

**A NARRATIVE EXPLORATION OF SENSE-MAKING, SELF, AND IDENTITY IN  
YOUNG PEOPLE DIAGNOSED WITH AN AUTISM SPECTRUM CONDITION**

**by**

**H SAMRA**

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University of Birmingham**

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## **ABSTRACT**

Autism Spectrum Conditions (ASCs) are part of the life course of some individuals and as such there are significant implications in relation to matters of identity and the need to ensure educational and professional practices are considered from an ethical perspective as related to self and identity.

However, despite the wide ranging literature in the area of autism, there is very little research that examines identity in relation to young people with ASCs. Furthermore, where identity is noted as an important consideration, the concept is often inadequately theorised and explained with reference to psychological frameworks of identity.

This study draws on narrative psychology and the concept of narrative identity (McAdams, 2011) to explore what insider perspectives, gained through life story accounts of lived experience, can tell us about processes related to sense-making, self and identity in young people with a diagnosis of a ASC.

The findings revealed that the participants were actively engaged in sense-making of their experiences and in the production of narrative identities. A rich and complex picture of identities emerged that went beyond the label of autism. The narrative accounts demonstrated the heterogeneity amongst participants and the need for understandings at the individual level in order to promote a person-centred approach to practice, education, interventions and ethics.

## **DEDICATION**

To my mother and father.

## **ACKNOWLEDGEMENTS**

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## TABLE OF CONTENTS

|   | PAGE |
|---|------|
| <b>CHAPTER I: INTRODUCTION</b>                    |      |
| 1.1 Background to the Research                    | 1    |
| 1.2 Justification for the Research                | 2    |
| 1.3 Research Aims and Questions                   | 5    |
| 1.4 Structure of the Thesis: Overview of Chapters | 6    |
| 1.5 A Note on Terminology                         | 7    |
| <b>CHAPTER II: LITERATURE REVIEW</b>              |      |
| 2.1 Introduction                                  | 8    |
| 2.2 The Voice of The Child                        | 10   |
| 2.3 Autism and Identity                           | 15   |
| 2.3.1 Selves as Experts                           | 16   |
| 2.3.2 Neurodiversity                              | 17   |
| 2.3.3 School Experiences                          | 24   |
| 2.3.4 Diagnosis and Identity                      | 25   |
| 2.3.5 Identity in Relation to Autism              | 38   |
| 2.3.6 Summary                                     | 47   |
| 2.4 Self, Self-Concept and Identity               | 48   |

|       |   |    |
|-------|---|----|
| 2.5   | Narrative Identity  | 57 |
| 2.6   | Autobiography   | 63 |
| 2.7   | Autism: Self, Identity, narrative and Autobiography               | 67 |
| 2.8   | Other Frameworks of Identity                                      | 69 |
| 2.8.1 | Social Identity Theory and Self-Categorisation<br>Theory Approach | 70 |
| 2.8.2 | Symbolic Interactionism   | 72 |
| 2.8.3 | Positioning Theory  | 78 |
| 2.8.4 | Identity Statuses   | 80 |
| 2.9   | Summary and Conclusion  | 82 |

## **CHAPTER III: RESEARCH DESIGN: PHILOSOPHY, STRATEGY AND METHODS**

|       |   |    |
|-------|---|----|
| 3.1   | Introduction  | 84 |
| 3.2   | Design Philosophy: Ontological and Epistemological<br>Assumptions | 85 |
| 3.2.1 | Positivism  | 88 |
| 3.2.2 | The Interpretative Approach                                       | 89 |
| 3.2.3 | Summary   | 92 |
| 3.3   | Design Strategy: Narrative Research                               | 93 |
| 3.3.1 | Theoretical Context   | 93 |
| 3.3.2 | Rationale for a Narrative Methodology                             | 95 |
| 3.3.3 | Focus of Analysis   | 97 |
| 3.3.4 | Case Study  | 98 |
| 3.3.5 | Trustworthiness   | 99 |

|       |  |     |
|-------|--|-----|
| 3.3.6 | Summary  | 103 |
| 3.4   | Design Methods: Ethical Considerations, Participants,<br>Data Collection, and Data Analysis. | 103 |
| 3.4.1 | Ethical Considerations   | 104 |
| 3.4.2 | Recruitment of Participants  | 107 |
| 3.4.3 | Data Collection  | 109 |
| 3.4.4 | Data Analysis  | 111 |

## **CHAPTER IV: ANALYSIS AND INTERPRETATIONS**

|     |                 |     |
|-----|-----------------|-----|
| 4.1 | Introduction    | 124 |
| 4.2 | Freddy's Story  | 125 |
| 4.3 | Racheal's Story | 139 |
| 4.4 | Andrew's Story  | 157 |
| 4.5 | James' Story    | 167 |
| 4.6 | Dean's Story    | 179 |
| 4.7 | Patrick's Story | 188 |

## **CHAPTER V: DISCUSSION AND CONCLUSIONS**

|     |  |     |
|-----|--|-----|
| 5.1 | Introduction   | 207 |
| 5.2 | The Voice of the Child and Selves as Experts                 | 208 |
| 5.3 | Neurodiversity   | 210 |
| 5.4 | Being Normal, Fitting In, Hiding It, Passing, and Disclosing | 212 |



|                       |  |     |
|-----------------------|--|-----|
| 5.5                   | School Experiences   | 217 |
| 5.6                   | Diagnosis  | 219 |
| 5.7                   | Agency   | 222 |
| 5.8                   | Implications for Practice  | 224 |
| 5.9                   | Limitations and Future Research  | 229 |
| 5.10                  | Conclusion   | 231 |
| <b>REFERENCES</b>     |  | 234 |
| <br><b>APPENDICES</b> |  |     |
| Appendix 1:           | Example Information for Parents and Participants   | 249 |
| Appendix 2:           | Consent Forms  | 255 |
| Appendix 3:           | Life-Story Grid and Prompts  | 257 |
| Appendix 4:           | Working Transcript for Participant One (Freddy)<br>showing Episodes, Sjuzet, Narrative Themes, and<br>Identity Constructs. | 259 |

## LIST OF FIGURES AND TABLES

|          |   | PAGE |
|----------|---|------|
| Figure 1 | A Representation of Key Concepts Relating to Self and Identity  | 55   |
| Figure 2 | Summary of Assumptions about the Nature of Social Science along a Subjective-Objective Dimension                          | 87   |
| Table 1  | Measures Noted in the Application for Ethical Review that would be taken to Mitigate Potential of Psychological Distress. | 107  |
| Table 2  | Example Section of Original Transcript  | 115  |
| Table 3  | Example Section of Working Transcript Corresponding to the Section of Original Transcript in Table 2                      | 116  |
| Table 4  | Collated Narrative Themes and Identity Constructs for the Working Transcript of the Interview with Participant 1.         | 122  |

## CHAPTER I

### INTRODUCTION

“My friend has something *wrong* with him too. He knows there is something *wrong* with me. We both know that there is something wrong with us because we both get support...but we don’t talk about it.”

(A comment made to me by a boy in Year 8 who was discussing his diagnosis of Asperger syndrome).

“It’s because of the way I am.”

(A comment made to me by a boy in Year 7 diagnosed with Asperger syndrome about why he thought he was being bullied.)

#### 1.1 Background to the Research

The above quotations are examples from several conversations I have had with individuals diagnosed as having an Autism Spectrum Condition (ASC) during my practice as an educational psychologist. The comments evoked a sense of unease in me and made me reflect on what meaning such statements may have held for the individual speakers. It struck me that the comments communicated something fundamental about what sense the individuals made of themselves and their experiences and were indicative of a psychology related to self and identity.

Further reflections led me to ask how individual sense-making, self-other interactions, and the wider social contexts such as school, society and culture may influence the development of self and identity. Thus, the context was set for the current investigation into sense-making related to self and identity focussed on the experiences of young people (YP) diagnosed with an ASC.

## **1.2 Justification for the Research**

The current thesis is situated within the wider context of a policy agenda to include the voice of children in matters pertaining to them (UNICEF, 2009; Gilling 2012). The importance of ascertaining the views of YP and also involving them in decisions and processes affecting them has been given further emphasis in more recent policy documents, such as the Special Educational Needs Code of Practice (DfE, 2015), which stress the need for person-centred approaches when working with YP.

In addition, some researchers argue that as ASCs are a part of the life course of individuals there are significant implications in relation to matters of identity, and as such, there is a need to ensure educational and medical interventions are considered from an ethical perspective pertaining to identity (e.g. Perry, 2012; Armstrong, 2010). Perry (2012) highlights the need explicitly to consider the impact of professional practices relating to matters of consent and intervention with regard to the identity of YP diagnosed with ASCs. Perry's paper is, 'positional,' in that it sets out an ethical and theoretical imperative to engage with

the narratives of individuals diagnosed with ASCs. Billington (2006a) also stresses the need for professionals to engage with, 'narratives of autistic experience,' (Billington, 2006a, pg 1) as a means of improving professional understandings and outcomes for individuals.

However, an initial review of the literature indicated that there is a paucity of research specifically looking at identity as related to ASCs. Where research does exist that cites identity as a key issue, the concept is often inadequately theorised and explicated. The experiences of individuals diagnosed with ASCs are often described as self-evidently related to or influencing their identity. These observations are often made without explicit explanation of identity as a construct and how it is conceptualised. For example, little consideration is given to psychological frameworks of identity, how individual experiences affect identity, how it may come into being, or how it may change or develop over time.

A few exceptions were identified that explored identity with reference to specific theoretical models. McLeod et al. (2013) draw on social identity theory to frame their research considering the views of YP in relation to diagnosis. Baines (2012) utilises the concept of positioning theory (Harre & Moghaddam, 2003) to explore how two students in an American high school construct identities through social interactions. Positioning theory links to discursive models of identity construction (Bamberg et al., 2011; Harre et al., 2009). Rocque (2010) draws on Mead's theory of symbolic interactionism (Mead, 1934), which emphasises self-other relations as a means of explaining self-hood and identity. However, Rocque's

work is not undertaken with individuals diagnosed with ASCs, but it examines how mothers mediate the identities of their children diagnosed with autism.

Molloy and Vasil (2004) and Gilling (2012) adopt a narrative framework in exploring identity in relation to Asperger syndrome and autism. Molly and Vasil focus on elicited life stories to examine how YP make sense of, and situate themselves in relation to, Asperger syndrome. Gilling (2012) takes an alternative stance drawing on narrative therapy. Her work uses the narrative accounts of a young boy aged 10 to demonstrate how narrative can provide a deeper understanding of a, 'preferred identity,' beyond the label of autism. Billington's paper (2006a) on working with autistic children and YP is clearly embedded in a narrative psychology framework and pertains to matters of identity.

A review of these papers led me to consider the different conceptualisations of identity and how these could be adopted in researching the lived experiences of YP with ASCs. Consideration of the wide ranging identity literature highlighted the potential utility of the theory of, 'narrative identity,' (McAdams, 2011), which unequivocally theorises identity in narrative terms. The approach draws on Erikson's formulations of identity formation (Erikson, 1958) and the concept of life stories or autobiography as a means of sense-making in relation to the self (Bruner, 1986, 1990).

The limited research focussed on identity in YP with ASCs, the lack of explicit reference to psychological models of identity and the continuing need to engage

with the voice of YP with ASCs led to the development of research aims and questions in order to explore identity and sense-making in YP diagnosed with ASCs. These are set out below.

### **1.3 Research Aims and Questions**

The research aims and questions were formulated following a literature review and consideration of the construct of identity in narrative terms. The research aims and questions were focussed on illuminating an, 'insider perspective,' adding to the literature on the voice of YP with ASCs and providing an insight into the experience of individuals and their identities, which may have implications for ethics and professional practice:

**Aim:** Explore sense-making as related to the experiences of YP with a diagnosis in relation to the development of their identity.

**Aim:** Privilege insider knowledge by giving voice to individuals' experiences, expose practices that may be oppressive and advocate change that may help overcome these.

**Research Question:** What do YP diagnosed with ASCs say about their lives?

**Research Question:** What do the stories that YP diagnosed with ASCs tell us about their identities?

## **1.4 Structure of the Thesis: Overview of Chapters**

In Chapter II I present a review of the literature where the focus is on research that considers identity in autism. The review highlights key areas of debate relating to, for example: the voice of the child; neurodiversity; school experiences; diagnosis; and identity. In addition to reviewing literature relating to autism and identity, I discuss the conceptualisation of identity and the construct of the self and consider the theory of narrative identity (McAdams, 2011). The concept of life-story constructs; themes that occur in the narrative accounts of individuals, is also presented. The process of sense-making is also considered in relation to narrative identity along with the related area of autobiography. The final section of Chapter II considers further theories of identity and self, including social identity theory, symbolic interactionism, positioning theory and the identity statuses paradigm.

In Chapter III I present the ontological and epistemological arguments for situating the research within an interpretative framework. The rationale for the use of a narrative approach to the study and the collection of life stories for analysis is outlined along with particulars relating to study design and methods. The concepts of, 'fabula,' and, 'sjuzet,' are introduced and explained as part of the analytical process. Briefly, the fabula relates to the content of a narrative whereas the sjuzet, as operationalised in the current research, relates to the meaning-making aspects of the narrative.



Analysis and interpretation of the life narratives of the six participants who took part in the study is presented in Chapter IV. Analysis is undertaken within each case rather than across cases in order to retain the coherence of each participant's individual story. In the final chapter I discuss the findings in light of previous research and elucidate them with explicit reference to identity frameworks. Implications for professional practice, the limitations of the study, and suggestions for future research are also presented.

### **1.5. A Note on Terminology**

Kennedy et al. (2015) conducted research into the terms used to talk about autism in the UK. They note that there is a plethora of terms used when talking about ASCs and note in the region of 11 different terms that are employed to describe ASCs. Their research concludes that there is no one accepted term that is universally accepted or preferred. As such, I took the decision to employ a number of terms throughout the thesis to refer to the range of ASCs, being mindful of the terms used by other researchers when discussing their work, in addition to being sensitive to the terms used by the participants who took part in the study.

## **CHAPTER II**

### **LITERATURE REVIEW**

#### **2.1 Introduction**

This chapter presents a review of the literature in relation to the research aims identified in Section 1.3 of the previous chapter.

The review undertaken covers a number of areas relevant to the overall research.

These being:

- The Voice of the Child
- Autism and Identity
- Self, Self-Concept, and Identity
- Narrative Identity
- Autobiography
- Autism and Atypical Development of Self, Identity, Autobiography and Narrative
- Other Frameworks of Identity

Section 2.2 begins with situating the research in the wider context of the debate relating to the voice of the child. Ontological and epistemological considerations

in understanding individuals' experiences from an 'insider perspective' are noted. In Section 2.3 a review of studies looking at autism and identity is presented. An initial scoping of the literature indicated that many researchers relate the individual's experiences, and the meanings given to these, closely to the concept of identity. The published literature on autism is vast in scope and as such, the decision was taken to look at studies specifically relating autism and identity. Papers were selected for review based on the parameters that the words 'identity/identities' appeared in the title or subject/keywords listing. Gilling (2012), notes that there exists a wealth of autobiographical accounts by individuals with autism. However, the decision was taken not to include such accounts but to focus on material published by researchers. This is not to dismiss the validity of autobiographical accounts, and what they may tell us about identity, but as they are different in nature to published research a separate analysis would be of value but beyond the scope of the current thesis. The selective review indicated that there is a paucity of research that explicitly links the experiences of individuals with autism with theoretical understandings of identity, thus this becomes the focus of the subsequent sections in this chapter.

A synopsis of conceptualisations and theoretical understandings of self and identity is presented in Section 2.4. A particular formulation of identity pertinent to an 'insider perspective,' that of narrative identity, and the related concept of autobiography, is presented in Sections 2.5 and 2.6, respectively. A brief commentary is given in Section 2.7 in relation to atypical development in autism in the domains of self, identity, autobiography and narrative. Although identity is

primarily conceptualised in narrative terms for the purposes of this thesis, other frameworks of identity, which feature in some of the literature reviewed on autism and identity, are highlighted in Section 2.8.

## **2.2 The Voice of the Child**

Universal principles and standards pertaining to the status and treatment of children, as enshrined in the United Nations Convention on the Rights of the Child, came into force in the UK in January 1992. Article 12 of the Convention specifically relates to the voice of the child, stating that children have a right to say what they think in matters concerning them and have a right to have their views taken into account (UNICEF, 2009). Gilling (2012) notes that, following the Children Act (1989) and the Special Educational Needs Code of Practice (DfEE, 2000), the voice of the child has been given greater precedence in legislation and a child's right to be heard and involved in decision making has been more clearly stated.

Since then, new legislation in the form of the Children and Families Act (2014) has been introduced and a revised Special Educational Needs (SEN) Code published (DfE, 2015). The legal obligations of Local Authorities (LAs) to consult YP and their families throughout the statutory process of special educational needs assessment is reiterated. In addition, the new Code includes emphasis on taking a person-centred approach when working with YP. Paragraph 9.22 of the Code

describes a person-centred approach in relation to the assessment process. It states:

The assessment and planning process should:

- focus on the child or young person as an individual;
- enable children and YP and their parents to express their views, wishes and feelings;
- enable children and YP and their parents to be part of the decision-making process;
- be easy for children, YP and their parents or carers to understand, and use clear ordinary language and images rather than professional jargon;
- highlight the child or young person's strengths and capabilities;
- enable the child or young person, and those that know them best to say what they have done, what they are interested in and what outcomes they are seeking in the future;
- tailor support to the needs of the individual;
- organise assessments to minimise demands on families;
- bring together relevant professionals to discuss and agree together the overall approach; and
- deliver an outcomes-focused and co-ordinated plan for the child or young person and their parents.

(SEN Code of Practice, DfE, 2015, pg 147-148).

It is clear that in order to ensure a person-centred approach it is imperative for practitioners to engage the voice of the child and promote an insider perspective.

The need to engage the voice of the child can be situated in a wider ontological and epistemological debate about how researchers and practitioners may come to understand and make sense of particular phenomena. Billington and Todd (2012) note the limitations of the positivist approach in accessing the qualitative aspects of being human, such as experience, meaning or value. Cohen et al. (2000) note that researchers subscribing to the interpretative paradigm reject positivist views of inquiry as mechanistic and reductionist in nature and note that such a view excludes notions of choice, freedom, individuality and moral responsibility. The interpretative approach aims to understand the social world from the perspective of the individuals who are part of the ongoing action under study. Critical theory notes the limitations of both the positivist and interpretativist paradigms as it regards them as presenting incomplete accounts of the social world as they fail to account for the political and ideological contexts of research. It advocates an emancipatory role through the illumination of issues concerning repression, voice, ideology, power, participation, representation, inclusion and interests (Cohen et al., 2000).

With respect to the voice of the child and autism, Perry (2012) notes that debates about autism have not filtered through to ethics to any notable extent. Clarke and van Amerom (2007, 2008) highlight the disparity between the beliefs about autism

held by parents of children with autism, organisations aimed at supporting individuals with autism and their parents, and those held by adults with autism. Perry argues that this disparity should lead to a rethinking of issues around consent within the field of bioethics in relation to autism research and interventions. Perry also raises the importance of taking into consideration the concept of identity:

“Autism is chronic, and therefore any paediatric interventions ought to consider the future identity of the autistic individual.” (Perry, 2012, pg 239)

Perry and others (Armstrong, 2010; Baker, 2011) note that, within a wider context of disability rights, groups or communities are beginning to form around, ‘genetic identity,’ where members may not view themselves as, ‘disordered.’ This concept of genetic identity, or neurodiversity, therefore needs to be given greater consideration within the context of ethics and the rights of individuals. This is all the more important considering the freedoms afforded to parents, and professionals, to make decisions about interventions that have potential to influence children’s future identities.

Due to the chronic nature of autism and issues relating to identity and rights, Perry (2012) argues that there is a strong case for considering the narratives of adults with autism to inform matters of consent and practice at paediatric level, where proxy consent by parents is currently given primacy. Although such an approach

may improve understanding of individuals and help inform consent, it still acts to exclude the voice of children and YP by giving precedence to adult narratives. In contrast, Gilling (2012) goes further than Perry and advocates the foregrounding of 'local' or 'insider knowledge' (White, 2007), where the narrative of the child is given prominence. Gilling subscribes to privileging complex accounts and resisting simplifications that position children with such difficulties into narrow categories. This is echoed by Billington (2006a) who argues that, in order to practise ethically in the field of autism, practitioners need to give prominence to issues of feelings, thinking, and meaning, and augment their understanding of how children with autism manage their worlds. In addition, Billington (2006b) sets out five questions to prompt professionals in practice and research to critically evaluate their positions in relation to work with YP by asking:

- How do we speak of children?
- How do we speak with children?
- How do we write of children?
- How do we listen to children?
- How do we listen to ourselves (when working with children)?

(Billington, 2006b, pg 8)

In summary, inclusion of the voice of the child incorporates a wide range of considerations. These relate to ontological and epistemological debates, ethics,



political concepts of disability and neurodiversity, and professional practice and conduct. Such matters are essential not only in accessing sense-making and identities, but also in considering how they may influence the experiences of individuals that give rise to sense-making and identity in the first instance.

With a view to the arguments above, Section 2.3 presents a review of the literature where the aim has been to help researchers and practitioners understand the social world and experience of individuals with autism from an insider perspective, and where this aim is explicitly linked to the concept of identity.

## **2.3 Autism and Identity**

A search was conducted for research papers containing the word identity/identities within the title or subject/keyword listings in conjunction with the subject area of autism and/or Asperger syndrome. The search was limited to publications dated between the years 2000 and 2015. A number of topics relevant to the current research were noted that related to: debates about selves as experts; medicalisation verses neurodiversity; school experiences; diagnosis, including debates about the changes to diagnostic criteria; and, as would be expected due to the focus of the literature search, identity. These respective topics are discussed in turn, below. However, these areas of debate should not be considered as mutually exclusive as they consisted of ideas and narratives that extended across their imprecise boundaries.

### **2.3.1 Selves as Experts**

The discourse of selves as experts can be seen as existing in the wider context of the voice of the child or individual. Brownlow and O'Dell (2006) undertook a discourse analysis of posts within an on-line chat group consisting of adults with autism. An important topic to emerge related to the broad theme of expert knowledge of autism. Individuals with autism within the chat forum challenged the dominance of professional and scientific knowledge and gave greater emphasis to experiential knowledge. Although credit was given to professionals and experts for their knowledge of autism, individuals with autism were positioned as the, 'official experts.' Despite this, the power of professionals was acknowledged in relation to them being in a position to provide an official diagnosis. The excerpts from the on-line forum in Brownlow and O'Dell's paper indicate that a strong emphasis is placed on group identity and resistance to interventions aimed at, 'normalising' by the individuals involved. This may explain why these individuals did not identify with wider contributions made by professionals, such as in relation to social support or educational interventions.

The narrative of selves as experts is also prominent within the neurodiversity movement. It featured a number of times in papers considering the diagnostic process as experienced by individuals and in the wider debate about changes to diagnostic protocols (discussed below). The concept of individuals as experts in

their own lives is of course consistent with calls for psychological practice to be driven by insider perspectives and a person-centred philosophy.

### **2.3.2 Neurodiversity and Identity**

A number of studies identify the contradictions between a medical view of autism and the concept of neurodiversity. The difference between the two approaches centres on respective views of autism as disability or autism as identity. Kappa et al. (2013) note the medical model aims for normalisation, reduction in symptoms, and the elimination of deficits that result in impairments in conducting life activities. The medical model relies on biological markers and where these are absent, deficit is construed in relation to behavioural differences or deviations from what is considered the norm (Anckarsater, 2010). Such a framework ignores advantageous behaviours, reasons for behaviour, and the role society plays in defining appropriate behaviour, thus failing to differentiate between conditions that arise from a poor, 'person-environment fit' and those conditions that cause deterioration and death (Kappa et al., 2013; Baker, 2011). Baker (2011) notes that while advocates of neurodiversity tend to subscribe to a social model, where disability is seen as a consequence of inaccessibility of social and political systems, autism is also seen as caused by biological factors but acknowledged and celebrated as part of natural human diversity and variation.

Themes emerging from this debate relate to cure. Results from an on-line survey conducted by Kappa et al. (2013) revealed that autistic participants and those people more aware of the concept of neurodiversity were less interested in a cure than those who were not, whilst parents were least likely to dismiss the value in finding a cure. However, whilst awareness of neurodiversity contributed to a positive autistic identity, individuals showed acknowledgment of the deficits associated with autism and were supportive of intervention strategies aimed at amelioration. This leads Kappa et al. to propose a 'deficit as difference' concept where celebration and amelioration are both valued and not seen as opposing concepts within a false dichotomy.

Similarly, in an extension to the debate, Baker (2006) discusses the concepts of neurodiversity and neurological disability in the context of public sector policy and infrastructure. Baker argues that in order to support programmes that reduce the disabling aspects of public infrastructure, consideration of both neurodiversity (where disability becomes an element of identity for individuals, families or communities) and neurological disability (when inclusion in a broad public and societal sense becomes restricted) is required.

Kappa et al.'s (2013) findings indicate that a biological explanation was favoured by individuals with autism and that they endorsed an essentialist biological explanation. Kappa et al. suggest that this offers individuals a sense of exoneration. Brownlow and O'Dell (2006) also report a similar finding from their

discourse analysis of conversations within an on-line forum involving adults with autism, where neurological explanation was given weight in explaining difference between autistic and non-autistic (or neurotypical) individuals.

The concepts of deficit as difference and neurodiversity are further explored in a cross-cultural examination of autism by Kim (2012). Kim looks at how autism is construed in different countries (Canada, South Korea and Nicaragua). Kim's study reveals that different cultures view and construct autism differently. In Canada a biomedical view prevails. Kim notes that Reactive Attachment Disorder is used synonymously with autism in South Korea, where mothers are often blamed for having children with disabilities. Kim explains that there is a strong concern with the judgements and perceptions of others in South Korean culture where disability within families is a source of shame. In contrast, Kim's observations in Nicaragua indicate that within certain communities autism seemed to exist as another term for a generic notion of disability. Kim's observations lead her to a social constructionist view of autism and she forwards the concept of 'differ-bility,' that is, an understanding that differences need not necessarily be positioned as disabilities.

A number of researchers present a more critical view of the neurodiversity movement and, amongst other critiques, claim that it essentialises and reduces identity to biological terms. Ortega (2009) notes that the neurodiversity movement emerged during the 1990s and has been dominated by individuals with Asperger

syndrome or high functioning autism. The movement has a preference to account for difference through the employment of a narrative of atypical neurological wiring rather than pathological cognitive organisation or psychosocial explanations. Ortega notes that this preference cannot just be reducible to a rejection of psychological explanations, but can be understood due to the proliferation and diffusion of biological and neurological claims in societies where the biomedical model is a dominant paradigm. Ortega argues that this has led to neuroscientific claims, technologies, and therapies that affect how we think about and construe ourselves. This increasing influence of neuroscience has led to what Ortega refers to as, 'cerebral subjectivation,' that is, the constitution of self in cerebral terms.

Ortega (2009) argues that, although there remains no clear consensus on the aetiology of autism, the arguments of the neurodiversity approach, 'neurologizes,' differences and in doing so, identity is rendered natural and physical, with constructs such as diversity, uniqueness, and creativity being defined in terms of the brain. Paradoxically, differences and diversity which are claimed as being brain-based also lead to a process of homogenising neurodiverse brains. Autistic brains are construed as homogenous against neurotypical brains which too are homogenised. (Ortega, 2009). Ortega notes that, as such, the brain metaphor as used in defining the self, limits individual and institutional dimensions and constrains the factors of conflict, denial, and repression, and acts to remove the subjective and experiential (Ortega, 2009).

Other writers also note the binary division of the neurodiverse and the neurotypical. Rosqvist, Brownlow and O'Dell (2015) examined the discourses within the publication 'Empowerment,' a magazine of the Swedish National Society of Autism. The researchers note that the organisation had traditionally been dominated by the parents of children with autism, but there had been a process of trying to increase the participation and influence of individuals with autism themselves in the running and operation of the society. Rosqvist et al. (2015) report their analysis revealed two contrasting and competing discourses, which they term, 'integrationist/reformist,' and 'separatist,' and which were associated with different styles of collective action. The integrationist approach was most closely linked to the work of parents and involved viewing autism as a disability, with action centred on advocating for services, changes to policy, and integration and inclusion within mainstream society. In contrast, the separatist discourse was associated more closely with individuals with autism and involved viewing autism as an identity, with action centred on relating to others with autism (whilst excluding neurotypicals) through the creation of autistic only spaces and forums, and with a struggle for power rather than integration.

Similarly, Runswick-Cole (2014) also highlights such tension between different advocacy movements using the terminology, 'autism-advocacy,' and 'autistic-advocacy,' to differentiate action motivated by the contrasting views of autism as disability and autism as identity. In examining arguments framing the neurodiverse and neurotypical binary, Runswick-Cole's focus is concerned with looking at the debate as it is situated in the context of neoliberal times, that is, in

terms of the influence of free-market capitalism. Runswick-Cole argues that the increasing commodification of autism resulting in an, 'us and them,' politics of identity, has given rise to other forms of marginalisation. She notes, for example, that the argument of autism as difference brings into question the legitimacy of claims of disability and disadvantage that might hinder full participation in neoliberal society, and that warrant access to redistributive welfare policies. She further argues that the neoliberal emphasis on the, 'individual, rational, able and ideal' ignores the lived experience of those disabled people who are dependent on others. Runswick-Cole concludes by arguing for a politics of identity that is not based on essentialist binaries.

Fein (2015), although not directly critiquing the concept of neurodiversity, like Runswick-Cole, also draws on the concept of neoliberalism to provide a perspective that challenges debates about the increase in diagnosis of autism. Fein explores how sociocultural factors may be contributing to developmental outcomes that might be giving rise to the increase in diagnosis. Fein notes that debates about the increase usually centre on two possibilities. The first explains the increase as resulting from expanded diagnostic criteria and improved awareness of the condition, and the second claims that there has been a real increase due to biological changes during development, possibly as a result of environmental toxins. In contrast, Fein offers a third argument drawing on the concept of, 'identity capital,' where the social world is a market place where successful relationships are developed based on personal characteristics attained through prior success. The concept of identity capital can be situated in the wider



debate on the influence of the neoliberal context as discussed by Runswick-Cole (2015). Fein explains that changes to the social environment in modern times mean that friendships, interactions and other relationships are primarily driven by voluntary choice and concerned with sustained mutual satisfaction. A consequence of this, according to Fein, is that those slower to develop social skills and competencies are systematically denied opportunities to develop them, which leads to further difficulties and the perpetuation of a cycle of exclusion and atypical development (Fein, 2015). Fein notes that her argument is most likely to apply to those individuals on the, 'borderlands,' of diagnostic criteria.

The concept of neurodiversity challenges the medical model of disability and puts forward a concept of autism as identity based on natural diversity of the human brain. However, in doing so, the neurodiversity movement maintains an essentialist biological view of autism and by extension essentialises identity as neurological. Also, as noted, this has the affect of reducing the importance of the experiential in the construction of self. Furthermore, it has been observed that proponents of the movement only represent a small number of the wider autism community and thus its claims and objectives need to be viewed with this in mind (Giles, 2014).

### **2.3.3 School Experiences**

A number of studies identify school experiences as an important theme to emerge from research with people with autism. This would be expected, of course, in studies involving YP (Molloy and Vasil, 2004; Baines, 2012) due to the time that YP spend in educational contexts. However, the influence of the school experience was also evident in studies involving adult participants (e.g., Punshon et al., 2009; Townson et al., 2007). Issues to emerge in this area include: factors associated with bullying; being misunderstood by professionals and peers; attempts to hide autism and be, 'normal,' and fit in; a sense of a lack of belonging; and dilemmas about whether to share an autism diagnosis with peers.

The research reviewed indicated variability in the views held by individuals with autism. This reinforces the importance of seeking the voice of the individual child in relation to his or her experiences, rather than aiming to simplify findings in order to come to a generalised understanding that is applied to all individuals with autism. This point can be illustrated by looking at contrasting views given by two adolescent participants in the study by Molloy and Vasil (2004). Chee Kiong is a 17 year old boy who describes difficulties with socialising and the need to make friends as his biggest problem arising from having Asperger syndrome. In contrast, Luke, who is 14, appears happy with his own company and sees teachers and parents as too forceful when encouraging socialisation. He notes:

“I don’t mind my own company at all and have nothing in common with most other boys. This seems to cause teachers a problem.” (Molloy and Vasil, 2004, pg 127).

The literature on the school experiences of students with autism is wide ranging (e.g, Humphrey and Lewis, 2008; Harington, 2014; Saggars, 2015, Saggars et al., 2011). However, very few papers were identified that discuss these experiences in terms of identity. In cases where identity was discussed it was not always explicitly explored or clarified with reference to psychological models of self and identity.

#### **2.3.4 Diagnosis and Identity**

The importance of considering the impact of diagnosis on identity has been given greater impetus in recent years following changes to the Diagnostic and Statistical Manual (DSM) of the American Psychiatric Association (APA). The publication of DSM-V (APA, 2013) saw the replacement of Autistic Disorder, Asperger syndrome Disorder, Childhood Disintegrative Disorder, and Pervasive Development Disorder - Not Otherwise Specified, with a single diagnosis of Autism Spectrum Disorder (The National Autistic Society, 2015). The changes reflected the general move away from classification based on discrete categories to one based on a dimensional approach (Giles, 2014; Carmack 2014). The implications of the changes to DSM-V in the UK are still unknown as most clinicians in the UK use

the International Statistical Classification of Diseases and Related Health Problems (ICD-10) guidelines which still contains Asperger syndrome as a diagnostic label (The National Autistic Society, 2015).

However, the proposal to change the diagnostic protocol led to much debate about identity, particularly for those who identified with Asperger syndrome. A number of papers were found that had undertaken research into the views of people with autism leading up to the changes. Spillers et al. (2014) employed a phenomenological approach undertaking an inductive content analysis of data collected from on-line discussion forums to look at the views of individuals with Asperger syndrome or autism in relation to the changes. Spillers et al. identified that individuals were concerned with the loss of identity associated with Asperger syndrome. However, there were others with a diagnosis who were neutral or unconcerned about the changes, perceiving all categories and diagnosis as arbitrary. Other concerns related to: whether individuals would be perceived as cured if they did not meet the new criteria; that services would not be tailored to individual needs as a result of everyone being described by the same term; and that those coping and managing may not qualify for a diagnosis and subsequent support. As a response to these concerns some users suggested greater advocacy and solidarity based on the premise that individuals with Asperger syndrome are the experts in their lives. A key observation made by Spillers et al. was that there was a divide and diversity in the opinions of forum users.

Similarly, Giles (2014) also reported on his analysis of internet forum threads looking at the reactions of individuals who identified with Asperger syndrome to the proposed changes in DSM-V. Giles noted themes that were either supportive of the change or against it. Supportive threads were labelled as, 'Acceptance' and 'Reassurance.' Threads relating to acceptance welcomed the changes as individuals saw the autism/Asperger divide as being based on a false assumption that severity was linked to IQ. Others argued that a categorical approach was divisive and that the spectrum approach would allow for a greater sense of belonging and solidarity within the autistic community as a whole. Giles notes that some individuals accepting of the changes had adopted a new identity moniker, 'spectrumite,' as a way of embracing the changes. The threads relating to reassurance were seen by Giles as an attempt by community members to ease the concerns of fellow members who feared negative outcomes. Four threads labelled, 'Fear,' 'Rejection,' 'Defiance,' and 'Suspicion', were identified as being against the changes. Some individuals feared the loss of services, and others rejected the changes on the grounds that they were inaccurate, unfair, or unscientific. Comments within the Defiance thread related to: views that little could be done to damage the Asperger community itself; hostility towards being grouped together with those with autism; and the argument that members of the Asperger community were the authority and experts on matters relating to Asperger syndrome. Comments from the Suspicion thread related to the view that the changes were politically motivated in response to media reports of increasing diagnosis and over-stretched services. Like Spillers et al. (2014), Giles also noted the wide range of contrasting views emanating from the data.

In contrast to Giles and Spillers et al., rather than using social media posts, Carmack (2014) reports research which analysed traditional print news coverage about the debate surrounding the changes to the diagnostic categories within DSM-V. She notes that debates can take place within a technical sphere (in this case psychiatry) and within a public sphere which may consist of people with or without specialist knowledge. Each sphere influences definitions and understandings of autism with resulting implications for identity. These spheres are seen to inform each other but there is a reliance on the role of the experts to define the accepted argument. The analysis revealed a polarisation of views between the opponents of change and the proponents of change. Carmack points out that Asperger syndrome is not just a diagnostic term or health identity but also a social identity. In contrast to acquired health identities Asperger syndrome is not something that an individual develops but is an integral part of who they are. Arguments put forward by community members to support the idea of Asperger syndrome as a social identity included emphasising uniqueness, academic giftedness, and defining that Asperger syndrome is not autism, which was seen as a deficit. In addition, members of the Asperger community have been able to problematize what is considered, 'normal.' For example, Carmack cites a number of film and television portrayals of characters with Asperger syndrome who are seen as quirky rather than disordered, and thus, she claims, Asperger syndrome has increasingly been seen as being within the public sphere's view of normal. She notes that the use of a moniker (e.g. Aspie) and identifying role models (e.g., famous historical and contemporary figures thought to have Asperger syndrome)

creates a sense of community. This construction of a community is then used to argue that Asperger syndrome is kept as a separate diagnosis (Carmack, 2014).

Carmack's study indicated that arguments presented in the print media from proponents of the change rely on the authority of scientific knowledge and experts, and on arguments focussed on biology. Such arguments noted that: a dimensional view rather than a categorical approach was consistent with the concept of symptoms existing on a continuum of mild to severe; there is little biological and developmental difference between mild autism and Asperger syndrome; the removal of categories reduced risks of misdiagnosis; and a greater focus could be placed on treatment of other associated medical conditions rather than spending clinical time trying to establish the correct category.

Carmack noted there to be a polarisation between a health identity view of autism and Asperger syndrome and a social identity view, where the proponents of changes to DSM criteria are medical experts and those opposed to the changes are from the Asperger syndrome/autism community. This conclusion does not reflect the diversity of opinion within the autism community reported by Giles (2014) and Spillers et al. (2014). Carmack's study focussed on the data collected from print news media. It is possible that a journalistic style, where two arguments from opposing sides are presented and contrasted, gave rise to a polarised view. Despite this, Carmack does offer valuable insights into the arguments associated with health identity and social identity. It is also worth noting that despite the

media portrayal (as reported by Carmack, 2014) there was not a uniform consensus amongst experts about the changes to DSM criteria (Wing, Gould & Gillberg, 2011).

A further observation of interest made by Carmack concerns the arguments associated with Asperger syndrome as a different ability rather than a disability by those advocating for it to remain a separate diagnosis. Carmack notes that this argument of normalcy challenges the concept of what is normal and what needs treatment or intervention. However, Carmack makes the astute point that this argument is tempered by the fact that opponents of the change to DSM criteria were not arguing for Asperger syndrome not be included at all, but for it to remain separate. Thus, she argues, Asperger syndrome as a social identity is still grounded in how it is defined and constructed by medical professionals.

Spillers et al. (2014), Giles (2014) and Carmack (2014) all discuss identity specifically in relation to the changes to the diagnostic criteria in DSM-V and therefore provide a specific and somewhat narrow view of identity. It is of note that they do not frame their discussions in terms of any particular theories of identity. The research by Spillers et al. and Giles is limited to data sourced from internet forums which may not be representative of the wider autism community. In fact, Giles (2014) acknowledges that discussions about the changes to diagnostic criteria only constituted a relatively small amount of the posts on the



sites he used and thus the debate may not have been of importance to the wider majority of users.

A number of studies report on the experiences of YP in relation to diagnosis. MacLeod, Lewis and Robertson (2013) draw on social identity theory to explore how six higher education students made meaning of their diagnosis of autism/Asperger syndrome. These researchers used Interpretative Phenomenological Analysis (IPA) to generate three over-arching themes. These were reported as being, 'perceptions of others diagnosed with Asperger syndrome,' 'acquired knowledge of Asperger syndrome,' and 'personal identification with Asperger syndrome.'

With reference to the theme related to perceptions of others, MacLeod et al. claim that in order to engage with an autism identity, individuals must be aware of other people with autism, and that how these others are perceived and perceive themselves will determine the degree to which an autism identity is viewed in positive terms. The participants in the study varied in terms of their engagement with other YP with a diagnosis of autism. Two participants had regular contact with others via on-line forums, however most participants made some generalisations about others with autism and distanced themselves from these. Although not engaged with others with an autism diagnosis, these participants expressed a willingness to develop self-understandings through contact with others on the autism spectrum.

Describing the theme relating to acquired knowledge of Asperger syndrome, MacLeod et al. note that the information provided at the point of diagnosis is important in terms of how and whether individuals integrate autism into their personal identities. The comments reported under this theme indicated that: participants were active in the diagnostic process to varying degrees; that information given at the point of diagnosis did not reflect individuals' experiences; that individuals tended to learn about the condition through external means (i.e. being made aware of difference by others, rather than through self-awareness); and that participants tended to describe difficulties by describing others' perceptions of the difficulties rather than providing their own insights about themselves. These observations, along with the misconceptions and stereotypes held by the general public, were hypothesised to contribute to fluctuating and inconsistent autism identities.

MacLeod et al. (2013) suggest that if individuals are to incorporate an autism identity into their self-concept, then individuals must first develop a notion of how it relates to them personally. Personal identification with Asperger syndrome was discussed as part of the final theme. Some participants were able to identify how they were affected by autism in relation to their learning styles. The participants were university students, so learning may have been a particularly salient consideration for them. In addition, some students were able to identify positive associations with autism such as having gained a greater acceptance of others as a consequence of being repeatedly judged themselves due to their autism.

MacLeod et al. indicate that participants identified to varying degrees with an autism identity but often distanced themselves from it. Personal identification with autism would be a prerequisite to the development of a group identity and as such the participants in the study did not align themselves closely to a collective autism identity. The research findings lead MacLeod et al. to suggest that individuals need to be able to identify with a group that is perceived as constructive and empowering, and that this could be done through access to positive role models or mentors with autism so that identification with a group identity can be positive. In addition, they suggest that individuals should have opportunities to learn about the condition through access to relevant and meaningful information rather than generalised information written by professionals and parents. MacLeod et al. (2013) primarily draw on social identity theory to examine the potential for collective action by individuals who identify positively with the Asperger label. As social identity theory may be able to offer further understandings in relation to the experiences of individuals with autism it is discussed in detail in later sections.

In their paper Mogensen and Mason (2015) present findings of a thematic analysis of the experiences of 13-19 year olds related to having a diagnosis of autism, with the aim of understanding impact on identities and the meanings of the diagnosis. Their analysis considered the impact of diagnosis at a personal level and at a social/public level. These researchers classify the impact on individual identity as being oppressive, liberating or facilitating control. It was seen as oppressive for one participant who had been confronted with a concept of herself as different from others, of which she was not aware prior to the diagnosis. Diagnosis was

sometimes seen as liberating, as it allowed some participants to understand themselves in relation to a normative position and integrate knowledge about their condition in their lives. Some participants saw diagnosis as a means of facilitating or gaining control. These participants already knew themselves to be different and so the diagnosis allowed the development of a common identity with others. Mogensen and Mason (2015) describe the impact of diagnosis at a personal level as being multi-faceted and complex. For some, diagnosis was a negative experience; for others, it was considered as a fundamental part of who they were, and so was perceived positively; and for others still, it was observed that diagnosis did not have significant implications for the way they constructed their identity.

In terms of the impact of diagnosis at a socio-relational or public level, participants discussed the dilemmas of disclosure due to prevailing stereotypes and negative attitudes within society. Some participants discussed employing social strategies in order to facilitate being perceived as normal. Mogensen and Mason, cite the term, 'masquerading,' as a description of these attempts to meet normative expectations. For another participant, it was not a concern if others knew, as his friends already had some idea of his differences.

Mogensen and Mason (2015) discuss the significance of diagnosis on the participants' sense of agency and control, and whether it was seen as advantageous or otherwise. They make the observation that, where diagnosis facilitated a sense of self-understanding and control, it was perceived to be

advantageous. In contrast, where the diagnosis was seen to limit control and impact negatively on identity, it was experienced as a disadvantage. They go on to conclude that there exists more complexity and heterogeneity in the ways in which YP make sense of their diagnosis than is currently described in the literature.

Like MacLeod et al. and Mogensen and Mason, Molloy and Vasil (2004) also report on the experiences of YP with autism. These researchers specifically used a narrative approach to explore the experience of teenagers with Asperger syndrome. A key finding to emerge was that teenagers in the study had a view of diagnosis as a sense-making narrative. Diagnosis was often seen as providing a framework for the explanation of many of their experiences. As noted earlier, diagnosis can provide a sense of exoneration. The participants referred to feelings of relief when hearing the diagnosis, but this also provoked anger in cases when parents had not shared the diagnosis with the child until later.

A similar theme emerged in a study conducted by Punshon et al. (2009) with ten adult participants who had received a diagnosis of Asperger syndrome in adulthood. On the whole, diagnosis was seen to result in positive change for those concerned. Diagnosis was cited as having the affect of: reducing feelings of blame and guilt; permitting identification with others with Asperger syndrome; allowing access to groups where individuals felt they fitted in; and facilitating a greater appreciation of the positive aspects of Asperger syndrome to emerge.

Molloy and Vasil (2004) and Punshon et al. (2009) note that participants went through a process of reinterpreting their past experiences in light of their diagnosis. This would indicate the powerful influence that diagnosis has on one's understandings of one's life experiences. Townson et al. (2007), in a research project on advocacy and autism, noted participants saw late diagnosis as contributing to ill health and, 'suffering,' due to a lack of understanding, particularly within the context of educational settings.

Punshon et al. (2009) and Townson et al. (2007) explicitly link diagnosis with the concept of one's identity. However, they do not discuss the concept of identity and identity formation, or seek to explore and explain it within psychological or other theoretical frameworks. Mogensen and Mason (2015) make a brief reference to identity as narrative and how the stories we relate can be a key approach to understanding disability identity. Nevertheless, they do not go on to develop the concept nor situate their research explicitly within this approach. Molloy and Vasil (2004) do situate their research in the narrative psychology tradition, collecting life story accounts which they analyse thematically across cases. However, their reference to narrative identity as a conceptual focus is limited to noting that it is through narrative we form and present an identity.

The fact that diagnosis appears as a dominant theme within the research may reflect the cultural dominance of the biomedical model in Western society's understanding and construing of the world. In contrast, Gilling (2012) challenges

this primacy given to the biomedical model and emphasises the value in taking an alternative, narrative perspective, noting that it:

“... moves away from a focus on essentialist truths in the diagnosis of autism and the often held view that labelling can help to understand, create a social identity and open up opportunities for support.” (Gilling, pg 33).

She goes onto argue that:

“In contrast, the narrative view is that identities are not fixed and our lives are ‘multi-storied’, that is, narrative captures non-essentialist identities and we may have different stories (events that are linked in sequence, across time and according to a plot) about different aspects of our lives.” (Gilling, pg 33).

Research that refers more explicitly to identity is discussed further below.

### **2.3.5 Identity in Relation to Autism**

Discussion of, and reference to, identity occurs throughout the reviewed literature that looks at the experience of individuals with autism. However, identity is often alluded to as a, 'given,' without reference to psychological frameworks of what identity is, or what it means, or how it may develop or change.

Baker's (2006) paper exploring the two concepts of neurodiversity and neurological disability concludes that public policy should address interests related to inclusion and those related to identity. Kappa et al. (2013) argue that the neurodiversity movement's celebration of the brain and embracing of an essentialist and biological explanation of autism appeals to individuals who think of autism as a 'natural part of themselves'. However, in exploring autistic identity through a survey/questionnaire method, Kappa et al. appear to have taken a rather simplistic view. They asked participants in their study whether they preferred the term, 'person with autism,' or, 'autistic person.' Kappa et al. claim the term, 'autistic person,' is consistent with an identity first view of autism. Their analysis did reveal that participants with an awareness of neurodiversity, and those identifying as autistic (whether diagnosed or not) were more likely to prefer the term 'autistic person' over 'person with autism' than their counterparts in the survey (parents, other family and friends) who showed no preference for either term. However, how such language and terms relate to identity, what validity they have as markers of identity, and what significance they have in relation to identity



is not explicit in discussion undertaken by Kappa et al. In addition, how an individual prefers to describe him or herself can only be a small part of identity.

Further discussion about the use of language used to refer to individuals with disabilities is provided by other authors. Dunn and Andrews (2015), writing in relation to disabilities in general (i.e., not specifically in relation to autism), note that the American Psychological Association advocate the use of person first language (e.g., people with autism) and link this use of language with the social model of disability (Oliver, 1990). Here the focus is on the person and not the disability and the aim is to avoid objectifying individuals by focussing on the disability. Identity first language (e.g., autistic person) is linked to a minority or diversity model of disability which asserts disability as a distinct, diverse, cultural, and socio-political experience and identity. Kenny et al. (2015) undertook research specific to the terms used to describe autism from the perspective of the UK autism community. The outcomes of their research revealed a complex picture leading them to conclude that there is no single accepted way to describe autism. It was noted that the terms used may vary by context and the authors argue against prescriptive guidelines. Both Dunn and Andrews (2015) and Kenny et al. (2015) note that diverse opinions exist and therefore the context and the preferences of individuals being referred to will also need to be taken into account.

Brownlow and O'Dell (2006) pick out identity as a theme that occurred from their discourse analysis of language used in an on-line discussion group involving

autistic and non-autistic (neurotypical) adults. The analysis indicated that difference is celebrated and assigned to neurology with discussion within the forum making comparisons between individuals who identify themselves as autistic and individuals who are neurotypical. They noted discussions that supported and celebrated difference and positioned those with autism as 'better' due to specific skills. They also noted that discussions about cure, or being more neurotypical, were discouraged. Brownlow and O'Dell's study, although highlighting identity as an important issue, fails to examine how identities were being constructed and reinforced through the forum. For example, excerpts reveal processes relating to in-group and out-group psychology and social identity theory (Tajfel and Turner, 1986) but Brownlow and O'Dell do not explicitly relate their analysis to such a framework.

As noted above, Punshon et al. (2009) conducted interviews with 10 adults diagnosed with Asperger syndrome in order to investigate psychological reactions to diagnosis. They used an IPA approach to data collection and analysis. Punshon et al. identified, 'identity formation,' as one of six superordinate themes to emerge from their research. The other five were: negative life experiences; experiences of services (pre-diagnosis); beliefs about symptoms of Asperger syndrome; affects of diagnosis on beliefs; and affect of societal views of Asperger syndrome. The theme of identity formation is presented separately in its own right and the focus of commentary is around the lack of understanding individuals had of their difficulties during their childhood and teenage years due to the absence of a framework within which to explain their difficulties. Punshon et al. suggest such

an absence led to the internalisation of what others say about the difficulties and that the lack of understanding by the participants contributed to mental health problems.

Although, Punshon et al. acknowledge that the other themes cannot be isolated from identity as they too affect identity formation, the arbitrary separation leads to a restrictive narrative and the constraint of a richer picture of identity formation being foregrounded. The other themes revealed issues of: bullying; not fitting in; failed intervention; misdiagnosis; concepts of difference and having something wrong with you; being misunderstood and blamed; attempts to fit in and hide difference and symptoms; and the impact of diagnosis, which are all relevant to the formation of identity.

Kelly (2005), aiming to combine sociology of childhood and disability theory perspectives, explores identity formation of disabled children with a range of, 'impairments,' including, but not limited to, autism. She conducted interviews with disabled children, their parents, and professionals (social workers). Results indicated that adults often failed to take into account the views and experiences of disabled children. Kelly's study noted that a consequence of this was that children developed their own idiosyncratic interpretations of impairment and disability as active, 'social interpreters,' predicated on their experiences and interactions with others.

Similarly, with the aim of discussing autism in relation to wider debates in disability studies, Myers et al. (2011) draw parallels between the deaf community, as a minority culture, and autism. They note that students with autism in mainstream schooling do not blend in seamlessly with neurotypical classmates, which can lead to bullying, social isolation, and greater risks to psychological and mental health (Myers et al., 2011). Myers et al. highlight four different permutations relating to identification with either hearing mainstream culture or deaf culture. Individuals failing to identify with either culture can be described as culturally marginalised; those who identify with the hearing mainstream, and see deafness solely as a disability, are described as culturally hearing; identification with the deaf community whilst viewing the hearing community as oppressive is described as immersion; whereas identification with both cultures leads to what is described as a bicultural identity.

Myers et al. (2011) draw on research with deaf students, which indicates that psychological well-being is directly related to an individual's sense of biculturalism, that is, their sense of belonging to the majority culture of their peers and their minority culture. They hypothesise that this may be due to access to an increased network of social support. The writers argue that encouraging ways in which YP can feel comfortable with their autism identity, whilst managing to take part and be accepted in the mainstream culture, may then be an effective method for promoting well-being and mitigating against risks to mental health. Myers et al. note that certain practices within mainstream settings may encourage students to 'hide' autism and present as neurotypical but that they should be allowed to

explore and embrace autistic identities, particularly as students with autism are often aware of their differences thus making them vulnerable to low self-esteem.

The researchers go on to recommend approaches that might help students with autism develop bicultural identities. These include: encouraging students with autism to be open about their diagnosis whilst teaching skills for living in the mainstream world; helping students adjust to the mainstream classroom but also adjusting the classroom to meet their needs; and attempting to change the mind-sets of neurotypical classmates. In relation to this final point they note that as sign language is sometimes taught to all students in a class, similarly peers could be educated about autism in order to reduce stigma.

Parsloe (2015), like Carmack (2014) above, writes from within the discipline of Communication Studies. She reports on a study looking at how members of the on-line autistic community engaged in discursive practices to, 'reclaim,' a positive autistic identity. 'Reclaiming' was defined as the process by which individuals with autism transform biomedical understandings of autism into cultural ones. Parsloe notes that such a process entails moving from viewing disability as an essentialist medical problem, where individuals are defined as victims of their abnormalities, to viewing disability as culture, where individuals create culture through sharing experience, celebrating difference, and incorporating this into a positive self-concept. Parsloe's analysis revealed a reclaiming of normalcy, symptoms, and agency. Normalcy was reclaimed through emphasising that individuals with

Asperger syndrome were different not disordered and that individual differences were a typical part of life. Language such as, 'differently wired,' on a 'different wavelength,' and 'differently-abled,' were cited as examples of how concepts such as disabled and disordered were transformed. The reclaiming of symptoms traditionally viewed as deficits involved transforming them to be re-presented as positive elements of identity. For example, 'narrow interests,' were reclaimed as the ability to, 'hyper-focus,' in order to take a deep rather than wide perspective. Agency was reclaimed through calls for changing aspects of one's life through activism.

A couple of studies reviewed did attempt to position identity in wider psychological frameworks. The research reported by MacLeod et al (2013) which made reference to social identity theory was discussed above. Also, it was noted that Mogensen and Mason (2015) and Molloy and Vasil (2004) drew briefly on narrative identity and narrative theory in their studies. In addition, Mogensen and Mason (2015) also make reference to the Goffman's (1963) work on stigma when explaining why YP in their study may have resisted autism as a public or social identity. Goffman's work is discussed further in Section 2.8.2.

Bagatell (2007) takes an ethnographic approach to provide an in-depth narrative account relating to the process of identity construction for one individual with autism. Bagatell describes identity as being multiple, fluid, negotiated, and constructed through interactions between discourse, power relationships, culture,

politics, and personal agency. Bagatell draws on the work of Bruner (1990), Foucault (1977, 1980), and the literary scholar Bahtkin as an interpretative framework.

Baines (2012) draws on positioning theory (Harre and Moghaddam, 2003) to explore how two students with autism constructed identities. Baines' conceptualisation locates identity as being shaped and enacted through participation across varying situations, and influenced by how individuals are positioned by themselves and also by others. Baines (2012) reports that the students in her study distanced themselves from dominant, 'storylines,' related to autism and endeavoured to fit in or, 'pass as normal.'

In contrast to much of the research reviewed above, where the focus has been on the experiences of individuals, Rocque (2010) explores the role of mothers of YP with autism in identity processes. He notes that the development of identity and self-hood is constructed and mediated by the mothers of children with autism. Rocque suggests that within the context of the, 'lived experience of disability' such mediation is essential for the formation and maintenance of positive identities. Mothers are seen to interpret the behaviour of their children for others and also help them understand the behaviours of others. In so doing, Rocque positions mothers as enacting a process of proxy self-hood for their autistic children.

Drawing on the work of Mead (1934), Rocque describes the development of self in terms of a process of interactive exchange with others resulting in the internalisation of the norms of their community into their own world view. Rocque explains Mead's view that this process allows the individual to:

“...discern the meaning of various situations, assess their place in them and adjust their behaviors to produce the desired responses from others. In other words, having developed a generalized other, individuals can reflect on their own actions from the position of the other and imagine the reaction of others to them in a given situation.” (Rocque, 2010, pg 487).

The evidence that individuals with autism have developed, ‘selves,’ and identities is seen as a challenge to dominant models of self-hood (such as the one described by Mead) as they appear to reflect, ‘normative self-hood and exclude the diversity of self-hood that humans may embody.’ (Rocque, 2010, pg 487). However, Rocque also acknowledges that the process of mediation takes places between mothers and typically developing children too. It may be the case then that factors influencing identity vary in degrees rather than in absolute terms for children with different development profiles.



### **2.3.6 Summary**

The above section reviewed studies where the aim of the research was to illuminate the lived experiences of YP and explore the relationship with the concepts of identity and identity formation.

A number of important themes were identified as emerging from the literature in relation to the experiences of individuals with ASCs. Five dominant themes relating to medicalisation and neurodiversity; individuals with autism themselves as experts; school experiences; diagnosis; and identity were discussed. It is likely that a greater number of themes would emerge from the wider literature on the experiences of YP with autism but the focus here was to consider papers where the concept of identity was linked to the experiences discussed.

The themes discussed above cannot be isolated from identity and identity formation as they appear to influence it in an integral way. Identity appeared to be represented as a fundamental factor within the research but was rarely explicitly situated in theoretical or psychological frameworks. The frameworks that were identified in the literature reviewed included: narrative psychology; social identity theory; symbolic interactionism; and positioning theory. However, the extent to which researchers drew on these frameworks to elucidate identity varied.

Explorations of identity within autism appear to be a relatively new research endeavour. The aim of the research here was to explore the experiences and related identities of individuals with autism more explicitly with reference to theories and frameworks explicating identity and identity formation. With the above aim in mind, the following section looks more closely at the concepts of self and identity before moving on to propose the use of narrative identity as a possible framework to explore the experiences and identities of YP with ASCs.

## **2.4 Self, Self-Concept and Identity**

Identity is a complex phenomenon. Lawler (2008) notes:

“‘Identity’ is a difficult term: more or less everyone knows more or less what it means, and yet its precise definition proves slippery” (Lawler, 2008, pg 1).

Within academia the varied conceptualisations and study of identity reflect this complexity and its problematic character. The elusive nature of an overarching definition of what identity is, how it is developed, and how it works is attributed to the existence of multiple ways of theorising the concept, each of which yield varying definitions and modes of analysis (Lawler, 2008; Vignoles et al., 2011). Furthermore, the varied conceptions of identity derive from multiple disciplines and sub-disciplines including: psychology (e.g., developmental, social, cognitive,

cultural and narrative psychology); sociology (e.g, The Chicago School of Symbolic Interactionism); biology; history; and literary studies, for example. It is perhaps this very complexity which may explain the reluctance of researchers to elaborate on the concept in some of the studies reviewed above.

Conceptualisation and understanding of identity is further complicated by its relationship with the equally intricate and multifaceted concept of self (Leary & Tangney, 2012). Oyserman et al. (2012) provide a basic overview in an attempt to differentiate between the constructs of self, self-concept, and identity and provide what they call a, 'working outline,' of the constructs in order to support ways forward in research. They note that sometimes the terms self and identity are used interchangeably and that what they refer to may differ within and across different publications. Oyserman et al. explicate the concept of self drawing on William James' classic work distinguishing self as subject and self as object. In addition, the importance of the ability to engage in the mental activity of self-reflection is emphasised as being at the core of what it means to have a self (Leary & Tangney, 2012; Oyserman et al. 2012). Oyserman et al. elaborate:

"Reflecting on oneself is both a common activity and a mental feat. It requires that there is an 'I' that can consider an object that is 'me.' The term *self* includes both the actor who thinks ('I am thinking') and the object of the thinking ('about me'). Moreover, the actor both is able to think and is aware of doing so. As the philosopher John Locke famously asserted, 'I think,

therefore I am.' Awareness of having thoughts matters." (Oyserman et al., 2012, pg. 71).

Oyserman et al. note that, rather than differentiating the two (I and me), the modern concept of self incorporates both the thinking, 'I' and the object of thinking, 'me.' The tripartite relationship between thinking, having an awareness of thinking, and adopting the self as the object for thinking is termed *reflexive capacity* and is considered critical to having a self.

Oyserman et al. note that reflexive capacity can include both an individualistic and collectivistic perspective. The individualistic view centres on how one is separate and different from others, whereas the collectivistic view focuses on how one is similar and connected with others. The two perspectives can be described as the separated, 'me' versus the connected, 'us' aspects of self. In addition, individuals can adopt immersed or distal perspectives: that is, taking the original perspective as agentive actor or the perspective which others may be taking (an outside-in view).

Understandings of self (and identity) are also framed by ideas about its stability versus its malleability: that is, to what extent the self is context specific and dynamically constructed in the moment or interaction. Oyserman et al. suggest that comprehensive theories of self posit stability and fluidity as co-existing features of self. Similarly, the dual role of self as a product of social situations, as well as

influencing and shaping behaviour in such contexts, is highlighted. Oyserman et al. observe that the social context can be conceptualised at the macro, meso-, and micro level. They note that at the macro-level, contexts might include the historical era, and culture and society. The meso-level context might include, one's family (and family socialisation processes), school, and neighbourhood. The micro-level contexts are defined by moment-to-moment situations and interactions that one experiences.

In addition, an individual's ability to reflect upon themselves in relation to these factors and view themselves from numerous standpoints gives rise to the concept of their being not just a singular, 'me' but a multiple me or selves. Therefore the intricate nature of self is further complicated when one considers whether there is one self or multiple selves.

To summarise, Oyserman et al.'s operationalization of the concept of self encompasses a view where the self is: stable yet fluid; ascribed social agency yet also a social product; and configured from numerous angles relating to combinations of temporal, individualistic-collectivistic, and self-other perspectives. They note that individuals are:

“...able to reflect on themselves over time and from multiple perspectives, people can evaluate themselves using multiple standards, predict how social interactions will go, and self-regulate by acting in ways that facilitate

future self-needs and wants. In that sense there is not a single *me* but multiple me's, or at least multiple facets to each me. Rather than consider these multiple selves, we propose considering each of these as structuring self-concepts." (Oyserman et al., 2012, pg 72).

Here, Oyserman et al. link the term self with the terminology 'self-concepts.' They explain that the mental concepts relating to the 'me' (who one is, was and may become) are the content of self-concepts.

"Self-concepts are cognitive structures that can include content, attitudes, or evaluative judgements and are used to make sense of the world, focus attention on one's goals and protect one's sense of basic worth." (Oyserman et al., 2012, pg 72).

The study of self-concept is divided into content (with evaluative judgments) and structural aspects. The content feature of self-concept may focus on a particular domain, e.g., athletic ability, and asks individuals how they describe themselves and evaluate themselves in relation to this. The structural aspects of self-concepts refers to the organisation of self-concepts. For example, individuals may organise and structure their self-concepts around some domains other individuals may employ to make sense of them, e.g., their race, gender, age or performance at school. If such social information is used to organise self-concept then the

individual may be described as being, 'schematic,' for that domain and will process related information more efficiently and remember it better (Oyserman et al., 2012).

Oyserman et al. link the construct of self-concept to identity. Identities are conceptualised as the traits, characteristics, social relations, roles, and group memberships that define who one is. They are connected to the past, present and future and are orientating in that they provide a meaning-making framework (Oyserman, et al. 2012). Identities constitute one's self concept (that is, what comes to mind when one thinks of oneself, one's theory of one's personality and what one believes is true of oneself). In addition, a sense of knowing oneself is derived from one's own experiences and is related to autobiographical memory (Fivush, 2011). The importance of autobiography is discussed further below.

Oyserman et al. (2012) claim that Erikson (1963) used the term identity in a fashion akin to what others have termed self-concepts. That is, the individual's understanding of who one is, was and may become. However, Oyserman et al. posit that the term identity can also be conceptualised as a way of making sense of some aspect or part of self-concept. For example, they note that the identity literature contrasts personal, role, and social identities. Vignoles et al. (2011) term these individual/personal, relational and collective identities. Social identities (Tajfel, 1981; Tajfel & Turner, 1986) relate one's knowledge and feelings of belonging to a group and its relationship with other groups. Role identity refers to membership in a specific role (e.g., student, parent, professional) that requires

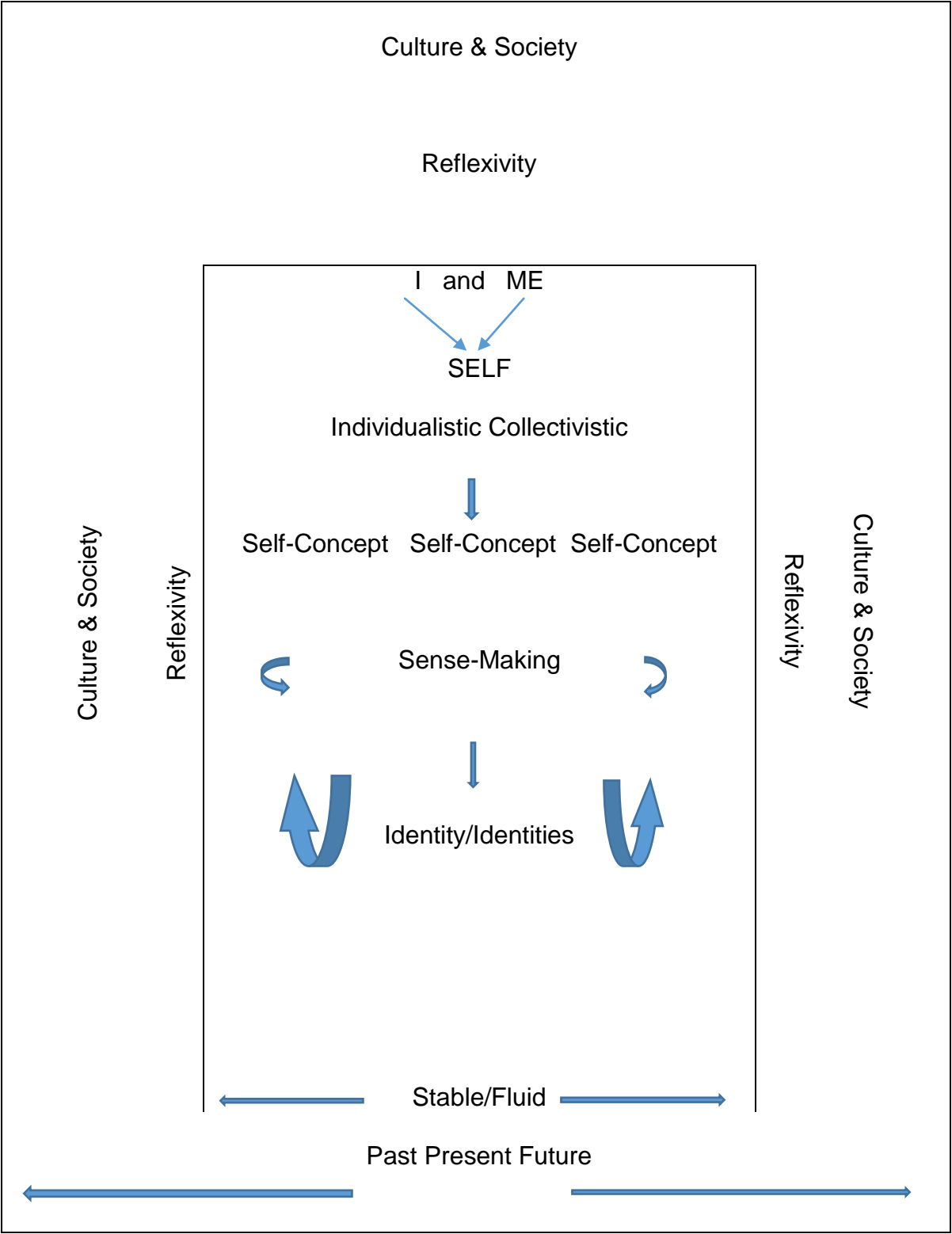
another or others to exist in corresponding or complementary roles. Personal identities refer to traits or characteristics, goals, values and beliefs. These may be linked or separate from social and role identities.

Oyserman et al. conceptualise self, self-concept, and identity as, 'nested elements,' where aspects of 'me' form self-concepts and identities are seen as being part of these self-concepts. However, it is acknowledged that the terms self and identity are often employed as if they are synonymous.

This section has provided a brief synopsis of the numerous factors relating to self and identity. Key concepts and debates arising in the study and conceptualisation of self and identity were discussed and these are summarised in Figure 1. (See page 55).



Figure 1. A Representation of Key Concepts Relating to Self and Identity



The outer frame of the Figure 1 captures the fact that an individual exists in a *culture and society* that influences his or her identity and that one exists over time giving rise to *past present and future* selves, which may be *stable* or *fluid* to varying degrees. In addition, identity is framed by one's ability to think about oneself, that is one's *reflexivity*.

At the centre of the diagram are the two components of the self, that is the self as subject and self as object. Together the *I* and the *me* give rise to *the self*. The self can be considered from *individualistic* and *collectivistic* perspectives. That is, one can think how one is separate and different from others and also consider how one is connected or related to others.

The ability to reflect on oneself from multiple perspectives gives rise to self-concepts. A process of sense-making and autobiography connect self-concepts with *identities*, which can be conceptualised as traits, characteristics, social relations, roles, etc. that define who one is. The arrows indicate the inter-relatedness of the various aspects of self, identity and sense-making.

As noted above, the identity literature is broad and disparate. What is of interest in the current thesis is the understanding individuals with autism have about their identities. The aspect that I am interested in concerns what the lived experience of individuals is, and what sense do these individuals make of their lives and experiences. As noted above, my interest is set against a context of increasing

politicisation of neurological difference and related debates in respect of ethics and emancipation. This interest in 'sense-making' is congruent with a particular field of identity research, that of narrative identity and the closely linked concept of autobiography. The section that follows discusses narrative identity.

## **2.5 Narrative Identity**

McAdams (2011, 2001) describes narrative identity as an internalised story of the self that an individual forms to make sense and meaning out of his or her life.

McAdams explains:

“Narrative Identity is an internalized and evolving story of the self that provides a person’s life with some semblance of unity, purpose, and meaning. Complete with setting, scenes, characters, plots and themes, narrative identity combines a person’s reconstruction of his or her personal past with an imagined future in order to provide a subjective historical account of one’s own development, an instrumental explanation of a person’s most important commitments in the realms of work, love, and moral justification of who a person was, is, and will be.” (McAdams, 2011, pg 100).

McAdams draws on the identity framework of Erikson and formulates it in narrative terms. McAdams references Erikson's conceptualisation of identity as a configuration of the self involving the integration of a person's talents, identifications, and roles (Erikson, 1963). This process of integration is seen to contribute to an, 'inner sameness,' which has a basis in the past and forms a basis for continuity in the future. McAdams quotes Erikson at length:

"To be adult means among other things to see one's own life in continuous perspective, in both *retrospect and prospect*. By accepting some definition as to who he is, usually on the basis of a function in an economy, a place in the sequence of generations, and a status in the structure of society, the adult is able to *selectively reconstruct* his past in such a way that, step for step, it seems to have *planned him*, or better, he seems to have planned it. In this sense psychologically *we do choose* our parents, our family *history*, and the *history* of our kings, heroes, and gods. By making them our own, we maneuver ourselves into the position of proprietors, of *creators*. (Erikson, 1958, pg. 11-12, cited McAdams, 2011, pg. 101, italics added by McAdams).

Although McAdams draws upon Erikson's framework and formulates it in narrative terms, a brief analysis is presented here to highlight their correspondence and make explicit some important theoretical underpinnings of narrative identity. McAdams' reading of Erikson's formulation of identity emphasises a number of

key aspects. These relate to seeing one's own life in a continuous and holistic manner by integrating the past, present and future: in McAdams' terms the 'evolving story of self.' Emphasis is also given to Erikson's view that the process of selectively reconstructing past experiences appears to, 'plan,' an individual or make them who they are. In McAdams' narrative recasting this appears to have synergy with the process of meaning-making, resulting in one's account of one's development, and explanation of who one was, is, and will be. Erikson also evokes history and the structure of society as influences in the identity process, and these could be said to be given form within the conceptualisation of narrative identity in the contexts of, 'settings,' and, 'scenes,' if these literary features are broadened to encompass a socio-cultural perspective.

McAdams' account of narrative identity postulates that identity work is aimed at developing a sense of sameness and continuity. Such work results in autobiographical accounts that are stable enough to allow for the emergence of themes which can provide researchers with psychological understandings of narrators and their lives. McAdams and McLean (2013) and McAdams and Guo (2015) provide an overview of such themes or, 'life-story constructs,' that have been identified in studies of life narration.

These include:

- agency, the extent to which the individual can influence change in their life;

- communion, the extent to which an individual communicates a sense of belongingness;
- redemption, where negative events eventually lead to a positive outcome;
- contamination, where a positive experience turns negative;
- generativity, the individual's commitment to promoting the growth and well-being of future generations through social behaviours (e.g., through parenting, teaching, mentoring and institutional involvement);
- meaning-making, where the individual gains some learning or insight from an event;
- exploratory narrative processing, the degree to which the individual communicates self-exploration and the development of self-understanding in their account;
- coherent positive resolutions, the degree to which tensions within the narrative are resolved.

(McAdams & McLean, 2013; McAdams & Guo, 2015)

Although these life-story constructs may be useful in examining life narratives, much of the research undertaken by McAdams resulting in the identification of the above constructs has been undertaken with mid-life adults, and therefore they may not be evident to the same extent in the narratives of individuals in other life stages, such as in adolescence.

The above section provided an account of narrative identity. However, there exists a contrasting view to the integrative life story forms of identity within the wider narrative identity literature founded in theories of discursive construction of identity (Bamberg et al. 2011).

The discursive approach to identity focuses on situated conversational contexts and the interaction between co-conversationalists that give rise to micro-genetic processes where identities are made or come into being (Bamberg & Georgakopoulou, 2008). In contrast to a canonical autobiographical narrative identity perspective, sociolinguistic discursive approaches are interested in the social function that narratives perform in everyday situations. The mode of analysis is on how individuals use stories and narratives in their daily interactions to create a sense of who they are. Therefore the focus is on situated language use as it is employed by individuals to, 'position a display of contextualized identities.' (Bamberg & Georgakopoulou, 2008, pg 379). Bruner, arguing from a cultural psychology perspective, echoes the principles of the discursive approach noting that self and identity exist in a transactional relationship with an, 'Other,' and are, 'dialogue dependent,' (Bruner, 1990, pg 101). The emergences of, 'transactional contextualism,' (Bruner, 1990, pg 105) within psychology positions self and identity (and social realities and knowledge) as *situated* within a cultural world and *distributed* between self and others (Bruner, 1990).

The discursive approach to narrative identity is located within postmodernist thinking where identities are seen as fragmented and short-lived (Gergen, 1991). McAdams (1997, 2011) acknowledges that lives experienced as fully integrated and unified entities represent an idealised psychological state. However he argues that, despite the complexities of postmodern societies and lives, individuals still aim for unity, purpose, and integration in order to achieve meaning that extends beyond any given social interaction and context.

“Narrative identity need not be *the* grand and totalizing narrative that makes all things make sense for all time in any given person’s life. Rather, people seek semblance of unity and purpose as they move into and through adulthood. They aim to make some narrative sense of their life as a whole. These efforts, as limited and fallible as they may be, are the stuff out of which narrative identity is made.” (McAdams, 2011, pg 103).

The discursive narrative and life story approaches to narrative identity are therefore unlikely to be mutually exclusive. For example, a self-other interaction will exist in any communication of autobiography, and everyday interactions will be influenced by existing self-concepts and reflective attempts at integrative meaning-making. However, as will be discussed further, narratives expressed through autobiographical accounts are best placed for the purposes of investigating the life experiences of individuals with ASCs relating to their identities. In the following section the concept of autobiography is explored in greater detail.



## 2.6 Autobiography

McAdams notes a number of scholars have emphasised that it is the action of narrative that provides human lives with a sense of unity in time Ricoeur (1984). Erikson (1963) contends that a major purpose of identity is to organise a life in time. Sarbin (1986), Polkinghorne (1988) and Bruner (1986) argue that people employ stories to make sense of goal directed behaviour as it takes shape over time. Such sense-making narratives or stories can take the form of autobiography. Erikson notes that:

“The autobiographies of extraordinary (and extraordinarily self-perceptive) individuals are one source of insight into the development of identity. In order to describe the universal genetics of identity, one would wish to be able to trace its development through the life histories of “ordinary” individuals.” (Erikson, 1968, pg 155).

Bruner (2001) notes that:

“In autobiography, we set forth a view of what we call our Self and its doings, reflections, thoughts and place in the world.” (Bruner, 2001, pg 25).

Bruner (1990) sets out the importance of autobiography in relation to the self (and hence identity). He argues that the self acts as a story teller constructing narratives about a life. In this process the self is not just a referent of the narrative, but also a product of such narrative (Bruner, 1990, 1997). In addition, Bruner comments on whether it is valuable to concern oneself with the ontological representations within such accounts. He argues that our interest is more to do with one's experiences and their related thoughts, interpretations, and understandings of these, rather than to do with whether an account is 'true' to a particular version of reality.

The development of autobiography and autobiographical memory has been studied by Fivush (2011) and Habermas and Bluck (2000). Fivush notes that the autobiographical memory needs to go beyond the simple recalling of what, when, and where (episodic memory), to incorporate an awareness and a sense of a subjective self who experienced the event (autonoetic awareness). This process involves going beyond a representation of what happened to considering how 'I' felt about it then and how 'I' feel about it now thus connecting the past self with the current self through time.

Habermas and Bluck (2000) provide a conceptual framework to bridge developmental research on story organisation with the process of autobiographical remembering and construction of life narratives. They note that the cognitive tools required to accomplish coherence in life story narratives develop during

adolescence. This observation is congruent with the view that identity comes to the fore in terms of psychological development during the adolescent years (Erikson, 1968; McAdams, 2001, 2011). Habermas and de Silveira (2008) caution that there is a distinction between coherence and stability and that the two should not be confounded. Coherence concerns the relations between different parts of a narrative and should not be confused with the stability of identity over time. Habermas and Bluck (2000) propose that there exist four types of coherence that are necessary for a global and coherent life story to emerge. These are temporal coherence, the cultural concept of biography, causal coherence and thematic coherence.

Temporal coherence involves remembering and reconstructing events in time and ordering them in relation to each other to achieve chronological semblance. The cultural concept of biography refers to normative cultural notions of events that occur within a life course and the sequence of these. For example, in Western societies this may involve a sequence involving birth, early family experiences, schooling and education, leaving home, getting a job, etc. Such biographies are framed by the societies within which one lives hence the use of 'cultural concept' as a descriptor. Temporal coherence and understanding of the biography particular to one's culture develop during the early childhood years. Bruner (1990) explains that:

“...human beings, in interacting with one another, form a sense of canonical and the ordinary as a background against which to interpret and give narrative meaning to breaches in and deviations from ‘normal’ states of the human condition.” (Bruner, 1990, pg. 67).

Bruner’s claim here is that through interaction we develop a sense of what can be considered ordinary and expected and what would constitute a violation of what is canonical. Bruner extends this to state that a requirement of narrative is that there is a, ‘readiness to mark the unusual and leave the usual unmarked.’ (Bruner, 1990, pg 78).

Habermas and de Silveira (2008) note that it is the development of causal and thematic coherence that emerges in the adolescent years and into adulthood that sets the scene for genesis of integrative life narratives. Causal coherence is seen as the integrative device that connects relationships between various events, past and present, and also between these events and the development of, and changes in, self and identity, again, both past and present. Habermas and de Silveira (2008) provide further details of what might constitute causal coherence. These include: natural causes of events and human motives for actions where the event or action is linked to later life, explanations of actions in terms of personality, explanations of changes in personality due to events, learning a lesson for the future, and the garnering of a life maxim from an experience.

Thematic coherence involves the ability not only to summarise, but also to interpret and reinterpret multi-episode stories. This relates to Bruner's observation that narrative cannot be voiceless, that is, it requires a narrator's perspective (Bruner, 1990). Thematic coherence involves an awareness of the inferential and interpretative aspects of relating a life narrative (Habermas and Bluck, 2000). McAdams (2011) notes that the development of thematic coherence allows one to identify overarching themes, values or principles that integrate different experiences in one's life to convey an overall sense of who one is. Habermas and de Silveira (2008) note that thematic coherence is more content focused than causal coherence and therefore more individualistic. However, as noted above, McAdams and McLean (2013) and McAdams and Guo (2015) have been able to delineate some commonly occurring themes which they refer to as Life-Story Constructs from the narratives of adults.

## **2.7 Autism: Self, Identity, Narrative and Autobiography**

Both Kanner and Asperger used the term, 'autism,' deriving from the Greek, 'autos,' meaning self, or directed from within to describe the behaviour of individuals in their clinical observations (Uddin, 2011). Frith & de Vignemont (2005) note that Kanner used the term 'egocentric in the extreme' to describe the children with whom he worked. However, such descriptions detract from an increasing understanding that autism represents an atypical development of self (Uddin, 2011; Lyons & Fitzgerald, 2013) rather than egocentric behaviour. Uddin

(2011) notes that the bulk of research to date has focused on differences in interpersonal and social cognition in autism but there is growing interest amongst researchers in understanding differences in intrapersonal and self-related cognition in autism.

Uddin (2011) and Lyons and Fitzgerald (2013) respectively review evidence from neuroimaging and a neuro-cognitive perspective to highlight the atypical development of self across a number of areas of functioning within individuals diagnosed with autism. Uddin's review of the literature leads her to conclude that physical and embodied self-representation is relatively intact, but psychological and evaluative self-related cognition may be impaired. However, Lyons and Fitzgerald present mixed findings in respect of body awareness and related agency. Uddin notes in particular that brain regions associated with self-knowledge and autobiographical memory (the ventromedial prefrontal cortex) may be altered in autism compared with typically developing controls. In respect of themes related to identity reviewed above, Lyons and Fitzgerald suggest atypical development and differences in the areas of: self-awareness across time; language in relation to awareness of self; autobiography (relating to the components parts of memory, emotions and self-related processing); and the narrative self.

Although the atypical development of self, narrative and autobiography is of significance, particularly if comparing atypical and typical development, it does not

preclude investigation into the sense-making and understandings of self and identity of individuals diagnosed with autism. Firstly, development in the noted areas is often described as different or impaired rather than absent altogether. This would suggest that individuals are still able to work towards semblance, unity and purpose in constructing narrative identities. Secondly, the review of the literature in Section 2.3 above indicates individuals with autism are often engaged in identity work. Thirdly, the research here is not focussed on the differences between atypical and typical development but interested in sense-making and identity as experienced by individuals with ASCs.

## **2.8 Other Frameworks of Identity**

It was noted earlier that the identity literature is vast and disparate and as such the focus of the current study would be on narrative identity due to its potential to provide a perspective and understanding of sense-making and individual experience. However, a number of studies reviewed above do make reference to other frameworks and theories of identity, albeit to varying degrees and utility. As noted earlier, explicit reference is made to: social identity theory, the ideas stemming from symbolic interactionism; and positioning theory. As such, each of these frameworks are reviewed below. In addition, although not referenced in the autism identity literature reviewed above, an overview of James Marcia's concept of, 'identity statuses,' is given. Kroger (2004) highlights the influence of Marcia's construct, noting it appears, 'in virtually every major textbook on adolescence,'

(Kroger, 2004, pg 39). As the study here investigates the experiences of adolescents with ASCs I felt it was important to consider the work of Marcia.

### **2.8.1 Social Identity Theory and Self-Categorisation Theory Approach**

Spears (2011) explains that social identity theory arose through the work of Tajfel and Turner (1986). Spears notes that the concept of social or group identity can be defined in both cognitive and evaluative terms. Social identity is therefore the part of the self-concept that relates to knowledge of one's membership of a group and with the value and emotional significance attached to that membership. For social identity to develop there needs to be a process by which categorisation into a group or identification with a group takes place and where social comparison between the group and other groups also takes place. Spears (2011) also notes that context is important in that social identity is relevant and becomes more salient in intergroup contexts.

Hogg and Vaughan (2005) note that traditional social identity theory has been extended and developed over time. They state that social identity theorists tend to describe at least two sets of identity, that is, social identity and personal identity, premised on different types of self. Personal identity relates to the self in terms of idiosyncratic traits and personal relationships and social identity defines self in terms of group memberships. (Hogg and Vaughan, 2005)



Brewer (2001) presents a further typological development. Brewer discusses: 1) the concept of, 'person-based social identities,' which examines how properties of the group identity are included as a part of the self-concept; 2) 'relational social identities,' which considers how the self is defined in relation to specific others in dyadic relationships; 3) 'group based social identities' which involves the contrasting of in-group attributes with specific out-groups or out-groups more generally; and 4) 'collective identity,' where group members share self-defining attributes but also engage in social action to influence how the group is represented and how it is viewed by others.

Social identity is associated with group and intergroup behaviours. These have included: ethnocentrism; in-group bias; group solidarity; inter-group discrimination; conformity; normative behaviour; stereotyping, and prejudice (Hogg and Vaughan, 2005). Behaviour is influenced by how others perceive the group in addition to how the group sees itself. Individuals strive for membership in positively perceived groups and in this case act to protect or enhance the esteem.

However, if evaluation of a group in society is unfavourable individuals may attempt to leave the group or, 'pass,' as member of another group. Where these actions are not possible, the group members may focus attention on other groups that are considered in less prestigious or favourable terms, or may engage in a new dimension of intergroup comparison, or redefine value of existing dimensions. Negative perceptions and evaluations of a group can also influence the behaviour

of the group in terms of collective action aimed at changing such perceptions and improving the status of the group. Such action might include, civil rights activities, political lobbying, and campaigning and revolutionary action, for example (Hogg and Vaughan, 2005).

Self-categorisation theory is closely linked to the social identity approach. Categorisation, of oneself and others, is thought to underlie the development of social identity. Hogg and Vaughan (2005) explain that individuals cognitively represent social group categories in terms of prototypes, that is a set of attributes that are considered typical or ideal, that describe one group and distinguish it from relevant other groups. This process of categorising leads to a process of depersonalisation where an individual defines, perceives, and evaluates oneself in terms of the in-group prototype and behaves, or aims to do so, in accordance with the associated attributes of that prototypical representation.

### **2.8.2 Symbolic Interactionism**

Hogg and Vaughan (2005) define symbolic interactionism as the:

“Theory of how the self emerges from human interaction that involves people trading symbols (through language and gesture)...” (Hogg and Vaughan, 2005, pg 117).

Blumer (1969) developing the work of Mead (1934), which itself was influenced by William James' conceptualisation of self as consisting of an, 'I,' and the multiple, 'me,' presents the concept of symbolic interaction as the means of the development of self and identity (Allan, 2011; Fulcher & Scott, 2011).

Central to Mead's concept of self is the human ability to be reflexive and to take the role of others. In addition, the self cannot be separated from society. Mead argues that self emerges through social experience. Social experience, involves interaction and communication with others and the exchange of symbols (such as language and gestures) which have shared meanings. Extending Mead's ideas, Blumer proposed three key concepts on which the framework of symbolic interaction is based (Allan, 2011). Firstly, human actions are based on meanings; secondly, these meanings are derived from social interactions; and thirdly, these meanings are mediated through an interpretative process.

Mead's concept of the self, as well as incorporating the concept of reflexivity, also includes the idea that the self is reflective. The self as reflective is based on Cooley's, 'looking-glass self', that is, the self derived from seeing ourselves as others see us, or how we perceive others see us (Hogg & Vaughan, 2005; Macionis & Plummer, 2012). Mead's work indicates that as an individual grows, they develop an increasing understanding of how others might perceive them that eventually leads to the development of the concept of a, 'generalised other,' which can be seen as the general attitude or perspective of a wider community.

Allan (2011) describes how Mead saw the individual develop a sense of self by going through a process of gaining social experience through taking the role of others, beginning with specific others before extending this role taking to a generalised other. Mead thought individuals were not born with a sense of self and that early stages of imitation and mimicking behaviour were undertaken without understanding as the child is unable to use symbols. Following this period, an increasing use of symbols allows the child to engage in play characterised by role playing and taking the perspective of another. Typically, the child was thought to engage in role play related to, 'significant others,' such as parents, taking the perspective of one, 'other,' at a time in one situation at a time. Later development sees the child engage in play which involves taking the perspectives of a number of people simultaneously. Mead proposes that this period of the development of self involves taking the perspective of several others in one situation, such as in a team game. The development of the concept of a generalised other occurs when an individual makes reference to widespread cultural norms and values in relation to evaluating oneself, that is, considering many others in many situations (Allan, 2011; Macionis & Plummer, 2012).

Fulcher and Scott (2011) note that Erving Goffman (1959), also working within the symbolic interactionist tradition, further extended Mead's work to put forward concepts relating to the social presentation of the self (or impression management) and, 'performing a self.' Goffman's work draws an analogy in theatrical terms with actors on a stage presenting to an audience leading to what Goffman terms, dramaturgical analysis, that is, the investigation of social

interactions in terms of theatrical performances. Goffman offers terms such as costume, props, script, manner, and stage to refer to dress, objects, language, tone of voice and gesture, and settings involved in social interactions (Macionis & Plummer, 2012). However, a crucial departure from viewing social interaction in solely theatrical terms is that, in any interaction an actor is also the audience for the performance of the individual or individuals they may be interacting with (Allan, 2011).

Allan (2011) notes that all we can know about a person's self is what the person shows us; it is portrayed (and so perceived) through cues we offer others. Cues can be manipulated for the purposes of impression management to manage the self we present. Allan also describes the concept of roles within Goffman's thesis. He notes that social situations contain roles that participants take up which are regularly expected and associated with the context. Goffman views roles as:

“...bundles of activities that are effectively laced together into a situated activity system.” (Allan, pg 78.).

Allan notes that individuals may be willing to perform roles and role-specific activities but at other times individuals may engage in role distancing, which may involve playing aspects of a role but not engaging in the role fully.

A further idea to be developed by Goffman relates to shame and stigma which may arise when an individual's performance of a role falls short, is outside expectations of the role, or is discredited. Goffman mentions disability as an example of stigmas where individuals may be discredited by what Goffman calls, 'normals.' It is argued that obvious stigmas create tensions in interactions leading normals to divert attention in order to reduce that tension, and leading those who have been discredited, to use humour, or minimisation, or work at passing as normal (Allan, 2011). Parallels can be drawn here with aspects of social identity discussed above where individuals may try to distance themselves from membership of a group which is negatively perceived.

Allan (2011) describes Goffman's three part typology of identity: social identity, personal identity, and ego identity. Social identity is conceived as the biography or story that distant others can relate about us. This takes a categorical approach. Each category having associated attributes and normative expectations. Categories are used to assume something about how the person works inside, and leads to culturally related expectations or demands. There are clear parallels here with aspects of social identity theory. Personal identities are stories held by people close to us, those who have known us longest, and with whom we had the greatest number of interactions, and to whom we have cued or communicated more of our idea of how we see ourselves. Personal identities involve more enduring characteristics and repeated presentations of a self with intimate others over time. Therefore an individual is more accountable to that self with less scope to present in different ways.

Social and personal identities are seen as related to the situational self. In contrast, in the concept of ego identity, Goffman proposes something different. Ego identity is:

“first of all a subjective, reflexive matter that necessarily must be felt by the individual whose identity is at issue. (Goffman, 1963, p106, cited Allen, 2011, pg 75).

Allan explains that ego identity is our own construction and the story we tell ourselves of who we are, which includes a sense of one's own situation, continuity and character derived as a result of social experiences. Goffman notes that this is not something derived from within but that we construct the story, through which we see our self, using the same cues and categorical expectations that those we interact with employ (Allan, 2011).

The concept of ego identity then, has parallels with the concept of narrative identity discussed above, in that both concepts involve reflexivity, biography and a sense of continuity of self.

### **2.8.3 Positioning Theory**

Positioning and its analysis broadly comprises an examination of how speakers describe themselves, and others and their actions, in one particular way over another, generating the performance of discursive actions that result in acts of identity (Bamberg, 2011).

Davies and Harré (1990) and Harré et al. (2009) conceptualise the production of self-hood as a discursive practice. The framework draws on the concepts of three inter-related factors or conditions: positioning; speech and actions; and story-lines, which arise in-situ and in-vivo in the local context of social interactions. They introduce the concept of, 'positioning,' as a means of looking at how experience and personal identities can be expressed and understood in terms of available discourses enacted in a local context; in the 'then-and-there,' (Harré et al., 2009). Positioning theory is interested in the meanings that individuals ascribe to the actions (including speech acts) of others and the meanings that they give to what they do and say themselves.

Davies and Harre note that:

“..discourse is a multi-faceted public process through which meanings are progressively and dynamically achieved.” (Davies & Harré, 1990, pg, 46).



Interactions that take place within local contexts are governed by the practices and beliefs tied to the particular context. Harré et al. describe this as individuals having certain, 'rights and duties in relation to the local corpus of sayings and doings,' (Harré et al., 2009, pg 6). Positioning theory, therefore looks at what a person 'may do and may not do.'

Positions are clusters of beliefs about how rights and duties are distributed in the course of interaction with others. A key point is that while discourse is considered constitutive, it is recognised that individuals have agency within this practice as they are capable of exercising choice in positioning themselves. Therefore, an individual can position themselves as well as being positioned by others within an interaction and also resist particular positions.

Positions can be understood in terms of speech acts which are seen as socially meaningful and as performances (Baines, 2012). In turn, positions and speech acts are enacted relative to the context of story-lines. Story-lines can describe events, histories and unfolding narratives within an interaction.

Positioning theory is aligned to an interpretative epistemology and discursive psychology. It has parallels with narrative identity in that it focuses on story but it pays lesser attention to in-situ and in-vivo interactions. It therefore focuses on performative/dialogic aspects of identity in contrast to a narrative identity with its focus on an evolving life story aimed at developing unity, purpose, and integration

in order to achieve meaning that extends beyond any given social interaction and context.

#### **2.8.4 Identity Statuses**

Marcia (1966) undertook work to develop the adolescence identity vs role confusion stage of Erikson's theory of psychosocial development. The purpose of this stage is to develop fidelity or make commitments in terms of one's identity in relation to various domains of adult life such as occupational, family, religious, political, and sexual, beliefs, goals, and relationships (Bee & Boyd, 2004; Kroger & Marcia, 2011). It is suggested that the process involves, to varying degrees, a period of, 'crisis,' which is defined as exploration, evaluation, and decision-making followed by commitment to specific roles and ideologies. Marcia proposed four different identity statuses as follows:

- Identity Achievement, the individual has been through a crisis and has reached a commitment to ideological or occupational roles;
- Foreclosure, the individual has not experienced a 'crisis' but has made commitments which may have been ascribed parentally or culturally;
- Moratorium, a crisis is currently being experienced but no commitments have been made; and

- Identity Diffusion, the individual is not in a crisis and no commitments have been made. Identity diffusion may represent a period before a crisis or failure to reach a commitment following a crisis.

Kroger and Marcia (2011) note that the construct of identity statuses can be used as an indicator of a global identity status based on several domains or that they can be used to examine identity commitment within a single domain such as occupational identity (Skorikiv and Vondracek, 2011). In addition, Kroger and Marcia present a review of the evidence relating to the construct validity of the identity statuses and their predictive validity (Kroger & Marcia, 2011).

Despite the enduring popularity of the construct, some researchers have noted the limitations of the concept. Bee and Boyd (2004) note the model is influenced by the culture of industrialised Western society, and that much of the research undertaken has been with college aged students therefore failing to account of identity in other cultures and demographically diverse groups. Kroger (2004) notes other limitations of the model, including its reductionist nature, in that it does not capture the richness of identity as envisioned by Erikson, and also its failure to encapsulate the phenomenological dimensions of identity.

Despite its limitations the model, may have some utility in the current study. The research is being undertaken in the context of Western society, and specifically with participants within the psychosocial stage it purports to study, that of

adolescence, and although the model is not phenomenological, per se, the narratives of young people may provide an insight into their past and present identity statuses.

## **2.9 Summary and Conclusion**

The above sections have highlighted that the voice of the child as it relates to qualitative aspects such as experience, meaning, value, diversity, and identity can be understood from an interpretative ontological and epistemological paradigm. A review of the literature which relates the experiences of individuals with autism to matters of identity, indicated that, although identity is seen as significant, very few researchers explicitly reference theoretical frameworks related to identity in their analyses.

An overview of the complex constructs of self and identity was given and key associated processes and concepts were discussed. The theoretical framework of narrative identity and the related concept of autobiography was presented and suggested as a possible means for elucidating sense-making and identities related to the experiences of individuals with autism.

It was noted that a number of other frameworks of identity were employed to varying degrees within the literature reviewed where connections between

constructs of identity and autism had been made. In addition to the presentation of narrative identity, an overview of these theoretical frameworks of identity was also given.

The above review highlights the need for further research in the area of autism and YP's experiences and sense-making, and the related constructs of identity and identity formation, within the context of theoretical frameworks of self and identity. Such research has the potential to add to the literature about the views of young people with ASCs and influence professional practices so that they are informed by, 'insider,' knowledge and experience.

## CHAPTER III

### RESEARCH DESIGN: PHILOSOPHY, STRATEGY, AND METHODS

#### 3.1 Introduction

The research aims and questions were presented in Chapter 1. They are noted again for ease of reference. The following research aims and questions were formulated following the literature review and consideration of narrative theory.

**Aim:** Explore sense-making as related to the experiences of young people with a diagnosis in relation to the development of their identity.

**Aim:** Privilege insider knowledge by giving voice to individuals' experiences, expose practices that may be oppressive and advocate change that may help overcome these.

**Research Question:** What do YP diagnosed with ASCs say about their lives?

**Research Question:** What do the stories that YP diagnosed with ASCs relate about their lives tell us about their identities?

This chapter presents the rationale for the adopted methodology and research design employed in carrying out the research in order to meet the stated aims above and address the specific research questions.

In Section 3.2, Design Philosophy, I begin by reviewing broad ontological and epistemological debates within social science research and situate the current research within an interpretative paradigm. In Section 3.2 the design strategy is discussed. I consider the theoretical debates framing narrative research and provide a rationale for narrative inquiry as the selected methodology. In addition, the focus and means of analysis are clarified and I consider the constructs of validity and reliability, or trustworthiness, in interpretative research. In Section 3.3 I outline ethical considerations and procedures followed, and discuss the design methods employed in collecting and interpreting data.

### **3.2 Design Philosophy: Ontological and Epistemological Assumptions**

Guba and Lincoln (1998) stress the interconnected nature of questions concerning ontology, epistemology and methodology. They argue that the way in which questions about one are answered constrains the answers to questions dealing with the other two factors. Ontology raises questions about the nature of being, the nature of the world, what exists, and what is reality and what form it takes (Guba and Lincoln, 1998; Usher, 1996). Epistemology is concerned with what sets apart different knowledge claims (Usher, 1996) and the nature of the relationship between the knower and what can be known (Moore, 2005).

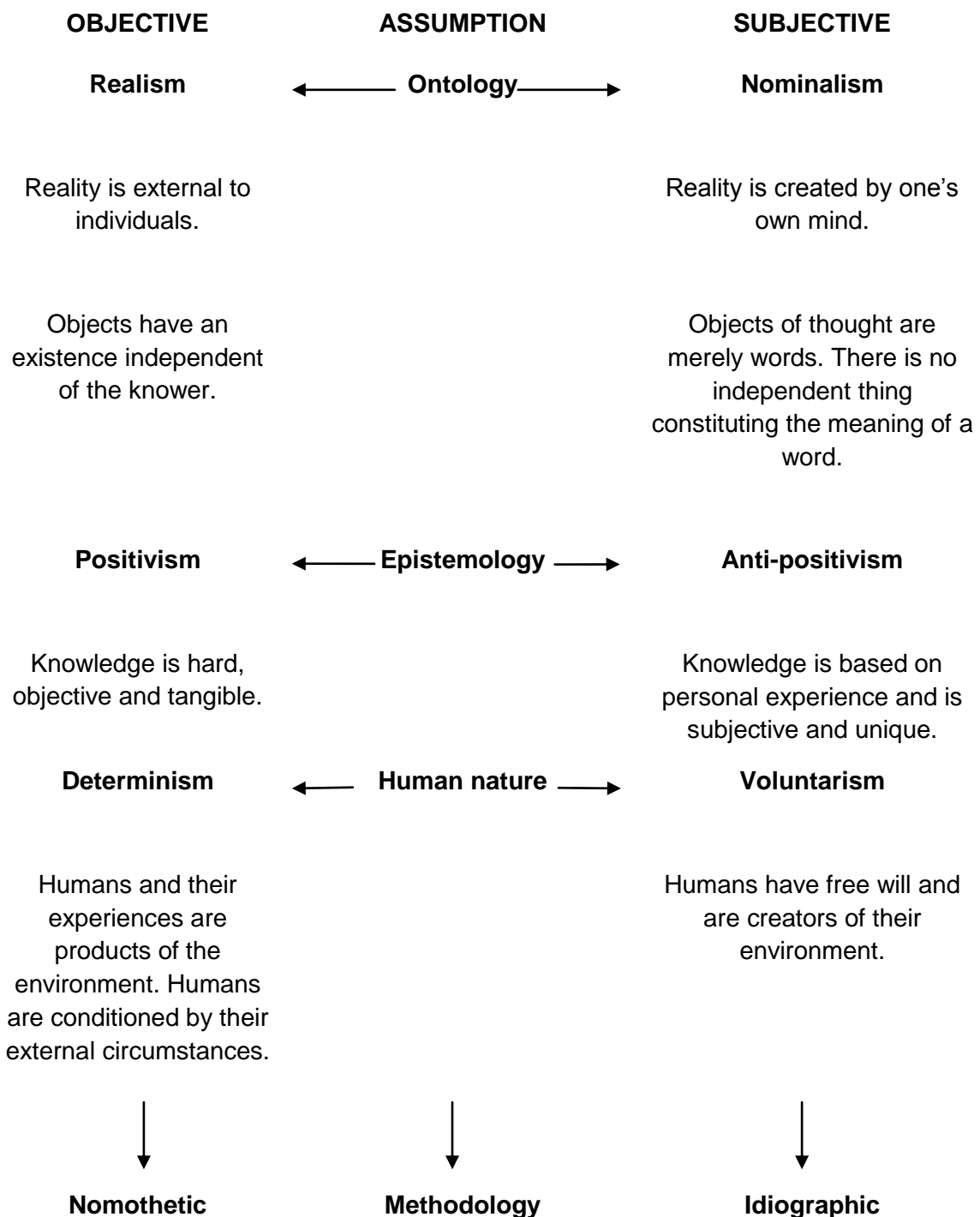
Methodological questions are about how the researcher goes, 'about finding out whatever he or she believes can be known,' (Guba & Lincoln, 1998, pg 201).

Cohen et al. (2000) discuss two contrasting views of social reality and the nature of social science along an objective-subjective (positivist-interpretative) dimension as identified by Burrell & Morgan (1979). The two views are underpinned by fundamental assumptions concerning ontology and epistemology, which in turn have direct implications for the methodologies adopted in research. Cohen et al (2000) outline the main features of these assumptions as noted by Burrell and Morgan (1979). These are summarised in Figure 2 below.

The objective/positivist approach results in methodology that is described as nomothetic. The nomothetic approach is characterised by procedures and methods designed to discover general laws. This methodology is positivist and usually quantitative in nature. The subjective approach, with its assumptions about ontology, epistemology, and human nature, results in methodologies described as idiographic. Idiographic methodology emphasises the particular, and the individual, in trying to understand behaviour. The focus is on understanding the way in which an individual creates, modifies, and interprets his or her world. The resulting methodology is interpretative (anti-positivist) and mainly qualitative in its approach.



**Figure 2. Summary of Assumptions about the Nature of Social Science along a Subjective-Objective Dimension**



Burrell & Morgan (1979, adapted from Cohen et al., 2000)

### 3.2.1 Positivism

The approach suggests that the assumptions and methods of natural science are also applicable to the social sciences. In the positivist tradition social scientists are seen as observers of social reality who are concerned with analysing and interpreting their subject matter in terms of generalisable laws and verifiable statements (Cohen et al., 2000). Robson (2002) describes further principles of the positivist approach. Positivism is concerned with objective knowledge that can only be gained from direct experience or observation. It suggests science separates fact from values and is value free. Furthermore, scientific propositions are based on fact against which hypotheses are verified. Science is concerned with universal causal laws established through correlations and manipulating variables and is evidenced on quantitative data.

Usher (1996) notes that positivist epistemological assumptions lead to an approach that emphasises and is characterised by certain key features. These include:

- determinacy- that there is certain truth that can be known;
  - rationality- that a single explanation prevails and that other contradictory explanations cannot co-exist;
  - impersonality- objectivity is paramount; the subjective (such as the researcher's values and concerns) do not interfere with the objective truth;
- and

- prediction- knowledge claims are made in the form of generalisations which have predictive value and lead to control of phenomenon/events.

The approach is considered unreflexive as it focuses on methods and outcomes. Reflexivity (enquiry into the research process itself) is considered unnecessary as long as the correct methodological procedures have been applied.

### **3.2.2 The Interpretative Approach**

The postmodernist movement argues that the principles of the positivist approach cannot be transferred to the study of the social/real world as the process assumes a closed orderly and lawful system versus an open system which is in flux and indeterminate. Attempts at closure lead to a changed system and issues of power (Usher, 1996).

Cohen et al. (2000) also note that:

“Where positivism is less successful, however, is in its application to the study of human behaviour where the immense complexity of human nature and the elusive and intangible quality of social phenomena contrasts strikingly with the order and regularity of the natural world.” (Cohen et al., 2000, pg 9).

In addition, Robson (2002) comments:

“...psychology and the other social sciences do not appear to have produced any ‘scientific’ laws yet, even though they have been at it for at least a century. This ‘failure’ has led some to consider that the whole scientific approach as inappropriate for social science.” (Robson, 2002, pg 21).

Robson (2002) also challenges the positivist notion that every scientist sees the same thing when studying the same apparent reality. He notes:

“...what observers ‘see’ is not determined simply by the characteristics of the thing observed; the characteristics and perspective of the observer also have an effect.” (Robson, 2002, pg 21).

As noted, in the literature review (Section 2.2, The Voice of the Child) Cohen et al. (2000) note that researchers subscribing to the interpretative paradigm reject positivist views of inquiry as being mechanistic and reductionist in nature and note that such a view excludes notions of choice, freedom, individuality, and moral responsibility. The interpretative approach aims to understand the social world from the perspective of the individuals who are part of the ongoing action under study.

Cohen et al. (2000) draw on the work of a range of authors to provide a descriptive overview of the distinguishing features of interpretative methodology. These are summarised below:

- People act intentionally and make meaning in and through their activities (Blumer, 1969).
- People actively construe their social world (Becker, 1970; Garfinkel, 1967).
- Situations and activities are dynamic rather than fixed; events and behaviour develop over time and are affected by context.
- Events and individuals are unique therefore limiting generalisability.
- The social world should be studied in its natural state without manipulation by the researcher (Hammersley & Atkinson, 1983).
- People interpret events and situations and act on the basis of those events.
- There can be many interpretations and perspectives of events.
- Reality is multi-layered and complex.
- 'Thick descriptions' (Geertz, 1973) are required rather than reductionism.
- Situations need to be studied from the perspective of the participants rather than that of the researcher.

Adapted from (Cohen et al., 2000)

Interpretative methodology contrasts with the determinant, nomographic, and objective approach advocated by the positivist paradigm. Gadeamer (1975, cited Usher 1996) argues that the researcher cannot separate him or herself from the historical/cultural context of the interpretative framework employed. Both object and subject are located in a framework of, 'pre-understandings,' which are situated in time, place, culture, gender, ethnicity, etc.

The interpretative paradigm and postmodernist approaches also emphasise the role of language in ontological and epistemological considerations. Usher (1996) notes that the challenge to the positivist monopoly on epistemology and the precedence or foregrounding of ontology leads one to consider the importance of language, discourses, and text and their constructive or, 'world making,' nature. Language is seen as both a creator and carrier of a culture's epistemological, 'code,' that is, the way researchers know and the way they are located in culture. Usher states:

“No form of knowledge can therefore be separated from language, discourse and texts at work within culture. The structures, conceptuality and conventions of language, embodied in discourses and texts- language as a meaning-constituting system- govern what can be known and what can be communicated.” (Usher, 1996, pg 26).

### **3.2.3 Summary**

The object of the research thesis is the identity of young people diagnosed with ASCs and an exploration of how identity is influenced by their sense-making of their experiences. The theoretical framework of narrative identity which was presented in Section 2.5 of the literature review, and matters relating to experience, sense-making, and voice of the child situate the research firmly within ontological and epistemological positions commensurate with the interpretative paradigm. In addition, as noted earlier, the context of the research is set against

agendas advocating inclusion of the views of young people in matters affecting them, and also against a context of increasing politicisation of neurological differences. Thus, the features of the interpretative paradigm described above are relevant to the current research endeavour.

Having outlined above the ontological and epistemological orientation of the research, the following section goes on to set out the rationale for employing a narrative approach to the study.

### **3.3 Design Strategy: Narrative Research**

The sections below provide a brief overview of the theoretical background to narrative inquiry and I set out a rationale for selecting this as the methodological approach for the current study. The basis for selecting the content of narrative, as the focus of analysis through the use of thematic exploration and hermeneutic procedures is explained. In addition, the concept of trustworthiness of the research is discussed.

#### **3.3.1 Theoretical Context**

Squire et al. (2013) identify two broad schools of thought which are historically associated with the, 'narrative turn,' in the social sciences. These are described as humanist approaches and secondly a range of movements associated with postmodern approaches related to Russian structuralist, French poststructuralist,

postmodern, psychoanalytical, and deconstructionist approaches (Squire et al. 2013). The humanist approach, in a challenge to positivist empiricism, aims to give priority to holistic, person-centred approaches and includes the attention to narrative at an individual level through case studies, biographies, and life histories. Postmodern approaches see narrative production (and understandings) arising from multiple and fragmented subjectivities, where narrative fluidity, contradictions, conscious and unconscious meaning, and power relations are of interest. (Squire et al. 2013).

A particular point of convergence between the two traditions is the treatment of narratives, 'as modes of resistance to existing structures of power,' (Squire et al., 2013, pg 4). Squire et al. suggest that it is perhaps because of this convergence that many researchers draw on both conceptual histories despite the differing assumptions about subjectivity, language, the social, and narrative itself. Squire et al. note that:

"Current syntheses of the two [approaches] often involve, for instance, maintenance of a humanist conception of a singular, unified subject, at the same time as the promotion of an idea of narrative as always multiple, socially constructed and constructing, reinterpreted and reinterpretable." (Squire et al, 2013, pg 5).

There are clear parallels here with the arguments presented in Section 2.5 of the literature review in relation to McAdams' construct of narrative identity and the



alternative view of Bamberg. McAdams argues that identity work is aimed at developing a sense of sameness and continuity within the contexts of postmodern societies and lives. For these reasons, there appears to be an appropriate theoretical correspondence between the research object, that is, narrative identity; and narrative inquiry as the research methodology. This is explicated further in the following section.

### **3.3.2 Rationale for a Narrative Methodology**

The research object is identified above as the narrative identities of YP diagnosed with ASCs. Narrative identity, takes shape as a linguistic autobiographical account and is a story (or narrative) of one's life. As such, the research object is, in its very nature, narrative, thus appropriately situated in the wider context of narrative research. However, this is not the only research framework that could be utilised in exploring narrative identity. The approaches of IPA and grounded theory also permit data to be in a narrative form.

However, Riessman (2008) notes important differences between the approaches. Firstly, the significance afforded to prior theory is minimised in grounded theory and IPA approaches where the theory is sought or emerges from the process of analysis. In contrast, narrative research allows prior theory to guide analysis but also permits new theoretical understandings to arise from data. Secondly, grounded theory and IPA tend to fracture narrative data, whereas narrative research aims to keep the story and the detail in extended sequences intact for

interpretative purposes. A further important difference is that of, what Riessman refers to as, a case-centred commitment in narrative research. Unlike in grounded theory and IPA where concepts are generated in order to theorise across cases, the narrative approach foregrounds the individual case (Riessman, 2008). Squire (2013), discussing the difference between thematic analysis in narrative research compared with other qualitative procedures, notes that the narrative approach is:

“...distinguished by its attention to the sequencing and progression of themes within interviews, their transformation and resolution. Thus, it foregrounds the specifically narrative aspects of texts’ themes.” (Squire, 2013, pg 57).

Here it can be seen that a case-centred approach would facilitate the type of analysis described by Squire as being particular to narrative methodology.

A narrative approach to the research is justified for a number of reasons. Firstly, there is a natural synergy between the research object: narrative identity; and narrative research, in that both share common theoretical roots. Secondly, the theoretical account framing the proposed research (that of narrative identity) has been made explicit. The investigation is aimed at exploring sense-making in relation to identity in order to add to the limited literature in this domain of autism research. Thus, the inductive nature of analysis foregrounded in other qualitative research approaches is of secondary importance in this study. Thirdly, the concepts of narrative identity relating to unity and semblance are consistent with a

case-centred approach and inconsistent with a process of fracturing data as part of analysis.

### **3.3.3 Focus of Analysis**

A further theoretical consideration relates to the content, structure, and context of narratives and their related modes of analysis. An examination of content focuses on, 'the told,' that is, 'what,' is said, and the information communicated. A focus on structure looks at, 'the telling,' that is, 'how' the narrative is said and organised to achieve the narrator's aims. Thus, the analysis moves from the narrator's experience to the narrative itself. A consideration of the context of the narrative broadens the scope of analysis to include questions relating, 'to whom,' the narrative is spoken and, 'when,' and for, 'what purpose.' (Riessman, 2008). The consideration of context takes primacy in approaches concerned with dialogic nature and performance aspects of narratives such as in discursive approaches to identity (Bamberg et al., 2011).

Bamberg (2012) notes that each of the perspectives (content, structure, and context) derive from different traditions, focus on different aspects of narrating, and pursue different types of research questions. The research aims and questions within the current study relate specifically to, 'narratives of experience,' (Squire, 2013), what sense is made of these experiences, and how this sense-making relates to matters of identity as evidenced through autobiography and life

story. The research is therefore primarily concerned with ‘what’ the narrative communicates, and hence, content focused.

Riessman (2008) notes that thematic analysis is congruent with narrative inquiry concerned with content and Squire (2013) highlights the significance of hermeneutics to the process. Squire (2013) notes that the search for a valid interpretative frame is one of the challenges of conducting narrative research. She notes that the process of describing data thematically:

“...involves moving back and forth between the interviews themselves and generalizations about them in a classic ‘hermeneutic circle’, using a combination of top-down and bottom-up interpretive procedures.” (Squire, 2013, pg. 57).

The specific approach undertaken in relation to the thematic analysis of the data is explained in Section 3.4.4 further below.

### **3.3.4 Case Study**

Biography or life history work can be considered as a particular kind of case study where the ‘case’ is an individual person (Robson, 2002). Although this particular genre is unusual in social science research, Robson argues there is no reason why life history research should not share the features of systematic study.

Qualitative case study facilitates investigation of a specific phenomenon within its context and is of particular utility when considering, 'how' and 'why,' questions; when it is not possible to manipulate the behaviour of participants; when the researcher may be interested in contextual factors relevant to the phenomenon; or where the boundaries are not clear between the phenomenon and the context (Yin, 2003).

The case study approach is relevant in the current study as I am interested in how individuals diagnosed with autism make sense of their experiences and how this contributes to the development of identity. In addition, if the phenomenon is taken as identity within the context of life story, then the phenomenon and context are clearly inseparable.

Yin (2003) also describes different types of case study: exploratory, descriptive, and explanatory, which are dependent on the research aims. The nature of the study here is essentially an exploratory investigation into identity in relation to the experiences of young people diagnosed with an ASC.

### **3.3.5 Trustworthiness**

Robson (2002) argues that reliability and validity (including generalisability) as operationalised in the positivist tradition are of limited utility in interpretative/qualitative designs. He notes that in order to establish reliability and

validity in the interpretative paradigm one needs to consider the credibility and trustworthiness of the research.

Riessman (2008) sets out a number of considerations specific to narrative research in respect of the demonstration of credibility and trustworthiness. She posits that two levels of validity are important in narrative research relating to: 1) the story told by the narrator; and 2) the validity of the analysis or the story told by the researcher. Moreover, it is argued that the validity of a project should be evaluated from within the situated perspective and traditions that frame it. Credibility and trustworthiness are construed in terms of correspondence (historical 'truth'), coherence, persuasion and presentation within the framework of narrative inquiry. These are discussed below in the context of the current research and were employed where feasible.

### *Correspondence*

Correspondence relates to establishing truth claims in relation to the data. In some research situations this could be done by way of establishing corroboration via references to other data or individuals, for example. However, within the context of this study establishing correspondence would have been difficult to obtain against extended life stories spanning several years, and in any case, not of particular importance. The research is concerned with life story sense-making and interpretations and so the concept of correspondence would have limited applicability. In fact, Bruner (1991) argues that in social reality the difference between fiction and the truth would be far from obvious. As such, narratives

relating to lived experience are not truthful reports but interpretations from a particular perspective. This is echoed by Elliot (2005) who notes that the internal validity of narratives is problematic if they are viewed as realist descriptions of the social world. However, this is not the case, if the research interest is in the meanings attributed to experiences and how these are communicated.

Establishing correspondence in relation to a researcher's interpretive work as part a project is also of concern. One suggestion is that this can be evaluated by considering the plausibility of reported findings by comparing consistency with existing knowledge. As such, my analysis and reporting is cross referenced with existing knowledge and previous findings where appropriate.

#### *Coherence, Persuasion and Presentation*

Coherence relates to whether a story, 'hangs together.' This can be evaluated by assessing whether accounts demonstrate causality and continuity (Riessman, 2008). However, where this is not the case, as may arise in the proposed study due to the differences in the narrative skills of the participants, Riessman suggests the researcher needs to make sense of any convergence and divergence. In respect of the researcher's analytic story, validity can be enhanced by promoting meaning and coherence theoretically by linking pieces of data.

Credibility and trustworthiness are also strengthened if the researcher's story is persuasive and the data and interpretations plausible, reasonable, and convincing. This is achieved when the theoretical position is supported by the narrators'

accounts, negative cases are included, and alternative interpretations considered (Riessman, 2008). Coherence and persuasion were enhanced by making the rationale and process of the research as transparent as possible. This included presenting details of how the study was conducted, how data were collected and interpreted, and by demonstrating why particular conclusions are drawn over others.

A further measure that can be taken in qualitative research to enhance validity is the process of engaging participants in reviewing the interpretations and conclusions drawn by the researcher (Riessman, 2008; Yardley, 2008). However, engaging in such a process is not always appropriate or feasible in some circumstances. For example, individual sense-making may change and develop between times of data collection and presentation of analysis; theoretical concepts driving analysis and conclusions may be inaccessible to participants; and the researcher's interpretations may reveal contradictions and alternative meanings, which although not invalid, the participant may find unhelpful or wish to challenge (Riessman, 2008, Yardley, 2008). For these reasons, the analysis and conclusions were not presented to participants for 'checking.'

In respect of external validity, that is, the extent to which findings can be generalised beyond the research context a number of arguments are noted. Although, case-centred narrative research is often based on the, 'individual,' and the 'particular,' and therefore difficult to generalise, Flyvberg (2006) argues that individual cases do contribute to knowledge within the given field of research. In



addition, Elliot (2005) argues that narrative research acts to inform us about the cultural context within which participants make sense of their world. Therefore, in these ways, findings can have significance beyond the immediate context of the research project. In order to promote this process, the writing up of findings aimed to make explicit new insights and contributions to the domain of autism and identity, and linked these to the cultural framework within which they arise.

### **3.3.6 Summary**

The contradictions within the assumptions of narrative research are acknowledged and a working synthesis is adopted which has a level of correspondence with the construct of narrative identity. Alternative methodologies were considered but rejected in favour of a narrative approach. A rationale for focusing analysis on the content of narratives over structural and contextual features is given. In addition, an analytical approach involving thematic analysis and hermeneutics is highlighted as the means to elucidate narrative content.

## **3.4 Design Methods: Ethical Considerations, Participants, Data Collection, and Data Analysis.**

In this section I outline the particular measures taken to ensure the study met ethical requirements, the selection of participants, how data were collected and the analytical approach taken in arriving at interpretations of the data.

### **3.4.1 Ethical Considerations**

The recruitment of participants and the research process was conducted in line with frameworks of ethical research practice advised by the following codes of conduct:

- The British Psychological Society's (BPS) Code of Human Research Ethics (BPS, 2010).
- British Educational Research Association's (BERA) Revised Ethical Guidelines for Educational Research (BERA, 2011).
- University of Birmingham Code of Practice for Research (2014).

Ethical considerations and challenges relating to the proposed study are set out below alongside my approach to managing these in order to satisfy the requirements of the University of Birmingham Application for Ethical Review procedures. The Application for Ethical Review was completed and submitted and approval from the Research Ethics Committee was confirmed before the commencement of the research project.

#### *Recruitment of participants*

The parents/carers of potential participants were made aware of the nature and rationale of the research and what the process would involve. If interest was expressed by the parent then a meeting was arranged with the individual young

person alongside the parent where the research was explained and a request made for consent following a period of reflection.

### *Consent*

Parental and individual consent from the YP was sought verbally and with a signature before interviews were conducted. In cases where there was an interval between gaining consent and the interview taking place verbal consent was sought again to ensure the YP was still happy to proceed.

### *Withdraw*

Parents and individual YP were be made aware of their right to withdraw from the project at any point without explanation using any method of communication that suited them.

### *Confidentiality and Anonymity*

No individual involved in the research was identified and transcripts were anonymised to remove any identifiers of the individuals concerned or third parties mentioned as part of life stories. Pseudonyms were used. Parents and participants were made aware that anonymised demographic information would be included in the write up. Parents and individual participants were made aware of the confidentiality procedures, with the usual qualifiers relating to professional duty of care requirements in relation to child protection/safeguarding and the continuation of illegal behaviours. Parents and participants were told that they

would be apprised of any intention to break confidentiality or anonymity and the reason for doing so where appropriate.

#### *Storage and handling of data*

All data were stored securely at all times. Electronic data held on a computer was password protected and data in hard copy locked in secure storage. Digital recordings of interviews will be destroyed following conclusion of the research and examination process.

#### *Subterfuge/ non-disclosure*

There was no subterfuge or non-disclosure as part of the research design.

#### *Risk*

The potential risks of psychological distress were discussed with parents and participants when consent was sought. Specific measures that I said I would undertake to mitigate against potential psychological distress as outlined in the Application for Ethical Review are highlighted in Table 1.

**Table 1. Measures Noted in the Application for Ethical Review that would be Taken to Mitigate Potential of Psychological Distress.**

|    |   |
|----|---|
| 1. | I will ensure that YP who are receiving professional support for psychological distress or vulnerability will not be approached to take part in the study.  |
| 2. | The interview process will not compel participants to discuss any aspect of their life histories they do not wish to disclose.  |
| 3. | If during the interview process there are signs of distress the interviewing process will be brought to a close and the YP encouraged to seek appropriate support and parents will be debriefed.                                      |
| 4. | If the participants shares information that may be indicative of physical or psychological difficulties then I will recommend or refer the YP to appropriate means of professional support and advice.                                |
| 5. | There may be potential for myself as the researcher to experience upset if participants chose to discuss distressing experiences. If this arose, it was agreed that supervision with my research supervisor would have been arranged. |

### **3.4.2 Recruitment of Participants**

Baxter and Jack (2008) note that to ensure a study remains reasonable in scope the case or cases needs to be determined and bound within certain parameters. As narrative interviews can generate large amounts of data and could involve a number of interviews the decision was taken to recruit six participants to take part in the research. It was appropriate to specify a number of conditions for ethical and design purposes when defining the selection criteria. These were as follows:

- Participants were required to be in the 15-18 age range as autobiographical identity development is thought to emerge in late adolescence (McAdams, 2001; Habermas & Bluck, 2000).
- Participants would need to have verbal language skill at or above the equivalent to National Curriculum Level 5 for Speaking and Listening.
- Participants would need to be aware of their diagnosis of an ASC.
- Participants should not be presenting with or have recently presented with significant mental health concerns.
- Participants should not take part if it was thought that talking about their lives to date would cause them psychological distress.

The participants were recruited from across two LAs in the West Midlands. Five participants were recruited through contact with their school's Special Educational Needs Coordinator (SENCo). A sixth participant was recruited following contact with the YP's mother which was brokered by a colleague who worked with the YP in relation to their ASC.

Direct contact via telephone was made with SENCos in secondary schools in order to describe the research project and ascertain if they knew of any students who would meet the selection criteria. If SENCos knew such students they were asked to approach the parents of the YP to see if they would be happy to meet with me to discuss the project further. Parents were given the choice of meeting with me with or without their child at this initial stage. All the parents chose to meet with me together with their child to discuss the project. The 'Information

Sheet for Parents,' and the 'Information Sheet for Participants' (see Appendix 1) were shared via SENCos and directly with one parent via email before the meeting and were reviewed with the parent and child at the initial meeting before consent was requested. Written consent was obtained from both the parent and the YP (see Appendix 2 for copies of consent forms).

Each participant was only interviewed once, with four of the interviews taking place at the individual's school and the other two in the participant's home.

### **3.4.3 Data Collection**

Riessman (2008) notes that most narrative studies in the human sciences are predicated on interviews. Narrative interviewing is aimed at producing detailed accounts rather than the traditional interviewer/respondent exchange with the constraining features of the researcher's agenda (Mishler, 1986). Thus, a climate that allows storytelling needs to be established, which may involve viewing the interview more as a conversation and the researcher yielding control and power and allowing the narrator to follow their own agenda (Riessman, 2008).

In relation to the nature of interviews, Kvale and Brinkman (2009) argue that conversations are the primary means of knowledge production and sharing understanding and as such should form the model for interviews. Squire (2013) notes that most experience-centred narrative interviewing is semi-structured and may range from the interviewer saying very little, to asking questions about

aspects of the life course if these are not forthcoming, to seeking expansion of points the narrator makes but does not elaborate on. Holstein and Gubrium (1995) also suggest the role of the interviewer is to facilitate the interviewee's interpretive skills as the meanings and understandings of life experiences do not necessarily come ready formed (Holstein & Gubrium, 1995; Elliot, 2005). Other researchers (e.g. Wengraf, 2006; Hollway & Jefferson, 2008) argue there is a place for minimal structuring in order to facilitate more improvised and extended accounts.

Czarniawska (2004) and Squire (2013) amongst others, appear to advocate a flexible approach to interviewing which can be dependent on the research focus and the participants involved. It is thus feasible that even within one bounded research project, varying approaches may be employed between cases in order to elicit narratives. As such, an informal and flexible approach to interviewing was undertaken in the study in order to facilitate the production of life stories.

McAdams (2008) has produced the, 'Life Story Interview,' schedule to help elicit life story narratives. This was used as a guide to develop a 'life story grid' along with a set of prompts to act as an aid during interviews (see Appendix 3). The purpose of the grid was to help the YP: 1) plot out different age phases to prompt them to think about their past, present and future; and 2) discuss key experiences (high and low points), important relationships, their thoughts, and feeling about themselves and in relation to their diagnosis, turning points, changes overtime, and their hopes and dreams about their future.



It was not intended that the grid was something to complete but a visual and structural aid to help guide the interview process. Nor was it intended that every aspect or prompt would need to be covered as the aim was to facilitate an informal conversational style of interview.

The interviews were recorded on a digital voice recorder for the purposes of transcription and analysis.

#### **3.4.4 Data Analysis**

In this section I set out the approach taken in the interpretation of the narrative accounts collected and describe the specific procedures followed. Broadly speaking the following procedure was followed:

- 1) recordings of the interviews were transcribed;
- 2) original transcripts were read a number of times and converted to working transcripts by sectioning them into episodes;
- 3) transcripts were re-read and narrative indicative of meaning-making was identified through examining the *sjuzet* (this concept is elaborated further below);
- 4) following further re-reading, narrative themes and related identity constructs were identified through a process of within-case thematic narrative analysis; and

5) themes, related episodes and identity constructs were collated in tabular form.

This process then allowed for the synthesis of themes with explicit expositions of identity through further interpretative work as presented in each of the participants' stories in Chapter IV.

In Chapter II it was noted that McAdams' account of narrative identity results in a developing sense of sameness and continuity, and that such identity work results in autobiographical accounts that are stable enough to allow for the emergence of themes which can provide researchers with psychological understandings of narrators and their lives. (McAdams 2011). Thus, the analytical approach commensurate with this conceptualisation and also consistent with the research aim of understanding meaning-making was that of thematic analysis. (Also see Sections 3.3.2 and 3.3.3 above).

Riessman (2008) notes that there are a number of approaches that can be taken within the broad range of narrative thematic analysis, but that a key feature is that narrative scholars attempt to keep an individual's story intact rather than examining themes categorised across cases. As such, analysis was undertaken within each life story account and not across the corpus of collected data in order to retain the integrity of the individual participants' stories.

A review of approaches to narrative analysis revealed there to be no one particular method that could be considered as representative of the manner in which to carry out analysis. Instead, it was apparent that a variety of methods and procedures were employed depending on researchers' objectives and interests.

In the current research, I was interested in a content focussed approach to the thematic narrative analysis of the collected life stories that included a focus on experience and related meaning-making. My particular interest was in narrators' meaning-making. This led me to draw on specific features of the framework of Narrative Oriented Inquiry (NOI), a psychological approach to narrative research proposed by Hiles et al. (2009). The framework was considered appropriate in relation to the current thesis as the authors note that it is focussed on research with personal narratives, and specifically, on data collected from narrative interviews. Furthermore, NOI is positioned as a broad framework for narrative research which is not prescriptive in its approach (Hiles et al. 2010), thus allowing flexibility in response to the particulars of a given piece of research. Therefore, I focussed on the aspect of the framework particular to meaning-making, that of the *sjuzet*. This concept is explained further below.

### *Transcription*

A professional transcription service was employed to convert the audio recordings of the narrative interviews into transcripts in tabular form. The exchanges, that is, the turns in conversation between myself and the participant were numbered. The talk was transcribed verbatim and included false starts. Extra-linguistic features,

such as, pauses, sighs, laughter, etc. were not included in the transcriptions as these were not a focus of analysis.

### *Working Transcripts*

Hiles et al. suggest that analysis needs to begin by breaking the raw transcribed text into numbered episodes or segments. They describe narratives as a sequences of episodes. A segment is considered to be a self-contained episode or 'move' in the telling of the story. Hiles et al. do not provide any further detail about what might constitute a segment or episode. Their exemplars however, often consisted of segments of no more than two or three connected sentences.

On reviewing the narrative accounts that I had collected, I decided to define episodes by changes or movements in the events or topic under discussion in order to allow episodes to retain a greater narrative coherence whilst remaining self-contained. This resulted in the demarcation of longer episodes than in the examples provided in the papers by Hiles and his colleagues (Hiles, et al. 2009; Hiles, et al, 2010; Hiles 2007). In addition, I chose to annotate each episode with a brief heading or description, as way of summary and as a means of orientating myself to the main points of the episode.

Table 2 shows a section of the original transcript from one of the interviews, whilst Table 3 shows how this original transcript was interpreted into two episodes (along with the other stages of analysis to be discussed below). See Appendix 4 for a full version of the working transcript for this participant.

A column is added to the right side of the original transcript to allow for comments and notes to be made (Hiles et al, 2009). Hiles et al. refer to this as the, 'working transcript,' upon which further narrative analysis can be undertaken.

**Table 2. Example Section of Original Transcript**

|    |                |  |
|----|----------------|--|
| 73 | Researcher:    | Right. Erm so, you are a character because when you are in a group, is that what you said, you felt like you want to do the opposite?  |
| 74 | Participant 1: | It is not that it's erm, I don't think I described it very well. Forget that train of thought but yeah they see me as a... probably because I generally tend to have my own tastes and interests and stuff.                        |
| 75 | Researcher:    | Okay. So not in a group, just generally, you are saying that you might be different to, other people see you as different, is that what you are saying?  |
| 76 | Participant 1: | Yes. Not bad, they still like me.  |
| 77 | Researcher:    | So what are your interests? What is it that makes you different to, to...?   |
| 78 | Participant 1: | I guess what makes me different is that there are very few topics that interest me, the ones that do, I like to dig deep into them. So anything I see that takes my fancy, I go deep into it. Erm...                               |
| 79 | Researcher:    | What type of things?   |
| 80 | Participant 1: | Philosophy. I didn't study philosophy at school but I like reading about it in my spare time. People like Marcus Auerlius and Machiavelli  |
| 81 | Researcher:    | Okay. So you have got some kind of strong interests in things.   |
| 82 | Participant 1: | Yes.   |
| 83 | Researcher:    | You say you go deep into them.   |
| 84 | Participant 1: | Yes.   |
| 85 | Researcher:    | You feel that makes you different to other people or your, your peers, your colleagues?  |
| 86 | Participant 1: | Well when I talk to other people, maybe they do, but whenever I talk to other people, a lot of my peers, I get the feeling that none of them are at the moment interested in stuff like that, or if they are, have never heard it. |
| 87 | Researcher:    | Okay, so you have got different interests, is that what you are saying?  |
| 88 | Participant 1: | Yes.   |

**Table 3. Example Section of Working Transcript Corresponding to the Section of Original Transcript in Table 2**

|  |    |    |   |   |
|--|----|----|---|---|
| Episode 14<br><br>Own tastes and interests.                                | 73 | S: | Right. Erm so, you are a character because when you are in a group, is that what you said, you felt like you want to do the opposite?   | <b>Theme: Difference</b><br><br>Has his own interests – so is seen as different by others.<br><br><i>Identity: Individualistic ‘they see me as’ - outside in view</i><br><br><b>Theme: Ordinarity/Normal</b><br>‘not bad’ 76<br><br><b>Theme: Friendship</b><br><br>But is accepted- still liked.<br><br><i>Identity: Social Relationships- Communion</i> |
|  | 74 | F: | It is not that it’s erm, I don’t think I described it very well. Forget that train of thought <u>but yeah they see me as a... probably because I generally tend to have my own tastes and interests and stuff.</u>                        |   |
|  | 75 | S: | Okay. So not in a group, just generally, you are saying that you might be different to, other people see you as different, is that what you are saying?   |   |
|  | 76 | F: | Yes. <u>Not bad, they still like me</u>   |   |
| Episode 15<br><br>Very few topics that interest me... I go deep into them. | 77 | S: | So what are your interests? What is it that makes you different to, to...?  | <b>Theme: Difference</b><br><br>Specific interests that others don’t understand – his depth of interest in the topics also marks him out as different.<br><br><i>Identity: Self-concepts – personal traits and characteristics (go deep)</i><br><br><i>Identity: Individualistic view (‘I’- agentive view)</i>  |
|  | 78 | F: | <u>I guess what makes me different is that there are very few topics that interest me, the ones that do, I like to dig deep into them. So anything I see that takes my fancy, I go deep into it. Erm...</u>                               |   |
|  | 79 | S: | What kind of things?  |   |
|  | 80 | F: | Philosophy. I didn’t study philosophy at school but I like reading about it in my spare time. People like Marcus Auerlius and Machiavelli thought.  |   |
|  | 81 | S: | Okay. So you have got some kind of strong interests in things.  |   |
|  | 82 | F: | Yes.  |   |
|  | 83 | S: | You say you go deep into them.  |   |
|  | 84 | F: | Yes.  |   |
|  | 85 | S: | You feel that makes you different to other people or your, your peers, your colleagues?   |   |
|  | 86 | F: | Well when I talk to other people, maybe they do, <u>but whenever I talk to other people, a lot of my peers, I get the feeling that none of them are at the moment interested in stuff like that,</u> or if they are, I’ve never heard it. |   |
|  | 87 | S: | Okay, so you have got different interests, is that what you are saying?   |   |
|  | 88 | F: | Yes.  |   |

### *Fabula and Sjuzet*

Having divided the raw transcript into episodes in order to derive a working transcript, the next step in the NOI model is to break down the text into two inter-related constituent parts, these being the fabula and sjuzet. Fabula and sjuzet are terms derived from literary theory and Hiles defines them as follows:

“The fabula is the “content” of the story, i.e. an account of the original events as they might actually have occurred, while the sjuzet is the “form” of the narrative, i.e. the “window” onto the events offered in the telling of the story.” (Hiles, 2007, pg. 36-37).

The fabula then, is the outline of events that occurred. The concept of the sjuzet can be further described as:

“the situated-occasioned action of the telling of the story, together with emphasis, commentary, reflections, etc. The sjuzet is the “way” in which the story is being told.” (Hiles et al., 2009, pg 61)

Hiles (2007) provides elaboration of the concept noting that the sjuzet plays an important role in how an individual positions themselves in relation to the narrated fabula through the means of ‘emphasis, commentary, witness, memory, identity, “plotting,” and coda, etc.,’ (Hiles, 2007, pg. 40). Here, Hiles, introduces the idea that sjuzet provides a perspective onto an individual’s identity positioning.

Hiles et al. (2009) place some significance on separating the fabula from the sjuzet and insist that this step must happen before any further narrative analysis can take place. However, I was presented with a number of challenges when examining how I would employ the model to the analysis of my data. Firstly, the inter-relatedness of the two concepts (fabula and sjuzet) can appear problematic. Hiles et al. acknowledge that there can exist an overlap in that some words and phrases may function as both fabula and sjuzet. A similar point is noted by Culler (1981, cited Patterson, 2013). Culler points out that as narration is highly selective, any clause may be present due to its evaluative functions rather than for the events (or fabula) it makes reference to. In addition, the conceptualisation of sjuzet offered by Hiles et al. (2009, 2010) appears to be very broad and incorporates a 'how' the story is told or structural perspective on the narrative text. The sjuzet, therefore can include: 1) the evaluations, and therefore the meaning-making, of the narrator; and 2) the structural, psycholinguistic and other features (such as laughter, crying, sighs etc.).

As noted above, the aims of the current study was to explore the experiences of YP with autism and specifically, what sense they made of these, and how this sense-making might relate to identity. The decision was therefore taken to focus analysis in terms of the sjuzet on those functions of the narrative that related to sense-making. This included examples of narrative indicative of, causal links, evaluative statements (relating to thoughts and feelings), reflections, explanations, conclusions, self-exploration and identity, for example. Such examples were underlined as is the convention described in the NOI framework. See Table 3



above for an example. The meaning making is underlined in the text, as described above in terms of how the concept of sjuzet has been operationalised here. It is acknowledged that in the terminology used by Hiles et al. (2009, 2010) this approach might be seen as an examination of form to some extent.

### *Thematic Narrative Analysis*

Having identified the sjuzet within the text as it related to meaning-making I undertook a thematic narrative analysis of each life story. Riessman (2008) notes that thematic analysis focusses exclusively on content, that is, on what is said. I took the lead provided by Braun and Clarke (2006) when conceptualising what constituted a theme. These authors note that:

“A theme captures something important about the data in relation to the research question and represents some level of patterned response or meaning within the data set.” (Braun and Clarke, 2006, pg. 82).

Therefore, a theme was identified if it related the participant's experience of who they were, how they came to be and how they thought their lives would progress in the future, that is, if it captured something significant about their identity. Particular attention was paid to references or evaluations that were repeated in the life story, and to the development of any particular narrative theme throughout the account shared. Therefore, the approach taken was congruent with Squire's observation that:

“...narrative analysis that is broadly focused on the content or semantics of stories, is distinguished by its attention to the sequencing and progression of themes within interviews, their transformations and resolution.” (Squire, 2013, pg. 57).

The following procedure was followed. The transcripts were re-read and identified themes were noted down. Following this, each episode of the working transcript was re-read in light of the themes generated and for further possible themes. Themes were noted in the right hand column of the working transcript and emboldened (see Table 3).

The simple generation of themes would have fallen short of the stated research aims of exploring identity. Therefore, during the thematic analysis process each episode and the underlined sjuzet were also considered in relation to identity. In doing so, I was able to highlight features of identity as they occurred within themes. A brief comment indicative of features of identity was noted in the right hand column and shaded grey for ease of reference (see Table 3). This interpretative process was driven by the findings presented in the literature review relating to both autism and identity and was therefore deductive in nature. The focus for the examination of identity was guided by the following concepts from the literature review in Chapter II, which together acted as the interpretive framework:

- Key Concepts Relating to Self and Identity (see Figure 1, Section 2.4)
- Life-Story Constructs (McAdams & Mclean, 2013; McAdams & Guo, 2015; see Section 2.5)
- Causal and Thematic Coherence (Habermas and de Silveira, 2008; see Section, 2.6)

In addition, reference was made to the concepts offered by social identity theory, symbolic interactionism, and identity statuses where appropriate (see Section 2.8).

#### *Collation of Narrative Themes and Identity Concepts*

Once the thematic narrative analysis process had been completed and reviewed, a table was constructed noting the resultant themes, the episodes in which they occurred, and what was gleaned about identity. (See Table 4 for an illustration of this). This resulted in the categorisation of sections of narrative relating to narrative themes within an individual life story. The narrative was retained in its holistic form up until this point. In addition, the themes tended to run through and develop throughout the narrative, therefore retaining a holistic composition. There was also overlap between some themes as sections of talk were indicative of more than one theme.

**Table 4. Collated Narrative Themes and Identity Constructs for the Working Transcript of the Interview with Participant 1**

| <b>Narrative Theme</b> | <b>Episode</b>                   | <b>Identity</b>  |
|------------------------|----------------------------------|--|
| Ordinariness           | 1, 5, 6, 7, 8, 10, 14, 16, 21,35 | Canonicity   |
| Friendships            | 2                                | Communion  |
|                        | 14                               | Social Group / Communion   |
|                        | 23                               | Communion  |
|                        | 24                               | Personal Values and Characteristics – Loyalty                    |
|                        | 29                               | Social Group / Communion   |
| Independence           | 3,4                              | Separateness from family   |
|                        | 32                               | Separate but connected   |
|                        | 33                               | Canonicity   |
|                        | 34                               | Separate from family   |
|                        | 35                               | Canonicity   |
| Self as Different      | 13                               | Individualistic – agentive                                       |
|                        | 14                               | Individualistic (outside in view)                                |
|                        | 15                               | Self-concept- personal traits/characteristics<br>Individualistic |
| Personal Growth        | 27                               | Meaning- making<br>Exploratory narrative processing              |
|                        | 30                               | Commitment to political ideology – Identity status               |
|                        | 31                               | Identity status – Achievement.                                   |
| Autism / Diagnosis     | 9, 10, 11                        | Canonicity   |
|                        | 12                               | Reflexivity / self-exploration processing                        |
|                        | 17                               | Canonicity   |
|                        | 25                               | Canonicity/Collectivist Identity.                                |

In summary, each transcript was converted into a working transcript by dividing the transcribed interviews into episodes. The *Sjuzet* as it related to meaning-making was underlined. Working transcripts were then interpreted for narrative themes and identity constructs. A table was created to collate the excerpts of narrative talk relating to each theme.

The following chapter presents the results of the interpretative process described above. Each individual participant's story is presented as a set of narrative themes, which are illustrated with excerpts from the interviews. Further commentary explicitly relating the contents of the theme to concepts of identity is incorporated throughout.

## **CHAPTER IV**

### **ANALYSIS AND INTERPRETATIONS**

#### **4.1 Introduction**

The results of the analytical process described in Section 3.4.4 of the previous chapter are presented here in Chapter IV. The life story of each participant, Freddy, Racheal, Andrew, James, Dean and Patrick, is presented in turn.

As has been noted previously, each narrative account was interpreted for narrative themes relating to the individual's life experiences and development of identity. The development of each theme is followed through the life narrative and illustrated with excerpts from the narrative account. Excerpts are referenced with the initial of the participant and assigned a number relating to the order in which they appear in the account for the purposes of cross referencing.

Identity constructs and processes as they relate to the narrative themes are elucidated and discussion of these is interwoven throughout the interpretive process.

## 4.2 Freddy's Story

Freddy was aged 17 at the time of interview and at the end of his time in Year 12. The following narrative themes were identified in his account: Ordinariness; Friendship; Being Different; Personal Growth and Understanding of the World; Independence; and Autism and Diagnosis.

### Narrative Theme: Ordinariness

Freddy's interview was characterised by a sense of, 'ordinariness,' of experience. He appeared to narrate the ordinariness of his life experiences to the extent that I considered it appropriate to designate it a standalone theme within his overall narrative. However, the 'ordinary' was also narrated, within the other narrative themes derived from his autobiographical account, as will be demonstrated in due course.

Freddy's recollections of his pre-school years noted the ordinariness of life:

*"Well I don't remember much before, before school because not anything significant happened if I am honest with you." (F1)*

When asked about any low points during his primary years, he remarked:

“Nothing really significant if I am honest.” (F2)

“Just general stuff, nothing major or specific that I can remember.” (F3)

“Just standard childish stuff like err playground fights, things like that. I didn’t get into any of them.” (F4)

Home life too, is portrayed as unremarkable. Freddy recollected something which may have been out of the ordinary, in that he had a private tutor to support him with preparation for the 11 Plus, but this too was rendered unremarkable:

“Erm at home it was fairly simple. We used to get home and just relax if I am honest with you. Later on it got, I had a tutor to tutor me for the 11 Plus. Later on, on top of my school homework which wasn’t much, I had to spend a bit more time working. But before that, even then it was still quite relaxed, I would just read a book, watch TV, go outside, play on the computer or something.” (F5)



Further in the interview, Freddy was asked to discuss any low points or events that may have made him feel sad or confused during his early and mid-adolescence. Freddy noted that he did not see his extended family as much as he used to. Freddy appeared to interpret this as an unfortunate outcome of ordinary changes in circumstances by using the phrase, “that is just what it is:”

*“...my extended family, I don’t see much of them nowadays anymore. It is probably just the fact that we have grown up and people are not finding the time to speak to each other but that is just what it is.” (F6)*

Freddy used a similar phrase when discussing his feelings about making new friends when he moves to university in the future. In doing so he evaluates the potential situation as part of ordinary life:

*“Not looking forward to but not dreading either. It is what it is. (F7)*

As noted above, Freddy incorporated an ordinariness narrative into other areas of his autobiographical account. These areas include the themes relating to ‘Autism and Diagnosis’ and ‘The Self as Different.’

In relation to the diagnosis of autism he noted:

*“They just told me had something called autism, which is a condition and then I never thought much else of it.” (F8)*

He later also made the observation that he did not think the diagnosis impacted on him in a significant way.

As part of the, ‘Self as Different,’ narrative theme, having noted differences between himself and his peers, Freddy explains that this difference is not seen as, ‘bad,’ and that he is still liked by his peers. My interpretation here is that these accounts resonate with the life as ordinary narrative above.

The interpretative framework did not provide a direct link to identity in respect of this theme. However it was noted in Section 2.6 of the literature review that Bruner (1990) argues narratives constitute a sensitivity to what is canonical and what violates canonicity. As such, Bruner argues, a requirement of narrative is to mark the unusual and leave the usual unmarked. Bruner emphasises this in the view that, ‘the very act of speaking is an act in marking the unusual from the usual,’ (Bruner, 1990, pg 79). However, in the theme illustrated above it appears Freddy is marking the unremarkable. Bruner’s account of narrative, perhaps then places too much emphasis on the non-canonical at the expense of the canonical, expected and ordinary. McAdams’ account of narrative identity notes it is a subjective retelling of one’s development and a justification of who one was, is, and might be in the future. In this sense, a plausible interpretation of Freddy’s

ordinariness narrative is that this is how he sees himself. He is ordinary, and by implication like everyone else.

### **Narrative Theme: Friendship**

A second theme to be identified related to friendships. Freddy mentioned friendship on a number of occasions and emphasised the importance of close friendships:

*“Primary school itself was just a positive experience because at the end of it, well start of it of course, you don’t know anyone, but near the end of it, especially us lads we were all a pretty much a tight-knit group.” (F9)*

Talking about his time at secondary school he noted:

*“Well, when I came here of course, I came here not knowing anyone, and now my year group is a tight-knit bunch of lads.” (F10)*

He also stressed the importance of friendship in this exchange:

*“S: So is having friends important for you?”*

*F: Well yes, because if you don’t have friends, you are going to be depressed aren’t’ you?”* (F11)

Also, as noted earlier, when discussing how he was different to his peers he noted that he was still liked:

*“S: ... you are saying that you might be different to, other people see you as different? Is that what you are saying?”*

*F: Yes. Not bad, they still like me.”* (F12)

At one point, I asked Freddy to elaborate on his friendships but I was surprised by his reply and reluctance to do so:

*“S: What kind of things do you get up to with your friends?”*

*F: Just things. I am not going to share that.”* (F13)

With reference to identity processes the friendship narrative presented by Freddy can be linked to McAdams and McLean’s life story construct of communion and also to the development of social group identities. As noted earlier, McAdams and Mclean (2013) define communion as the extent to which an individual

communicates a sense of belongingness. I interpret the use of the phrase, 'us lads,' as delineation of specific group identity and an articulation of connectedness and belonging. I believe this friendship group identity to be a strong identity concept for Freddy as he discussed it a few times, and did not want to discuss the group's activities with me, possibly because I was a non-group member. This reluctance may also reflect self-concepts relating to identity associated with personal characteristics and values, in this case, a sense of loyalty to friends and his social group. However, the comment could also have been in response to power differences and what Freddy thought was appropriate or safe to disclose to an unfamiliar adult in the context of the interview.

### **Narrative Theme: Being Different**

There are a number of occasions where Freddy expressed his uniqueness, that is, his sense of how he was different from others. He related that others saw him as a 'character,' explaining:

*"Well, okay, something about me, for some reason anytime there is a group trend going on, I always feel the need to do the exact opposite."* (F14)

When asked to elaborate, he explained that he is different, not only as he has his own interests that others don't share, but also because his level of interest is often deeper:

*"F: It is not that it's erm, I don't think I described it very well. Forget that train of thought but yeah they see me as a... probably because I generally tend to have my own tastes and interests and stuff.*

*S: ... you are saying that you might be different to, other people see you as different, is that what you are saying?*

*F: Yes. Not bad, they still like me.*

*S: So what are your interests? What is it that makes you different to, to...?*

*F: I guess what makes me different is that there are very few topics that interest me, the ones that do, I like to dig deep into them. So anything I see that takes my fancy, I go deep into it.* (F15)

Freddy then explained that he was currently interested in philosophy which he had taken up as an interest in his own time and that it was not something he was studying in school. He uses this as an example of his difference from others:

“Well when I talk to other people, maybe they do, but whenever I talk to other people, a lot of my peers, I get the feeling that none of them are at the moment interested in stuff like that, or if they are, I’ve never heard it.” (F16)

Here the narrative develops around the individualistic dimension of how one is separate and different from others. Freddy tells a narrative of difference by noting his individual agency expressing the need to do the opposite or not to follow ‘trends.’ Freddy draws on a personal self-concept relating to his characteristic of pursuing his interests in depth as way of explanation of difference. Here Freddy takes the immersed perspective by using ‘I.’ He also introduces a distal perspective, an understanding of how he might be seen by others, when sharing the, ‘outside in view,’ that others see him as a character because of this difference. Having acknowledged self as different, Freddy goes on to reiterate a self as connected with others in his comment that he is still liked linking this to earlier narrative talk illustrative of communion.

### **Narrative Theme: Personal Growth and Understanding of the World**

In response to a request to consider how he had changed over time, Freddy narrated a self-evaluative comment indicative of a view that he had experienced a sense of personal growth, and derived a better understanding of the world linked to the development of political and economic views, an experience which he noted as a positive one:

“Well, of course moving from Year 6 to Year 7 and being around a different group of people has definitely changed me. That was one big change in my personality, in the way I see the world. Also what I’ve, just general reading through stuff which has made me think about things and has also made me, especially during the last few years, made me significantly change the way I see things. So through Year 9 onwards, each year has always been a massive change in the way I see the world.” (F17)

“S: How has that changed or developed?”

F: Stuff like political and economical views which I am not going to share.”

(F18)

Here Freddy was able to reflect on a sense of personal growth, although he did not articulate a great deal of explorative narrative processing, he did identify change in school and being with different people, along with reading as causal explanations for his change in personality and world view. The narrative is indicative of some self-exploration and meaning-making in that he stated he has gained learning and insight from these experiences.

Examined via the perspective offered by Marcia’s identity statues, the narrative appears to indicate a sense that some exploration has taken place and that



commitment has been made to particular ideological values, thus falling within the identity achievement category.

### **Narrative Theme: Independence**

Freddy shares a number of narratives within his overall account which I interpreted as indicative of a narrative theme relating to developing independence. He described an early life high-point of going on primary school residential trips and being away from home:

*“Some of the high-points were when I went on my residential trips in Year 4 and 5, especially the second time. So that was a lot of fun, being 9 and 10 err respectively at each time, being away from home for the first time for a week. I found that quite fun.” (F19)*

In considering his life prospectively, Freddy discussed his ambition to go to university:

*“Well, right now err, I plan to do an X degree at a University, hopefully a good one. Somewhere that is far enough from home that I can move out, but not too far that it is going to be a pain in the arse to get back, do you*

*know what I mean. So like Z would be a no, that is too far. I can't be bothered with commuting.” (F20)*

I enquired about his thoughts and feelings about moving away. In his response, he mentioned his parents, a thread that was followed through later:

*“I don't really care if I am honest. I don't care. It's fine. It is not like I am never going to see my parents or anything like that.” (F21)*

The independence narrative can be explicated with reference to the life-story construct of agency.

### **Narrative Theme: Autism and Diagnosis**

As noted in the discussion above on the theme of ordinariness, Freddy's narrative about the diagnosis and autism appeared to mark it out as unremarkable. Freddy, described his understanding at the time of the diagnosis when he was in the upper years of primary school:

*“They just told me had something called autism, which is a condition and then I never thought much else of it.” (F22)*

He was asked to reflect on his understandings over time. Freddy again remarked that autism is not a significant feature of his life experience:

*“S: What about your understanding as time has gone on?”*

*F: Of course, I have got more knowledge but I still don't think much about it. I mean, it is like err, sometimes of course, you can tell when someone is severely autistic but in my case, most people wouldn't realise it unless I told them. That is how littlely it, err sorry, that's how insignificantly affected I think I am by it.*

*S: So you don't feel that it affects you particularly?*

*F: Maybe other people can see stuff that I can't, but yeah, I am not obviously autistic.*

*S: Okay. How does it affect you?*

*F: I am not sure, if I am honest with you. I have never really looked at it.”*

(F23)

I asked Freddy whether he shared his diagnosis with others. He responded indicating that he did not and the occasion did not seem to arise:

*“Not really. Not ashamed, I just don't feel the need to bring it up.”* (F24)

*“A lot of the time, I forget I have it. I have other things on my mind.”* (F25)

Freddy’s narrative account of his experience of autism reinforces the life as canonical, regular and unremarkable view presented in the ordinariness narrative theme. It appears that in Freddy’s lived experience of autism does not impact on him or his sense of identity. This is a challenge to the literature reviewed that often notes it to be otherwise. It is possible that the existing literature tends not to report cases where autism is not seen to have an influence in terms of an individual’s identity. Freddy’s narrative highlights that we need to entertain the idea that for some people with autism, it is not going to feature in their life stories or be a point for self-exploration or meaning-making.

### 4.3 Racheal's Story

Racheal was aged 16 at the time of the interview and was in Year 11. The following narrative themes were identified in Racheal's life story account: Being Different, Being Normal, and Fitting In; Confidence and Communication; Personal Growth; The Future and Independence; and Diagnosis and Autism.

#### **Narrative Theme: Being Different, Being Normal, and Fitting In**

The three overlapping aspects of this theme occurred as threads throughout Racheal's autobiographical account.

Racheal's earliest memories were framed in relation to her sense of being different. She recalled being in splints from an early age due to cerebral palsy and how this was restrictive. She pointed out that she did not, and does not, think that she had anything wrong with her. This comment was made in relation to cerebral palsy but it is reiterated later in her narrative account in relation to autism:

*"I think that was quite strange for me because up until now really, I don't feel like I have anything wrong with me but obviously that was like the only time in my life that stopped me from doing things."* (R1)

Despite this, 'self as normal,' narrative, contradictions were identified which indicated that Racheal did not always evaluate herself as fitting into what she thought was normal. For example, when talking about herself at primary school, she related a developing awareness of difference and contrasted this with how she perceived others fitting in normally:

*"Think it was, thinking back to it now, I think it was how people like spoke to each other and I never really thought I was like them, or belonged or...."*

(R2)

*"How, just how they acted around each other and everyone seemed to like normally fit into everything and I didn't think I was like them really."* (R3)

She elaborated on her sense of being different in respect of her relationships with peers at school:

*"Like how I could erm, like go out and play and things like that and I don't know if I didn't I just didn't want to I didn't want to play with them."* (R4)

*"Yeah it just looks, it felt like I was wrong, like I didn't, like I was thinking, like they, they're enjoying it I don't know why I don't want to do it."* (R5)

Racheal's evaluation here acknowledged a sense of, 'being wrong,' in contrast to her earlier comment that, to date, she still not feel there is anything wrong with her. However, when asked if this sense of being different was a source of anxiety Racheal said:

*"I don't think it was a concern for me because I didn't really like see that as important."* (R6)

It appears a number of aspects of Racheal's identity were being communicated through the above narratives. Racheal links her past self to her present self, maintaining a view of self as stable over time in her articulation, 'up until now I don't feel like I have anything wrong with me.' Here, she also challenges dominant discourses of illness or disability but acknowledges there were things that she could not do. Racheal communicates her sense of individualistic identity and being different from others. She noted the lack of sense of a collectivist identity and communion in her comment relating to her sense of belonging. This appears to co-exist with the evaluation that different does not mean having something wrong with you, and that she didn't see it as important at the time. However, there appears to be a contradiction in Racheal's sense-making of her experience as she also stated, "It felt like I was wrong." Possible explanations might include that: Racheal meant she felt different rather than wrong; feeling wrong is not the same as feeling like you *have* something wrong with you; or that Racheal had not come

to a positive resolution about her sense of difference at the time and therefore contradictions might be expected.

Racheal identified a number of ways in which she perceived herself to be different to her peers, this included the example of play and interaction above, but also having different interests in primary school. Racheal identified that she was different as she preferred to play with animals and that she had her own interests. Having different interests to her peers is again cited when she discussed her move to secondary school and trying to fit in with others there:

*"I would consider myself just like a quiet reserved person, they were a lot louder and brought up in different erm environments to what I was and they decided to act differently to me and then, and then children at that age, children in particular can be nasty can't they and erm, just ignorant to sort of like my, other people's interests I suppose like if I found something interesting... I think, I think even now kind of like things that music that I listen to and things like that, I think I am kind of mentally more mature than them, I think."* (R7)

Racheal also described how in primary school she would attempt to fit in with peers by copying their behaviours. She later described how in her teenage years she went on to use social media and the internet to seek likeminded friends:



"Reciprocating the image of them like what they were doing kind of like."

(R8)

"Yeah. I think finding friends online and that sort of thing, because I have got friends now like, it is a lot different to when I first started and when I was younger, I'd speak to people here but even though I have got those friends, they are different to me and I thought it would be nice to find people that are like minded." (R9)

The excerpts above depict the sense of individualistic identity and the difference felt by Racheal. Here Racheal's narrative also included her search for communion and an attempt to develop a collectivist identity through finding others with similar interests.

As part of her account Racheal described how she hit a, 'massive low point,' when aged 13 and was referred to Child and Adolescent Mental Health Services due to suicidal thoughts and self-harm. The referral resulted in the diagnosis of autism. She explained her feelings at the time:

"Yeah, just not getting on with my life in general and I just felt like there was no point in being alive or anything." (R10)

I asked if she thought these feelings were connected to autism and she responded by relating a narrative of trying to be normal and trying to fit in:

*“I think it was partly the autism because if you look at it, it was sort of like a big path for a teenager is like fitting in and, and thinking they can like communicate with others and being part of this normality, I don’t know, people want to be normal don’t they. Erm I think because I didn’t think I ever thought I would fit in here, I just thought it...”* (R11)

Here the need for communion and a collectivist identity is further emphasised. However, at another point Racheal reflected on being different and her narrative suggested that she had come to accept difference following a low point and period of sense-making therefore indicating a redemptive narrative sequence:

*“I do feel different. I think, I think I always will because I am different that’s like the reality of it. I am slightly different to people but I suppose we all are but erm, I have learnt to accept people more erm I get less angry when things don’t go my way and things and like that.”* (R12)

## Narrative Theme: Confidence and Communication

The two strands of this theme are inter-related as Racheal often linked her sense of confidence with her communication skills. She talked about being a shy and reserved person, who lacked confidence. Racheal discussed her early school experiences and made causal links to how the pressure to communicate may have led to the development of a stutter:

*“R: I think, I don’t think I really enjoyed school at all then. I used to, that was when I probably used to have a lot of time off and erm, I, I stutter now but I think that was when it first started when I had to, when I was kind of forced to talk to people.”*

*S: Okay, so you didn’t like talking to people? Or did you not want to talk to people.*

*R: Yeah.*

*S: Is that erm, so did you say you were forced? How do you mean you were forced?*

*R: Well not forced but like it was kind of an environment where I had to kind of communicate.” (R13)*

In the excerpt below, Racheal discussed how her confidence had changed and how it related to communication:

*“R: I, I’ve have changed a lot now because I am a lot more confident now, I used to be really, really shy like probably like last year I probably wouldn’t be here talking to you.*

*S: So what, what’s, why has that happened? What’s changed? What was the turning point?*

*R: I think it was gradual. I introduced myself to a lot more people and I don’t; know, I try and talk to people now because I know you can’t really get anywhere if I refuse point blank, refuse to communicate with people.*

*S: And how do you find that, how do you find communicating with people?*

*R: Erm, I find it easier now because I do things on my own terms so it’s not like I have to talk to people.” (R14)*

Racheal’s narrative portrays a sense of personal agency and control as the reasoning behind her improved communication and confidence. This was described further when she discussed meeting people on-line:

*“I suppose when you first talk to people like, I suppose on-line say if you, if you don’t like someone you meet them in person you can’t really tell them*

to go away but if you are online and you don't like someone you can just not talk to them, it's as easy as that because you have never seen them before so you don't have to talk to them you can just stop talking to them."

(R15)

Racheal also discussed the influence of her father on her confidence. Racheal had reported that her father was abusive to her mother, and that growing up in such an environment made her feel nervous and anxious. When he left the family home she said there was space available for her to relax and be normal. She saw this as a turning point in relation to her confidence. However, personal agency and her own proactive efforts are considered most important:

"I think it was when my dad left I was a little bit less jumpy and things. I think that, I think because there was no stress at home then it was easier for me to kind of figure out that that was the normal way to live without being in constant fear all the time. It was like... I could just relax more."

(R16)

"Yeah that was a big thing my dad and then I think it was like a personal thing rather than like I actually actively had to go out and try basically even if my efforts weren't exactly perfect I tried to talk to people and I tried to interact and I tried because obviously if I just sat there and did nothing I know nothing would improve." (R17)

Personal agency is again emphasised when Racheal discussed her future. She considered the benefits of moving to a new educational setting after Year 11 in order to challenge herself. However, she considers the risks of getting stressed and hedges towards staying in her current setting:

*“R: I just wanted to, I wanted change and I think this was part of the thing that I don’t like to be told that I can’t do things. I wanted to go out and try and be different and, and kind of throw myself into something that would probably make me anxious but, or build me as a person.”*

*S: Okay. So you are saying that by trying new things, although it makes you anxious, it does build you, build you up as a new person and adds to your experiences. Yeah?*

*R: But I think staying at Sixth-form as well, I think this is a time to not really toy with stuff like that making myself stressed out, I think I will just stay here, get on with the next two years and I can carry on with whatever then.”*

(R18)

### **Narrative Theme: Personal Growth**

Racheal was asked to consider the last few years of her life. In doing so, she noted how she had changed and developed as a person:

*“R: Erm the past couple of years I think is like it is when you kind of shape yourself as a person and, and decide what sort of person you want to be in life and how you want to act towards people and I think, and the sort, the sort of things that you want to do. I think it is important as a teenager to kind of get out your system of hanging around with people that are not really good for you and I don’t know, being mischievous or something like that.”*

*S: So during the last couple of years have you been thinking about the type of person you want to be?*

*R: I think, I think so. Like, I kind of... I don’t know I take things in a lot about other people like, I erm... I don’t know. Like I watch people and I can pick up how they are and things like that and I think that’s how I kind of formed my own personality of picking out the traits of people that I liked.” (R19)*

Here Racheal talks about herself in terms consistent with identity exploration and the person she wants to be, linking this to the development of personality and traits. Again, Racheal sites personal agency as the means of achieving this through being proactive in order to overcome her shyness:

*“What I kind of do is I kind of throw myself out there. Like I used to get more anxious than I do but erm, things that I do even like going to town when I meet with friends and stuff like that and getting back on my own I kind of. A few, a few years ago I wouldn’t have dreamt about going on a bus because*

I hate public transport and I don't like people but I think doing things like that, making myself do things like that and trying to be less shy and kind of forced myself to have to do it." (R20)

In the excerpt below, Racheal shared her thoughts and feelings about herself today.

"like I said really like autism is part of me so I am happy with that and erm I find that I am a better person now, I think it just takes time, just learning about yourself and sort of thinking about the person that you want to be. Just all takes time and you have got to work at it and everything in life affects you in different ways but you have got to try and make things be helpful to you. Even like the not so good experiences, they, they, they've all helped me in certain ways." (R21)

The excerpts above are representative of self-exploratory narrative processing. Meaning-making is evident in her view that challenging times also help develop her in certain ways, and how difficult times can lead to development, and some good can come of them. This indicates a redemptive sequence in her narrative.



## **Narrative Theme: The Future and Independence**

Racheal discussed her future self as part of her narrative. She identified that she would like to be a medical professional, possibly a paramedic:

*"I think now as well I am more, I am better with people and I think, I think that will be a job as well where I can, I don't know, kind of, flourish in the personality and the person I want to be it will help people and it will give me a sense of, I don't know like, it will give me a sense of happiness and my life has been for a purpose."* (R22)

Racheal linked her possible future occupational identity with her broader sense of self, 'the person,' she wants to be. She stressed that she wanted to be able to help people in order to achieve a sense of purpose to her life. Therefore, her narrative in the above excerpt is reflective of the generativity life-story construct.

Racheal's narrative account also included some deliberations about her future and her skills to cope and be independent. The narrative theme of being normal is again evoked here. Racheal's trepidation about the future is balanced by an optimism where achieving greater independence is linked with greater autonomy, choice and expression of her individuality, and hence her own identity:

*“Some because I know some things I am absolutely hopeless at. Like it, I couldn’t, it stresses me out thinking that one day I am going to have to make my own food and do my own hair and err work a washing machine. I can work a washing machine, but things like that, just the practicalities of life and things like that and paying bills like trying not to get stressed out about it because I know I will be capable of it but, err being able to sit down and think and do things and just work normally, just be a normal person.”*  
(R23)

*“I actually, I think it will be really good for me. Like erm, because at that point you can sort of choose who you want to, want to talk to, and you can make sense of your own life and do things for yourself and just be independent and I can have things my way that I want them, like I can decorate my own house and do things that I want.”* (R24)

### **Narrative Theme: Diagnosis and Autism**

Racheal’s narrative indicated that she drew on her diagnosis of autism as an explanatory framework. She reflected on her communication preference but also on her gross motor development in relation to autism:

*“I think it helped make sense of who I was.”* (R25)

*“Me not wanting to talk to people. I think, lots of things that happened I think why didn’t anyone pick up and even when I talked to my mum because I don’t know how no one picked it up. Erm I didn’t walk until I was 3 pushing 4 honestly so when I was starting nursery that was when I was learning to walk. And I don’t know whether that could be related to cerebral palsy and like autism as well. Erm I just really like just like sit back kind of thing and watch everything go by rather than...”* (R26)

*“When, I don’t know when, when people learnt to walk its sort of like involvement with like whoever is teaching there and wanting to look at them and talk to them and kind of listen to what they are saying and things like that.”* (R27)

Racheal explained that learning to walk would have been a socially mediated skill developed through interaction and communication with another. Here she extended the idea of, ‘autism as explanation,’ to an area of development beyond what is usually associated with autism. In the excerpt below, Racheal refers to autism as a way of explaining her perceived characteristic, of what she described as, being annoying and being a difficult person to get along with:

*“Erm I think I am very difficult person to be friends with. I am quite opinionated and I like being right and I like things done my way and it is hard to kind of erm, think about other people’s opinions and think about*

things that they want to do. I think I am... you know I've always said autistic people are really annoying and I think I am really annoying." (R28)

The narrative theme of being normal, discussed above was again evoked when Racheal reported that when she first got her diagnosis she protested, as she did not think there was anything wrong with her and she resisted the label. She explained that her view of autism as deficit, and hence her use of the word, 'wrong' at the time arose due a narrow perspective of autism:

"think all my life I had labels, cerebral palsy, being told I couldn't do things when I kind of defied them like, like even from when I was young like I was told that the doctor told me that I wouldn't ever be able to walk and I did, I just refused to listen to whatever people told me that I couldn't do." (R29)

"I think it was then because like the way it, like when people that don't know about autism when they think about it they think of I don't know, Rainman or err, a child locked in a room playing computer games and not talking to people." (R30)

Here Racheal's sense of identity appeared to have been challenged and influenced by cultural and societal factors. Racheal's understanding was based on narrow or stereotypical representations of autism in the media and wider

culture. Her narrative suggested she resisted this prescribed identity but it may also have reinforced concepts of difference and perceptions of what it means to have autism and be normal.

There were a number of occasions in Racheal's narrative where reference was made to autism that appeared directly associated with her sense of self and her identity:

"I think I have a different view of it now, I don't think, I, I think it was good that I was diagnosed later as well, well in certain aspects because I didn't have to grow up and say I am Racheal I have autism, I was just Racheal."

(R31)

"Like even though I found it more difficult and obviously it will probably be easier to just be able to err talk to people from a young age and just be normal and get on with life and things like that I didn't think I want to be like that, I don't like being like anyone else and I am me." (R32)

Excerpts R31 and R32 represent a level of sense-making and the life-story construct of redemption. Here Racheal acknowledged that in, 'certain aspects,' a later diagnosis allowed her to be separate from her diagnosis of autism when growing up. Also, she reflected on difficulties she experienced and considers

how life might have been without these but concludes that without these experiences she would not be her. The narrative of autism being integral to who she is suggested in the excerpt below:

“I think, I think with the autism things, I think if I look at it, I think it is a good thing because it has made me the person I am.” (R33)

Racheal’s narrative included movement towards a coherent positive resolution where tensions associated with who she is, being normal, and dealing with challenges are resolved:

“Like I said really like autism is part of me so I am happy with that and erm I find that I am a better person now, I think it just takes time, just learning about yourself and sort of thinking about the person that you want to be. Just all takes time and you have got to work at it and everything in life affects you in different ways but you have got to try and make things be helpful to you. Even like the not so good experiences, they, they, they’ve all helped me in certain ways.” (R34)

“I wouldn’t change me because that’s how I am and how I was meant to be.” (R35)

#### **4.4 Andrew's Story**

Andrew was aged 15 and in Year 11 when he was interviewed. He did not recall very many experiences before he went to secondary school at the age of 11. Following difficulties at his first secondary school he moved, during his time in Y8, to another school with the additional provision of an autism resource base. Two major themes were identified in Andrew's narrative account. These themes were labelled, Behaviour and School Management of Needs, and, Coping with the Future and Independence. There was some overlap between these two themes as the narrative of coping and not coping pervaded both. The theme of, Diagnosis and Autism, is also presented.

##### **Narrative Theme: Behaviour and School Management of Needs**

Andrew recalled primary school as being, 'fine,' and that he was mainly happy and enjoyed being with friends. He later noted that he did not have a Statement of SEN in primary school as his needs were being met:

*"Because the school was, the primary school was doing everything right for me."* (A1)

Following the move to secondary school Andrew noted that, 'it went downhill.' He described a context where he was bullied and reacted to this with anger and getting into fights. The bullying he experienced made him react physically. He reported that he felt angry and, 'wanted to go and kill them basically.'

*"I was keep on getting into fights, trying to back my, me up because of me getting bullied." (A2)*

*"Some were taking the mick out of me being fat and autistic and..." (A3)*

The following exchange shows his understanding of the situation:

*A: So it didn't help that the school didn't know how to cope with me.*

*S: Okay so the school didn't know how to, you think the school didn't know how to cope with you?*

*A: Yeah because they don't know how to, don't know how to word it.*

*S: What is it that they needed to cope with?*

*A: They can't suit, they don't suit the need.*

*S: They didn't meet your needs?*

*A: Yeah." (A4)*



Andrew's evaluation of his primary school experience indicated that he saw this time as canonical and uneventful. He noted there were no real problems because the school was doing everything right for him. This can be contrasted with his experience of his first secondary school. In terms of identity it appears that Andrew linked his self-concepts with the educational institutions he attended. His reflection that his secondary school could not cope with him locates the, 'problem,' as a function or facet of himself. This is reflected further in his description that the school did not suit his needs. With reference to the identity framework, the narrative here can be seen to be influenced by factors relating to the cultural and societal context in which Andrew is situated. Such factors might include a within-child deficit model, the education system and the particular school culture, for example.

Andrew went on to say that the difficulties experienced in his first secondary school led to him getting a Statement of SEN and moving to his current school which had an autism resource base provision. He noted that nothing was going right for him in his first secondary school:

*"S: Okay, so you, the primary school was doing everything right but then when you moved to secondary school they weren't doing things right for you? What sort of things can you remember what sort of things weren't right or....?"*

*A: Everything. Lessons. Teachers. Pupils. Everything." (A5)*

He went on to describe how he used to abscond from lessons and hide, in particular if he saw his Head of Year approaching because he instantly thought he was in trouble. He recounted that on one occasion his dad had to come to school and get him, 'come and find me himself,' he recounted. Andrew contrasted this experience of his first school not managing his needs to his current school provision where he said, 'they get me more here,' and, 'they understand me like a book.' He noted:

*"When I started here I was a devil." (A6)*

He then recounted how things had changed over time. He noted that his current school: employed teaching assistants in lessons; had a card system to allow him to leave a class; and had a resource base area for him to do work and calm down. He gave a summative evaluation and noted that the school gave him the support he needed and sorted everything out:

*"S: What have been the high points here?"*

*A: That I can actually cope in this school.*

*S: So you feel like you can cope?"*

*A: Yeah.*

*S: Do you, do you know what it is that helps you cope?"*

*A: Being in to a resource base.*

*S: So having access to the resource base.*

*A: Yeah.*

*S: Do you know how it helps? Do you know how it helps being in the resource base?*

*A: Sort of like gives you the support what you need.*

*S: So you get the support....*

*A: Whatever the need you have got they can sort something out." (A7)*

Andrew went on to say that he felt he had matured a lot since being at his current school because he was able to employ the available strategies to avoid conflict and manage anger.

Andrew's self-concepts related to his behavioural responses are summarised in the comment that he was a devil. His identity again is influenced by the culture of the educational provision he finds himself in. His sense of personal development and maturity is linked to the idea that he can cope with the school setting he is in.

## **Narrative Theme: Coping and Independence**

In the theme above, Andrew noted that his first secondary school did not know how to cope with him, whereas his current school is able to cope with his needs. Similarly, Andrew noted that he can cope in his current school. The theme of coping and not coping was further developed in Andrew's narrative when he was asked to consider his future.

Andrew noted that he would like to study cookery after Year 11, although he was doubtful that this would happen now. He explained that his current school offer cookery but it was not the sort of course he wanted to do, it being more theory than practical. He explained that he had visited a Further Education college (with the implication being to see a more practical course), however this had left him with doubts about the suitability of this programme too:

*"So yesterday I went to a college open day, open evening, and I went to see the kitchen there, and it was all nice and all that but I've... if you watch the... Gordon Ramsey it will be like that all the time and like I don't think I am going to be able to cope." (A8)*

*"A: Yeah. I could cope with it but it is just when they want something there and then.*

S: *How, how do you mean if they want something?*

A: *If the chef asks for chicken in two minutes I probably wouldn't get it out at that time.*

S: *Okay. So you are a little bit worried about the pressure of working in that environment or learning in that environment?*

Yeah. *And it isn't something what I want to do anyway, I just want to go round and teach people how to cook. Not be in the restaurant business.*

(A9)

Andrew then went on to say that he would like to remain in his current setting, even though the course there was not suitable. He noted that his parents and the school's SENCo also think he should remain:

"A: *It isn't, they've even said it isn't the course what that would suit you.*

S: *So why, why do you want to stop here?*

A: *Because I've got used to being here.*" (A10)

He then provided his reasoning for this:

"A: *And they can support my autism.*

S: *Okay. So there is a bit of erm, a bit of a difficulty in that if you move somewhere else you might not get all that support?*

A: *Exactly, that's why I want to stop here.* (A11)

The excerpts above indicate a developing commitment to an occupational identity but this is being tempered by Andrew's sense of whether he will cope, not just with a new study programme, but also cope outside his current educational setting. His self-concept relating to competence and coping is associated with autism and the support provided by his school. It appears that this aspect of Andrew's identity and related sense of personal agency are closely linked with the relationship he has with his educational provider.

Andrew also discussed his longer term future. I asked Andrew whether he had any concerns about the future due to autism:

*"How will it... Sometimes, a little bit because how am I meant to get a job if I have got autism?"* (A12)

*"Because disability kids don't always get the jobs."* (A13)

*"I will need support that's the thing."* (A14)

Andrew said that his feelings about the future were, 'not good.' This was followed by a narrative which related to his concerns about developing greater independence. He noted:

"My Mum expects me to get taxis all my life even though that I'm 16 now and I can get my bike licence." (A15)

"I want to get independence." (A16)

"but I can't get it because I am getting taxis all the time. And I don't like the bus either and I'm just trying to cope with the bus now and in the week off I think it is me and my Mum are going to do a trip to here on the bus. At the right time." (A17)

Andrew's narrative took a pessimistic tone when he discussed the future. His recount is again focused on coping. He appeared to be striving for increased personal agency by considering how he can achieve greater independence. This part of his narrative might represent identity development as part of a process where Andrew is trying to gain greater autonomy and separateness from his family. Interestingly, this need for greater independence appears to be balanced with an acknowledgement that he may need support in achieving this and with future employment.

Cultural and societal factors are also evoked in Andrew's narrative associated with disability and economic inclusion. Self-concepts relating to disability, and being disempowered in relation to economic participation, may be derived from an understanding of wider narratives prevalent within the cultural and societal context in which Andrew is situated.

### **Narrative Theme: Diagnosis and Autism**

Andrew's narrative did not include many references to his diagnosis of autism. Some references are included in excerpts above and have already been discussed. In addition to these, Andrew noted that he did not, 'bother about it,' when he was younger. More recently, in secondary school, he said he knew more about autism because of being with other students with the diagnosis (in the resource base) but he was not able to elaborate on how his understanding had changed.

Andrew clearly has some awareness of autism and the impact or potential impact on him as evident in the excerpts above (A11-A14). However he did not explicitly narrate further thoughts and evaluations about it, nor did he appear to use it as a sense-making framework, and therefore perhaps it can then be said that it does not consciously shape his narrative identity.



## 4.5 James' Story

James was aged 15 and was in Year 11 at the time of his interview. Four major narrative themes were identified in James' story. These were labelled as: Relationship with his Granddad and its Influence; Confrontations; Being Different; and Diagnosis and Autism.

### **Narrative theme: Relationship with his Granddad and its Influence**

A major theme running through James' narrative account was related to the relationship he had with his granddad and how this relationship shaped his values and identity. James related how he had an interest in the army from a young age, which he explained came about through the stories his granddad used to tell him of his own experience in the army. James explained that he was close to this granddad as his own father was not around. He also noted that he did not have a strong connection with other people beside his granddad. When asked to think about a difficult time in his life James related the death of his granddad. He began this account by relating how he used to visit his granddad frequently after school, and how they would sit together and talk:

*"[He] would say these kind of like words to me, a puzzle which I would never understand." (J1)*

James continued with the account and described a particular time he went to visit his granddad just before the end of his time in Year 6:

“And I sat next to him and he was like, he said James, and I was like yeah, and was like one day I am going to go and you are going to have to take care of the family and erm, I listened to that and I never really understand it obviously and I was a bit, I said Granddad you can’t go and I just kind of like took that and never really understand it.” (J2)

I asked James what he understood now about what his granddad had said. He responded:

“J: That you have to learn responsibility to step up and take care of everyone else that is left when you go.”

S: Okay. And how do you feel about that?

J: I feel like I have matured a lot more now and do listen and I have grown up a lot. So I understand it and I do try my best to do that now.” (J3)

Later in the narrative account James discussed the future and said he would like to join the army as a combat engineer. I asked if he had any worries or concerns about the future. His response, as illustrated by the following excerpts, provided

an insight into the influence of James' relationship with his granddad on his construal of self:

"I don't want to let my granddad down." (J4)

"He wanted me to become a good person. Not like my dad." (J5)

"He wanted me to be respectful and erm, what was it? Faithful, and wanted me to have a respect for my family and take care of my family and erm, really just do what's right." (J6)

A number of interpretations can be made here in relation to James' identity. James' narrative conveys a sense of communion achieved through the relationship with his granddad. The relationship appears to mediate James' sense of values relating to family, morals, duty, and the kind of person James feels he should be. The relationship could also have influenced James developing occupational identity in that he wants to join the army and perhaps saw this as a means for living the values he believes his granddad wanted him to subscribe to. In this sense, the choice of occupation may reflect foreclosure in terms of the identity statuses' construct. The foreclosure status involves making commitments to an identity that has been ascribed by parents, family or wider culture without going through a process of identity exploration. However, it is possible that

James may have gone through an exploration of alternatives which was not shared before coming to this conclusion about his occupational wishes. Taking a wider cultural and societal perspective the relationship between James and his granddad forms the means of transmission and communication of ways of being in relation to concepts such as patriarchy and gendered roles.

The sense of morals and what is right is evident in another theme that was identified running through James' narrative: that of getting into confrontations. This is discussed below.

### **Narrative Theme: Confrontations**

James noted that although he was popular with peers, he did get into a lot of confrontations. When asked to give an example of what he meant, he discussed a confrontation with a supply teacher. The narrative suggests that he got into a dispute with a supply teacher who did not know him very well during a debate about the rights and wrongs of war:

*"Like he brang it up on the board and it goes some people like the Taliban believe that they can kill these people and then the teacher said well 'why do English soldiers kill members of the Taliban?' You know obviously I brang up my thought which was like because they are there to help against*

people that are basically bad or going against other people, and obviously they are there to help, and he got angry about it and he was like raised his voice and I was like....” (J7)

James went on to recount how he responded by also getting angry and how the incident escalated in him throwing a chair. When asked about his feelings in relation to what had happened he replied:

“I thought I did the right thing because he gave me a reason to do it.” (J8)

James recounted another incident that occurred, this time with a fellow student. James related how the other student was about to hit a female teacher and how he intervened. James began with an explanation of his actions in the story that he recounted:

“Mmm. I guess my Granddad was quite like patriotic and how he brought me up was like to respect this country, and everyone in it and like all that, and to defend what’s kind of right and your family and defend your own, and erm like my Granddad always told me like never hit a woman ever,”  
(J9)

*“J: And one time it was one of the female teachers who helps me a lot in base, she put a lot of time into this boy and he went to like hit her and I just lost it and I got mad and I like threw him across the room and I started hitting him and beating him up or whatever, but then they asked me to say sorry and I didn’t because it, I felt like the actions that I took were right.*

*S: What, what actions were you taking? What were you trying to do?*

*J: Defending a woman.” (J10)*

Here it could be said we see James’ identity in action. His sense of moral values leads to actions that are consistent with his identity construct related to moral reasoning. James sees himself as doing what is congruent with his beliefs about respect and defending what is right. This value system also acts as the means for the justification of his actions.

### **Narrative Theme: Being Different**

James highlights a number of ways in which he perceived himself to be different to his peers. This sense of difference related to: his responses and behaviours associated with sensory processing differences; his school routines and educational provision; and to his understanding of others.

James recalled some behaviours that he engaged in, such as hiding under tables and jumping on chairs, and the response of teaching staff from his early school years:

*"I didn't like, I don't think they really understood why but they still told me off but they tried to kind of find ways around it so that I wouldn't do that."* (J11)

He explained his understanding of his behaviours:

*"J: Not really I just felt like, sometimes I would feel uncomfortable if something or the sound of something can I just block everything out and no one would understand why, they would just think I am being ignorant."*

S: So, so when you say that the sound of something can you give me an example.

J: *Like metal scraping against metal.*

S: Okay.

J: *It's a sound but, it in a sense hurts me.*" (J12)

*"Well... there would be some people that would be able to talk to me and kind of like, keep me you know there and I would listen but I would be just*

*automatically aggressive because of the bother of the sounds and noises.”*

(J13)

James reported his thoughts and feelings about himself at the time.

*“I guess I was confused or I didn’t understand like what was bothering me.”*

(J14)

During this section of the narrative account James was recounting how he was different to others, and therefore his sense of identity can be explained with reference to the individualistic-collectivist construct of identity. He did not at this point link or explain his behaviours in relation to autism but did so later in his account when discussing his diagnosis and his understanding of himself.

*“Cause obviously I like I knew there was a reason behind why I acted that way to certain things.”* (J15)

James reported that he knew he was different as he did not follow the same routines nor have the same provision as other students. For example, he would not follow the same lunchtime procedures as peers. He recounted that he had his dinner brought in from home as he would not eat the school dinners. He also



discussed how he would not understand when peers got into conflict with each other, nor understand their interests and jokes, and emotional responses:

*“Mmm, and like when a teacher is about to leave everyone would be there crying and hugging the teacher and I wouldn’t really have any sympathy for it.” (J16)*

Here James highlights again his sense of being different to others. Interestingly, this sense of difference appears to arise in two different ways. Both are related to reflexivity, that is, thinking about himself, but his sense of difference is also reinforced through the organisational structure of accommodations made by his school. James does not provide any evaluative comments about how this may have influenced his sense of self, if at all. It is worth noting that in contrast to other participants, James’ narrative of difference is not set within a broader account of being normal or wanting to fit in. However, the concept of normal is referred to in his narrative relating to autism. This is discussed below.

### **Narrative Theme: Diagnosis and Autism**

James shared his thoughts and feelings about his diagnosis of autism. His narrative suggests that he felt excluded from the process of diagnosis. James recounts that he, ‘heard,’ during meetings in school and that he wasn’t meant to

know what the doctor was assessing him for. The narrative provided suggests issues of power and exclusion from the diagnostic process and a lack of information sharing:

*“I think I heard, I had meetings with the school I was with my Mum because they said for me to go to have a diagnosis, I think it was like when I was 12,13.”* (J17)

*“A lot which I had loads of switches of different doctors and there was this one guy and he erm, I knew already what they were doing but I don’t think I was meant to know because I already knew what they were trying to test me in because I had looked it up on the internet.”* (J18)

Further comments made by James about the diagnostic process appear to reinforce narratives of deficit, and not being normal, or having something wrong with you, which he resists:

*“J: Okay. Erm I obviously went to the doctors, and I didn’t, I, I thought I was like nor... not normal but I thought I was, had nothing wrong with me, like because to me how I acted is normal to me so I thought everyone should act that way.”*

S: Okay.

*J: And obviously so I was angry about the fact that I had to go for this test because I thought well I am fine." (J19)*

James further discussed autism in relation to his thoughts and feelings. This is illustrated in the excerpt below:

*"S: Okay. So when, when you found out about the diagnosis erm how, how did you feel about yourself then?*

*J: Oh, I was like erm, they were like 'there's nothing wrong with you', I was like, but like this is it, and I was like 'oh what's that mean?' and I don't think they could really explain it because I wouldn't kind of care and erm... I, coz I didn't really care what people thought I just wondered how it was going to make a difference because having that on a piece of paper saying I have got autism, I thought it was pointless because I didn't think it was going to make a difference.*

*S: Aha.*

*J: Because it's just a piece of paper saying I have got autism.*

*S: Okay but did it make you feel different or think differently about yourself?*

*J: I guess it made me, made me realise maybe why I acted the way I did.*

*S: Okay so it helped, did it help or....?*

*J: Understand.*

*S: It helped you understand?*

*J: Because of the reasoning behind it.*

*S: Reasoning behind some of the way you acted?*

*J: Yeah.*

*S: Did it help you understand about the way you think?*

*J: Kind of I guess. Yeah. I just thought it was me being the way I am.*

*S: Okay. It was just you being the way you are?*

*J: Mmm.*

*S: Okay.*

*J: Me being me." (J20)*

In the above excerpts James relates that he questioned the significance of the diagnosis and whether it, in itself, would change anything. At the same time, he acknowledges that he did draw on the diagnosis as an explanatory framework as it helped him understand some of his behaviours. It appears that for James there was a process of sense-making where he rejected the deficit aspect of the diagnosis but accepted that it helped act as a framework to explain some differences in the way he acted.

## 4.6 Dean's Story

Dean was 18 at the time of interview and had recently completed his A-Level examinations. Four narrative themes were identified in Dean's autobiographical account. The themes related to: Interaction and Communication; Teacher Conflict; Diagnosis and Autism; and Self-Reflections.

### Narrative Theme: Interaction and Communication

Dean discussed how he perceived himself when thinking back to what he was like in primary school. He described himself as being, 'anti-social,' and, 'just not interacting and talking much.' He reported that he found interactions uncomfortable, 'after any extent of time,' and that he preferred short interactions and spending time alone:

*"Like in terms of amount I had quite a lot of friends but it was uncomfortable-ish." (D1)*

*"From memory I tended to go off into my own imagination a lot." (D2)*

*"I don't remember any problems. I would choose either to do my own thing or to, break time is short so I could do something with someone else. I think normally I would do my own thing." (D3)*

In describing his relationships with peers in secondary school he recounted that he tended to have one friend at a time:

*"D: I tended to have like one like very good friend at a time.*

*S: One friend at a time.*

*D: Yeah so it changed like two or three times who it was and then I would have you know just other acquaintances and minor friends." (D4)*

In considering what the above narrative indicates about Dean's identity, the communion life construct appears to be relevant here. Although Dean related that communication with others was uncomfortable, he did not indicate that he was driven to seek communion or that this was problematic. It does appear that he would spend time alone, but again it is difficult to glean whether this was a way of managing uncomfortableness of interactions, simply a preference, or for some other reason. Some conclusion may be garnered from Dean's description of his friendships during school. Perhaps the serial monogamous style of friendship allowed for the achievement of communion balanced within a simpler dyadic social

dynamic. If this was the case, then spending time alone perhaps was indicative of the management of uncomfortableness.

Dean went on to relate that during his sixth-form years relationships with teachers and peers had improved which he attributed to an improvement in his communication skills:

*“D: Well sixth-form I have had just better relationships with the teachers and with the students as well.*

*S: And what was, why do you think that’s been?*

*D: I don’t know, I think maybe I suppose maybe I just got better with interactions over time.” (D5)*

He noted he now spent longer talking to people, ‘Whereas before it would have been just awkward.’ He noted that conversations tended to centre around:

*“Either the day, or just like anywhere where I can find a shared interest...”*

*(D6)*

*“Well I mean you know just TV programmes, games, books anything....”*

*(D7)*

In the above excerpts, Dean noted an improvement in interactions with others allowing for development of communion. Again, it appears that the connectedness had to be managed as Dean indicated that interactions took place around shared interests of which he had some knowledge. Dean reported that if conversations moved on to other topics then he found the interactions difficult.

### **Narrative Theme: Teacher Conflict:**

Dean was asked to think about the early years of secondary school. He responded, noting that he enjoyed the sixth-form years more than previous years and explained he did not get on with the teachers previously:

*“D: I got in, I didn’t get along with the teachers really before then because, well because I was a bit of a prat really. I was kind of lazy and didn’t do much work.”*

*S: Okay. Did you just say you were a bit of a...?*

*D: Prat.*

*S: A bit of a prat, okay. So did you get into conflicts?*

*D: Yeah with the teachers over just not really doing work properly.*

*S: Okay*



*D: And that was, I mean a lot of it was due to generally being like just terribly disorganised but....*" (D8)

This short exchange within the overall narrative was of interest from an identity perspective. Dean used the terms, 'prat,' 'lazy,' and previously 'anti-social,' to describe himself. Notwithstanding possible differences in language use and understanding associated with autism, the use of these terms potentially communicated something about Dean's self-concepts. In terms of identity processes, the question arises as to whether these self-concepts derive from intrinsic self-evaluations or internalised views of how others might have perceived him. The narrative account did not provide information to help delineate this.

Also of interest here is the causal link that Dean made between teacher conflict and difficulties with work and his organisational skills. Later in the narrative, as will be discussed below, Dean links organisational skills with autism, however, here no such link is made, perhaps indicating that Dean does not use autism as a sense-making framework in this instance.

## **Narrative Theme: Autism and Diagnosis**

Dean recounted that he was not sure how his diagnosis of autism had come about, that he did not have much understanding of it, and that it did not result in any significant change:

*“I have never researched it or looked into it. I just, it was just something, it was just a thing.”* (D9)

*“I don’t think, no change really. Like it was, it was, no, I just stopped thinking about it after, quite soon after and doesn’t....”* (D10)

*“It didn’t make a great impact.”* (D11)

*“No it was just something that was there.”* (D12)

Dean noted that he had more understanding of autism than he used to through input from the SENCo at his school and the visiting educational psychologist, although he had not actively sought information himself:

*“Miss Halliwell or sometimes she brings in people like the EP and so I like, and they have given me some information, enough information to get along easily, but I have never made an independent attempt at....”* (D13)

In the following excerpt Dean went on to link difficulties with organisational skills with autism:

*“S: Were there any problems or difficulties you were experiencing that meant that they had to get somebody in or....”*

*D: Well as I say like I was disorganised and stuff and apparently that had something to do with the ASD but I, it like....”*

*S: So the disorganisation what does that look like?*

*D: It manifests itself in just forgetfulness and yeah mainly that.”* (D14)

It was indicated earlier that Dean may not reference his diagnosis of autism as a sense-making framework. In the above excerpt he reveals that he did not have much information about autism and that the diagnosis did not make a significant impact. He did explain being disorganised in terms of autism but did not explicitly link this to lack of work and conflict with teachers when he was younger. Although Dean noted he had received support with his organisational skills, he did not connect this with the improvements in work and social relationships he reported had occurred during his time in sixth-form. Dean did not re-interpret past

experience in light of his diagnosis and therefore his use of it as a sense-making framework could be described as minimal. Interestingly, Dean did not reference autism in his discussion earlier about his limited interactions with others and his sense of uncomfortableness.

### **Narrative Theme: Self-Reflection**

There were a number of occasions during Dean's account where he made comments which suggested that he did not engage in much self-reflection. He talked about how he was good academically at primary school and as a result was, 'arrogant,' as he thought he was better than his peers. I asked him to share any other thoughts and feelings he had about himself at the time. His response indicated some difficulties in thinking about himself:

*"D: Yeah, I mean I don't think I tend to notice anything about myself really.*

*Like....*

*S: Okay.*

*D: So like I didn't pay any real attention to myself.*

*S: Okay. What about looking back on it now?*

*D: Looking back on it now I, I don't know." (D15)*

When asked to consider his future self, Dean noted:

*“I have never had any image of myself in the future, I don’t, it’s always, any decision I make is normally a last minute thing. I know I am planning to go off to university next year.”* (D16)

At the end of the interview when asked for any further reflections he replied:

*“I have nothing I can put into words, no.”* (D17)

Reflexivity, that is, the ability to reflect on oneself is key to identity processes. In addition, being able to construct a story about oneself and therefore put oneself into words is a key tenet of narrative identity. Dean’s comment that he found it difficult to think about himself (interestingly a self-reflection in its very self) may be indicative of the nature or extent of his sense of self and narrative identity.

## 4.7 Patrick's Story

Patrick was aged 16 at the time of interview. He had just completed his GCSE examinations. Patrick talked explicitly about autism in relation to himself throughout much of his narrative account therefore a separate theme relating specifically to autism was deemed unnecessary. Four themes were derived from Patrick's autobiographical account. These were: Confidence, Communication and Social Anxiety; Hiding it, Being Normal and Fitting in; Change and Personal Growth; and Future Self.

### **Narrative Theme: Confidence, Communication and Social Anxiety**

Patrick reflected on his primary age school years and noted that he had developed an interest in music and animation, which he stated continued to the present today. He remembered playing the recorder in front of his year group and said that this achievement helped boost his confidence. He added a causal explanation linking his lack of confidence with his diagnosis of autism:

*"that's something that has helped to boost my confidence and as I'm autistic I don't have a lot of confidence."* (P1)

When asked to discuss his confidence further, Patrick linked low confidence with the pressure of communicating appropriately in social situations and with expressing his feelings and emotions. He stated:

"I think my confidence in primary school it was yeah it was pretty low. It was pretty low around people, like if I was going to speak to someone new or what not, I would be very to myself, I wouldn't really express my opinions or express how I feel, even to my close friends. I was more outgoing with my closer friends but I didn't really speak as much as what was going on, like how I felt or anything. I just kind of like... yeah I wouldn't really speak how I felt or anything. Sometimes I would, if I did speak in front of like people that I don't know, huge crowds or what not, I would say something that I didn't mean because of all the pressure that was kind of gaining on me and that's the only reason why I would say something out of turn or stuff like that." (P2)

Patrick makes sense of his low confidence and social anxiety in terms of his diagnosis of autism, and in particular, in relation to his communication skills, that is, knowing what to say in social situations. His narrative suggested low confidence and social anxiety have been part of his lived experience for some time and therefore in terms of identity, enduring self-concepts.

Patrick noted that he still experienced social anxiety, although he felt less pressure. He implicitly linked low confidence and social communication with being socially anxious. He also gave an account of his experience of communication and his thoughts and evaluation of this experience. He noted that he would be upset and blame himself for miscommunicating:

*“No that hasn’t changed. I mean it’s improved I have managed to erm not be affected that much by pressure or what not but I still get it, I still get socially anxious around people.”* (P3)

*“I knew that if I said something and then it didn’t really come out right or I got told off for it I would be like really upset and think oh yeah I have just messed up it’s all my fault and something like that”* (P4)

The inter-play between self-other interactions on his self-evaluations is implied in the suggestion that he sometimes felt “told off” for miscommunications. Patrick’s internal attribution as evident in, “it’s all my fault,” further indicates the impact of social communication on his self-concept.

Patrick went on to note that getting communication right at secondary school was of greater importance due to changing social dynamics (P5). Patrick exemplified what he meant by recounting an incident where one of his peers was not behaving



in a manner conducive to the completion of a shared school project. Patrick tried to sort this out but ended up causing offence. He attributes peer conflict to communication skills:

*"It was different at secondary school because you start to grow up and you start to learn more about what is going on around you and you realise that if you say one thing that you kind of didn't mean or something like that people can take it the wrong way and can really get, you know, they can really put you down and really shame you for that and it's like you have to be careful for what you say and you sometimes, you will do something, and it seems normal but for other people to get really offended or something like that."*

(P5)

Again, Patrick demonstrates that he is aware of miscommunicating at times and that at secondary school he had to be increasingly vigilant due to the social consequences of miscommunications. It appears such situations would have reinforced social anxiety and Patrick's self-concept in relation to this. In addition, Patrick's desire to establish a sense of collectivist identity or communion with peers would have been frustrated by miscommunication and associated anxiety. This is discussed further in the, 'Hiding it, Being Normal and Fitting in,' theme below.

Patrick described a further situation, which was illustrative of his experience of social anxiety and his difficulties with knowing how and what to communicate. The situation involved Patrick having to tell a female friend who was romantically interested in him that he did not feel the same way about her: In the excerpt below, he attempted to parse his experience into what might be typical in such a situation from what aspects he thought could be explained by autism.

*“I think everyone has it in some sort of way they just they don’t want to let people down and I don’t think that’s something autistic related. I only think autism related is really like social anxiety in a way like, I only think the real problem was that autistic related was just kind of like, was kind of like the pressure of what would happen next and over thinking the consequences of if I actually said what I said what was on my mind. And it’s like I keep over thinking and because you know I want everyone to kind of like like me in a way and because I keep over thinking my answers and what not and that’s kind of social anxiety in a way because you don’t want to be let down yourself or you don’t want to cause any problems for anyone so I think social anxiety is related to autism but in terms of letting people down I think no one really wants to let anyone down.”* (P6)

Here there appeared to be explicit exploration in relation to what is autism influenced and what might be considered universally applicable. Although, Patrick used autism as a sense making framework when considering his confidence and

communication he is careful not to over-rely on it as an explanation for his feelings and thoughts about managing the situation with a female friend. This was emphasised during another part of his narrative account when he said, 'I just know that I can't just blame everything on autism.'

### **Narrative Theme: Hiding it, Being Normal and Fitting in**

Patrick's account included three overlapping themes related to trying to fit in with others by hiding his autism and being normal.

Patrick recounted that he was aware of his autism from when he was in primary school and that his peers in primary school would also have known. He recounted that when he transferred to secondary school he made an effort to conceal his diagnosis. He stated that he was aware of being different in some respect to others and wanted to be normal:

*"I went to secondary school and I knew I was autistic and I kind of, because in primary school everyone knew in my class that I was autistic but in secondary school I wanted to find a way to cover that. I kind of knew some of the stuff that kind of made me different to everyone else and I wanted to be normal. And it's only until the start of this year, the end of last year where the actual realisation of what autism means and all the stuff that you*

know causes me to be different from the average Joe actually starts, started to kick in. (P7)

Later in his account, Patrick reiterated that he tried to keep the diagnosis from his peers and that the efforts to conceal it affected him. He noted that he thought that there was a benefit to keeping his diagnosis secret as it allowed him opportunity to understand the 'real' world. The tone of the final part of the excerpt suggested that along with this benefit came a negative affect:

"And no one actually knew at my secondary school because I tried to keep it on the low." (P8)

"I mean I think what it has done it has kind of helped me see the real world and how people really are and in a way keeping under the radar as hard as it has...well it hasn't actually been...well what can I say sometimes it's....let's just say it's really it has affected me keeping it under the radar..."  
(P9)

Patrick explained his reasoning for trying to keep his diagnosis from others making reference to wanting to be a normal person:

*“Back then I was ashamed of being autistic, I was ashamed of being autistic, I didn’t want anyone to know I thought it was a bad thing, everyone was going to hate me for it and it just wasn’t going to look good for me at all and I wanted to be a normal person because I thought autism just made me like a weirdo. I didn’t like that.” (P10)*

Patrick’s desire to hide his autism and be normal can be considered in terms of the individualistic vs collectivist aspects of identity. It appears he evaluated the individualistic aspects of the self, that is the differences between himself and others, negatively and sought to minimise these through trying to behave in a manner which he perceived to be normal. In doing so, it appears that he was trying to enhance or reduce risks to the collectivist aspects of the self with the aim of fostering connectedness with others. The risks to communion and belonging as perceived by Patrick are evident in excerpt (P10) and can be explained as an outside-in view, or rather more precisely as a prophesied outside-in view. In excerpt (P9) Patrick reflected that keeping his autism secret allowed him to see the real world and how people really are but at some affective cost to himself. This reflection is indicative of the redemption life-story construct where some negative circumstances or situation leads to a positive outcome, in this case the positive outcome being Patrick’s insight in to the ‘real world’.

Patrick evaluated his attempts at trying to be normal and framed his behaviour in relation to wanting to be popular:

"It was kind of hard yeah trying to be normal because you know sometimes I would stutter or sometimes I would say something I didn't mean just to kind of like make myself look good and back then it's just like you have got every kid has got that ideology oh yeah, 'I want to be popular I want to be with the popular kids,' so I would try and say stuff that I didn't mean but obviously that didn't work and because I was socially anxious as well and I was trying to push myself to do something that I clearly couldn't do and I clearly wasn't ready for like you know... But that didn't work at all and eventually over the years I have kind of learnt that you know maybe it wasn't a good idea to keep it under the radar maybe I just needed to realise that that isn't me and I needed to be more myself." (P11)

In excerpt (P11) Patrick engaged in an extended sequence of meaning-making. He noted that trying to be normal was hard, he explained why he wanted to be normal (to fit in with the popular kids), noted what happened to frustrate his attempts (he would stutter and say things he didn't mean) and reflected on why this was (because he was anxious and was trying to push himself to do something he wasn't ready for). The sequence concludes with Patrick sharing the lesson learnt from his experience and the insight gained that he needed to be more himself. Similar meaning-making is explored further below in the narrative theme relating to change and personal growth.

Congruent with the theme of being normal and fitting in, Patrick described two phenomena in particular that he encountered as ways of being. One phenomenon related to his black Afro-Caribbean ethnicity and the other to adolescent social culture as influenced by social media. Narrative excerpts related to each of the phenomena are quoted below:

*"Yeah, yeah. Because every black kid in my year they have pretty much got some street credibility in some sort of way and they get all the girls and what not and then there is just me and everyone thinks oh yeah you should be like everyone else, 'I am sure all these black kids have all gone to prison once,' or something like that and I'm like I, I was like really ashamed of myself because I was like well I am not living up to the expectations and maybe I should and it just doesn't work for me, that's not my identity." (P12)*

*"P: So I know that like all the other kids I didn't really go out that much, I didn't go out and hang out with my friends and what not. I used to keep inside and I used to do creative stuff inside which I was happy about and then seeing everyone post it on social network sites just made me feel like my life was kind of nothing. That kind, that kind of made me feel depressed in a way but...*

*S: So social media you were seeing what was happening.*

*P: Seeing what else was happening because I wasn't really the social kind of person and I had only been between Year 7 to like the start of Year 11 I*

*had only gone out with, like hung out with a friend once and compared to everyone else always going out with their friends and always socialising I always thought you know that I was a social outcast and I kept degrading myself in that manner." (P13)*

An examination of the construct of identity can be undertaken here from a cultural and societal perspective. It appears that Patrick has been exposed to possible identities that he could adopt or conform to; related to race and adolescent social culture. Patrick's narratives here indicate some tensions and dilemmas in relation to these possible identities which he explores. He appears to have reached a resolution at the end of excerpt (P12) with respect to the identity he associated with being black. He also appears to reach a resolution in regard to adolescent social identity which is illustrated in the theme below.

### **Narrative Theme: Change and Personal Growth.**

Patrick's narrative accounting was related in the past tense. However within some narrative episodes he would move to use the present tense. I interpreted this as indicative of change and Patrick talking about his experience of his present self but in connection with and in relation to a past self. This communicated the sense of continuity of self overtime, but also that of an evolving self.



Patrick's narrative account contained a number of episodes where he described changes in his understandings of himself. In excerpt (P7) above he noted he used to try to conceal his diagnosis. The excerpt ended with the marking of a shift to the current time and a change in Patrick's perspective. This part of the excerpt is re-presented here:

"And it's only until the start of this year, the end of last year where the actual realisation of what autism means and all the stuff that you know causes me to be different from the average Joe actually starts, started to kick in." (P14)

In excerpt (P14) Patrick noted that he had begun to realise what autism means thus indicating the processes of exploration of self and meaning-making in relation to identity was underway.

He went onto explain that he had started to attend a group aimed at supporting communication skills with others with a diagnosis of Asperger syndrome:

"I have only started to sort of understood it. I have gone into like stuff like Craft of Communication which is like a socialising group where I used to talk with people who had the same, was in the same predicament as I was and that really helped me understand that you know I wasn't alone in this

and helped me understand that you know I am not the only one who is kind of like that.” (P15)

A possible turning point or catalyst for Patrick’s changing perspective may have come from his attendance at the social skills group with other students with autism. Here it appears that he encountered a sense of social group identity and communion with others. He talked about others being in the same predicament as him, of him not being alone ‘in this’ and not being the only one who was like this. This part of Patrick’s narrative can be contrasted with talk of trying to be normal and the search for communion through trying to minimise differences between himself and peers as reviewed in the previous theme.

Patrick related that, ‘this year,’ in Year 11, he has started to share his diagnosis with friends and noted the positive impact that it had had on him and his sense of happiness:

“And it’s only this year as well where I have actually began to tell people at my secondary school that I was autistic as well.” (P16)

“I think it’s kind of like boosted my confidence because it means that if people know who I am and what I am like, and what I could, like about my social anxiety they can kind of help me to get through it and that’s what’s

kind of happened, it's like I feel like I am being helped through all my problems, through the problems that I have had because I have explained who I am and I feel like I can be more myself and I have been feeling like a lot happier since, since you know partly understanding how it all works and..." (P17)

Patrick noted that his experiences of sharing his diagnosis has been positive and that he felt supported in that others have helped him manage his social anxiety. It appears that the risks associated with sharing his diagnosis referred to in excerpt (P10) did not result in the predicted loss of communion with others but may have actually increased it.

In reflecting on his attempts to be normal Patrick discussed his realisation that he needed to be more himself. He discussed his experience of overcoming the sense of shame of not fitting into the ethnic related identity that was being prescribed and accepting that his was not the kind of person that he wanted to be:

"I think the change is because eventually there is only a certain length of time where you can try and be someone that you are not and eventually I got to like the end of Year 10 and it's just... the stuff that I was doing it wasn't reflecting my character and it wasn't making me happy anyway and I wanted to try and be myself and you know try and show everyone that this is who I am and try and act more something that is related to me rather

than something that everyone wants me to kind of like be because... I don't know how to say it because not explaining that you are autistic; I have no regrets in not saying that I was autistic at the same time because it's kind of made me understand how people really are. I think I have already said that and it's kind of like because I am black, I am big, everyone is like oh yeah you should be hard and what not and you should be like a thug and everything like that and just... but I have tried and tried, I have tried to be that kind of character and I think I have realised that you know that isn't me, that isn't who I am. I am not that kind of person.” (P18)

The extended narrative section presented in excerpt (P18) consists of a number of life construct themes. Firstly, the account is representative of self-exploration and exploratory narrative processing. Patrick noted that trying to be someone that you are not has to be time limited, that is, “eventually” matters have to come to a head. He noted that his behaviour was not reflective of his character and that this was making him unhappy. Secondly, the construct of agency is evoked as part of this exploration. Patrick’s use of terms such as, “I wanted to try and be myself...,” and “I have realised that you know that isn’t me,” indicate that he is personally affecting change in his life through his growing understanding of who he is. Thirdly, the account is representative of meaning-making as Patrick is expressing insights about his life. Fourthly, the concluding lines of the narrative suggest a coherent positive resolution has been reached as the dilemma faced about the type of person Patrick will be (or not be) appears to be resolved.

He also discussed how his perspective had changed on the adolescent social culture portrayed via social media that he once thought he had to be part of in order to be happy:

*“I mean I have gone out a lot more over the summer holidays and meeting up with my friends but I have realised that, even at home, I don’t have to always go out and socialise to be happy because I am happy at home with my family like with my brother and my mum and though we have our ups and downs it’s kind of like I really feel comfortable at home and I have always felt comfortable.” (P19)*

Here Patrick appears to have found a balance between what he used to think was a preferred way of being and contentment with this current situation. This narrative is reflective of the achievement of a positive resolution to previous tensions.

When asked to reflect on any high and low points during the period of secondary school, Patrick included reflection on his development of his own perspectives and voice as a positive experience. In addition, it was evident that ambivalent thoughts and feelings he experienced related to who he is still exist to some extent:

"I think, okay, I mean... I think some high point experiences are like when I finally get an opinion and finally express my opinion to everyone and erm make myself, my opinion stand out in front of everyone and that kind of makes me feel like proud that I don't have to follow what everyone else is saying and I have got my own voice." (P20)

"I have to say this year in the whole so far it's been my happiest year and it has been depressing as well because it's kind of like you are happy because I am finally realising who I am and what not but along with that comes moments where you doubt that being me is enough for everyone else and at that point I just, I can feel really, I felt really really depressed."  
(P21)

Excerpt (P20) and part of (P21) suggest a narrative that would be consistent with the achievement identity status. However, the final lines of (P21) introduce uncertainty in relation to whether a coherent positive resolution has in fact been reached or whether further explorative narrative processing is required.

### **Narrative Theme: Future Self**

In discussing the future Patrick communicated that he wanted to use his creativity to inspire and influence people. In response to my question in the excerpt below

Patrick made reference to using his creative skills to communicate to others about autism. He also made reference to his choice of A-level as a means for understanding autism further:

*"P: Erm I want to do something in the media. I want to, well not like, I don't know I want to kind of like be able to get out there in the world and kind of like voice my opinions and just be myself along the way and I want to do that through like the use of camera and filming, taking pictures, I want to like do something along those lines or make films that can you know kind of inspire others in the world. Kind of like make kind of films and produce my own films and I would like to do something in music as well as, I haven't got an actual focus I have just got like a load of opportunities in my mind that I want to do for the future. I mean I would like to erm produce my own music as well which I already do but I would like to do it like professionally as well and that's kind of like an aspiration for me as well. And because I want to do all that to kind of like, inspire, influence people in a way.*

*S: Is it a way of communicating?*

*P: A way of communicating and also a way of communicating to people about autism and what not I would kind of like to communicate that in the future and that's why I chose psychology for an A Level as well because I wanted to see if that kind of helps me understand my autism a bit more.*

(P22)

Patrick's sense of a future self involves an emerging occupational identity which he hoped to link with self-expression and communication about autism. The narrative reflects the generative life construct as Patrick wants to inspire and influence. In addition, it appears that Patrick hoped to actively gain further insights into himself and who he is through pursuing studies in psychology, thus highlighting his continuing need for sense-making in relation to self and identity.



## **CHAPTER V**

### **DISCUSSION AND CONCLUSIONS**

#### **5.1 Introduction**

The life stories shared by each of the participants in this study provided a rich and complex picture of their narrative identity and of the on-going identity work in which they were engaged.

In contrast to previous research, which on the whole has relied on cross-case analysis, the narrative approach taken here allowed for the foregrounding of the individual accounts of the experiences of YP diagnosed with an ASC. Prior research with individuals with ASCs has primarily focussed on their identities as related to autism but the interpretation of the narrative accounts in the previous chapter allowed for the emergence of narrative identities beyond autism. The case-centred approach taken here allowed for an insight into the development and progression of narrative themes within individual accounts, and also into the process of meaning-making which resulted in evolving stories of the self.

The interpretations of the narratives are discussed below in light of the areas of debate concerning autism and identity that were noted in Chapter II. The discussion is presented in relation to the following areas:

- The Voice of the Child and Selves as Experts
- Neurodiversity
- Being Normal, Fitting In, Hiding It, Passing, and Disclosing
- School Experiences
- Diagnosis
- Agency

The theme of, 'Being Normal, Fitting In, Hiding It, Passing, and Disclosing,' was discussed in chapter II but was not presented separately to other themes. It is presented here for explicit discussion due to its occurrence as a theme in a number the accounts of participants in this study. In addition, the narrative identity life-story construct of agency is also given more explicit consideration in the discussion below due to the observation that it occurred as a theme across a number of the participants' stories.

In the final part of this chapter I go on to draw conclusions in relation to the implications of the findings for professional practices; share reflections on the limitations of the current study; and discuss possibilities for future research.

## **5.2 The Voice of the Child and Selves as Experts**

I would like to begin by returning to the research aim of privileging insider knowledge by giving voice to individuals' experiences. It was noted that attempts to elucidate the perspectives of individuals with ASCs can result in approaches

that focus on the general and homogenise the experiences of individuals with ASCs. The production of narratives of experience and hence narratives of identity provide an alternative approach to working with YP with a diagnosis, and indeed, with YP in general. The engagement of YP with the purpose of helping them relate their personal narrative identity of who they are, and who they would like to be, is commensurate with the person-centred approach to practice. It allows YP to share their views, avoids professional jargon, can allow access to an individual's strengths and their personal concerns, and may help them consider their lives in prospect in order to share their hopes and fears about the future. Such insights afforded by the narrative approach should allow professionals to work with YP to engage in person-centred planning.

It was noted in Chapter II that Perry (2012) has argued that due to the long term nature of autism and its implications for identity, practices and interventions with YP should be informed by the narratives of adults with autism. However, the accounts of YP presented as part of this thesis clearly illustrates that YP can be the experts in their lives, express coherent narratives, and share their thoughts, feelings and wishes, which should be central to the work undertaken by professionals with and for YP. Warham (2012) notes narrative based case-work allows individuals to bring to the fore matters pertinent to them and to go beyond the constraining topics of the professional's agenda. Similarly, Gilling (2012) notes that narrative practices can help re-author preferred identities. The interpretation of the accounts in the current thesis provide an example of how this can be achieved through the means of eliciting biographical narratives. Identities

were varied and went beyond the discourse of autism. Examples of identities beyond autism included: James' expression of an identity related to his position within the family and his belief in particular morals and values; Patrick's negotiation of a black identity; Freddy's identity related to a sense of belonging to a friendship group; Andrew's narrative talk relating to how he wanted to establish greater independence; and Racheal's desire to help others as a way of finding a purpose to life.

It was noted in Chapter II that some within the autism community emphasise that individuals with ASCs are, and should be, the official experts in relation to autism and in relation to their lives. The research findings here provide evidence that YP, by sharing their narrative identities and sense-making, can indeed provide coherent and expert accounts of their lives and experiences.

### **5.3 Neurodiversity**

The literature review indicated that some individuals with autism make sense of their diagnosis by drawing on the concept of neurodiversity and metaphors of the brain as different. The analysis undertaken in the previous chapter did not reveal that the YP participating in this study drew on such conceptualisations. In fact, none of the participants cited biological explanations in their meaning-making narratives of themselves. A possible reason for this is that the YP had not been exposed to the wider discourses which Ortega (2009) suggests have led to the proliferation of neurological claims, and a process of, 'cerebral subjectivation.' and

an understanding of the self in neurobiological terms. To the contrary, the accounts of narrative identity made available by the YP in this study appear to be grounded in the experiential. Of course, to some extent this will be a facet of the research design, with the focus on narrative, experience and sense-making, but this would not preclude the emergence of neurobiological explanations as a framework for meaning-making. It is also possible that, as previous research into the influence of the concept of neurodiversity on identity has relied predominately on the views of individuals using internet forums, previous findings have been influenced by a particular group within the autism community. This possibility again highlights the heterogenic nature of views, positions, and identities within the wider autism community, and places a greater imperative on professionals to ascertain and act sensitively to the lived experience of individuals they work with.

Parsloe (2015) highlighted how some participants in her study of discourses taken from on-line forums engaged in talk to promote more positive identities by, 'reclaiming,' normalcy, symptoms and agency. Although there were a few examples, the participant narratives did not involve explicit reclaiming talk related to normalcy and symptoms to any notable extent. Racheal's sense-making included the comment that everyone is different which could be seen as reclaiming normalcy and Freddy's observation that he goes deep into his interests could be seen to reclaim, what from a biomedical perspective might be considered, a symptom. What was more notable was that some participants in this study appeared to be reclaiming agency, or at least evoking narratives of agency in their accounts. Parsloe (2015) identified a reclaiming of agency through discourses of

activism where individuals aligned themselves to other marginalised groups and attempts to challenge discrimination. In contrast, the participants in this study tended to reclaim agency in a more subtle manner, for example, through discussing actions personal to themselves. Patrick wanted to communicate about autism to others through creative media and learn more about autism himself; Racheal talked about how she was gaining confidence because she would, ‘throw’ herself ‘out there,’ in order to face challenges and try to overcome her anxieties; and Andrew discussed how he was learning to travel more independently. The theme of agency is discussed further below.

#### **5.4 Being normal, fitting in, hiding it, passing, and disclosing.**

Discourses relating to individuals wanting to be, ‘normal;’ fit in with their peers and school communities; and hide or reveal their diagnosis and differences have been well documented in previous research. In line with these reported findings, a number of the participants in this study also shared similar discourses through their narrative accounts. This particular theme can be understood with reference to the frameworks of identity discussed in the literature review in Section 2.8.

Firstly, from a narrative identity perspective and with reference to life-story constructs the construct of communion is of most relevance. McAdams & McLean (2013) note that the theme of communion that occurs in the life-stories of adults relates to the extent that a sense of belonging is communicated through the narrative. In the findings here, it appears it is the sense of the, *need and search*,

for belonging that the YP were communicating. This difference in emphasis could relate to a narrative of autism as a barrier to communion and belonging. Another explanation could be due to the differences in the age of participants in this study compared with the work of McAdams undertaken with mid-life adults, with adolescence being a time for identity development and a search for one's place in relation to, and with, others. However, it is worth noting that participants in this study talked about being aware of a sense of not belonging from an early age.

Secondly, the narrative identity construct of communion can be linked with social identity theory, where the individual aims to develop a social or collectivist identity in order to achieve communion and a sense of belonging. The social identity and self-categorisation approach then is also able to offer an understanding of the different aspects of this wider normalcy and communion theme. The participants were self-categorising (for example, through self-awareness and self-reflection of some differences between themselves and others), and were being categorised (for example, through the diagnostic label, stereotypical and media representations of individuals with autism, and educational practices) as not fitting within a definition of normal. This categorisation then leads to broad groupings of, 'normal,' and, 'not normal,' providing the basis for group comparisons and evaluations. We can assume that being categorised as belonging to a group considered, 'not normal,' leads to negative evaluations.

Social identity theory postulates that individuals strive for membership of positively perceived groups and that, where the evaluation of a group is negative, it predicts

that individuals will try to leave the group or attempt to pass as a member of another group. Of course, in order to pass and fit in with the normal group, an individual would need to keep their diagnosis secret, thus explaining the desire and motivation of individuals in hiding their diagnosed status. We saw that Patrick had made a concerted effort to fit in and pass, both in terms of a normal reference group but also in relation to a group based on his black ethnic identity which he was trying to negotiate. For Racheal difficulties with passing and not having a sense of communion with a group she perceived as normal led to a low point in her well-being. Interestingly, both Racheal and Patrick went on to share narratives, where after self-exploration and a process of sense-making, they appeared to change their behaviours in relation to attempting to pass and fit in.

These changes can also be accounted for by tenets of social identity theory. The theory proposes that when unable to pass as a member of another group, individuals might attempt to re-evaluate their current group. Racheal's narrative indicated that she had come to accept that in fact, everyone is different to some extent. Having gone through some exploration and meaning-making in terms of her relationships with peers, Racheal seeks communion through other means, such as finding others with like-minded interests on-line. She also re-evaluates autism as, 'a good thing,' because it has made her the person she is. Patrick noted that he realised he was not the only one who experienced difficulties with social interaction after meeting others with autism at a social interaction intervention group. Following a period of sense-making, he derives a life maxim noting that you cannot try to be someone that you are not. He notes that he can



be happy at home engaged in his creative pass times, and that he does have some friends he can go out with, therefore focusing on what is going well for him in terms of his social identity and relationships with others, rather than trying to be someone he is not.

Patrick also noted that he wanted to communicate about autism to others through making use of his interest in creative media. This could reflect a process described in social identity theory where individuals or a group attempt to counter negatives perceptions of the group they belong to. Freddy's narrative also included talk of difference. Freddy did not categorise himself as, 'not normal' but emphasised difference on the account of, 'going deep,' into topics he was interested in. Freddy perceived differences between himself and others as minimal and was thus able to categorise himself as normal and relate a narrative identity characterised by canonicity and ordinariness of experience.

Social identity theory also predicts that individuals might engage in collective actions to improve the perception and evaluation of their group. Similar to the findings reported by McLeod et al. (2013) none of the participants were engaged in a collective movement focussed on their autism identities. This could be explained due to a lack of communion with others with autism, attempts to continue to distant themselves from the negative perceptions of the label, and a lack of interest or understanding of political activism, for example. The relatively young age of the participants may also have been a factor as they were beginning to explore their sense of identity, which may be a prerequisite of collective action.

Also, the research reviewed previously noted that internet forums had facilitated a collective identity movement but participants in this study did not indicate that they were engaged in any such forums.

It was noted in Chapter II that Myers et al. (2011), drawing analogies with deaf culture, argue for the promotion of a bicultural identity for students with autism as a means to promote well-being. Myers et al. suggest openness about diagnosis, adjustments to the classroom, and changing the mind-sets of neurotypical classmates through educating them about autism to reduce stigma. These suggestions can be related to social identity theory in that they may act to broaden the scope of what is considered 'normal.'

Findings from previous research relating to the, 'being normal and fitting in,' theme has mainly been descriptive, identifying different aspects of the discourse and observing it to be a frequently occurring subject of discussion. The examination of narratives undertaken with explicit reference to theories of identity in the current research has provided novel and deeper understandings of the psychological processes involved and their influence on the thoughts, feelings, and behaviours of individuals in relation to ideas of being normal, trying to fit in, or pass by hiding autism, and in relation to dilemmas about decisions to disclose a diagnosis to others.

## **5.5 School Experiences**

It was noted in the literature review that although there has been considerable research undertaken with YP diagnosed with autism in order to ascertain their views about their school experiences (e.g., Humphrey & Lewis, 2008), such research often fails to consider these experiences in terms of identity other than making the general observation that identity is affected.

Andrew's narrative gives an insight into the impact of his school experiences on his identity. Andrew had moved from one school which was unable to cater for his needs, to one where the system facilitated his inclusion through adaptation of school procedures and the environment. The difficulties in his first secondary school placement led to a narrative theme of coping and not coping and is clearly an influence on his narrative of who he was, is and can be.

It appears that his identity is entwined with the educational institutions that he attend during his secondary school years. Andrew comments that remaining in his current setting for further education may not be suitable, but that moving elsewhere is a risk as the new setting may not know how to cope with his autism. In terms of narrative identity constructs, Andrew's school experiences mould his sense of agency, or lack thereof. With reference to a symbolic interactionist perspective, it could be argued that Andrew perceives himself in the way others have, that of someone not coping or someone whose autism needs coping with.

James' narrative revealed that adaptations made for him in school reinforced his sense of difference and separateness from others. James also noted that sometimes noise levels in the school environment made him be, 'automatically aggressive,' thus influencing his self-concept as someone who was aggressive. Racheal's sense-making of the development of dysfluency of speech was related to her observation that school was a place where she was forced (i.e., required) to talk. Her causal sense-making suggests that her sense of being different and not normal was reinforced by practices aimed at making her conform to expectations of communication and therefore, 'normalise' her.

Dean made use of a number of words which were negative when he was describing himself within talk relating to the school context. These included self-descriptions such as, 'antisocial,' 'prat,' 'lazy,' and 'disorganised.' It is possible that these concepts were derived externally from how others perceived him; in terms of symbolic interactionism, a 'looking-glass' self. Although, Dean did not suggest that others viewed him in this manner or anyone used these terms, the possibility that these self-concepts are derived from Dean's school experiences has to be considered.

The challenge is then for schools to consider the impact of interventions that they employ (or not) on identity, and how students are 'reflected' back to themselves in a way that influences their self-concepts positively, whilst mitigating against the development of negative self-concepts.

However, the models of identity (narrative identity, social identity theory and symbolic interactionism) that were drawn upon as part of the interpretative process in Chapter IV, do not appear to explicitly capture the relationship between an individual's identity and a meso-structure such as a school. Positioning theory was discussed in Chapter II but was not employed as part of the interpretative process as it focusses on the discursive production of identity which was not a focus of the current thesis. However, it is possible that use of positioning theory may be able to bridge the gap between how the social world is mapped onto subjective experience in the contexts of conversations (Winslade, 2012).

## **5.6 Diagnosis**

Some of the research reviewed in Chapter II focussed on the changes to diagnostic criteria for autism (Spillers, et al., 2014; Giles et al., 2014; Carmack, 2014). The participants in this study did not make references to these changes or the debates surrounding these. It has been noted above that the participants were not users of on-line forums where such debates were being conducted; they did not present with a collective autism identity, which might have been a factor in the engagement in such debates; and that their ages may have been a reason for a lack of political engagement in relation to autism.

Previous research has noted that a diagnosis of autism can act as an explanatory framework for some people but that individual responses are more complex, varying from negative to positive. Mogensen and Mason (2015) noted that

diagnosis was seen as advantageous when it facilitated agency and control. Consistent with previous findings, there were a range of responses from participants in relation to their diagnosis in this study. The narratives of Racheal, Patrick and James included talk reflective of diagnosis employed as a sense-making framework. Dean linked one aspect of his behaviour, being disorganised, to autism but noted that the diagnosis did not have a great impact on his life. Andrew did not explicitly employ his diagnosis as a sense-making framework but it did seem to frame his sense of reduced personal agency and control. Whereas for Freddy, his diagnosis seemed to be inconsequential for him, with autism not being an important feature of his narrative identity.

One possible recommendation stemming from the findings could be to support individuals understand themselves using the diagnosis of autism as a sense-making framework. However, such a move has potential to narrow an individual's perspective and understandings of themselves, and as Gilling (2012) noted, may restrict other identities from being voiced or being established. There are also ethical implications to consider, for example, when would it be right to intervene, what might the consequences be, how might any intervention be undertaken. The narratives of some participants revealed they were engaged in making-sense of their lives by considering which experiences were framed and influenced by autism and which were not; a finding also observed by Molloy and Vasil (2004). Intervention in such circumstances has the potential to intrude into the very making of selves and identities and deny individuals opportunities to engage in

self-exploration in order to make sense of their own lives as part of their evolving selves and identities.

A further factor related to diagnosis in previous research has concerned the experiences of YP in the diagnostic process. Research by McLeod et al. (2013) noted that participants in their study found information shared at the point of diagnosis to be limited and not reflective of the individual's experience. The findings of this study generally concur with those reported by McLeod et al. Many of the participants were unclear about how their diagnosis came about and appear to have had limited explanation of the significance and implications of the diagnosis. For example, James noted, 'it's just a piece of paper,' saying he had autism and he did not see how it was going to make a difference. It appears then that YP are not active participants in the diagnostic process and therefore denied opportunities to be experts in their lives.

Ascertaining life stories and narratives of YP as part of the diagnostic process could act as a way of giving prominence to the voice and lived experience of YP, and ensure that their identities and the impact of a diagnosis on these, is a central consideration in the sharing of information and subsequent support or planned intervention. The challenge would be to share information about autism and make it relevant to the individual's experience without promoting autism as the exclusive framework for sense-making. As noted above, the ethical implications of any process aimed at supporting an individual's identity work would need careful consideration and should be an area of further research. However, it should also

be noted that current diagnostic practices do impact upon identities and a first step for professionals would be to acknowledge this and ensure an appropriate debate about ethics is instigated.

## **5.7 Agency**

McAdams and McLean (2013) and McAdams and Guo (2015) identified themes or life-story constructs that occur as part of life narratives. Examples of each of life-story constructs, with the exception of the construct of contamination (where a positive experiences turns negative) were identified across the narrative accounts of the six participants. However, there was variability within individual accounts and not all constructs were evident in the narratives of all participants. Narrative talk reflecting the constructs of communion, or belonging, and of agency, the extent to which an individual can influence change in his or her life, was the most frequent. The construct of communion was discussed in relation to the '*Being normal, fitting in, hiding it, passing, and disclosing,*' theme above. This section therefore focuses on the construct of agency.

A number of participants evoked personal agency as a factor in their view of their personal growth over time and their possible futures. For example, as noted above, Andrew's narrative indicated a desire for increased personal agency and increased independence. This was in resistance to a narrative of someone who needed support and was seen as not coping. Andrew's rhetorical comment asking how is he supposed to get independence if he is taking taxis all the time



resonated with the concept of identity capital (Fein, 2015), where those slower to develop social skills and competencies are systematically denied opportunities to develop them, leading to further exclusion and delays in skill development. Andrew's narrative suggests his desire for independence is frustrated by lack of opportunity to develop it and therefore his sense of personal agency, the extent to which he can influence change in his life, is also frustrated. Racheal and Patrick evoked personal agency in their narratives when explaining how they had challenged some of the difficulties they had experienced in relation to their autism related identities. Participants also cited the construct of agency in the themes of personal growth highlighting how they had developed as individuals over time. For example, they talked about how they had matured, gained confidence, and changed their understandings of the world, for example. All participants were asked about how they saw themselves in the future. The majority of participants related narratives reflective of a desire for increased personal agency in their lives and a number related this to a wish for greater independence.

McAdams and McLean (2013) describe the life-story construct of agency as the extent to which an individual can influence change in their life. It was noted earlier that the life-story constructs described by McAdams and McLean are derived from the narratives of mid-life adults and therefore the constructs may not be evident in the narratives of adolescents. The findings of the research here may be useful in providing some qualification and elaboration to the life-story construct of agency. It appears the construct of agency was in fact evident within the narratives of the participants. However, it was often related to talk of a search for greater

independence and agency. The concept of independence can be closely related to agency as it might be a facilitating factor for the development of personal agency. However, some personal agency may also be required in order to facilitate the development of greater independence, therefore indicating a reciprocal relationship between the two. The search for greater personal agency and independence may be a sub-theme of the overall construct of agency which is particular to the developmental stage of adolescence and/or specific to individuals where the development of agency may have been frustrated due to factors associated with disability or difference.

## **5.8 Implications for Practice**

The discussion above has generated a number of implications for the practice of educational psychologists and other professionals working with YP with a diagnosis of an ASC. These implications are discussed further below.

Firstly the importance of engaging with the narrative identity of individuals through ascertaining autobiographical life-story accounts was highlighted. There is significant potential for such an approach to be a key driver of person-centred practice and for ensuring the voices of individuals are heard and acted upon. The use of life-story work also has the potential to increase the specificity and relevance of information provided to YP as part of diagnostic processes and ensure they are involved in the process as experts about themselves. In addition, the use of narrative accounts has potential to increase the relevance and

involvement of YP in the co-configuration of any interventions to support their needs relating, not only to autism, but also to identities beyond autism.

Further to this point, personal narratives could also be used to promote deeper understandings of the individual. This may be of benefit in training staff who may be working with the individual to utilise bespoke approaches in meeting needs, rather than relying on practices based on generalisations of the needs of the YP with autism. Personal narrative accounts may also be of benefit to support work being undertaken with peers to improve their understanding of the individual in order to decrease stigma, promote inclusion or even elicit support.

The use of narrative interviewing as a means to support narrative identity work in its own right is another consideration that could be of potential benefit. McAdams and McLean (2013) have noted that certain aspects of the construction of narratives such as greater personal agency and exploration are associated with better psychological well-being. The opportunities to develop and share life narratives may be limited for some individuals with ASCs due to differences in access to social interactions and self-reflective practices compared with neurotypical peers. Thus, structured opportunities to share stories about oneself may provide occasions for meaning-making and exploratory narrative processing that may give rise to understandings of the self which may not otherwise occur.

The use of narratives also has the potential to act as a tool in increasing reflexivity at an institutional level to examine practices that may be influencing identity

processes in individuals with ASCs. Such an approach has potential to highlight both positive and unhelpful or oppressive practices that may be at play, that is, practices that may support or constrain positive identity development. The key to determining how school or other institutional practices may be operating for any one individual would be through accessing their interpretations of these as part of their meaning-making in narrative accounts. It was noted previously that in the theory of symbolic interactionism meanings are mediated through interpretative processes (Allan, 2011). Therefore, it is conceivable that different individuals may make sense of the same institutional practices differently, resulting in varying impacts on identity. As a consequence, it is important that individuals with ASCs are not treated as a homogenous group.

The discussion above highlighted the importance of the reoccurring theme of being different and fitting in for individuals with ASCs. It was noted that an underlying factor relating to this discourse was the motivation and need for achievement of a sense of communion with others and for individuals to evaluate themselves positively. Practices that may then support individuals could include those that:

- promote identification with positive aspects of an individual's autism identity;
- re-focus self-evaluations beyond autism identities to other positive self-concepts;
- support the development of collective identity with others with ASCs;

- support the development of communion with neurotypical peers;
- challenge accepted discourses of 'normal' by reducing stigma through increasing acceptance of difference and diversity; and
- promote the development of bicultural identities.

A further consideration regarding implications for practice relates to the findings above concerning the importance of personal agency. McAdams and McLean (2013) note the significance of personal agency in relation to psychological well-being. Considering how professionals might support the development of personal agency then is essential when working with individuals with ASCs. Again, the use of narrative accounts has the potential to support in identifying what personal aspirations and goals individuals may hold, what barriers might exist to the realisation of these, and what changes may be required to support the development of independence and personal agency in order for these to be achieved.

A significant implication of the research findings concerns the ethics of professional practices and interventions in relation to YP with ASCs. The suggestions for professional practices outlined above must be considered in terms of the ethical implications for individual identities at the forefront. Identity is a personal matter, fundamental to the very being of individuals. The rights of professionals to access narrative accounts of identity to inform practices and interventions needs further debate. This would be particularly important where

individuals may not understand the implications of sharing their stories or be able to give fully informed consent in relation to how these may be used.

It was reported earlier that Carmack (2014) had noted, as part of the debate about diagnostic criteria, that the technical/professional and public/personal spheres inform each other. However there was a tendency to revert to the expert view for the accepted argument where there were disagreements. There exists a danger in that a similar position could evolve when ascertaining the personal narratives of individual to inform practice. That is, a professionals interpretations of a narrative may be given greater importance compared with the individuals own sense-making.

A possible means for reducing the risk of such an occurrence would be to ensure the individual is fully informed about the purpose of collecting their story, what might be done with it, how it might be shared, and how it might be acted upon. Narratives, once gained, are subjected to interpretation. The professional is then interpreting someone's interpretations of their own experiences. Returning to the individual to validate any interpretation of their narrative and discuss possible actions that might be considered would also be a means of ensuring the process remains person-centred and the individual is positioned as the expert in their life.

## **5.9 Limitations and Future Research**

Due to the research object being narrative identity and the positioning of the research within a framework of narrative psychology the method of data collection was through a semi-structured interview designed to elicit a life story account. However, this focus on deriving data through a face-to-face semi-structured interview may have limited the expression of stories by some of the participants. The design primarily relied on verbal interaction with the use of a visual prompt, a life story grid, to help structure the account. Differences in social communication and interaction are inherently associated with autism and therefore the interview method may restrict production of narratives in some aspects. Some authors have suggested alternative approaches which could be employed in future research aimed at looking at narrative identity. Riessman (2008) and Bell (2013) discuss more visual approaches to narratives, Barrow and Hannah (2012) describe a computer-assisted interviewing method, and Winstone et al. (2014) describe activity-oriented interviews that could be usefully employed with YP with ASCs, for example.

A further limitation concerns the validity or trustworthiness of the analytical process. The decision was taken not to return to individuals with my interpretations and conclusions of their stories for the purpose of checking that these were congruent with their understandings. The reasoning for this decision was outlined previously in Section 3.3.5. However, had such an approach been employed then the trustworthiness of the research may have been enhanced.

Above, of course, I have advocated that where interpretations of narratives are going to lead to planning and intervention for the YP concerned that it would be vital to ensure interpretations are presented for checking and comment by the individual.

In presenting the findings in Chapter IV, I took the decision to support and exemplify my interpretations using excerpts from the narrative interviews. The majority of excerpts are presented somewhat out of context, in isolation of the questions and comments I made around their articulation as the dialogic nature of the narrative was not a focus of analysis. Nevertheless, narrative interviews are essentially co-constructed accounts and my influence in shaping them is somewhat lost, perhaps giving an impression of greater narrative coherence and processing than would have otherwise been.

A further limitation and consideration for future research concerns the criteria used to select participants for this study. Firstly, for ethical reasons it was decided that individuals who may have been presenting with concerns in relation to their mental health and psychological well-being would not be selected to take part. However this will have acted to exclude the voices of individuals whose experiences are likely to be important in providing an insight that might have resulted in alternative perspectives into narrative identity and sense-making in YP with ASCs. In addition, the selection of participants known to have relatively good verbal skills has excluded others whose stories may have also provided a new perspective in relation to narrative identity and their lived experience. Future research into



narrative identity perhaps then should focus on the selection of a wider range of individual from within the autism community.

In addition to the future research suggestions identified in relation to the limitations of this study described above, possibilities for further research exist in relation to some of the implications for practice noted in Section 5.8.

Research evaluating the utility and effectiveness of a narrative approach to underpin person-centred practices with YP with ASC is an area of possible research that could usefully inform professional practice. Research evaluating whether a narrative approach ultimately leads to the achievement of outcomes desired by the individual would be of use. Research examining the viability of increasing personal agency and the development of communion could also be a fruitful area of future study. Further research addressing the ethical implications of interventions that impact on identity would also be vital in informing professional practices.

## **5.10 Conclusion**

The thesis presented here set out to explore the experiences of YP diagnosed with ASCs with the aim of highlighting the processes of sense-making as related to self and identity. The existing literature examining identity in relation to individuals diagnosed with ASCs was reviewed and shown to be limited in its use of psychological theories of identity. Narrative identity was chosen as the primary

identity framework in this study due to its synergy with lived experience and the privileging of an insider perspective.

The research findings revealed that participants were actively engaged in sense-making of their experiences and in the production of narrative identities. The employment of a narrative approach allowed for the emergence of a rich and complex picture of identities that went beyond the label of autism. The narrative accounts demonstrated the heterogeneity amongst participants and the need for understandings at the individual level in order to promote a person-centred approach to practice, education and interventions.

The use of narrative accounts is therefore a particularly useful method for engaging the voice of YP with autism. The fact that some themes related to identity reported in existing literature (e.g. neurodiversity and essentialist/biological explanations) did not feature as part of the narrative accounts collected here highlights the need for professionals to engage with personal narratives and be mindful that published research may not capture the themes of the personal identities of individuals they are working with.

Furthermore, the use of psychological frameworks of identity to interpret the narratives of the YP in this study proved useful in providing richer understandings of some themes that had been previously reported in the literature. For example, the themes relating to the constructs of communion and personal agency were identified as important features of the on-going identity work that was being

undertaken by the participants. The construct of communion along with social identity theory helped provide deeper understanding of narratives relating to, 'being normal and fitting in,' which have been frequently reported in previous research. Thus, explicitly interpreting narrative accounts in terms of psychological theories and models, whether these be related to identity or other psychological phenomenon, provides a means for richer understandings of an individual's lived experience.

Using the concept of narrative identity to understand personal experiences with the aim of supporting person-centred practices and interventions promises to be a useful approach for professionals working with YP with autism. However eliciting and using personal narratives must be based on careful negotiation of ethical considerations relating to, for example: interpretation; power; consent; confidentiality; and the impact on identity.

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**APPENDIX 1:**  
**EXAMPLE INFORMATION FOR PARENTS AND PARTICIPANTS**

**Research Study**

A Narrative Exploration of Sense-Making, Self and Identity in Young People  
Diagnosed with an Autistic Spectrum Condition.

My name is Sam Samra and I work for X Educational Psychology Service. I am currently undertaking doctorate research in Educational Psychology at The University of Birmingham.

As part of my studies, I am interested in researching the life experiences of young people who have been given a diagnosis of an ASC. Through collecting life stories I hope to understand more about how young people diagnosed with an ASC make sense of their experiences and what this may tell us about their identities.

The research will allow professionals to understand the perspectives of the young people they work with and take these into consideration when planning educational and other services.

The research process will involve 1 or 2 informal interviews where your son/daughter will be asked to talk about their life and experiences and their thoughts and feelings about these. The interviews may take place in your son's/daughter's school/college or somewhere else, such as at home, if you or he/she prefers.

The interviews will be recorded on a digital recorder and then a transcript will be made of the interviews for analysis. The analysis will look at what young people say about their experiences and what this can tell us about their identities. I understand that your son/daughter has a diagnosis and I would like to invite them to take part in the research.

I have attached some information for you and your child which gives more details and may help answer some of your questions. This will help you decide if you are happy for your child to be involved in the research.

## **Information Sheet for Parents and Frequently Asked Questions**

### **Does my child have to take part?**

No. Your child does not have to take part. I am seeking volunteers who would like to take part in the research.

For ethical reasons, I will require consent from both you and your child.

### **If we are happy to take part what will happen next?**

- 1) If you are happy for your child to take part I will ask you to complete and sign the consent form.
- 2) If you give consent and have checked with your child they are happy to meet with me then I will arrange to meet your son/daughter at his/her school/college.

At the meeting I will make sure your child is happy to take part and ask him or her to sign a consent form.

- 3) The first interview with your child will take place at this time. The interview will be recorded on a digital recorder.
- 4) A further interview may be arranged. For example, in order to complete the life story or for your child to provide further details.
- 5) Once the project is finished, and the thesis has been passed, I will provide you and your child with a summary of the findings.

### **What will happen at the interview? What will you ask my child?**

At the interview I will ask your child to talk about their life so far and about their thoughts for the future. I will use questions to help them remember key information. The interview will be informal and I will aim to make it more like a conversation.

Your child will not have to talk about anything they do not want to talk about.

If your child shares information that indicates that they or someone else is at harm or that something illegal is happening I may have to share this information with others, such as you, the school or child protection services, for example.

### **How will the interviews be recorded?**

The interview will be recorded on a digital recorder. The recording will be transcribed by myself or a professional transcriber ready for analysis. The interview data will be held securely.

### **Anonymity and Confidentiality: Is the study confidential? Who will know I have taken part?**

The recordings of the interview will contain what your child says. Transcripts will be altered in order to change names of people and places (such as towns or schools) making it difficult for your child to be identified. The transcripts may be included in the final write up as appendices and therefore will be available to others. Myself, the professional transcriber, and my University supervisor will have access to exactly what was said. The digital recording of the interview may be held for up to 10 years.

Some other people may know your child is taking part in the research, such as school staff, if the interviews take place in school for example, but they will not know what your child has said.

Your child will not be identified in the write up of the findings.

If your child shares information that indicates that they or someone else is at harm, or that something illegal is happening or has happened, I may have to share this information with others, such as you, the school or child protection services, for example. Your child will be told that I may have to share such information before they agree to take part in the study and before each interview.

### **If we say yes, can we change our minds and pull out of the study?**

Yes. If for any reason you or your child want to change your mind and withdraw from the study it is ok to do so. Please just contact me to let me know. You will not have to give a reason for withdrawing.

Your child will also be allowed to pull out of the study during an interview if they want.

If interviews have taken place it may still be possible to withdraw from the study. The interview data will not be analysed as part of the study and will be destroyed or deleted.

If you or your child wish to withdraw from the study after the interviews have taken place you should let me know within 10 days of the last interview.

**Are there any reasons why my child shouldn't take part in the study?**

The study will involve your child talking about past experiences which might include things they have found difficult or that may have upset them. If your child has received help for anxiety or emotional stress in the recent past it may not be appropriate for them to take part if talking about past experiences may cause them distress.

If during an interview, I notice your child is becoming distressed then I will end the interview and advise that help is sought from someone who may be able to support your child such as your GP, Child Adolescent Mental Health Services or other agencies.

**How can we contact you?**

My contact details are:

Sam Samra, Educational Psychologist,

Telephone: X

Email: X

University Supervisor: Dr Jane Leadbetter

Telephone: X

Email: X

## **Information Sheet for Participants**

Hi. My name is Sam. I would like to invite you to take part in a research study. The study will look at the life experiences of young people diagnosed with an ASC. I am interested in finding out about your life experiences and how these relate to your sense of identity.

### **What is the study about?**

The study will help professionals understand the point of view of young people with ASCs better and will help them think about how best to work with, and for, these young people.

### **What will I have to do?**

If you choose to take part you will be asked to talk to me about your life so far and think about your life in the future. I might ask you to talk about good and bad experiences you have had, family, school, friends, the diagnosis of Asperger Syndrome or Autism and your thoughts and feelings during different times of your life so far and about the future. I might ask you questions to help you remember your experiences.

You will not have to talk about anything you do not want to talk about.

### **Where will the discussion or interview take place?**

If you agree to take part I will arrange to meet you at school, college, or may be at your house. We might meet again to finish our discussion if we run out of time.

### **How will what I say be recorded?**

I will record our discussion on a digital recorder. After the discussions the recording of what was said will be typed up ready for analysis.

**Is what I say in the interview confidential?**

When I write up the study I will use pretend names for you, people you talk about and places you mention to make it harder for anyone to know what you said.

The transcripts will be included in the write up as appendices and will therefore be available for others to see. The digital recording of the interview may be held for up to 10 years.

If you tell me something where I think something is happening or has happened that is against the law or if I think you or someone else is at risk of harm then I might have to share this information with other people.

**Are there any reasons why I should not take part?**

I will be asking you to talk about your life experiences. You will not have to talk about anything you do not want to talk about. Sometimes thinking about our experiences can lead to us getting upset. If you think taking part in the study will cause you to get upset then you may not want to take part.

**If I say yes to taking part, can I change my mind?**

If you agree to take part but then change your mind that will be ok. You can even change your mind up to 10 days after the last interview. After this point I will have started analysing our discussions and I will not be able to remove your information from the study.



## **APPENDIX 2: CONSENT FORMS**

### **Research Consent Form (Parent/Carer)**

**Project:** A Narrative Exploration of Sense-Making, Self and Identity in Young People Diagnosed with an ASC.

**I give consent for my child, [Name].....to take part in the above research project.**

**Parent Signature**

.....

**Date**

.....

If I wish to withdraw consent I understand I can do so by letting the researcher know up to 10 days after the last interview or any time before.

## Research Consent Form (Young Person)

**Project:** A Narrative Exploration of Sense-Making, Self and Identity in Young People Diagnosed with and ASC.

I, [Name].....agree to take part in the above research project.

**Participant Signature**

.....

**Date**

.....

If I wish to withdraw consent I understand I can do so by letting the researcher know up to 10 days after the last interview or any time before.

### APPENDIX 3: LIFE-STORY GRID AND PROMPTS

#### Life-Story Grid

|                                       | 0-5 | 6-11 | 11-13 | 14-16 | 16-18 |
|---------------------------------------|-----|------|-------|-------|-------|
| High points                           |     |      |       |       |       |
| Low points                            |     |      |       |       |       |
| Family Experiences                    |     |      |       |       |       |
| School Experiences                    |     |      |       |       |       |
| Interactions with others              |     |      |       |       |       |
| Other important events or experiences |     |      |       |       |       |
| Thoughts and Feelings about yourself  |     |      |       |       |       |
| Thoughts and feelings about diagnosis |     |      |       |       |       |
| Anything Else                         |     |      |       |       |       |

## Life-Story Prompts

|                                       |  |
|---------------------------------------|--|
| High points                           | Think of a positive experience. This might be a happy or exciting time. What happened, when, where, who was involved, and what were you thinking and feeling?  |
| Low points                            | Think of a low point or a difficult time? This might have been a sad or confusing time or a time when you felt angry for example. What happened, who was involved, and what were you thinking and feeling?           |
| Family Experiences                    | What was it like for you at home at this time?   |
| School Experiences                    | What was it like for you at this time at school?   |
| Interactions with others              | Can you tell me about your relationships with other people at this time, this could be family, friends and other children in your school, teachers, other people that worked with you, or any other people you knew? |
| Other important events or experiences | Are there other important events/stories/experiences/memories from this time you want to share?  |
| Thoughts and Feelings about yourself  | What was it like to be you at this time? What are your memories of yourself at this time?  |
| Thoughts and feelings about diagnosis | What were your thoughts and feelings about (if any) about diagnosis/autism/ASC   |
| Anything Else                         | Is there anything else you would like to tell me about this time and what it was like for you?   |

### Additional Prompts

How do you think you have changed over time? What were the turning points? What are your dreams, hopes, and plans for the future?

## APPENDIX 4: WORKING TRANSCRIPT

### Working Transcript for Participant One (Freddy) Showing Episodes, Sjuzet, Narrative Themes and Identity Constructs.

|   |     |     |  |   |
|---|-----|-----|--|---|
| Episode 1<br><br>Can't remember anything before school. | 1.  | S:  | I'm just gonna start there. Right. We have been through the stuff that we need to talk about. Erm, can you think back to your early life and just tell me what that was like for you? What can you remember from maybe before you went to school?      | <b>Theme:</b><br><b>Ordinariness /Normality</b><br><br>Uneventful ordinariness emphasised.<br><br><i>Identity:</i><br><i>canonicity</i>                     |
|   | 2.  | F:  | Well I don't remember much before, before school because <u>not anything significant happened</u> if I am honest with you.   |   |
|   | 3.  | S:  | Do you remember anything at all? Do you remember what you were like?   |   |
|   | 4.  | F:  | <u>I remember it being alright because you know you are a baby and life is simple then. Of course, in that sense it was just OK.</u>   |   |
|   | 5.  | S : | There weren't any problems?  |   |
|   | 6.  | F:  | <u>No problems, no like traumatic events or anything.</u>  |   |
|   | 7.  | S:  | Okay. What about friends or family experiences? Can you remember any before you went to school?  |   |
|   | 8.  | F:  | Not really, no, it was a long time ago.  |   |
| Episode 2<br><br>Tight-knit group                       | 9.  | S:  | Let us have a little chat about then what it was like at primary school err in your early years from say, the err age of 6 to the age of 11. Err any important significant memories that you have got? Any special memories? Any positive experiences? | <b>Theme:</b><br><b>Friendship</b><br><br>Primary school is a positive experience because of close friendships.<br><br><i>Identity:</i><br><i>communion</i> |
|   | 10. | F:  | Primary school itself <u>was just a positive</u>   |   |

|  |     |    |  |   |
|--|-----|----|--|---|
|  |     |    | <u>experience because at the end of it, well start of it of course, you don't know anyone, <u>but near the end of it, especially us lads we were all a pretty much a tight-knit group.</u></u>   |   |
|  | 11. | S: | So that is a positive for you, the fact that you had a close friendship group?   |   |
|  | 12. | F: | Yeah.  |   |
| Episode 3<br><br>Residential trips were fun.     | 13. | S: | Okay. Can you think of any specific high points, erm you know a time where you felt happy or excited?  | <b>Theme: Independence</b><br><br>Being away from home. But no evaluation of how the experience may have changed or developed him. But emphasises that it was fun.<br><br><i>Identity: separateness from family. Independence</i> |
|  | 14. | F: | Some of the high points were when I went on my residential trips in Year 4 and 5, especially the second time. <u>So that was a lot of fun, being 9 and 10 err respectively at each time, being away from home for the first time for a week. I found that quite fun.</u>   |   |
|  | 15. | S: | It was fun. And your thoughts and feelings about that, about being away from home?   |   |
|  | 16. | F: | <u>A good experience.</u>  |   |
|  | 17. | S: | It was a good experience? Erm, do you think it changed you in any way?   |   |
|  | 18. | F: | <u>Not really, no. It was just a fun time.</u>   |   |
|  |     |    |  |   |
| Episode 4<br><br>It was an excellent experience. | 19. | S: | It was a fun time. What was it you were doing? What was happening, what was fun?   | See Episode 3   |
|  | 20. | F: | We were staying in a house. It was like an old Victorian house that used to be owned by some Landlord and erm we used to, it was near some woods. They've now changed it so it is specifically designed to take err primary school kids onto residential trips and they have got activities such as rope climbing and raft building and problem solving. |   |
|  | 21. | S: | So you enjoyed doing all that? Erm who were you with? School friends?  |   |
|  | 22. | F: | It was our teachers, school friends and their staff.   |   |
|  | 23. | S: | Okay erm, what were your feelings about that?  |   |

|                                  |     |    |  |   |
|----------------------------------|-----|----|--|---|
|                                  | 24. | F: | <u>My feelings about that was it was a good, overall it was an excellent experience.</u>   |   |
| Episode 5<br>Playground flights. | 25. | S: | Excellent experience, okay. Can you think of any low points during primary school or any difficulties, a difficult time? It might have been at school or at home so it doesn't have to be at school. | <b>Theme: Ordinarity/normality</b><br><br>No specific low points in primary.<br><br><i>Identity: Canonicity</i> |
|                                  | 26. | F: | <u>Nothing really significant if I am honest.</u>  |   |
|                                  | 27. | S: | Okay. Any occasions where you felt angry or sad or confused?   |   |
|                                  | 28. | F: | Of course, there were but not in the sense that erm I remember if I am honest with you.  |   |
|                                  | 29. | S: | Okay, so there wasn't a particular incident that sticks in your mind?  |   |
|                                  | 30. | F: | No.  |   |
|                                  | 31. | S: | When you say there were things, was that sort of general...  |   |
|                                  | 32. | F: | <u>Just general stuff, nothing major or specific that I can remember.</u>  |   |
|                                  | 33. | S: | What was the general stuff? What was that, what happening in the general stuff?  |   |
|                                  | 34. | F: | <u>Just standard childish stuff like err playground fights, things like that. I didn't get into any of them.</u>   |   |
|                                  | 35. | S: | Okay. It wasn't like a regular thing? Just an occasional thing.  |   |
|                                  | 36. | F: | No.  |   |
| Episode 6<br>Tutor for 11 plus.  | 37. | S: | OK. What was it like for you at home at this time?   | <b>Theme: Ordinarity/normality</b><br><br>Home life was relaxed.  |
|                                  | 38. | F: | <u>Erm at home it was fairly simple. We used to get home and just relax if I am honest with you. Later on it got, I had a tutor to tutor me for the 11 Plus. Later on, on top of my school</u>       |   |

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|   |     |    | homework which wasn't much, <u>I had to spend a bit more time working. But before that, even then it was still quite relaxed,</u> I would just read a book, watch TV, go outside, play on the computer or something.  | Emphasising canonicity of life.<br><br><i>Identity:<br/>Canonicity</i>   |
| Episode 7<br><br>Tutor was fine.                          | 39. | S: | So you were having a tutor for the 11 Plus.   | <b>Theme:<br/>Ordinariness/<br/>normality</b><br><br><i>Identity:<br/>Canonicity.</i><br><br>Tutor was fine.   |
|   | 40. | F: | Yes.  |  |
|   | 41. | S: | OK, so erm was that a positive or how did you feel about that? Were you under pressure at all?  |  |
|   | 42. | F: | <u>That was fine.</u>   |  |
|   | 43. | S: | That was fine. You were quite happy were you with the tutor? Okay so that was for the move into secondary school, okay.   |  |
|   | 44. | F: | Yes.  |  |
| Episode 8<br><br>You're not going to have major problems. | 45. | S: | OK. Can you tell me about your relationships with other people at this time, during the primary years at home or at school? This could be with family, friends, teachers...   | <b>Theme:<br/>Ordinariness/<br/>normality</b><br><br><i>Identity<br/>Canonicity.<br/>Communion with family</i>   |
|   | 46. | F: | <u>Well, my relationship with my family, so my mum and dad, brother and sister was back then as it is now, erm, fairly positive, no major, especially as a kid, you are not going to have any major problems with your parents or your siblings so it was all fine.</u> |  |
| Episode 9<br><br>Diagnosis                                | 47. | S: | When did you get a diagnosis, do you remember anything about the diagnosis?   | <b>Theme:<br/>Diagnosis</b><br><br><b>Theme:<br/>Ordinariness/<br/>Normality</b><br><br>Characterised as unremarkable.<br><br>Diagnosis is also positioned as unproblematic? |
|   | 48. | F: | I think I was about 8, 9 or 10, around that time when I started going to this err, meeting Gillian Webb and I started going to that psychiatrist place in Bradley, near Blake Hall.   |  |
|   | 49. | S: | So what led you to go, to go to see this...?  |  |
|   | 50. | F: | <u>I am honestly not sure.</u>  |  |
|   | 51. | S: | You are not sure what, how you got referred?  |  |



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|   |     |    |   | Doesn't have a recollection of how the diagnosis came about.<br><br>Identity:<br>Canonicity  |
|   | 52. | F: | No idea if I am honest with you.  |  |
|   | 53. | S: | Was somebody seeing a difficulty or a problem?  |  |
|   | 54. | F: | It was probably a third party, yes, that suggested that I might want to get this checked out but...   |  |
|   | 55. | S: | So you got the diagnosis about then?  |  |
|   | 56. | F: | Yes, about then.  |  |
| Episode 10<br><br>Never thought much else about it. | 57. | S: | And what was your understanding at the time of the diagnosis?   | <b>Theme:</b><br><b>Diagnosis</b><br><br><b>Theme:</b><br><b>Ordinariness/ Normality</b><br><i>Identity:</i><br><i>Canonicity</i>  |
|   | 58. | F: | <u>They just told me had something called autism, which is a condition and then I never thought much else of it.</u>  |  |
|   | 59. | S: | At the time?  |  |
|   | 60. | F: | Not really, no.   |  |
| Episode 11<br><br>I am not obviously autistic.      | 61. | S: | What about your understanding as time has gone on?  | <b>Theme:</b><br><b>Diagnosis.</b><br><br>Diagnosis does not seem to have had an impact on his sense of self – because, he says the affect of autism has been insignificant.<br><br><i>Identity:</i><br><i>Canonicity. Self-evaluation in relation to autism</i> |
|   | 62. | F: | Of course, I have got more knowledge <u>but I still don't think much about it.</u> I mean, it is like err, sometimes of course, <u>you can tell when someone is severely autistic but in my case, most people wouldn't realise it unless I told them. That is how littlely it, err sorry, that's how insignificantly affected I think I am by it.</u> |  |
|   | 63. | S: | So you don't feel that it affects you particularly?   |  |
|   | 64. | F: | Maybe other people can see stuff that I can't but yeah, <u>I am not obviously autistic.</u>   |  |
| Episode 12<br><br>Not sure of affect.               | 65. | S: | Okay. How does it affect you?   | <b>Theme:</b><br><b>Diagnosis.</b><br><br><i>Identity:</i><br><i>Canonicity.</i>   |
|   | 66. | F: | I am not sure, if I am honest with you. <u>I have never really looked at it.</u>  |  |

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|   |     |    |  | <i>Identity:<br/>Reflexivity</i><br><br><i>Not considered<br/>the impact of it.</i>  |
| Episode 13<br><br>See as a<br>character.          | 67. | S: | Okay. And how do you think other people see you?   | <b>Theme:<br/>Difference</b><br><br>Does the<br>opposite-<br>different to<br>others.<br><br><i>Identity:<br/>Individualistic<br/>/agentive<br/>Looking glass<br/>self? Seen as<br/>character.</i>  |
|   | 68. | F: | <u>A character.</u>  |  |
|   | 69. | S: | They see you as a character? Tell me more about that then.   |  |
|   | 70. | F: | Ahh, how do I put that? <u>Well, okay, something about me, for some reason anytime there is a group trend going on, I always feel the need to do the exact opposite.</u>   |  |
|   | 71. | S: | Okay. Just wait for the phone to ring out. [Silence as phone rings out]. You okay talking over it, it's just sometimes hard for the tape to...   |  |
|   | 72. | F: | We'll just wait.   |  |
| Episode 14<br><br>Own tastes<br>and<br>interests. | 73. | S: | Right. Erm so, you are a character because when you are in a group, is that what you said, you felt like you want to do the opposite?  | <b>Theme:<br/>Difference</b><br>Has his own<br>interests – so is<br>seen as different<br>by others<br><br><i>Identity:<br/>Individualistic<br/>(outside in view)</i><br><br><b>Theme:<br/>Ordinariness/No<br/>rmal 'not bad'</b><br>76<br><br><b>Theme:<br/>Friendship</b><br>But is accepted-<br>still liked.<br><br><i>Identity:<br/>Social-<br/>Communion</i> |
|   | 74. | F: | It is not that it's erm, I don't think I described it very well. Forget that train of thought <u>but yeah they see me as a... probably because I generally tend to have my own tastes and interests and stuff.</u> |  |
|   | 75. | S: | Okay. So not in a group, just generally, you are saying that you might be different to, other people see you as different, is that what you are saying?  |  |
|   | 76. | F: | Yes. <u>Not bad, they still like me.</u>   |  |

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| Episode 15   | 77. | S: | So what are your interests? What is it that makes you different to, to...?  | <b>Theme:</b><br><b>Difference</b>   |
| Very few topics that interest me... I go deep into them. | 78. | F: | <u>I guess what makes me different is that there are very few topics that interest me, the ones that do, I like to dig deep into them. So anything I see that takes my fancy, I go deep into it. Erm...</u>                               | Specific interests that others don't understand – his depth of interest in the topics also marks him out as different.<br><br><i>Self-concept – personal traits and characteristic (go deep) 78</i><br><br><i>Identity: Individualistic (agentive view) 86.</i><br><br><i>Positive evaluations- 'strong'</i> |
|  | 79. | S: | What kind of things?  |  |
|  | 80. | F: | Philosophy. I didn't study philosophy at school but I like reading about it in my spare time. People like Marcus Auerlius and Machiavelli thought.  |  |
|  | 81. | S: | Okay. So you have got some kind <u>of strong interests in things.</u>   |  |
|  | 82. | F: | Yes.  |  |
|  | 83. | S: | You say you go deep into them.  |  |
|  | 84. | F: | Yes.  |  |
|  | 85. | S: | You feel that makes you different to other people or your, your peers, your colleagues?   |  |
|  | 86. | F: | <u>Well when I talk to other people, maybe they do, but whenever I talk to other people, a lot of my peers, I get the feeling that none of them are at the moment interested in stuff like that, or if they are, I've never heard it.</u> |  |
|  | 87. | S: | Okay, so you have got different interests, is that what you are saying?   |  |
|  | 88. | F: | Yes.  |  |
| Episode 16   | 89. | S: | Okay erm, how does that make you feel, that you might have these different interests.   | <b>Theme:</b><br><b>Ordinariness/ Normal</b>   |
| I don't think much of it.                                | 90. | F: | <u>I don't think much of it to be honest with you.</u>  | Having different interests not a concern –<br><br><i>Identity:</i>   |
|  | 91. | S: | It doesn't bother you?  |  |
|  | 92. | F: | No, not really.   |  |

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|  |      |    |   | <i>canonicity</i>  |
| Episode 17<br><br>I'm not ashamed.     | 93.  | S: | Okay. Earlier, just going back, we were just talking about your diagnosis and you said something like erm people wouldn't notice unless you told them. So is that something you do share with people? | <b>Theme:</b><br><b>Diagnosis</b><br>Autism and diagnosis do not have a big impact – forgets that he has it.<br><br><i>Identity:</i><br><i>canonicity</i> Not a feature of his self-view of his identity |
|  | 94.  | F: | <u>Not really. Not ashamed, I just don't feel the need to bring it up.</u>  |  |
|  | 95.  | S: | You don't feel the need to bring it up.   |  |
|  | 96.  | F: | <u>A lot of the time, I forget I have it. I have other things on my mind.</u>   |  |
| Episode 18<br><br>Trip to north wales. | 97.  | S: | Absolutely Okay. Erm can we have a little think about secondary school now or that period of your life, so from when you moved to the school and up 'til now, what have been the high points?         | power dynamics relating to how he can express himself. 100   |
|  | 98.  | F: | The Ski trip in Year 9.   |  |
|  | 99.  | S: | OK.   |  |
|  | 100. | F: | I have been on two residential trips so far, one to North Wales which was bad. <u>I was going to say the other word, but I don't think I am allowed to use it.</u>                                    |  |
|  | 101. | S: | <u>You can use whatever words you like.</u>   |  |
|  | 102. | F: | <u>It was a bit crap if I am honest with you.</u>   |  |
|  | 103. | S: | That's Okay. Why was that?  |  |
|  | 104. | F: | I just generally found it boring, if I am honest with you.  |  |
|  | 105. | S: | What was...?  |  |
|  | 106. | F: | Activities, the weather, food.  |  |
|  | 107. | S: | Okay. Was it just not an interesting experience or was it a negative experience?  |  |
|  | 108. | F: | It was just not interesting.  |  |
|  | 109. | S: | Not interesting. Did anything happen that was   |  |

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|                                      |      |    | difficult at the time?   |  |
|                                      | 110. | F: | Not really.  |  |
| Episode 19                           | 111. | S: | And the Ski trip?  | <b>Theme:<br/>Independence ?</b>   |
| Ski trip to Switzerland              | 112. | F: | <u>The Ski trip was quite good because it was the first time I had ever been to a foreign country.</u>   |  |
|                                      | 113. | S: | Okay. Where was that?  |  |
|                                      | 114. | F: | We went to Switzerland in the Swiss Alps. We stayed in the village, SA and we went to the Ski resort SA. We also went to SB which is the one we were originally supposed to go to but I think due to, I am not sure, weather maybe, I can't remember exactly. For the first few days, we were at the other ski resort. |  |
|                                      | 115. | S: | Okay. Again, you liked the experience?   |  |
|                                      | 116. | F: | <u>It was a good experience and I got to do something I never otherwise probably would have ever done.</u>   |  |
|                                      | 117. | S: | OK. So you enjoyed it because it was something different.  |  |
|                                      | 118. | F: | Yes.   |  |
| Episode 20                           | 119. | S: | Okay. Any other kind of memories at being at the school so far, that you feel are important?   | power dynamics relating to what he can express   |
| None that I am willing to share.     | 120. | F: | <u>No. None that I am willing to share.</u>  |  |
| Episode 21                           | 121. | S: | Okay, that is fine. You don't have to talk about anything that you don't want to talk about. Erm, so, low points? Any, any points that were a difficult time at secondary school or in that age group, either at home or at school, a sad or confusing time?   | <b>Theme:<br/>Ordinariness/<br/>Normality</b><br><br>Change is presented as canonical.<br><br>Changes in family relationships- evaluated as a result of ordinary changing circumstances. |
| Doesn't see extended family as much. | 122. | F: | Nothing.   |  |
|                                      | 123. | S: | Okay. What about family experiences in the last 5 or 6 years, how have they been?  |  |
|                                      | 124. | F: | <u>My family... Well, the only thing I can probably comment on is the fact that how, and this does</u>   |  |

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|   |      |    | not make me sad, and this is just what it is, is that my extended family, I don't see much of them nowadays anymore. <u>It is probably just the fact that we have grown up and people are not finding the time to speak to each other but that is just what it is.</u> | <i>Identity:<br/>canonicity</i>   |
|   | 125. | S: | OK. And you see that as unfortunate or sad?  |   |
|   | 126. | F: | No, no, no. <u>As I said it doesn't make me feel sad or happy it just.. Again, I don't really think much of it because,</u> I, like them, have other things on my mind at the minute so like...  |   |
|   | 127. | S: | Would you like to see more of them? Are they important?  |   |
|   | 128. | F: | It would be nice but again not really that bothered. I don't mean that to be a slight against them.  |   |
| Episode 22<br><br>Got on well with extended family. | 129. | S: | Okay. Who is this extra extended family, is it aunts, cousins...?  |   |
|   | 130. | F: | Aunts, cousins , stuff like that.  |   |
|   | 131. | S: | Are they people that you used to spend time with?  |   |
|   | 132. | F: | Yes.   |   |
|   | 133. | S: | And err you got on well with them?   |   |
|   | 134. | F: | Really well with them.   |   |
| Episode 23<br><br>Friendships developed over time.  | 135. | S: | Okay erm, what about your friendships at school over the last 5 or 6 years?  | <b>Theme:<br/>Friendship. 136</b><br><br>Friends are important – ref earlier episode.<br><br><i>Identity:<br/>communion<br/>social identity</i> |
|   | 136. | F: | <u>Well, when I came here of course, I came here not knowing anyone, and now my Year group is a tight-knit bunch of lads.</u>  |   |
|   | 137. | S: | Okay. So you feel quite close to your friends?   |   |
|   | 138. | F: | Yes.   |   |
|   | 139. | S: | OK. Can you tell me a little bit more about that?  |   |

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|   | 140. | F: | It is something that developed slowly in the year.  |  |
|   | 141. | S: | So your friendships have developed over time? Do you have a best friend?  |  |
|   | 142. | F: | No I don't think I have a best friend. I don't think anyone has a best friend now.  |  |
| Episode 24<br><br>Not going to share that.      | 143. | S: | What kind of things do you get up to with your friends?   | <b>Theme: Friendship</b><br><br><i>Identity: Personal Value. Loyalty?</i><br><br>power dynamics relating to what does he feel he can and cannot share. – in-group/out-group reasons? |
|   | 144. | F: | <u>Just things. I am not going to share that.</u>   |  |
| Episode 25<br><br>Rephrase                      | 145. | S: | OK, that is stuff that you don't want to talk about okay. Erm are there, as you have been in high school, in secondary school, has the, your diagnosis of autism had any impact on your thoughts and feelings about yourself?   |  |
|   | 146. | F: | Can you re-phrase the question?   |  |
| Episode 25<br><br>Laziness and procrastination. | 147. | S: | Whilst you have been at high school, err how do you think the autism or the diagnosis has impacted on you?  | <b>Theme: Diagnosis</b><br><br><i>Identity canonicity</i><br><br><i>Collectivist view 'other kids'- same as others</i><br><br><i>What is autism related and what is not?</i>         |
|   | 148. | F: | Sometimes I feel I don't work as hard as I could <u>but that could probably just be due to basic laziness because other kids have the same problem as well. Err, procrastination that's probably not autism specific.</u> I am not sure if I am honest with you. <u>Like I said, it's so minor.</u> |  |

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| Episode 26<br>No.                            | 149. | S: | Okay erm, is there anything else that you can think of during the last 5 or 6 years that you think is important or you would like to share about your life story?   |   |
|  |      | F: | ...No.  |   |
| Episode 27<br>Change in how I see the world. | 150. | S: | How do you think you have changed over time? What were the turning points, how do you think you have changed?   | <b>Theme: Personal growth / Understanding of the world</b><br><br><i>Identity: meaning making.<br/>Exploratory narrative processing?</i><br><br>Massive changes in how I see the world. Changed me. Changed my personality. |
|  | 151. | F: | <u>Well, of course moving from Year 6 to Year 7 and being around a different group of people has definitely changed me. That was one big change in my personality, in the way I see the world. Also what I've, just general reading through stuff which has made me think about things and has also made me, especially during the last few years, made me significantly change the way I see things. So through Year 9 onwards, each year has always been a massive change in the way I see the world.</u> |   |
| Episode 28                                   | 152. | S: | Okay could you tell me, you said from moving from Year 6 to 7, changed your personality, is that what you are saying?   |   |
|  | 153. | F: | I don't know.   |   |
| Episode 29<br>Oh crap I don't know anyone.   | 154. | S: | How did you change?   | <b>Theme: friendship</b><br><br>Friends and the importance of making friends.<br><br>If you don't have friends you're going to be depressed.<br><br><i>Identity: Communion and social group.</i>                            |
|  | 155. | F: | I guess it is more to do with like, in primary school, of course this was the first group of friends I had and at the time of course they would be the only people I would spend significant time with, apart from time with family. Now being in Year 7, especially not knowing anyone, they are a different group of people.  |   |
|  | 156. | S: | So you had a group of friends and then you came to a school where you didn't know anybody. How were you thinking and feeling at the time, back in Year 7.   |   |
|  | 157. | F: | <u>I was thinking 'Oh Crap I don't know anyone, I have got to make friends fast'.</u>   |   |



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|   | 158. | S: | Okay, how was that making friends, how did you manage that?   |   |
|   | 159. | F: | <u>Just talked to people.</u>   |   |
|   | 160. | S: | Was it OK, was it successful?   |   |
|   | 161. | F: | Yes.  |   |
|   | 162. | S: | <u>So is having friends important for you?</u>  |   |
|   | 163. | F: | <u>Well yes, because if you don't have friends, you are going to be depressed aren't you?</u>   |   |
| Episode 30<br><br>Political and economical views. | 164. | S: | Yeah. And you said something also about Year 9 in that you think differently. Can you tell me how you think different or what you think differently? Your outlook on the world, I think is what you said.   | <b>Theme:</b><br><b>Understanding of the world</b><br>Reluctance to share views.<br><br><i>Identity: commitment to political ideology.</i><br><i>Identity statuses: Achievement</i> |
|   | 165. | F: | Yes.  |   |
|   | 166. | S: | How has that changed or developed?  |   |
|   | 167. | F: | <u>Stuff like political and economical views which I am not going to share.</u>   |   |
| Episode 31<br><br>Positive change                 | 168. | S: | Okay, if you don't want to that is fine. So you kind of think your view, your understanding of the world has changed. In a positive way?  | <b>Theme:</b><br><b>Understanding of the world</b><br><br><i>Identity: Identity statuses – achievement.</i>   |
|   | 169. | F: | <u>I see it as positive.</u>  |   |
| Episode 32<br><br>University                      | 170. | S: | You see it as a positive. Can you just have a little think about the future for you? What are your dreams and hopes, plans for the future?  | <b>Theme:</b><br><b>Independence.</b><br><br>Seeking independence?<br><br><i>Identity: separate but connected?</i>  |
|   | 171. | F: | Well, right now err, I plan to do an x degree at a University, hopefully a good one. <u>Somewhere that is far enough from home that I can move out, but not too far that it is going to be a pain in the arse to get back,</u> do you know what I mean. So like Z would be a no, that is too far. I can't be bothered with commuting. Erm but yeah I need to look at the universities at the minute. I haven't been to any open days because I didn't manage to book any in time. |   |

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| Episode 33                   | 172. | S: | How do you feel about the move to University? Not the physical move but moving on from here and you know moving to a new part, new chapter in your life, how are your feelings around that? | <b>Theme:</b><br><b>Independence</b>   |
| No worries about University. | 173. | F: | <u>I don't really care if I am honest. I don't care. It's fine. It is not like I am never going to see my parents or anything like that.</u>  | <i>Identity:</i><br><i>Echoes of 'this is canonical'</i>                         |
|                              | 174. | S: | You don't have any worries or...  | <i>Personal agency</i>   |
|                              | 175. | F: | No really no.   |  |
| Episode 34                   | 176. | S: | So you are looking forward to it? Are you looking forward to moving?  | <b>Theme:</b><br><b>Independence</b>   |
| Just being on my own.        | 177. | F: | Yes.  | Being on my own  |
|                              | 178. | S: | Okay what is it that you are looking forward to?  | <i>Identity: Agency</i>  |
|                              | 179. | F: | <u>...Just being on my own.</u>   |  |
|                              | 180. | S: | Being on your own?  |  |
|                              | 181. | F: | Yes.  |  |
|                              | 182. | S: | Away from...?   |  |
|                              | 183. | F: | Parents   |  |
|                              | 184. | S: | Parents. So having some independence from parents?  |  |
|                              | 185. | F: | Yes.  |  |
| Episode 35                   | 186. | S: | Okay and what about meeting other people whilst you are at University? Is that something that you are looking forward to?   | <b>Theme:</b><br><b>Ordinariness/nor</b>   |
| It is what it is.            | 187. | F: | <u>Not looking forward to but not dreading either. It is what it is.</u>  | <b>mal</b>   |
| Episode 36                   | 188. | S: | It is what it is. Okay. Is there anything else that you think erm, if I was asking about your life, anything else that you think is important or anything you want to share?                | power dynamics<br>The reliance of my structuring?<br>Perhaps the need to say ore |
| Ending interview.            |      |    |   |  |

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|  | 189. | F: | Erm I can't think of any. <u>Maybe if you have a few suggestions.</u>   | because it was invited... |
|  | 190. | S: | I think I have been through my prompts so I think it is just an opportunity in case we have missed anything that you think, but if you have nothing that is fine. We can stop there. Is that alright? |                           |
|  | 191. | F: | Yes fine.   |                           |