

University of Birmingham

Appendix 15. Email Correspondences Regarding Interpretative Phenomenological Analysis

School of Education

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