THE SPIRAL OF SELF-IDENTIFICATION OF AUTISM. UNDERSTANDING SELF-IDENTIFICATION OF AUTISM THROUGH FIRSTHAND EXPERIENCES.

by

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Abstract

The following thesis uses a qualitative primacy, sequential mixed-methods approach, employing the principles of participatory research, to explore the significantly under researched phenomenon of self-identification of autism. Evidence is gathered through semi-structured interviews and an online survey. These are reinforced with autistic narratives, both book based and via online blogs. As such, they provide a unique element to the exploration of available literature and reinforce the data collected through this research. In total, one hundred and thirty-five individuals participated in this study, spanning all adult age ranges, seven genders, nine ethnicities, eleven religions and twelve countries.

This study is significant, as it shows there is a sizable population of people that self-identify as autistic and that they have more negative life experiences than their diagnosed counterparts. Self-identification was seen as a process of claiming back an identity, from the deviant one placed upon them by others, or the 'self' presented through adaptive morphing undertaken as a security mechanism driven by fear of negative attention. The process of self-identification is a modern phenomenon facilitated by the growth of social media and the global community. Importantly, the data indicates that regardless of diagnosis, the autistic identity cannot be built in isolation.

The experiences shared provide clear evidence that because the individual's journey begins with being labelled as deviant, both externally and internally, the autistic identities are reduced to a politicalised static identity, as the need to validate themselves from the perspectives of doubt and prejudice of others becomes more important than embracing the plurality and fluidity of their autism. Both the necessity of adaptive morphing and then

politicalising their autistic identity has long term implications on the individual’s mental health and sense of self. The results of this research significantly indicate that this often results in a diagnosis being sought as a means of biocertification, more for the benefit of others than the individual.

The ‘spiral of self-identification of autism’ is developed to represent the way in which the individual is trapped in a vicious cycle, unable to effectively facilitate the autistic identities into their nexus of identities, which has a significant impact on their long term, mental well-being. The experiences shared through this research indicate that the autistic individual is often dominated by the powers of others, which the ‘spiral of self-identification’ seeks to demonstrate. It is through discourse that power can be challenged, and therefore this thesis has enabled a discourse, and in turn has provided recommendations for change, to break the spiral and enable the autistic individual to hold their own power.

Recommendations are given to changes required in the way society values diversity, with a specific focus on reducing the ‘them and us’ atmosphere that the medical model, social model and neurodiversity continues to promote. Changes to the education system is proposed, to move away from the ‘factory model’ of education, as this is where the participants reported significant trauma. An urgent call for action is also presented to provide much needed support for those seeking diagnosis or newly diagnosed, to enable them to understand the autistic identities, build positive peer-to-peers relationships and support structures, which in turn would reduce significant mental health challenges.

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CHAPTER ONE: INTRODUCTION

1.1 Background to the research

> *"This is one of the reasons that a person on the autism spectrum needs love and support. They need to feel alright just as they are, lovable just as they are, in order to be able to take risks and express their true selves. Love, including self-love, overpowers fear." (Cook & Garnett, 2018, p55)*

When I read the above quote, I unexpectantly found myself feeling emotional. The strength in their words about self-love and fear resonated with me on a level I had not anticipated. The reason for this lies in my own personal journey and why I have come to undertake this research. As an autistic adult, I was diagnosed late in life, having thirty-one years of lived experiences before they were associated with autism. These experiences have shaped who I am today, good and bad, and have stoked my desire to further understand the phenomenon we label autism, and the lived experiences of others like me.

> *"autism touches many, and yet, it is one of the most misunderstood developmental disorders" (Holliday-Willey, 2015, p15)*

While this statement was written six years ago now, despite advances, it continues to be relevant. As an autistic adult I am privy to a way of thinking about autism other researchers may not understand and I take this as a real strength in the work I undertake. On top of that I have three autistic children and an autistic husband. I have worked for eight years with students in mainstream secondary education who have a wide range of 'special educational needs', and when I left that role, I filled my time with studying the field of autism. So, one could argue that I am an internal 'expert' in my field. The term expert is presented in inverted commas purposefully however, as a key driving force of this research lies in the fact that even with all these lived experiences, when someone asks me “so what is autism”, I find it incredibly hard to answer. Wylie, Lawson & Beardon. (2016) state that:

> *“When we talk about ‘autism’ we’re not actually talking about a single condition but a large group of conditions that share overlapping core symptoms. This is probably one of the biggest reasons why the phrase ‘when you’ve met one person with autism, you’ve only met one person with autism’ rings so true” (p17)*

I find that this statement resonates with my experiences, however, only serves to reinforce my uncertainty of what autism actually is. The question suggests a singular concept, yet professionals suggest a ‘spectrum’, that is irreducible to a singularity. Rhodes, Nocon & Wright (2008) in their exploration of epilepsy provides an thought provoking concept that appears to mirror autism, they write:

> *“much of the difficulty in categorising both epilepsy and mental illness lies in the fact that despite official broad definitions which encompass mental illness and so-called ‘invisible’ impairments, lay notions define disability in terms of stable, permanent and visible physical manifestations. On each count epilepsy fails to conform.” (p390)*

It would seem possible that autism also fails to conform. It is hoped that by exploring the autistic identity with individuals that have actively chosen to embrace it into their own lives, it may help me to begin to unpick these key questions.

1.2 Justification for the research

The current thesis is situated within the wider context of respectfully representing lived experiences in research (Fletcher-Watson et al, 2018). Challenging the previous dominant approach, of undertaking research ‘on’ participants (Oliver, 1992, 2013) and the transfer model of research (Guldberg, 2017). Instead prioritising the value of participation, individual experiences, and authenticity of voice.

It is my aim, to acknowledge and undertake, a two-stage analysis whereby the participant seeks to make sense of their experiences followed by myself, as the researcher, attempting to make sense of their interpretation of their lived experiences (Huws and Jones, 2015). It is suggested that as an autistic individual undertaking research in this area I will be able to act as Beauchamp-Pryor (2011) terms the 'insider' (p13) with the ability to interpret the lived experiences of other autistic people in a way that non-autistic researchers may not. Furthermore, it is hoped that the findings of Kitchen's research will be mirrored, in that the participants of this research may feel more comfortable and therefore open up with me due to my 'insider status' (Kitchen, 2000), producing original and innovative conclusions.

The participatory focus of this research is central as it recognises the long-standing concern that understanding of autism is developed by those that do not directly experience it.

> *"..right from the start, from the time someone came up with the word 'autism', the condition has been judged from the outside, by its appearances, and not from the inside according to how it is experienced" (Williams, 1996, p14)*

Participatory research is therefore incorporated to produce a more socially robust and context transferable basis of knowledge (Bergold and Thomas, 2012; Milton, 2014; Gillespie-Lynch et al, 2017) as well as a higher potential for research impact (Seale, Nind and Parsons, 2014). It further reinforces Kagan's argument that research needs to shift towards a new focus, on how people identify themselves (Kagan, 2002). It is on these very premises that the following research is justified. The population of individuals I seek to research, which will be rationalised in more detail in the methodology chapter, are specific to the place and time of this study, their experiences and categorisations, alongside societal changes make them distinctive and therefore a justifiable population to research.

In 2018 Ebben conceptualised the changing rate of diagnosis of autism as an ‘epidemic’ (Ebben, 2018). While the use of this term has faced a varied response, the metaphor does illustrate a wider agreement by professionals that the rate of diagnosis of autism has increased since its first occurrence seventy-seven years ago. This is illustrated in articles across Western civilisation such as (Bachmann, Gerste and Hoffmann, 2019) who site that in Germany from 2006 to 2012 the diagnosis of 0 to 24-year-olds rose from 0.22% to 0.38%. The work of Arvidsson, Gillberg, Lichtenstein and Lundström, (2018) considers the increasing prevalence rates of autism diagnosis and present four reasons for this:

1) widening of the diagnostic criteria
2) increased public awareness of autism
3) increasing recognition of autism among professionals
4) People being diagnosed despite not fully meeting criteria in order to ensure access to support, especially at school age.

(Arvidsson, Gillberg, Lichtenstein and Lundström, 2018)

While this is a study based on experiences in Sweden and therefore the generalisability of the findings require consideration, the four points they raise match those findings that will be illustrated in the following section and therefore, it will be important to consider whether these are also mirrored in my research findings. Factor two, as illustrated above, argues that increased public awareness of autism will lead to an increased number of people seeking an autism diagnosis. This, alongside the incorporation of factor one, is reinforced in the work of Lai & Baron-Cohen (2015), who argue that:

> *"Autism's conceptual expansion, broadening of diagnostic criteria and increased awareness have resulted in a 'lost generation' whose autism remained undetected until adulthood"* (p1013).

This would appear to fit succinctly with my own research that is largely considering this 'lost generation' and the avenues they take to discover their own autistic identity. Despite such recognition of a specific population of undiagnosed autistic individuals, research into this area has been sparce. In spite of this chasm in available research specific to self-identification, which will be illustrated further in the literature review chapter, Arvidsson, Gillberg, Lichtenstein and Lundström, (2018) ascertain that there is a growing awareness of autism which is likely to impact on the individual's ability to self-identify. One of the reasons suggested for this is the development of the internet:

> *"one of the most significant contributions of the Internet is its ability to link people in networks… By networking, people establish the connections necessary to form a collective identity" (Parsloe, 2015, p340).*

Disability theorists have, over recent years, seen the internet as having a significant impact on the development and sustainability of specific identities such as autism. Willis and Tranter (2006) suggest that, at the time of writing, the number of internet users have increased dramatically, which provides individuals with opportunities to connect with a wider array of people than previously possible. The growth in the use of the Internet has resulted in a huge change to society, moving individuals away from the seclusion of their day-to-day experiences towards having an opportunity to explore and understand the experiences of millions of others. As such the internet has become entrenched in the day to day lives of most people in western societies (Willis and Tranter, 2006; Valentina and Skelton, 2008). Mirrored in the wider societal change facilitated by the internet is the use by autistic individuals, to seek out information and build relationships that may not have been previously possible (Grinker, 2020). With reference to Hacking's theories, as outlined in the following chapter, he goes further to suggest that the use of the internet has provided a medium for the autistic voice to be shared, for those seeking the information reliance on portrayals via TV and films was no longer needed.

> *"no aspect of the phenomenon of autistic narrative is more influential than the Internet, a lot of which is biographical or autobiographical. It is a place for autistic people to "come out" (Hacking, 2009b, p499)*

Hacking's reference to 'coming out' implies a process of embracing or developing one's autistic identity. A concept that has been suggested by other researchers and taken further to suggest that the internet may have facilitated the growth of a new kind of identity, beyond the medical label given (Charland, 2004; Ward and Meyer, 1999; Brownlow and O'Dell, 2006). This will be an important point to consider within this research, as the participants will all be internet and social media users and therefore, this is likely to play a significant role in the construction of their autistic identity.

All the participants of this study will be over the age of eighteen, the impact of age and the consequential time without recognition of autism is therefore important within this population. My literature review will highlight that there is a significant focus on children and their ability to recognise 'self' (Hobson. 1990, Ferrari and Matthews 1983), however little consideration is given to how these abilities change over time into adolescence and then, importantly for this research, into adulthood.

Research that focuses on childhood have suggested that a secure sense of self begins as a child, during school years, as a result of interactions with their peers (Harter, 1982; Bagwell et al., 1998). Peper and Dahl (2013) reviewed past research papers and suggested that the changes in the brain that occur due to the increase in hormones at puberty may make autistic individuals more sensitive to the world around them:

> *"Puberty appears to create a neurobehavioral nudge towards exploring and engaging the social complexities" (Peper and Dahl, 2013, p135).*

Both the increase in testosterone for boys and oestradiol in girls appear to increase "approach related behaviours" and decrease "behavioural inhibition" (Peper and Dahl, 2013, p136).

A suggested impact on an autistic individual's reduced sense of self, derives from this period of self-appraisal based on negative experiences with their peers.

Sreckovic, Brunsting and Able (2014) argued that while youths with disabilities were at a heightened risk of bullying, youths with autism were even more likely to experience bullying. While this research specifically identifies those that are diagnosed with autism, Milton and Sims (2016) make reference to an 'othered' identity, being on the 'out-group' of societal norms. They argue that such experiences are linked to feelings of social isolation, anxiety and depression and would impact on the individual's ability to develop a secure sense of self/identity. It will be important to consider whether the participants of this study have experienced bullying and what impact this had on their own identity and in turn their ability to embrace the autistic identity.

In 2006, Lewis argued that 1:68 Americans had autism, but that diagnosis often did not occur until adulthood in individuals without intellectual disability. She also argued that this was the foundations of adults beginning to self-diagnose (Lewis, 2016). The participants of my proposed study will also be adults and therefore it is this cohort of individuals that society may have missed that it is seen as an important hidden population:

> *"The fact is that characteristics of autism have only recently been fully described and taught, even to specialists in psychology and psychiatry. If you saw a mental health professional as a child, or even just a decade ago, the odds are that they were completely unfamiliar with AS!" (*Wylie, Lawson & Beardon, 2016*, P87).*

Arguments, such as seen in the above quote validate the likely existence of individuals, possibly in significant numbers, that may have gone undiagnosed (Wylie, Beardon and Heath, 2014) or simply unrecognised (Fitzgerald, 2014. In Wylie, Lawson and Beardon. 2016. p52).

Autistic writers and researchers have begun to acknowledge a group of individuals that have not experienced a third party identifying them as autistic. But have independently become aware of it and in turn identified with autism (Hacking, 2009a). It is these individuals that this research calls 'self-identifiers'. A conscious decision has been made to not use the term 'self-diagnosed' as used in some literature, in order to move away from the medicalisation of autism and assumed value of diagnosis. As a distinct population of people, they have been under-researched, yet by recognising their existence, this research is already raising significant questions that could impact on our wider understanding of disability and identity. Primarily as Watson (2002) suggested:

> *"In the hierarchy of social values prevalent within British society, which accords little or no status to disabled people, describing oneself as disabled cannot be seen as a positive step" (p525)*

Why therefore would an individual want to identify as autistic? While some commentators question the validity of self-identification and therefore the justification of acknowledging them as an appropriate population of study, Brownlow (2010) takes the above quotation as a basis to argue against such claims, suggesting that:

> *"given a dominant perspective that people with autism are considered to be a group of people characterised by 'impairments' in certain abilities, it is felt that it is unlikely that a person without autism would take on the identity of a person with autism" (p20).*

It is not the basis of this research to question the validity of the individual's connection with the autistic identity. Primarily because, regardless of whether an ontological truth could even be achieved, the individual still has experiences of believing they are autistic, and it is those experiences that are the important foundation of the following research. One participant in the research undertaken by Sarrett (2016) is quoted as saying:

> *"I would venture to suggest that people with autism know more about it than mental health professionals. Professionals can only see the symptoms, we know about the experience." (p30)*

Such a philosophy is reinforced by Billington (2006) who stresses that, professionals need to engage with, 'narratives of autistic experience,' (p1) in order to improve understandings and outcomes for individuals.

The construction of identity in relation to autism is an area of growth in research over the past two decades. As identity and autism are both commonly used words but both paradoxically difficult to define (Beart, Hardy & Buchan, 2005) their relationship to each other has encouraged much thought. Academics such as Brownlow (2010), Hacking (2009a), Shakespeare (2006), and Holt (2012) have all provided us with noteworthy considerations of how the autistic identity has developed and mirrored the wider views of disability at a societal level. Rhodes, Nocon & Wright (2008) and Beauchamp-Pryor (2011) detail the shifting disability agenda within society, suggesting that the language of disability is saturated with cultural, personal, and political meaning. From religious ideological categorisations linked to punishment and sin (Gordon and Rosenblum, 2001), through industrialisation and the resulting exclusion of individuals perceived as a social problem, to modern day focus on socially constructed disability where conflict lies between seeking to embrace a disability as a positive while being required to pathologicalise it to gain support. As Purkis (2020) writes in her blog entitled 'A problematic dichotomy':

> *"The problem seems to be the difference in intent and objectives…If I want to feel good about myself and feel positive about neurodiversity and difference I need to put my 'autistic pride' hat on….Conversely if I need to access funding…I will put my 'medical model' hat on." ([blog])*

The cultural construction of disability and autism will be an important foundation to this research alongside the implications and functions of power to construct disabling identities. As such Social Learning Theory and Foucault's concept of biopower are central concepts that arise in the discussion and conclusion of my results.

In Summary, the population to be studied is an under researched phenomenon, the following thesis is therefore ideally situated to address a gap in current research, while positioning itself within the secure foundations of the growing field of identity and disability studies.

1.3 Research aims and Research Questions.

> *"Do disabled people know who they are because of the fact that they have an impairment, because of the fact that they face discrimination or because of who they, ontologically, believe themselves to be?" (Watson, 2002, p512).*

The above quote from Watson provides a correlation to the following research. While the participants of this study are not formally classified as disabled, the aim of this research is to explore the way in which identity is constructed, specifically focusing on autism.

The research aims and questions were formulated following careful consideration of the available literature both academic and autobiographical. Equally the methodological approach is developed following scrutiny of research philosophies ensuring that the approach taken mirrored the value of, giving a 'voice' to the autistic individual, empowering them to be heard, where they may have otherwise not shared their views and understanding (Bogdan and Biklen, 1998). The journey of exploration to ensure the validity of my approach can be seen in the following chapters.

Dewey's Pragmatism is used to develop a qualitative primacy, sequential mixed-methods approach. Using semi-structured interviews and Interpretive Phenomenological Analysis to explore experiences in depth. Followed by a process of translating the findings of the interviews into a survey to triangulate the results, test generalizability and in turn produce data with a greater degree of external validity. Details of these methods and the construction of the sequential mixed-methods design will be explored fully in the methodology chapter.

The following thesis is therefore set to explore the following aims and question:

AIM: To explore, through first-hand experiences, the phenomenon of self-identification of autism

AIM: To develop a better understanding of the autistic identity and advocate for change that will better serve the autistic community

QUESTION:

1. what is an autistic identity/ies?
    a. what facilitates the process of self-discovery of autism?
    b. what is the impact of the delayed realisation of the autistic identity?
    c. what is the purpose of self-identifying as autistic?

1.4 Structure of the thesis: Overview of Chapters.

A review of the available literature is presented in Chapter two. As the voice of the autistic individual is prominent throughout the following research, the literature review provides an evaluation of not only academic literature but also of autobiographical literature from autistic authors.

The philosophical foundations of the research are explored in Chapter three, with a clear and concise guide to my journey to ensure the methodological framework of the study and the accuracy of the research questions are sound. Following this the methods of the research are outlined including ethical considerations and sample construction.

In Chapter four and five, a transparent process of data analysis is presented followed by the data collated from the semi-structured interviews and then the online survey. In both chapters every endeavour is made to let the data speak for itself.

After which, a discussion of the data conveyed in chapters four and five is presented in Chapter six, considering the implications of the findings and their connection with wider literature. Followed, in chapter seven, by a reflection of the impact of the methodology on the data collated, alongside limitations of the study. Finally, in Chapter eight, the main conclusions of the study are articulated and recommendations for further research given.

1.5 A note on Terminology.

Kenny et al (2015) in their UK study, drew attention to the fact that individuals use many different terms to talk about autism. Their study highlighted the most highly endorsed term was ‘autism’ and as such this is the term that is used throughout this research. Furthermore, identity first language is used consistently. It is recognised that there is much disagreement of whether identity first (autistic person) or person first language (person with autism) should be used, and this is further referred to within chapter seven, however as identity is the central foci of this research it has been deemed more suitable to used identity first language as an appropriate terminology.

CHAPTER TWO: ACADEMIC LITERATURE REVIEW

The following literature review will be divided into three sections. 2.1 will consider the theoretical underpinnings of the key concepts within the research question. 2.2 will review the empirical research within the sphere of autism and self-identification. 2.3 will explore the concepts within the field of autism and identity, evidenced within first person autistic written accounts. An equal divide between academic literature and the autistic voice mirrors the construction of this research and the central role the individual's experiences has on improving our knowledge base.

2.1 Theoretical Considerations

As the basis of the research centres around the concept of autism it is essential to first consider what we mean when we use such a term. Through extensive reading, attending conferences, practical experience, and academic qualifications I have arrived at the conclusion that I agree with the statement outlined by Holmer Nadesan (2005):

> *"efforts to define the precise essence of autism escape the best representational practices of scientists and medical practitioners: consequently, even at the dawn of the 21st century, we do not know what autism is." (p9)*

This is in itself a central component that needs further consideration when reviewing the findings of this research, what is it that people are experiencing that they are categorising as autism?

While there may be a lack of knowledge regarding the fundamental proponents of autism, it remains a described medical entity and is therefore diagnosable through the Diagnostic and Statistical Manual of Mental Disorders (DSM) and the International Classification for Diseases (ICD). As a result of the continuing ambiguity regarding the aetiology of autism, the diagnostic criteria are largely based on perceived observable features of the condition. At this stage therefore it is important to outline the currently agreed central characteristics of autism in 2021.

DSM-V defines autism spectrum disorder as:

> *"persistent difficulties with social communication and social interaction" and "restricted and repetitive patterns of behaviours, activities or interests" (this includes sensory behaviour), present since early childhood, to the extent that these "limit and impair everyday functioning". (American Psychiatric Association, 2013).*

It is significant to note that, following the introduction of this new definition in DSM-V, previous diagnostic labels such as: 'autistic disorder', 'Asperger disorder', 'childhood disintegrative disorder' and 'Pervasive Developmental Disorder – Not Otherwise Specified (PDD-NOS)' have been removed, replaced by the collective term autism spectrum disorder. Such changes were mirrored in the International Classification for Diseases (ICD) eleventh edition published in 2019. In 2020, Pohl et al, reported that autism is estimated to be present in 1-2% of the population, diagnosed more frequently in males at a ratio of 3:1.

Changes to the diagnostic criteria for autism have occurred several times since Kanner's first account in 1943 (Kanner, 1943), but it is currently still classified as a medical disorder and therefore is positioned as such within the classification of disability. Each of these changes, has reflected a shift in the perceptions of autism and has had consequential implications for wider society. Such changes and their implications will be outlined and considered further in order to ensure an accurate understanding of the current term and its archaeology.

Medicalisation of disability is seen as the historical model, while still present today, by which societal understanding of disability has been framed. Perceptions of autism have often been associated with this model of disability, which portrays autism as a deficit requiring a cure (Sarrett, 2011; Yudell et al, 2012). In their study of college students, Cox et al. (2017) found that students often use language to describe themselves, such as “abnormal” (*p* 81) which indicates a continuing influence of the deficit-based medical model of autism. Similarly, Chamak et al (2008) reported that the process by which parents of autistic children seek treatments and interventions, in order to make their child appear more normal, indicates an alignment with a reinforcement of the medical model:

> *“There is of course more than one way of looking at what happened in the consulting room. According to the medical model, the presence of impairment which had been located in me and which has existed prior to the interview was revealed and identified. Alternatively, the condition described to me could be viewed as a social construction, an identity produced by dominant discourses and practices.” (Limburg, 2016, p141).*

Lindberg’s reflections of her own experiences succinctly illustrate the differences suggested between the medical model of disability and the social model of disability. The social model of disability grew in direct conflict with the deficit-based medical model, instead arguing that disability is constructed based on a lack of cultural acceptance and adaptions to people with differences (Armstrong, 2010; Bagatell, 2010). Disability and culture therefore relate to how “cultural definitions of illness and health underscore the evaluative dimensions of disability” (Coopman, 2003, p259).

In contrast to the bilateral assumptions of the medical v social model the biopsychosocial model, prominent in medical studies, argues that concepts such as mental health, chronic pain and in this case, autism, should be understood by considering the ways in which the medical, psychological, and social elements interact with each other. The biopsychosocial model therefore acknowledges the biological basis of autism, as well as the disabling behaviours of the individual, however, argues that there is no direct link between the two. Instead suggesting that there is a need to understand the cognitive processes that mediate the relationship between the factors, to construct a complete understanding of autism. (Lind and Williams, 2011).

It is essential to recognise the differing approaches to understanding autism, as these will have a significant impact on the way in which autism is presented and diagnosed on an individual level in addition to the way it is perceived by others.

2.1.1 Stigma, Stereotypes and Labels

The term stigma derives from the Greek, meaning “a mark or branding on the body made with a sharp instrument” and plural, stigmata, is clearly evident in religious text. Today, the term stigma, is often used as a verb, to stigmatise, relating to individuals that are marginalised based on a perceived difference to the societal construction of ‘normal’. As such, stigma is often interrelated with a desire for acceptance (Goffman, 1963), and is a notion that is variable between cultures, and across time (Tyler and Slater, 2018). Currently, the most stigmatised groups, tend to be those that do not match the concept of the ideal worker outlined within capitalist societies, Grinker (2020) describes the ‘ideal worker’ as "the autonomous, self-reliance, individual" (pS56), therefore individuals with physical differences, cognitive differences and mental health challenges do not meet this strict ideal. Societal structures, prejudice and stereotypes all work together to maintain stigmatism (Rusch et al. 2005, p531).

Stereotypes are knowledge structures understood, both explicitly and implicitly, by most members of a social group (Rusch et al. 2005), they serve as a system by which culture directly impacts on the individual's perception of knowledge. In recent years this has been facilitated, allowing access across society, by the development of mass media:

> *"With the intervention of media, how children with Autism Spectrum Disorder are perceived in the school setting begins long before they physically enter classrooms. School community members often have firm, preconceived perceptions about students with Autism Spectrum Disorder emerging from the "socially storied representations" they have virtually or socially experienced. Much of this cyclical "knowledge," perhaps more aptly described as perspective, is rooted in popular media" (Sarrett, 2011 as cited in Belcher and Maich, 2014, p98).*

This account from Sarrett clearly illustrates a negative impact of the media in creating an understanding of autism. This is reinforced by Draaisma (2009) and Loftis (2015) who both articulated concerns over the construction of autistic stereotypes within the media and the impact this has on the language used to understand autism more widely. Loftis (2015) gives the example of the 2012 school shooting in America, whereby the media outlets made specific connection between the serial killer and their autism diagnosis. The consequence of this was reported to be a growth in the common perception that autism and violence were frequently linked, not just in this one individual but that autistic individuals became a homogeneous group and therefore this characteristic would be present in everyone within this group. Much in the same way Draaisma (2009) discusses the media portrayal of savantism as an essential component to autism. With the prime example of the film Rain Man (1989) arguing that this portrayal provided a stereotype that autistic brains were robotic and therefore less than human. As the National Autistic Society state, the 'Rain Man' presentation of autism became the dominant stereotype and had a significant impact on narrowing people's understanding of autism (autism.co.uk, 2018). While stereotypes serve to reinforce stigma, Rusch et al. (2005) argue it is not sufficient alone, needing cultural and political foundations to maintain it. The suggested role of stereotypes in limiting general understanding of autism, will be important to consider, especially whether it played a role in individuals not identifying their connection with autism at an earlier age.

According to labelling theory, stigma and stereotypes are reinforced through the process of defining an individual as 'deviant' by society. Labels are constructed at a cultural/political level and is suggested as a form of social control (Sjostrom, 2018). Modified Labelling theory (Link, Cullen, Struening, et al., 1989), developed from Becker's original concept, propose that individuals self-stigmatised because of such labels, therefore the label becomes part of an individual's identity and sense of worth. As can be seen in the research of Cox et al. (2017) as referenced above. Literature surrounding labelling and autism often finds similarities and comparisons in the labelling of homosexuality. Homosexuality was included in DSM-II as a mental disorder and as such, individuals 'suffering' from this iatrogenic concept were labelled as deviant and in need of a cure (Charland, 2004). Proponents of this comparison argue that autism, like homosexuality, is a difference to the socially constructed norm and therefore the medicalised labelling is unethical and has significant effects on those that are so labelled:

> *"when people are labelled, they are placed into a cultural category that makes the category stereotypes salient and personally relevant. Labels carry cultural meaning*

> *that can be activated in diverse settings, which can make them difficult to dispute, ignore, or hide. (Smith and Hipper, 2010, p411).*

The principles of labelling will be important to consider, as the participants of this research will not have been labelled as autistic in the same way as iatrogenic labelling through diagnosis, therefore their experiences may be different. They may however have been given different labels and it will be important to consider if the impacts if this is different from that of diagnosed individuals.

Labelling and diagnosis are inescapably intertwined, with labelling of deviant behaviours and stigma often leading the individual to seek out a diagnosis. "I'd sort it, in large part, because I had always experienced myself as deficient." (Limburg 2016 p143). Diagnosis firmly finds its foundations in the medical model of disability. While the medical model of diagnosis seeks to uncover a pre-existing deficit in the individual, that only an 'expert' professional could understand and in turn treat, the social model claims that diagnosis is a cultural product, with medical categorisations, and therefore disabilities are subject to change. In the case of autism, and its variable manifestation, constructing a reliable medical diagnosis is complex (Sarrett, 2016). Therefore, it has been argued that in the absence of biological markers, either undiscovered or undiscoverable, psychiatry constructs diagnoses on the basis of perceived behavioural deviancy (Anckarsater, 2010; Kapp et al., 2013), which is in turn justified by biocertification:

> *"biocertification - a process by which social identities are acknowledged and confirmed through medical, governmental, or psychiatric practices and documentation" (Sarrett, 2016, p24).*

The desire to achieve a medical diagnosis and the suggested positive impacts of such, is being attributed to biocertification and biological citizenship. Fernando (2009) argues that we are in “the decade of the brain” (p1162) whereby we are increasingly understanding our behaviours and personalities as fundamental proponents of our neurological structures. The process of biocertification can be compared again to the labelling of homosexuality and in turn sexuality, whereby a socially constructed label is positioned as able to bestow an understanding of a scientifically determined condition (Spargo, 1999). Biocertification therefore is a cultural construct, but despite this, has become a powerful tool in the “interventions and regulatory controls” characterising the modern biopolitical state (Foucault, 1998, p139). Biocertification has grown more significant with the developments of biotechnologies, arguably shifting away from medicalisation to biomedicalisation (Clarke et al. 2003; 2009). Navon and Eyal (2016) suggest a framework of ‘looping genomes’ building on the work of Hacking (1995a; 2002) which will be explored further subsequently. They suggest that the genomic gaze (Singh, 2016) produces ideas and perceived evidence which then alters the way in which autism is understood. There is growing literature around the possible use of MRIs to produce images of the brain which would identify autism and therefore provide diagnosis (Dekhil et al., 2018), suggesting a shift away from social markers of autism towards neuropsychiatry and the neurosciences and a reinforcement of the growing role of biomedicalisation and biocertification in our understanding of autism. Sarrett (2016) found in her study that biocertification remained important for individuals that self-identified as autistic, and often led to them seeking diagnosis as confirmation of self-knowledge. The findings of my research will be used to consider whether this assertion is reinforced.

The emphasis of biocertification can be linked with the work of Foucault and his concept of biopower. While Foucault is accredited for the concept of biopolitics, its routes can be found in the work of Aristotle and Arendt (1958) who both, in their different epochs, identified a difference, based on a perceived variance in biology, between which lives counted as important within a political sphere. Foucault argued however that:

> *"for the first time in history…. Biological existence was reflected in political existence…. For millennia, man remained what he was for Aristotle: a living animal with the additional capacity for a political existence; modern man is an animal whose politics places his existence as a living being in question." (Foucault, 1980, p142-143)*

Foucault introduced the idea that the regulation and disciplining of the human body, were the central parameters for the establishment of modern capitalism, not sovereignty, as others had proposed. The concept of the 'ideal worker' as referenced within the discussions surrounding stigma above, is reinforced not only in the individual's economical ability to work but also in terms of its political obedience and militarily usefulness.

Biopower, is the power that comes from biopolitics. Foucault uses racism, sexuality and disability as examples of the way biopower is used to categorise, stigmatise, stereotype and label individuals based on a discursive object rooted in biology. Which in turns provides the basis to justify such actions. Foucault's concept of biopower related to:

> *"the set of mechanisms through which the basic biological features of the human species became the object of a political strategy, of a general strategy of Power," (Foucault, 1978, p16)*

The development of biotechnology has further developed the sphere of biopolitics as the human body is now seen as a "re-writable text" (Lemke, 2012, verbal citation), prompting the philosophical questions relating to the understanding of life.

In some of his most influential works, spanning the past four decades, Foucault explores how we are the product of our histories; how 'archaeology' (Foucault, 1970) is the discovering of past rules within epistemes and genealogy (Foucault, 1975) is how we got to where we are now, or how history has affected our minds. For Foucault power is defused, it is unidirectional, not in the sense of one person or authority, behind the scenes pulling the strings, but in the structures, language, classifications and ways we see ourselves. As Rajchman (1991) is quoted to explain:

> *"the great 'complex idea of normality' has become the means through which to identify subjects and to make them identify themselves in order to make them governable" (Rajchman, 1991, p104).*

For Foucault biopower was influential and pervasive because it *"enables subjects to act in order to constrain them[selves]" (Tremain, 2001; 2002, cited in Curran, 2016, p435).* One of the ways this can be argued to be observed is in what Orsini (2009) referred to as 'autism wars'. The way in which individuals united under a similarity, continue to be fragmented due to external cultural forces. This is evident in the contentious debate surrounding person-first language (PFL) or identity-first language (IFL) a conflict that is constructed out of the wider cultural concepts of disease, normality and deviancy. Advocating that language can impact on the individual and the way they are accepted, or not, in society (Milton and Sims, 2016; Parsloe and Holton, 2017). Such infighting, within the view of biopower, serves to prevent those affected from challenging fundamental concepts collectively, such as acceptance, which both sides individually advocate for, and therefore limit their power.

A further example can be seen in the exploration of self-identification of autism and biocertification. The neurodiversity movement, which will be discussed in a subsequent section, advocates against the power of medicalisation of autism, suggesting that the individual’s experiences and expertise are superior to the medical professional. However, in a contradictious manner, they also often devalue the process of self-identification arguing that a diagnosis by a medical professional is needed. Directly conflicting therefore with their origins of fitting within the social model of disability rather than the medical model. Within the remit of biopower, such contradictions serve to allow the illusion of individualisation while maintaining the biopolitical power:

> *“if the identity of the subject of the social model (“people with impairments”) is actually produced in accordance with these political arrangements, then a social movement that grounds its claims to entitlement in that identity will inadvertently extend those arrangements” (Tremain, 2005, p10).*

The philosopher and historian of science Ian Hacking has extended Foucault’s work, developing the concept of *human kinds* (Hacking, 1995b) to refer to categorisations not rooted within *natural kinds* of individuals, but come into being based on cultural and linguistic construction. He calls this phenomenon “the looping effects of human kinds” (Hacking, 1995b, *p61)*. For example, Ward and Meyer (1999) have suggested that autistic self-advocacy evolved following the publication of DSM-III, which was the first time it was made widely available to the non-medical population. Grinker (2020) refers to this change, producing a dictionary that for the first time, gave individuals a language, which they perceived to have an ontological truth, to make sense of themselves, (Bertilstotter-Rosqvist et al, 2015), therefore creating a new *human kind:*

> *“after diagnosis, the language used to talk about myself began to change, and with this new kind of talking, it could be said that I was calling a new identity into being: ‘fidgeting’ became ‘stimming’.. By using these terms, drawn from the first person and professional discourse around AS and autism, I was in effect creating a new aspergic self (Limburg, 2016, p149).*

Developments in understanding and perspectives surrounding autism have grown with the development of language and in particular the accounts of autistic individuals in the media. Hacking writes: "a quarter century ago there was no language for autistic experience, emotions, and intentions" (Hacking, 2009b, p503). His action analysis therefore seeks to explain the appearance of kinds of people, alongside the development of concepts for them (Mallon, 2016). Opponents have argued that Hacking's action analysis is incomplete, one argument is that it fails to provide an explanation of the origins of concepts or that they are different to what has come before. Ellenberger (1970) takes Hacking's reference to Multiple Personality Disorder as an example to contend that such a *human kind* was not new/novel as it was predated by the phenomenon of spirit possessions. When viewing Hacking's analysis in line with the role of anthropology in the work of Foucault however, while the original origin of a concept may not be traceable in the current day, we can see how the process of identification develops and changes in line with the culture and the language available to the individual. The identity of autism therefore would be viewed as culturally and time specific, as whilst we can trace its development through our history it is possible and likely that it will change again in our near future. The shifting language of autism therefore, would facilitate the phenomenon of self-identification and may mean that it will continue to change and develop over time.

Despite the evidence relating to stigma and stereotypes, the very fact that self-identification of autism occurs suggests that there has been a shift in perspectives over recent years to minimise or modify their impact. Indeed Grinker (2020) suggests that through mediums such as social media, perceptions of disability are shifting generally. In line with Rapp and

Ginsburg (2011) who argue that there is an "expanding arena of public intimacy around the experience of disability" (*p*395). Autism stigma is therefore suggested to be specifically reducing due to the developing language of a spectrum, movement away from a culture of blame and the blurring of boundary lines.

Research has suggested that it is the process of stigmatisation that facilitates the creation of subcultures based in deviancy, alongside the growth of identity politics within the 21st century:

> "*Particularly regards to newer diagnosis' such as eating disorders, autism and attention deficit hyperactivity disorder (ADHD), it appears that patients are becoming more inclined to form a sense of belonging and solidarity with those similarly labelled" (Cohen, 2018).*

The autism rights movement seeks to construct a collective identity around autism, it mirrors other rights movements such as disability rights and gay rights for example. Different to the autism rights movement, but working collaboratively, is the neurodiversity movement which developed out of the social model of disability, advocating that autism should be viewed as a natural variant of humanity and should therefore be treated with equality (Bagatell, 2010; Bumiller, 2008; Cascio, 2012; Parsloe, 2015) and therefore actively opposes constructs of autism that suggest a 'cure' is required (Ortega, 2009). Parsloe (2015) outlines a suggested positive impact of the neurodiversity movement on an individual's identity:

> *"describe those with Asperger's syndrome as being "differently wired", "on a different wavelength", and "differently abled", rather than abnormal or disabled. These descriptions produce a more neutral "we are simply different" stance. Indeed, referring to those not on the spectrum as neurotypical's achieve the same goal in that it avoids assigning these people, "normal" status, and by default, assigning Aspies "abnormal" status. Instead, these discursive approaches leave room for different versions of "normal". (Parsloe, 2015, p345).*

Proponents of Foucault's biopower, including Foucault himself (Tremain, 2005), have questioned this rhetoric. Suggesting that the shift in terminology from 'normal' to 'neurotypical' and 'abnormal' to 'neurodiverse' is mere semantics. While it mirrors the changing importance and concepts of knowledge within the given culture, the foundations of distinction based on biological differences remain, so do the biopower that regulates them. It maintains a 'in-group' 'out-group' phenomenon, which finds its routes in stigmatism and labelling. This is further reinforced by the neurodiversity movement's emphasis on biomedicalisation. With proponents often using terminology such as "differently brained" (Meyerding, 1998, title) or "differently wired" (Parsloe, 2015, p345) as seen in the quote above. This shifts the analysis of behaviours, emotions and beliefs from the social and cultural realms to the neurochemical (Rose, 2007) or the 'cerebralization' of the self (Ehrenberg, 2004; Vidal and Ortega, 2007; Vidal, 2009). The neuroscientific language used to refer to autism, acts as a justification for positivity and acceptance, but by maintaining the process of biocitizenship can exclude those, such as individuals who self-identify, as not having a valid identity.

A new subculture within this shift in identity formation can be seen in the neuroqueer movement. The Cargo Collective defines neuroqueer as:

> *"a spectrum of identity in which the individuals presented are no longer contained by the patriarchal boxes of definition when it comes to gender. There is no longer a need to classify and personalize one-self as male or female, abled or non-abled" (Canessa, n.d.).*

While the routes of this movement appear to be in the gender identity realm, the inclusion of disability is clear. Their advocates support the inclusion of all and appear to steer clear of the 'normal' or 'abnormal' division within any language construct. Significantly with regards to power, the neuroqueer movement has not received much publicity and does not appear to be referenced in many research articles, especially in comparison to neurodiversity. Therefore, reinforcing the concept of biopower manipulating the consciousness of the wider population. Of further importance, to this study, is also the neuroqueer rhetoric that

> *"people are the only experts on themselves – outside evaluations might be useful for some folks sometimes – but the only expert is the NeuroQueer person themselves, not any professional" (O'Toole, 2015; quoted in Friedner and Block, 2017)*

Once again this is not an opinion that appears to have gained much popularity and can be seen to reinforce the unidirectional nature of biopower and biocertification.

2.1.2 Identity, Self and Self-Identity.

Within the current western culture, the rights of an individual and their autonomy is outlined in law (Beauchamp and Childress, 2001). Charland (2004) suggests that this is reflected in an "openness to pluralism and diversity" (*p*342) in our current world. In parallel to the suggested shift in stigmatism surrounding autism, there has developed a new phenomenon of self-diagnosis, which this study seeks to explore further. Sarrett (2016) argued that self-diagnosis of autism is a somewhat unique phenomenon, when compared to other comparable conditions. Especially in the sense that often, self-diagnosed individuals align themselves within an advocacy culture, like neurodiversity. Despite this, in the literature search that was undertaken, as outlined and discussed further in section 2.2, only two articles specifically included participants that self-diagnosed. While others referenced its existence and growing popularity it was explored no further. Where self-diagnosis is discussed, it is often believed to be linked to a missed diagnosis in childhood, therefore suggesting there is a current population of adults that now feel they can relate their experiences of feeling different to the norm, to the modern categorisation of autism (Lewis, 2017). The difference between the language connotations of self-diagnosis and self-identification are prevalent in online autistic communities and relates to the previous discussions surrounding biocertification and neurodiversity. While Sarrett (2016) argues that individuals are better positioned to diagnose themselves than psychiatric professionals, she also evidences that the power of biomedicalisation means the term self-diagnosis is fought against. As such the term self-identification or self-knowledge is preferred, but it can be argued, continues a 'them and us' culture as self-identifying individuals experience marginalisation from the cerebralization of autism. In order to prevent biomedicalisation becoming a central feature of this research the term self-identification will be used in favour of self-diagnosis. In doing so this places importance on the concepts of identity and self, which will be reviewed further within the current literature review search remits.

Although identity is a term that is used frequently both in lay terms and in academia, paradoxically it continues to be a term that is difficult to define. (Beart, Hardy & Buchan, 2005). There are several ways the concept of identity has been theorised (Lawler, 2008), as well as long-standing debates regarding the distinction between personal and social identity (Watson, 2002) as well as the concept of 'self'.

The online version of the American Psychological Association (APA) dictionary of psychology defines identity (noun) as:

> *"an individual's sense of self defined by (a) a set of physical, psychological, and interpersonal characteristics that is not wholly shared with any other person and (b) a range of affiliations (e.g., ethnicity) and social roles. Identity involves a sense of continuity, or the feeling that one is the same person today that one was yesterday or last year (despite physical or other changes). Such a sense is derived from one's body sensations; one's body image; and the feeling that one's memories, goals, values, expectations, and beliefs belong to the self. Also called* ***personal identity".***

And Self (noun) as:

> *"the totality of the individual, consisting of all characteristic attributes, conscious and unconscious, mental and physical."*

By reviewing the definitions together, the concepts of self and identity share considerable overlap in their meaning. Through the subsequent exploration of these terms and their uses I will begin to explore how different theories understand them in relation to autism.

The dominant view, held in much of western society, links the 'self' to biomedicalisation as previously discussed, or reductive physicalism within philosophical thought. That everything about individuals can be explained through understanding the science of our bodies. For example, Crespi and Dinsadale (2019) undertook the rubber hand illusion, a task commonly used by neurologists and psychologists to investigate and quantify 'self', specifically in terms of the activation of the insula region of the brain. The insular cortex, part of the cerebral cortex, is believed to be involved in a variety of functions including sensory processing, characterisation of feelings and emotions as well as decision making (Gogolla, 2017). They concluded that the participants on the autism spectrum showed reduced impact through the task and therefore suggests a brain-based reason for a proposed deficit of conceptualising 'self' in autism.

This is in stark contrast to Subject dualism, and Descartes famous statement that "I think, hence, I am" (Descartes, 1899, p35), which while still popular with some, has become largely refuted because of the value placed on scientific knowledge in our current culture. A middle ground between those theories can be seen in interactionism, that believes both body and mind effect each other. As Mauss articulates:

> *"there has never existed a human being who has not been aware not only of his body but also of his individuality, both physically and spiritual" (Mauss, 1985, p3).*

Therefore, while the biocertification that I have outlined remains influential in the physical reductionism of autism, the personal experiences driving an individual's construct of autism, as central to this research, would suggest that for some interactionists, it is vital.

The concept of self and autism, and more widely, disability, is a much-considered area. As previously outlined, there is a historical acceptance of the medical theory which reinforces disability as deviant, and therefore something not to be embraced. The process of trying to disregard this identity can have negative implications on a person's sense of self. Watson (2002) argues that a person with an impairment often has a reduced sense of self as they adapt their lives to try and match the expectations of 'normal'. This is suggested to be heightened for differences such as autism which are classified as 'invisible'. Rhodes et al (2008) explain that general assumptions of disability are that of physical differences which are clearly visible to others. The individual who does not have a visible disability is forced to hide it behind their social portrayal of themselves in order to avoid being questioned as to their legitimacy of their behaviours. Such fragmentation between a socially constructed 'self' and a 'real self' has been linked to the interactionist thought, viewed in the work of, James (1890) and Mead (1934) who outlined three principles of symbolic interactionism. Firstly, that meaning is central to human behaviour, secondly, that language gives humans meaning and thirdly, that reflection is vital to embed meaning into the development of the 'self' (Hughes, 2012). As such the 'self' is a fluid entity that reflects the language available to use, therefore dependent on culture and *human kinds* (Hacking and Hacking, 1999) and the individual's memories and conceptualisation of the social world (James, 1961: Damon and

Hart, 1988). These principles can relate to previous discussions surrounding biopower, Looping theory and autism, as the ‘self’ is constructed based on external forces. Yet the ‘self’ is often perceived as something the individual has ownership over and therefore this can cause conflict within personal understanding of ‘self’ and ‘identity’. Reflecting this dichotomy, William and later Mead divided the ‘self’ into two main components; the self as an object (me) and the self as a subject (I). Jackson, Skirrow and Hare (2012), presented evidence that the Asperger’s group, within their study, demonstrated an impaired sense of the self as an object, the ‘me’ in Mead’s (1934) characterisations, yet autobiographical accounts often suggest that the social construction, the ‘me’ is often cognitively understood, yet an understanding of the ‘I’ is lacking.

> *“Mead’s (1967) notion of the ‘me’ helped to make sense of how I could act on the social situations I encountered. I began to make sense of who I might be through the lens of Mead’s ‘me’ which became the ‘other’ I wish to project during my encounters with the outside world.” (Hughes 2012, p97)*

Indeed, it appears the fragmentation between the ‘me’ and ‘I’ relates to the process of masking as represented above, where there is ‘identity nonverification’ (Burke and Stets, 2009, *p2)* and indeed Limburg (2016) when reflecting on her own journey extended this to suggest two distinct ‘selves’, when she refers to a Self A and a Self B.

> *“Which self, did they mean? Did they mean the person I shall call Self A, woman….. Who would…answer every question and talk and talk and talk …unwittingly dominating the group, inadvertently intimidating the other members and being that awful thing- off putting? Or did they want me to be Self B, the person I’d spent the last 20 years of my life learning to be in order to not have to be that child any more… In the end, I went for the usual compromise, which meant that self B spent the session policing self A and rationing her contributions” (p 143).*

This representation of masking is not unusual, with one recent study suggesting 70% of their autistic participants reported consistently camouflaging (Cage and Troxell-Whitman, 2019). According to Swain et al (1999) the ultimate goal for any individual is the development of a healthy sense of self. This is achieved when an individual accepts their multiple identities and compiles an honest self, alongside 'identity-verification' (Burke and Stet, 2009, *p2*) from others. Often when an individual embraces a disability identity, they refer it to 'coming-out', much like a homosexual person does when they embrace their identity and share it with others. If a healthy sense of self is the goal, the route, as it can be seen for the undiagnosed autistic individual, is often a reduced sense of self which leads to a predominate focus on being different to the normal and a resulting search for why this is the case (Watson, 2002). Furthermore, it can lead to a belief in the ontological truth of the autistic self, that needs reclaiming. Such an argument is compelling within the given to study, as to why the process of self-identification occurs.

The belief that there is an underlying 'reality' within a person finds its route in the theory of essentialism. Essentialism originates in the work of theorists such as Plato and Aristotle. For essentialists there is a belief, that each human being has a fixed attribute, an 'essence', that forms the basis of who they are and therefore their identity (White, n.d.). An example of this is given in the form of men being naturally more aggressive due to their hormonal differences rather than any social implications or ability to choose to act differently (Twine, n.d.).

The theory that a person's disability is a fixed attribute of each individual can be related to the medical model of disability. As such, some supporters of this theory argue that disabled people are not heterogeneous but instead have a shared essence relating to their medical condition. As Rhodes et al (2008) articulate, it is the essentialist beliefs that have underpinned much of the writings into disability to date, which emphasises cure and rehabilitation (Rhodes et al, 2008). Since the original understandings of autism, it has been viewed through the essentialist model which defines an individual's identity through disadvantaged experiences due to their fixed 'abnormality' in contrast to the expected 'normalcy' (Hosking, 2008). Therefore, an autistic person's identity was defined at an individual level, pre-dating any social interaction/influence.

The essentialist model is not fixed to the medical model however, as it can be seen through the social model of disability also. The biocitizenship previously discussed, alongside the neurodiversity movement, illustrates how autism is essentialised and constructed as an ontological truth. This is evident in the use of language surrounding autism research, and proposed outcomes for individuals, for example, Hughes (2012) suggests that:

> *"actively engaging with one's own life story narratives can help the Asperger's learner come to terms with his or her Asperger's self" (p94).*

The language choice illustrated here, suggests that the 'asperger's self' is a separate entity which the individual needs to strive to achieve. The fragmentation of an autistic self from the individual's self will be important to consider within this research, with regards to whether self-identification is a process of reflection and fusion of the 'me' and the 'I', or a search for an essential 'I' fragmented from the 'me'.

Existentialism as a contradictory theology from essentialism grew in popularity in the mid-20th century, especially in the aftermath of World War II when people began to question how such horrors could occur. While essentialists believe each human being is born with an essential component that they must live up to, existentialists believe such searching for the meaning of life is 'absurd'. Jean-Paul Sartre, is a theorist in this area and believes the world has an abundance of freedom, not that it lacks in meaning but meaning only comes from individual construction. To live an 'authentic' life one must accept the freedom and that we create our own essence through the way we choose to live. (Existentialism: Crash Course Philosophy #16, 2016)

Identity therefore, in the existentialist view, is that identities are not a given entity but something that we choose for ourselves (Giddens, 1991) and exist in relation to the social construction and dominant dialect of the time (Rhodes et al, 2008), built from interactions with others (Cox et al, 2017). In relation to the quote from the work of Limburg, used above, to demonstrate the fragmentation of the 'I' and 'me', with the 'I' being an essentialist proponent, her work can also be used to show how her self-discovery bought her to the conclusions of refuting the notion of an autistic essence to believing both the 'I' and the 'me' were constructed.

> *"Rather than representing an 'authentic' pre-cultural self which stands in opposition to the knowingly-constructed 'self b', the self a which I have come to call 'autistic' is also to some extent performative in nature. As constructed and performed identities, both lay and they will continue to require "ingenuity, creativity and much hard work" (Bagatell, 2007) in their management and maintenance." (Limburg, 2016, p149).*

Due to the freedom that existentialism places upon identity there is an acceptance that identity is fluid and can be theorised in a number of ways, leading to the obscurity of the true definition of the term identity (Lawler, 2008). As Holland et al (1998) states "we are reminded how unlikely it is that one's identities ever settled, once and for all" (p189). While existentialists believe that ultimately people should throw off the constraints of society and have the freedom to develop their own identities, theories have developed acknowledging that within a capitalist society this does not represent the current possibilities of practice. Theories have progressed therefore that acknowledge the dismissal of identity relating to essence while suggesting that they are developed in relation to external forces, such as biopower as discussed previously. In relation to self-identification of autism therefore, it will be important to consider whether individuals feel the autistic identity is a social construct and whether it is seen as a fluid, adjustable entity that forms only one part of their changing personal identities.

Theories relating to identity are vast and complex and have been discussed for many years. I will outline three elements of identity theory: person, role, and social, with a specific focus on how they relate to autism. To understand the way in which identity may be viewed with regards to self-identification of autism.

Identity theorists use the term personal identity to conceptualise innate individuality of the person rather than a role-holder or a member of a group (Stets, 1995). For Identity theorists, cultural classifications do occur, however the personal identity is created based on the individual internalising chosen categories to construct their sense of self. As categorisations are culturally dependant, Identity theorists suggest that others may self-categorise based on similar grounds and therefore comparisons will occur in order to facilitate identity verification (Burke and Stets, 2009). Therefore, the categorisation of autistic is an individual process, however a consensus of meaning of autism produces a process of comparison and facilitates others to judge the individual's identity as either verifiable or not. While Identity theorists argue for the innateness of the individual, they do not generally relate to the essentialist notions of predispositions. Instead, like role and social theorists, recognise the way in which culture and others impact on the individual. While Identity theorists acknowledge the multiple identities, an individual is likely to hold, they also suggest that one identity may become a dominant identity (Burke, 2004), which links to the concept of authenticity. Social Psychologists have argued that authenticity is a relatively new term which relates to a feeling of being true to one's core self, that persists across situations, time and relationships. This has important correlations to autism and whether it holds the role of master status, and what the implications maybe if the individual perceives they lack authenticity.

Role identity was developed by the early theorists exploring the concept of identity. They argued that the role an individual played was central to their identity (Burke, 1980, McCall and Simmons, 1978). A role in this perspective is a set of expectations tied to a social position, such as: student, teacher or male (Burke and Stets, 2009). Equally as important is how the individual internalises these expectations and interprets meaning to them. To view autism within the role identity theory, therefore, is to see it as a socially constructed concept that describes it as a 'social type' (Stryker and Statham, 1985, *p*323), which individuals are socialised into what it means to be autistic (McCall and Simmons, 1978), and then internalised to become that identity. Furthermore, in role identity theory Rose (1962) argues that "a role cannot exist without one or more relevant other-roles toward which it is oriented." (*p*24). Therefore, suggesting that the autistic identity could not exist without a specified counter role of a non-autistic identity.

Some have argued that role identity and social identity are similar in their understanding of identity, and therefore the distinction between the two can become unclear (Burke and Stets, 2009). Social identity, is suggested to build on the above premise, reinforcing the idea that identity is a social construct, and the self therefore is a categorisation based on differing social roles (Thoits and Virshup, 1997).

Social identity (SI) theorists perceive identity to be based upon an individual's identification with a social group (Abrams and Hogg, 1988). Through the process of comparison and categorisation individuals ascertain whether they are part of the in-group or out-group. "the self, then, does not cause a social situation; it occurs as a result of social situations" (Brannaman, 1997, quoted in Lawler, 2008, *p*107). Within this approach it is assumed that a level of uniformity of thought occurs within social groups, furthermore that interaction is not needed with the social group, for such uniformity to occur. Therefore, autism as a social identity, would mean that there is a uniformity of thought across all autistic people.

SI theorists suggest that there can, however, be a level of differentiation amongst ingroup members. While there is a prototypical representation of an ingroup member (Burke and Stets, 2009) variations from this will occur. The prototype serves as a polarized example of the ingroup member to ensure its maximum distance from a prototype of the outgroup (Hogg, 2006). Therefore, the stereotypical autistic person may be seen as the prototype, while variations of this will occur. This also accounts for why social identities may change over time as the prototypical representation of autism will be culturally dependant. When individuals seek to embody the group prototype a process of depersonalisation is said to occur, where the individual seeks to identify themselves with the prototype rather than with their own individuality. Therefore, the autistic individual seeks to identify themselves with the collective understanding of autism rather than with personal characteristics such as talkative, shy or clever.

Oakes (1987) argued that social identity becomes active through the processes of accessibility and fit. Accessibility relates to whether the social identity is available to the individual, while fit is suggestive of the individual undergoing a process of reflection to ensure the identity matches their experiences. This has specific relevance to autism, and in particular self-identification, as it would be able to account for how cultural changes have allowed the autistic identity to become available to individuals, therefore justifying why such identification had not occurred in the past, a concept that will be discussed further in subsequent sections.

The principles of SI theory pose questions specific to autism as the traditional view held is that autism entails a fundamental lack of sense of self (Limburg, 2016). Indeed Tanweer, Rathbone and Souchay (2010) reported in their study that autistic participants produced fewer social identity statements than the non-autistic group. It will be important, within this study, to bear this in mind, and reflect on the process of building an autistic identity and whether the autistic identity fits within the SI theory.

While the three approaches to identity theory are represented as separate, there is a commonality between them. Each posing specific questions in relation to autism and identity. And furthermore, to the wellbeing of the individual if the autistic identity is not verified by others. Burke and Stets (2009) argue that all three forms of identity verification are required for personal wellbeing:

> *“Thus, as verification of role identities fosters self-competence and the verification of group identities fosters self-worth, the verification of person identities fosters self-authenticity”. (p20).*

2.1.3 Situated Learning Theory

One of the theories that has become apparent through this literature review, that draws upon the role of the individual as well as the social and emotional, is found within the work of Lave, Wenger-Trayner and Wenger-Trayner, with their development of communities of practice, situated learning and Landscapes of Practice:

> *“This meaning-making person is not just a cognitive entity. It is a whole person, with a body, a heart, a brain, relationships, aspirations, all the aspects of human experience, all involved in the negotiation of meaning. The experience of the person in all these aspects is actively constituted, shaped, and interpreted through learning”* (Wenger, 2010, *p180).*

Lave and Wenger (1991) defined a community of practice as a social entity consisting of a group of people with “similar interests, perspectives and activities” (Lave and Wenger, 2017, *p*32), individuals join such communities and fall within the legitimate peripheral, learning from established members of the community. As time passes, they become full members of the community and consequently others learn from them. Learning therefore is always ‘situated’, it is always affected by the situation of the learner. While the principles and reach of Communities of Practice is wider than this following research project, the theory does consider identity formation as a central proponent to its wider implications, which therefore becomes beneficial to contemplate. As Wenger (2010) states:

> *“The focus on the social aspect of learning is not a displacement of the person. On the contrary, it is an emphasis on the person as a social participant, as a meaning-*

> *making entity for whom the social world is a resource for constituting an identity."* (*p*180)

Identity within and across the landscape of practice is said to occur in different modes of identification, engagement, imagination and alignment. Engagement is defined as the most direct association with practice, as it incorporates direct experiences of participation and indeed non-participation. Imagination in contrast refers to more abstract experiences, whereby the individual can imagine their connection with a community of practice they may not have direct experiences with. Finally, Alignment refers to the structures surrounding a community of practice and the way the individual engages with it. Due to the complex interplay of social experiences, Lave and Wenger (1991) ascertained that identity is a continuously evolving entity, reflecting the continuously changing experiences of the individual. This raises important questions when researching the autistic identity as by establishing it as a concept to research, I may be perceived to be suggesting a singularity and 'reality' of such an identity. It will be important to consider through the research whether the experiences of the participants suggest it is viewed in this way or whether it is indeed seen as an identity that changes over time and just one of many identities that the individual will hold at any given time.

2.1.4 Ecological systems model

The impact on the individual, of their environment, their relationships and their age, similar to the points outlined above, have been theorised within Bronfenbrenner's Ecological Systems Model (Bronfenbrenner 1977; 1979; 2005). The principles and history of the theory are complex and would be outside of the remit of this study to explore in detail. However, a brief consideration will be given to the key features that impact on the construction of the autistic identity as discussed within this literature review. The Ecological Systems theory lays out the existence of complex layers, surrounding the individual that directly impact on their continual development (Baltes, 1997; Baltes, Lindenberger & Staudinger, 1998; Elder, 1998). As such, Bronfenbrenner, working within the constructivist model, saw the individual as an active participant in experiences and the process of understanding them (Shelton, 2018). The ecological systems model in relation to identity does not directly prescribe to an essentialist or existentialist basis, which may also be termed as the nature v nurture debate. Instead, it can be seen to acknowledge the nature of the individual, however as nature is deemed to be static, the development of the individual must be viewed with the context of the environments it engages with (Christensen, 2016). By using the example of bullying, the ecological systems model would ascertain that such experiences with the individual's peers, occur within their immediate surroundings, or the *microsystem*. At this level Bronfenbrenner argues experiences have *bi-directional influences*. As such they not only impact on the child but also impact on the other person involved. So, the child may develop an 'othered identity' (Milton and Sims, 2016) and feel part of the out-group, but at the same time the bully is reinforced as part of the 'in-group' therefore reinforcing a fragmentation between 'normal' and 'abnormal'. The chronosystem can also be drawn upon, in relation to this research and the autistic identity, as it stresses the role of time. In this research the participants will all be adults and therefore time will be a central consideration in how they react differently to their environments and how this determines their identity formation (Paquetter and Ryan, 2001). One area, not identified within Bronfenbrenner's ecological system's model is the vast technological developments and its impact on the individual as referenced previously. Christensen's (2016) argument that such developments have led to an increased emphasis on a relationship between the global and the local systems, can be seen in the work of disability theorists and relates to the role of stigma and identity development:

> *"these chat rooms offer solace and solidarity for the pain and alienation sufferers usually experience as a result of stigma associated with their disorder" (Elliott 2003 p218).*

While this system may not be recognised, the expanded definition of the microsystyem in 1994 saw Bronfenbrenner acknowledge the importance of interactions with words and symbols as well as with other people. Such a recognition can be related to Hacking's concepts of creating human kinds (Hacking, 1995) and the development of language surround autism enabling the construction of the autistic identity.

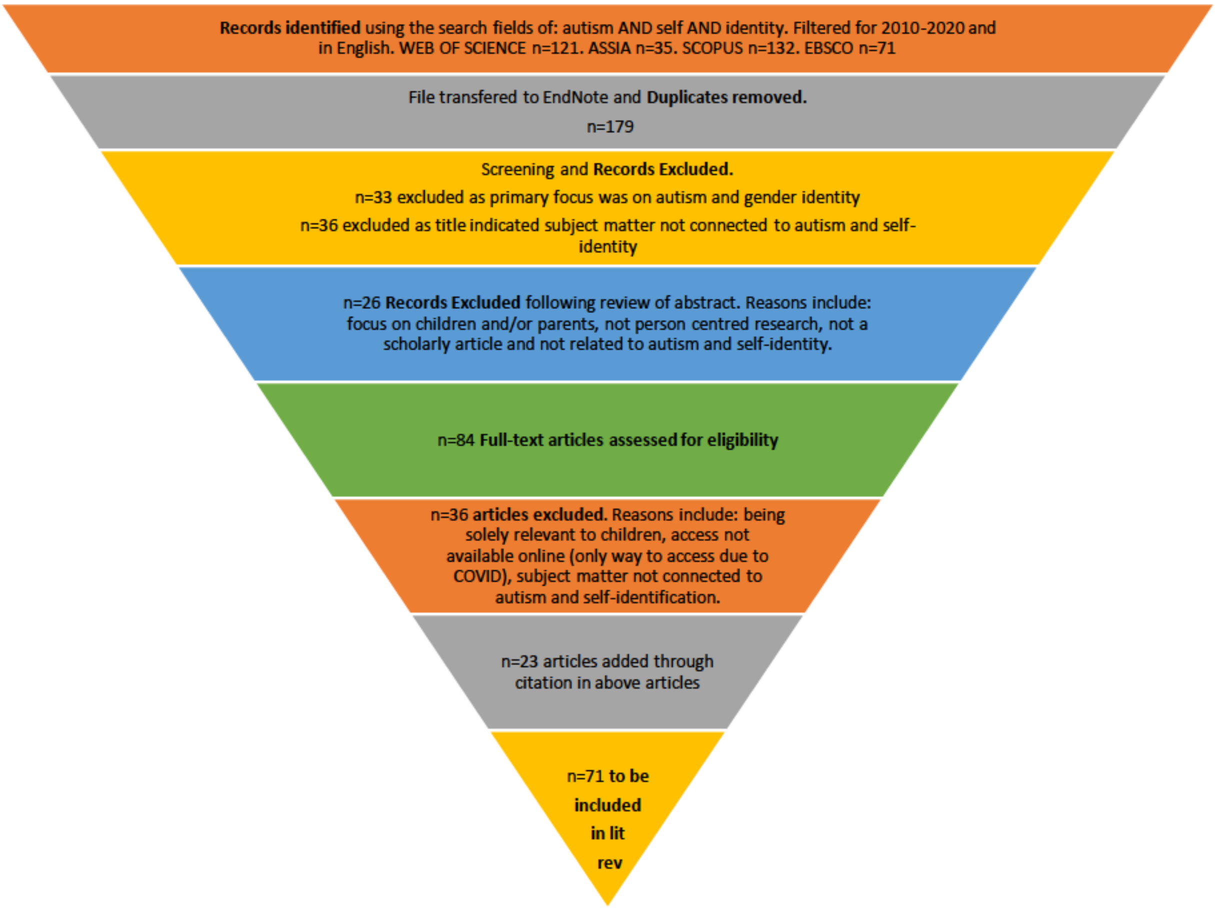
The principles of Bronfenbrenner's ecological systems model will be important to consider when reviewing the evidence collated in this research. By viewing the process of self-identification, I will be exploring and questioning at what level the individual is an active participant in experiences that shape their autistic identity.

Summary

The literature surrounding autism, identity theories and ecological systems is vast and as such I have tried to outline within this section a brief review of the key theories and arguments that relate to this study on self-identification. By doing so most concepts have left questions rather than answers, which I would suggest is due to the lack of research specific in this area of identity and autism. In order to back up this assumption, empirical research within the area of autism and self-identification is explored in the following section, alongside reflections as to what this means for my proposed research.

2.2 Empirical Research

A systematic literature review was undertaken, to explore articles with the topic words of autism AND identity AND self. The process by which articles were identified, excluded, and included is represented in the Prisma, outlined in figure 1.



Records identified using the search fields of: autism AND self AND identity. Filtered for 2010-2020 and in English. WEB OF SCIENCE n=121. ASSIA n=35. SCOPUS n=132. EBSCO n=71

File transfered to EndNote and **Duplicates removed.**
n=179

Screening and **Records Excluded.**
n=33 excluded as primary focus was on autism and gender identity
n=36 excluded as title indicated subject matter not connected to autism and self-identity

n=26 **Records Excluded** following review of abstract. Reasons include: focus on children and/or parents, not person centred research, not a scholarly article and not related to autism and self-identity.

n=84 **Full-text articles assessed for eligibility**

n=36 **articles excluded.** Reasons include: being solely relevant to children, access not available online (only way to access due to COVID), subject matter not connected to autism and self-identification.

n=23 articles added through citation in above articles

n=71 **to be included in lit rev**

Figure 1: Literature Review Prisma

Once the articles to be included were confirmed, they were printed off, read, and highlighted to identify key themes. Themes were then collated to construct into written structure, developing the themes relationships to each other, to ensure connections between concepts are clearly identified. The following literature review will therefore explore these sub-themes within the themes of Diagnosis and Self-Identification

2.2.1 Diagnosis

Through the analysis of the literature, the suggestion that diagnostic rates of autism positively correlated with other sociological factors became apparent. Adelman and Kubiszyn, (2017) in their American study argued that literature over time has demonstrated; race, ethnicity, and social economic status all have a significant influence on diagnostic rates (Broomfield & Dodd, 2004; Lantz et al., 2006; Longway, Johnson, Garwood, & Davis, 2000; Valicenti-McDermott, Hottinger, Seijo, & Shulman, 2012). While this is acknowledged to be limited by its American focus, the validity of the statements can be reinforced when compared to other research such as that undertaken by Boshoff et al., (2019) who found that in the UK diagnosis was also impacted by culture, linguistics and place of residency. A further issue offered for consideration in the study by Boshoff et al., (2019) was the role of parents in the diagnosis process, those parents who had greater awareness and the ability to ‘fight’ for what they wanted were more likely to be successful in the diagnosis process.

A study undertaken by Durkin et al., (2015) argued that most of our knowledge on autism and research into diagnosis is focused around ‘high income countries’. It would be logical therefore to assume that the diagnostic criteria, which is built from the research, will not be reflective in all societies.

One of the key areas which over recent years has been highlighted as illustrating a diagnostic bias is that of gender. There is now a growing amount of evidence to suggest that the diagnosis of autism is biased to the male gender (Adamou, Johnson and Alty, 2018). While females have been identified as a disadvantaged gender is important to also acknowledge that there is little research into how transgender and/or non-binary gender is are impacted through the diagnosis process.

As with all areas of inequality often one facet can be made to feel more prominent due to the exposure it receives. While this is not to undermine the importance of the work undertaken within these areas, this literary review has highlighted diagnostic inequalities exist in multiple areas. With such diagnostic variances it is logical to assume that there will be a population of individuals that have not been diagnosed with autism and therefore match the unique population of this study.

Few articles were identified that considered the impact of diagnosis on the individual. Interestingly a study by Crane et al., (2016) found that parents felt the outcome of being diagnosed with autism did not support the individual needs of their child but instead tried to categorise them into more a generic label of autism. In contrast, Huang, Arnold, Foley and Trollor, (2020) argued that the process of diagnosis gave autistic adults, a “new framework to interpret their experiences”. This was argued to be a positive step in self-acceptance as it reduced negative feelings the individual had towards themselves. They argued their findings supported the work of Bertilsdotter Rosqvist, (2012); Lewis, (2016) and Powell & Acker, (2016). The work of Powell & Acker was investigated following this reference and resulted in an article focusing purely on the effects of diagnosis on seventy-four UK individuals two to three months after assessment/diagnosis. While the evidence within this article provides important considerations, which are clearly used by Huang et al to reinforce their work, I have hesitations relating to the generalisability of the findings, as while a 69% response rate of their sample is statistically good, there remains questions as to whether the experiences of only seventy-four people within one location can be generalised beyond that, as it is likely that they all will have had similar experiences with the same service. When triangulating their results however with the findings from the work of Bertilsdotter Rosqvist, (2012) there is an improved level of validity as both studies reinforce the concept of diagnosis offering a pathway to self-understanding, even though they undertook their research in different countries with differing approaches at different times. These articles collectively would appear to argue that diagnosis for the individual provides an opportunity to explore one's 'true self', therefore suggesting that diagnosis is an essential key to self-awareness. However, it is noted that this is not specifically stated and the evidence basis to support this argument, while improved through triangulation, remains limited based on the articles I have analysed.

While I have shown that some articles consider diagnosis to be a necessary gateway to self-exploration, others present the argument that the principal purpose of diagnosis, in people's experiences, is to gain appropriate support (Mansell and Morris, 2004; Midence and O'Neill, 1999). This is indeed a mindset that I have experienced through my own professional and personal experiences, that autism specific support services will only offer support with the evidence of a diagnosis. What became noteworthy however, through the review of these articles, was the repeated expression of experiences of dissatisfaction towards level of support post diagnosis (Crane et al., 2018; Griffith et al., 2012; Lewis, 2017b; Raymond-Barker et al., 2018). Arvidsson, Gilberg et al (2018), present the argument that diagnosis should not be the basis for support, but societal changes should be undertaken to provide support based on need. While the basis for this argument is not under consideration through this review, it is included as it provides an additional consideration as to the role of diagnosis, not only what it is, but what it should be.

Despite the questions over the validity of diagnosis, it is evident that it is continually sought, and research has argued it has a positive impact on the individual. With studies stating that diagnosis offered individuals self-acceptance, validation, improved self-image, and the gateway for learning and understanding (Hayne, 2003; Horn et al., 2007; Dinos et al., 2004; Punshon et al., 2009; Bilderbeck et al., 2014; Leedham et al., 2019). These studies do not however specifically include self-identification as a variable and therefore it is unclear whether diagnosis is still sought to provide self-acceptance, it will therefore be important to consider this within this research.

2.2.2 Self-Identification

Hayes, McCabe, Ford and Russell, (2020) look in detail at the current role of teams of professionals within the diagnostic process. They present evidence that an important element of the diagnosis process arrives from the professional expressing a ‘feeling’ that the individual may be autistic. This is an significant factor to consider within the realms of self-identification, as through this process it is the individual who has a ‘feeling’ that they may be autistic. The sense of awareness from the individual is often seen as invalid, especially in terms of recognition from others, however; as a society we value the opinion of an ‘expert’ who is faced with second-hand information more. The exclusion of a role for self-identification within the diagnosis process can also be seen to be reinforced when reviewing the National Autistic Society's website page on diagnosis, as they inform individuals that self-referral for diagnosis is rarely possible and therefore even to begin the diagnosis process the opinions of a medical professional, often who has little to no knowledge of the individual, is valued more highly than the individual themselves (Autism diagnosis for adults, 2016).

Within the seventy-one articles analysed as part of this literature review, only seven specifically related to autism and self-identification. Furthermore, while seven articles were found, three were written by the same author as different sections of one research project and therefore it could be argued this reduces the total down to four articles for consideration. Following the analysis of the articles, this total must also be further reduced down to three articles as while one referred to individuals who self-identify as autistic it became apparent that this was meant in the terms of being open about their diagnosis rather than being self-diagnosed. When reflecting upon the fact that when undertaking a basic search using the word autism in ProQuest it arrives at three hundred and eighty-five thousand, two hundred and seventy-one results, a field of three clearly highlights a significant gap of research in this area.

As such a small number of articles are available, each will be reviewed to consider what can be learnt from them in connection with my research, what limitations there are to their research and what areas for further investigation they highlight.

As indicated three articles are written by the same author, Laura Foran Lewis. Two articles are written in 2016: one being qualitative and one being quantitative. As the third article written in 2017 brings the two studies together, it is merely the third study that requires complete analysis. Lewis (2017) outlines a sequential mixed methods research design, with a total sample size of one hundred and fourteen participants: seventy-seven diagnosed individuals and thirty-seven self-diagnosed individuals. This is illustrative of a large sample size and an advantage of the research. It is demonstrative of a similar sample size to my research however it is offering contrasting residential data as Lewis' was predominantly USA based with some UK while mine is predominantly UK with some USA (and other countries). The participants in this study were mostly males with a fifty-six to forty-four ratio, although Lewis does state that the 44% of females indicated a higher percentage than the suggested diagnostic ratio and therefore it remained statistically valid.

Lewis argued that the phenomenon of self-identification had been influenced by the growth in the media portrayal of autism. This could be seen to reinforce the work of Polyak, Kubina and Girirajan (2015) who found that between the school years of 2000-2001 and 2010-2011 the number of students in the American education system with autism rose by 331% while the proportion of children assigned as having a special education need stayed the same. They suggested that this is a result of the reducing stigma surrounding autism, that this label therefore becomes more appealing than other stigmatised labels. A possible reduction of stigma associated with autism could account for an increased comfort of associating ones-self with autism. Despite such a shift however, Lewis argued that participants reported feelings of self-doubt when undertaking self-diagnosis, in direct comparison to the validation her participants who were formally diagnosed reported they felt. This could be argued to be an extension of the experiences of low self-worth, inadequacy and isolation, Lewis demonstrated her participants experienced prior to self-awareness of autism.

Of further interest was Lewis' illusion towards the power of language in self-acceptance:

> *"Most individuals felt that a diagnosis of any kind, self or formal, gave them words to explain the previously unexplainable, saying, "I found the words to describe many thoughts I could never explain." (Lewis, 2016, p4).*

While this statement was at the end of her results outline and was not expanded on further in her write up, the evidence from my previous theoretical considerations would suggest that the development of language has a significant role within the construct of identities.

This is an interesting study that is unique in its sample size and focus on self-diagnosis, however some concerns remain regarding the lack of evidence provided to substantiate the stated facts within the study. One key example is that she references herself and her 2016 study to argue that "participants described an average of 3.25 years between the point when they self-diagnosed and the point when they were formally diagnosed" (Lewis, 2016, p3) however when reviewing said study, it does not clearly articulate how this figure was arrived at from the data gathered. Such a significant statistical statement would be more reliable with an evidentiary foundation.

Despite reliability concerns, this study is significant in its focus and reinforces the questions as to whether self-awareness may be more influential than diagnosis in achieving self-acceptance and understanding of individual strengths and weaknesses.

Much like Lewis, Zener (2019) argues that autism identification is greater in the current generation than ever before. However, the focus on her analysis of personal experience and academic literature lies in her belief that females are "minimally recognized and understood" (p6). In agreement with the findings of Lewis, Zener suggests that popular media has a central role in the increase of autism awareness. She suggests from her own experiences, in contrast to empirical research, that TV characters that display autistic characteristics provide individuals with an avenue in which to see themselves represented and therefore evolve their own self-understanding.

Curiously, despite this article being referenced as linking to autism self-identification, the only reference to the phenomenon comes in the statement that:

> *"Self-diagnosis is sometimes the only option if they cannot access or afford a formal assessment. Others choose not to seek out a diagnosis because they are satisfied knowing for themselves. These individuals do not see a benefit to having a formal evaluation. To them, the diagnostic process will not improve their self-understanding, or provide access to any tangible financial supports or disability service" (Zener, 2019, p9).*

The statement can be seen as merely a statement of opinion and therefore offers little empirical validity or reliability.

The third article written by Jennifer Sarrett (2016), I found to be a fascinating read. It considers self-diagnosis within the autistic community explicitly and offers some insights which importantly correlate directly to my research. Sarrett argues that self-diagnosis is:

> *"a response to the inability of science to confirm autism as a natural kind and is an act that is devalued because of the presumed unreliability of autistic voices" (Sarrett, 2015, p2)*

In some ways, her argument that self-identification is a result of a failure of science is seen to reinforce the literature suggesting there are a significant number of adults that have missed diagnosis as a child and therefore seeking answers in adulthood. Important also to consider however, is the fact that this study is now seven years old, this would suggest that its findings may be somewhat outdated. Especially, I would argue, within the realms of reliability of autistic voices. Since its publication there has continued to be a growth in the availability of autistic literature and the reliability of such has grown in congruently.

Sarrett also argues that self-diagnosis is a unique phenomenon to autism, in the sense that it is not often found in other psychiatric, developmental, and intellectual disabilities. While I find this statement interesting, especially in relation to the suggested association with a politicalised identity, Sarrett does not offer any evidence to back up her statement and therefore the validity of such remains in question.

In considering the identification of autism, Sarrett reviews the neurodiverse movement and how it relates to biocertification. She references how the neurodiverse movement seeks to move away from the medical model and is connected to the field of disability studies. She argues that supporters of neurodiversity consider autism to be situated in neurological differences not deficits. She does also highlight an irony, that autistic self-advocates argue that their experiences and knowledge are superior to researchers and professionals however continue to argue biocertification by such professionals is more valid than a person’s own experience and knowledge.

A further consideration raised from this research is the way in which the neurodiversity movement has positioned autism as an entity or ‘group identity’ and whether it has reinforced the essentialist view point that autism is ‘within us’? in contrast to the often-stated individualistic idea by the neurodiverse community that ‘if you’ve met one autistic person, you’ve met one autistic person’. This study raised significant contradictions within the current popular understanding of autism which it will be interesting to consider if they are mirrored in the wider experiences of autism within the research population.

Lewis (2015) and Sarrett (2016) are the only articles to directly study self-identification and have both employed online research methods similar to those planned in this research. Not only does this serve to reinforce the value of online research methods, but also emphasizes the concept that the media is a central facilitator in autism awareness and self-identification. It is however, also recognised that by focusing on online populations there could be a population of self-identifying autistic people that are continuously excluded from research. While it is not possible to rectify that within this research it is an important consideration for any future research in this area.

Summary

It is clearly evident that there is a significant gap in the available empirical literature on self-identification of autism. While this reinforces the value of the proposed research it also increased the risk of researcher bias as concepts are unable to be developed from the findings of other professionals. For this reason, alongside the central importance of including the autistic voice throughout this research, the following section will explore autobiographical books by autistic authors and online autobiographical accounts from autistic bloggers to explore the concept of self-identification and autism in more detail.

2.3 Autistic Voice Literature Review

2.3.1 Rationale

As my research places significant emphasis on the voice of the autistic individual the structure of the following literature review will mirror this. As Van Goidsenhoven and Masschelein (2018) ascertain that in recent years we have experienced a “memoir boom” (p 171) this would appear a logical medium in which to explore autistic voice more widely. A selection of autobiographies and blogs have been chosen, purposively, to represent authors who discuss their own life experiences of autism. In order to reduce bias, I also sought to ensure that at least a basic diversity between genders and age were included. Autobiographies were chosen based on recommendations that they would include appropriate experiences for this topic, once identified, a process of reading and identifying headings that related to the concept of autism and identity was undertaken. In total fourteen autobiographies were used, eight of which were by male authors and six of which were by female authors, (two of these books contains stories of multiple women). Two of the fourteen books were by teenage writers, while the remaining were written by adults. Autistic blogs were identified through a google search of ‘best autism blogs’ and a review to ensure the author was autistic, as a significant number of blogs are written by parents or teachers and I did not feel they would be valid for this research. A list of top eighty autism blogs (Top 80 Autism Blogs and Websites to Follow in 2021, 2021) was used for initial research, of which forty-nine were rejected; twenty-four because they were written by parents, sixteen were written by organisations, four had a specific focus on research and five on education. Of the eighty blogs therefore thirty-one met the initial criteria of being written by an autistic individual (appendix 1). Following a period of reviewing the blogs and searching for articles relating to identity, a further seven blogs were found to have no relevant articles to be included in a review. Thirty-One blogs were concluded to contain experiences relating to the subject, fourteen of which were written by female authors, eight by male authors and nine by a mixture of genders. Information pertained from blogs were included with the fourteen books within the following review (appendix 2).

A key point to identify is that the nature of autobiographies stipulates a prominence of retrospection, this means that caution is required when trying to establish whether understanding/thought processes/emotions occurred at the time or whether the process of retrospection has allowed this to occur with the author presenting it as happening at the time. As Holliday-Willey (2015) writes "though I was not to know it then, it seems obvious to me now that it was my AS behaviours" (p52). Blogs require more immediate responses and therefore a reduced level of retrospection which it is hoped will counter-balance the limitations of autobiographies.

The autobiographies and blogs were read and the contents of such categorised into themes relating to the key concepts identified in the previous sections of the literature review. Themes will be discussed in turn focusing on the lived experiences of the authors and then related back to the academic literature in the previous sections. The following literature review will therefore include the subsequent themes and subthemes:

- Changes over time
- Identity
- Importance of meeting others
- Diagnosis

- Self-identification

2.3.2 Changes over time.

Importantly, the analysis of the literature with autobiographies and blogs indicated that self-awareness and understanding was not static but changed based on age and experiences:

> *"the older an autistic person becomes, the more unique the constellation of traits becomes. A person's experiences, upbringing, and circumstances will bear heavily on the presentation of criteria." (Vance, 2021, (blog}).*

A significant theme deriving from the literature is how self-awareness in relation to being different changes/develops with age. Several writers articulated a lack of awareness at primary school age that they were in some way different, or perceived to be:

> *"what I didn't realise at the time was that many of the other pupils were laughing at me rather than with me thinking that I was very strange" (Mitchell, 2005, p11).*

> *"at that time, although I felt different I felt normal about being different" (Hall, 2002, p14).*

Furthermore, the literature suggests that a change occurs as the child matures, especially into secondary school, and they develop a degree of self-awareness:

> *"cognitively, I know that I was aware of the unique attributes apparently shared with no one" (*Holliday-Willey*, 2015, p33).*

> *"in sixth grade I was really sad every day….I looked around middle school and I saw that being different was the worst sin of all our peers." (Kedar, 2012, [blog]).*

The retrospective nature of autobiographies appears to be beneficial in tracking this change of perception, as the authors are able to look back and compare their levels of awareness. For example, Tammet (2007) writes:

> *"I never felt any sense of wanting to share my toys or experiences with him [my brother]. Looking back, those feelings seem somewhat alien to me now" (p30).*

An increased awareness of difference around the teenage years led in many autobiographical accounts to a feeling of isolation, as Mitchell (2005) writes he was "feeling more isolated than ever" (p28). Tammet, Fleisher and Holiday-Willey attribute the feeling of isolation to an increased desire to be sociable, which they had not contemplated before:

> *"I was gradually becoming more and more aware of my loneliness and began to long for a friend" (Tammet, 2007, p94).*

> *"It was my sister who provided a vital separation from my feelings of isolation in not being able to make other friends" (Fleisher, 2003, p23).*

> *"the loneliness was beginning to hurt my heart" (*Holiday-Willey*, 2015, p58).*

> *"I think I was at my most pseudotypical during this time, because this is when I was most concerned with fitting in and being liked, and would put in a lot of effort into trying to be socially appropriate and adhering to people's expectations."* (Silvertant, 2021, {blog}).

These experiences may provide additional evidence to the questions raised as to whether age changes such as puberty may impact on an individual's relationship with their ecological systems. It will be interesting to explore this further in my research.

Another factor which was articulated in nearly all accounts analysed and had a significant impact on awareness of difference was that of bullying. Accounts articulated that, in agreement with the importance of changes with age, while physical bullying was experienced at an early age, psychological bullying was not identified until teenage years:

> *"What I was blind to was what they thought of me when they were laughing. I didn't realise that they were mocking me" (Mitchell, 2005, p19).*

> *"The many bullying experiences, discrimination, misunderstanding, and gaslighting made a place inside my head, filling any silence present before and in my decades of self-injury. My self-image was so blurred and broken."* (McElroy, 2020, {blog}).

In all cases the presence of bullying prompted an increased awareness of the individual's differences in comparison to the perceived norm:

> *"Such experiences reinforce the perception that I was an outsider and did not belong" (Tammet, 2007, p90).*

> *"I have always been an outsider but I spent most of my life until now trying to get in, even to the detriment of my wellbeing, thinking that embracing others' narrow view of the ordinary was the only option."* (Ryan, 2018, {blog}).

The experiences articulated in these reflective accounts, reinforces the impact of bullying especially with the formation of an 'othered identity'.

As is evident from the previous sections within this literature review, the general understanding of the term autism has changed and developed over time, and it is thought-provoking to see how this is reflected in the personal accounts of autistic individuals alongside what impact this has had upon diagnosis and identity. Authors such as Temple Grandin (2008) and Hendrickx (2015) write of the issues faced fifty years ago whereby professionals and lay people alike labelled children as emotionally disturbed and were consequently institutionalised. Equally Mitchell (2005) writes of missing the opportunity to gain an accurate diagnosis at primary school as there was not such a diagnosis available. Issues such as these help to understand why there may be a significant population of people that despite challenges may not have been able to gain a diagnosis in childhood, as is outlined in 2.1, Autism. Since the time of institutionalisation, the autistic authors help us to see through their experiences how life has changed in the sense of diagnostic opportunities and societal awareness/acceptance. Tammet (2007) writes:

> *"autism is a complex developmental disorder was little known among the general public at this time my behaviour was not what many assumed them to be typically autistic" (p24).*

> *"I grew up in the 1980s in a very rural setting, and our access to information about autism was extremely limited. One of my earliest memories was a television news special about autism, where they asked questions about whether or not we were really people inside, or just walking automatons."* (Des Roches Rosa, 2019, {blog}).

While these statements reinforce the issue of reduced knowledge in past decades it also raises an issue of stereotypes, and how they have an impact on people's understanding of the autism spectrum:

> *"Unfortunately, most people have the wrong picture of autism. They expect 'autistics' (I hate that word) to be trapped within themselves, unable to communicate in anyway" (Dumortier, 2004, p13).*

> *""If you're a woman on the spectrum, within moments of mentioning to an acquaintance that you're autistic or have Aspergers, you'll often be asked, "Have you heard of Temple Grandin?....This is a bit like asking a physicist if they've heard of Stephen Hawking. Probably, right?" (Kim, 2013, [blog]).*

> *"On this journey of embracing my autistic self, I encountered these stereotypes and almost emulated them. The pressure to act like a stereotype based on inadequate*

> *information and ignorance made me feel like I could never be my autistic self."* (Trick, 2019, {blog}).

Stereotypes can be a powerful influence on people's understanding of others. While the autobiographies mention their impact, little detail is given to the root cause of these, aside from ignorance, but this is probably reflective of the autobiographical purpose of recounting experiences, rather than seeking to theorise them.

The multitude of changes that occurred in our society since the initial labelling of the term autism has led to a position whereby the concept of the autistic label having its foundations within the notion of deviancy is being directly challenged. This it is argued will have a significant impact upon an individual's willingness and indeed desire to associate with such labels. An example of this change can be seen in the writings of autistic individuals whereby a strong emphasis on autism being abnormal alongside the drive to be normal is articulated:

> *"We are not allowed to simply be. Being "normal" is the goal. When we cannot "be normal" we should, at least, "act normal". If we don't or can't, we are failures, not good enough." (Sequenzia, n.d.B, [blog]).*

However, more recently there is beginning to be a greater consideration, especially via bloggers/advocates and online autistic communities, of what normal is and how and why it is defined as such:

> *"The funnier thing though, is that the feeling is mutual. Autistic people perceive non-autistic people as "lacking in social skills" even if we don't express it that way. Go to any autistic-only group on Facebook and you'll see discussion about the weird or confusing ways non-autistic people communicate" (Hanson, 2019 [blog]).*

> *"where many in our community see our alternatively wired minds as something to be proud of" (Sinclair, 2020, {blog}).*

Such a shift in perspectives can be related to the previously outlined social identity theory, with the collection of autistic people becoming the ‘in-group’ and the negativity indicated towards the ‘out-group’, those that do not have autism and therefore do not understand.

2.3.3 Identity

The term identity was not clearly classified in many autobiographies. While I have shown that they discussed changes in their awareness of themselves throughout their lives, they did not often specifically relate this to their identity. In comparison autistic blogs, in their more focused/present-day structure make far more frequent references to the concept of identity. Understanding why this is the case can only be done through hypothesis, however one may offer conjecture that this supports the argument that identity is a fluid construct, reinforcing the existentialism theory of identity as previously outlined. Therefore, accounts which occur over time, such as autobiographies, are less able to present the concept of identity succinctly whereas blogs which only articulate the person in the here and now can define their identity without any consideration to their past selves or indeed future selves. In relation to the concepts of essentialism and existentialism, as previously discussed, the deliberations around identity and self-awareness in both blogs and autobiographies offer differing evidence for both theories. In relation to essentialism a number of writers presented the feeling that autism was innately part of them and their make up:

> *“But autism is not a terminal disease. It is a trait - or a collection of traits - that a person is born with, and which help define their personality, way of thinking, and - yes - identity.”* (Nannery, 2020, {blog}).
>
> *“Being autistic, similar to being deaf or blind, is intrinsic to one’s identity and culture, and cannot and should not be separated from people.”* (Crosman, 2019, {blog}).

This was also eloquently illustrated by a young autistic blogger Cadence (The Autism Label, 2016):

In this illustration Cadence is arguing that autism is comparable to her biological components and therefore is a part of who she is regardless of external experiences/context. This is reinforced by Ido (Kedar, 2012) another young blogger who writes:

> *"I've even embraced it in some ways because I saw that hating autism made me depressed. Accepting that I could make a meaningful life myself with autism changed everything" ([blog]).*

This quote suggests a situation whereby autism is essentially part of him, and the only positive life strategy is to accept that and embrace it. As both these accounts are from young writers it would be easy to assume that the concept of essentialism can be linked to age and therefore a lack of experiences and social understanding. However, there is also evidence from older autistic writers that articulate beliefs relating to the essentialism theory. For example, Ackerman (2019, [blog]) writes: "autism is part of me just as having brown eyes or hair may be part of you". Such comparisons between autism and biological features reinforce the views of Cadence seen above and link to the essentialism theories. Mitchell in his autobiographical accounts is less succinct in his connection with essentialism as he does refer to the concept of socially developed language and its importance; however, he relates this to understanding who he is in essence: "I finally had a name, or characteristic, for who I am" (Mitchell, 2005, p62) which it therefore can be argued fits within the essentialism theory.

From the autobiographies and blogs read as part of this literature review there was a stronger collection of evidence that correlates with the existentialism theory of identity; in particular, Becker's labelling theory (2018) and Tajfel and Turner's social identity theory (1979). Within her blog Kim (2015) discusses her developing sense of self alongside her developing understanding of autism. She articulates how she uses her involvement in the 'online blogging community' to research the experiences of others and relate these back to her own experiences thereby developing her autistic identity. Therefore, when using Tajfel's social identity theory it could be argued that she completed the stage of social identification. It can also be argued however that Kim's experiences can relate to the principles of labelling theory made prominent by Becker as outlined in 2.1. Labelling theory would offer the argument that through her research Kim came upon a socially constructed label of difference/deviance and chose to incorporate this into her self-identity. Much like Kim, Holiday-Willey (2015) discusses her experiences of developing her own understanding of herself and believes that an understanding of the language developed around autism and the labels associated with these helped her understand herself, and she expressed the desire to have understood these earlier. In contrast to the positive use of labelling with regards to identity both Grandin (2008) and Jackson (2002) express a more negative view, arguing with specific reference to the concept of a label and how this should not define the person it is placed upon:

> "don't think that they have somehow changed because they have a name for their behaviours. Your kid is still your kid regardless of his or her life." (Jackson, 2002, p29).

The label itself can be perceived positively and negatively dependent on the individual person and their own experiences. This will be considered further in the following subsection.

The concept I found of interest when reading about other people's lives and thought processes was the differing focus on negative and positive attributes of autism. As has been seen in the above sections, often feelings of isolation and failure develop alongside an awareness of difference. For this reason, it is not unsurprising that often the road to diagnosis for these authors focused upon the negative effect autism had on their lives. This cannot be more clearly seen than in the case of Dumortier (2004) who from a precipice of crisis began to create a list of negatives within her life, and this list then became the basis for her diagnosis. The account articulated in this autobiography is a negative view of autism and almost presents autism as a separate negative entity to herself:

> *"Now I know that I'm suffering from autism…… I have learnt to see the difference between autism and me" (p9).*

In contrast authors such as Hall (2002) writes at an early age of his awareness of his autism, and his writing is starkly different in the sense that it is positive in nature. This is reinforced by the fact that he has a whole chapter on his strengths and then when talking about negatives he talks about what is different about him presenting it is a positive way:

> *"Honesty is one of the best parts about AS - may be the very best." (p65).*

These two vastly different accounts lead to questions regarding what impact delayed diagnosis has on not only the person's mental health in the sense of their self-esteem but also their association with the term autism:

> *It is a way of trying to fit in, by denying one's core identity. It takes a toll, in self-esteem, energy, stress, and watchfulness. One is always "on guard," (Strauss, 2014, {blog}).*

If an individual has had numerous years of feeling 'abnormal' and creates a list of negative personal attributes when they arrive at a self-identified term such as autism is this done as a positive step forward or merely a reinforcement of abnormality? For example, Kim (2015) wrote:

> *"My first instincts were to research all of the ways Asperger's made me different. I thought if I could "fix" my aspie traits I'd finally feel like a "normal" person. (after years of feeling that she was failing at being normal)" ([blog]).*

This will be an important area for investigation in the subsequent research.

2.3.4 Importance of meeting others

One factor identified as changing over time is the desire and ability to meet others on the autism spectrum, facing similar life experiences as yourself. All authors that talked of experiences of autistic social groups articulated the significant positive impact it had on their own sense of identity and self-esteem:

> *"my attendance at these classes did my self-esteem much good and I soon felt confident enough to go back to university" (Mitchell, 2005, p63).*

> *"the course helped me to accept my autism and I felt just like ET finally arrived on his own planet" (Dumortier, 2004, p50).*

> *"I ask instead that you seek out other autistic individuals, our online communities, in-person autism groups, and allies; for support, further information," (Urban, 2020, {blog}).*

In both these cases meeting other people on the autism spectrum was done in a group environment; however, others discussed the impact the Internet has had on enabling such connections:

> *"there is something exciting and reassuring for individuals on the autistic spectrum about communicating with other people over the Internet" (Tammet, 2007, p181).*

> *"I found my people. Disabled people. I found my pride. Disabled pride. Autistic pride." (Sequenzia, n.d. [blog]).*

> *"Autistic bloggers, on the other hand, seemed like regular people. Women like me, with average lives, writing about experiences that felt familiar…. There was a sense of community among the writers and their readers that was unfamiliar to me." (Kim, 2015, [blog]).*

The concept of raising one's sense of identity through social interaction with like-minded people, alongside the use of the Internet to facilitate reaching out to wider communities, has a significant correlation with the proposed research. However, it should also be noted that in all cases, within the autobiographies, connections with fellow autistic people was sought following diagnosis and not before. In the case of this research individuals are seeking an autistic community to connect with prior to any formal diagnosis which serves to reinforce the unique phenomenon this research will investigate.

2.3.5 Diagnosis

From my review of the selection of autobiographical and blog accounts, it can be argued that the life experience of each individual has differing impacts based upon whether the individual has a diagnosis of being on the autism spectrum. For those who received a diagnosis a sense of relief was articulated followed by an acceptance of difference:

> *"Actually, I was kind of relieved to find out there was something wrong with me." (Grandin, 2008, pxxii).*

> *"when I heard that I had a yes I was very pleased because I had been wondering why everyone else seemed to be acting strangely. So I felt a bit relieved." (Hall, 2002, p14).*

> *"I felt like charging out into the streets and shouting, 'hey, look at me, I have Asperger's syndrome. I am not a freak.' " (Jackson, 2002, p34).*

> *"That may seem like a trivial question, but when left unanswered for decades, it can become unsettling and haunting. Finally having an answer opened the door for me to do something I'd never been able to do: accept myself as I am." (Kim, 2015, [blog]).*

For those individuals that were not aware of their diagnosis, a feeling of failure and confusion maintains:

> *"My real difficulty came when I began to tell myself my differences were not just superficial incidentals, but cracks in my dignity." (*Holiday-Willey*, 2015, p53).*

> *"I felt misunderstood and let down. I felt I was so different and I spoke another language" (Dumortier, 2004, p7).*

For those individuals, whose raised awareness leads only to an acknowledgement of difference and not a rationale as to why, the resulting effect is often 'pretending to be normal' (Holiday-Willey, 2015). This means that the individual learns how to present themselves differently in order to not attract attention (Hendrickx, 2015) While possibly reducing the risk of isolation and bullying, this can also have severe mental health consequences:

> *"The total denial of a right to live was a consequence of learning to act normal… On the inside I knew that by definition this meant that whatever and whoever I was, I naturally was unworthy of acceptance, belonging or even life." (Williams, 1999, p70).*

> *"The pseudotypical has internalized other people's judgments so completely that they are unable or unwilling to see who they truly are, and those judgments leak out and start playing a role in interactions with others."* (Silvertant, 2021, {blog}).

Lack of self-worth and associated mental health difficulties was the articulated reality for those authors who did not have a label to justify their behaviours/feelings. It was this continued struggle that eventually led them to the door of autism:

> *"As someone who made it well into adulthood undiagnosed, I had devised many alternative explanations for why I struggled with things that seemed to come naturally to my peers. None of my explanations were positive. Often they revolved around me needing to try harder or being fundamentally incompetent in areas like social skills and communication." (Kim, 2015, [blog]).*

It is important to note that in the significant majority of autobiographical accounts reviewed, a formal diagnosis was actively sought. In most cases they were parent driven, however two were independently sought; one following the diagnosis of their daughter. This in itself would present significant evidence of the importance of diagnosis, while also possibly suggesting a lack of ‘voice’ within the autistic autobiographical community from those who directed their own diagnosis. In some blogs, the experiences of self-diagnosed individuals were expressed, but always in the sense of wanting a diagnosis but feeling like they were barred from achieving such:

> *“I am actually self-diagnosed. Because I am a Muslim woman of color, there are barriers to me obtaining a “formal” diagnosis from a health professional because a lot of the autistic experience is centered on a cis-hetero white male/cis-hetero white female”* (Noor, 2021, {blog}).

In all cases, diagnosis was important as it brought a better understanding of themselves as an individual. In contrast to all autobiographical accounts reviewed, Tammet (2007) was the only author to not describe the process of gaining a diagnosis, which seems significant in its absence. All other authors refer to the importance of diagnosis (Dumortier, 2004) to themselves and their own self-acceptance:

> *“when we didn’t know and didn’t have a diagnosis (or when told about it) it was 1 million times worse than you can ever imagine” (Jackson, 2002, p25).*

It is noteworthy that the focus is predominantly on the positive impact diagnosis has on the individual’s self-esteem:

> *“I was 20 years old and I experienced what I feel is the most defining moment in my life to date. I finally had a name, or characteristic, for who I am” (Mitchell, 2005, p62).*

> *“The beginning of that self-discovery journey and re-learning who I am through that new lens was something that for me was very powerful” (Holmans, 2018, [blog]).*

In many cases professionals, such as teachers for example, believe diagnostic labels to be predominantly for gaining access to support services (Grandin, 2008, p9). However, evidence would suggest that, while support services are important, the self-acceptance element of diagnosis is more fundamental. This it could be argued would provide evidence as to why individuals actively seek diagnosis independently at a later age.

It was interesting to read in several autobiographies a comparison between autism and homosexuality, which mirrors the comparisons made in academic literature regarding the way society responds to them alongside understanding one's own identity and developing a healthy sense of self. Jackson (2002) directly relates the process of sharing one's autism diagnosis with the process of telling others that you are homosexual. I believe the comparison relates to the hidden nature of difference, as one could not see the different thought processes. Alongside the societal labelling of normal and abnormal and therefore necessitating having to identify as different from the norm and share this with others. Tammet (2007) who shares in his autobiography of being homosexual provides an illustration of homosexuality which can be used in comparison to autism:

> *"from the age of 11 I knew that I was attracted to other boys, although it would be several years before I considered myself 'gay'…… I never felt shame or embarrassment about the feelings I had, because I did not consciously choose to have them." (p138).*

I find this articulation of self-awareness of homosexuality very similar in context to that described above in relation to developing awareness of difference. Homosexuality, much like autism, is not viewed as different until society begins to impact on us. Tammet's (2007) accounts of his homosexual identity can also be related to the drive for diagnosis when he writes:

> *"I became tired of not knowing who I was, a feeling disconnected from a part of me I'd long been aware of." (p163).*

In contrast, one blogger writes that it is the connection with identities such as homosexuality that makes the concept of diagnosis inappropriate:

> *It's just as oppressive and ignorant to ask someone to "prove" their Autism as it is to demand someone prove they're transgender or gay" (Sequencia, 2016, {blog}).*

In this way the link to diagnosis could be argued to be more associated with the acceptance of others, rather than the labelling of a medical condition. The acceptance that is sought is negatively hindered by autism (and indeed homosexuality) being a hidden difference, therefore resulting in a lack of understanding by others. Dumortier (2004) writes:

> *"I look normal, even as a child I looked normal, and therefore I was always expected to fulfil all demands." (p3).*

2.3.6 Self-identification

None of the book form autobiographies were from individuals who self-identified as autistic, and even in the cases where diagnosis was later in life, none of the individuals arrived at the question of autism before it was suggested to them. The only possible exception to this is, in the case of Holiday-Willey (2015), while she articulated an awareness of difference throughout her life it was not until she led on getting her daughter diagnosed that she began to label her own experiences as autistic. This is significant, as it leads me to question why self-identification did not occur in these individuals and equally why individuals who have self-identified have not shared their experiences through published means. One suggestion for why this is, may come from Holiday-Willey herself when she articulates her experiences of identifying her own struggles with her daughters:

> *"Why were my observations being discounted as so unimportant and unreliable?" (*Holiday-Willey*, 2015, p117).*

In this case, it is evident that self-identification is not widely accepted by society and arguably that individuals still face an element of prejudice, questioning the legitimacy of their self-understanding. It will be interesting to investigate this further with research participants of the study.

Jackson (2002) reinforces that individuals' perceptions may not be seen as valid through his need to argue that medical professionals ought to take seriously an individual's self-articulation that they may be autistic "after all, you know yourself best!" (p36). Hendrickx (2015) also writes: "it is extremely rare to find a person, who is incorrect about themselves" (p39). Some autistic authors have written about the power of the Internet in developing a self-identity. In this way Internet-based social autistic groups provide an opportunity for self-identification:

> *"It was through the internet that I discovered AS and the whole concept of neurological differences, without the internet I'd still be seeing myself as the cause of my own 'failure' (failure to be NT).. it wasn't until I met other aspies on the internet that I was able to gain a deeper understanding of what being aspie means" (Blume, 1997, [blog]).*

In contrast to the autobiographical accounts in book form, two blogs included within this review were from self-identifying autistics. This could be suggestive of the strong connection between self-identification and the internet.

> *"I have found solace and comfort within our autistic community. I found other autistic people with common experiences and understanding of what it really means to be autistic… and I found people with substantially different experiences and understandings, too."* (Des Roches Rosa, 2019, {blog}).

Furthermore, these writers, advocated for the growth of the online community and the power they should hold in developing diagnostic criterion, above that of medical professionals.

> *"We, autistic individuals, need to form our own research-based and clinical consortiums to address the underdiagnoses of natal females, transgender men, and people of color." (Urban, 2020, {blog}).*

> *"The thing is, doctors and therapists are not the true experts on autism, Autistics are." (George, n.d., {blog}).*

As well as opportunities for discovery, all autistic writers considered as part of this literature review stressed the importance of not only understanding yourself but having others that understand and accept you. A great importance was placed upon the ability to meet other like-minded people, as has been discussed above.

Literature Review Summary

Through the analysis of the literature in 2.1, 2.2 and 2.3, it is clear that the areas of autism, identity and self-identification are in themselves ambiguous terms/processes. There is an argument to suggest that all these key terms are merely social constructs and therefore it will be important to consider how they are viewed by the participants and indeed, whether they feel an autism identity is an ontological concept that should be viewed as achievable.

Both the academic literature and the review of the autistic voice illustrated a divide as to whether autism is perceived by individuals within an essentialist or existentialist perspective. This will be a key element to consider when constructing interview questions as their responses could fundamentally affect the way we view the autistic identity and the support that is consequently given.

Overall, the preceding literature review has raised many considerations that will be essential to take forward to the data gathering stage to build on our understanding of the process of self-identification of autism. At this stage, key questions that this literature review is leading me to consider and therefore construct within the data gathering stage are:

- the meaning of the word autism
- what impact has the changing society had on people?
- do people view the autistic identity in an essentialist or existentialist viewpoint?
- has there been any shift towards more positive foundations of an autistic identity?
- is there an impact on the concept of self, due to delayed diagnosis?
- is autism seen as one of multiple identities?
- does the autistic identity change over time?
- Is self-identification perceived as a valid way of identifying with autism by the individual and by others?
- What impact does diagnosis have on identity? And the lack of diagnosis and identity?
- Can an autistic identity be built in isolation from other people?

While it may not be possible to consider all these areas within this research, such considered questions provide an enlightening gateway to the construction of an appropriate methodology and methods of data gathering.

CHAPTER THREE: METHODOLOGY

The research aims and questions were presented in Chapter one. They are noted again here for ease of reference.

AIM: To explore, through first-hand experiences, the phenomenon of self-identification of autism

AIM: To develop a better understanding of the autistic identity and advocate for change that will better serve the autistic community

QUESTIONS:

1. what is an autistic identity/ies?
    a. what facilitates the process of self-discovery of autism?
    b. what is the impact of the delayed realisation of the autistic identity?
    c. what is the purpose of self-identifying as autistic?

The following chapter outlines the rationale for my adopted methodology and research design, to meet the stated aims and address the specific research questions.

In section 3.1, Philosophy, I have outlined my consideration of the journey to arrive at a sound ontological and epistemological foundation to the proposed research. Subsequently in section 3.2 consideration of the case design for the research is outlined, followed by a focus on the research design including justifications for the mixed methods approach In Section 3.3 and 3.4. Section 3.5 reviews the practical considerations of the research design including Sampling and Ethical considerations. Section 3.6 and 3.7 outlines the data analysis stages and the importance of the lessons learnt through piloting.

By the end of the chapter, secure foundations and practices are established to proceed with the data collection phases.

3.1 Philosophy

The foundation of any good research practice lies in a secure philosophical grounding. It is important to establish what the perceived optimum outcome of any research is, with regards to knowledge and truth, alongside the researcher's desired outcome of such knowledge, specifically whether it is merely to describe a phenomenon or to provide a basis for action, promoting change. Such questions, when devising my research, have led to significant analysis, not only to position my research aims within a specific philosophy, but equally to understand how my aims do not fit within other philosophies. I outline my journey in this exploration, as I believe it is important, in this case to know the journey in order to understand the destination.

3.1.1 The Journey

From the early onset, it was clear to me that I wished my research to be based around experiences of individuals both practical and emotional, rather than second hand assumptions of autism. As such a constructionist approach was deemed as a foundation to the approach. Arends (1998) asserts that constructivism promotes the importance of individual creation of meaning through experience and that meaning is affected by prior knowledge and new experiences. This was a direct result of my Masters dissertation which focused on experiences of autistic people. This methodology produced data, which was powerful, and could not have been sought using anything other than a person-centred approach. I wanted therefore, to continue with this approach "to show autism from the 'inside' " (Hacking 2009a). Giving a voice to a cohort of people who might believe it would not otherwise have a voice to share their experiences (Bogdan and Biklen, 1998). This desire led me to investigate research philosophies that facilitated a qualitative focus, deriving at "thick" (Geertz, 1973, p6) descriptive accounts of the phenomenon in question. This is rather than a quantifiable approach concerned predominantly with occurrences or statistical analysis (Smith, 2015).

Working therefore within a constructivist philosophy my initial consideration was that the two theoretical perspectives which may be appropriate were grounded theory and phenomenology. Both approaches provided elements that were appealing and appeared to fit the research proposal, however, it became apparent that both also lacked elements I desired, when taking the research forward.

Grounded theory, more specifically Strauss' grounded theory, from the onset was my preferential approach. I favoured this approach as Strauss acknowledged the necessity to undertake some literature analysis prior to research, while believing this should be at a minimum in order to proceed with research without predefined theoretical biases (Corbin and Strauss, 1990). The appeal of this approach arrived from my consideration of research focused on gender, which will be outlined within the consideration of my case design. Rejecting the need to define my research by gender encouraged me to approach the research in a way that dismissed previous categorisations and assumptions and instead opened up my research structure to allow an outcome of unpredictable data.

> *"The researcher can (and we believe should) also study an area without any preconceived theory that dictates, prior to the research, 'relevancies' in concepts and hypothesis." (Glaser and Strauss, 1967. p33).*

Grounded theory offered a number of advantages. It suited small-scale individual research and provided an adaptable approach lending itself to the development of qualitative data. It provided a structured analysis system, by reflecting on the data, which was person centred, making connections between theories developed and the reality of lived experiences (Denscombe, 2017). Grounded theory provided an opportunity to explore the phenomenon without prejudice and gather a rich basis of a variety of data, however, this unlimited data gathering approach led me to question the viability of developing my desired breadth to the research. As the methods necessary to successfully follow a grounded theory methodology would not provide an environment appropriate to explore emotional understanding of events by each participant, which I believe is vital to develop a full and valid theory illuminating the phenomenon (Denscombe, 2017). As Mjoset (2005) articulates:

> *"it [grounded theory] is thus a programme of gaining as general knowledge as necessary (given the research problem), without losing context." (p3).*

Other limitations of grounded theory are suggested to be, the complexity and unattainable principle of approaching research without prior influence, alongside uncertainty of the role of empirical data in the discovery of truth. As demonstrated, one of the appeals of grounded theory was the 'open-minded' approach, however critics have questioned the practicality of this, specifically in relation to researcher bias, as researchers are inevitably influenced by their own personal experiences and prior research (Bryant and Charmaz, 2007). Grounded theory is critiqued due to the assumption that it fits within a qualitative approach. However, some have argued that the reduction of information into themes and codes merely reduces language-based detail into statistical processes for comparison therefore losing an element of detail and depth (Annells, 1996).

As the possible limitations of grounded theory for my research project became apparent, a differing approach within the same qualitative 'family' was explored. Phenomenological research became a possible consideration, as its main purpose is outlined to be, the seeking of "reality from individuals' narratives of their experiences and feelings, and to produce in-depth descriptions of the phenomenon." (Yuksel and Yildirim, 2015, p1). It is immediately apparent that such an approach would offer a solution to the concerns raised, that grounded theory would limit the detailed exploration of personal meanings attributed to lived experiences. In addition to this, phenomenology offered an exploration of how the participants in the study make sense of their personal and social world (Smith, 2015) which correlates well with my research focus on understanding the individual and the way in which they have made decisions, and why, regarding their personal identities. Other advantages of phenomenology include the possibility to explore complex issues going beyond the superficial features of social reality (Denscombe, 2017) while offering a level of respect to the individuals involved ensuring a humanistic style of research (Wertz, 2014). The person centred, in-depth descriptions of phenomenology while offering several advantages also appeared to present several disadvantages. Fundamentally the descriptive process of gathering personal experiences may preclude the possibility of wider analysis. Furthermore, phenomenological research ascribes that social reality is not a fixed entity but rather a product of human experiences. Therefore, the experiences articulated with any one research project could not be meaningfully attributed to a wider population (Overgaard and Zahavi, 2009). Alongside the normally small numbers of participants, due to the depth of information required, there remain significant questions regarding representativeness of data, and this limits any justifiable generalisations beyond the participants (Jasper, 1994). Following considerable analysis of these two theories I was left with an approach which I felt would provide me with the opportunity to develop wider understanding/theories from my research, while preventing the exploration of sufficient detail (grounded theory) alongside an approach which would provide rich data but would limit the avenues in which this data can be taken forward to impact the lives of others (phenomenology).

3.1.2 The Destination

The conflict between what I wanted from these two theories led to a development in my research approach, as it became clear that I wanted the depth of understanding that phenomenology would offer while also gathering a breadth of knowledge to offer generalisability beyond the research that grounded theory might offer. I sought appropriate foundations to enable the ability to accurately describe a phenomenon in detail, while also provoking change/development of understanding as a result of such knowledge.

My realisation that the basis of my research was, as stated, to provoke action, meant that the interpretivist philosophy and qualitative methodological approaches would not be sufficient on their own. An approach was needed that did not focus on where the ‘knowledge’ was coming from but instead where it was going. While searching for a middle ground between grounded theory and phenomenology that would suit my needs, I came to the realisation that a mixed methods approach could be the solution. This move away from the concept of singularity unlocked a freedom to develop my research in the way it was intended, rather than adjusting it to ‘fit’ into somebody else’s ideas. While mixed method research provided a solution to the quandary of methods that the differing theories have offered, it remained important to me to ensure that my research was founded within an appropriate philosophical framework. As Hesse-Biber (2010) argue, mixed method designs are often “methods-centric” (p10). I wanted to ensure this was avoided, instead developing a mixed method practice that was securely rooted within an appropriate research philosophy and methodology. As Green (2002) eloquently articulates “methods gain meaning only from the methodologies that shape and guide their use” (p260). Often, mixed method research does not fit comfortably within the context of traditional philosophies of knowledge (Morgan, 2014). However, Dewey’s Pragmatism became apparent, which as Hall (2013) states is “an alternative epistemological paradigm” (p19). Dewey’s refocusing on the experience of inquiry and their outcomes, rather than an emphasis on abstract ontology and epistemology (Morgan, 2014) spoke to the dilemma I had experienced in positioning my research within the given philosophical frameworks. In specific contrast to the limitations, I perceived grounded theory and phenomenology to offer, Dewey’s pragmatism argued that knowledge was not something just to be gathered for the sake of it but should be done for the sake of action (Garrison, 1993).

> *"Philosophy recovers itself when it ceases to be a device for dealing with the problems of philosophers and becomes a method, cultivated by philosophers, for dealing with the problems of men." (Dewey, 2008. p46).*

For Dewey 'knowledge' was an outcome of enquiry instead of something in existence before knowing (Talisse and Aikin, 2008). Inquiry was to be conducted as a response to a 'problematic situation'. The term situation has a specific meaning in Pragmatism, which was defined as such:

> *"what is designated by the word 'situation' is not a single object or event or set of events. For we never experienced nor form judgements about objects and events in isolation, but only connection with the contextual whole. This matter is what is called a 'situation'." (Dewey, 1938. p66-67).*

For Dewey, therefore, the aim of enquiry is not the discovery of a predefined object of knowledge but the creation of a new 'situation'.

The following elements of Dewey's pragmatism, in contrast to the differing forms of pragmatism, offer specific evidence as to how it matches my research methodology: the role of emotional understanding, the impact of Darwin, and the role of language and generalisability. Each will be discussed in turn to justify why Dewey's pragmatism is an appropriate approach.

Dewey's focus on the importance of experiences was built around the concepts of belief and action. For Dewey, the two were inseparable with the origins of beliefs arising from the outcomes of actions. Experience therefore creates meaning by bringing belief and action together (Morgan, 2014). Importantly, in relation to my research, Dewey argued that experience always has an emotional element and these need to be understood as key links between beliefs and actions (Morgan, 2014). As previously stated, seeking a basis on which to not only gather experiences but also to understand emotional aspects of them is an important feature of the proposed research and therefore is one way in which Dewey's pragmatism appears to fit my research succinctly.

A further way in which Dewey's pragmatism matches my research, can be seen in the way he was profoundly influenced by Darwin's theory of evolution (Garrison, 1993). Dewey stresses that we are part of nature and nature is not a static state but something evolving. Reality in this sense then is a "dynamic and self-evolving" process (Dewey, 1976) and therefore has ontological significance. The theory of constant development and change relates to the history of autism. Since its first identification, our understanding of autism has constantly been evolving, and therefore so have our actions, our language, and social constructions. Any research within this field therefore must be part of this constant process of evolution, rather than a final discovery of truth. It will provide knowledge or as Dewey terms it "warranted assertability" (Garrison, 1993, p7) which enables us to act appropriately. The warranted assertability for Dewey (in contrast to James and Peirce) did not place value on belief in its different forms. As Dewey put it:

> *" [Warranted assertion] is preferred to the terms belief and knowledge [because] it is free from the ambiguity of these later terms, and it involved reference to inquiry as that which warrants assertion" (Boydston, 1986, p16).*

Warranted assertability therefore derives from lived experiences within a dynamic world, which strongly correlates with the concept of researching the lived experiences of autistic individuals, which are likely to be different dependent on context.

As has been identified in the literature review, the role of language in developing autistic identities is clear. Hacking himself, who has been fundamental in understanding the role of language, is associated with the *New Pragmatism* which has evolved from the classic pragmatism of authors such as Dewey. For Dewey, language is a prerequisite to meaning (Garrison, 1993), he explains:

> *"Language is specifically a mode of interaction of at least two beings, a speaker and a hearer, it presupposes an organised group to which these creatures belong, and from whom they have acquired their habits of speech. It is therefore a relationship." (Dewey, 1981. p145).*

Dewey reinforced the idea that language, and therefore meaning, was socially constructed and consequently language in isolation does not provide meaning it has to be combined with the way in which individuals interact with their environment (Prawat, 1995). This is significant for my research and has impacted on the sampling structure that was developed.

The final element of Dewey's pragmatism to be viewed as a reinforcement of an appropriate philosophy for my research, is the concept of generalisability. Through my consideration of grounded theory and phenomenology this became an important factor in my proposed research. For Dewey, there are not general laws which are isolated from human experience (Cochran, 2002) and knowledge is time restricted, therefore generalisability over time would not be appropriate. Where generalisability is an option however, is in the use of methods which serve to triangulate the data sourced and therefore provide evidence that the 'warranted assumptions' are relatable to a wider group of people at that time. Such triangulation can be sought through mixing methods and pragmatism, and as such, it can be argued it leads the way in promoting mixed methods as a research alternative (Denscombe, 2017).

The journey to arrive at Dewey's pragmatism as an appropriate methodology upon which to base my research was a less than straightforward one. However, the path has ensured I have an accurate foundation that my research design has been built upon, namely Pragmatism and its close relationship with mixed method approaches.

3.2 Case Design

The case study approach is a common research method used in multiple social science fields whereby the purpose of the research is to focus on a specific phenomenon (Yin, 2014). The approach suits small-scale projects and allows the use of a variety of methods depending on the appropriate needs of the research to be undertaken (Denscombe, 2017). The case study approach, therefore, is suitable to the research to be undertaken. For Dewey's pragmatism inquiry is:

> *"an investigation into some part of reality with the purpose of creating knowledge for a controlled change of this part of the reality" (Goldkuhl, 2012, p139).*

In order to follow this notion therefore, it is important to establish the specifics of a 'case' in which knowledge is to be created.

Much like my considerations of the appropriate philosophy upon which to undertake this research, the construction of an accurate case definition has also been a journey. When initially proposing the research plan, my intention was to specify the case design of two features: self-identification of autism and women. The female element of the case design resulted as a continuation of interest from my Masters thesis, alongside my personal connections with Autistic Facebook groups, whereby I was able to identify that there were a high percentage of women in social groups that had no formal diagnosis, but still felt they were autistic. This led me to question whether there was a hidden population of women with autism that were not being diagnosed and that was why the diagnostic ratio remained more prominently male. When I began looking at the philosophical basis of this research, one of the biggest issues, I struggled to unpick, was the categorisation of gender. In this sense I mean; does gender really exist? Am I confident enough to declare it as a 'truth' and therefore a foundation by which to build my case design upon?

We live in a society where gender has always been very prominent in the categorisation of people into two specific groups: male or female. These groups have always signified what people should wear, what toys they should play with, what jobs they should get, whether they should be allowed to vote etc. Society today is developing a less binary view of gender with a current estimate of over fifty different gender choices (Gender Spectrum, 2019). One of which is the choice of complete disassociation with the concept of gender. This naturally causes a great deal of contemplation, when producing a project with gender so significantly placed. I was faced with three specific approaches which would have a significant impact on my research.

1) One could argue that gender has been a binary system within our society for a significant period of time therefore with the study based on people's past experiences it would be appropriate to address it with such a gender divide. This approach would allow an understanding of female stereotypes and the implication these have on societal expectations and consequential presentation of autism symptomatology.

2) One could argue that by using a binary system of gender within the research would serve only to reinforce a categorisation imposed on society many years ago and may not be an

accurate reflection of the way in which people really are, causing results that lack external validity.

3) One could challenge the assumption that self-identification only occurs in women. There is a growing literature on the difference of women with autism however by focusing the research purely on them it does not allow for any evidence that may suggest these features are also present in people with different gender orientations with autism. This is likely to be used as evidence to actively reinforce that, autistic women are different to other genders without any valid comparison data to back this up, which would be problematic.

Each of these three considerations could alter the structure of the case within this research and in doing so affect the validity of the data produced. By following this journey of consideration and research into gender, it raised the question as to whether gender should even be an element of case as pragmatists are interested “not only for what ‘is’, but also for what ‘might be’; an orientation towards a prospective, not yet realized world” (Goldkuhl, 2012, p140). Taking this into consideration, alongside Ragin and Becker’s (2009) articulated fundamental differences in concepts between a ‘case’ and a ‘variable’ I have come to believe that gender should be viewed as a variable which can be considered through the data analysis stage, and not a fundamental of the case. In arriving at the conclusion to remove gender from the construction of the case to be studied, the case design becomes more succinct in the initial stages with possibilities of variables becoming evident through the data analysis stages. According to Denscombe (2017) this is a benefit of the case study approach as it allows a more ‘holistic view’ while providing the ability to uncover how parts within that whole impact on one another. The case study approach is further beneficial within this research project as it allows, and some might say encourages (Denscombe, 2017), the use of mixed methods in obtaining data.

In managing a small-scale study, it is essential to incorporate a number of variables into the case study design in order to produce a dataset that is suitable for analysis. Therefore, it is important to acknowledge that further variables within this research will be computer users, people aged eighteen and above and able to communicate effectively in English. Justifications for each of these variables are subsequently outlined.

3.2.1 Why Online?

For this research, I have decided to solely use online mediums. The justification for focusing my research online centres around meeting the needs of the participants, specifically in this case those on the autism spectrum. Communication is a central area of difficulty for anyone on the autism spectrum and it is well documented that some autistic people find participating in 'real life' discussions too difficult (Murray and Pukki, 2015). As the Social Research Council states, researchers have an obligation to find "the most appropriate medium of communication to enable participation." (SRA, 2003, online).

In contrast to 'face-to-face' communication, computers offer an accessible resource to facilitate discussions for a considerable number of people on the autism spectrum (Murray, 2002) and can reduce anxieties by talking with a 'faceless person' (Bolte et al, 2010). There are a number of reasons why this may be so, firstly it has been argued that computers do not offer the same social demands experienced in face-to-face discussions and also minimise distracting stimuli which may affect concentration and sequential thinking (Murray and Pukki, 2015). Studies have also shown that computers support a relative weakness of episodic memory that autistic people may experience (Bowler et al, 2000; Russell, 1996; Milward et al, 2000). In this sense it is argued that as social interaction can be seen in a visual form, the autistic person can reread what has been said, where necessary, and therefore does not have to rely on remembering the context of the conversation. Further benefits of computers with autistic people are outlined in Murray's chapter within Powell and Jordan (2011):

> *"Why computers suit autistic individuals.*
>
> - *contained, very clear-cut boundary conditions.*
> - *Naturally monotropic, thus context free.*
> - *Restricted stimuli in all sensory modalities*
> - *rule governed and unpredictable thus controllable*
> - *safe error making*
> - *highly perfectible medium*
> - *possibilities of non-verbal or verbal expression*
> - *interacts cotropically with the individual"*
>
> (p 89)

It is evident that a computer can minimise the challenges of communication for some people on the autism spectrum which in turn will increase the validity of the data gathered through the research project. This will; however, not be true for all autistic people and face to face interviews, via computer videoing software, will be offered as an alternative should participants wish to approach communication in that way. It is further acknowledged, that it is a limitation of the following research that the use of online mediums may exclude such participants that do not feel computers suit their communication needs.

A secondary area of validity, during the semi-structured interviews, will be gained through the opportunity to express emotions via pictorial form which may otherwise have been unexpressed during a face-to-face discussion. Researchers and autobiographical accounts have shown that autistic individuals do not lack the experience of emotions but often find it difficult to articulate them, as Mahari (2005) wrote “difficulty expressing emotions doesn’t mean we don’t feel” (online). An interview which relied on the participants to verbally express emotional understanding of experiences could lack validity, as one could not confirm whether the emotion had been expressed accurately or merely missed out due to lack of vocabulary. Although the computer system does not totally alleviate this challenge, it does allow for visual representation of emotions, such as emojis, which facilitates the expression of emotions more easily. The semi-structured nature of the interviews will also allow clarification of the choice of emoji should this be necessary.

A further element of benefit that computers will offer this research is through the engagement with the online ‘autistic culture’, whereby some autistic people now participate in internet-based communities in order to communicate with fellow autistic people (Murray and Pukki, 2015). As previously stated, as an autistic person myself, I am in a unique position to have membership of such communities and therefore the computer will facilitate my sampling processes and prevent the research being location dependent. Therefore, offering a further dimension and level of validity to the research findings.

It is acknowledged however, not all autistic people are likely to be computer users or be part of the online communities that will facilitate my recruitment. Therefore, there are sampling implications that are important to consider as they could impact upon the validity of the data produced. It is acknowledged that my research is not intended to reach every autistic person, as clearly this would not be feasible. The use of computers therefore is an inclusion criterion that will reduce the wider autistic population down to a smaller sample size. Discussions following data analysis will acknowledge the limitations that this may produce.

Further considerations with regards to sampling when conducting online research are that the researcher knows little of the wider population (Dillman, 2000) and equally cannot guarantee that the profiles provided are accurate. Furthermore, the success of recruiting through the medium of Facebook groups is restricted by the number of active members at that time. Generating a sample frame therefore is challenging and predicting possible participation across the Facebook groups is largely hypothetical. While statistical figures have been estimated, to allow for consideration of sample sizes (appendix 3), the demographic/characteristic information of potential participants remained uncertain until requests to be involved commenced. For the non-probabilistic sampling element of the research such issues were less of a concern, however for the self-selecting section such sampling issues could impact on my ability to make generalisations (Wright, 2006). While this remains a concern, it is not necessarily a problem that is unique to research online, as I would be likely to face such challenges should I undertake research through other mediums. Therefore, while the uncertainty does not indicate a rationale for avoiding online research, it is important to be mindful of during each sampling stage. Should limitations to the variety of the sample occur this will be considered further during the analysis of data produced.

3.2.2 Eighteen Plus

The initial decision to stipulate the requirement that participants were over eighteen appeared an easy one, as I was seeking the experiences of self-identification and I had assumed that under the age of eighteen there was a much higher probability that diagnosis would be identified and led by adults. I am however now aware that this assumption, or indeed bias, will lead to a level of limitation within the study. This became evident during the initial sampling process whereby a sixteen-year-old, that self-identified as autistic, approached me and asked to be a participant within the study and met all the criteria apart from age. As a changing society, it is thought provoking how the process of self-discovery in the teenage years is allowing for greater exploration of differences (Centre for Parent and Teen Communication, 2018). However, I believe such consideration would be outside the remits of this study, and alongside ethical considerations of including participants under the age of eighteen, the decision to make a minimum age of eighteen as a specified inclusion criterion appears valid. It is hoped however that the findings of the study, once concluded, may have a positive impact on younger people going through the self-identification journey.

3.2.3 Ability to communicate effectively in English.

My initial decision was to specify that a variable within the case sample would be UK residents only. I arrived at this conclusion due to my concern that cultural differences would have a significant impact on individual experiences and therefore would need accounting for, to increase the reliability of the dataset (Brothers, 2001). However, following the piloting process of the interview which involved a Norwegian lady, it became evident that the impact of cultural differences on her experiences in relation to the study were minimal. And furthermore, through discussion, such cultural differences would be no more varied than the numerous different cultures that may be present within the multicultural society of the United Kingdom. In this sense, it is meant that, there are in most UK cities people living that have heritage from different countries and/or have different religious beliefs (Eagan, 2015).

The decision was therefore made to remove the location of the participant from the defines of the case, while maintaining the requirement to be able to communicate effectively in English, in order to ensure an effective interview and prevent possible misunderstandings which would have a negative implication on the validity of the findings.

3.2.4 Self-Identification

It was initially proposed that the research would only include individuals that self-identified as autistic as the central premise was to gain their experiences. However; the sequential nature of the research provided the opportunity for this to develop and adapt in order to increase the validity of the data gathered. During phase one of the research, the case specified that the participants were those that self-identified as autistic. This was decided upon as the qualitative nature of the phase sought to explore the experiences of self-identification in detail and therefore it would not have been appropriate to include those that did not self-identify. Following the analysis of the data in phase one and the consequential construction of the phase two survey, I decided to include variables within the case that encompassed those that had self-identified and then gone on to get a diagnosis, as well as those that had received a diagnosis without self-identifying. This decision was made as I felt the ability to compare experiences across such variables would enable more accurate understanding of the phenomenon. As such the inclusion of diagnosed individuals provided a control group in which to 'compare to' (Yates, 2004) and therefore enable the exploration and deciphering of which experiences were unique to the self-identifying group.

In concluding the considerations for the development of the case for this research, an appropriately defined ‘case’ is therefore proposed: individuals who are above the age of eighteen, can communicate effectively in English, and have access to computer communication software. For phase one individuals who self-identify as autistic and phase two anyone that had an autistic identity, regardless of diagnosis status. By rigorously ensuring the validity of the foundations upon which to build case study methodology, I will now begin to explore the methods to be used.

3.3 Research Design - Mixed Methods

As previously outlined, it is my intention to move away from a singular methods approach into the third methodological movement (Tashakkori & Teddlie, 2003) in order to incorporate a mixed research design (Johnson & Onwuegbuzie, 2004). Although a quantitative primacy approach is suggested to be the favoured design model (Hesse-Bieber, 2010) to ensure the prominence of the participant’s voice it is the qualitative methodology that will remain most prominent within this research using quantitative data to assist the qualitative data in developing. Therefore, semi-structured interviews were undertaken first, analysed, and then used to formulate a survey which was then analysed and directly compared with the findings of the interviews. The primary objective of using a mixed methodology approach is to moderate the weaknesses identified by using singular methods which would have fit appropriately with interpretivist philosophies, for example the breadth but lack of detail of focus groups and the depth but the lack of generalisability of semi-structured interviews. By reducing weaknesses and capitalising on strengths of differing models I believe I can produce much stronger and more credible findings, as it will enable a more holistic understanding of the research phenomena.

As has been outlined above, Dewey's pragmatism offers an epistemological justification for using a mixed method approach. However, further justification will be provided as to why mixed methods is appropriate specifically to this research design.

There are a number of justifications for using mixed research designs, in the case of the following research a mixed research design can be justified through the process of triangulation, complementarity and development (Greene et al, 1989). Complementarity is a rationale for using a mixed research design in order to gain a fuller understanding of the phenomenon alongside clarifying research results. As has been previously identified, the lack of generalisability and subsequent action of merely detailing personal experiences of a phenomenon, is seen as a significant hindrance to creating effective outcomes of the research proposal. Therefore, by using qualitative methods to illustrate detail to inform the construction of a quantitative method to describe general trends (Greene et al, 1989) I will be able to develop a more complex picture of the phenomenon and produce more valid and reliable research data.

Triangulation is another important argument for why mixed method research is appropriate. In this sense triangulation is the process of developing more reliable and valid conclusions by grounding them in multiple methods (Denzin, 1978; Lincoln and Guba, 1985). Plano Clark and Ivankova (2016) articulate that:

> *"in mixed methods research, triangulation is the argument for using mixed methods to obtain more valid conclusions about phenomena by directly comparing the results obtained from quantitative methods to those obtained from qualitative methods for convergence and diversions." (p84).*

In this sense, the results from the quantitative method will be used to test whether the detailed explanations offered through the qualitative method is duplicated with the experiences of a wider sample size of people. Therefore, identifying elements which are participant specific as opposed to those that are generalisable to a wider population. As Denzin distinguishes, this approach would be classified as *between-methods* triangulation. Denzin recommended the use of this on the basis that:

> *"the bias inherent in any particular data source, investigators and particularly method will be cancelled out when used in conjunction with other investigators, and methods." (Denzin, 1978, p14).*

The final justification of mixed methods is argued to be that of development. Development is the way in which mixed methods are used to develop more valuable and sophisticated conclusions by using the results of one method to shape the secondary method (Greene et al., 1989). As has been expressed, it is the intention of this research to use a qualitative method to gain detailed accounts of the phenomenon and then use these accounts in order to develop a quantitative method to test the generalisability of the qualitative findings. Such an approach can also be termed sequential triangulation (Morse, 1991), which may be more appropriate as this process is directly correlated to the process of triangulation.

The outlined arguments for using a mixed method approach, on the basis of complementarity, triangulation and development provide a secure foundation upon which to build my sequential qualitative-quantitative design (Plano Clark and Ivankova, 2016) which accurately fits the priorities of exploring a "phenomenon in-depth with a few individuals but also wanting to expand these findings to a larger population" (p124).

While the benefits of mixed methods research are clear, it is also acknowledged that other professionals have identified concerns in undertaking this approach. However, I believe that a number of these apprehensions have been resolved by my careful outlining of the rationale for using this method. An example is Bryman (2006) who argues that many researchers do not explicitly state their rationale for using mixed methods; I have counteracted this concern by clearly doing so. Sale, Lohfeld and Brazil (2002) also question the appropriateness of triangulation as an argument for mixed methods, arguing that it is not possible for quantitative and qualitative methods to study the same phenomena. While acknowledging their position I would have to disagree with the conclusions, while the outcome of any study would be different based on the approach, the focus of the phenomenon could still be the same. This is reinforced by Cook (1985) who coined the term *critical multiplism* to specifically refer to the concept that it is often useful to combine different methods within anyone research question. Equally, even specifically strong supporters of pure qualitativism such as Lincoln and Guba, have on occasion made statements that would suggest the appropriateness of mixed methods when studying one phenomenon:

> "Indeed, there are many opportunities for the naturalistic investigator to utilise quantitative data-probably more than appreciated" (Lincoln and Guba, 1985, p198-199).

The concern raised by Hesse-Bieber (2010) regarding the training and time implications of mixed methods, is important to take account of. They articulate that the researcher using mixed methods must be familiar with both approaches and undertake training as necessary. Data analysis of more than one approach is logically also going to be more time-consuming than a singular methods approach. While they do not suggest this argument should exclude the use of mixed methods research, it is a concern that can arise without appropriate prior planning. I acknowledge the rationale behind this argument and as a result I have given a great deal of thought and time in the preparatory stages of research to ensure that this decision is correct, and that suitable training has been undertaken to safeguard that my knowledge is of an appropriate standard. Timetabling, it will be shown, will consider the time implications for analysis of multiple strains of data and therefore plan for these effectively.

3.3.1 Participatory Research

The principles of mixed methods research facilitate the incorporation of participatory research (PR) methods:

> *"Participatory research attempts to negotiate a balance between developing valid generalisable knowledge and benefiting the community that is being researched" (*Macaulay et al, 1999, p1).

PR is described by Meyer (2000) as a process which involves people, with the fundamental aim of creating change. Taking the adapted modes of participation as outlined by Probst and Hagmann (2003) it is suggested the design of the following research matches the categorisation of "consultative". Due to the nature of a PhD thesis, as the researcher, I have to maintain power of many decision-making processes, however I mediate this with the proposed work to include participants throughout the process. Schrijvers (1991) advises that research will be unsuccessful if the power differentials are too large, therefore in line with the principles of PR the methodology proposed ensures that participants are aware of my own autism diagnosis, to bridge the possible detachment between us that may impact on the data gathered. Hajdukowski-Ahmed (1998) provides evidence for the importance of such a decision when they argue that gathering knowledge necessitates the researcher to know the community it is studying from within and to use the same language as the participants to ensure accurate communication and understanding.

Power will be additionally defused by piloting of the research questions to adapt and change the language and structure to suit the population as well as the planned construction of phase two survey questions based on the findings from phase one participants. Specifically, during the construction of the survey, the following questions were asked based on the findings in phase one. Without this process of ensuring the power is disseminated to the participants, such questions would not have been asked and therefore valuable data would have been missed:

> Q16 - Initial research suggests that an autistic identity can only be built through comparison to others. From your own experiences, do you agree with this?
>
> Q22 - Initial research has suggested individuals find themselves searching (in many different ways) for a group of people that they feel they can relate to, Likeminded people. Do you think you have experienced this?
>
> Q40 - Initial research suggests that an autism identity needs to feel like a 'perfect fit' in order to accept it. Do your experiences match this?

> Q41 - The following quote came from initial research: "I feel like I've always been searching for an answer of what makes me different from other people" From your experiences, how do you respond to this?
>
> Q45 - The following are all quotes that came from initial research discussing the impact of self-identifying. Which one do you feel most accurately reflects your experiences?
>
> Q50 - The following are all opinions of others about the role of diagnosis. Which ones do you feel reflects your experiences? (Tick all that Apply)
>
> Q51 - Below is a list of labels which in initial research, people said they had experience of being place upon them by others. Which labels have you had placed upon you, by others, in your past? (Tick all that Apply)

In contrast to other methodologies of rigid design, PR is distinguished by such flexibility and reflexivity (Pafkin, 1994; Chambers, 1992), and by focusing on the process of chronological consideration and action (Cornwell & Jewkes, 1995). Therefore, the methods outlined of including participants in the formation of questions, mirror the principles of PR.

A further fundamental element of PR is that of critical reflection, significantly that which supersedes researcher bias. Chambers (1992) refers to the importance of gathering participant experiences while also allowing for the further exploration of the knowledge gathered with the individual. In order to ensure this principle is incorporated into this research, the opportunity to ‘participant check’ my evaluations of phase one interviews was offered to all participants (of their own interview) in order to ensure meaningful validation (Meyer, 2000). While it is acknowledged that such participant checks are not possible during phase two, the opportunity to provide additional information to each answer ensured that participants could challenge the options provided and in turn have the power to alter the data gathered.

It is anticipated that throughout this research the centrality of the voice of the participant is evident in all processes that are undertaken. Reflecting the views of Van der Riet when she writes of PR:

> "By grasping the participants' vision of the world, their meanings, understandings, interests, and motivations; and facilitating distanciation, the mechanisms of PR function to uncover the significance of human action, enabling us to interpret it, and render it intelligible" (Van der Riet, 2008, p17).

3.4 Data Collecting Methods

The research methods chosen to fit within my research design will be subsequently outlined. Theoretical justifications for each stage of the research will be considered separately including the practical implications of sampling and recruitment. Following this, ethical factors will be considered in addition to the process of piloting and the findings there of.

3.4.1 Phase One

Following a judgment that focus groups would not provide sufficient detail to fulfil the research design, a decision to undertake interviews was made instead. Of the three fundamental types: structured, semi-structured and unstructured, (Gill et al, 2008) I utilized semi-structured interviews, for the reasons I will outline subsequently. Semi-structured interviews provide significant benefits for the exploration of personal experiences and in the "seeing beyond mere appearances" (Armstrong, 1993, p7). This is because it allows the definition of the key exploration areas prior to commencement, but also allows me as the interviewer, or indeed the interviewee, an element of flexibility to pursue an idea or response in more detail (Britten, 1999). Therefore, importantly, reinforcing the balance of power dynamics important in Participatory research. Interviews, it is argued, are the most appropriate research design, where there is little already known about the phenomena to be studied, as well as the exploration of sensitive topics where participants are unlikely to want to explore these within a group environment (Gill et al., 2008). This is particularly relevant to this research and to the exploration of autism. The phenomenon of self-identification of autism, as has been shown, is without doubt, an area where very little is already known. But significantly, the discussion of this phenomenon with the participants is likely to explore sensitive and emotionally driven experiences that a group situation (such as the pre-considered focus groups) may prevent the participants from disclosing fully (Gibbs, 1996). The semi-structured interview approach will also support the possible communication challenges autistic individuals may experience. This is due to the argument that the concept of an interview is well understood, as Atkinson and Silverman (1997) state we currently live in an *interview society*, therefore, participants will commence the research with an understanding of what is expected of them, reducing anxiety which may impact on the individual's willingness or ability to communicate. Furthermore, the semi-structured approach will allow me, as the researcher, to support the engagement of individuals by rephrasing questions or providing more detail, or simply encouraging them to reflect on their experiences in greater depth. This is vital within the field of autism, as the National Autistic Society state (Autism.org.uk, 2017) autistic people often struggle with open-ended questions, and therefore an ability to support this will make effective participation more likely. This level of researcher flexibility will ensure greater insight into the experiences expressed by the participants (King and Horrocks, 2010) and therefore provide richer data to analyse, to answer the research questions set. In keeping with Dewey's pragmatism, semi-structured interviews have been chosen because they are the most appropriate way in which to inquire into experience to build knowledge. Rorty (1979) a neo-pragmatist, argues that conversation is the fundamental way of knowing. Brinkman and Kvale (2015) refer to the metaphor of an interviewer being a traveller in which the process of asking questions and analysing of data is intertwined as a way of constructing new knowledge, not uncovering knowledge that already existed. As Dewey states:

> *"the object of knowledge is eventual; that is: it is the outcome of directed experimental operations, instead of something in existence before the act of knowing" (Dewey cited in Talisse & Aikin, 2008, p23).*

Interview research is defined by Brinkman and Kvale (2015) as "a craft that, if well carried out, can become an art." (p19). While this sounds poetic, the reasoning for defining interview researchers as such, is that unlike other methodologies, this approach lacks standardised rules or mutual methodological principles. This is an important consideration when undertaking interview research, and as such, I have given much time to learning from other competent interviewing researchers, to gain knowledge through exemplary cases, to up skill myself as the interviewer and therefore ensure my interview management results in valid data. An important consideration is my role as an autistic researcher within the field of autism. Brinkman and Kvale (2015) conclude that qualitative interviewing is not a mechanical process but, the success of the process lies within the interview skills and their personal judgements in questioning participants. It can therefore be argued that as an autistic interviewer my ability to speak “aspergese” (Attwood, 2015) gave me superior personal judgements to formulate questions in such a way that uncovered the most detailed data.

3.4.1.1 Sampling

As with any research project, it is not possible to consider researching the entire population of individuals who self-identify as autistic, largely because the number of such individuals is unknown and without diagnostic processes, there are no external records that may be called upon for reference. For these reasons therefore, sampling processes must be undertaken, in such a way as to obtain data from a small group of the total population while maintaining a level of representativeness of the overall cohort. (Cohen, Manion and Morrison, 2005;2018).

It is recognised that there are two main methods of sampling: probability and non-probability sampling (Cohen and Holliday, 1996; Schofield, 1996). The sampling method for the qualitative interviews was non-probabilistic. The reason for this is that as a researcher, I am targeting a particular group, however, there are certain elements such as the necessity that they use online social media, that means a probabilistic sampling is more problematic. There are many different types of non-probabilistic sampling, and the following was used in this research. Purposive sampling is whereby, as the researcher, I handpicked the cases to include in my sample, based on my own judgement, thereby building a sample that satisfies my research needs. Clearly an element of researcher bias is appropriate to consider here, however, it is important to note that candidates were not chosen based on their views or possible research data they may elicit, but merely on their positive attributes in relation to the research and their connection with myself to increase their availability for participation in the interviews. Furthermore, the process of triangulation will serve to reduce implications of bias (Shenton, 2004). As Smith (2015) articulates, it is rarely practical to gather and analyse in-depth qualitative data from large samples; therefore, sample sizes with qualitative research tend to be relatively small. Following this classification, the expectation in this research was for a sample size of between six and ten participants, with a final sample size of ten participants an element of stratification (Thomas, 2018) was possible, dividing those participants into different variables to add data analysis.

It is acknowledged that by undertaking such exploratory sampling (Denscombe, 2017) processes, the generalisability of the findings will be significantly reduced, as the sample may not be reflective of the wider population. However, as already identified, the qualitative methodology within interviewing would not produce generalisable data anyway and strategies through the mixed methods approach and subsequent sampling were put in place to address this further.

3.4.1.2 Pilot Review

Piloting has a fundamental role in increasing the reliability, validity, and practicality of research (Aldridge & Levine, 2001). As previously discussed, the construction of the interview structure and questions can be difficult, as one must ensure that the wording is clear, succinct and leads the participant to consider experiences that the researcher wishes to concentrate on. To ensure that this is achieved, I undertook a pilot interview with an autistic individual to gauge whether they were able to understand and answer the questions provided to them as well as ensuring structures were in place to maintain the ‘flow’ of the discussion. By ensuring that the pilot was by an autistic individual, I evidently incorporated a principal element of participatory action research, collaboration within the planning process (Benjamin-Thomas et al, 2018).

Recruitment for such a pilot was through a personal connection of an autistic individual who was willing to aid in my research. Following the pilot interview the subsequent areas were considered as key to the future development of the study.

Skype was used as a medium for our conversation with the prompts given that // should be placed at the end of any given answer to indicate that they had said all they wished to, and … would be sent, should the interviewee wish to add more to their answer despite the // being placed. This process proved a successful way in which to ensure the flow of the interview. While the written nature of the interview meant that there were often extended periods of time when I was waiting for an answer to be sent, I felt this was beneficial as it allowed the participant to take their time in constructing an answer and rewording as necessary to ensure they felt they have made their point accurately (Trull, 1964) But equally it meant that as the interviewer, I could use this time to continuously review what had been written and ensure that future questions reflected what was said, and it provided the opportunity for further clarification/development as needed. This is reinforced by James and Busher's work (2009) where they outlined that time given to consider a reflective response can provide a deeper understanding of the participants' experiences.

While according to the Media Richness Theory, text-based communication is categorised as 'lean' rather than 'rich' (Salmon, 2010), I found myself in agreement with O'Sullivan, Hunt and Lippert (2004) and Erickson & Herring (2005) that the interviewee demonstrated other ways in which to exhibit cues that may have been more apparent in a face-to-face interview. For example, extended spelling, capital letters and emojis were used to provide emphasis and emotional attachment. It is arguable that as an autistic researcher and with autistic participants this rich information may have indeed been ‘lost in translation’ (Hinchcliffe and Gavin, 2009) had I undertaken face-to-face interviews and therefore the use of the text based online medium offered a ‘richer’ medium than the Media Richness Theory suggests.

It was planned that the semi-structured interview would provide a clear baseline for ensuring key questions were discussed while allowing the opportunity for the interviewee to expand on this, as necessary. One of the key elements that made this successful, I feel, was the decision to give the questions to the participant in advance, to prepare (appendix 4). It was evident from the answers provided that this processing time had allowed the participant to think deeply about areas I was interested in, that she had not previously thought about. This in turn ensured that the data I received was more detailed.

> *“the questions were great. it made me be aware of a few things.” (pilot transcript).*

While I understand the arguments put forward by some professionals that pre-warning of questions may reduce the ‘gut reaction’ answers (Stanlick, 2011) these type of answers were not the intention of the study and therefore the processing time it allowed gave the participant thinking time and it would appear, produced a more rounded answer. Furthermore, by enabling the participants to feel prepared for the interview, it empowered them, reducing the power imbalance often evident within interviews. This conscious attempt to address the power dynamics with the research matches the tenets of participatory research (Cargo & Mercer, 2008; Frisby, Reid, Millar, & Hoeber, 2005; Kidd & Kral, 2005).

The third fundamental area that came into consideration following the piloting process was whether my intended data analysis method was sufficient for the nature of the study and the required outcomes. Prior to the piloting process it had been my intention to undertake a thematic analysis (TA) (Braun and Clarke, 2006) largely due to the fact that this had been the analysis process I had undertaken at Masters level, while still relatively new to the data analysis processes, which Braun and Clarke (2006) argue is one of the main reasons researchers consider TA. However, once the pilot transcript was compiled and I attempted to trial the analysis process (alongside my increased research skills and knowledge) it became clear that thematic analysis was not the only approach and interpretive phenomenological analysis (IPA) should also be considered. Through considerable reflection of the literature surrounding TA and IPA I still found it quite challenging to demystify how the two approaches differed from each other. In many ways the approaches were quite similar, in the sense that they both offered analysis based on coding and themes however there had to be fundamental differences between them for them to be separate entities. This difference, it would seem, came down to the fundamentals of the participants experiences. It was clear from reviewing the pilot transcript that I needed to consider each experience individually and question not only what the participant was telling me but also how they chose to tell it and equally what may be implied but not directly said. Such close reading of the data (Turner, 2017) contrasts with the process of analysis across the larger dataset, which is intended in TA (Braun and Clarke, 2006). The process of piloting and consequential data analysis research led me to the conclusion therefore that the most appropriate process by which to place the experiences of the individual and their understanding of such in detail (McLeod, 2001), would be through interpretative phenomenological analysis.

3.4.2 Phase Two

As previously stated, the quantitative method, in this case a questionnaire, formed the secondary element of the proposed research. The purpose of the questionnaire was to complement and triangulate the findings of the interviews. The questionnaire followed the interviews in sequence, so the findings of the interviews were analysed and formulated, to structure appropriate questionnaire questions. Such an approach is unique to this research, however I maintain that it has provided me with stronger data, the consideration of such will be explored further in chapter seven. The aim of the questionnaire was to take the situation dependent information gathered from the interviews and test its generalisability across a larger population. In order to do this, my questioning strategy (Peterson, 2000) included a structured questioning approach whereby all participants were asked exactly the same questions, in the same way, and in the same order, alongside a full disclosure approach, whereby all participants were fully informed of the research process and intentions. The purpose of using a highly structured, close ended questionnaire, is to ensure that the data produced through this method, was complementary to the interviews and did not merely provide additional data. Criticisms of multimethod approaches often state that quantitative and qualitative methodologies produce differing datasets which are not complimentary to each other. However, this can be directly challenged, by ensuring the questionnaire develops as a result of the interviews and provides questions which seek to reinforce the data previously held or identify disparities in data or unique individual cases

(Duffy, 1987). This approach can also be seen to reinforce the principles of participatory research as it demonstrates the collaboration incorporated between myself as the researcher and the community of participants (Benjamin-Thomas et al., 2018). The questionnaire was a cross-sectional study as it involved examining a population at one specific point in time who are similar in one characteristic, namely the identification of autism, but different in others (Miller et al, 2010). It was proposed that the differing characteristics formed cohorts in which to compare data within the data analysis stage. Clearly the cross-sectional element of this study will be descriptive in nature and will not seek to offer any differing variables. This type of research is frequently used to describe a given population within a certain time period, this correlates with Dewey's pragmatism, in the sense that he argues that the universe is continually evolving and changing (Garrison, 1993). Therefore, the knowledge presented at this time could not and should not be argued to be representative of knowledge in the future.

One of the primary considerations with regards to questionnaires, is the issue of encoding and decoding. It is necessary to contemplate and appropriately plan for the fact that participants need to decode questions in the way the researcher intended (Foddy, 1993) to provide answers that are reliably comparable. Equally the participants need to encode their answers to ensure it contains the information that is requested from them. Any breakdown in the encoding or decoding process will result in miscommunication and information that lacks meaning (Peterson, 2000). The questioning strategy identified above aided the planning, to ensure the limitation of such issues, alongside careful consideration of question-and-answer wording and word structure. Wording is another important consideration when constructing a questionnaire. Several writers have discussed the issue of wording and their misinterpretation in impacting on results (Cantril and Fried, 1944; Belson, 1981; Hunt et al, 1982). Belson (1981) for example, identified that several everyday words such as: ‘people’, ‘generally’ and ‘weekday’ elicited different interpretations which would in turn impact on results given. Within my study there are a few words which may also provoke different interpretations from participants and therefore it was necessary to ensure that such words were accompanied with appropriate explanations to ensure uniformed decoding and encoding by the participants. Furthermore, questions that include words that may elicit differing interpretations had a text box included, for participants to add details to their answer. If data produced from any given question appeared to be impacted by varying interpretations, the text-based answers were used to provide greater understanding and recoding if appropriate.

3.4.2.1 Sampling

For phase two of the research, the questionnaire was seeking to offer more generalisability in the data produced, therefore, an element of probabilistic sampling was aimed for. However, due to the nature of the research and the limited understanding of the population as a whole, it was hard to predict sample size and procedures that may be possible. This is reinforced through pragmatism and can be seen through the work of Hoinville et al, (1985):

> *“In practice, the complexity of the competing factors of resources and accuracy means decision on sample size tends to be based on experience of good judgement rather than relying on a strict mathematical formula” (p 73).*

The initial plan for the sample size of participants undertaking the quantitative questionnaire ideally was around one hundred individuals. It was believed that this would enable a large enough response rate to analyse the data effectively and allow the possibility of developing subcategories of participants for comparison and further analysis. The final sample size of one hundred and thirty-five was developed through opportunistic sampling and snowball sampling (Hajimia, 2014). Opportunistic sampling arose from the need to focus recruitment through known avenues such as Facebook autistic groups and professional contacts, therefore sampling will be based upon the convenience of being part of these groups (McLeod, 2014). It is possible that where participants were identified they also then informed other individuals, who in turn participated. Cohen, Manion and Morrison (2005) explains that snowball sampling can be a useful tool when sampling a population where access is difficult. This is clearly the case within this study and therefore snowball sampling offered an opportunity to increase the sample size and consequently provide more reliable information. The process of sampling to build a phase two research population did not ask participants to specify general abilities, such as cognition or communication abilities as it was felt that such classifications would be based on personal assumptions and therefore would not be accurately comparable. It is however acknowledged that this did make it unfeasible to identify such variables within the data set, which may be seen as a limitation of the research.

3.4.2.2 Pilot Review

Much like the interview, it was necessary to pilot the questionnaire before distribution (Hussey and Hussey, 1997), not only to check the accessibility of the research medium but also to increase the reliability and validity of the findings (Hoinville and Jowell, 1985). As well as ensuring the continuation of collaboration as specified in participatory research (Benjamin-Thomas et al., 2018). As the questionnaire was based upon the results of the first phase of the research process, piloting of the questionnaire commenced after data analysis of phase one had been completed and ethical amendments had been confirmed. Recruitment for such pilots were through personal connections of autistic individuals that would be willing to aid in my research but who may not match the inclusion criterion of the case study. In total five individuals piloting the survey and provided feedback. Following the pilot survey, the following areas were considered as key to the future development of the study: opportunity not to answer, more open-ended questions and use of language. Each is outlined subsequently in more detail.

In constructing my survey, I wanted to ensure I had a high degree of validity in the responses given, as such I tried to ensure that every question would have an answer that could be directly compared with the answers of others. However, through piloting, I realised that it is not possible for everyone to answer every question, and importantly, that this may not be because they do not wish to, but because they do not know. By forcing participants to choose a predefined option, I was in fact reducing the validity of my research findings (Hagelin, Nilstun, Hau and Carlsson, 2004). I also needed to ensure that ethically I provided everyone with the option to refuse to answer.

During the pilot, the use of open-ended questions was explored. It was decided that the survey would benefit from more options to express opinion. Especially in relation to the issue identified above where explanation could be given for a lack of answer. By providing the opportunity for participants to express themselves without restriction, validity would be increased. This can be seen to have been beneficial when reviewing the full analysis of the survey, whereby, when participants were asked what the autistic identity was to them, many people choose to leave a different explanation than the ‘closed’ options I had provided. In doing so I was able to read their comments and re-categorise the answers, meaning my conclusions were more representative of the participant’s experiences and further reinforced the principles of participatory research.

A key positive identified during the pilot stage was the language used that directly referenced the first stage of the research. Quotes from the interview participants that were used, were seen to have a humanistic nature, meaning the individuals felt more comfortable relating to them in contrast to abstract concepts.

Some questions were raised over the use of specific words, especially if they implied meaning or assumed knowledge (Williams, 2003) This was therefore addressed and questions re-structured to promote neutrality of the researcher.

3.4.3 Recruitment

During both stages, recruitment was undertaken through closed Facebook groups and personal professional contacts, such as university lecturers and employees at local autism organisations. A recruitment letter was sent to the administrators of each group (appendix 5) to outline the proposed research, confirm ethical approval (appendix 6), and seek their consent for a recruitment advert to be posted within the said group. Once consent was provided an advert was posted for phase one of the research (appendix 7) briefly outlining the request for participants in research and offering further contact details for those who were interested, to contact me, and receive the participant information sheet (appendix 8). A further advert was placed for phase two of the research (appendix 10) once ethical amendment was confirmed (appendix 11). Before any individual was officially recruited as a participant, a number of ethical considerations/processes had to be undertaken.

3.4.4 Ethics

As a social researcher, the need to approach any research in an ethical manner is fundamental. Ethical issues should be considered within the research design stage to protect participants from research which may cause them harm. As a University of Birmingham student, I followed the ethical guidelines and approval system the University outlines, and as such, ensured that my research was reliable before commencing with any participant communication. Although pragmatists such as Toulmin argue that:

> *"it does seem possible to engage in morally reasonable and responsible action without complete agreement on universal ethical theory. For pragmatists, moral conduct is more akin to the skilled craft than the logic of mathematical reasoning." (Brinkman and Kvale, 2015, p100).*

It is important in this case, that I ensured the agreed principles of ethical research were adhered to. To meet the university guidelines, the four principles of ethical research as outlined by Denscombe (2017) will be discussed and outlined in further detail.

3.4.4.1 Principle One: protects the interests of the participants.

This principle upholds that there is a general agreement between researchers that no harm should come to those involved because of the research undertaken, either short or long term. To adhere to this, as a researcher, it is important to consider in advance any likely consequences and plan for them accordingly. In this research, I did not need to accommodate for any risk to physical harm; this is a significant benefit of incorporating an online research methodology, as participants did not need to leave their homes and did not risk harm as a result. Psychological harm, however, did require consideration, as we discussed sensitive matters that may have cause emotional distress. To plan appropriately for this, I offered support throughout, that participants signed to confirm what they were aware of before commencing the project. I also planned to signpost individuals to professional support had I become concerned that anyone was demonstrating emotional distress, however this was not needed.

A further area of protection of harm arises from the defence of the identities of participants. Ethical guidelines for social researchers consistently state that confidentiality is a central feature of social research, the definition for this is taken from the British Sociological Association (BSA) who states that:

> *"Confidentiality is taken to mean that identifiable information about individuals collected during the process of research will not be disclosed without permission" (BSA, 2004 [online]).*

The BSA continue to explain that it is good practice, that research participants are made aware of how their identifiable data will be processed and who will have access to it (Oliver, 2003). This process was undertaken through the participant information sheet (appendix 8) which was sent out to all phase one participants prior to confirmation of involvement. Clarity was given to the process of within team discussions, that did occur between myself as the researcher and my university supervisors, as this is acknowledged as good practice (Gilbert, 2001), while maintaining participant confidentiality.

By undertaking these features, with the goal of protecting the interests of the participants, it is hoped that everyone involved felt in control of their information, and understood they had access to review it at any time.

3.4.4.2 Principle 2: Ensuring that participation is voluntary and informed consent.

Most guidelines for ethical research stipulate that it is fundamental to ensure that anyone participating does so voluntarily, based on an accurate perception of their role and the purpose of the research, including the impact it may have upon themselves. In this sense, it is implied, that all participants will “choose freely to give consent and to subsequently participate in the research” (Iphofen, R. 2011. p66). Appropriately free decision making was possible as anyone declaring an interest was given full information about the research through the participant information sheet and was also offered the opportunity to ask questions throughout the process, in line with Faden and Beauchamp’s (1986) argument that as researchers we must invite participants to actively engage in exchanging information. Following the Social Research Association (SRA) Guidelines (2003) the participant information sheet (appendix 8) for phase one as well as the first page of the questionnaire, will outline any possible consequences of participation and proposed opportunities to counterbalance such concerns.

It is equally acknowledged, that consent does not imply a requirement to participate, but an on-going process throughout the research which can be reviewed and amended as necessary (Iphofen, 2011). The participant information form and consent form (appendix 9) for phase one, outlined that each participant was entitled to refuse at any stage, and for whatever reason, to give information or withdraw previously supplied information within an agreed timescale (SRA Guidelines, 2003). Voluntary informed consent was gathered through a consent form, sent to the participant via email. For phase two, the initial pages of the survey (appendix 11) was used to provide participant information and gain informed consent for involvement. Due to the nature of the online survey platform, participants that wished to not supply information or withdraw at any time did so, without the requirement of justification.

3.4.4.3 Principle 3: Avoids deception and operates with scientific integrity.

Good research demands an avoidance of deception. As the proposed research did not involve any element of covert study or sponsor funding, this is not perceived to be an issue that needs detailed accounting for. As previously mentioned, a participant information sheet was given to all who ask for information, so that they were fully aware of the purpose of the research. Ethical approval information alongside research details was also provided to group administrators as part of the recruitment process to ensure that when they gave me consent to recruit within their groups, they did fulfil their role in protecting the interests of those individuals who may have approached me for more information.

In line with the avoidance of deception, scientific integrity is key to undertaking good research. It is clarified that the work of other researchers will be used to further my understanding relating to this research, however all such work will be referenced so as to avoid plagiarism and therefore give credit where it is due.

A key area that I have been acutely aware of and tried to plan against, is the possibility of personal bias. As with any research, personal biases impact on the way research is planned and conducted. This needs to be acknowledged, as clearly my own experiences with autism and the fact that I have chosen the topic to be investigated, indicates I have biases that will influence my decision-making processes. For this reason, I have given a significant amount of time to reviewing appropriate research philosophies, methodologies, and theories to ensure I have an adequate basis for my research, away from my initial personal thoughts. Alongside this, I have created a structure whereby I ensured all data could be provided, not merely that which may 'prove my point' (Yin, 2014) which ensured a reduction of the impact of any personal bias. Processes of triangulation and participant checking also ensured that the information I have collated is an accurate representation of the data set and not swayed by my personal opinions. By undertaking these processes, I can ensure I achieved a conclusion, within my research of data, which was an accurate reflection of the participants involved.

3.4.4.4 Principle four: Comply with the laws of the land.

It is not unique in research to specify that there is an expectation that the laws of the United Kingdom are adhered to, however there is a specific element of data protection that requires consideration.

Since its implementation in 2018 the General Data Protection Regulation (GDPR) has impacted on research with regards to how data is handled and used (Cornock, 2018). To ensure my compliance with the legislation, a data management plan is outlined (appendix 12) detailing my actions which are subsequently approved by the university Information Technology manager for Research and Education.

As previously stated, the ethical approval process managed by the University was used to ensure that all ethical guidelines were met and adhered to. To ensure that appropriate consideration was given to all elements of the research, ethical approval was sought in two phases. Phase one was focused upon the qualitative element of the research and then phase two was submitted after the first qualitative stage with a focus on the quantitative element of the research. Once approval for each phase was granted but before research was undertaken with confirmed participants, a process of piloting was undertaken as has been previously outlined.

3.5 Data Analysis

3.5.1 Phase One Methods

Although Interpretive phenomenological analysis (IPA) did not offer a complete methodological foundation for this research, the qualitative element of the mixed methods design does seek to explore in detail how each participant is interpreting their own experiences (Tomkins, 2017) and therefore requires the inclusion of the IPA to data analysis. This is reinforced by Smith, Flowers, and Larkin (2009) who argue that IPA is most appropriate for data collection which aims to “invite participants to offer a rich, detailed, first-person account of their experiences” (p.56).

The close examination of the responses given by each individual, of their experiences, was analysed to capture meaning and common features across participants (Starks and Brown Trinidad, 2007). IPA is also a valid medium, as it recognises the centrality of the researcher in the analysis process (Brocki and Wearden, 2006). As Smith (2004) states:

> *"the participant is trying to make sense of their personal and social world; the researcher is trying to make sense of the participant trying to make sense of their personal and social world".* (p.40).

This is important, as I recognise my role as an autistic researcher and the impact this may have had on the way in which I will interpret the data that was collated. IPA recognises that it is not viable, to truly understand another person's experiences completely, however by being an autistic researcher it was my intention that my interpretations will be as 'close' to the individual's experiences as possible (Larkin, Watts, & Clifton, 2006).

As the interviews were text-based, transcriptions of audio files were not necessary, simply the text from the interview was copied from the chat forum to a word-based document. The first stage of analysis included the reading and rereading of the transcript, using the left margin to annotate, summarise or paraphrase significant points or to identify note-worthy uses of language (Huws and Jones, 2008). Following this first stage, a subsequent process of identifying emergent themes was undertaken and listed on a cover sheet for the transcript. Each interview transcript was analysed and coded individually within the same week of the interview being undertaken to ensure that I, as the researcher, remained engulfed in the data and could identify and recall all elements from the interview. Once all the interviews had been concluded and analysed, a secondary period of analysis was undertaken whereby the themes of each interview were compared against each other, to begin to develop superordinate themes across all the interviews. It was necessary at this stage to return to the original text of the interviews to ensure that the superordinate themes were appropriately applicable to the verbatim transcript.

During this period, a process of participant checking was undertaken to ensure the participants were confident that I had interpreted their experiences accurately, while also providing an opportunity for them to add more detail or for me to ask further questions, especially where a superordinate theme had become apparent but was not discussed in some interviews.

These superordinate themes were then utilised to develop the second phase of research and consequential second phase of data analysis.

3.5.2 Phase Two Methods

In comparison to the first stage, the second stage of data analysis focused on quantitative data and therefore the methods for analysis were different. Once again, computer-aided software was used to manage the larger quantities of data and aid its constructive analysis. Microsoft Excel was used as an appropriate medium, largely because it is a program I am confident with using and therefore was more likely to be assured in its manipulation of the data. The survey was active for a period of one month, once the final deadline had been reached, statistical analysis was undertaken and visual representation such as graphs, were used to illustrate the range of responses for each question.

There was a limited number of open-ended questions within the survey to ensure the opportunity for responses that did not match the predefined categories. The answers to these questions were reviewed and either formed the basis of an amendment to the answer categories and therefore became a count within a new category or were added to the analysis of results to express the additional information that was provided.

3.5.3 Processes

The successful amalgamation of the data is the key to effectively utilizing the mixed methods approach (CIRT, n.d.). Throughout the research, the integration of data occurred through ‘building’ (Fetters, Curry and Creswell, 2013) as each phase built from the findings of the phase before. Once the analysis of each phase was undertaken the findings were discussed together, rather than amalgamated into one, which is in line with the pragmatist view of the importance of ‘empirical and practical’ information (Johnson and Onwuegbuzie, 2004) and the process of triangulation to increase the validity and reliability of results.

3.6 Validity and Reliability

Several elements have been outlined previously, which have had a significant impact on the development of high internal validity. For example, internal validity was increased by the introduction of the piloting element to ensure that the questions were appropriate and structured in a way that sought data relevant to the research questions (Denscombe, 2017). Equally, the participant checking element of the data gathering, ensured amendments to any factual errors, checked the adequacy of the analysis, and provided opportunities for further information which in turn increased internal validity (Cohen, Manion and Morrison, 2005). A further important factor in this research is the fundamental use of mixed methods, which provides a strong process of triangulation. As previously outlined the mixed method methodology of this research, has a sequential triangulation structure, which increased the validity, and informative capability of a study, decreased investigator biases, and provided multiple perspectives (Denzin, 1978).

External validity can be more problematic; as it refers to the extent to which the findings can be generalised to the wider population (Cohen, Manion and Morrison, 2005). The incorporation of the mixed methods approach has increased the external validity of this research, as a purely qualitative approach would have had little external validity. However, as discussed within the sampling section, it is acknowledged that there are limitations to the extent of the self-identifying autistic population I can reach, and therefore it is acknowledged that while improved, the external validity may also be limited in the sense of generalising findings into different contexts and participants. Bogdan and Biklen (1998) however, argued that generalisability should be construed differently, viewing the extent to which the findings can be generalised across different people within similar settings/situations. Should generalisability be viewed in this sense, the external validity of this research is significantly increased.

Reliability as a concept can be seen as scientific, in the sense that it seeks to establish consistency and replication over time, which clearly is easier within the scientific realms of experiments than it is with human interaction. Some proponents argue that reliability should not apply in interpretive research (Thomas, 2018), however, while I understand the rationale for this, there are elements of reliability which I believe are important to ensure are present throughout all research. For example, I have strived to articulate a clear philosophical structure and process for the given research, this in turn will improve the reliability as it could be repeatable based upon these clear foundations. Equally whereas an interview structure could reduce reliability, as it is based on individual interpretations and experiences, the incorporation of ‘foundation questions’ (appendix 4) would mean that such interviews could also be repeatable. Silverman (1993) also suggests that reliability can be enhanced by piloting interviews as this ensures both interviewer and interviewee understand the questions in the same way, which I have done.

3.7 Limitations

As discussed throughout, the main limitation of this research, is the limited sample of participants I was able to access, from the larger population of self-identifying autistics (which is unknown). In particular the demographic data within phase two (figure 17) indicated that 65% of the participants were living with another person either in a relationship or through friendship, which may suggest that the sample of respondents was more favoured towards individuals that are more socially active and therefore may not be representative of the more socially isolated population.

Summary

In this chapter I have outlined and justified the appropriateness of my philosophical foundations and methodological structures, by detailing my exploration of alternatives and rationale for their rejection.

The following chapter will demonstrate the data I collated by using these secure foundations.

CHAPTER FOUR: PHASE ONE RESULTS

The following chapter will outline the data produced via phase one of the research, through semi-structured interviews. As was outlined in the methodology chapter, the findings of each semi-structured interview were analysed within the same week of the discussion. An IPA approach was undertaken to analyse the narrative accounts into subordinate themes which were then compared with the accounts of the other interviews to construct superordinate themes. Commitment and rigour were ensured through prolonged analysis of the data, allowing for "contemplative and empathic exploration of the topic" (Yardley, 2000, p222). The following discussion pertaining to the results of this phase, it is aimed, will be transparent and coherent to accurately portray the analysis process and consequential results (Bruner, 1991).

4.1 Demographic Information

Prior to interviews, participants were asked for demographic information, listed in Figure 2 below.

Alias	Age	Age of Self Identification	Gender	Religion	Comorbid diagnosis'
Emily	39	36	Female	Spiritualist	Temporal lobe epilepsy and prolapse disc in spine
Anna	28	27	Female	Christian (not religious)	
Martin	46	30	Non-Binary	Pagan	Depression, anxiety
Margaret	28	25	Female	Christian (practicing)	
Kathy	38	37	Female	None	
Neil	42	40	Male	Panpsychism	

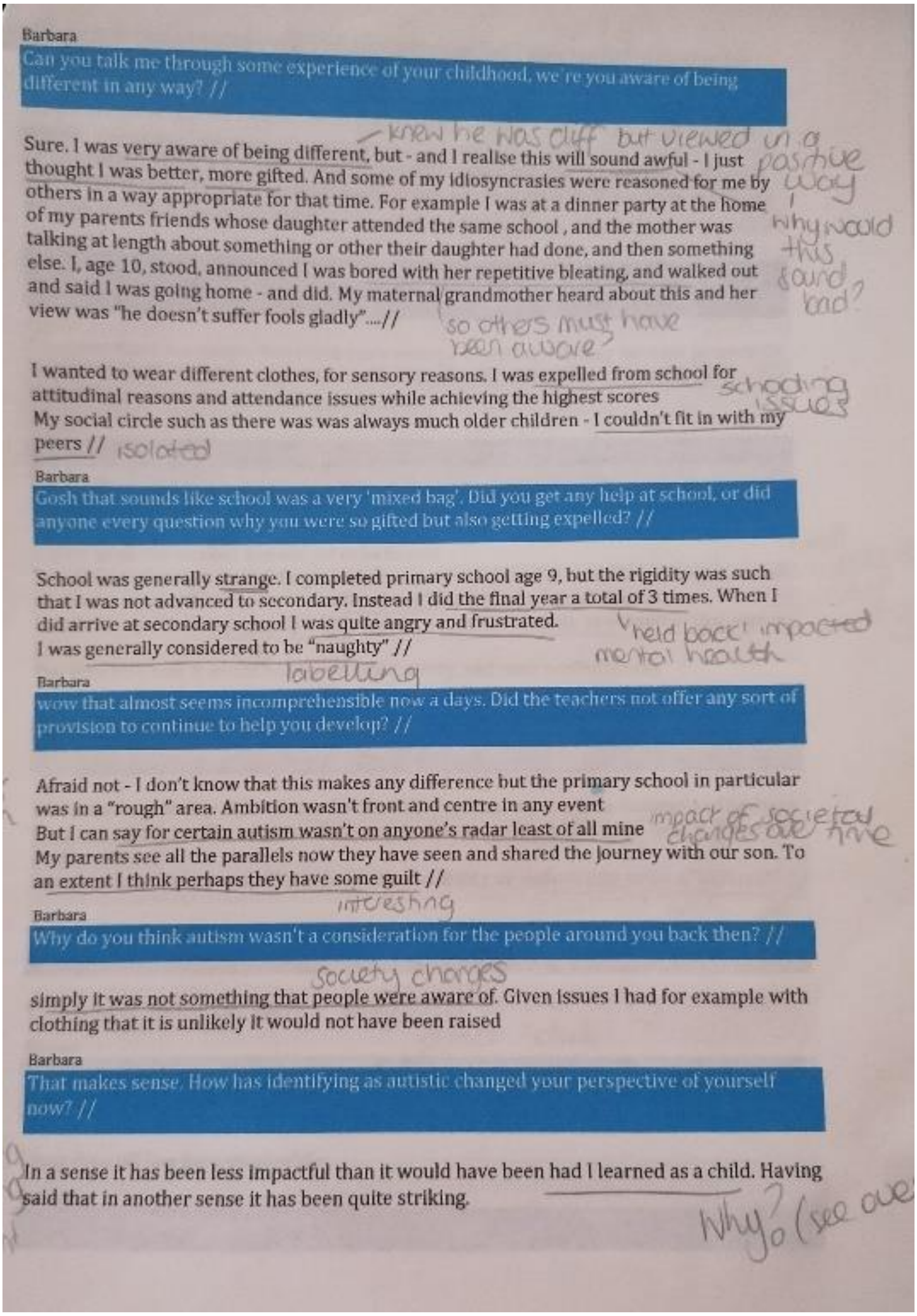
Cara	33	33	Female	Spiritual	
Mark	44	43	Male	None	
Brad	46	42	Male	None	
Julia	78	77	Female	None	recent appearance of arthritis

Figure 2: Participant demographic information

While participants were asked to identify where in the world they lived, I have chosen not to indicate that here as it may make it more difficult to keep the identity of the participants anonymous.

Of the ten participants there was an average age of forty-two, an average self-identification age of thirty-nine. Indicating an average age difference between self-identification and current age of three years. The gender divide across the interviews were three male, six female and one non-binary. In line with the ethical considerations previously outlined, participants were assigned aliases to be used during the data gathering and analysis stages, to ensure they could not be identified by their answers, Participants are therefore named as follows: Emily, Kathy, Cara, Anna, Neil, Mark, Margaret, Martin, Brad and Julia.

Due to the nature of the text based online discussions, transcription of the conversation merely involved copying the text onto a word document for manageability. The conversation was read, repeatedly, and annotations added to the transcript of interpretations and possible themes. An example page is shown subsequently:



Barbara

Can you talk me through some experience of your childhood, we're you aware of being different in any way? //

knew he was diff but viewed in a positive way

Sure. I was very aware of being different, but - and I realise this will sound awful - I just thought I was better, more gifted. And some of my idiosyncrasies were reasoned for me by others in a way appropriate for that time. For example I was at a dinner party at the home of my parents friends whose daughter attended the same school , and the mother was talking at length about something or other their daughter had done, and then something else. I, age 10, stood, announced I was bored with her repetitive bleating, and walked out and said I was going home - and did. My maternal grandmother heard about this and her view was "he doesn't suffer fools gladly"....//

why would this sound bad?

so others must have been aware?

I wanted to wear different clothes, for sensory reasons. I was expelled from school for attitudinal reasons and attendance issues while achieving the highest scores

schooling issues

My social circle such as there was was always much older children - I couldn't fit in with my peers // isolated

Barbara

Gosh that sounds like school was a very 'mixed bag'. Did you get any help at school, or did anyone every question why you were so gifted but also getting expelled? //

School was generally strange. I completed primary school age 9, but the rigidity was such that I was not advanced to secondary. Instead I did the final year a total of 3 times. When I did arrive at secondary school I was quite angry and frustrated.

I was generally considered to be "naughty" //

held back! impacted mental health

labelling

Barbara

wow that almost seems incomprehensible now a days. Did the teachers not offer any sort of provision to continue to help you develop? //

Afraid not - I don't know that this makes any difference but the primary school in particular was in a "rough" area. Ambition wasn't front and centre in any event

But I can say for certain autism wasn't on anyone's radar least of all mine

impact of societal changes over time

My parents see all the parallels now they have seen and shared the journey with our son. To an extent I think perhaps they have some guilt //

interesting

Barbara

Why do you think autism wasn't a consideration for the people around you back then? //

society changes

simply it was not something that people were aware of. Given issues I had for example with clothing that it is unlikely it would not have been raised

Barbara

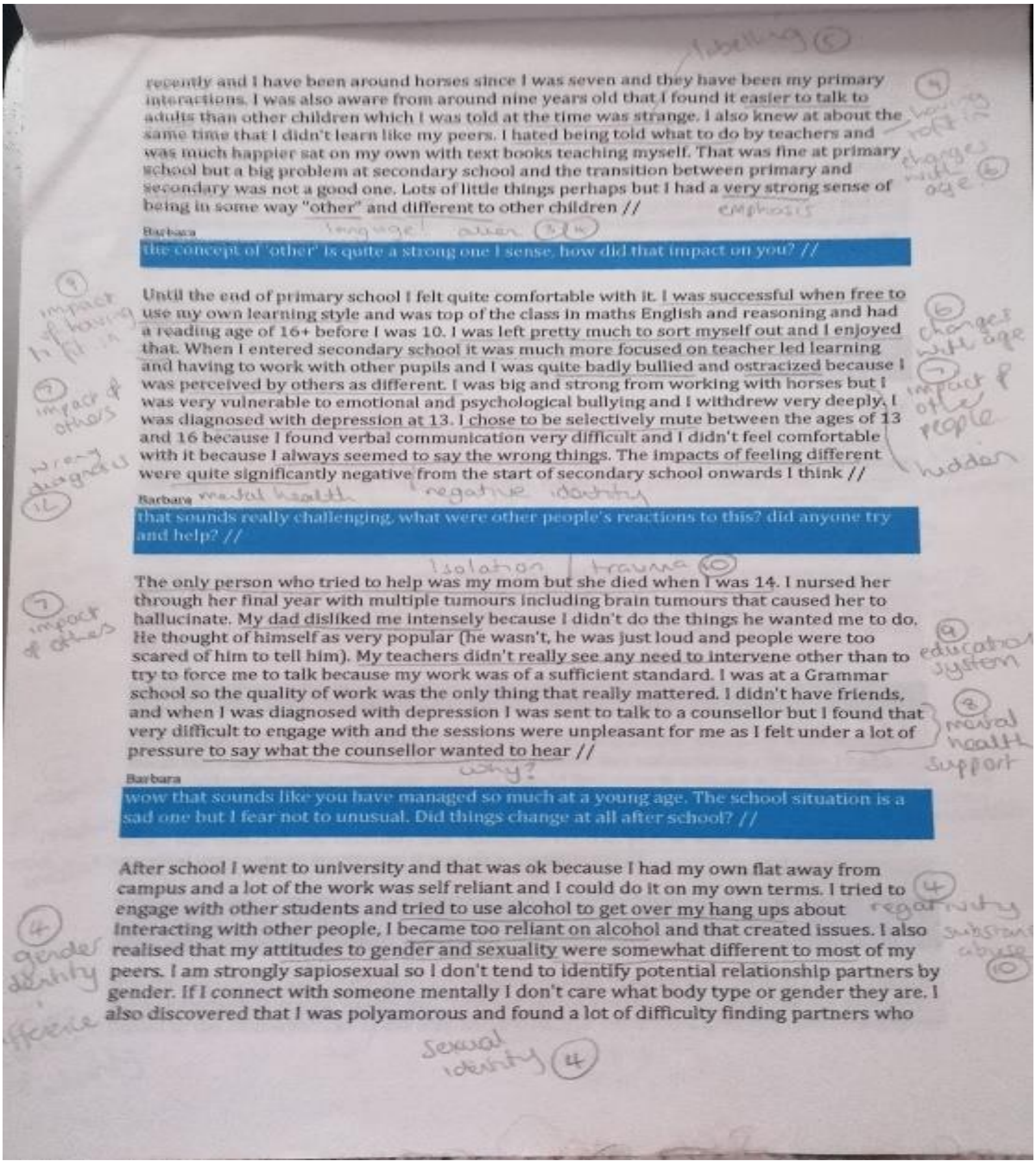
That makes sense. How has identifying as autistic changed your perspective of yourself now? //

In a sense it has been less impactful than it would have been had I learned as a child. Having said that in another sense it has been quite striking.

Why? (see ove

Figure 3: Example of IPA coding

The annotations were used to develop thematic categories, which were listed on a single page attached to the start of each transcript and numbered. Transcripts were then reviewed again, and numbers added to signify where each theme was evidenced in the text:



recently and I have been around horses since I was seven and they have been my primary interactions. I was also aware from around nine years old that I found it easier to talk to adults than other children which I was told at the time was strange. I also knew at about the same time that I didn't learn like my peers. I hated being told what to do by teachers and was much happier sat on my own with text books teaching myself. That was fine at primary school but a big problem at secondary school and the transition between primary and secondary was not a good one. Lots of little things perhaps but I had a very strong sense of being in some way "other" and different to other children //

Barbara

the concept of 'other' is quite a strong one I sense, how did that impact on you? //

Until the end of primary school I felt quite comfortable with it. I was successful when free to use my own learning style and was top of the class in maths English and reasoning and had a reading age of 16+ before I was 10. I was left pretty much to sort myself out and I enjoyed that. When I entered secondary school it was much more focused on teacher led learning and having to work with other pupils and I was quite badly bullied and ostracized because I was perceived by others as different. I was big and strong from working with horses but I was very vulnerable to emotional and psychological bullying and I withdrew very deeply. I was diagnosed with depression at 13. I chose to be selectively mute between the ages of 13 and 16 because I found verbal communication very difficult and I didn't feel comfortable with it because I always seemed to say the wrong things. The impacts of feeling different were quite significantly negative from the start of secondary school onwards I think //

Barbara

that sounds really challenging, what were other people's reactions to this? did anyone try and help? //

The only person who tried to help was my mom but she died when I was 14. I nursed her through her final year with multiple tumours including brain tumours that caused her to hallucinate. My dad disliked me intensely because I didn't do the things he wanted me to do. He thought of himself as very popular (he wasn't, he was just loud and people were too scared of him to tell him). My teachers didn't really see any need to intervene other than to try to force me to talk because my work was of a sufficient standard. I was at a Grammar school so the quality of work was the only thing that really mattered. I didn't have friends, and when I was diagnosed with depression I was sent to talk to a counsellor but I found that very difficult to engage with and the sessions were unpleasant for me as I felt under a lot of pressure to say what the counsellor wanted to hear //

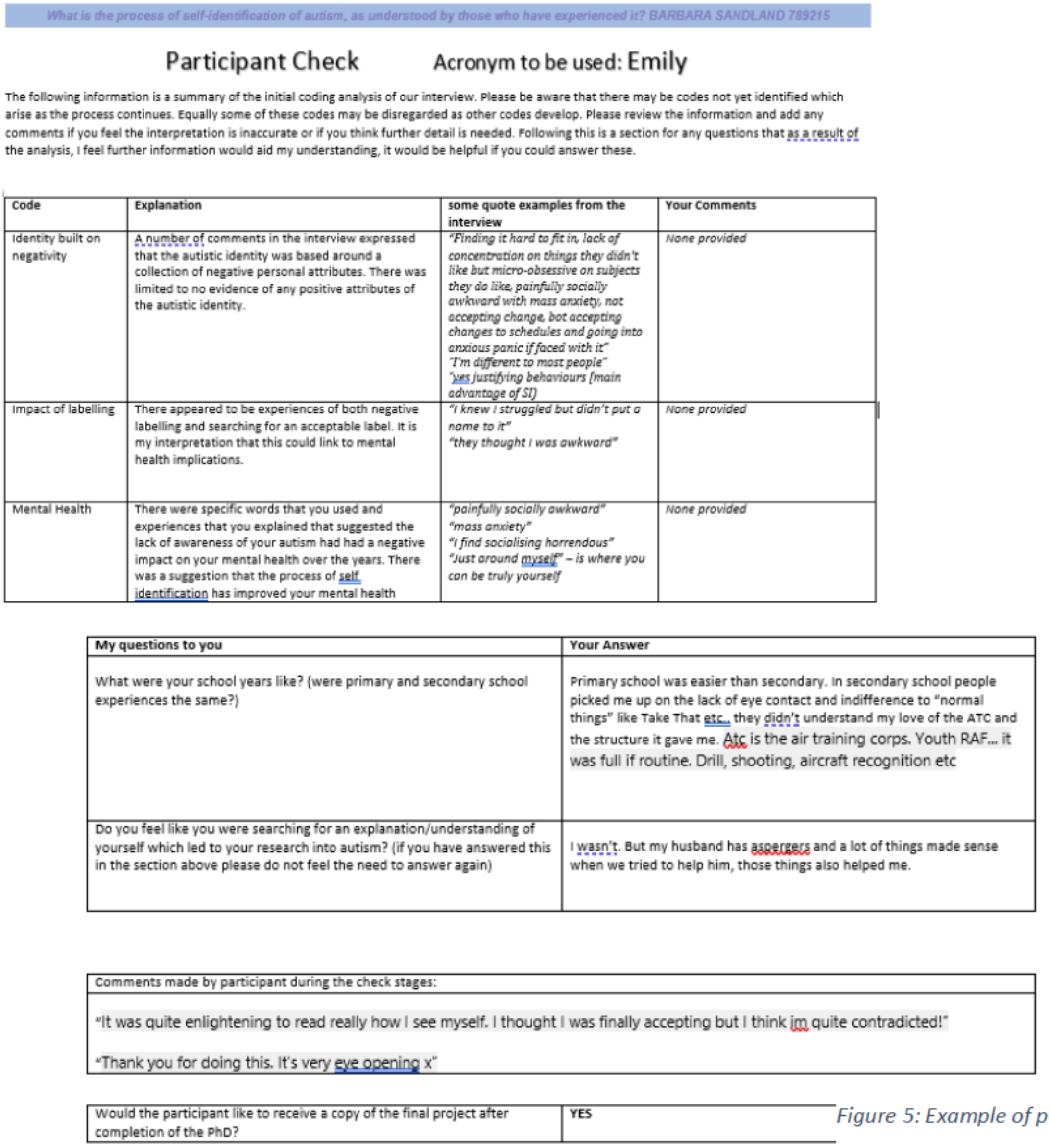
Barbara

wow that sounds like you have managed so much at a young age. The school situation is a sad one but I fear not to unusual. Did things change at all after school? //

After school I went to university and that was ok because I had my own flat away from campus and a lot of the work was self reliant and I could do it on my own terms. I tried to engage with other students and tried to use alcohol to get over my hang ups about interacting with other people, I became too reliant on alcohol and that created issues. I also realised that my attitudes to gender and sexuality were somewhat different to most of my peers. I am strongly sapiosexual so I don't tend to identify potential relationship partners by gender. If I connect with someone mentally I don't care what body type or gender they are. I also discovered that I was polyamorous and found a lot of difficulty finding partners who

Figure 4: Example of IPA theme coding

Once this process had been completed a table of themes and evidence from the transcript attached to these themes was compiled and sent to each participant, for them to check they were happy with my interpretation of their experiences and to add more detail if they wished to, therefore reinforcing the participatory nature of the research, allowing a diffusion of power over the data analysis process. This also gave me the opportunity to ask further questions or explore if a theme identified in other transcripts was relevant if there was no evidence in their original transcript. Of the ten participant checks sent out, only two participants replied and provided further information. An example of the first and last page of one participant check is shown below:



What is the process of self-identification of autism, as understood by those who have experienced it? BARBARA SANDLAND 789215

Participant Check Acronym to be used: Emily

The following information is a summary of the initial coding analysis of our interview. Please be aware that there may be codes not yet identified which arise as the process continues. Equally some of these codes may be disregarded as other codes develop. Please review the information and add any comments if you feel the interpretation is inaccurate or if you think further detail is needed. Following this is a section for any questions that as a result of the analysis, I feel further information would aid my understanding, it would be helpful if you could answer these.

Code	Explanation	some quote examples from the interview	Your Comments
Identity built on negativity	A number of comments in the interview expressed that the autistic identity was based around a collection of negative personal attributes. There was limited to no evidence of any positive attributes of the autistic identity.	*"Finding it hard to fit in, lack of concentration on things they didn't like but micro-obsessive on subjects they do like, painfully socially awkward with mass anxiety, not accepting change, bot accepting changes to schedules and going into anxious panic if faced with it"* *"I'm different to most people"* *"yes justifying behaviours [main advantage of SI)*	*None provided*
Impact of labelling	There appeared to be experiences of both negative labelling and searching for an acceptable label. It is my interpretation that this could link to mental health implications.	*"I knew I struggled but didn't put a name to it"* *"they thought I was awkward"*	*None provided*
Mental Health	There were specific words that you used and experiences that you explained that suggested the lack of awareness of your autism had had a negative impact on your mental health over the years. There was a suggestion that the process of self identification has improved your mental health	*"painfully socially awkward"* *"mass anxiety"* *"I find socialising horrendous"* *"Just around myself" – is where you can be truly yourself*	*None provided*

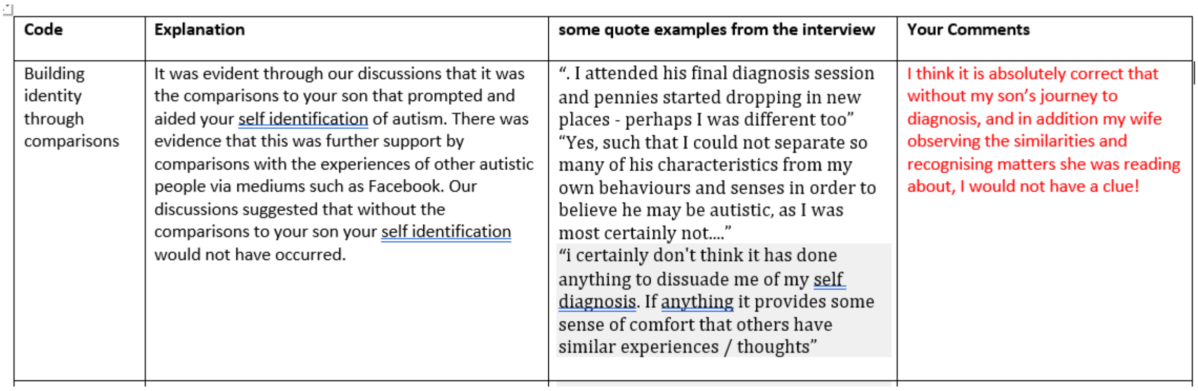
My questions to you	Your Answer
What were your school years like? (were primary and secondary school experiences the same?)	Primary school was easier than secondary. In secondary school people picked me up on the lack of eye contact and indifference to "normal things" like Take That etc., they didn't understand my love of the ATC and the structure it gave me. Atc is the air training corps. Youth RAF… it was full if routine. Drill, shooting, aircraft recognition etc
Do you feel like you were searching for an explanation/understanding of yourself which led to your research into autism? (if you have answered this in the section above please do not feel the need to answer again)	I wasn't. But my husband has aspergers and a lot of things made sense when we tried to help him, those things also helped me.

Comments made by participant during the check stages:
"It was quite enlightening to read really how I see myself. I thought I was finally accepting but I think im quite contradicted!" "Thank you for doing this. It's very eye opening x"

Would the participant like to receive a copy of the final project after completion of the PhD?	YES

Figure 5: Example of participant check sheet

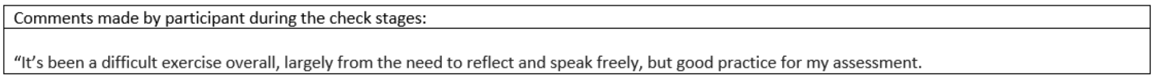
The incorporation of the participant check stage was vital to ensure the continued conscious actions to address the power dynamics within research. Following the principles of participatory research, the checks facilitated the interviewee to regain control over the meaning attributed to their experiences (Reinhartz, S, 1992). Where participants agreed with the analysis I had made, the language used in their feedback results in an increase in confidence both by myself as the researcher, but also in my perception of how they felt towards me. An example of such is given below:



Code	Explanation	some quote examples from the interview	Your Comments
Building identity through comparisons	It was evident through our discussions that it was the comparisons to your son that prompted and aided your self identification of autism. There was evidence that this was further support by comparisons with the experiences of other autistic people via mediums such as Facebook. Our discussions suggested that without the comparisons to your son your self identification would not have occurred.	“. I attended his final diagnosis session and pennies started dropping in new places - perhaps I was different too” “Yes, such that I could not separate so many of his characteristics from my own behaviours and senses in order to believe he may be autistic, as I was most certainly not....” “i certainly don't think it has done anything to dissuade me of my self diagnosis. If anything it provides some sense of comfort that others have similar experiences / thoughts”	I think it is absolutely correct that without my son’s journey to diagnosis, and in addition my wife observing the similarities and recognising matters she was reading about, I would not have a clue!

Figure 6: Example of Participant Check additional information.

The participant check process further facilitated the opportunity for the participant to express how they had experienced the interviews which added a further dimension to my analysis, which would not have been possible without this stage. For example, Mark wrote:



Comments made by participant during the check stages:
“It’s been a difficult exercise overall, largely from the need to reflect and speak freely, but good practice for my assessment.

Figure 7: Example of Participant Check feedback

During the interview and follow up stages, Mark communicated confidently and without this comment I would not have had an inkling that he had found the discussions challenging.

Once again, by ensuring the participants were actively involved in the entire process ensured a greater validity of data collected.

Following a period of two weeks to allow for returns of participant checks, themes across transcripts were then collated and categorised to develop superordinate themes, with links to where in each transcript the theme is identified:

Superordinate Themes	Themes	person/number
Changes with Age	Issues get worse with age	Kathy 11
	masking	Kathy 18
Check Emily	bullying	Kathy 10
	Schooling	Neil 9
Does 'In-group theme fit into this??	issues got worse with age	Cara 12
	Masking	Cara 11
	Bullying	Cara 9
	isolation	Cara 8
	School	Martin 9
	masking	Martin 14
	Isolation	Martin 3
	Changes over time	Anna 3
	Masking	Margaret 13
	No help at school	Margaret 4

Superordinate Themes	Themes	person/number
Negativity	*Is this separate or does it go with Identity?*	Kathy 13
Check Cara		Neil 6
Anna		Margaret 12
		Martin 4
Changing Society		Anna 6
Check# Anna		Margaret 15
		Martin 1
		Martin 5
		Cara 4
		Neil 3
		Neil 5
		Neil 10
		Neil 2
		Neil 11
		Kathy 4

Superordinate Themes	Themes	person/number
Identity		Margaret 12
		Anna 1
Check Neil		Martin 4
		Cara 19
Add on identity built through comparison *Think EssvEx*		Kathy 1
Perspectives of others		Neil 8
check Kathy		Cara 10
		Cara 7
disclosure?		Martin 7
		Anna 4
		Margaret 14
Difference in autism		Margaret 16
		Anna 9
Check Kathy		Martin 13
		Cara 17
		Neil 15

Diagnosis		
Contradiction?? What does this mean and where does it link?		

Superordinate Themes	Themes	person/number
'Perfect fit'	a complete fit	Margaret 12
Check Anna	a complete fit	Martin 4
Emily Neil	perfect fit	Cara 2
	perfect fit	Kathy 5

Superordinate Themes	Themes	person/number
Mental Health	mental health	Kathy 2
	bullying	Kathy 10
	wanting to understand issues	Kathy 13
	mental health	Neil 4
	abnormality	Neil 7
	mental health	Cara 1
	seeking understanding	Cara 3
	bullying	Cara 9
	trauma	Cara 13
	SI improved mental health	Cara 6
	mental health	Emily 4
	negativity	emily 1
	abnormality	Emily 1
	mental health	Martin 8
	trauma	Martin 10
	isolation	Martin 4
	negativity	Martin 4
	Mental Health	Anna 2
	emotionally driven experiences	Anna 8
	mental health	Margaret 1
	Trauma	Margaret 6

Figure 8: Construction of Superordinate themes

4.2 Themes

At the completion of the process the following themes were identified and will be reviewed in turn:

4.2.1 Mental Health,
4.2.2 Changes with age,
4.2.3 Changing Societal Perceptions of Autism
4.2.4 Impact of others
4.2.5 Masking
4.2.6 Differences in autism,
4.2.7 'Perfect Fit'
4.2.8 Diagnosis.
4.2.9 Value of self-identifying.

The order of themes is presented to mirror the frequency that the theme emerged in the transcripts. Excerpts, from interview transcripts, are pasted verbatim in order to accurately represent participants, therefore a conscious decision has been made not to amend typographic errors.

4.2.1 Mental Health

The impact of not being diagnosed as autistic was considered by all the participants in differing ways, with six of the participants making specific reference to challenges with their mental health:

Emily	*“painfully socially awkward….mass anxiety”*
Kathy	*“I used to be terrified that if I ever told anyone about how I often felt on the brink of craziness…..I haven't articulated this to anyone before, it's making me feel a bit emotional”*
Cara	*“I was under a lot of stress and was finding managing things very difficult….During this time I became very depressed and anxious about things and being stuck in this way”*
Anna	*“It's about how I feel tired, feel exhausted, feel like I am 60 years old even when I was a teenager”*
Margaret	*“I'd been self harming. Panic attacks at work. Suicidal thoughts… I pull out my eyelashes and have pulled out my hair or eyelashes since I was about 8. struggled a long time”*
Martin	*“I was very vulnerable to emotional and psychological bullying and I withdrew very deeply [during secondary years]... I was diagnosed with depression at 13. I chose to be selectively mute between the ages of 13 and 16 because I found verbal communication very difficult and I*

> *didn't feel comfortable with it because I always seemed to say the wrong things."*

It is evident that the participants had had several mental health challenges over the years, the extent of their experiences make this theme an important area for consideration. What is further important to consider is the connection between this theme and the theme of changing with age, as a few participants reported the start of mental health challenges around the secondary school age.

While mental health challenges were evident prior to self-identification there was evidence that there was an improvement in mental health implications after self-identification. In my discussion with Brad the use of the word 'wonderful' when referencing self-identifying and consequently meeting other people that shared his experiences indicates a positive impact on his mental health. He also talked about wanting to positively impact on others' wellbeing which suggests that he identified as having this experience himself and wanted to share it. Five other participants clearly articulated the positive impact they felt self-identifying as autistic had on their mental health:

Kathy	*"I think that's why self-identifying as autistic has been so positive for me. It's like a weight lifted off my shoulders. And it's also a feeling of not being alone*
Cara	*"But after identifying I finally found some peace with myself and did not hate or disliked myself as much anymore"*
Neil	*"it was a huge relief"*
Mark	*"It has also allowed me to reflect and in a sense be kinder to myself. As an example, I have a great degree of anxiety but I never felt able to recognise and accept that"*

Margaret	*"I just decided to live like I have it and it's been amazing"*
Martin	*"but it made sense that I was different and because I was starting to see it as part of who I was rather than a medical issue I could accept that it was ok to be different"*

In contrast to these quotes that show an agreement in experiences, one participant did suggest that self-identifying had not improved her mental health:

Anna	*"Sometimes it makes me sad because I understand that some things will never get better or I will never learn. (For example I can never pretend good enough to fool everyone around that I am a team player or understand all the social rules and most importantly, remember them in the moment when I have to follow them)"*

While mental health is one area that the results indicate is positively impacted by self-identification, there were also indications that the changes the individual experienced in relation to their age also impacted on their mental health.

4.2.2 Changes with age

There was an apparent trajectory of changing self-acceptance/identity with age and schooling. Six of the participants specifically suggested that at the age of primary school they had an awareness of their own identity, and some awareness of this being different to others, but this was not seen in a negative way:

Emily	*"Primary school was easier than secondary"*
Kathy	*"I didn't think anything of this at the time, but I did feel like I was always on the outside of other friendship groups in school"*

Cara *“Yea I didn't care so much as a child was happy being awkward and horrible (as people would say)”*

Anna *“When I was a kid it felt a bit like a tunnel vision. It's like there was my own world”*

Martin *“certainly from starting school. I always played on my own, I never had friends to invite to birthday parties so I never had them…that was fine at primary school”*

Mark *“Sure. I was very aware of being different, but - and I realise this will sound awful - I just thought I was better”*

From the age of around secondary school (possibly puberty) there was a change where individuals started to want to ‘fit in’ with others, which could have reduced their own personal identity:

Emily *“In secondary school people picked me up on the lack of eye contact and indifference to “normal things” like Take That etc.. they didn’t understand my love of the ATC and the structure it gave me”*

Kathy *“Certainly when I was in secondary school I regularly consciously changed from hanging around with one group of people to another when I felt like I wasn't fitting in and was made to feel uncomfortable. I remember around year 5 or 6 feeling very angry and hurt and sad that people didn't like me and I didn't know why”*

Cara *“but as I got older and had problems with friends I wanted people to like me so really tried to learn what people like, kept reinventing myself and changing things to try and fit in”*

Anna *“It's only when I had to "exit my head" and face outside world when I realized there is some problem... “. I don't think it was posing any particular problem until puberty.”*

Martin	*"but a big problem at secondary school and the transition between primary and secondary was not a good one. Lots of little things perhaps but I had a very strong sense of being in some way "other" and different to other children"*
Mark	*"I went from having an angry streak at 9-11/12, to simply disliking the formal environments and looking for ways to distract from / escape from that. This led to alcohol and nightclubs every night from Wednesday – Sunday each week for the age of 14. My parents were unable to control that."*

In two cases the participants further articulated that this continued to change - moving away from wanting to 'fit in' to the 'normal' to wanting to find their own group of people that were 'different' like them:

Kathy	*"I started to 'own' being a bit different instead of wanting to fit in, and often gravitated to other 'outsider' types as friends"*
Brad	*"While I figured out how to "accepted" myself in my early twenties"*

The results clearly indicate that the participants were more content in themselves at a primary age but around the age of puberty/secondary school they, as Anna so eloquently put it "had to exit my head" and consequently began to become more insecure in their self-identities. The generalisability of these findings will be important to explore in phase two.

4.2.3 Changing Societal Perceptions of Autism

Nine out of ten participants referenced how society had changed which had facilitated their exploration of autism and their consequential ability to self-identify as autistic. Three participants felt that generally knowledge of autism had improved:

Emily *“I guess no one knew much about it in the 80s”*

Mark *“simply it [autism] was not something that people were aware of”*

Neil *"the state of things at Eastern block in early 80’s, they were unable to identify what is going on”*

Two participants referenced that they felt the presentation of autism was viewed as more severe in the past and therefore the awareness of more subtle features of autism allowed them to recognise themselves in the depiction:

Anne *“I watched some documentary about autism, didn't think anything about it as it was about kids with quite visible impairments”*

Julia *“BUT I never thought that I could be on the spectrum myself, because I do not have extreme sensory issues (only small ones)”*

This development of awareness can be attributed to the role of the media alongside increased research into the field of autism. Four of the ten participants referenced how the media had facilitated their exploration of how they felt different, using a range of TV documentaries, reading and the internet to find information to associate with:

Martin *"when I watched a horizon documentary on Temple Grandin”*

Julia *"However by chance I heard Anne Heggerty talking on TV live from OZ on November 18th 2018”*

Anna *“I started reading about autism more and found a lot information on Asperger's and autism in women”*

Neil *“I play online strategy game called Warzone, and autism happened to be topic of discussion”*

While the media was identified as a key feature in allowing individuals to understand autism better it was also acknowledged as a source of hindrance, as inaccurate stereotypes reinforced the lack of understanding:

> **Martin** *"If your frame of reference is rain man (who wasn't autistic - Kim Peek who was the man who inspired the character was macrocephalic rather than being autistic) then your experience of autism is probably going to be challenging"*

In conjunction with the medium of the media, increased academic literature and research were identified as reasons for increased opportunities to understand autism:

> **Cara** *"decided to do my dissertation in the end on it"*

> **Margaret** *"She had just looked at it during her uni course (psychology or something like that) so I looked into it some more"*

While participants did not necessarily articulate how or why changes had occurred, there is strong evidence that all participants felt that significant changes had transpired over the past twenty years which had shifted their and others' understanding of autism. This in turn facilitated their ability to self-identify. It is further suggested that the development of the differing forms of media has played an important role in this which will be important to investigate further in phase two of my research.

4.2.4 Impact of others

The role other people made in each individual's construction of their identity, throughout their lifetime, prior to self-identification, was key and in itself is a central finding for consideration.

As the previous theme identified, prior to self-identification individuals were aware of being different to other people and how this may have led to negative implications, affecting their willingness to behave ‘naturally’ and consequential development of a secure identity:

Emily	*“I knew I struggled but didn’t put a name to it”*
Anna	*“feeling frustrated that I have to obey stupid social rules so that people don't hate me”*
Neil	*“I experienced a lot of shaming because I engaged in activities other people considered as having ‘no value’ ”*
Martin	*“I tried to engage with other students [at uni] and tried to use alcohol to get over my hang ups about interacting with other people, I became too reliant on alcohol and that created issues”*

There was also an awareness of how other people placed several negative labels on the individual, which could have impacts on mental health and self-concept:

Neil	*“people claiming there is something evil within me”*
Mark	*“When I did arrive at secondary school … I was generally considered to be “naughty”*
Martin	*“I was also told many times that I was very blunt in conversation and that I lacked filters and talked about inappropriate things”*

It was shocking to see how four of the participants not only experienced negative emotions due to their difference but also experienced physical and emotional abuse both as children and adults:

Martin *“early childhood I had vocal and physical stims but my dad beat those out of me pinning my arms and legs and slapping me around the back of my head when I barked.”*

Brad *“After 3 though things escalated. I grew up thinking my dad hated me and that the next time I made him mad he might kill me”*

Julia *"the need for help ASAP regarding bullying and PTSD-type symptoms now"*

Margaret *“worked in a church for a year where I got bullied loads”*

It would seem that other people had a significant impact on individuals building very negative self-images, which it is suggested would have subsequent implications on the ensuing themes of masking and mental health.

An interesting contrast of experience with regards to bullying was evident in the discussions with Mark when he expressed that:

Mark *“There was no bullying of me. I am ashamed to say that on occasion I showed bullying behaviour, as part of trying to fit in as one of the cool kids.”*

While it is evident that in this case, Mark was not impacted by bullies, he still experienced negative implications to his self-image as he was drawn into enacting bullying behaviour as a way of being accepted by his peers. This differing account of bullying reinforces the associations with the subsequent themes of masking and mental health.

Two of the participants expressed a stage where they felt they ‘accepted’ their difference and stopped trying to alter their ways to fit in. What was fascinating however was their expression that this was a superficial acceptance and they continued to seek understanding:

Brad	*“While I figured out how to "accepted" myself in my early twenties, it wasn't until I learned I am autistic that I really began to understand myself.”*
Kathy	*“I think one is about the surface things, that people could see and comment on, and one is about what was going on inside my head. I wanted to be comfortable and wear things that I thought looked cool, despite knowing it was outside the norm. That was 'owning' external difference. But I didn't know why I felt so lonely so much of the time, or why people didn't seem to care about me the way I cared about them, or the way they cared about each other. I didn't know why I didn't know who I really was and was always just trying to please other people to be liked. That's more of the internal stuff I wanted to find explanations for”*

The internal struggle articulated by Brad and Kathy was enlightened and provided an additional depth to the theme of searching which is encompassed within the impact of others. Six of the participants expressed differing experiences of ‘searching’ for acceptance or their ‘in-group’ (one participant did not clearly explain whether they searched or not and two participants were not searching):

Anna	*“I always wondered why I have certain difficulty”*
Neil	*"I felt like an alien here for my whole life”*
Margaret	*"I had been thinking about it for a year or so”*

The suggested search individuals experienced would seem to reinforce the presence of negative experiences, while also providing evidence that the participants were seeking connection with others, as well as a personal reflection and understanding.

While there is clear evidence that the participant’s identity formation was affected by others, there is equal evidence that the process of self-identification of autism also required the influence of other people. All participants provided evidence that experiences of others were used to directly compare with their own, and this helped build and secure an autistic identity:

Emily	*“[realised I was autistic] through working with autistic children. I realised I shared their traits and how they felt they fitted in”*
Kathy	*“through them I was led to an understanding of autism in women and girls, which then led me to a couple of other groups and self-identifying”*
Cara	*“yeah i enjoy reading peoples posts on facebook from autistic groups where I can totally relate to things they are talking about of struggling with”*
Anna	*“The first book I was reading at work I nearly started crying how close it was describing how I feel”*
Neil	*“what helped to break that stereotype was a lot of things. Communications with other autists. Reading blogs and watching videos of autistic people”*
Mark	*“I attended his final diagnosis session and pennies started dropping in new places - perhaps I was different too”*
Margaret	*{joined FB groups} “to find out more and be more certain about my conclusions”*
Martin	*“I started to research her history and background and found a theme of commonalities that made a lot of sense if I thought of myself as* being autistic.”
Brad	“It definitely helped with developing my identity. Hearing from so many other people and sharing thoughts and ideas on things like neuro-diversity; really helps with that identity.”

Julia	"Another point she [Anne Hegerty] made was about enjoying her own company but not feeling lonely, I feel the same way, but like her I can enjoy a social life outside the flat"

The data therefore suggests that the impact of others was fundamental in the construction of an autistic identity. This is a key finding within these results and will need to be explored further to establish its wider implications.

4.2.5 Masking

Seven of the participants made specific reference to masking in the discussion of their experiences, two participants did not mention it and were not directly asked to do so (therefore no assumption can be made as to whether they did or did not mask). No predefined definition of masking was provided to the participants as to not bias the answers they provided.

Based on the experiences shared, masking was suggested as a consciously used tool to 'fit in' when the individual became aware that they were in some way different:

Kathy	*"Especially the masking stuff. I have been consciously aware from childhood of having to observe other people's actions and copy them to fit and and seem normal"*
Cara	*"I'm very good at masking, mimicking or pretending to be what people want me to be"*
Mark	*"I have reflected before on when it began, ironically I can remember the first time I consciously changed; I wore a sweater to the first event at secondary school outside of school hours, of my favourite pop band. I was teased mercilessly as it was not a fashionable band. Everything*

after that point was focused on 'fitting in', and I believe that 'fitting in' sensation was one I sought thereafter."

Martin *"It's a constant struggle for me to maintain a viable sense of self as I spent a long time trying to be whatever people around me wanted me to be (people pleasing is a big issue for me)"*

Brad *"Yes [it was a conscious decision] I have been masking most of my life. My first recollection of masking I was about 3 years old."*

In contrast, one individual suggested that masking was not a conscious decision:

Margaret *"At the time I was trying desperately to hold onto my mask even though I didn't realise I was wearing one, so I don't think they saw 'me'. They saw the scraps of my mask with other bits showing through."*

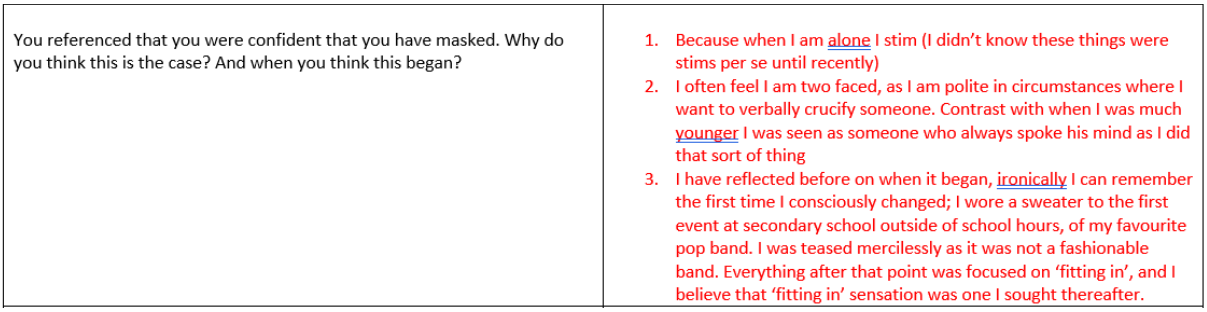
Masking is evident as a key feature in the lives of the interview participants. What was interesting to explore was the suggested relationship between masking and a negative impact on their ability to get a diagnosis and for people to accurately understand their experiences:

Kathy *"I also feel like I've hidden my emotional and social difficulties very well, so have managed to do things like have interesting jobs and get onto a PhD course at university, so I might get told I am too successful to be autistic"*

Furthermore, is the impact that masking has on the individual's mental health:

Anna *"If I am in prolonged situation where I have to pretend than I will exhaust my powers sooner."*

Of all the areas of discussion, masking proved to be the area that participants felt most comfortable talking about. There is consideration to be had about whether this corresponds with the theme of the impact of media, as masking has received a growth in attention over recent years. This, it can be argued, is illustrated in the participant check additional information offered by Mark on the subject of masking:



You referenced that you were confident that you have masked. Why do you think this is the case? And when you think this began?	1. Because when I am alone I stim (I didn't know these things were stims per se until recently) 2. I often feel I am two faced, as I am polite in circumstances where I want to verbally crucify someone. Contrast with when I was much younger I was seen as someone who always spoke his mind as I did that sort of thing 3. I have reflected before on when it began, ironically I can remember the first time I consciously changed; I wore a sweater to the first event at secondary school outside of school hours, of my favourite pop band. I was teased mercilessly as it was not a fashionable band. Everything after that point was focused on 'fitting in', and I believe that 'fitting in' sensation was one I sought thereafter.

Figure 9: Participant check additional information on Masking

As can be seen, Mark shares that he now interprets his behaviours as stims, an autism specific term, had he not become aware of this term through media (previously explained as through Facebook groups), he would not have classified it as such and therefore would consider it an element of masking. The above, also illustrates the subjective nature of understanding masking. While Mark refers to the change in the way he adapted as he aged to accommodate others, as an example of masking, one could suggest that this is merely an accurate representation of the expected social development from child to adult.

While the data suggests a careful consideration is required as to the ontological understanding of masking, the depth of discussion across participants on the subject matter indicates that masking is an important area for further exploration, especially in how it impacts on other themes such as mental health and the ability to receive a diagnosis.

4.2.6 Differences in autism

In a previous theme, reference was made to different presentations of autism and how it impacted on the individual's ability to self-identify. Aside from the stereotypical media presentation, two participants discussed personal experiences of this, in relation to other family members, and how this difference impacted on their ability to self-identify:

Brad	*"but nothing ever really clicked with me because I never had the speech and language delay he had and I didn't see much of myself reflected in him"*
Emily	*"I don't know to be honest. My husband who was diagnosed aspergers is almost narcissistic in his achievements" [comment made to show how he differs to Emily]*

There is a consideration to be given to whether autism presents differently or whether autism can often present with additional difficulties, and this affects an individual's ability to recognise the underlying autistic symptomology.

In order to consider whether autism is a singular identity or in fact that there are differences and therefore making it different dependent on the person, the themes relating to how the individuals viewed their autistic identities are considered collectively.

When participants were asked to discuss the concept of autism and where they position it within the notion of identity, all participant's language was suggestive of autism being a single entity, of which they sought to take ownership. Four of the ten participants made specific reference to the autistic identity being an essential part of their identity, something that underpins what makes them who they are:

Cara	*"Its central because it dominants every part of my life"*

Neil *“its impossible to not notice that I am autist in the same way that it is impossible to not notice that I am human or that I am male”*

Martin *“It is the significant part of my identity, its fundamental to being me.”*

Brad *“My autism has a massive impact on my perspective and everything I do, so I would say it's essential to who I am”*

Margaret *“ASD is as much part of me as my hair colour. or eye colour (because hair colour can be changed)”*

Two significant conversations arose through this discussion that was suggestive of the autistic identity being essential to the individual, but importantly, not by choice. In discussion with Cara, I got the sense that there was a difference between how central autism was to her life and the role she wished autism would play in her identity. In the sense that at present it affected everything she did and therefore it was ‘forced’ to have a central role, however if things were to change so it did not affect everything so significantly then it would be just one part of her identity:

Cara *“I suppose it is central to me. But the way i wish others to perceive and see me as me, but understand and not make me feel bad due to my autistic ways”*

Equally, Kathy made specific reference to the concept of identity being more of a social construct, that there is an expectation that an individual will adopt it:

Kathy *“There are things that we're supposed to consider our 'identity' on forms and things, like being White, being British, being Female, and I would consider being Autistic in this category. But honestly, I don't really relate to any of them in a way that feels like an identity.”*

There is an interesting question developing here, whether the term autism is an essentialist component of an individual's make up, or whether it is a socially constructed term which individuals are, without them realising, encouraged to use to give a name to their difference to the norm. The suggestion that it may be a label to identify societal categorisations of abnormal is reinforced in the theme that developed from the individual's experiences around the autistic identity being built on negativity. When coding the transcripts, seven out of the ten participants' experiences related to the initial theme of identity built on negatives, with extensive lists of things they could not do being used as the foundations of the autistic identity. Furthermore, in only one interview were positive attributes identified, and these were paired with an apology for thinking that way:

> ***Mark*** *"and I realise this will sound awful - I just thought I was better, more gifted"*

At this stage it would not be appropriate to consider the generalisability of the relationship between the autistic identity and negative attributes, however, this will be important to consider further in phase two of the research, while ensuring opportunities to identify positive elements in order to avoid unreliable results.

4.2.7 'Perfect Fit'

Despite their lack of diagnosis one of the themes that was clearly evident in six of the ten participants was the importance of the autistic identity feeling that it had to be a 'perfect fit' in order for them to accept it. This is evidenced by five of the participants having dismissed other diagnoses' (some professionally given) in favour of the autistic identity:

Kathy	*"I've at various times thought that I might have bipolar disorder, dissociative disorder or be a sociopath, but none of these have been a perfect fit."*
Cara	*"But I was not completely satisfied this [other mental health diagnosis'] was the reason I was the way I was….[with autism] finally everything started coming together and my life started making sense"*
Margaret	*"I was dx with Avoidant PD, Dependent PD and "significant traits of EUPD". So it's not very simple, but I generally feel that ASD works better than any of the above, and better than a stupid mix of them"*
Martin	*"I realised that a lot of what had been diagnosed as mental health conditions were actually much more likely to be consequences of being autistic and not realising"*
Brad	*"I spent quite a few months really scrutinising myself to make sure there wasn't any other explanation"*

While not specifically referenced in the discussion with Julia, it was noted that despite living 70+ years without making a connection to autism, and having only recently self-identified, her language and answers did not illustrate any level of doubt of the accuracy of her self-identification. Equally while no reference was made by Neil or Emily, their use of language in discussions suggested they had no doubt as to the 'perfect fit' nature of autism:

Emily	*"I'm 100% sure I'm on the spectrum"*
Neil	*"I didn't need any paper for what I know full well actually"*

Of those participants where the 'perfect fit' did not relate, Anna referred to not being 100% sure of whether autism was a perfect fit:

Anna *“Couldn't find any other explanation and autism made at least some sense”*

Equally while Mark did not make any specific reference to this theme, there was a discussion surrounding how he thought he felt insecure in acceptance of the autistic identity:

Mark *“don’t think I’ve worked that out yet to be honest”*

For both Anna and Mark, diagnosis was seen as essential in allowing them to construct an autistic identity/ies and therefore this may relate to their trepidation surrounding the ‘perfect fit’ nature of the autistic identity. The data surrounding diagnosis will be reviewed subsequently.

4.2.8 Diagnosis.

Each participant was asked their views on diagnosis and whether they felt it was needed or whether self-identification was sufficient. The opinions of the participants were not unanimous. Seven participants felt diagnosis was needed while one felt it was not. Two participants suggested they wanted a diagnosis but felt it would take too long to get, so had dismissed it. For those who continued to seek a diagnosis, the reasons could be sub-divided into wanting it for individual benefit and for the benefit of others. The rationale for seeking a diagnosis for individuals centred around the process of seeking validation, allowing the individual to confidently accept their autistic identity:

Emily *“not thinking I’m loopy”*

Margaret *“validation….I never completely trust my own judgement in anything”*

Cara *“Also wanted to clarify I am not deluded and have some sort of official and professional proof I'm not crazy.“*

Anna *“I wanted to know I am not imagining it, I wanted to know it is real”*

Kathy *“I think it will allow me to stop doubting my sanity and my conduct, and give me the security of knowing that there is an underlying reason why I do things and thing and interact in different ways to most people.”*

Mark *{so am I right in interpreting that for you the purpose of the formal diagnosis is to help you work out your true identity?} “I think that’s probably right.*

Two participants specifically stated they did not want a diagnosis for validation purposes but did require it to gain support:

Neil *“I need it for assigning status of ‘person disadvantaged due to health’“*

Martin *“Not sure if they still do but the NAS last time I asked required a formal diagnosis to offer any support and there have been several research projects I've wanted to be involved with that required a diagnosis”*

With five people seeking the diagnosis for personal reasons, more people (including those in the previously mentioned category) believed they needed the diagnosis to change the impact of others upon them. For example, Margaret explained that she felt having the diagnosis of autism would mean she was treated more fairly than with her other diagnosis’:

Margaret *“I have had a nurse refuse to turn a machine off that was majorly upsetting me (she told me it couldn't be turned off), then an hour later another nurse came in and said 'oh that's annoying isn't it?' and*

> *turned it off. If I'd been able to say 'I have ASD, please can you turn that machine off' she might have been more understanding. Or at least it'll mean no PD stigma"*

Equally Brad provided the example of his wife and how he felt the diagnosis would improve her interactions with him:

> ***Brad*** *"My wife has occasionally thrown it in my face that I don't have a diagnosis. I guess from that perspective I feel like a diagnosis would prevent her from being dismissive like that."*

Cara also reinforced that the diagnosis was needed for acceptance from family members:

> ***Cara*** *"My father follows suit however did say he can't believe it till I have something official stating I am"*

Only two of the participants felt a diagnosis was not needed. Julia had previously thought it was needed to get support but had discovered support through YouTube videos and conferences and therefore decided not to seek a diagnosis as she felt it would not be achievable at her age, while Emily was more definite that self-identification was all that she needed:

> ***Emily*** *"I think I'd be waiting for years for one. I'm 39 now and I'm 100% sure I'm on the spectrum. I don't think a piece of paper would change anything"*

It is evident that the majority of participants felt that a diagnosis was needed either for self-validation, support or to alter the perspectives of others. This would therefore suggest that self-identification was not perceived to be the 'end goal' but merely a stepping stone to diagnosis. This leads me to question what the value of self-identification is then on the individual.

4.2.9 Value of Self-Identification

One of the key areas which participants expressed was impacted by self-identification was their own self-acceptance and consequential individual support strategies, which links closely to the theme of mental health:

Cara	*"Yes I'm starting to learn what I can cope with, things that trigger or affect my health, things that effect how I respond and interact with others, trying to avoid things that are not good for me, managing my energy, sleeping, eating, self care"*
Anna	*"now I learned to let things go and stop controlling and planning every minute of my life because I found that it is not sustainable for me"*
Margaret	*"I don't do things that I know will be too much. I wear sunglasses when I need to, and don't care what people think. I have given myself permission to wear soft clothes as soon as I get in the house. I do some things I know will be 'too much' but I make sure that I have time to rest after."*
Martin	*"It has helped me to understand myself and to accept that I always have been and always will be out of step with mainstream society and that it is ok to be out of step. The most important thing it has given me is a sense that I'm not broken, or weird, or messed up, or damaged, I'm autistic and that's ok. I might well be all of those things as well lol! But under all of that I'm autistic and I have a sense of where I fit in"*

Further positive implications expressed were improved family relationships:

Neil	*"as for my family, my relationship with them significantly improved…because they got a framework for understanding me finally"*

And a reduced feeling of isolation:

Kathy *"Now I feel like I have a place to share those experiences with other people who get it and relate to them as perfectly normal. It's very reassuring"*

Mark reflected on whether self-identification made him more susceptible to behave/be more autistic, however felt that this was not the case:

Mark *"I suppose there is a danger that being more aware / accepting of it may increase propensity, but I think that's at least counterbalanced by consciously taking steps to identify what causes and exacerbates it"*

The implications of self-identification were predominately expressed as a positive experience. Some participants did express negatives in relation to how other people reacted to their self-identification, feeling an element of prejudice towards them and this may relate to the previous theme of diagnosis.

4.3 Conclusion

The themes identified and the experiences shared, have provided an enlightening account of the phenomenon of self-identification. Initial analysis suggests that self-identification improves mental health, while a lack of identification negatively impacts on the individual's mental well-being. Age plays a significant role in the impact on the individual, with experiences implicating secondary school years as specifically traumatic resulting from a shift in the individuals desire to engage with the social world. The media is suggested to play a central role in the growth of the phenomenon of self-identification while also paradoxically hindering diagnosis due to inaccurate stereotypes. A conflict of whether the autistic identity is a singular entity or plural as well as whether it forms an essential part of the individual or merely one part of many identities was evident which had implications on an expressed internal struggle for self-understanding and masking behaviours.

In line with the proposed methodology, further conclusions are not be made at this stage, however the results identified, alongside the superordinate theme categorisations are used to construct an online survey as the basis of Phase two of my research. In order to achieve this, the survey was constructed into the following sections:

- Demographic information
- Concept of autistic identity
- Connection with others
- Changes connected with age and searching.
- Media
- Mental health
- Masking
- Self-identification specific – incorporating all above themes.
- diagnosis

The findings of this phase will subsequently be drawn together with phase two results in the ensuing discussion chapter.

CHAPTER FIVE: PHASE TWO RESULTS

My findings from the literature review, alongside the results of phase one of my research were amalgamated to form hypotheses. These were then carried forward to test within the online survey undertaken in phase two. The questionnaire was active for a period of one month, a copy of which is recorded in as appendix 14 for reference.

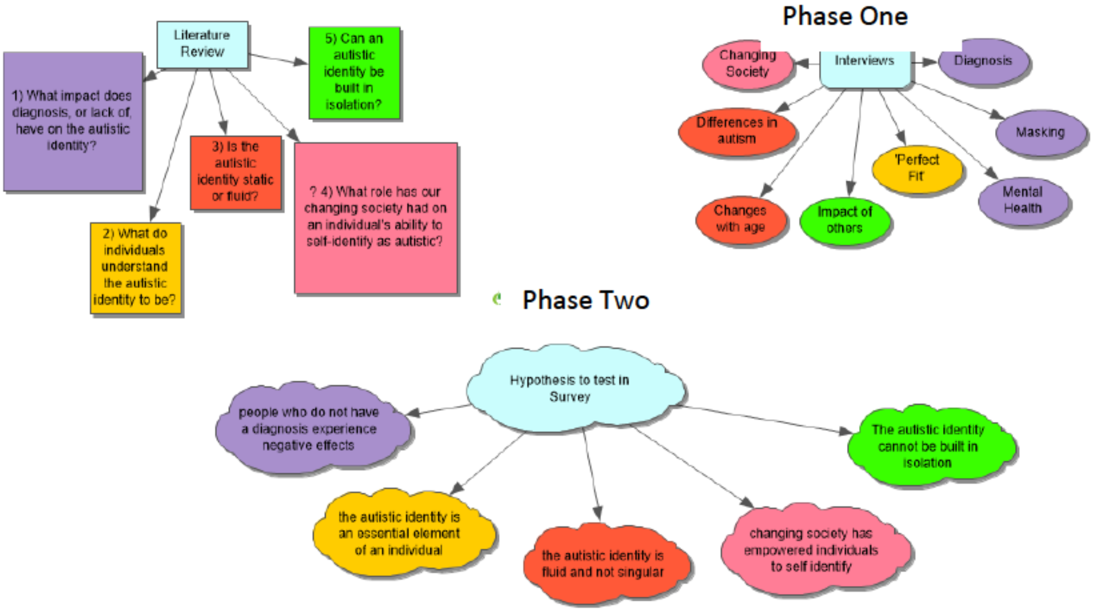


Figure 10: Themes to hypothesis for phase two

As the figure above illustrates, (which is copied as appendix 14 for easier viewing) the questions arising from the literature research were colour-coded to match the themes that arose from the semi-structured interviews. For each colour, a hypothesis was constructed that would accurately reflect the data previously gathered while also serving to develop my research further. Following consideration of the overall response rate and demographic information, each hypothesis will be reviewed in turn, outlining the data collated through phase two research (example of a completed survey is attached as appendix 13), concluding whether the hypothesis has been proven or disproved.

5.1 Response Rate and Demographic Information

5.1.1 Response Rate

As with any survey, completion rate was not 100% and this therefore needs to be taken into consideration. Initially I used the percentage progress rates that Qualtrics offered me and grouped them A-F. I then went through the data to see where each group had stopped their survey and recorded this. The percentage progress rates did not appear to accurately correlate to the data e.g. one person in group D answered more questions than one person in group E, and five people in group E answered all the questions but were not recorded as 100%. One person marked as 100% completion stopped at question fourteen! I therefore recategorized, based on the point at which they ended the survey and calculated completion numbers from this. This meant that I did not need to disregard any data collated, for each question the number of respondents is accepted to be different and therefore percentages of the total answers are given to indicate a fair comparison. In total one hundred and seventy-three people began the survey, as the table below indicates, forty-three people did not progress past the consent stages and therefore in total one hundred and thirty people provided usable data. The planned response rate for the survey was one hundred people, therefore the number of participants was above that which was expected.

A	did not progress from looking at consent form/information	43
B	filled in demographic information and did not progress any further	6
C	filled the first page of questions (up to question 15)	5
D	finished at question 30	6
E	finished at question 39	1
F	finished at question 48	1
G	finished at question 52	111

Figure 11: Survey Response rate. Table

According to ProProfs, a 40% response rate is average for surveys distributed via email, and 50-60% is considered good to very good; for online surveys, 30% is average. (The Marketer's Guide to Surveying Users, n.d.). With 64% of people completing the survey at the end, this response rate under these categorisations would be deemed as 'very good'. It is acknowledged that for the purposes of this research the analysis included is as described, however there was valuable data that would merit analysis on its own but was outside the scope of this research due to the volume. This data therefore will be appropriately stored in line with previously outlined ethical guidelines, and reviewed at a later date, outside the realms of this thesis, to ensure maximum impact of the research gathered.

5.1.2 Demographic Information

The basic demographic information of the participants: Age, Location, Gender, Ethnicity, Religion, Relationship Status, Way in which they identify as Autistic and what prompted their identification is outlined as this provides important context to the data collated.

5.1.2.1 Age

Field	Minimum	Maximum	Mean	Std Deviation	Variance	Count
Under 18	2	3	2.67	0.47	0.22	3
18 - 24	1	4	2.58	0.95	0.91	12
25 - 34	1	4	2.12	0.93	0.87	34
35 - 44	1	3	2.12	0.82	0.67	25
45 - 54	1	3	2.06	0.7	0.5	36
55 - 64	1	4	2.31	0.72	0.52	13
65 - 74	2	3	2.17	0.37	0.14	6
75 - 84	1	1	1	0	0	1
85 or older	0	0	0	0	0	0

Figure 12: Survey Demographic Information – Age. Table

It is noted that three of the participants were under 18 and therefore out of the ethical approval for this study and consequently their data was disregarded.

5.1.2.2 Location

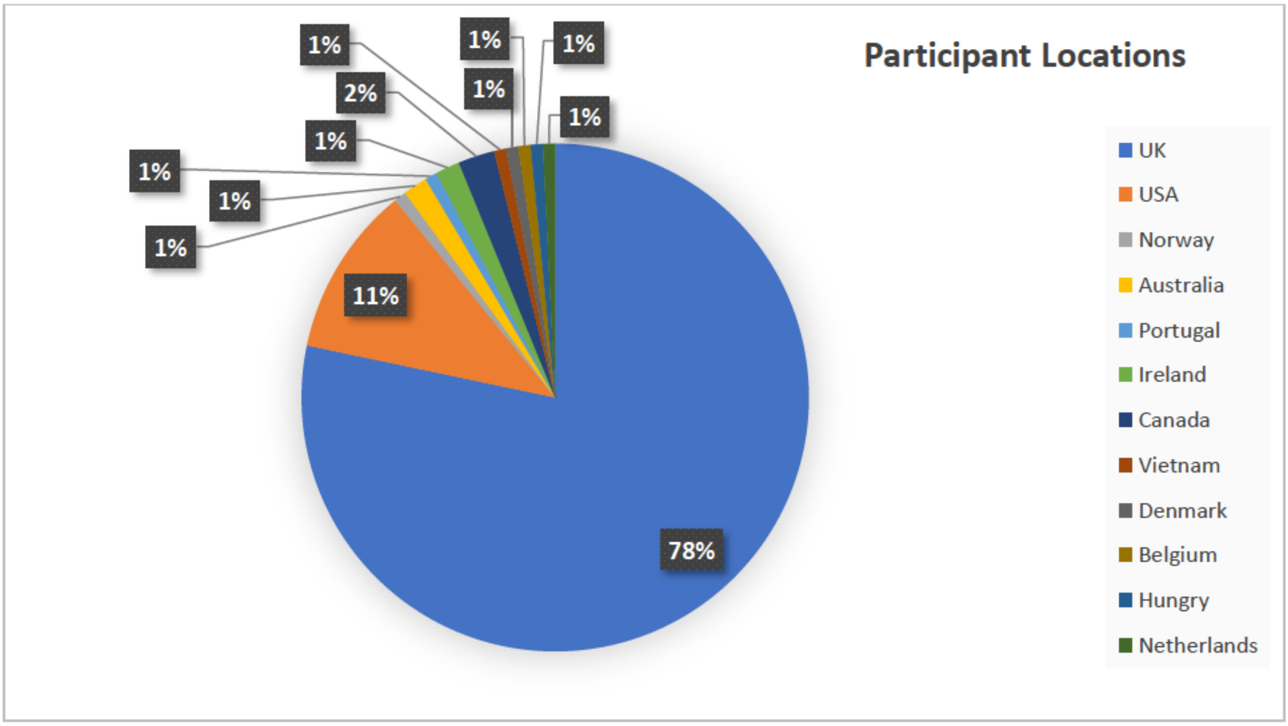


Figure 13: Survey Demographic Information – Location. Graph.

5.1.2.3 Gender

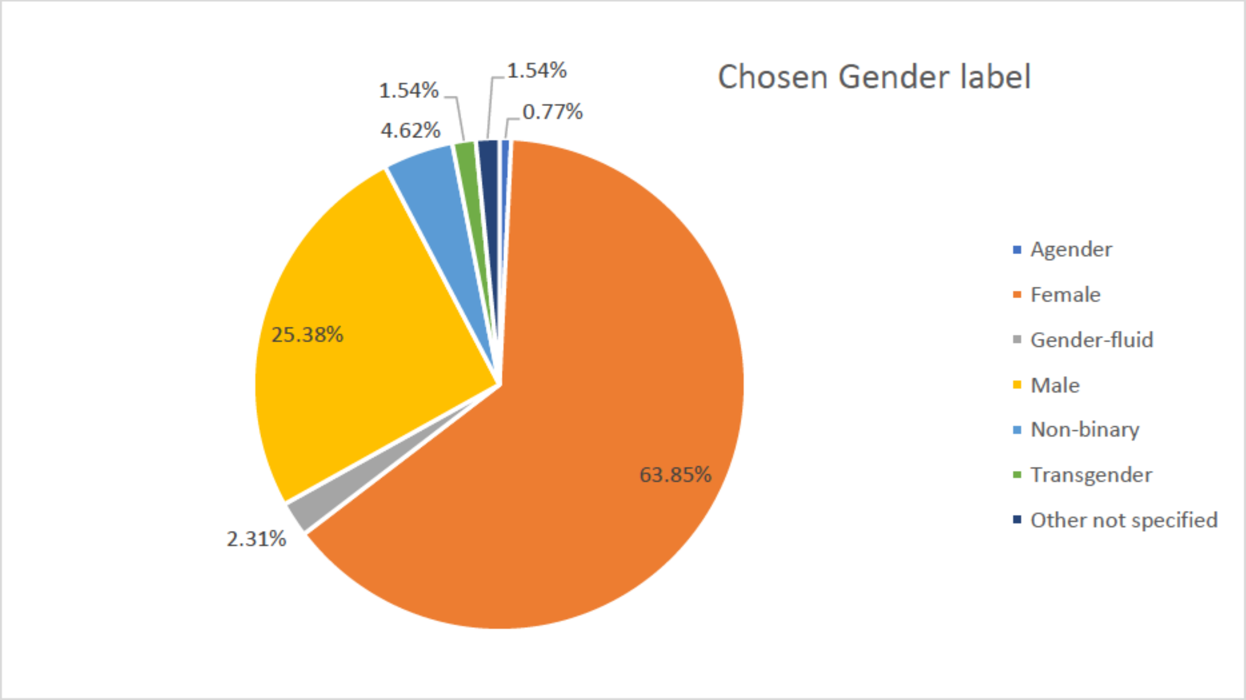


Figure 14: Survey Demographic Information – Gender. Graph.

5.1.2.4 Ethnicity

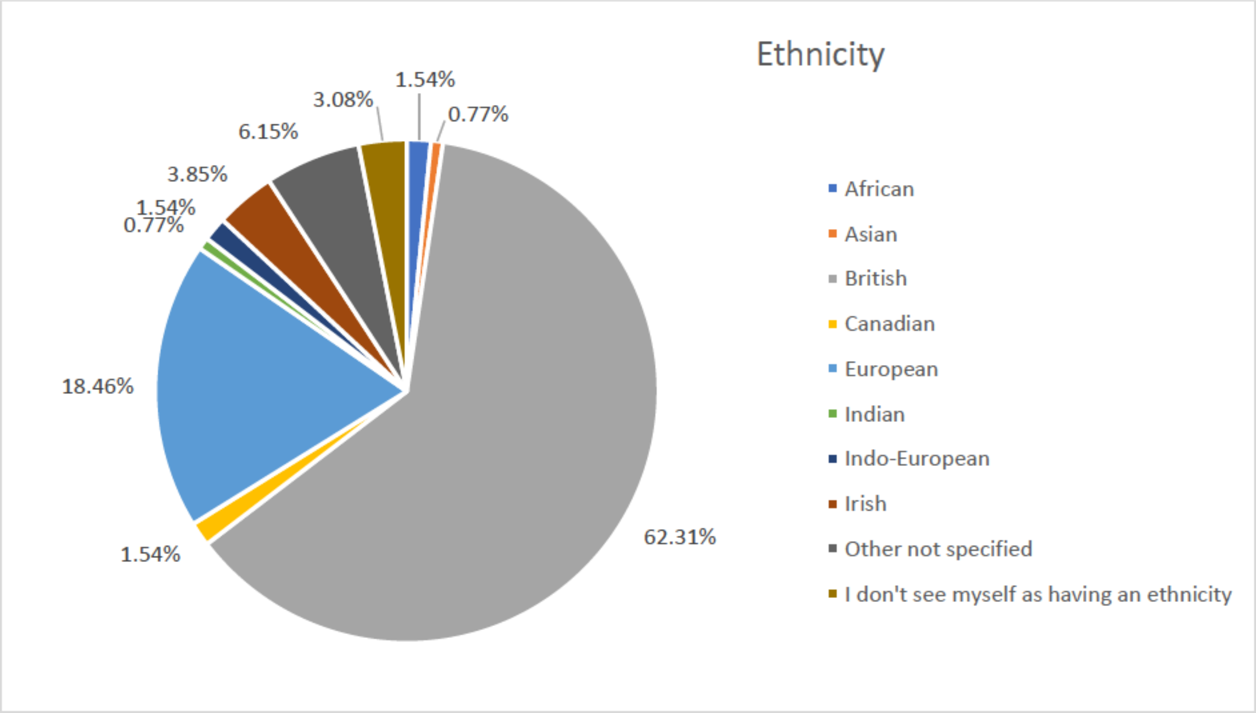


Figure 15: Survey Demographic Information – Ethnicity. Graph.

5.1.2.5 Religion

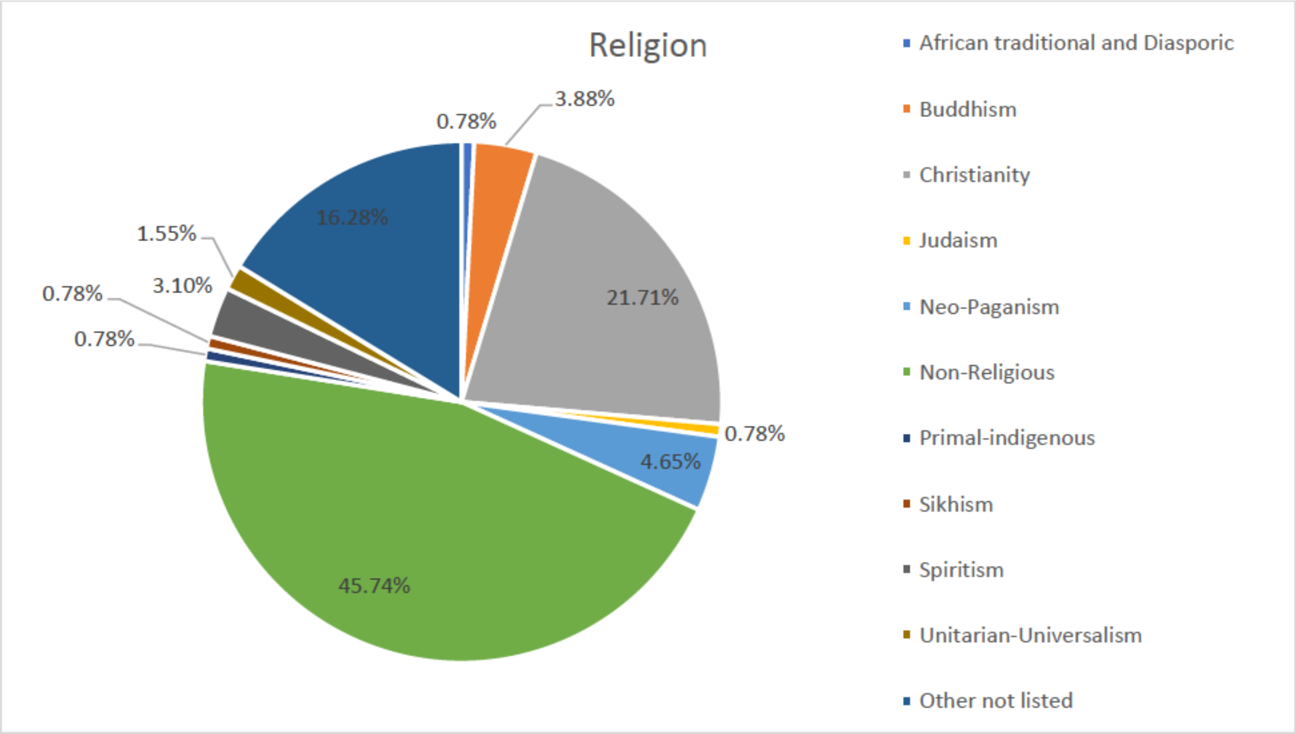


Figure 16: Survey Demographic Information – Religion. Graph.

5.1.2.6 Relationship Status

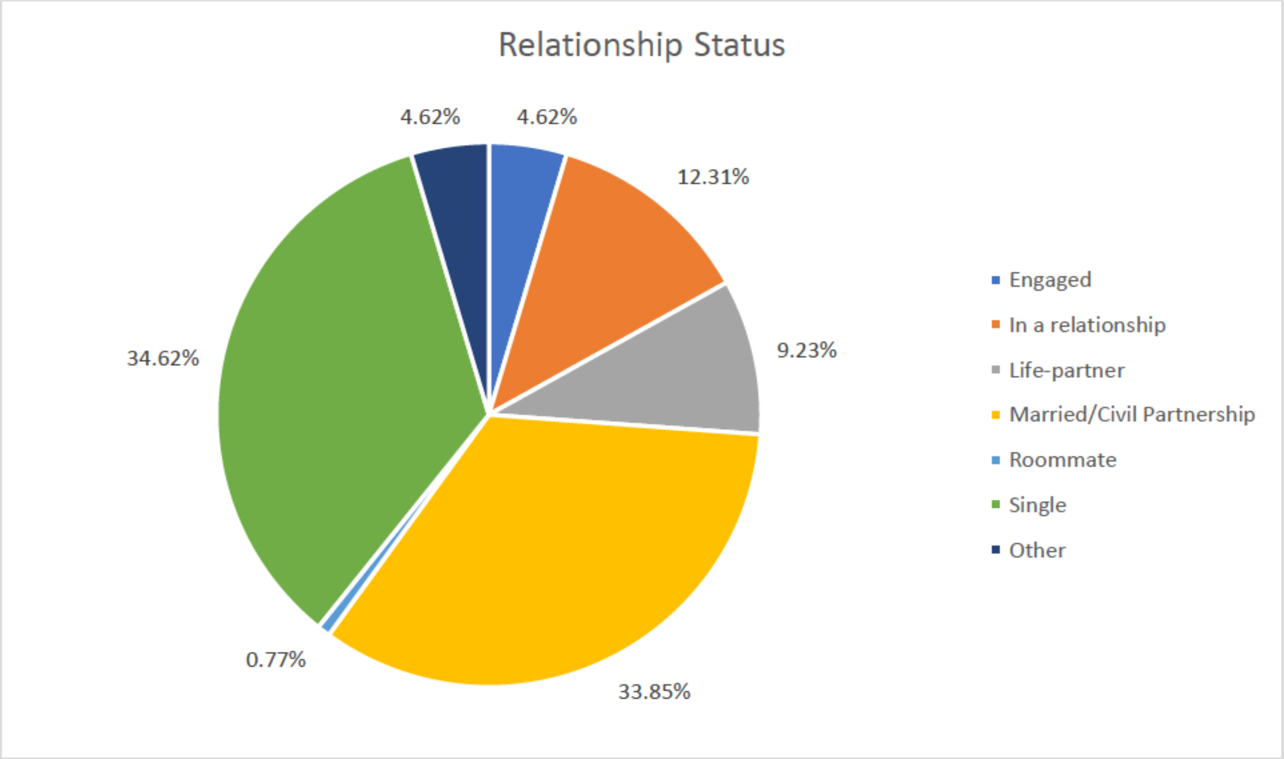


Figure 17: Survey Demographic Information – Relationship. Graph.

5.1.2.7 Way in which they identified as autistic.

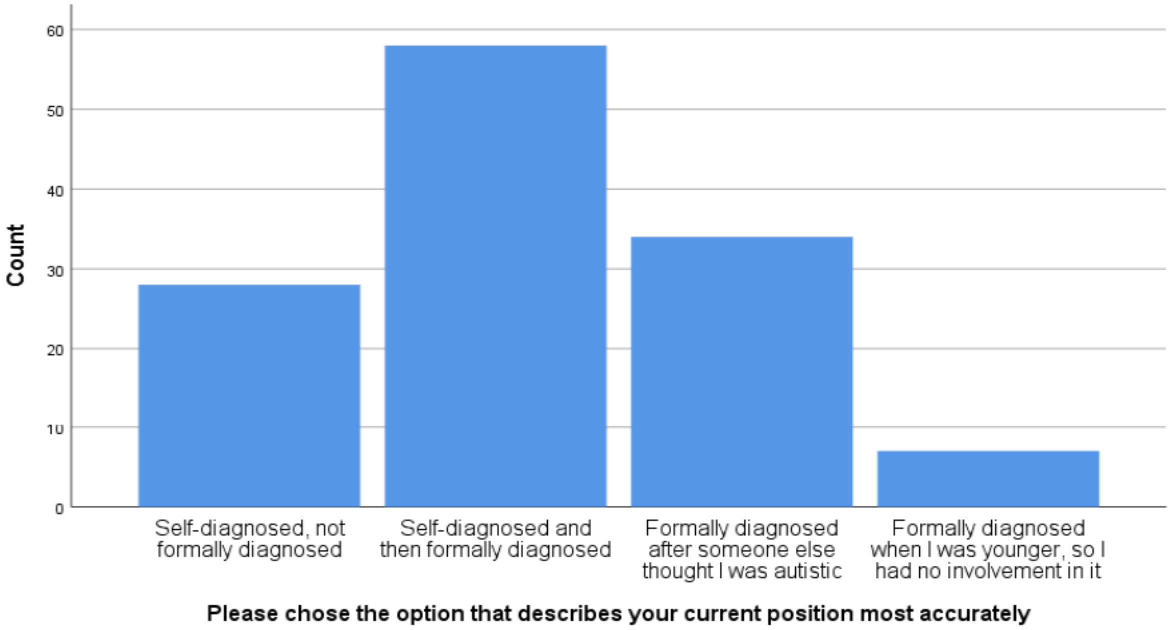


Figure 18: Ways participants Identified. Graph.

5.1.2.8 Prompted Identification?

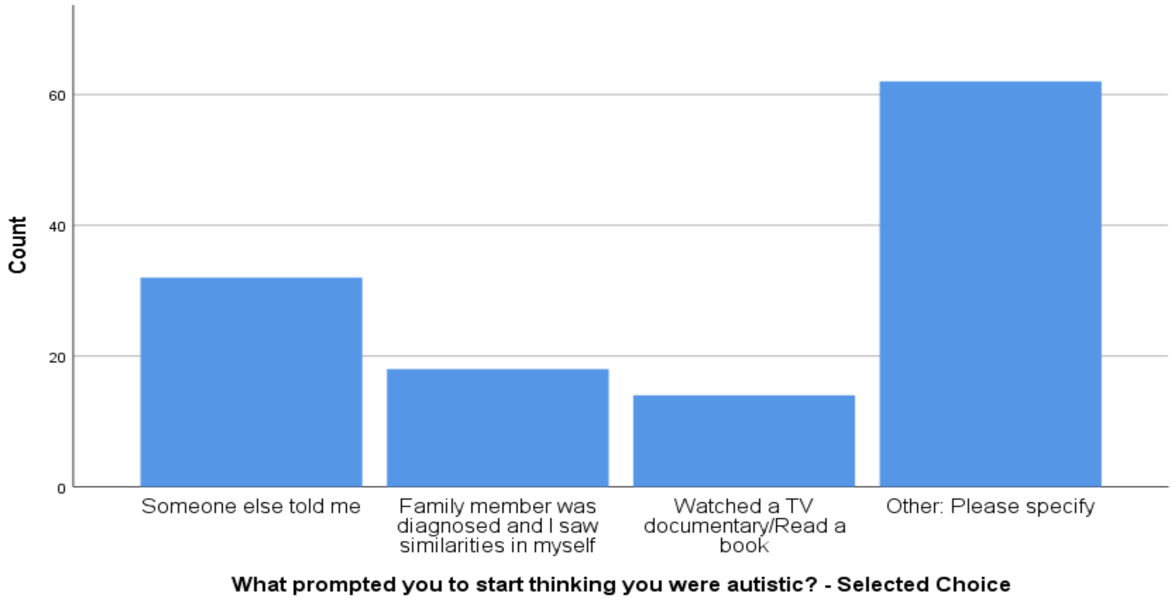


Figure 19: What prompted identification with autism. Graph.

As so many people chose 'other' in the previous question I analysed the comments and re-grouped then. In some cases, their answer directly matched an option already available. For some, the wording was too specific for them to feel their answer matched, so the wording of the category was amended. For others, new groups were created based on their answers. This allows for better analysis as having so many 'others' made interpreting the previous data unreliable.

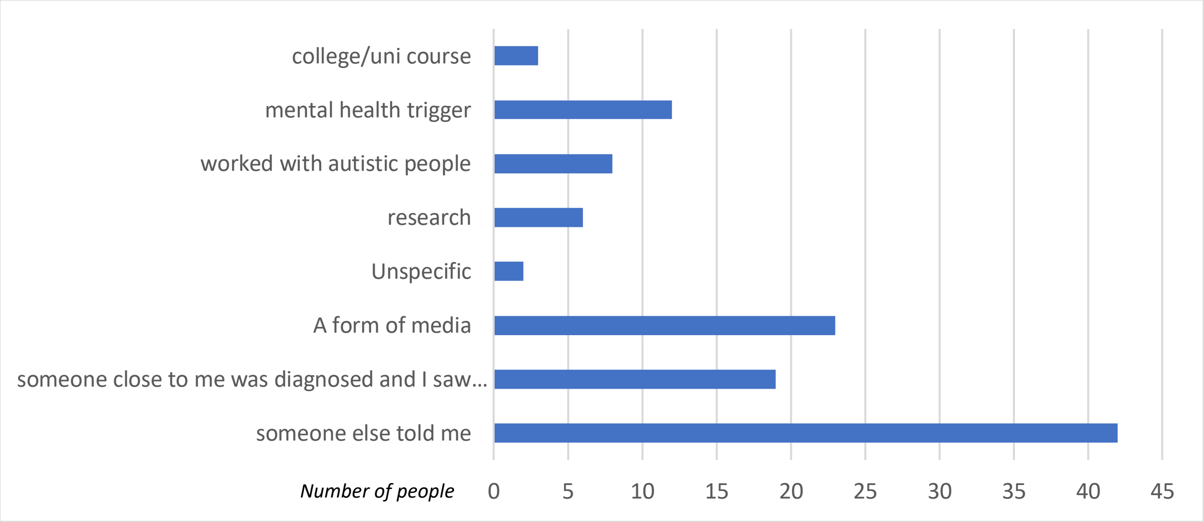


Figure 20: What prompted identification. Graph

5.2 Demographic Comparisons

5.2.1 Age of participants, against what prompted them to believe they were autistic:

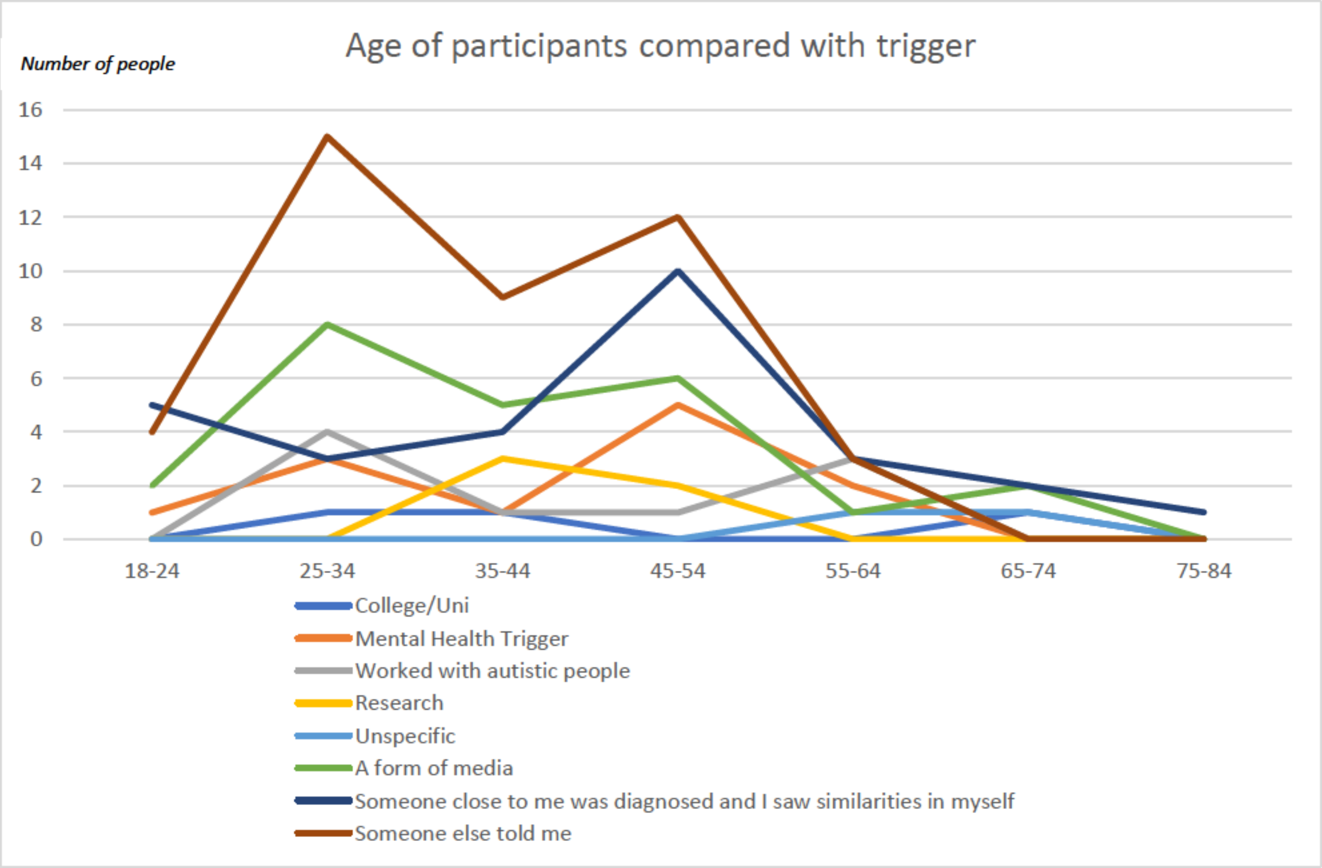


Figure 21: Age of participant compared with trigger. Graph.

It is important to note the difference in the way individuals began their identification of autism journey in comparison to their age. For example, it was less likely to be prompted by someone else as the age of the individual increased. Equally it was more likely to be promoted by the media in the younger age ranges.

5.2.2 Age difference between current age and age of self-identification or formal diagnosis

		Minimum	Maximum	Average number of years between current age and SI/D	Std Deviation
18-24	Years Since Self Identification (SI)	0	7	3.8	1.72
	Years Since Diagnosis (D)	0	19	6.3	7.06
25-34	Years Since Self Identification (SI)	0	16	4.7	4.45
	Years Since Diagnosis (D)	0	21	5.7	6.27
35-44	Years Since Self Identification (SI)	0	25	7.2	7.26
	Years Since Diagnosis (D)	0	38	8.5	10.64
45-54	Years Since Self Identification (SI)	0	37	6.9	7.55
	Years Since Diagnosis (D)	0	47	6.7	10.90
55-64	Years Since Self Identification (SI)	2	48	9.8	14.52
	Years Since Diagnosis (D)	0	10	4.0	3.04
65-74	Years Since Self Identification (SI)	2	33	13.0	14.88
	Years Since Diagnosis (D)	1	33	12.5	13.84
75-84	Years Since Self Identification (SI)	10	10	10.0	0.00
	Years Since Diagnosis (D)	no data	no data	no data	no data

Figure 22: Different between age and age of identification. Table

Unsurprisingly the higher the age range the higher mean age difference between self-identification/diagnosis and current age. What is notable however is the range of ages, with some participants self-identifying as autistic for over 30 years, indeed in the 55-64 year age range the maximum age difference between self-identification and current age was forty-eight years. It is also important to note the high standard deviations in the data set, indicating a significant variance between individuals, especially within the older age brackets.

5.3 Hypothesis Testing

As phase two of the research did not specify an inclusion criterion of self-identification, the way in which the individual identified themselves has been used as an independent variable in the analysis of results. Dependant variables are compared against this to identify the different experiences of those who self-identify.

5.3.1 Hypothesis One: “People who do not have a diagnosis experience negative effects”.

Figure twenty-three illustrates the dependent variable of whether individuals felt there was a direct correlation between autism and mental health. It is noted that both positive and negative options were given to the participants to choose from as a direct development of my phase one data analysis. The intention was to reduce any bias towards negative connotations of mental health and therefore provide more reliable results.

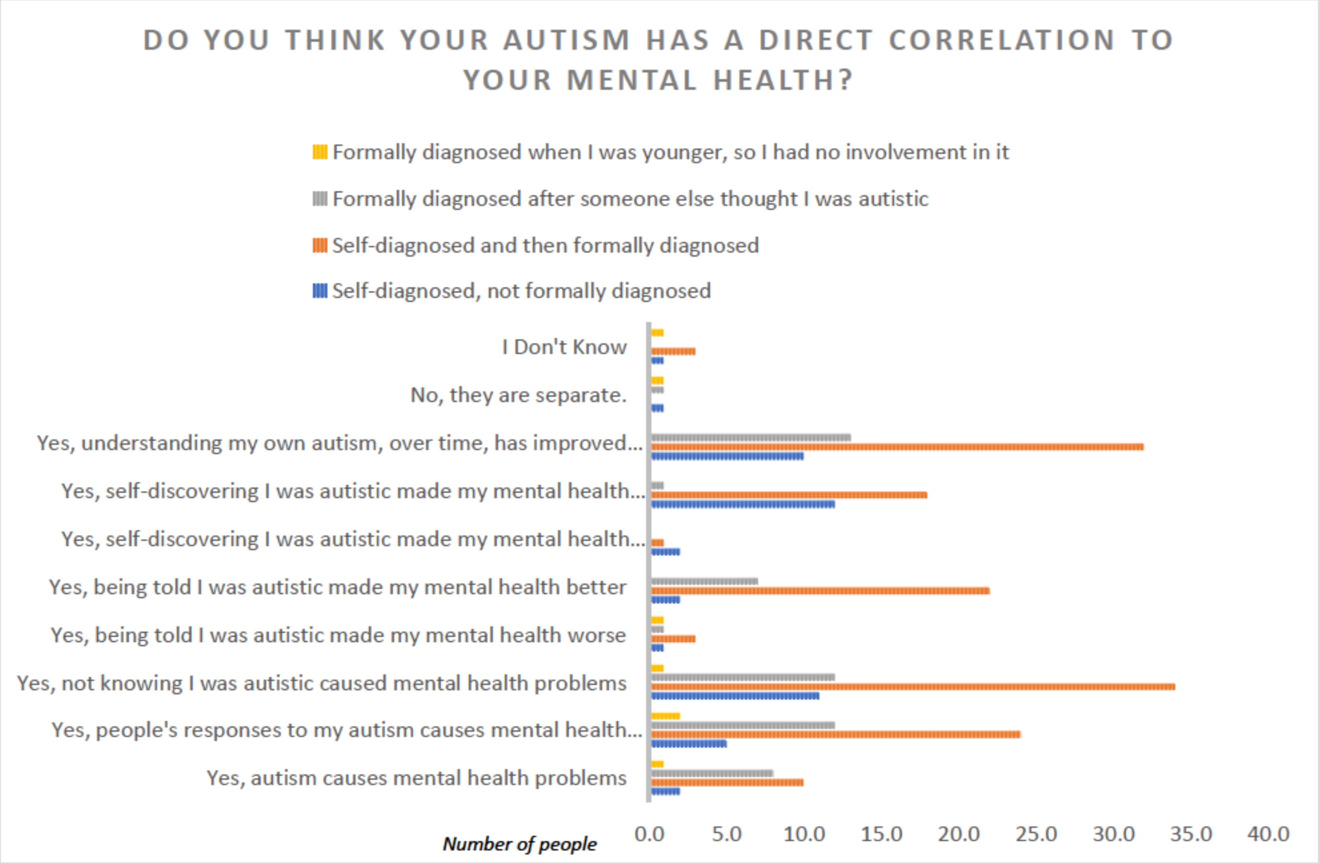


Figure 23: Opinions on autism correlation to mental health

The results illustrate that, for those individuals that self-identified, they felt their mental health was worse prior to self-discovery and better afterwards. On the surface a correlation could be assumed, suggesting that self-identification improves mental health. However, this is approached with caution, as it is questionable whether the process of self-reflection that must occur to undertake self-identification, would automatically lead to better mental health? Another factor to note from these results, is that those who were formally diagnosed at a younger age reported a higher response rate of other people impacting negatively on their mental health, suggesting therefore that the diagnostic label may result in increased mental health implications in specific areas than those who self-diagnose do not experience.

Figure twenty-four outlines the percentages of responses to the direct question of whether participants felt that not realising they were autistic at a younger age negatively impacted their mental health:

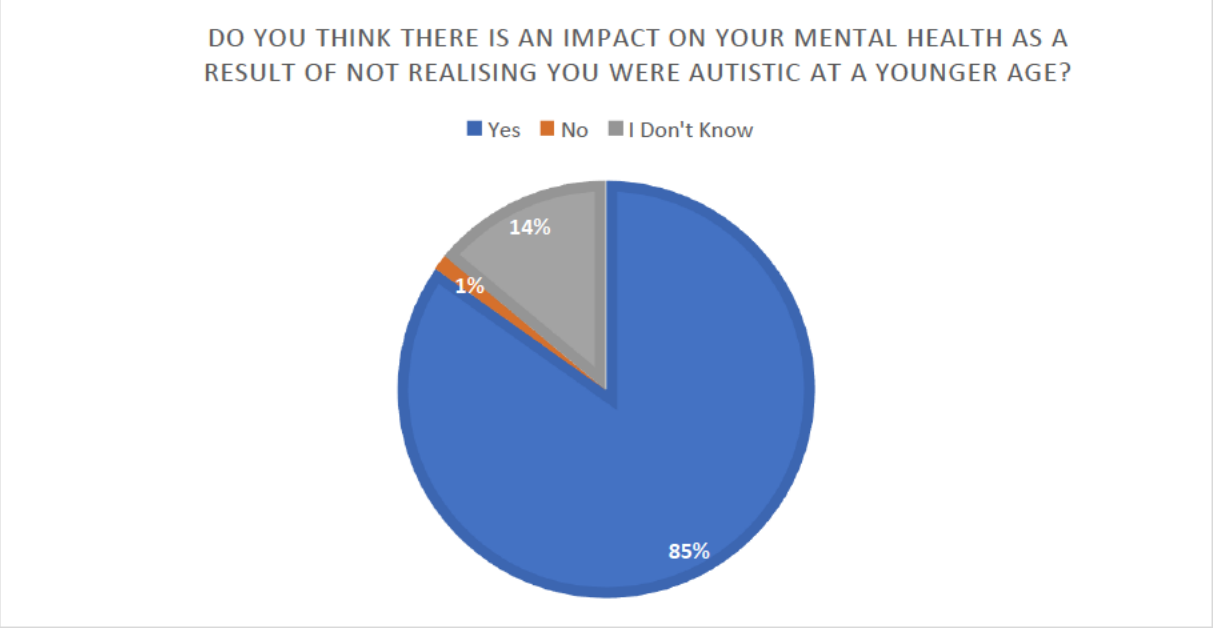


Figure 24: Opinions on impact on mental health and delayed identification

The data illustrates clear evidence that participants felt that their mental health was negatively impacted by not identifying as autistic at a younger age. This was reinforced by the additional text participants chose to add to their answers, such as:

> *"Yes because I could have been helped more in school and I wouldn't of hated myself so much for being different no matter how hard I tried to fit in"*

> *"Yes, absolutely - from an early age when I was teased about my stims, to preteen age when I struggled socially and experienced a lot of rejection, to misunderstandings as an adult it has had a profound impact"*

> *"IF I COULD SAY YES ANY HARDER I WOULD. single biggest regret."*

One comment illustrated the connection between negative impacts of non-identification and the changes occurring within society and general awareness:

> *"When I was young there were no such things as EHCP's or reasonable adjustments so maybe it would even have just given the bullies another weapon in their arsenal."*

> *"If I could have been diagnosed when much, much younger....oh that would have been so much better and saved so much heartache. However, attitudes towards autism and neurodiversity were not as they are now...."*

These comments raise, alongside those identified above, further questions as to whether it is the lack of identification that caused mental health implications or the intolerant attitudes of others to difference. This is demonstrated succinctly further in additional comments participants added to their answers:

> *"It would have made more of a difference if they'd picked up on the abuse. I was a very capable kid autism or not, and also resilient."*

> *"I felt invalidated. also felt like an alien."*

Figure twenty-five outlines the dependent variables of mental health issues experienced against the previously stated independent variable. It is noted that participants were asked to identify any mental health issues they felt they had experienced (multiple could be chosen) and not just ones with which they had been diagnosed.

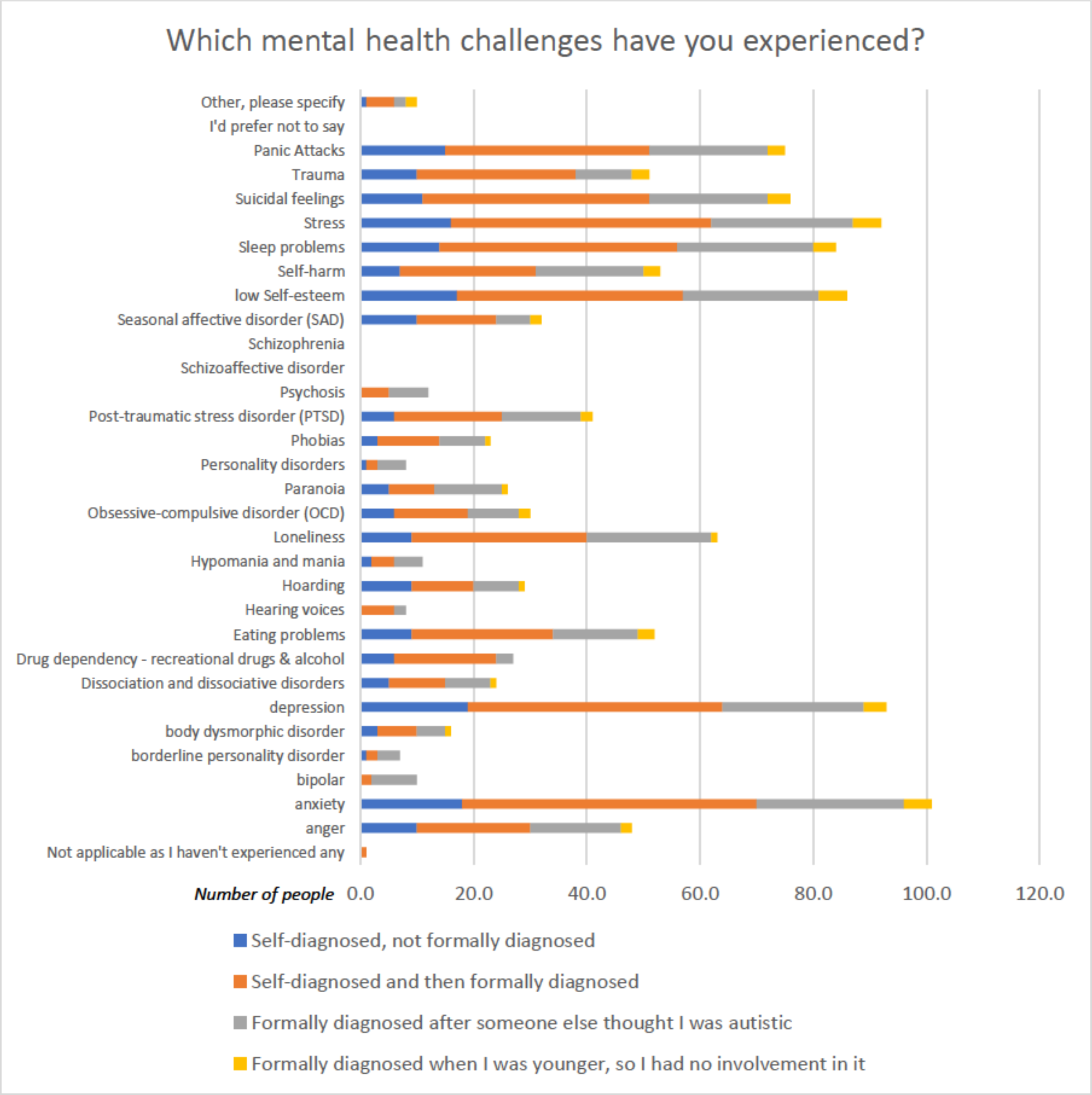


Figure 25: Mental Health experiences. Graph.

The number of responses provided make this a busy graph to interpret which indicates that participants had experienced several mental health challenges. Unpicking the graph however, it can be noted that those categories chosen most by participants who self-identify could also be considered mental health issues that people are more likely to self-identify with rather than being medically diagnosed with, for example depression, anxiety, anger, low self-esteem and panic attacks. To understand the breakdown of categories in more detail, the percentage of responses within each independent variable was compared, to ascertain which variable chose a mental health category the most (highlighted yellow).

	Self-diagnosed, not formally diagnosed	Self-diagnosed and then formally diagnosed	Formally diagnosed after someone else thought I was autistic	Formally diagnosed when I was younger, so I had no involvement in it
Not applicable as I haven't experienced any	0.0	0.2%	0.0	0.0
Anger	4.7%	3.5%	4.5%	3.6%
Anxiety	8.5%	9.2%	7.3%	9.1%
Bipolar	0.0%	0.4%	2.3%	0.0
borderline personality disorder	0.5%	0.4%	1.1%	0.0
body dysmorphic disorder	1.4%	1.2%	1.4%	1.8%
depression	8.9%	7.9%	7.1%	7.3%
Dissociation and dissociative disorders	2.3%	1.8%	2.3%	1.8%
Drug dependency - recreational drugs & alcohol	2.8%	3.2%	0.8%	0.0
Eating problems	4.2%	4.4%	4.2%	5.5%
Hearing voices	0.0	1.1%	0.6%	0.0
Hoarding	4.2%	1.9%	2.3%	1.8%
Hypomania and mania	0.9%	0.7%	1.4%	0.0
Loneliness	4.2%	5.5%	6.2%	1.8%
Obsessive-compulsive disorder (OCD)	2.8%	2.3%	2.5%	3.6%
Paranoia	2.3%	1.4%	3.4%	1.8%
Personality disorders	0.5%	0.4%	1.4%	0.0
Phobias	1.4%	1.9%	2.3%	1.8%
Post-traumatic stress disorder (PTSD)	2.8%	3.4%	4.0%	3.6%
Psychosis	0.0	0.9%	2.0%	0.0
Schizoaffective disorder	0.0	0.0	0.0	0.0
Schizophrenia	0.0	0.0	0.0	0.0
Seasonal affective disorder (SAD)	4.7%	2.5%	1.7%	3.6%
low Self-esteem	8.0%	7.1%	6.8%	9.1%
Self-harm	3.3%	4.2%	5.4%	5.5%
Sleep problems	6.6%	7.4%	6.8%	7.3%
Stress	7.5%	8.1%	7.1%	9.1%
Suicidal feelings	5.2%	7.1%	5.9%	7.3%
Trauma	4.7%	4.9%	2.8%	5.5%
Panic Attacks	7.0%	6.3%	5.9%	5.5%
I'd prefer not to say	0.0	0.0	0.0	0.0
Other, please specify	0.5%	0.9%	0.6%	3.6%

Figure 26: Mental Health Experiences. Table

It is noted that those participants who were formally diagnosed are highlighted yellow more frequently than those who self-identified. Out of thirty-two possible options 31% were chosen most often by those that self-identified (first two variables), with 59% chosen most often by those that were formally diagnosed (second two variables).

To consider past experiences, questions were asked of the participants relating to their childhood and school years. Figure twenty-seven illustrates the age at which participants stated they started to feel different to those around them.

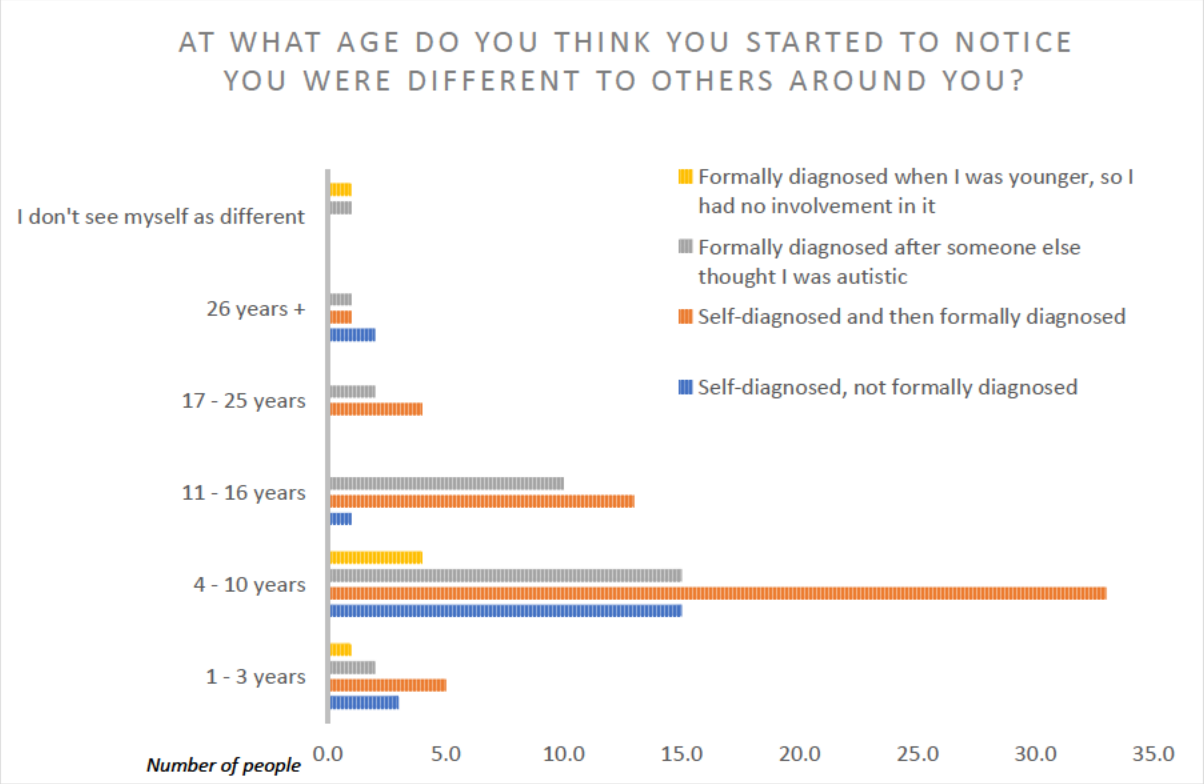


Figure 27: Age participants started to notice difference. Graph

It is astonishing to see from these responses that regardless of diagnosis, participants predominantly noticed their difference between the ages of four and ten. When relating this to perceived school experiences it is shocking to note that while a significant number of participants were acknowledging their difference between the ages of four to ten, there were still some positive experiences acknowledged at this stage, as illustrated in figure twenty-eight.

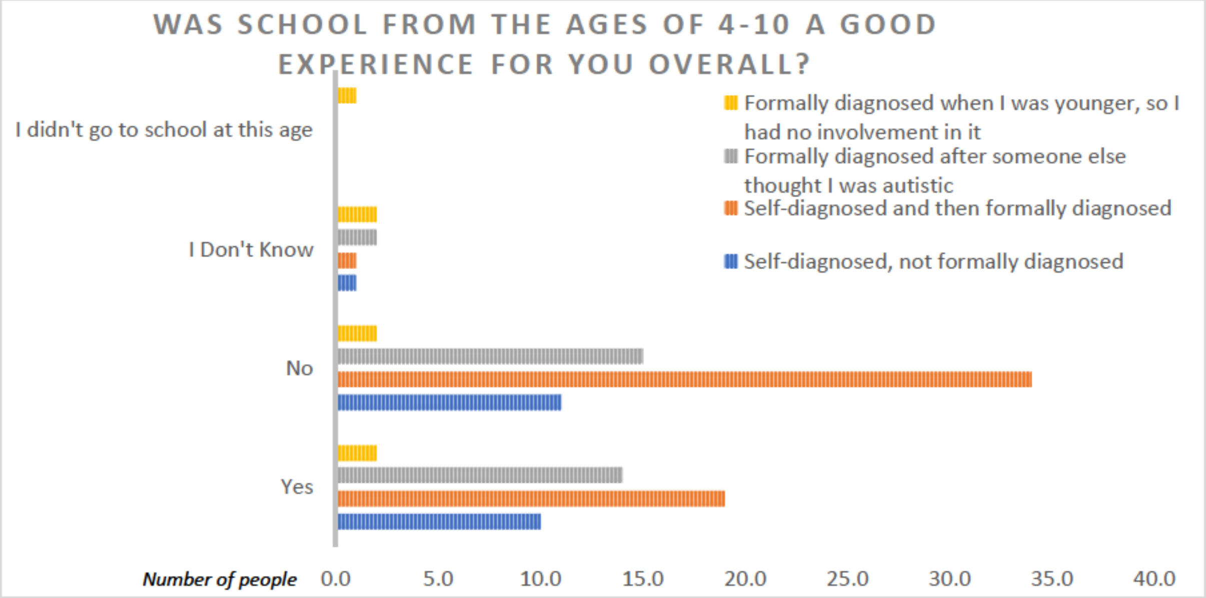


Figure 28: Experience of School. 4-10 years. Graph

In stark contrast however, a higher percentage of people reported negative school experiences between the ages of eleven and eighteen, as illustrated in figure twenty-nine.

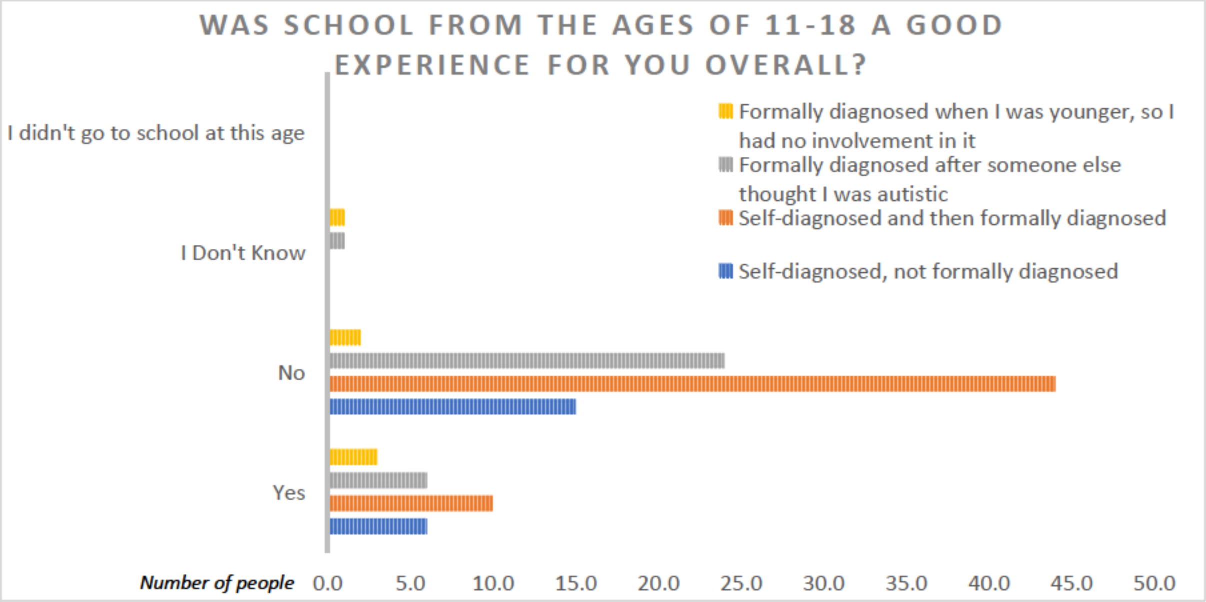


Figure 29: Experience of School. 11-18 years. Graph

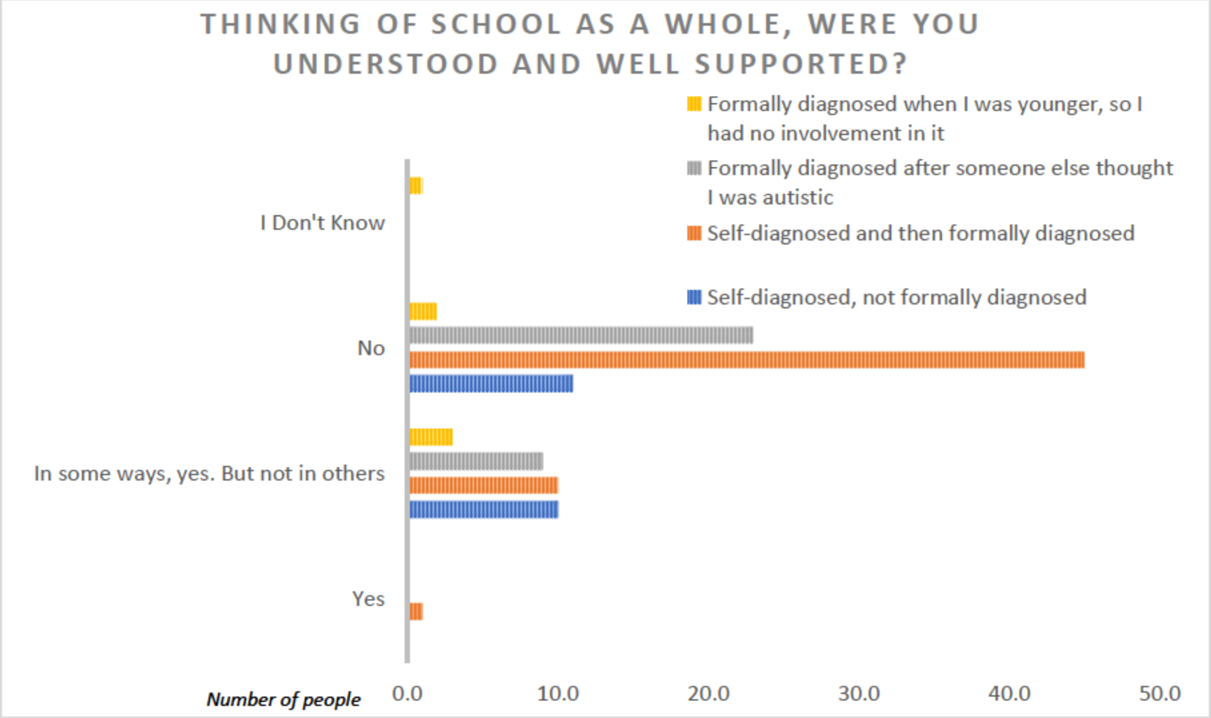


Figure 30: Experience of school overall. Graph

Figures Twenty-eight through to thirty indicate stark data that school, on the whole, but predominantly post 11 years, was not a positive experience for the vast majority of the participants in this study. This correlates with figure thirty-one's illustration of experiences of bullying:

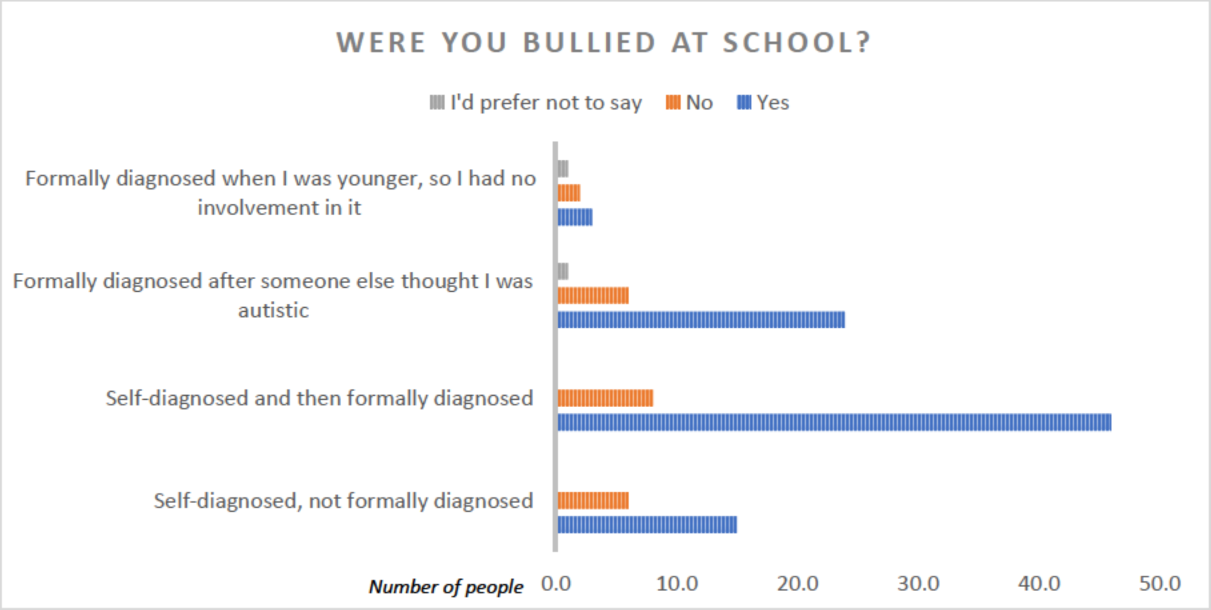


Figure 31: Experience of bullying. Graph

It is clear from this representation of the results that more participants felt they were bullied at school than those that felt they were not. With those without a diagnosis reporting that they were bullied at a higher rate than those with a diagnosis. Therefore, suggesting that those without a diagnosis have more negative experiences at school.

As masking has been increasingly reported within the field of autism and as a key theme in phase one research, it was important to consider its role within the hypothesis of negative experiences. Figure thirty-two provides succinct evidence that when reviewing the answers given by participants on masking over five questions, most people reported they undertook masking, and importantly that this was unaffected by formal diagnosis. As the graph below indicates the difference between masking and non-masking was comparable throughout. This suggests that the current process of diagnosis does not provide individuals understanding and confidence in their autism, leading to reasonable questions as to the validity of the process for the individual. This will be reviewed further in subsequent sections.

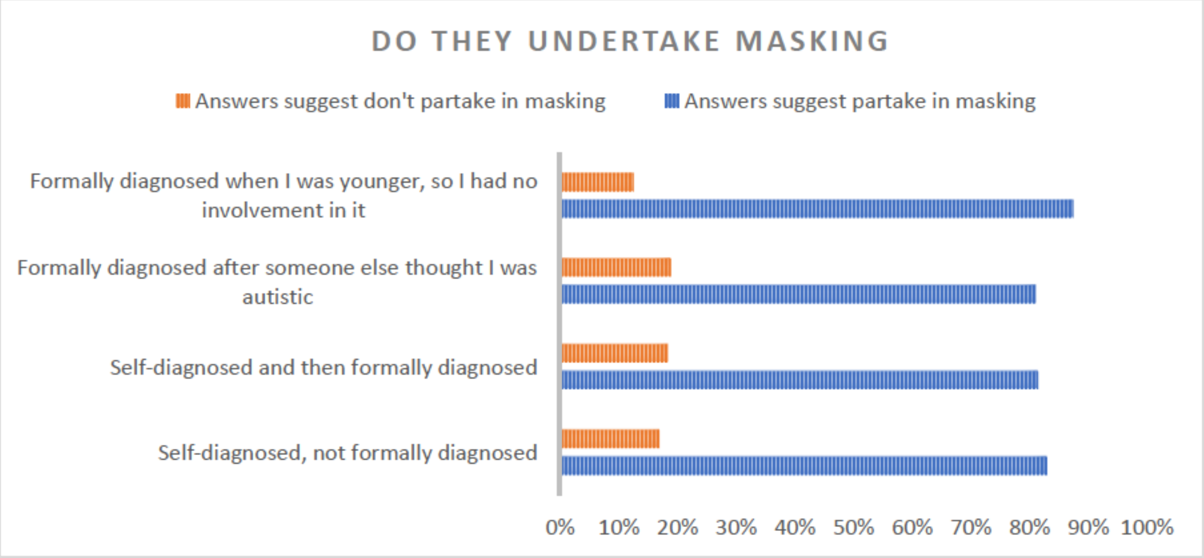


Figure 32: Experience of masking

The following graph equally indicates that participants felt masking had a direct impact on mental health and this once again was not affected by formal diagnosis.

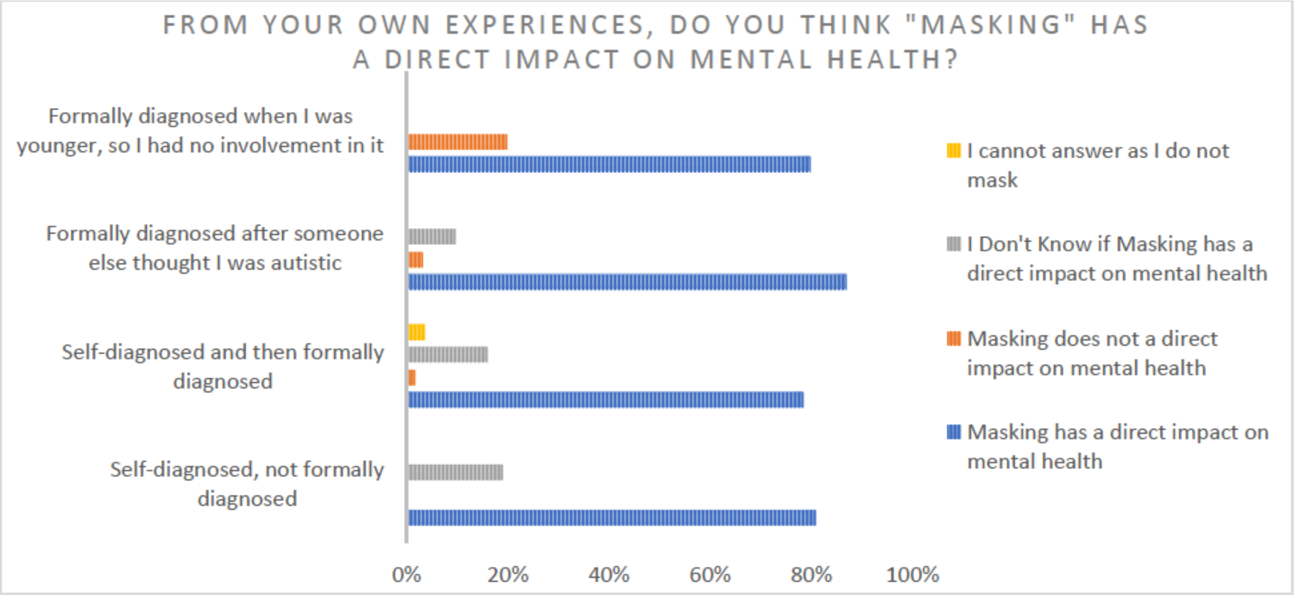


Figure 33: Opinions on masking and mental health. Graph

While it is easy to assume that such results indicate that individuals are undertaking masking and therefore are experiencing negative mental health implications, a comparison of whether masking is perceived to correlate with mental health against whether masking is perceived as a negative or positive, as shown in table twenty-four, clearly indicates this assumption would be incorrect. While individuals perceived there was a direct correlation between masking and mental health, this was perceived as both positive attributes of masking as well as negative ones.

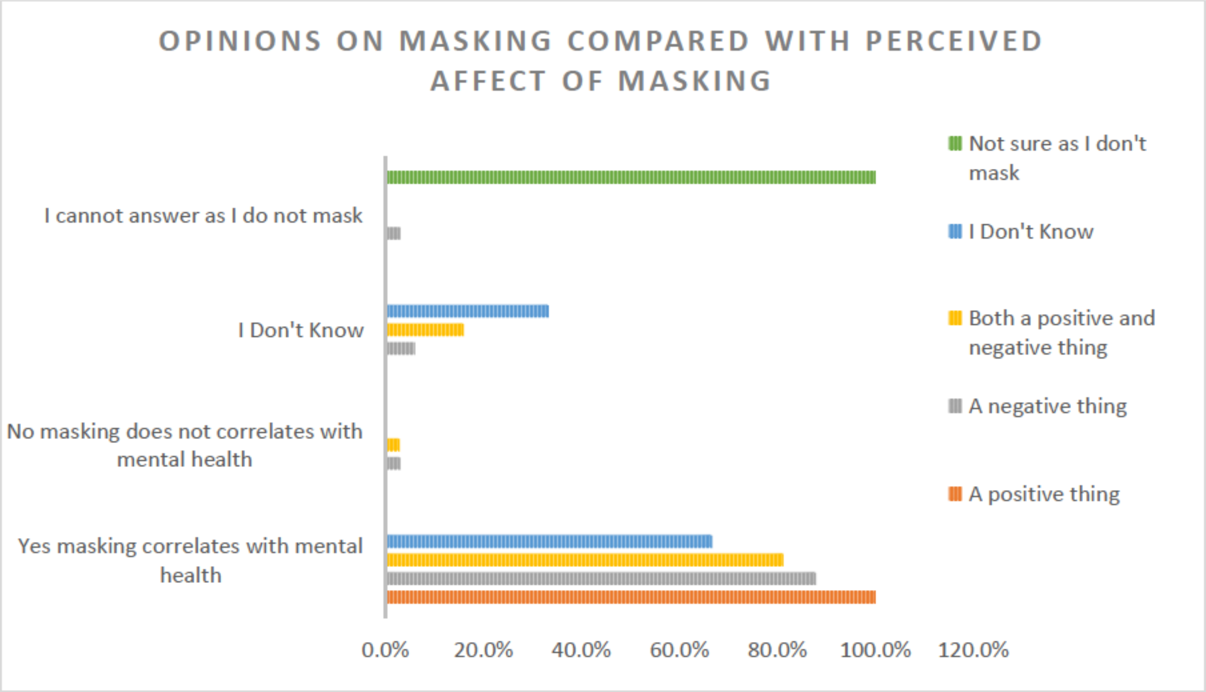


Figure 34: Opinions on masking and its affect. Graph

Summary

The above data was viewed concurrently to consider the hypothesis that those without formal diagnosis have more negative experiences than those with a diagnosis. It is concluded that the data suggests that in some areas the experiences of those who self-identify are not significantly different to those that are formally diagnosed. However, key findings can be found in the rate of negative experiences, by those without a diagnosis, during school, especially at secondary level, and bullying, therefore suggesting that in these areas there are more negative experiences than their diagnosed counterparts. This is therefore a key area for further discussion in the following chapter, with specific focus on the implications for improving education between the ages of four to ten as well as mental health provision.

5.3.2 Hypothesis Two: "The autistic identity is an essential element of an individual".

Participants were given six options to choose from when they were asked what the autistic identity meant to them.

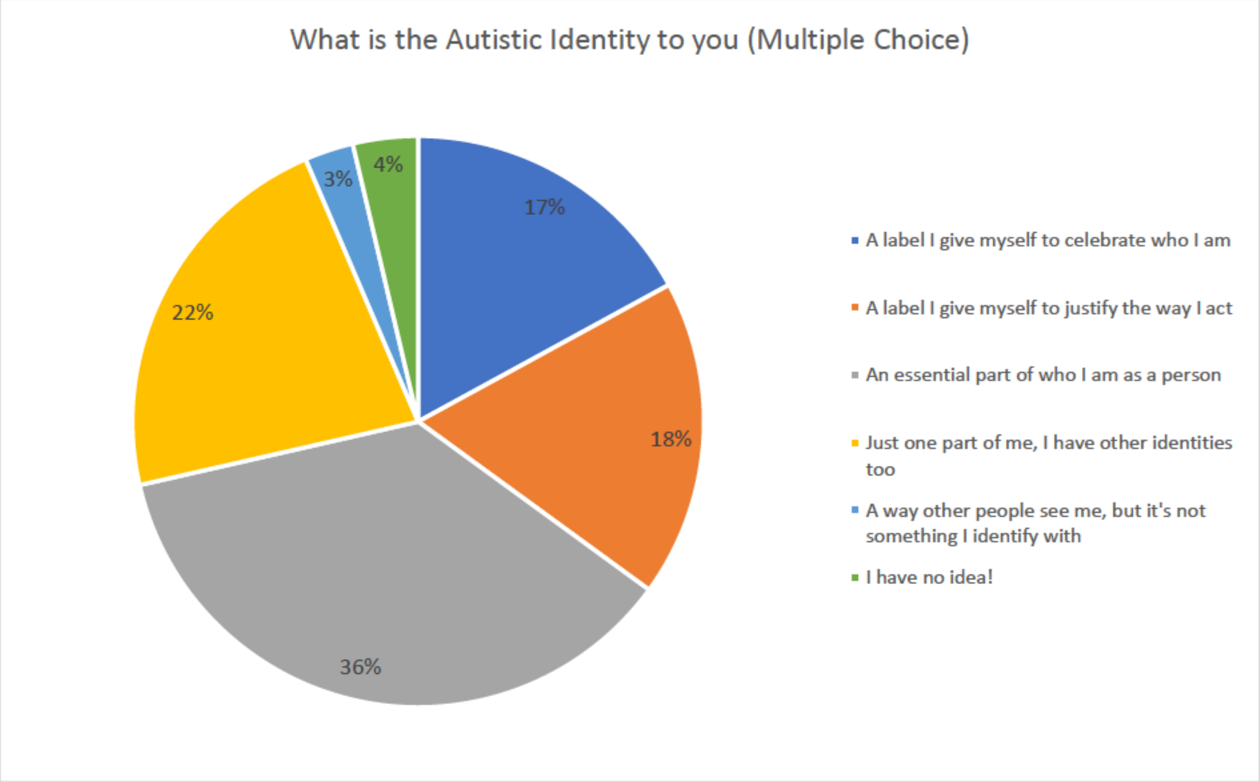


Figure 35: Opinions on what the autistic identity is. Graph

Twenty-six people chose to leave an additional comment, and these were read and categorised into: It is just me, Personal explanation of difference, help others understand, something to be proud of, general comment and community. Three comments fitted with the 'an essential part of who I am category', "It helps me understand my brain". Eleven comments fitted within the category of personal explanation and would also match the category of 'a label I give to justify the way I act'. However, objection was taken to the use of the word 'justify' as they felt this insinuated the search for an excuse:

> *“'a label I give myself to justify how I act' is a particularly insensitive suggested answer. I was accused of seeking a diagnosis for an excuse. I wasn't looking for an excuse I was looking for an explanation as for why thing are the way they are despite my best efforts. Not an excuse! That's something parents say or teachers say behind a child’s back.”*

Three people felt it was for the benefit of others, “A reason to help others to understand me and help me” while two people specifically commented that it was something to be proud of, which could also fit within the category of ‘a label I give myself to celebrate who I am’

> *“I'm proud of my autistic identity. It has given me many skills I would not otherwise have had, for example I have several degrees, I have studied both sciences and the arts, and I have worked in many different roles (although this was often a result of bullying). I consider it has given me a rich and interesting life.”*

One participant felt the autistic identity was more to do with community membership, “A community I belong to”. Four comments were disregarded as providing no additional information relevant to the question and therefore categorised as ‘general comments’.

It is evident from the graph above that when viewing the responses as a whole, more people felt the autistic identity was an essential part of who they were. This can further be explored when comparing responses with the pre-assigned independent variable.

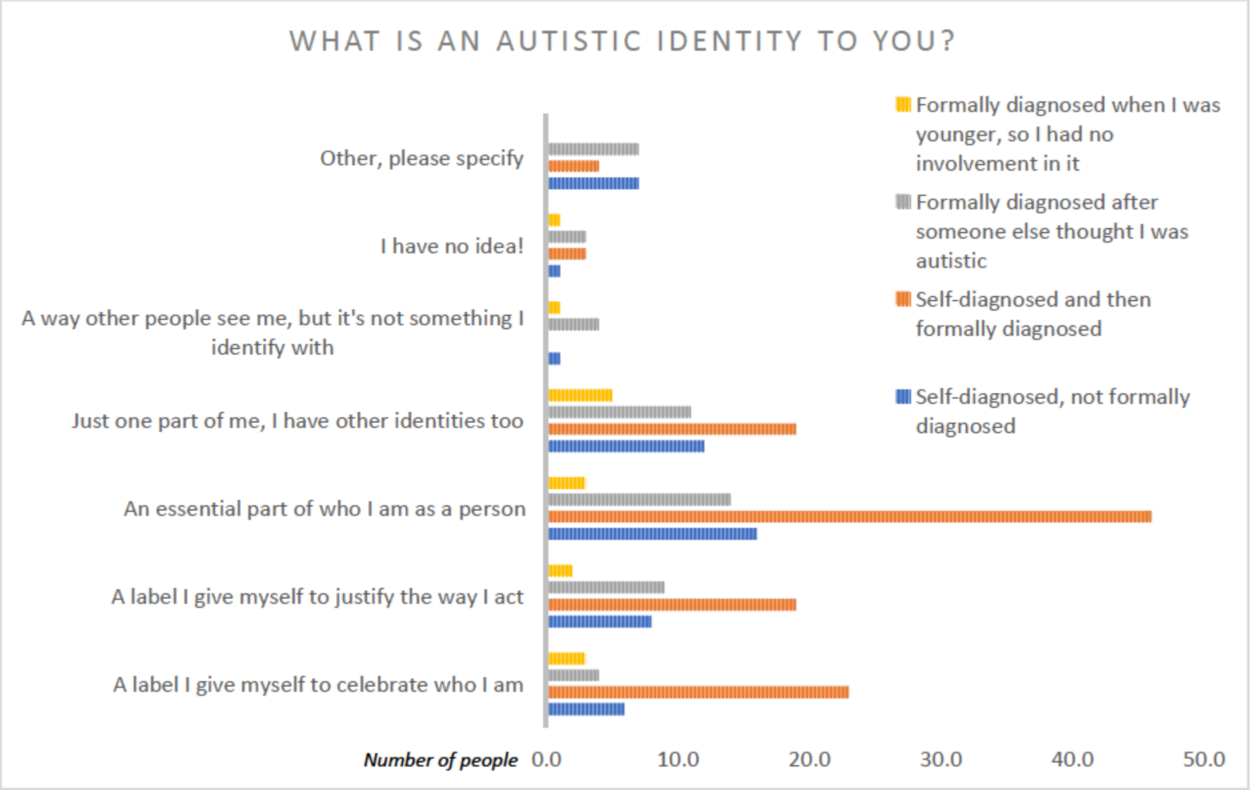


Figure 36: Essential or Existential view on the autistic identity. Graph

As the above graph illustrates for those individuals who self-identify, the most popular opinion was that the autistic identity was an essential part of who they were, however, this was dramatically more so in the group that self-identified and then received a formal diagnosis. It is note-worthy that those individuals who were diagnosed at a younger age were more likely to feel that the autistic identity was just one part of who they were.

This concept was further explored when participants were asked to categorise the autistic identity in comparison to other identity categories, they may be aware of. As the graph below illustrates in all categories significantly more people felt the autism identity was part of their genetic makeup. Therefore, reinforcing the data of the graph above.

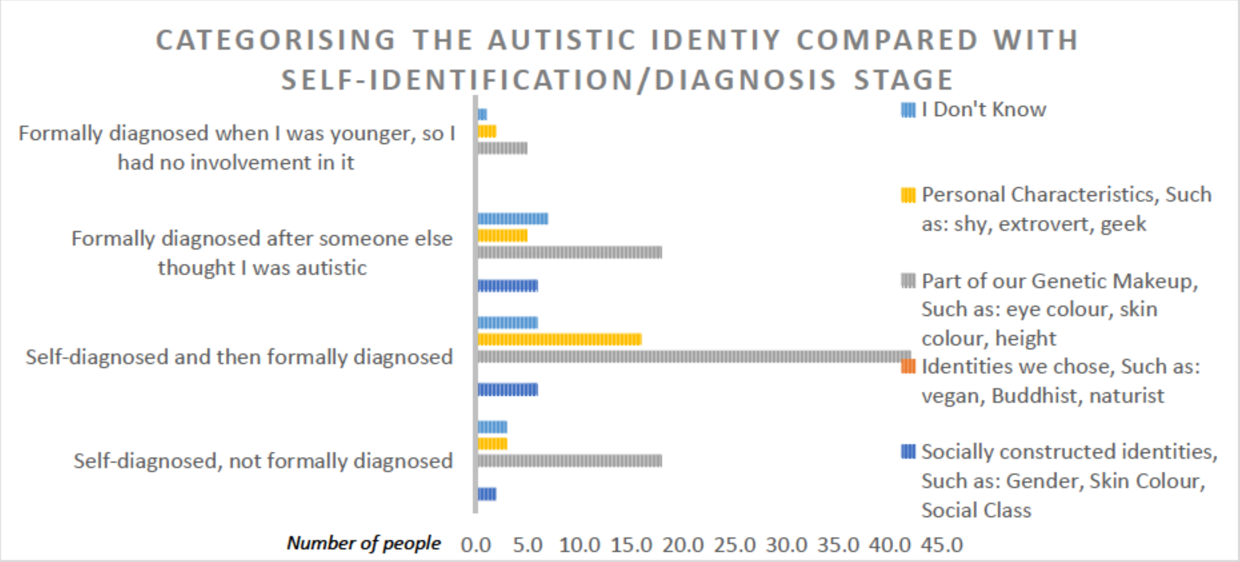


Figure 37: Categorising the autistic identity. Graph.

To further explore how participants viewed their autistic identities, they were asked to select from a list of attributes they felt were part of their autism.

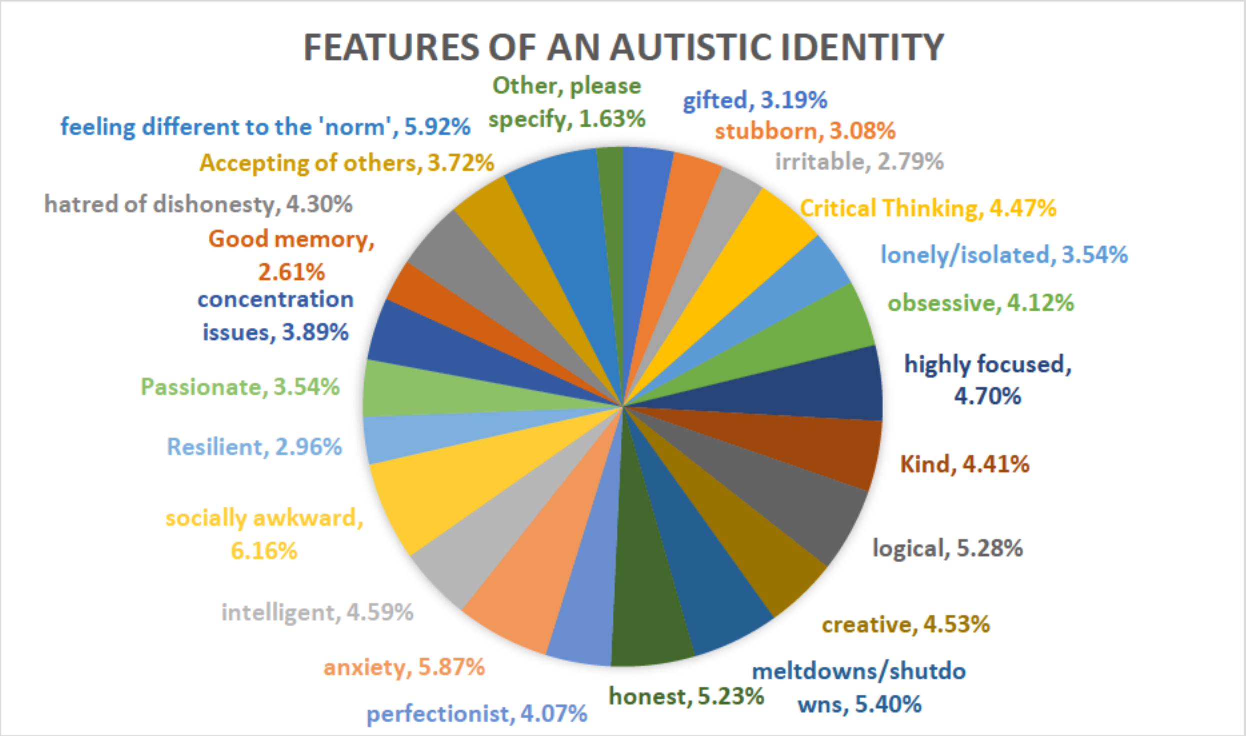


Figure 38: Features of an autistic Identity. Graph

It is fascinating that the divide of choices appears so equally spread, especially when considering both positive and negative options were provided. Although when breaking down the figures the main features identified were: ‘anxiety’ (one hundred and one), ‘socially awkward’ (one hundred and six) and ‘feeling different to the norm’ (one hundred and two). When reviewing how the data compares when the independent variable is incorporated, there is little difference, to the overall view of the pie chart. In the first three categories the top three identified features of autism are:

	Self-diagnosed, not formally diagnosed	**Self-diagnosed and then formally diagnosed**	**Formally diagnosed after someone else thought I was autistic**	**Formally diagnosed when I was younger, so I was not involved in it**
1	feeling different to the 'norm'	*Jointly* anxiety and socially awkward	socially awkward	*Jointly* socially awkward & meltdowns/shutdowns & passionate
2	anxiety		feeling different to the 'norm'	
3	socially awkward	feeling different to the 'norm'	anxiety	

Figure 39: Top 3 features of the autistic identity. Table

It is note-worthy that while positive options were chosen overall, in three out of the four categories negative features were identified more often. It is also notable that of those that were diagnosed at an early age they identified positive attributes to autism that those in the other groups did not, however this is highlighted with caution due to the small number of participants in this category.

The final element of data relevant to this hypothesis directly referenced the theme that developed from phase one, namely the ‘perfect fit’. Participants were asked directly whether the theme of ‘perfect fit’ was relevant to their experiences. As the table below illustrates, the data of those who self-identify provides evidence that this is not generalisable, as more people felt that it did not need to be a perfect fit, just close enough. For those that self-identified and then continued to receive a diagnosis however, the concept of the ‘perfect fit’ was chosen more often.

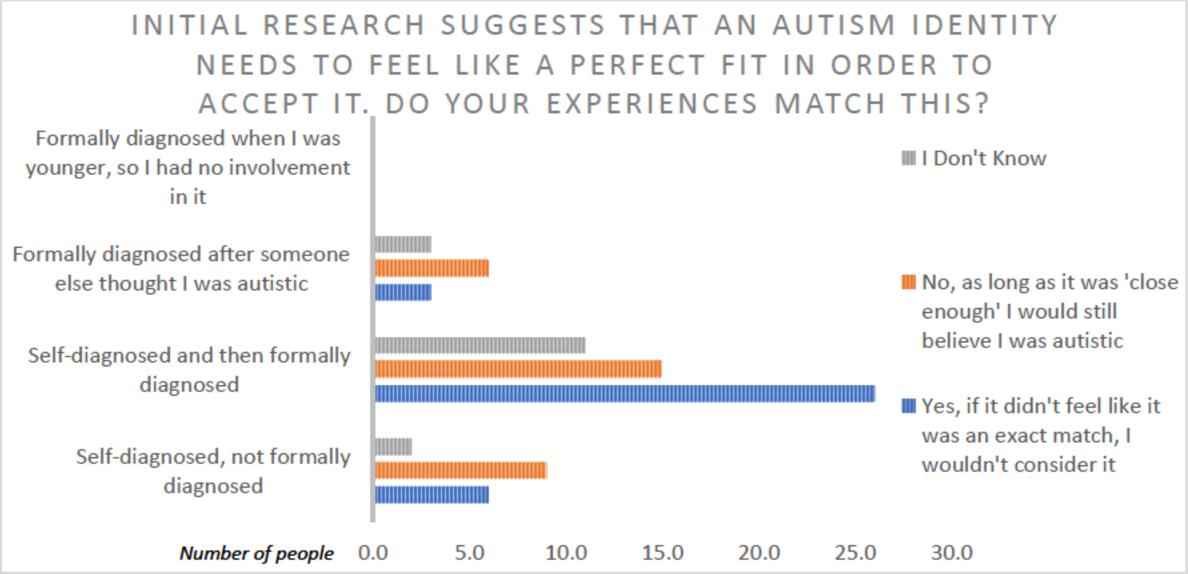


Figure 40: Does the autism need to feel like a perfect fit? Graph.

Summary

The key features of autism identified for those that self-identify were largely comparable to those with a formal diagnosis. While the concept of the 'perfect fit' did not prove to be generalisable, evidence was provided that confirmed the hypothesis that the autistic identity is viewed with an essentialist perspective. The implications of this will be considered in the discussion chapter.

5.3.3 Hypothesis Three: "The autistic identity is fluid and not singular".

Participants were asked to reflect on the fluidity of the autistic identity based on their own perceptions, as shown in the following graph.

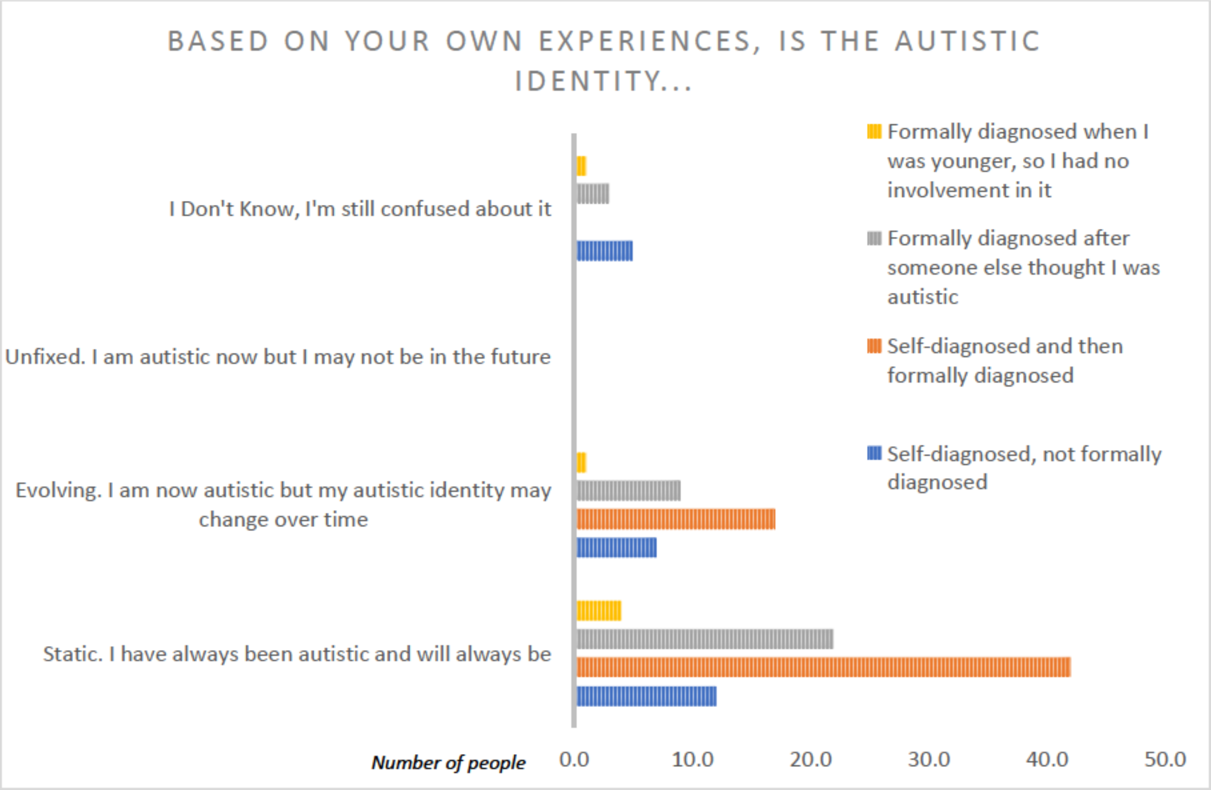


Figure 41: Fluidity of the autistic identity. Graph

It is fascinating that the stage of self-identification/diagnosis did not alter the significant agreement by most participants that the autistic identity was static. This trend is mirrored when participants were asked whether they felt the autistic identity was something they were effectively born with or something that had developed through experiences, with the majority of participants feeling that regardless of recognition it was a static identity since birth.

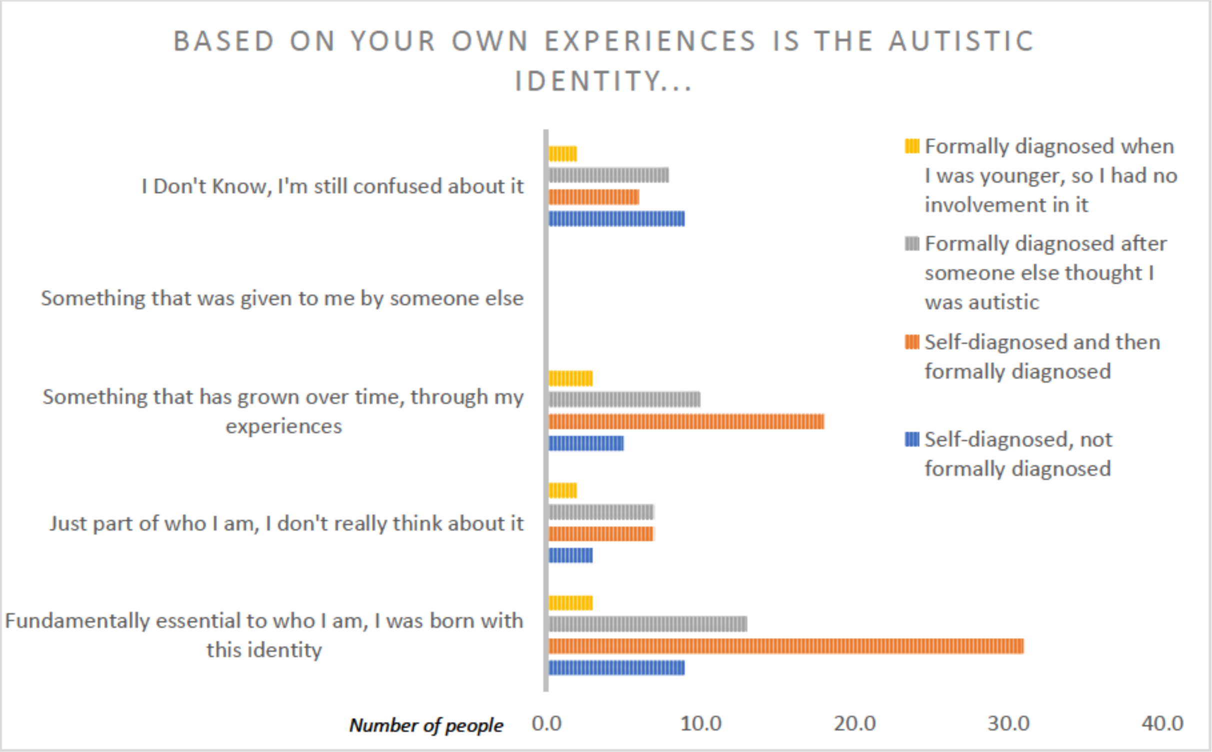


Figure 42: Is autism an essence? Graph

This expression of rigidity surrounding the autistic identity is interesting when considered alongside the possible labels participants were asked to identify if they had related to, either now or in the past.

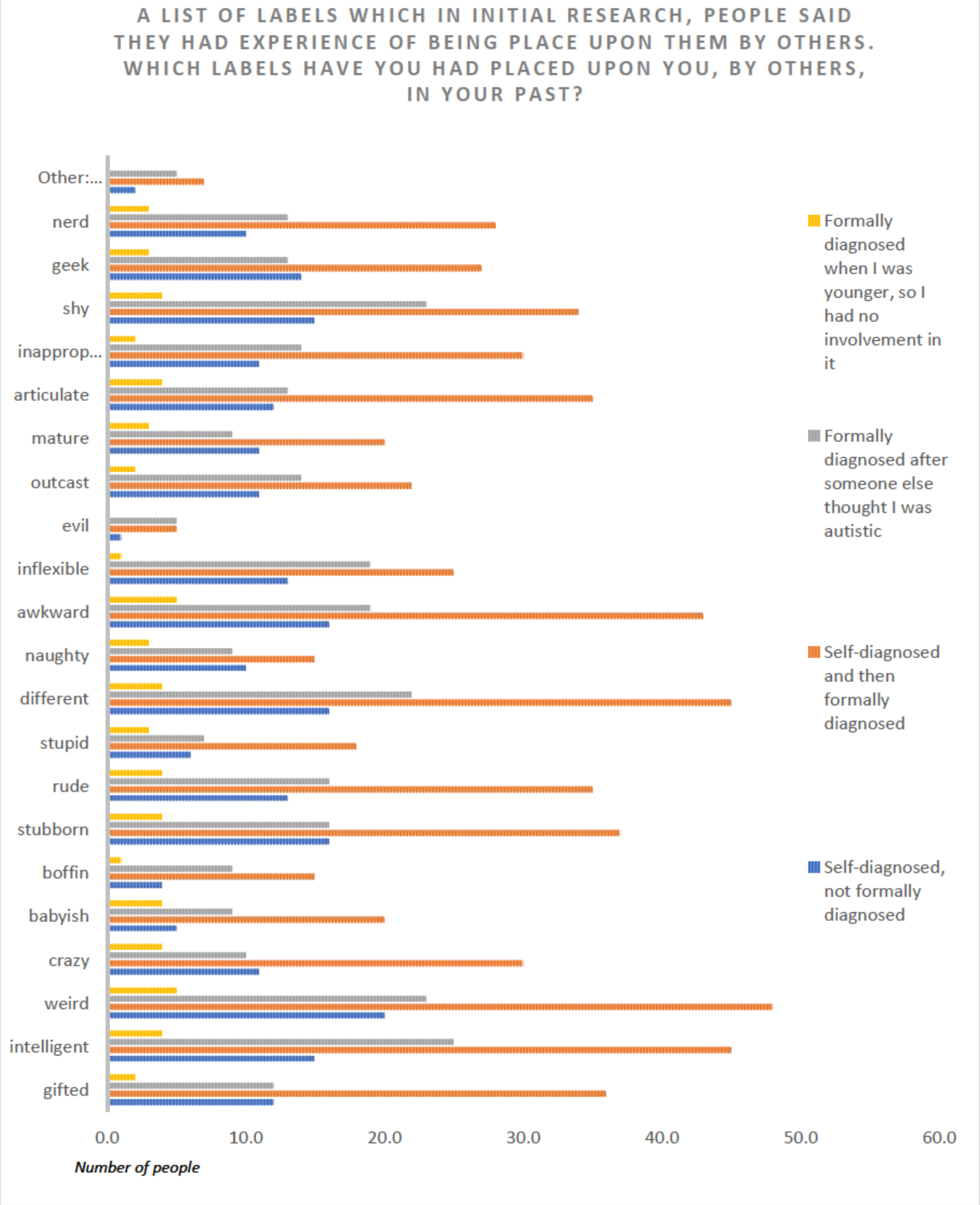


Figure 43: Labels. Graph

It is significant, that despite the array of labels identified, both positive and negative, throughout their lives, participants still felt that these did not change the autistic identity, suggesting therefore that such labels were separate or inaccurate from the perceived consistent ‘truth’ of autism. This belief would also appear contradictory when compared with the opinions expressed regarding how the autism identity is felt to be different from one individual to another.

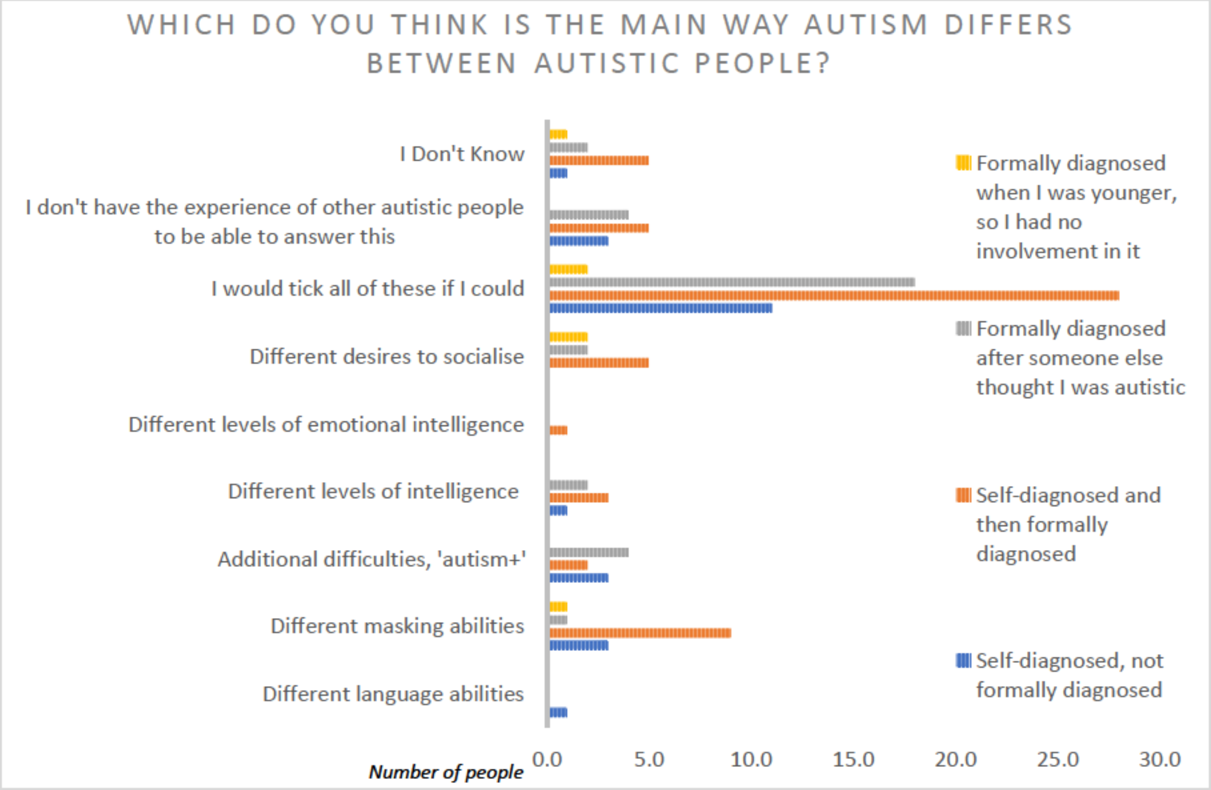


Figure 44: Opinions on how autism differs. Graph

As this graph illustrates, most people, regardless of diagnosis, felt that all the differences listed were all relevant explanations for differences between autistic people. It would seem contradictory to express that autism is static yet differing, which may therefore suggest that the static nature of autism suggested is more intricately linked to a desired ownership/recognition of the identity, rather than an actual rigidity.

Summary

The data specifically asking participants whether the autistic identity was fluid and/or singular suggests that most participants, regardless of diagnosis, felt that it was a singular entity for them and static for them. Contradictions however become apparent when evidence is also seen that individuals believe autism to be different between people. This can also be seen in the evidence provided in the previous hypothesis where data surrounding features that make up an autistic identity were explored, the very fact that not everyone agreed on the key features suggests a possible plurality of autistic identities. The implications surrounding this contradiction will be explored further in the discussion chapter.

5.3.4 Hypothesis Four: “A changing society has empowered individuals to self-identify”.

Participants were asked to reflect on why they had not received a diagnosis or realised they were autistic at a younger age.

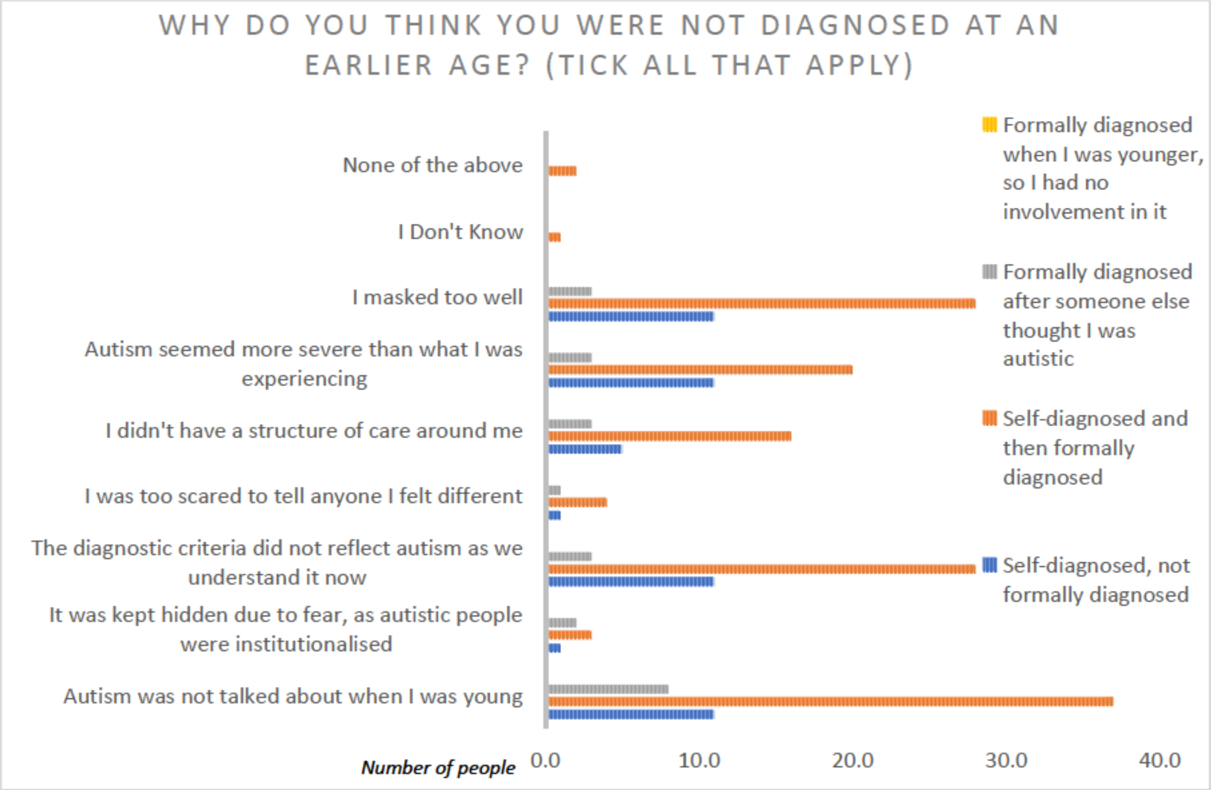


Figure 45: Opinions on reasons for missed diagnosis. Graph

It is striking that in the majority of cases, it was believed that they had not identified with autism because of external factors such as inaccurate diagnostic criterion and lack of societal awareness. It is fascinating however to also consider that many participants who self-identified felt their autism was not recognized because they masked so effectively. This is further reinforced by the following data:

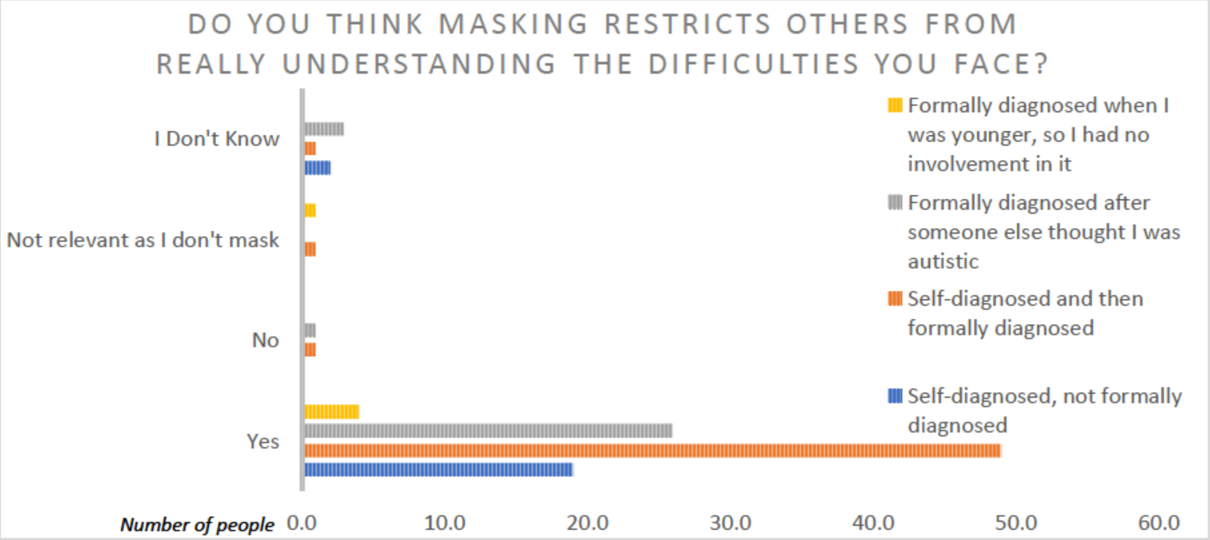


Figure 46: Opinions on whether masking restricts understanding. Graph

For those participants who felt society had changed allowing them to self-identify, they were further asked to pinpoint what they felt had changed specifically:

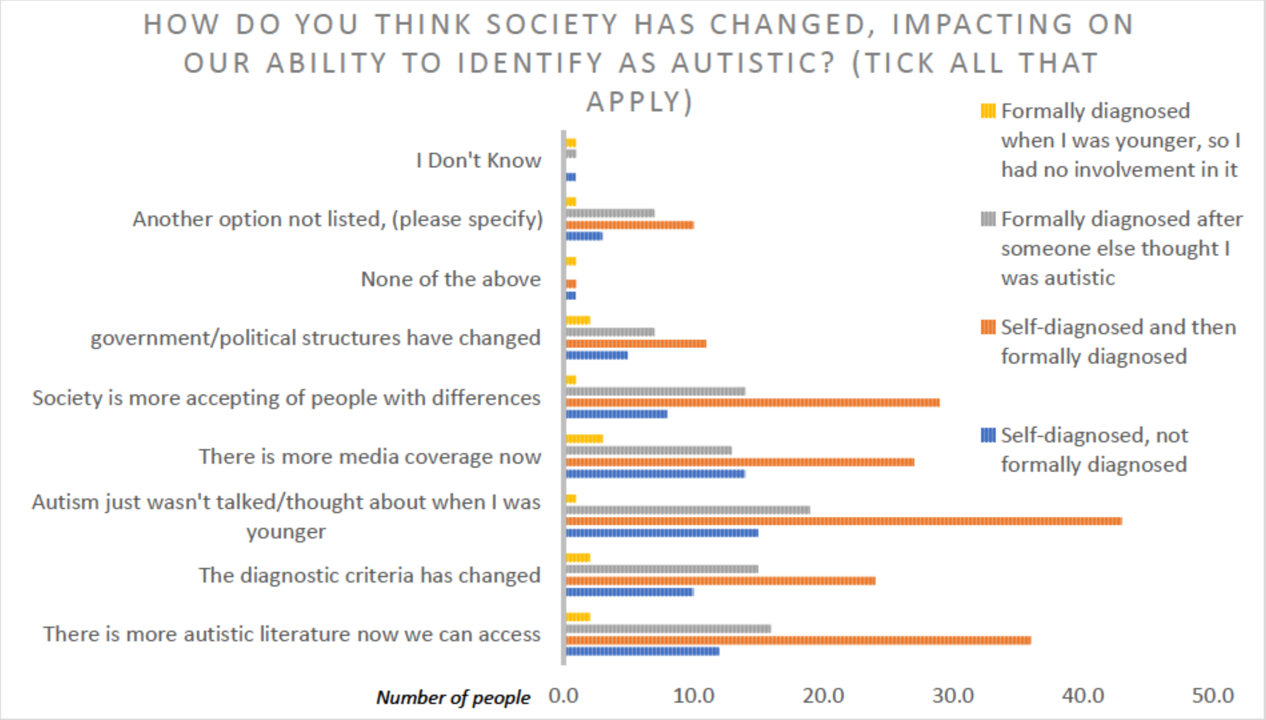


Figure 47: Opinions on how society has changed. Graph

It is fascinating to note the main changes identified relate to language developments, both in written and verbal form. It was suggested that these forms may be able to be categorised into ‘the media’ and therefore participants were asked to consider whether the media (in all its forms) had played a key role in their ability to understand their autistic identity.

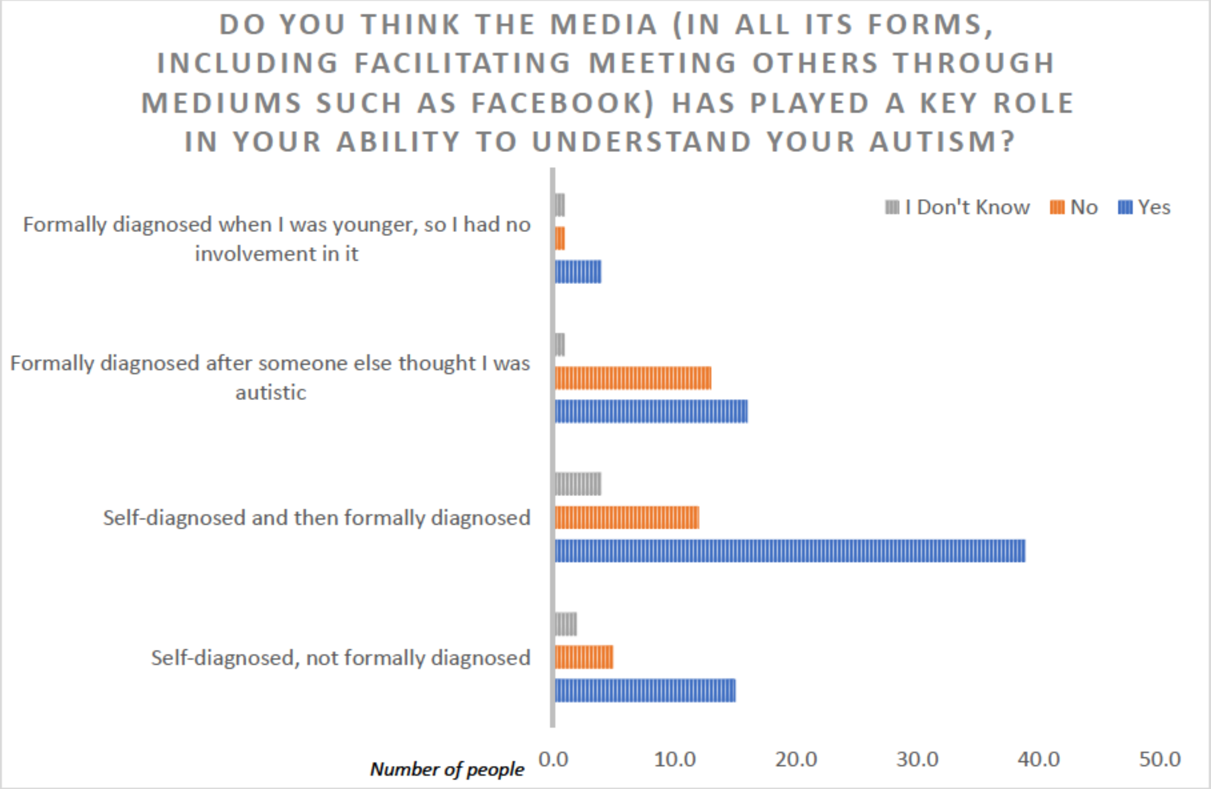


Figure 48: Opinions on the role of the media in developing identity. Graph

It is striking, but maybe not surprising, that the media played a more central role for individuals who self-identified than it did for those who were formally diagnosed. In contrast to the above data, participants were also asked to consider whether they felt the media had hindered their development of the autistic identity.

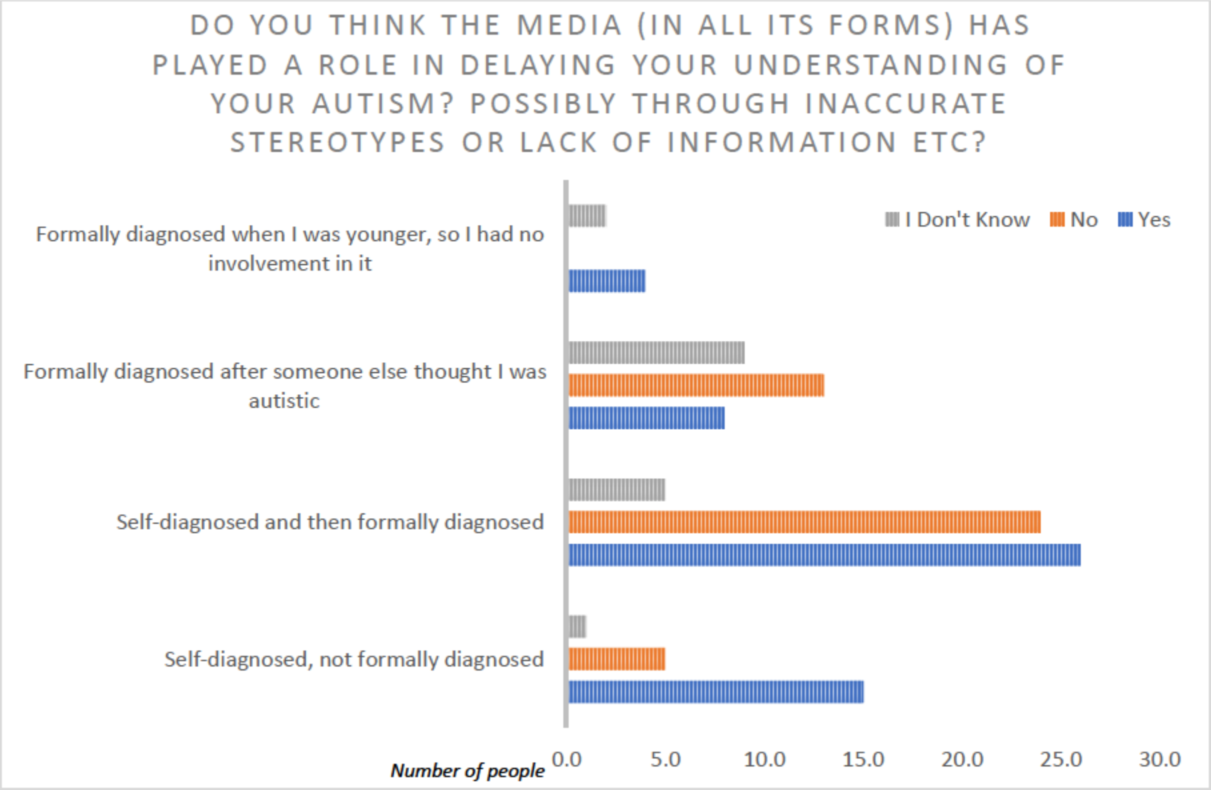


Figure 49: Opinions on media delaying understanding. Graph

Within this data the participants that self-identified without a formal diagnosis stood out as feeling the media did hinder their identification more than any other group.

Summary

There is evidence that participants felt a change in society has occurred which allowed them to self-identify. High numbers of self-identifying participants highlighted that change/development of language around autism had occurred, both in terms of diagnostic criterion, media representations, literature, and everyday discussions. The relationship between language development and identity will be considered further in the following chapter. Further consideration will also be undertaken into the significance of masking on the development of other's understanding of the autistic identity especially when combined with the data analysed in hypothesis one and five. The evidence has suggested that the media has played both a positive and a negative role in identity construction and this will be reviewed further in the following hypothesis and then in the discussion chapter.

5.3.5 Hypothesis Five: "The autistic identity cannot be built in isolation".

Participants were first asked to consider the role others played generally in their sense of identity.

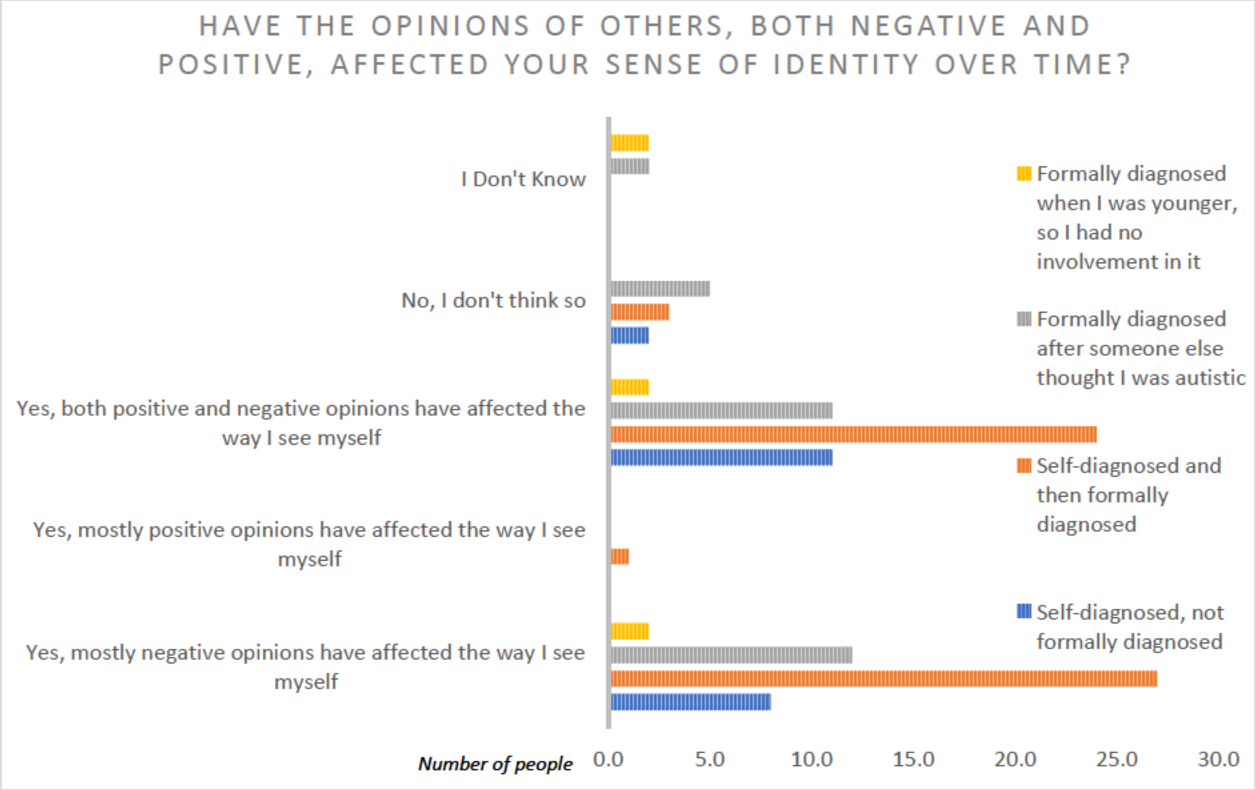


Figure 50: Opinions on how others have impacted on them. Graph

It is evident from the results that most people felt others had impacted on their sense of identity (this links to table thirty in hypothesis three). It also suggests that while some acknowledged that both positive and negative opinions played a part, there was a significant bias towards negative opinions and their impact (this is likely to also link to hypothesis one and mental health). Taking this concept further, participants were asked to specifically consider whether the autistic identity could be built in isolation.

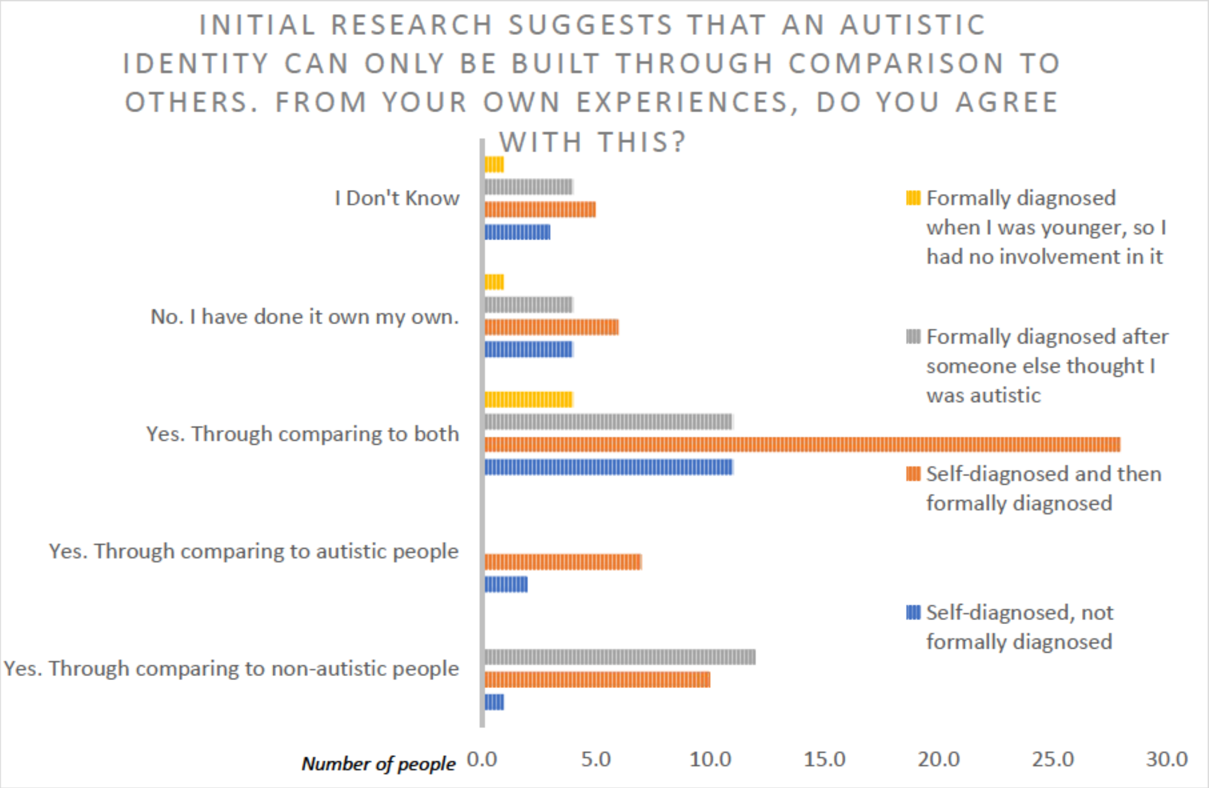


Figure 51: Importance of others in building identity. Graph

This data suggests that, regardless of diagnosis, most people felt that the autistic identity must be constructed with others. Most participants who self-identified felt they needed to compare not only to autistic people but also to non-autistic people to build an accurate autistic identity. In contrast, while around half the non-self-identified participants felt they needed to compare to both, around half felt they only needed to compare to non-autistic people.

To consider the role of others in the development of an autistic identity, participants were asked to identify ways in which they connected with other autistic people.

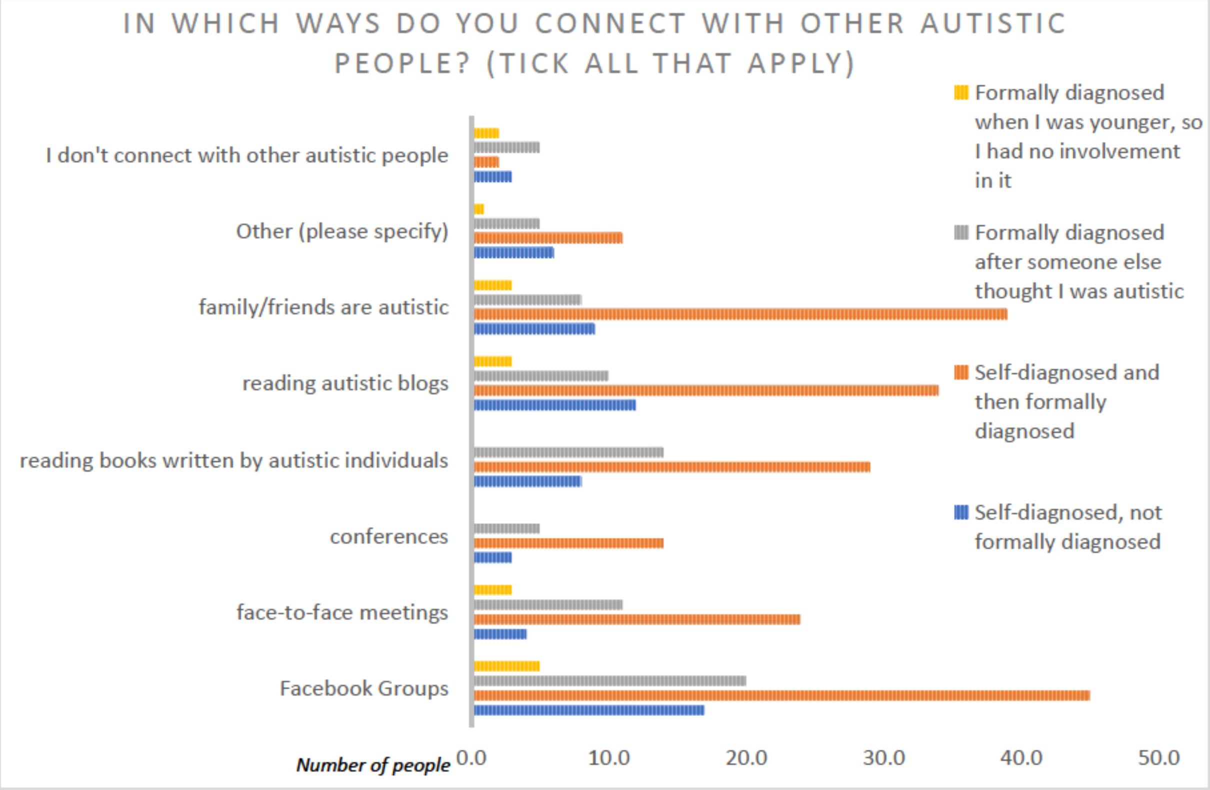


Figure 52: Experiences of connecting with other autistic people. Graph

It is evident that social media fora such as Facebook were particularly useful when connecting with other people. However, this is not surprising as a high percentage of participants became involved in this research due to Facebook connections. Of the participants that chose 'other' most comments related to examples of other social media forums as I had been overly prescriptive in my options specifying Facebook groups.

Participants were asked to specifically consider what the main value of connecting with other autistic people was.

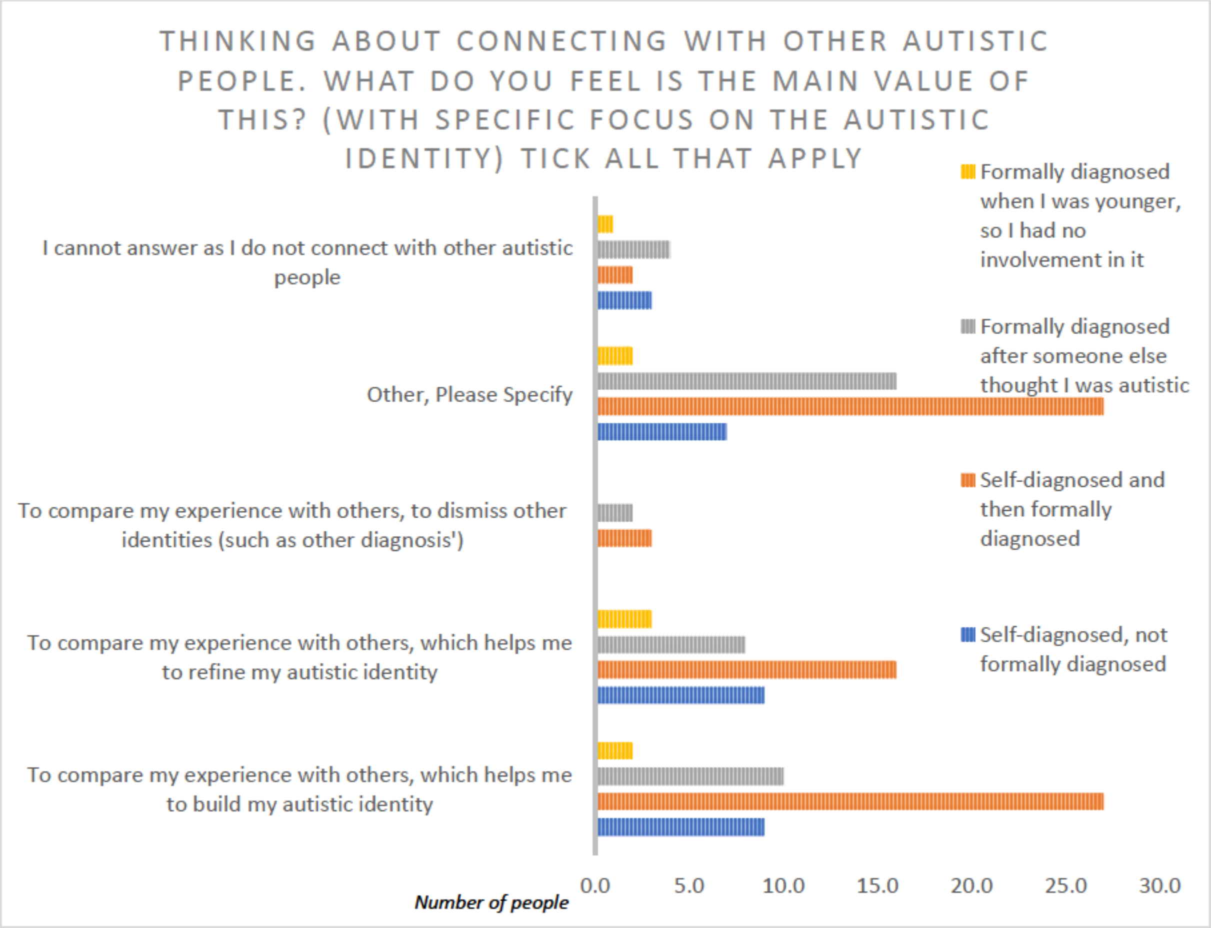
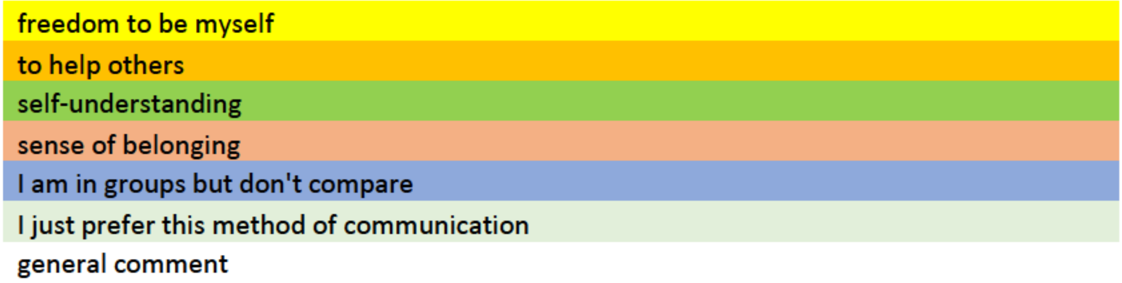


Figure 53: Opinions on the value of connecting with others. Graph

It is significant to see that in most cases, meeting others was more about refining and developing an autistic identity than it was about investigating and dismissing other identities. Suggesting that when people begin to connect with others, they already have a basic security in their autistic identity. This data is further thought-provoking when considered in relation to table thirty-one and the conclusions of hypothesis three, as the findings that participants felt the autistic identity was singular and static is contradictory to their choices here, that they use interaction with others in order to develop and refine their identity and therefore suggest an element of fluidity.

There were a significant number of people who chose the ‘other’ option when answering this question, the comments provided were read and categorised into the following categories:



freedom to be myself
to help others
self-understanding
sense of belonging
I am in groups but don't compare
I just prefer this method of communication
general comment

Figure 54: Recategorization of figure 50 options. Table

With twenty-two comments, ‘sense of belonging’ was the most popular reason given with ‘freedom to be myself’ the second with eleven responses. I would suggest that both these options require an element of comparison to occur, however; maybe the comparison is not overtly made and therefore the individual is less aware of it.

As social media groups must be sought out, I wanted to consider with the participants whether they felt they had been specifically looking for a group of people with whom to compare their life experiences:

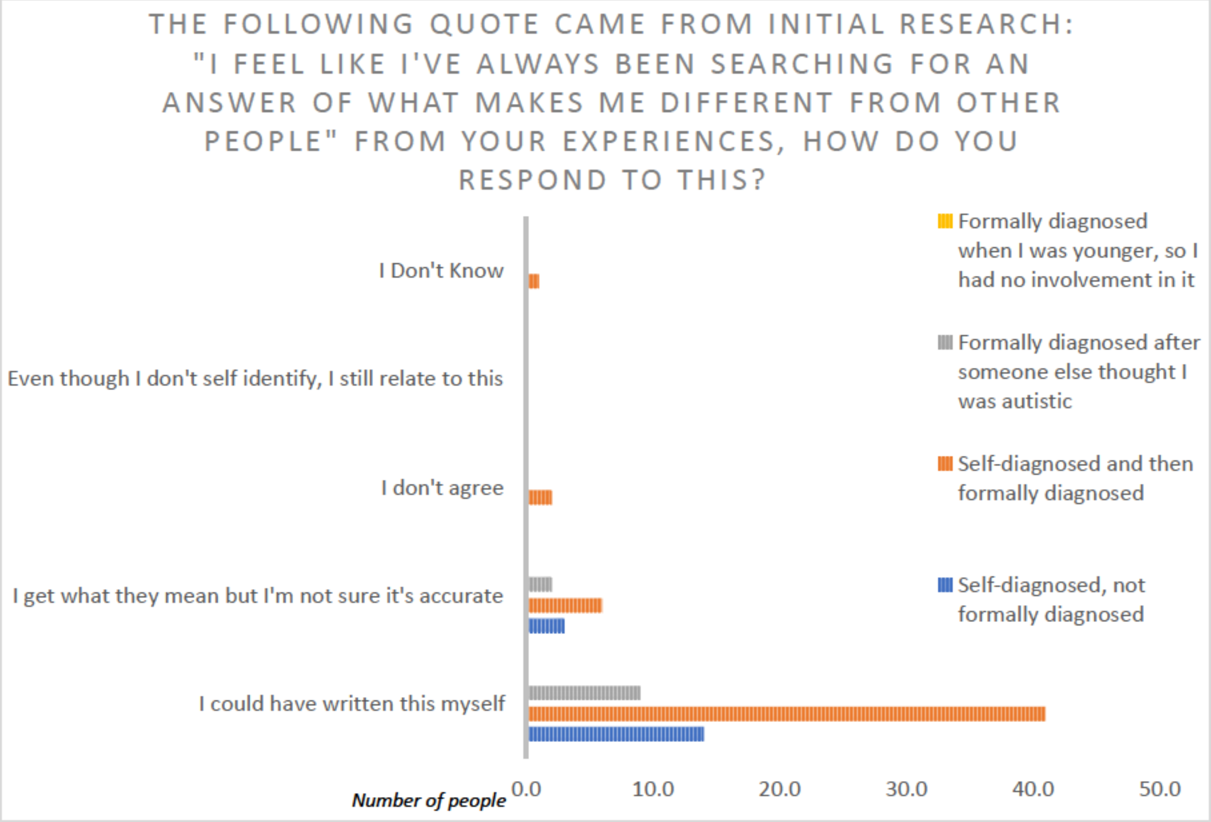


Figure 55: Opinions on searching. Graph

The responses indicate that regardless of diagnostic status individuals were searching for likeminded people. To take this concept further I asked whether they felt this search had coincided with the age at which they noticed they felt different.

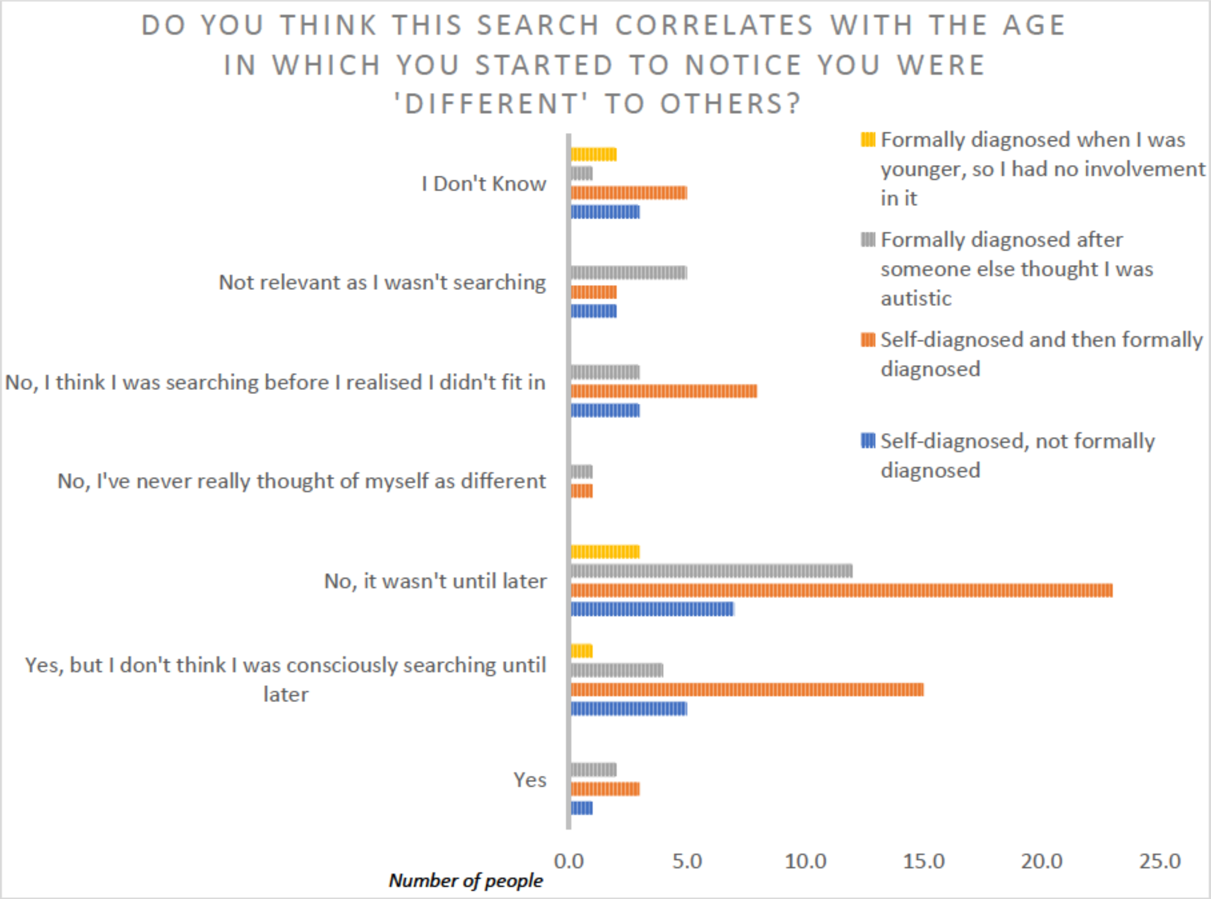


Figure 56: Opinions on whether searching correlates with difference. Graph

It was surprising to me that regardless of diagnostic status the most popular option was no, a search did not begin until later. However, on reflection, this may relate to the findings in hypothesis one that the age of first noticing difference, was in a relatively positive period of schooling with issues not becoming problematic until secondary years.

Summary

The data suggests that the autistic identity requires connection with others to be developed and refined. Importantly however, it also suggests that a basic awareness of the autistic identity needs to be in place first for this to occur. The implications of this will be considered further in the discussion chapter. Further consideration will also be given to the concept of in-group and out-group searching and how this relates to the discussion emerging from hypothesis one surrounding the implications of age, schooling, and mental health, as well as the data surrounding the development of the autistic identity and how this relates to the data in hypothesis three.

5.4 Self-Identification and Diagnosis

The previous subsection provided an analysis of data relating to the concept of the autistic identity. However, before further consideration of these findings can be explored it is essential to reflect on the data specifically relating to the phenomenon of self-identification. Therefore, data will be analysed that provide evidence distinctive to the concepts of purpose of self-identifying, impact of self-identifying and role of diagnosis.

5.4.1 Purpose of Self-Identifying.

Participants who had experience of self-identifying as autistic were asked to specifically reflect on the purpose of self-identifying as autistic. In the first instance they were given multiple options and asked to choose as many as they felt matched their experiences.

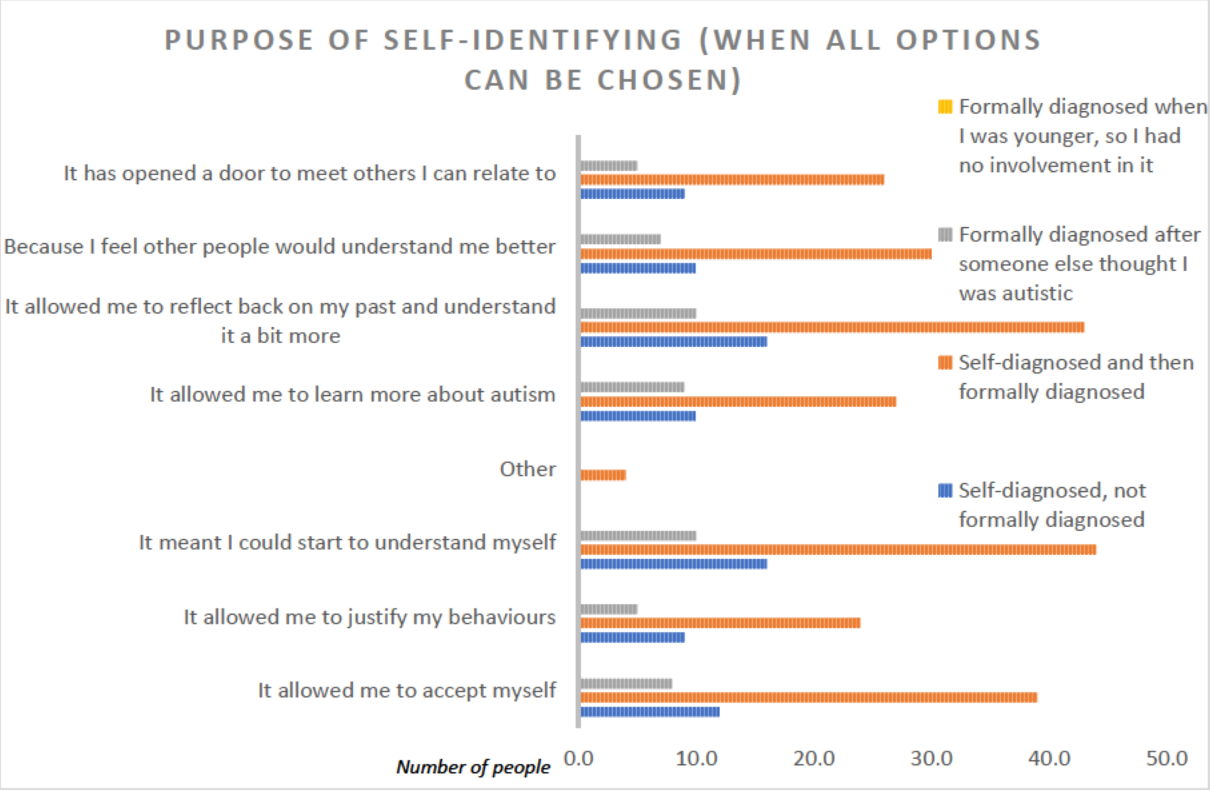


Figure 57: Opinions on purpose of self-identification. Graph

While there is an array of answers the two most popular in both self-identifying categories are 'it allowed me to reflect back on my past and understand it a bit more' and 'it meant I could start to understand myself'.

With the same options, participants were further asked to pick what they felt was the main purpose of self-identifying for them.

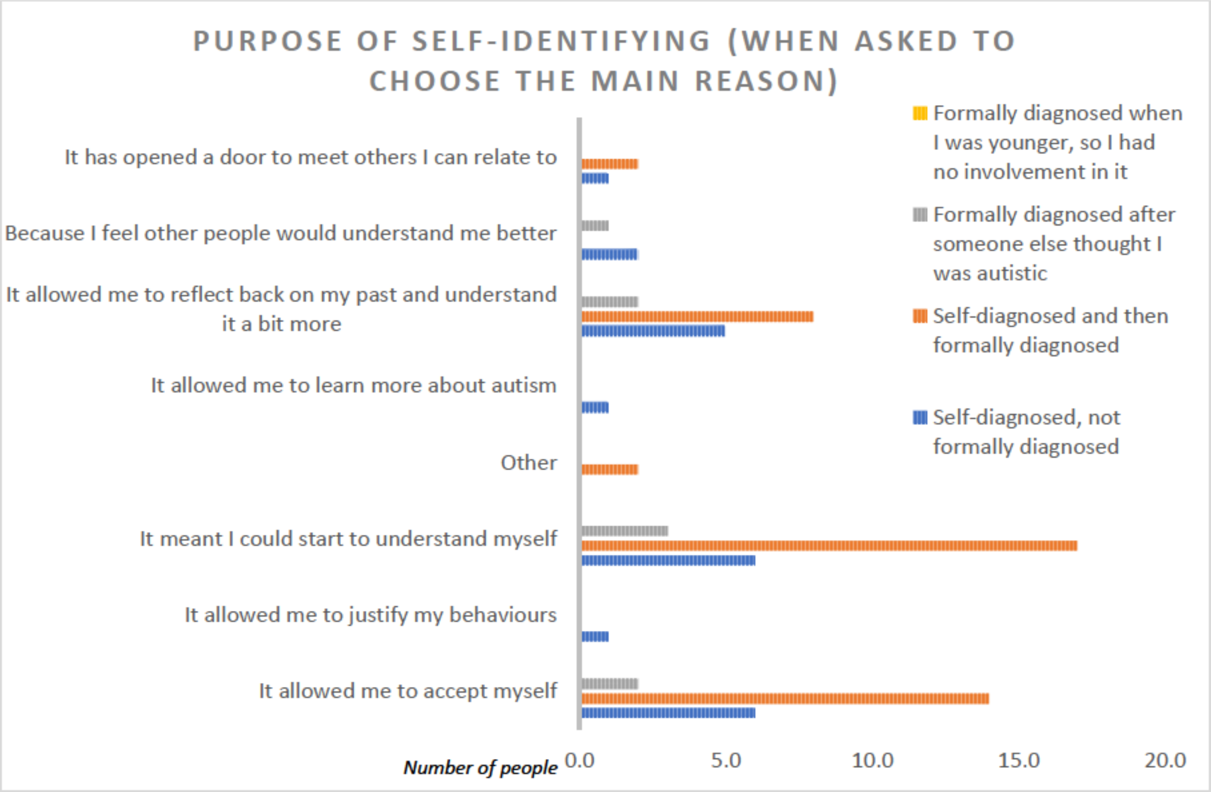


Figure 58: Main reason for self-identifying. Graph

As can be seen the main purpose of self-identifying was to enable self-acceptance and self-understanding, both of which would relate to considerations surrounding mental health and would also reinforce the concept of self-identification being a journey of development and not a static entity.

5.4.2 Impact of Self-Identifying

Quotes and themes were used from phase one of the research to provide options to consider the impact of self-identifying as autistic.

Figure 59: Opinions on Impact of Self-Identifying. Graph

The pattern of responses is comparable between self-identification categories, with five and six being chosen most often. Conversely, those that did not go through the process of self-identification did not follow the same pattern, choosing option four and five more often. All three options chosen, do however represent, that the impact of self-identification is more on self-reflection and acceptance and less to do with others.

Following the review of mental health prior to self-identification, participants were asked to reflect whether they felt their mental health had improved since self-identifying.

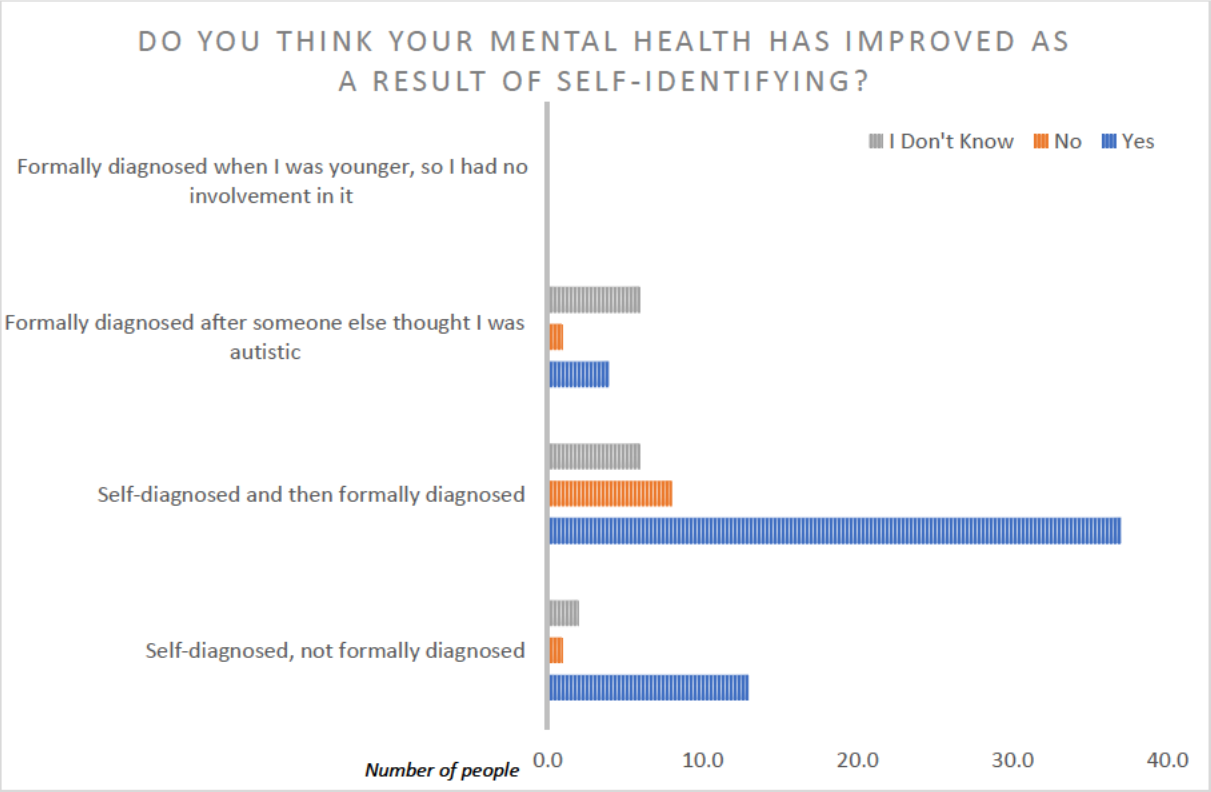


Figure 60: Opinions on mental health and self-identification. Graph

This clearly indicates the impact of self-identifying as an improvement of the individual's mental health. It is however noted that it is not clear whether it is a direct product of self-identification through the self-acceptance as shown in table forty-nine or as a result of the self-reflection that occurs because of self-identification. However, both options reinforce that self-identification does have a positive direct impact on mental health in a significant number of people.

5.4.3 Role of Diagnosis.

When reviewing the demographics of the participants I noted that the majority who had self-identified went on to receive a diagnosis, so I considered it important to reflect on why they had felt self-identification was not enough and indeed how all participants viewed formal diagnosis as it currently stands. Initially, opinions were taken from phase one of the research and given as options for the participant to choose which one matched their own experiences.

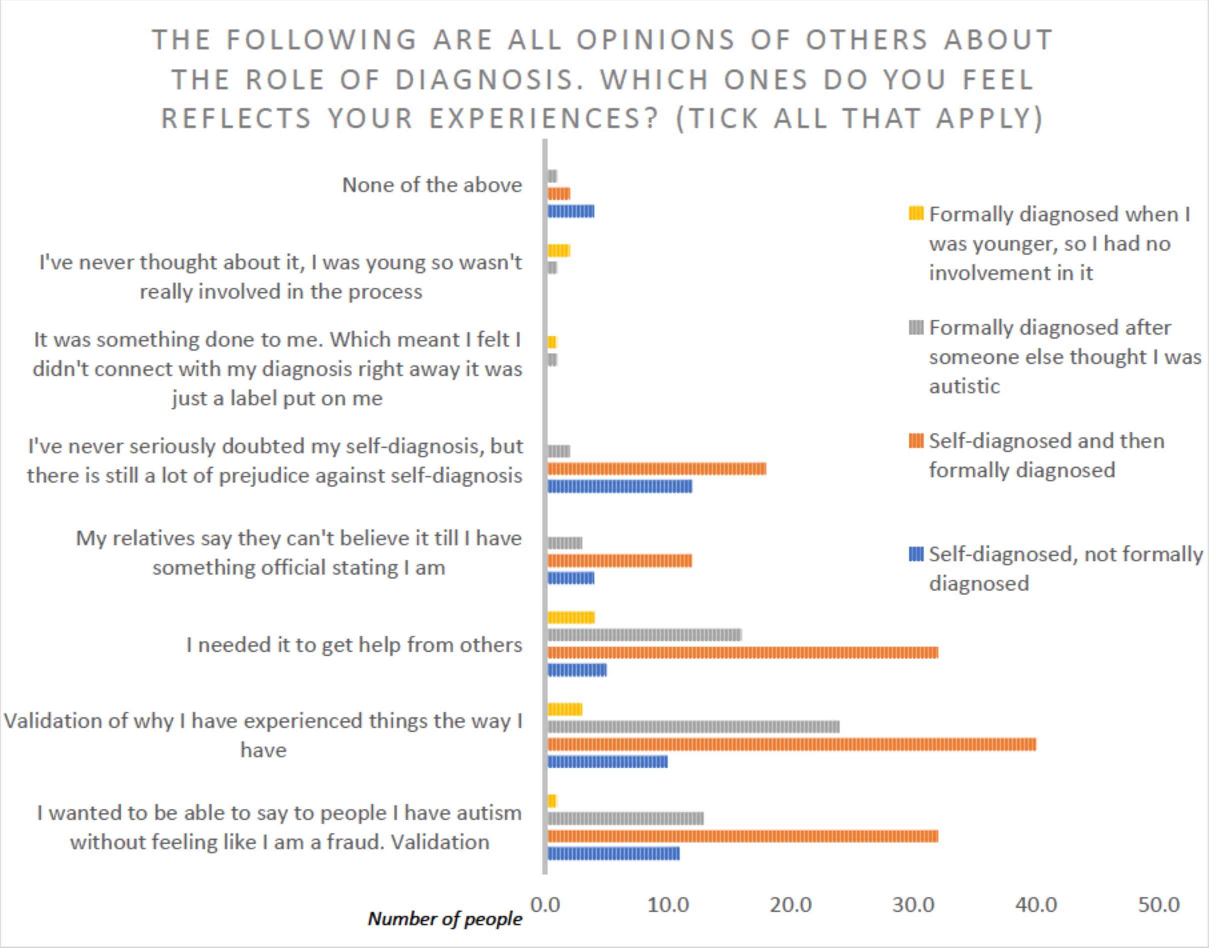


Figure 61: Opinions on the role of diagnosis. Graph

For the subgroup that self-identified and then went onto get a diagnosis, diagnosis for them was about validation and then about getting help, whereas for the subgroup that self-identified without a diagnosis, diagnosis for them was more about avoiding the perceived prejudice from others concerning validity of self-identification than about personal validation.

In relation to diagnosis and identity, participants were first asked how important diagnosis is in embracing the autistic identity.

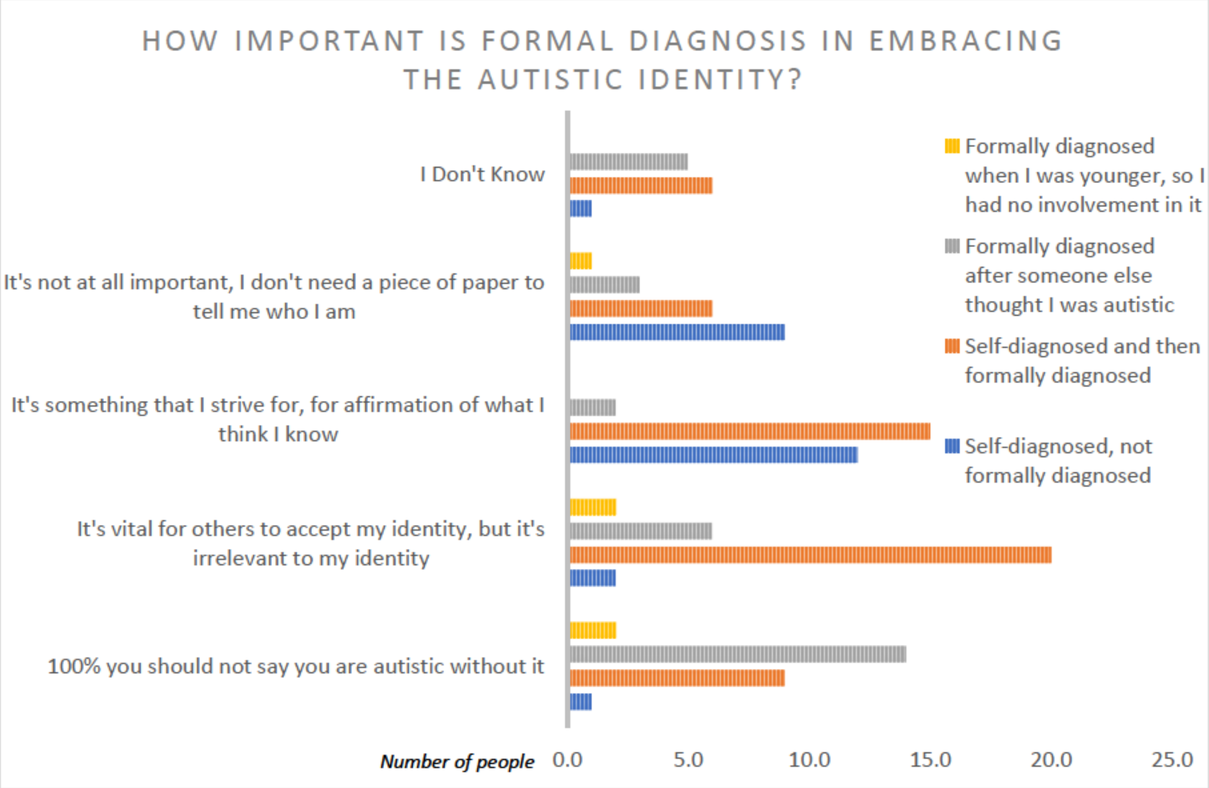


Figure 62: Opinions on importance of diagnosis. Graph

There is a significant divide in opinions here, that has not been evident throughout the other questions. For those without a formal diagnosis, diagnosis would allow them to embrace their identity and it serves to reinforce the validity of their beliefs. In contrast, for those that self-identified and went on to receive a diagnosis, diagnosis becomes more focused towards others accepting the individual's identity rather than for themselves.

The relationship between diagnosis and identity was considered further, by seeking a response to the question of whether diagnosis can give you an identity.

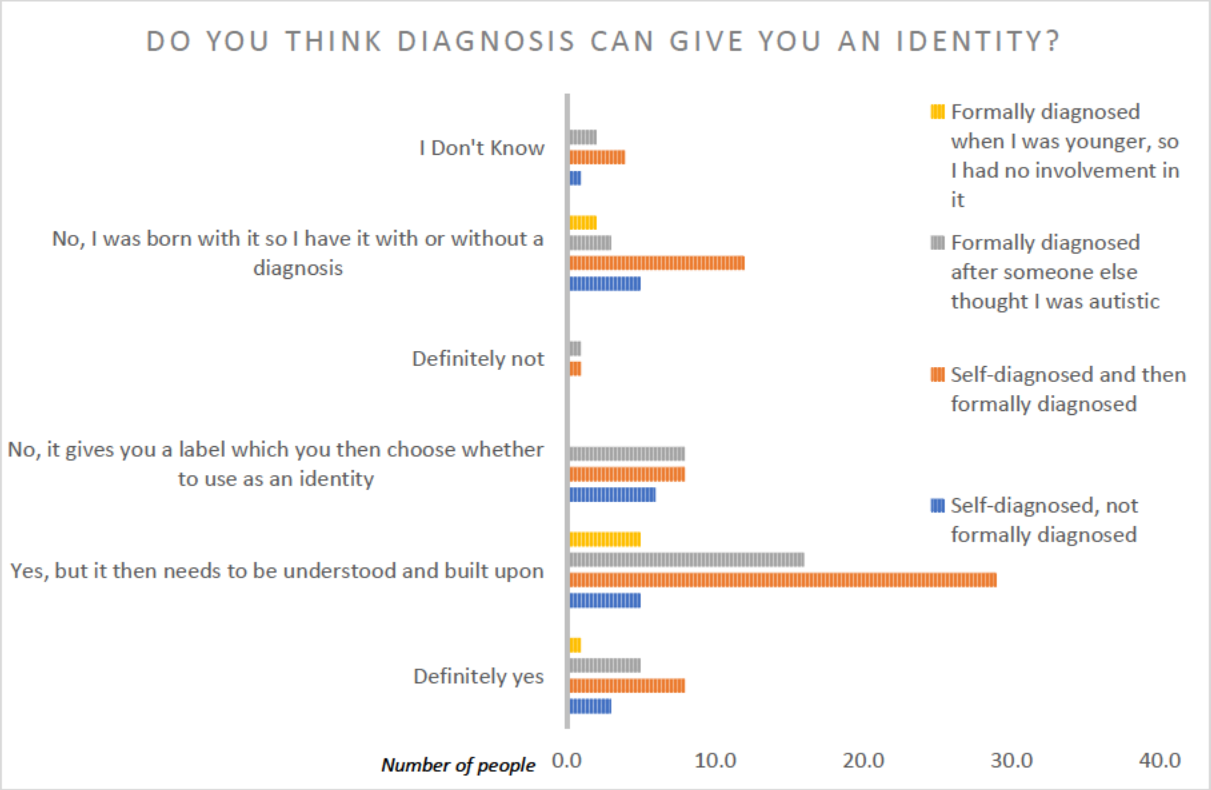


Figure 63: Opinions on whether diagnosis can give an identity. Graph

Once again, I am struck by the contradictory nature of the data uncovered. In table thirty-six evidence was provided that participants who self-identified and went on to receive a diagnosis felt the autistic identity was essential to them. Here, however, only a few people answered with an essentialist viewpoint, instead suggesting that diagnosis can give an identity and not only that, but it is a fluid identity as it needs to develop based on understanding.

5.5 Conclusion

The data through this phase of the research has provided insights into self-identification and the autistic identity. While it is acknowledged that the population of participants is merely a sample of the wider population, with a significant bias towards those that engage with social media, it continues to raise three significant questions and will be considered in line with the original research questions in the following chapter:

- What is the implication of the contradicting views expressed by these participants around the concept of autistic identity/ies?
- What are the implications of language development and how has this facilitated self-identification?
- What is the role of diagnosis? with such conflicting views on its purpose and impact, alongside the development of the neurodiverse movement what value does a diagnosis hold?

CHAPTER SIX: DISCUSSION

The experiences shared through this sequential mixed methods research have facilitated the development of rich and enlightening data surrounding the phenomenon of self-identification of autism. Due to a gap in the research within this area, the findings, driven by the voice of the autistic individual, provide essential insight into the concept of autism and identity as well as the processes by which the autistic individual begins to understand and develop them.

Within the following chapter, the themes developed through Phases one and two of the research will be drawn together, alongside academic literature, to consider the overarching research question set out in Chapter one.

1. what is the autistic identity/ies?
    a. what facilitates the process of self-discovery of autism?
    b. what is the impact of the delayed realisation of the autistic identity?
    c. what is the purpose of self-identifying as autistic?

In order to provide a visual distinction from wider literature, quotes from this study are indicated in bold type.

6.1. What is the autistic identity/ies?

The term autistic identity/ies was used without significant deconstruction of its meaning, prior to the start of my research, in the same way we often use everyday terms without really thinking about the meaning behind them. As a PhD researcher in the field of autism, and an autistic adult, I often remarked at the irony that I found it hard to explain succinctly what autism is and it soon became apparent, through the research, that I was not alone in this matter. There was an element of contradiction that weaved its way through the data collected that became fundamental in the development of knowledge around the concept of autism and identity. My research findings have indicated four specific contradictions that will be explored further: plurality v singularity, static v fluid, essentialism v existentialism, and identity first v person first.

6.1.1 Plurality v Singularity

> *"Everyone who works or knows people with autism recognises that each person's autism is different. But when it comes to researching autism, there is a strange and totally mistaken assumption that Autism is a SINGLE condition with a SINGLE underlying cause." (Blacow, 2020 {blog}).*

The above quote, taken from an individual's blog accurately summarises the contradiction that was evident in my data. While it only references research, I would argue that this contradiction is much wider reaching. In both phases of the data collection, individuals spoke of autism as a static entity to them, with most participants expressing that, regardless of diagnosis, autism was a static identity since birth. In stark contradiction when viewing other people's autism, the data collected illustrated a belief that there are many ways in which autism can be different between individuals. When participants were asked the features of their autistic identity/ies, a significant array were chosen, as illustrated in figure

38, indicating that there was not one concrete construction of an autistic identity/ies that was comparable across participants. During the participant check stage of interviews, one participant referenced my theme and explanation of ‘contradiction’ and added the comment of:

> ***“It was quite enlightening to read really how I see myself. I thought I was finally accepting but I think I’m quite contradicted!” (Emily).***

Emily’s reflection indicates that not only is this contradiction occurring but importantly that the individual is not necessarily aware of it. Using my own knowledge, to position the data I collected, I would suggest that this contradiction with autism being perceived as a singularity, derives from the individual’s internal conflict of feeling the need to fight to claim the autistic identity/ies as valid. Olney and Brockelman (2003) argue that “those with invisible disabilities express concern that others would not believe that they had a bona fide disability” (p.48). Holliday-Willey (2015) articulates that at the stage when she began to articulate to others that she was autistic she experienced negative responses “people told me I was under too much stress that I had fallen prey to the latest psychological trend almost saying to me that a.s. was nothing more than the flavour of the month” (p.117). This is mirrored in Hendrickx (2015) where a whole chapter is created under the title “you don’t look autistic”. Similarly, a blog written by Ashlea McKay, on the common subject of; things autistic people wish you did not say to them, highlights the presence of the suggested internal conflict. Position number one on her list is “*you don’t look autistic to me*”, at number four falls “*Your autism must be mild- you seem normal to me”, and at number six “I heard that EVERYONE is on the spectrum”* (McKay, 2017). Bonello (2017) further elaborates on McKay’s number six, when he writes “when you tell an autistic person that ‘we’re all a little autistic', I can almost guarantee that their first reaction will be to feel like you're trivialising the difficulties". It is clear to see in autistic literature that an insecurity relating to whether others believe their autistic identity/ies is commonplace. My research indicates that for those without a diagnosis, it is perceived that medical confirmation would provide this personal validity and therefore reduce insecurities, whereas those with a diagnosis felt that the diagnosis was insufficient to counterbalance personal insecurities and is therefore used as a tool to justify their identity to others.

For many of the individuals who self-identify as autistic and for those individuals who are formally diagnosed as autistic, the autistic identity/ies has become singular, due to, the process of constructing something tangible which can then be used to justify themselves to others. The conflict between awareness of differences within autism and the process of minimisation of 'autism' into a singularity, to serve a purpose, can further be seen in the conflicting data of whether the autistic identity/ies are static or fluid.

6.1.2 Static v fluid

In line with the data suggesting individuals reviewed their autism as singular, as well as recognising differences in others, there was also a suggestion that individuals believed their autism to be static while identifying that changes did occur to their identity over time. Data from the survey clearly illustrated a wide variety of labels individuals had felt were part of their identity over time, while also stating that, regardless of diagnosis, participants felt they had always been autistic and always would be. These findings mirror that of Jackson, Skirrow and Hare (2012) who reported that participants in the autism group (in comparison to a non-autistic group) viewed self-continuity in terms of enduring cognitive abilities and static self-characteristics. While this may suggest implications for an autistics person’s ability to understand identity, such data must be viewed with trepidation as the systems used to arrive at such conclusions do not explore why this may be the case. The static nature of identity formation within this research can be seen to be similar to the contradictions indicated above. It is therefore suggested that this reduction of autism to a static state results from a desire to claim the identity, not only in the present, but also in the past and the future. Evidence is provided in personal accounts that the recognition of autism, either through diagnosis or personal exploration, results in a re-evaluation of one’s past through the autistic perspective (Holliday-Wiley, 2006; Huws and Jones, 2008). While this revalidation could be argued to be logical, especially as diagnosticians and researchers confirmed that autism is present from birth and will remain with the individual throughout their lives (Fein, 2011), there is consideration to be given to the notion that self-identity should be fluid and adapted over time (Giddens, 1991). Limburg (2016) provided a fascinating insight into the way reflection, post diagnosis in her instance, results in a construction of a static identity rather than the discovery of such.

> *“As the person I was changed [after diagnosis], so did the child I had been. Out of scraps of memory and written record… I worked together to construct, retrospectively, the identity of a child with AS. We were not uncovering the child who had always been there: we were narrating her into being, or rather, into <u>having been</u>.” (p149).*

Viewing the process of reflection, whether after diagnosis or self-identification, as a construction of a static entity, offers a further connection with the contradictions surrounding the presence, or not, of an ‘essence’ of autism.

6.1.3 Essentialism v Existentialism

In the above section it was highlighted that individuals often reflected on their past and then reconstructed their identity through the autistic lens. For many participants, regardless of diagnosis, this resulted in the view that the autistic identity was, to them, an essential proponent of who they are as individuals. The contradictions here lie in the fact that participants articulated the processes by which they came to identify as autistic and how their experiences and comparisons with others shaped the way their identity was constructed, therefore fitting more with the existentialist model that identity is constructed as a creation of experience, not as a prerequisite to existence. However, for the majority of participants the autistic identity was believed to be comparable to biological markers such as eye, skin colour and height. This viewpoint would seem to reinforce the concepts outlined above, that individuals are constructing autism into a singular, static entity, that is fundamentally essential to who they are as individuals. As Dumortier (2004) powerfully states "to deny autism is to deny my identity" (p8). Such findings can be referenced back to the literature review that explored the possible fragmentation between a socially constructed self and essential self (Limburg, 2016). It is suggested that, especially for those individuals who self-identify or have gone many years without a diagnosis, the autistic identity lies behind a different, socially constructed persona (the 'mask') (Cox et al, 2017). In relation to the essentialist view therefore the autistic identity is the individual's way of claiming back what they perceive to be the 'real' them in comparison to the mask. "I was nearly 20 years old and I was just finding out why I was the way I was and possibly the most important and most defining part of who I am" (Mitchell, 2005, p55). Implications of masking will be explored further in the following sections.

There is a concept articulated in phase 1 of the research, that in a contradictory manner reinforces the argument of the autistic identity being essential while also suggesting this, in itself, is a social construct and also in turn, succinctly reinforcing the argument that the autistic identity is made to be tangible to fight societal doubt:

> ***"I suppose it is central to me. But the way I wish others to perceive and see me is as [Cara] but understand and not make me feel bad due to my autistic ways" [Cara]***

The results of this research further would argue that this is a significant phenomenon for those individuals who self-identify or come to a diagnosis later in life. It was noted during the analysis of phase 2 results, that for those individuals who were diagnosed at a younger age, the autistic identity was more likely to be seen as merely one part of who they were with 33% of participants opting for this choice in comparison to 21% of self-diagnosed, not formally diagnosed, 15% self-diagnosed then formally diagnosed and 19% formally diagnosed after someone else prompted awareness. It is however acknowledged that due to the nature of the research question the numbers of participants within the group of 'formally diagnosed at an early age' were significantly lower than the other groups and therefore the data may be lacking in external validity.

6.1.4 Identity v person first language

While the principles of identity-first versus person-first language were not discussed specifically within this research it is highlighted here as having a specific relationship to the above contradictions. Person first language advocates that 'person with autism' should be used, whereas identity first language argues 'autistic person' is the preferred language. It is highlighted here in the way in which such contradicting standpoints can use similar arguments to justify their positioning. For example, the following quote is taken from an Identity-First argument:

> *"In the autism community, many self-advocates and their allies prefer terminology such as "Autistic," because we understand autism as an inherent part of an individual's identity — the same way one refers to "Muslims," "African-Americans," "Lesbian/Gay/Bisexual/Transgender/Queer," "gifted," or "athletic," (Brown, n.d.{blog}).*

In contrast, the same justifications can also be used for using person-first language:

> *"My daughter has autism. I do not like the term "autistic" because it does not define her. She has autism the same way she has big brown eyes and asthma and dimples and no patience in her being. None of those things alone define her" (The Autism Blog. 2013. {blog}).*

The popular debate surrounding identity verses person first language is used here to illustrate its relationship to the contradictions discussed above and will be positioned as such as conclusions are drawn on the impact that contradictions have on our ability to accurately define whether there is such thing as an autistic identity/ies. It also, however, illustrates implications within the theme of biopower which will be explored further, subsequently.

Summary

Clear evidence is provided that participants, in large numbers, regardless of diagnosis, felt that their autistic identity was constructed with a wide array of features that were not comparable across all participants. Similarly, participants felt autism differed between people in many different ways. Despite this, evidence is also provided that, on an individual level, participants perceived autism to be a single entity that persists statically over time. It has been put forward that this phenomenon relates specifically to individuals' experiences of doubt from others and the consequential process of trying to validate themselves in their eyes. By taking this viewpoint, the autistic identity can be seen within the realms of identity politics, which as Calhoun (1994) and Philipson (1991) ascertain, is the concept that a single identity is constructed based on membership to a group who believe themselves to be different from the rest of society. This would therefore place it alongside other identities advocating for change such as 'black lives matter', the gay-rights movement or the late 20th-century woman's movement. By viewing the autistic identity in comparison to other established groups it is suggested autism can be singular and plural, static and fluid, essential and existential. To unpick this, I suggest that autism in the context of identity politics is singular, static and essential, in order to provide a framework to embrace individuals behind a common goal (Leveto, 2018). This would account for why person-first language or identity-first language can use similar arguments as they are both using the term to argue (although differently) to advocate for change/acceptance. In contrast, autism as a personal identity is plural, fluid and existential, as Garnett in Spectrum Women (2018) eloquently articulates "While finding out we were on the spectrum was the beginning of a joyous movement, it is not the whole symphony." (p52). Unfortunately, it is suggested that the societies in which the participants resided, fundamentally continue to devalue diversity, and therefore force the promotion of the political identity while suppressing the possible exploration of autism being merely one facet in an individual's personal construct, which may not even need a label.

6.2 What facilitates the process of self-discovery of autism?

> *"All of us come to be who we are (however ephemeral, multiple and changing) by being located or locating ourselves (usually unconsciously) in social narratives rarely of our own making." (Somers, 1994. P.606).*

The evidence from this study indicates that changes across our societies are the fundamental facilitators of the new phenomenon of self-identification of autism. Therefore, suggesting autism as an identity is specific to the culture, time and place. As Foucauldian Discourse Analysis identifies, 'knowledge' as a concept, refers to the constructs of meanings used by people to shape their environments (Jager and Maier, 2009).

While participants indicated they believe they had always been autistic, it was clearly evidenced that this only became a 'truth' to them, once a process of reflection on past events had occurred. There was no evidence that participants had felt autistic from birth. Participants highlighted key changes within society, such as language development and the growth in media as central in allowing them to explore autism, using it as a learning process, to develop their self-identity. The very fact, therefore, that individuals have shared experiences of negotiating their own identities indicates that an identity cannot be constructed in isolation, but instead, exists in relation to the social construction and dominant dialect of the time (Rhodes et al, 2008, Lawler, 2008).

The way in which the participants articulated their experiences and the symbiotic relationship their identity had with those around them would indicate a reinforcement of a theory of learning dominated by the role of social interaction (Lave, 1988; Rogoff, 1995). The Social Learning Model finds its foundations in the idea that knowledge is not abstract and symbolic but contextually located and is therefore influenced by the environment and the culture in which it is used (Berger and Luckmann, 1966; Blackler, 1995; Brown, Collins and Duguid, 1989). Prior to the development of the social learning model (Cobb and Bowers, 1999), research on learning focused on the cognition of the individual and the principles that knowledge is individually constructed and therefore can be passed from expert to novice through 'data transfer' and equally can be researched as such in laboratory settings focusing on a "stimulus-mediation-response scheme" (Anderson, Reder and Simon 1997, cited in Cobb and Bowers, 1999, *p*4). DeCorte, Greer and Verschaffel (1996) argue that the development from this type of research approach has emphasised the effect an individual's environment, society and history has on their knowledge, outlining the shift as such:

> *"from a concentration on the individual to a concern for social and cultural factors; from "cold" to "hot" cognition; from the laboratory to the classroom as the arena for research; and from technically to humanistically grounded methodologies and interpretive approaches" (p.491).*

While the social theory of learning, generally, can be seen to reinforce the conclusions that the autistic identity is not developed in isolation it does not provide a holistic justification for the emotional implications and the associated mental health concerns the participants expressed. Such features of learning can be seen in the work of Freud and then Holzkamp-Osterkamp (1976), Rogers (1969) and Berlyne (1960) who separately explored the role our emotions had on individual's ability to learn.

It is inappropriate within this research, to consider the validity of each approach in exploring *all* learning, or even the many facets that they have been used to explore. However, given the nature of the experiences expressed from the participants of this study, the conclusions of Illeris (2018) resonate with me when he writes:

> *"all learning always comprises three dimensions: the content dimension, which is usually, but not always, cognitive; the incentive dimension, which includes engagement, interest and motivation and is mainly emotional; and the interaction dimension, which is social (also when it is a text, a picture, a film or the like) and may have many layers, ranging from the immediate situation, the local, institutional, environmental, national and other conditions to the global context in general" (p11)*.

Taking this into account, the principles of Communities of Practice are recognised as facilitating an accurate exploration of "identity trajectory and emotion work which is entailed in personal learning trajectories" (Wenger-Trayner et al, 2015, *p*33). While I acknowledge the role of cognition in learning, it was not identified as a variable in participation of this study and therefore could be viewed as a limitation of the data collated as it prevents further exploration. It is however, recognised as part of the journey of identification.

When positioning the situated learning model in relation to identity it is argued that individuals use the knowledge they build within a social context, to develop identities. Importantly, it is acknowledged, and reinforced, that "Identity is not some primordial core of personality that already exists" (Wenger, 1998, p154), therefore identity is something that must be constructed contextually.

Wenger (1998) writes that

> *"when we come in contact with new practices, we venture into unfamiliar territory. The boundaries of our communities manifest this lack of competence along 3 dimensions [engagement, imagination, alignment]. We do not quite know how to engage with others. We do not understand the subtleties of the enterprise as the community has defined it. We lack the shared references that participants use. Our non-membership shapes our identities through confrontation with the unfamiliar." (p.153).*

By reviewing the data found in my research and positioning it with my own experiences the above quote from Wenger reads as if it was written about autism. I suggest this, because of the experiences of the participants, indicating that autistic individuals find, what they term the neurotypical world, “unfamiliar territory”. In their more recent work concerning ‘landscapes of practice’ (Wenger-Trayner et al, 2015) a greater recognition has been given to the role of marginalisation and how identity is not only constructed within a community but also within the spaces between communities (Handley et al, 2006). Equally it is recognised that autistic individuals are not members of only one type of community in practice and therefore their identities should be complex, constructed from multimembership (Wenger-Trayner et al, 2015). However, my data suggests that participants experienced that most communities enforce an identity of abnormality and deviancy, as one participant states.

> **“I felt like an alien here for my whole life” [Neil]**

The incorporation of negative past experiences within different communities of practice reinforces an identity into the present and the future (Wenger-Trayner et al, 2015). While authors such as Wenger-Trayner have developed their understanding of learning at the boundaries of communities of practice, emphasis is given to the importance of language in conceptualising ‘failure’ and therefore learning from it. Consideration is not evident however in situations where marginalisation occurs without the necessary language to conceptualise experiences.

In the literature review chapter, I explored the work of Ian Hacking (2009), specifically how he argued that “a quarter century ago there was no language for autistic experience, emotions and intentions” (Hacking, 2009b, *p.*503). When asked to reflect on what has changed in society, allowing them to self-identify, the most popular answer given by participants was that autism was not talked about when they were younger (phase 2, table 34). Significant literature was explored during the literature review chapter, of how developing language and Looping Theory (Hacking, 2009b), can be viewed as a facilitator of new identities (Bucholtz and Hall, 2006). Indeed, my evidence would reinforce Hacking's argument that in the recent history of the participants, there was no means by which to articulate autistic experiences (Hacking, 2009b), which therefore hindered or even prevented an individual from self-identifying as autistic. As language is a concept imbued with culture, the learning process surrounding autism and identity that is hindered because of it, as Bruner argued, is not of biological origin, but a search for meaning within the context of culture (Smidt, 2013). In line with the thinking of Vygotsky, Bruner reinforced the argument that learning is undertaken through cultural tools, with their foundations in language, such as books or the spoken word. Equally, Vygotsky argued that learning is led by the 'more experienced other' which has significant implications with regards to the power of language within societal categorisations which will be discussed further within the subsection *power and illusion.* The development of new descriptive language therefore, as Hacking argues, facilitates individuals to relate their own experiences to the experiences of others and therefore construct an identity. As language is arguably the prerequisite of identity construction (Preece, 2016), Hacking would argue that the lack of language as well as inaccurate stereotypical representations across society, has in the past prevented individuals from associating their experiences with autism, preventing movement forward on a learning process. This is why we are experiencing a change within our current society as the growth of the internet and autistic literature is shifting the stories and therefore allowing individuals to progress onto the next stage of learning which Brown, Collings and

Duguid, (1989) define as reflection. Further implications of language and its role will be explored in relation to Foucauldian understandings of power.

The second change identified in society, which it could be argued has provided a medium by which to proliferate the new language surrounding autism, is that of the mass media. It is unavoidable to acknowledge that over the past four decades, the way in which we communicate with others has changed dramatically. The entrenchment of the Internet into everyday life has removed individuals from the restrictions of local communities and provided access to people and information from across the world (Dekker, 1999). Kirby (2006) references 'digimodernism' which has characterised this relationship between the individual and technology. The evidence from this research has suggested that the media, (term used to encompass all forms, for example: Internet, books, news, TV, radio, social) has impacted positively and negatively in the construction of the autistic identity. It featured as a more central role for individuals who self-identify than it did for those that were formally diagnosed.

The proposed positive impact the media had on the individuals within this research is used to further suggest that the autistic identity is not formed in isolation. Participants articulated a process by which they acknowledged a feeling of difference and then used a range of media outlets to research other's experiences that may correlate with their own and therefore create a self-identity. Davidson (2008) suggests that a high percentage of autistic voice advocacy takes place online, which facilitates a new opportunity for positive self-identification of autism (Singer, 1999; Brownlow, 2010).

> ***"I think because I had what I saw as a positive role model for being autistic I had a more positive perception of myself as autistic" [Martin].***

The presence of self-advocacy, through the Internet, has developed what researchers have referred to as an autistic culture (Dekker, 1999; Davidson, 2008; Brownlow, 2010), which as Watson (2002) would argue, is a necessary facilitator to the creation of identity.

While my findings suggest that the autistic identity requires connection with others, often through the Internet, to be developed and refined, it also suggests that a basic awareness of the autistic identity needs to be present to serve as a prompt to begin the process of exploration and connection with others. Therefore, for those individuals that are not privy to a basic knowledge of autism or have this and then do not have access to medians such as the internet, it is suggested that the ability to construct an autistic identity/ies would be hindered, and maybe prevented. Suggesting therefore that our awareness of the numbers of people worldwide that could align themselves with the autistic identity/ies is likely to be inaccurate and vastly underestimated.

My research findings suggest that the media can also play a role in hindering an individual's basic awareness and therefore delaying their identification as autistic.

Within phase 2 of my research, participants that self-identified without a formal diagnosis, stood out as feeling the media portrayal of autism hindered their identification, more than any other group. This is reinforced by Draaisma (2009) and Loftis (2015) who both articulated concerns over the construction of autistic stereotypes within the media and the impact this has on the language used to understand autism more widely. Swain, Barnes and Thomas (2004) argue that such misrepresentation goes beyond language to a core understanding, by providing examples of how the media alters their language (to more politically correct terms at that time) – however, the core misunderstanding behind their interpretations remains. Weimann (2000) reflects on Plato's Allegory of the Cave, suggesting that in the modern world the TV and computer screens have become the new cave wall. Taking all three positions into consideration, there is clearly an argument that the representation of autism in the media, is shaping a 'reality' amongst the wider populations. And should this be flawed, which my research participants have experienced, it will hinder their ability to find commonality with the autistic culture and therefore bar them from beginning a process of self-discovery. In this sense the role of the media in regulating information can easily be attributed to concepts of power which have been developing through this discussion of results. Wodak and Meyer (2009) suggest that 'discourse' is an institutionalized way of talking that controls action and thereby exerts power. Therefore, in relation to the data of this study, it is suggested that the media exerts substantial power on what is believed to be 'knowledge' regarding autism and what this means to everyday life. This implies that the autistic identity is shaped by others and is a means of power functioning through knowledge (Kendall and Wickham, 1999).

It is note-worthy that the participants of this study also acknowledged that the blame for a flawed representation of autism in the media can be partially held at their feet. The following interpretation of my understanding of the masking experiences of individuals will be reflected upon further in the following section, however it is important to acknowledge here also:

I do so because of the section of the 'vicious circle' highlighted by the red

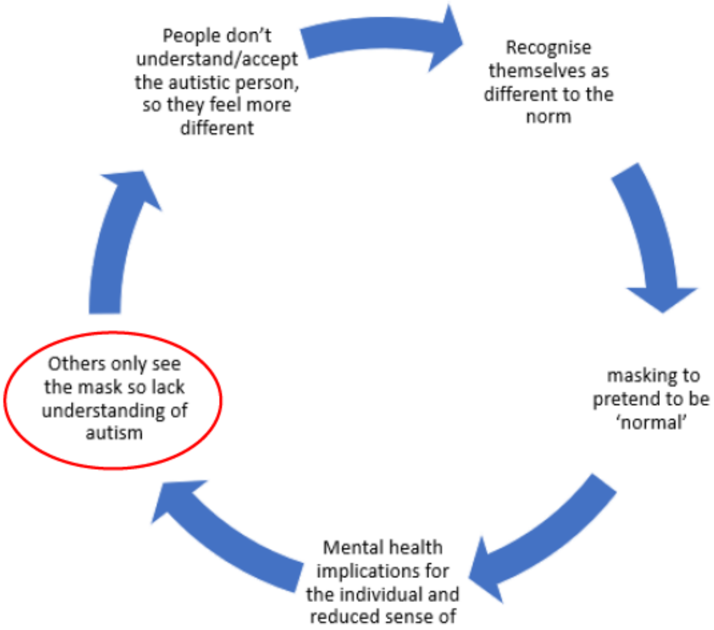


Figure 64: Vicious Circle of Identification

circle. It identifies that 57% of participants, regardless of diagnosis, felt the act of masking would negatively impact on other people's understanding of their autism.

> ***"At the time I was trying desperately to hold onto my mask even though I didn't realise I was wearing one, so I don't think they saw 'me'. They saw the scraps of my mask with other bits showing through." [Margaret]***

This is a concept that to my knowledge has not been widely acknowledged but provides an alternative perspective on the impact of masking. This will be discussed further under the heading 'Impact of delayed realisation of the autistic identity/ies'.

Summary

Clear evidence is provided to argue that increased opportunities to encounter other's experiences of autism and the consequential language development that this provokes, allows individuals to associate their own experiences with the socially available term of autism and has therefore facilitated this phenomenon. However, in contrast, it is also suggested that inaccurate portrayals of autism in the media have also hindered individual's abilities to self-identify as autistic earlier in their lifetime, indicating a significant amount of power held by the media in constructing identities that will differ depending upon the time, space, and culture of the society in which it exerts its power.

The ability for an individual to continue to develop their autistic identity/ies may be hindered by the reification of autism as an ontological truth. The classification of autism becomes pivotal in constructing meaning: "aspects of human experience and practice are congealed into fixed forms” (Wenger, 1998. *p.*59). By providing a fixed concept in autism, we may miss the lived complexity of identity.

6.3 What is the impact of the delayed realisation of the autistic identity/ies?

In the demographic analysis of data in phase two of my research, differences between participants’ age and age of self-identification/diagnosis were explored. While this provided an interesting analysis of the differing age ranges, to fully explore the impact of delayed realisation of autism, I further delved into the available data. Number of years between birth and recognition of autism (either through diagnosis or self-identification, whichever came first) was calculated. As participants only identified themselves within an age range, calculations were made based on the lowest possible age within that range, to give the minimum number of years of delayed realisation. It is therefore noted that the figures I report may in fact be higher. Of the hundred and twenty-two participants who provided data in this field, the average number of years an individual lived before identifying themselves as autistic was 29.38 years, with a standard deviation of 14.84 years. With one hundred and five participants, or 86% of the research population having lived more than 50% of their lives without recognition of autism, it is important to consider what impact this may have on the individual and the development of the autistic identity/ies.

From the very beginning of phase 1 of my research and then throughout phase 2, the participants’ mental health emerged as a fundamental theme. Simplistically, the data suggests that for individuals who self-identified as autistic, their perception was that their mental health was worse prior to self-discovery and better afterwards.

> *"There is a lot of pain that comes from knowing that you're different but not knowing why" (Kim, 2013. P.42).*

This is important as it resonates with the work of Cassidy, Robertson and Townsen (2020) who found that autistic individuals were significantly more likely to die from mental health challenges and associated self-harm or suicide (Hirikoski, et al., 2016; Hwang et al, 2019; Kirby et al., 2019). As these studies only included those that had a formal diagnosis of autism there is an argument to suggest the figures may be higher if individuals who self-identify were included.

Mental health post self-identification will be considered further in the following section. This section, in keeping with the theme, will focus on mental health prior to self-identification. The data suggests that there are four key themes that impacted on an individual's mental health and these will be explored in turn: schooling, bullying, adaptive morphing, in-group/out-group.

6.3.1 Schooling

The data collated in relation to school in both phase one and phase two of the research was fascinating and provides fundamental considerations for a system of education. As is outlined in phase two, participants' responses illustrated that, regardless of diagnosis, individuals predominantly noticed they were different to their peers between the ages of four and ten. However, more participants expressed positivity with schooling during this age range in comparison to the 11+ age range which was significantly more negative. In contrast to those that self-identified, participants who were formally diagnosed at an early age identified that secondary school could be both negative and positive suggesting that those without a formal diagnosis had more negative experiences at school. It is unclear whether this difference correlates with support offered due to diagnosis that may not have been offered to others.

During the review of previous literature, the concept that puberty has an impact on the way in which individuals viewed the world and themselves within it, would appear to correlate with this proposed change around the age of eleven (Tantam, 2012. p101).

> ***"It's only when I had to "exit my head" and face outside world when I realized there is some problem... ". I don't think it was posing any particular problem until puberty." [Anna]***

Wenger (1998) relates this to his argument that identities are built "As we encounter our effects on the world and develop our relations with others, these layers build upon each other to produce our identity" (*p.*151). Therefore, should children at school encounter positive relationships and positive connotations of diversity they are more likely to develop a more positive identity and reduce consequential mental health concerns (Kirby, 2021a). Experiences articulated in phase one of the research indicated that they had not encountered positivity towards diversity in their lives and this had a negative impact on them:

> ***“I think earlier than that {secondary school} was that my sense of identity didn’t match what other people saw me as, which was confusing and upsetting and felt unfair” [Kathy]***

The findings from this study would suggest that the result of such marginalisation negatively impacts on an individual’s identity and mental health, which is unlikely to occur if the individual were able to hold onto the positivity of difference experienced at primary school into later life.

6.3.2 Bullying

The results of phases one and two highlight that participants suffered significant experiences of bullying while at school:

	Self-diagnosed, not formally diagnosed	Self-diagnosed and then formally diagnosed	Formally diagnosed after someone else thought I was autistic	Formally diagnosed when I was younger, so I was not involved in it
Yes I was bullied at school	71.4%	85.5%	72.7%	50.0%

Figure 65: Rates of bullying. Table

When correlated with previous studies on bullying and autism, the 50% reported by those formally diagnosed at a younger age, roughly compares with Sterzing et al (2012) who reported bullying at 46.3% and Van Roekel, Scholta and Didden (2009) who recorded it at 46%. Both these studies focused on youngsters who had been diagnosed autistic. When comparing this with my data that over 70% of participants reporting bullying within the categories that were not diagnosed at an early age, this would suggest that a lack of diagnosis may increase the probability of experiencing bullying. Arseneault, Bowes and Shakoor (2010) in their review of empirical studies on bullying and mental health concluded that being a victim of bullying is:

> *"associated with severe symptoms of mental health problems, including self-harm, violent behaviour and psychotic symptoms; has long lasting effects that can persist until late adolescence; and contributes independently to children's mental health problems" (p.717).*

It is argued therefore that a lack of awareness of autism by the individual, alongside a lack of positivity surrounding diversity as highlighted in the above sub section, increased the chances of bullying, which in turn increases the individual's chances of experiences mental health concerns.

6.3.3 Adaptive Morphing

Masking (the term used in the research questions) was identified in phase one of the research and explored further in phase two. Over 80% of participants in all categories, regardless of gender, as has been reported as a key feature of masking in the past, (Lawrence, 2019) reported they undertook masking. The two highest options chosen for explaining what masking is, were 29% believing it to be a safety mechanism due to fear of others and 26% believing it to be a conscious decision to try to fit in. There was disagreement as to whether masking was a conscious or unconscious act (or both), however it appeared to be more widely accepted that, as one survey participant added to their answer, “something that is driven by anxiety or fear”. Which was mirrored in the interviews with comments such as:

“I was constantly building up my mask to prevent negative attention” [Brad].

Lawson (2020) argues that it is the very nature of the act of changing one’s behaviour in order to ‘feel safe’ which results in what he terms ‘adaptive morphing’. He argues that as the process is a “state that attempts to hide us from harm, enabling us to stay and feel safe” (p1) and not a simple act of deliberately deceiving others, it should not be referred to as masking or camouflage. This argument relates back to Hacking’s Looping Theory and the impact of language construction. As the researcher, I am alerted to the bias that may have been implicated by choosing to use the term ‘masking’ in my thematic analysis and consequential survey design. Through the analysis of the results, what I termed ‘masking’ would more appropriately be classified as ‘adaptive morphing’. While this new term will be used in the subsequent discussion of this phenomenon, the term ‘masking’ will continue to be used when referring to the data provided by the participants, to accurately represent the questions they were answering.

The justification for ‘adaptive morphing’ can be linked to ‘a biological response to a perceived threat’ (Lawson, 2020. p524) deriving from the negative experiences at school and of bullying that builds an atmosphere of fear of others which results in the desire to hide from harm. Cage, Monaco and Newell (2018) found in their study of one hundred and eleven autistic adults that autism acceptance from external sources, and in turn experiences of ‘camouflaging’ significantly predicted depression and stress. This is reinforced by the fact that, for those individuals who experienced a school system that accepted difference, such as Neil in phase 1, they reported no issues with bullying and no masking with their peers:

> ***"So for me school became the source of good things from the very beginning."***
>
> ***[Neil]***

Interestingly, Neil was also one of the participants who was comfortable with his own self-identification and did not feel the need to get a diagnosis.

Around 80% of participants in all categories felt masking had a direct impact on their mental health. While 59% of participants felt there were both positive and negative implications, when reviewing the top three popular choices in each group (appendix 15), it is evident that most people felt that masking had a negative impact on their mental health, with exhaustion featuring above all else. The relationship between adaptive morphing (masking as it was termed then) and essentialist views were discussed in the above section as well as in the initial literature review, suggesting that the process of adaptive morphing results in a distinction between a socially presented self and a perceived underlying autistic self. *"But living a masked existence has robbed me of me."* (Heyworth, 2018). Hull et al (2017) and Bargiela (2016) argue that not only does the presentation of a socially acceptable self-occur, but it also erodes the individual's sense of identity, in turn potentially damaging the individual's mental health (Cage, Monaco, Newell. 2018). Figure sixty-one is drawn upon again as a representation of this process.

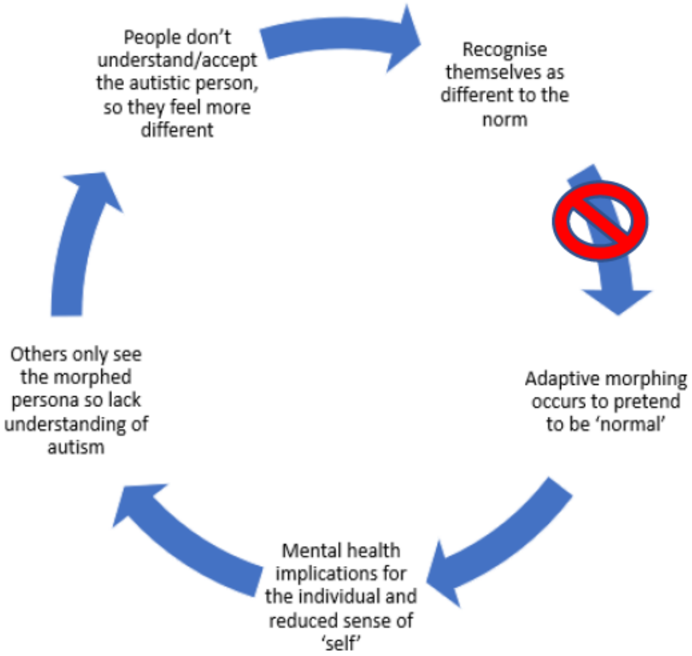


Figure 66: Vicious circle of identification

Encompassing the discussions surrounding school, bullying, mental health, and adaptive morphing, I would argue that the vicious circle as I illustrate here can only be broken by developing an environment of acceptance that everyone is different from the norm, and that being non-disabled is a temporary state as most people will experience disability at some stage of their life time (Shakespeare, 1996). Where we would not need the process of 'coming out' as an individual's needs would constantly be considered and valued (Kirby, 2021b). Until this is the case, individuals will continue to feel the need to morph themselves to 'survive', especially when they are not able to explain their difference and will therefore continue to experience negative mental health implications.

6.3.4 In-group/out-group phenomena.

According to stigma theory (Johnson and Joshi, 2016), the identification of a common difference in individuals creates a stigmatised group, leading to the individual altering their view of themselves because they feel socially devalued (Crocker & Major, 1989; Goffman, 1963; Link et al, 1989; Rusch et al., 2009). Through negative experiences and bullying, individuals from this study, expressed incidents of feeling on the outside of the 'popular groups' or friendship groups at school. Barron (2009) found similar experiences when exploring race within the classroom. He suggested that, although often unconsciously, the Pakistani children within their study were made to engage in the periphery of an activity. This exclusion impacted on their self-image as it was born out of perceptions of not being equal to others along with a lack of language and experiences required to be accepted. Social identity theory argues that a person's identity is developed through their relationship to what they term the 'in-group' and the 'out-group' (Olney and Brockelman, 2003). The experiences of the participants in this study would suggest that the delayed recognition of autism resulted in an identity being built on the assumption of being in the out-group of society, and deficit-based labels as seen in Barron's study (2009).

> ***"I just thought I am a very difficult character. I thought I am very stubborn, grumpy, rude, heartless sometimes, not able to love and that it was my fault that I am irritable and never able to enjoy life" [Anna]***

This quote from Anna is emotionally driven and helps us to understand the blame that the individuals felt lay at their own feet for their difference and marginalisation. Equally in Cara's experiences she explained that:

> ***"My counsellor says I'm desperate for acceptance from my family and have been all my life" [Cara]***

In the experimental works of Asch (1951) and Milgram (1963), the power of situation in conformity was highlighted. The experiences emphasized through Anna and Cara here can be seen within the realms of normative social influence, whereby an individual is compelled to comply with socially constructed ideas of normality due to a need to be liked or feel that they belong. Equally the work of Festinger (1957) can be drawn upon with his notions of Cognitive Dissonance, specifically where an individual experiences discomfort, or conflict, when their thoughts, beliefs or behaviours are incompatible with others and the individual tends to want to resolve that tension.

As was identified in the section of the 'facilitators of self-identification' the autistic identity/ies cannot be built in isolation and it is the process of seeking to resolve the internal tension, as suggested above, that leads the individual to search for a group of people whom they feel share their experiences and therefore construct a new ‘in-group’ that allows the possibility to form a new positive identity (Bagatell, 2007).

> *We are not born with complex identities. We become multiplied through our trajectory across the landscape…identity and knowledgeability is best understood not as a function of participation in a single community of practice but in terms of multimembership. (p.79).*

Autism therefore is not just an identity born from engagement with the autistic community but a multimembership experience of exclusion and the associated emotional implications of this followed by engagement with the autistic community as it stands. This is reinforced by the fact that 87.7% of participants, or 100 out of 114, expressed that they were, or had been, actively searching for people they could relate to. This results in group polarisation, whereby discussions lead to a new in-group of individuals adopting attitudes or actions that promote the process of reification, and therefore may be more extreme than the initial attitudes of any one individual group member.

Wenger (1998) discusses the importance of mutual recognition as a key foundation to identity. Questions are raised, however, on the impact of delayed arrival at a group identity, as evidence from this study suggests that for self-identifying autistics’ recognition may be one-sided, either lacking recognition from the autistic community or/and recognition from people they engage with in their everyday lives. In a number of cases, participants expressed that they only shared their autistic identity/ies with fellow autistic people online but were not open with people in their everyday lives:

> ***“I think generally as a) there is a lack of certainty without a third party providing a professional diagnosis, b) there is then a consequent lack of validity, and c) I***

> ***therefore am concerned with how people will react, particularly if for any reason a diagnosis is not forthcoming" [Mark]***

It is suggested that the marginalisation experienced during secondary school years and beyond, and the entrenched fear of others that ensues, significantly hinders an individual's ability to openly express their autistic identity/ies in their everyday lives. While the principles of Social Learning Theory have been illustrated to aid our understanding of the construction of the autistic identity, this process of marginalisation shines a light on an area that is under researched. As I have expressed, it is evident that the principal theory underpinning the approach, is that individuals construct knowledge/identities by engaging in differing forms of communities. It is suggested that a significant gap in the literature is present, surrounding individuals that are marginalised from a community yet have no language in which to understand or justify such marginalisation and therefore while they are seeking connection with 'like-minded' others, they are restricted from seeking specific communities based on shared experiences. The evidence from this research clearly indicates that a significant number of the participants in this study experienced marginalisation and being made to feel different in some way to the perceived norm, without an understanding as to why. This status of 'illegitimate peripheral participation' (in comparison to Lave and Wenger's legitimate peripheral participation, 1991) forces the individual to be unable to form a trajectory into another community and therefore the individual is left morphing their own behaviours, to gain legitimacy of participation in the community in which they have become marginalised. In line with the principles of Communities in Practice I suggest that for autistic individuals who are unaware of their autism, the trajectory of identification is as outlined in figure sixty-seven below.

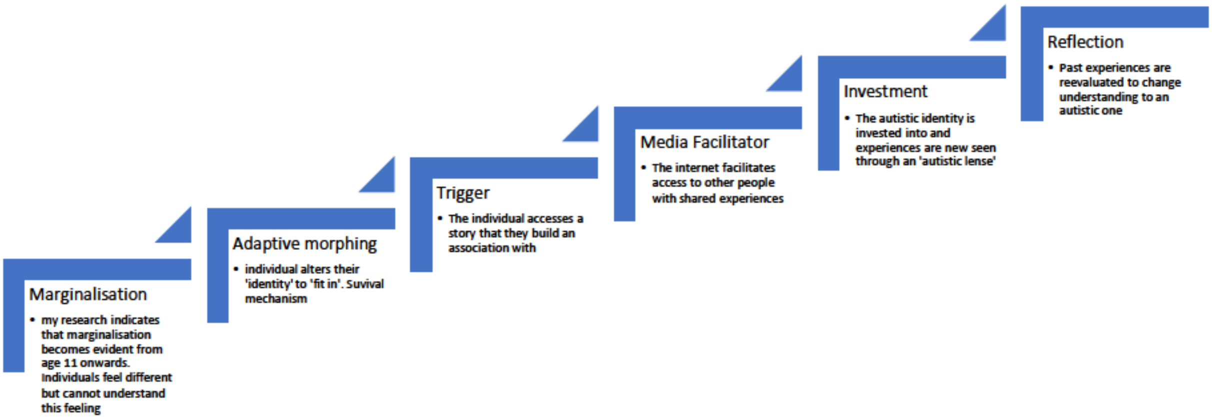


Figure 67: Trajectory of Identification

The trajectory as outlined above in figure sixty-seven, which finds its roots in marginalisation and reduced sense of identity, when viewed alongside the principles of identity construction within the Social Learning Theory and, in turn Communities of Practice, provide important barriers to identity.

6.3.4.1. A Nexus of Identities

Findings of this research have revealed that experiences of adaptive morphing, physical and mental abuse alongside mental health implications impact upon the way in which the autistic identity is invested into. The identity often becomes central to the person's awareness of themselves. Individuals expressed the belief that autism is essential to them, and that everything they do/experience/think is impacted by their autism. Wenger (1998) argues that there should be a nexus of identities that work together, therefore any one identity should not hold any level of superiority over another identity. Ironically, Wenger

(1998) talks of the plurality of identities forming “pieces of a puzzle that go together” (p159) however the puzzle piece is often used to represent the singularity of autism and the confusion in understanding where it fits within the wider picture.

The data within this study provides a connection to the work of Foucault and sexuality. Specifically, how the identity is in itself cultural, but discourses incite us to believe they are natural therefore maintaining specific power relations (Spargo, 2000). In much the same way that the autistic identity was seen in my study as being an overarching identity for the individuals, Foucault (1984) also suggested that “homosexual was seen as being totally suffused with sexuality: “It was everywhere present in him: at the root of all his actions.” (p43). This, Foucault argued, was as a result of the social control that labelled differences to the norm as deviant and in turn marginalised those with such a label. The negative construction of the autistic identity/ies that was expressed in my results reinforce this argument that the dominance of the autistic identity, instead of a nexus of identities, originates from its foundations of being different to the ‘norm’. As table 35 within the analysis of phase two indicated, the autistic identity was predominantly shaped by feeling ‘ab-normal’.

	Self-diagnosed, not formally diagnosed	**Self-diagnosed and then formally diagnosed**	**Formally diagnosed after someone else thought I was autistic**	**Formally diagnosed when I was younger, so I was not involved in it**
1	feeling different to the 'norm'	*Jointly* anxiety and socially awkward	socially awkward	*Jointly* socially awkward & meltdowns/shutdowns & passionate
2	anxiety		feeling different to the 'norm'	
3	socially awkward	feeling different to the 'norm'	Anxiety	

Figure 68: Identity and Abnormality. Table

I would suggest that all the elements identified in the table above are socially constructed based on the concept of 'normal' and 'ab-normal'. Foucault does identify that such discourse produced reverse discourse (Spargo, 2000), whereby individuals with shared experiences of marginalisation, provide alternative language to advocate for themselves. This reinforces my previous argument that the autistic identity/ies has become politicised, and one such reasoning for that is the lack of a nexus of identities. In the same way, individuals with similar experiences of sexual orientation and skin colour, as examples, may advocate on behalf of a given identity. The lack of a nexus of identity therefore serves to enable an individual's rights and political power. However, in reality this is no more than an illusion of power, in order to maintain and reinforce the biopower of categorisation and division, which will be discussed further in the section 'power and illusion'.

6.3.4.2. Trajectory

Within communities of practice, the importance of mutual recognition is provided as a key foundation to identity. Evidence is presented within this research that suggests, for individuals who self-identify as autistic, recognition may be one-sided, either lacking recognition from the autistic community and/or recognition from the neurotypical community. The restriction of mutual recognition places the individual within the periphery of an inbound trajectory, and for many of the participants within this research it was indicated that a formal diagnosis may provide a 'key' to move past this into full membership.

When discussing how his autistic son viewed his self-identity of autism Brad explained:

> ***"I think in his mind my empathy lacks a little credibility or authenticity as he is "different" [Brad]***

There is an interconnect here with the discussion above relating to a nexus of identities, as the self-identifying autistic person is potentially marginalised from two different communities of practice, too 'ab-normal' for their everyday lives but not 'ab-normal' enough for the autistic community:

> ***"there is still a lot of prejudice against self diagnosis..the National Autistic Society last time I asked required a formal diagnosis to offer any support and there have been several research projects I've wanted to be involved with that required a diagnosis." [Martin]***

As such the individual is 'black-mailed into diagnosis" (Hodge, 2005, p346), in order to move into the autistic community and begin to develop mutual recognition. This will be considered further within the subsection of 'diagnosis'.

6.3.4.3. Local-global interplay

Equally affected by one's mutual recognition is the impact of local-global interplay (Wenger, 1998). By individuals building identities based on marginalisation (Valentine and Skelton, 2008), a 'them and us' culture is created (Kirby, 2021a), which prevents the individual constructing an autistic identity/ies that is able to travel across contexts (Wenger, 1998).

Self-identifying autistic individuals often experience mutual recognition within autism specialist groups online at a global level. Social Psychology has begun to explore virtual group polarisation, whereby the internet, and in particular social media, has facilitated group polarisation as a result of information biases, social comparison and the individual adjusting their beliefs or actions to the groups norms (Brauer et al. 1995; Mercier and Landemore, 2012). Social identity model of deindividuation effects (SIDE) suggests that the anonymity promoted through online communication, impacts the individual's identity, in the sense that they associate with the collective identity resulting in a loss of individual identity (Postmes et al., 1998). This suggested deindividuation could be associated with one of the important outcomes of this research, that the individual's identity within virtual associations at a global level do not mirror their identities in their day-to-day lives off-line, at a local level. "Claiming a voice without having to claim the body" (Zubal-Ruggieri, 2007 quoted in Parsloe, 2015. p340). Referring to the work of Bruner, previously discussed, he argued that we try to make sense of the world within the context of our culture. However, the evidence from my research, and the virtual group polarisation, would suggest that autism often superseded the individual's immediate culture. It is acknowledged that cultural differences would impact on this, which may not have been fully represented within the current research population. Communities of practice stress the importance of identity being "an interplay between the local and the global" (Wenger, 1998. p162). However, in this case there appears to be more emphasis on the global than the local, which is in direct contrast to the suggested movement from local to global that communities of practice discuss. This shift in perspective to the globalisation of the autistic identity has significant implications for the way we approach research and future policy, and as such will be returned to in subsequent discussions.

It is my belief that the negative experiences individuals undergo prior to understanding autism, alongside the societal nervousness of difference, result in an association with the autistic identity that is tied with participation in a community. The community engages in virtual group polarisation; therefore, the participants are bound by their mutual engagement in autism advocacy. Conversely however, it is suggested that the reification of autism into a singular identity, hinders the individual’s ability to construct multiple collaborative identities that reflect the holistic person. Therefore, by developing the autistic identity/ies into a single over-arching identity, it is hypothesised that the individual may be hindered from discovering themselves beyond the autism which in turn hinders their ability to form connections with other people on a local level. This would have significant implications on the individual and their well-being and therefore would benefit from further research.

6.3.4.4. Identity is not an object.

As previously stated, Communities of Practice stress that identity is not an object but an entity that continually adapts and changes based on the life experiences and social context of the individual. This would appear to be in direct conflict with the findings of this study that suggests individuals feel the autistic identity is a static entity that they have always been and will always be able to identify with. It has been referenced to my findings and the work of Foucault that such reification of autism serves as a discourse to produce and transmit knowledge. It is noted however that the dubious construct of the ontology of autism does not make it any less real for those that identify as such, but does require consideration of how such an identity can be positioned to traverse different landscapes of practice (Wenger-Trayner and Wenger-Trayner, 2000).

Summary

Through the exploration of school, bullying, adaptive morphing and in/out groupings there is clear evidence that the delayed recognition of autism has a significant negative impact on the individual. It is also argued that the marginalisation that occurs encourages the formation of an 'out-group' of society focused on the singular identity of autism. In line with the questions surrounding the politicisation of the autistic identity/ies, it is suggested that a focus on promoting diversity, in schools and consequently into society, would result in autistic advocacy being unnecessary therefore allowing the development of the autistic identity on a individual level.

> *"As long as our society lacks truly inclusive attitudes and practices, autistics will need to continue to display chameleon-like responses in socially threatening situations. Our mental, emotional, physical and financial lives depend on it" (Lawson, 2020.* p*523).*

6.4 What is the purpose of self-identifying as autistic?

While the above discussion surrounding adaptive morphing would indicate that individuals may not want to openly identify themselves as autistic, there is a clear contradiction in the fact that the phenomenon of self-identification is occurring. It is for this reason that consideration is given to the purpose of self-identifying, based on the experiences of the individual. Within this discussion themes of reflection, self-acceptance, mental health, community, acceptance of others and diagnosis will be explored.

6.4.1 Reflection

Phase two of my research indicated that the two most popular reasons for self-identifying were that ‘it allowed me to reflect back on my past and understand it a bit better’ and ‘it meant I could start to understand myself’. It is evident that the phenomenon of self-identification is an individualistic process, focusing on the method of reflection on one’s own life to date.

As was demonstrated in the literature review, research has suggested that autistic individuals show an impairment in the ‘self-as-an-object’ and ‘self-as-a-subject’ elements of self-understanding (Jackson, Skirrow and Hare, 2012). Such an argument would seem contradictory to a process that relies upon understanding of oneself. It is noted that there appears to be a gap in research that focuses upon autistic abilities to recognise self in adulthood, as most studies focus on early childhood (Hobson. 1990; Ferrari and Matthews 1983). As this study indicates, there is a difference between an autistic individual’s ability to recognise ‘self’ in relation to others in early childhood and latter childhood into adulthood, which would therefore make the findings of studies only focusing on early childhood unrepresentative of the wider population. One study that did focus on adults was undertaken by Lombardo et al (2007), who researched thirty adults and possible impairments in their construction of self. Their study confirmed that while autistic adults have some difficulties in the ‘self-referential cognitive domain’, they were not ‘completely impaired in self-referential information processing’ (p7), a finding which they believe is mirrored in the work of Berthoz and Hill (2005). The sheer numbers of individuals participating in this study would provide clear evidence that autistic individuals do have skills of self-referential cognition. Furthermore, the process of self-identification acts as a gateway to promote the individuals to develop knowledge of themselves by turning mind-reading capacities upon themselves, therefore reinforcing the mindreading before metacognition model (Carruthers, 2009). As Holliday-Wiley (2015) expresses, it is the process of using third person mind-reading skills upon one's own memory of experiences that allows the development of metacognition around the autistic identity/ies. In relation to Communities of Practice, as introduced above, Wenger argues that investing in the autistic identity/ies changes their perspective, with a tendency to see things in a particular way (through an autistic lens). A process of reflection occurs (negotiability of a repertoire) whereby past life experiences are reflected upon, and their meaning reinterpreted to now fit the autistic lens (Leedham et al, 2020). Constructing a narrative out of reflection therefore is complex, and culturally shaped by the language available to us (Smidt, 2013). Wenger would argue against the belief however, that this reflection is a discovery of an identity, instead reinforcing the claim, outlined in previous sections, that

> *"[identity] is not an object - but a constant becoming. The work of identity is always going on." (Wenger, 1998. p.154).*

This strengthens the argument expressed in hypothesis one, that through reflection the autistic identity is constructed into a static entity (Limburg, 2016).

6.4.2 Self-acceptance

Self-acceptance was used as a term to articulate a feeling of awareness of self as well as an acknowledgment that this self was in some way natural to them. Participants throughout phase one and two articulated that they felt the process of self-identification allowed them to begin to accept themselves:

> ***"But after identifying I finally found some peace with myself and did not hate or disliked myself as much anymore" [Cara]***

This is mirrored in the work of autistic authors like Kim (2013) who expressed that self-discovery "helped me begin healing some very old wounds" (p43).

When my data is explored further however, and correlated with other research, there is a suggestion that the feeling of self-acceptance is not as simplistic as it would initially suggest. Carson and Langer (2006) explored self-acceptance in relation to mindfulness, and in doing so identified key features that facilitate true self-acceptance. In line with the discussion surrounding reflections, as seen above, one element of self-acceptance that is evident here is that of self-evaluation. The purpose of self-identifying as autistic therefore is to facilitate individuals to reflect and re-evaluate their constructed self, removing their belief regarding other's assessments of them to be replaced by their own evaluation:

> *"The beginning of that self-discovery journey and re-learning who I am through that new lens was something that for me was very powerful" (Holmans, 2019, {blog}).*

This is reinforced in the work of Kim (2013) who positioned 'retrospection' as the second step in what she termed the "sensemaking process" (p38).

Carson and Langer (2006) would argue however that it is this process of re-evaluation that may serve to hinder true self-acceptance. They argue that by relying 'too rigidly on categories and distinctions created in the past' (p38) the individual narrows their own self-image and restricts their ability to accept all elements that make up who they are. It is thought provoking to see how this argument correlates with my research findings surrounding the construction of a rigid autistic identity, and how this can unintentionally restrict self-acceptance. Similarly, by referring back to Communities of Practice, it is evident that Wenger (1998) sees identity not as a singular entity, but as a "nexus of multi-membership" (p159) whereby different elements of a person's life "become part of each other, whether they clash or reinforce each other. They are, at the same time, one and multiple." (p159).

6.4.3 Mental Health

The results of this study explicitly indicate that the process of self-identifying as autistic was perceived by the participants as having a positive impact on their mental health. Therefore, it would be logical to argue that a purpose of self-identifying as autistic is to address specific mental health challenges. This links specifically with the quote provided at the initial stages of this chapter indicating that learning is not just cognitive or social but also encompasses an emotional motivator.

Through analysis of my results, alongside the above discussions relating to reflections and self-acceptance, I suggest that it is the process of embracing the autistic identity that positively impacts on an individual's mental health rather than the product of the identity in itself. Specifically, the results of this research, as discussed above, illustrate the negative impact others have on the autistic individuals construct of self, which in turn results in the fragmentation between a socially presented self and a hidden self. The process of reflection that is integral to the process of self-identification of autism allows the individual to shine a light on their hidden world and begin the process of understanding and acceptance, which as Carson and Langer (2006) argue is crucial to good mental health. It is however stressed, that within a society which values difference, fragmentation would not occur, thus while the purpose of self-identifying would continue to be self-understanding and self-acceptance it would be within the premise of typical child development and therefore would not require an improvement in mental health.

6.4.4 Community and Acceptance of Others

Alongside the process of self-reflection and self-acceptance is the significant role of reduced isolation through the autistic community as a purpose of self-identifying as autistic:

> ***"The first book I was reading at work I nearly started crying how close it was describing how I feel" [Anna]***

The emotion articulated through this comment in phase one of my research is clear to see, and while it does not specifically state it, alludes to a loneliness felt because she was not able to understand how her experiences related to others. This is an emotional state that is echoed in the work of other autistic authors:

> *"I am ten and I know that I am different to them in a way that I cannot express or comprehend" (Tammet, 2007, p93).*

For Wenger (1998) participation, the process of identifying with another person's experiences, is crucial to the formation of an identity. Therefore, the scarcity of opportunity for the autistic person to engage in this activity will negatively impact on their sense of identity and in turn their mental health:

> ***"I think that's why self-identifying as autistic has been so positive for me. It's like a weight lifted off my shoulders. And it's also a feeling of not being alone" [Kathy]***

Due to the benefits of being within the autistic community, I am able to position my knowledge to understand that the statement made by Kathy in phase one of the research is not unique. A short search into autistic blogs illustrates discussions such as:

> *"Autistic bloggers, on the other hand, seemed like regular people. Women like me, with average lives, writing about experiences that felt familiar…. There was a sense of community among the writers and their readers that was unfamiliar to me." (Kim, 2015, {blog}).*

Since the 1990s, an increase in social science research around what has become known as an autistic culture, demonstrates that the use of the internet as a medium for communication has brought together diverse groups of minorities to share 'unmorphed' life experiences (in contrast to Lawson's (2020) principles of adaptive morphing). Dekker (1999) has argued that the internet is a form of communication akin to sign language for the deaf. Equally Cohen (1995) suggests that the growth of the autistic community online mirrors, but is some way behind, the deaf culture. The evidence of this research would reinforce the suggestion that there is a perceived community online, whereby individuals feel able to communicate effectively with people who they believe can understand them. Furthermore, the growth of social media has allowed this community to grow and begin to welcome those that self-identify as autistic (although there continue to be many groups that do not). Therefore, for this reason, self-identifying as autistic is a key to opening the door to this 'gated community'. Taking into consideration Wenger's importance of trajectories on identity, it would seem that the self-identification of autism fits within the classification of *inbound trajectories* which is defined as “newcomers are joining the community with the prospect of becoming full participants in its practice. Their identities are invested in their future participation, even though the present participation may be peripheral.” (Lave and Wenger, 1991, p154).

While it is evident that the online community allows autistic individuals to “let others see one’s true self” (Carson and Langer, 2006), evidence from my research also suggests that this is restricted to the online world and individuals continue to not feel able to be open with people in their everyday lives. As the discussion above relating to adaptive morphing and bullying illustrates, there is evidence that this is due to a fear of mistreatment/judgement. The interplay between a local and global identity was discussed within the subsection relating to the research question ‘impact of delayed realisation of the autistic identity/ies and has further implication here. While the purpose of self-identifying is suggested to gain access to the autistic community online (at a global level) it is the findings of this research that suggest that this imbalance between global and local identities is reinforced and possibly exacerbated by the nature of some autistic groups online and the consequential politicisation of the autistic identity. According to Olney and Brockelman (2003) social identity theorists argue that the process by which a new group builds an identity, naturally involves seeking out negative proponents of what they now see as the outgroup:

> *“Go to any autistic-only group on Facebook and you’ll see discussion about the weird or confusing ways non-autistic people communicate” (Hanson, 2019 {blog}).*

The joining of autism advocacy with an autistic online culture, re-enforces a ‘them and us’ culture. When paralleled with the negative experiences that individuals have articulated they suffered without an understanding of their autism, it is understandable why conversations are aimed at validating an individual’s difference and quantifying it as a static identity. However, it is argued that, by reinforcing autism as a ‘foreign culture’ (Silverman, 2008, p3) and the consequential need to ‘hide’ parts of their identity with people in their day to day lives, the ability to achieve holistic self-acceptance is hindered. So, while acceptance by others is seen as a purpose of self-identifying, it can in turn reinforce differences and therefore prevent acceptance.

6.4.5 Diagnosis

In phase one of the research, nine out of the ten participants felt self-identification was not an end goal, therefore suggesting that the purpose of self-identification was as a steppingstone to diagnosis. It is an acknowledged limitation of this study that phase two of the research was not used to gather quantifiable data specifically on the number of self-identifying individuals who were seeking a diagnosis. Participants were however asked the importance of diagnosis in embracing the autistic identity/ies. It is note-worthy that the data in phase one and phase two both indicated that there was a divide between the belief that diagnosis was for an individual benefit and for the benefit of others. For the subgroup that self-identified and then went on to get a diagnosis, diagnosis for them was about validation and then about getting help. Whereas for the subgroup that self-identified without a diagnosis, diagnosis for them was about avoiding the perceived prejudice towards the validity of self-identification and then about personal validation. Suggesting therefore a process:

Figure 69: Process of self-identification

This illustrates a reinforcement of the discussions seen above around the lack of acceptance in society surrounding self-awareness and diversity. It illustrates how diagnosis is seen to be a gateway to acceptance and support. Importantly the metaphorical key to the gateway is not held by the individual but at present by a medical professional, which relates to the Foucauldian questions of who holds the power, in creating the individual's identity. It leads me to question why steps 2, 3 and 4, illustrated in figure sixty-nine, are needed. During the literature review, research was outlined that argued that diagnosis offered individuals validation and a gateway to self-understanding (Leedham et al, 2020; Dinos et al, 2004; Hayne, 2003; Punshon et al, 2009). While the data from this research supports that this is the case for some people, by exploring the phenomenon of self-identification, I raise the suggestion that if we targeted societal processes of celebrating individuality and provide educational structures to aid individuals to explore this at an early age, diagnosis may not be needed. As an example, currently in the UK, it is deemed good practice to diagnose autism within a multidisciplinary team. In reality, however, this often works by one person leading on the information gathering process and then presenting the information to a wider team of professionals. Hayes, McCabe, Ford and Russell, (2020) looked in detail at the role of such teams in the diagnostic process. They presented evidence that an important element of the diagnosis process arrives from the professional expressing a ‘feeling’ that the individual may be autistic. This is an interesting factor to consider within the realms of self-identification and the flow diagram above, as through this process it is the individual who has a ‘feeling’ that they may be autistic. The sense of awareness from the individual however, as I have demonstrated, is seen as invalid, especially in terms of recognition from others., Yet; as a society we place higher value on the ‘feeling’ of an ‘expert’ who is faced with second-hand information. This is further reinforced in the neurodiverse movement and autistic self-advocates, who argue that their experiences and knowledge are superior to researchers and professionals however, conversely, continue to argue biocertification (Lewis, 2016) by such professionals, is more valid than a person’s own experience and knowledge. The role of the ‘external expert’ will be explored further in the subsection ‘power and illusion’.

Researchers have previously argued that diagnosis of autism is the route to self-understanding (Bertilsdotter Rosqvist, 2013; Powell & Acker, 2016) however my data suggests that this can and does occur as a facet of self-identification and therefore diagnosis does not necessitate this. Indeed, the label assigned through diagnosis has been seen to be counterintuitive to self-understanding as it often becomes more significant than the individual (Hodge, 2005). Crane et al. (2016) found that parents felt the outcome of being diagnosed with autism did not support the individual needs of their child but instead tried to categorise them into more a generic label of autism. As well as Blaxter (1978) who argued that diagnosis is simply the pre-existing set of classifications decided on by the medical profession to assign a label to the individual. The evidence of this research has illustrated that the process of diagnosis for the participants was predominantly driven by external validation from others, in particular for the subgroup that self-identified without a diagnosis, diagnosis for them was more about avoiding the perceived prejudice towards the validity of self-identification and then about personal validation. Furthermore, several comments provided as additional comments in the survey indicated a feeling that the process was more driven towards the needs of others than of the individual:

> ***"I needed 'proof' so that I had something to protect me in the workplace against unfair mistreatment for being different."***
>
> ***"The medicalised diagnostic report was not a positive thing for me. The assessors were lovely and very supportive of neurodiversity and a positive autistic identity but at the same time they have to do the medicalising thing will all the 'deficit' and 'disorder' labels and it felt contradictory and uncomfortable to read the formal report".***

With some comments suggesting that the process did not make any difference at all:

> ***"TBH, a formal diagnosis hasn't really helped at all. It neither opened nor shut doors. It hasn't created any opportunities, or changed people's perception of me or really changed how I think about myself."***

The above quote appears to be in direct contrast with the popular view that diagnosis is in the best interests of the individual. What is more striking and harder to read was that the quote ended with ***"I hated myself anyway".***

This has very real implication with regards to identity, especially, as just over 50% of participants in the survey indicated that a diagnosis can give you an identity. If the diagnosis process is a negatively driven experience, that has little tangible impact on others and the individual's perceptions of themselves, it becomes nothing more than a process of reinforcing the biopower of normal and abnormal. Shakespeare (1996) argued that this dichotomy is an illusion, and that disability or impairment is merely one aspect of the human condition. Therefore, suggesting that everyone has the potential to have a form of impairment and furthermore that everyone will be disabled at some stage of their lives. Should disability be viewed in this perspective, reinforcing the Foucauldian approach to disability, there remains significant questions as to the validity of the current diagnostic process. Giddens, thirty years ago, argued that.

> *A person's identity is not to be found in behaviour nor - important though this is - in the reaction of others, but in the capacity to keep a particular narrative going' (Giddens, 1991, p.54).*

Despite this long-time frame, it has been demonstrated in this research, that the experiences of my participants indicate that the process of diagnosing autism is predominantly for the benefit of others and to manage the reaction of others. While this process serves the current structure of society, it is my belief that this process should be considered in more detail with the aim of directly addressing societal beliefs around autism and in turn providing the individual the support to develop their own narrative and not feel the need to justify themselves in the eyes of others. Should further research and work be undertaken in this area we may arrive at a time where the diagnosis process is no longer required.

6.4.6 Power and Illusion

I have evidenced how the process of marginalisation of individuals who are different (in this context autistic, however it is acknowledged that this argument can be used in relation to all differences) results in an identity constructed from negatives and an inbound trajectory to communities of practice whose mutual engagement lies in advocacy. The purpose of self-identifying therefore could be seen as a way to claim back power over identity away from the imposed deviancy label they have experienced. I have further suggested that a Foucauldian approach to disability, indicates that however well-intentioned, the development of the autistic identity reproduces the biopower of our societies.

Foucault approaches power not within the concept of strength but influence, how it can be productive as well as oppressive. For Foucault, biopower is the process whereby societal structures work to divide people into categories based on perceived biological differences and significantly that the continued process to identify oneself as different from the complex idea of normality (Rajchman, 1991) is nothing more than an effective, if illusive tool, to maintain governability:

> *"This form of power that applies itself to immediate everyday life categorizes the individual, marks him by his own individuality, attaches him to his own identity, imposes a law of truth on him which he must recognize, and others have to recognize in him. It is a form of power that makes individuals subjects." (Foucault, 2002, p.331).*

This argument can be illustrated through the exploration of the history of autism and importantly, for Foucault, the historical foundations that led to its categorisation. Foucault argued that the Victorian period saw the rise of classification and the "invention of man". As such, he argued that prior to this time there was "no epistemological consciousness of man" (p209). However, during the 19th century "human-beings are made subjects", they become objectified, in the sense that they are the subject and the object at the same time as the human species becomes the object of study, in its own right, for the first time. The objectification becomes subjectification however, as it has power over the individual. It becomes authoritative, encouraging them to act in specific ways. It is the structure of classification that the modern era builds upon to explore the 'hidden' knowledge, discovering what is inside the object. Importantly the shift to the hidden secrets of an object gives rise to the power of the authority that can see beyond the object to that, which is hidden. It is by understanding the history beyond the first naming of autism that Foucault would argue we understand our current 'knowledge' of it and in turn can help us understand the biopower that does not directly act on the individual but

> *"is exercised through productive constraints, that is, when it enables subjects to act in order to constrain them[selves]" (Tremain, 2001; 2002).*

The modern phenomenon of objectifying humans, results in concepts of 'normal' and 'ab-normal' and creating standards to measure human ability. It is upon these historical foundations that when Kanner (1943) first identified what we now term autism, it was classified as ab-norm in comparison to what was socially accepted. At that time, it was referred to as a form of childhood schizophrenia and treatment would often involve institutionalisation. Equally in 1944 when Asperger presented a similar phenomenon, his focus was on 'troubled' boys (Asperger, 1944). Therefore, at this early stage, the behaviours of the child were observed, categorised as deviant and medical treatment was imposed. This label of deviancy was taken further in 1967 when Bettelheim placed the blame on the mothers of these children, arguing that it was their deviancy that was to blame for the autism seen in the children. From 1977 onward, there is a shift from the mothers to research into genetics and biological differences in the brain. While this could be viewed as a positive shift in opinions, regarding power, the medicalisation of autism continues, but actually provides further legitimacy and therefore power to the concept of autism being ‘abnormal’. A significant challenge to this view was seen in the promotion of the social model of disability which reinforced that the medical model was oppressive and argued that segregated facilities should be replaced with “opportunities for people with impairments to participate fully in society” (Shakespeare,2006 p214). Foucault, however, argues that this shift in perspective was nothing more than an illusion, hiding the fact that power by categorisation was maintained. He argues this on the premise that:

> *“if the identity of the subject of the social model (“people with impairments”) is actually produced in accordance with these political arrangements, then a social movement that grounds its claims to entitlement in that identity will inadvertently extend those arrangements” (Tremain, 2005, p.10).*

Foucault’s argument can also be translated into the many central cognitive theories that have proposed that autism can be explained through an identified deficiency within the brain, ranging from weak central coherence (Frith and Happé, 1994), executive dysfunction (Ozonoff, Pennington, and Rogers 1991), a theory of ‘mindblindness’ (Baron-Cohen et al., 1995) or a neurophysiological theory of mirror neuron dysfunction (Williams et al, 2001). Even to the present day where the term neurodiversity has been hailed as challenging the deficit model, evidence from this research indicates that its foundations lie in the categorisation of neurotypical and neurodiverse which in terms of Foucault’s theory of biopower can be argued to be nothing more than a re-naming of the traditional divide between normal and ab-normal.

The work of Hacking has been previously discussed in relation to the development of language as a positive avenue for individuals to understand their experiences within the context of autism. However, it is important to acknowledge that Hacking himself refers to his Looping Theory as an extension of the work of Foucault in relation to power and knowledge. Hacking refers to '*human kinds'* as an illustration that people become categorised and therefore:

> *"the people who are classified as members of a kind come to have knowledge of the relevant kind, which changes their self-perceptions and behaviour, motivates them to forge group identities, and often forces changes to the classifications and knowledge about them." (Hacking 1999,2002; quoted in Tremain, 2005, p.7).*

He has argued that the language that develops for discourse such as autism is driven from biopower and governance, without the individual's knowledge they are guided, influenced, and limited in their beliefs and actions. The importance of language can be further seen in the conflict between person first language and identity first language. Briefly discussed in relation to contradictions surrounding the autistic identity, it was evidenced that the differing beliefs, which are often strongly debated, can be seen to have similar arguments. A Foucauldian approach would view this as an illusion of conflict, a 'game of truth' (Foucault, 2002) to maintain segregation and categorisation.

My discussions surrounding diagnosis and the 'external expert', within a Foucauldian analysis demonstrates how a medical professional when confronted with a phenomenon, understands, and categorises it, based on its history manifestations of political concerns, norms and values of the society in which the medical professional works (Foucault, 2000). For Foucault therefore, 19th century medicine transformed from a focus on health to 'normality' where life is measured according to the bipolarity of normal and ab-normal. Such an argument is reinforced within my findings, furthermore that despite a move towards individuals categorising themselves as 'ab-normal' the power of biopolitics remains significant as individuals continue to believe that they require legitimisation through a medical professional:

> ***"Also wanted to clarify I am not deluded and have some sort of official and professional proof I'm not crazy." [Cara]***

Laing (1990) provides a correlation with schizophrenia, diagnosis and identity in relation to the all-consuming autistic identity that has been evidenced in this research. He suggests that:

> *"To give a person a diagnosis of schizophrenia therefore is not to give a person one identity amongst others; instead, it is to suggest that a person is schizophrenic, that schizophrenia determines the very being of that person." (p.38).*

In much the same way, some of the participants that self-identified without a diagnosis, positioned this label on themselves:

> **"Its central because it dominates every part of my life" [Cara]**

In fitting with the contradictions that have been central to my exploration of the autistic identity, even those participants who felt that autism was not an identity, continued to explain their justifications along the same belief structure as seen above.

> ***"It affects all parts of my identity, but doesn't define me… If you asked me how I identify myself I'd say 'Christian and Vegan' not Autistic, but autism defines how I see those things" [Margaret]***

It is suggested that the contradictory nature of the autistic identity reinforces an illusion of power within the individual to embrace their own uniqueness while ensuring that such an identity is perceived within the realms of deviancy, and as such requires the individual to assess their own thoughts and feelings and to seek support (which is regulated by the 'external expert') to adapt these to 'become normal' (Foucault 1991).

> “The problem seems to be… If I want to feel good about myself and feel positive about neurodiversity and difference I need to put my ‘autistic pride’ ‘hat’ on…. Conversely if I need to access funding [support]… I will put my ‘medical model’ hat on. (Purkis, 2020 {blog}).

It is important to stress that this Foucauldian analysis of biopower does not deny the phenomenon of autism, but that it should be understood within the context of historical and political discourse.

Summary

By positioning my data, alongside that of biopower seen in the work of Foucault, I would argue that for the participants in this study the purpose of self-identifying lay in a desire to claim back an identity from the ‘deviant’ one placed upon them. However, the actions undertaken to do this, result in an illusion of power, which in truth only serves to reinforce the authority of categorisation and division. This in turn weakens the identity for the individual as it prevents them from embracing the ‘normalcy’ of their complex personhood.

6.5 The Spiral of Self-Identification of Autism

The findings of this study have facilitated much discussion in several key areas: marginalisation, language, social learning theory, biopower and virtual global polarisation. It is however important to view how these areas work together to impact upon the individual, and in turn their association with the term autism. Bronfenbrenner’s Ecological Systems Theory (2005) has been influential in seeking to explain the way in which the combination of the individual’s qualities and their environments interact to influence how they develop (Darling, 2007). Emphasising the importance of several ecological systems, in contrast to previous theories such as Piaget’s (1964) that placed the cognitive development of the individual as fragmented from any external influences, Bronfenbrenner’s system can be used to draw together the findings of this study, to explore the development of the autistic identity. Marginalisation can occur in both the micro and meso systems and the encompassing constraints of biopower can clearly be seen in the macrosystem. Where limitations occur however, is in recognition of the central role that social media plays in facilitating the phenomenon of self-identification. In Bronfenbrenner’s ecological system the mass media were positioned within the exosystem, as an indirectly influential body. The way in which social media was used as a central facilitator with the participants of this research, would suggest that the exosystem is not an appropriate positioning for social media, however it is unclear whether any of the other defined systems are also applicable. The interweaving nature of social media into an individual’s microsystem, mesosystem and exosystem suggests the possibility of a new system, termed here to illustrate its role in this research, *the metasystem*. The word, *meta*, is chosen based on its origins in Greek meaning “after, behind, among, between” (meta-Origin and meaning of prefix meta- by Online Etymology Dictionary, 2021) which reflects the system of global connecting that prior to the expansion of social media was not possible.

With the incorporation of the metasystem, the experiences of self-identification explored within this research can be illustrated with the ecological systems model.

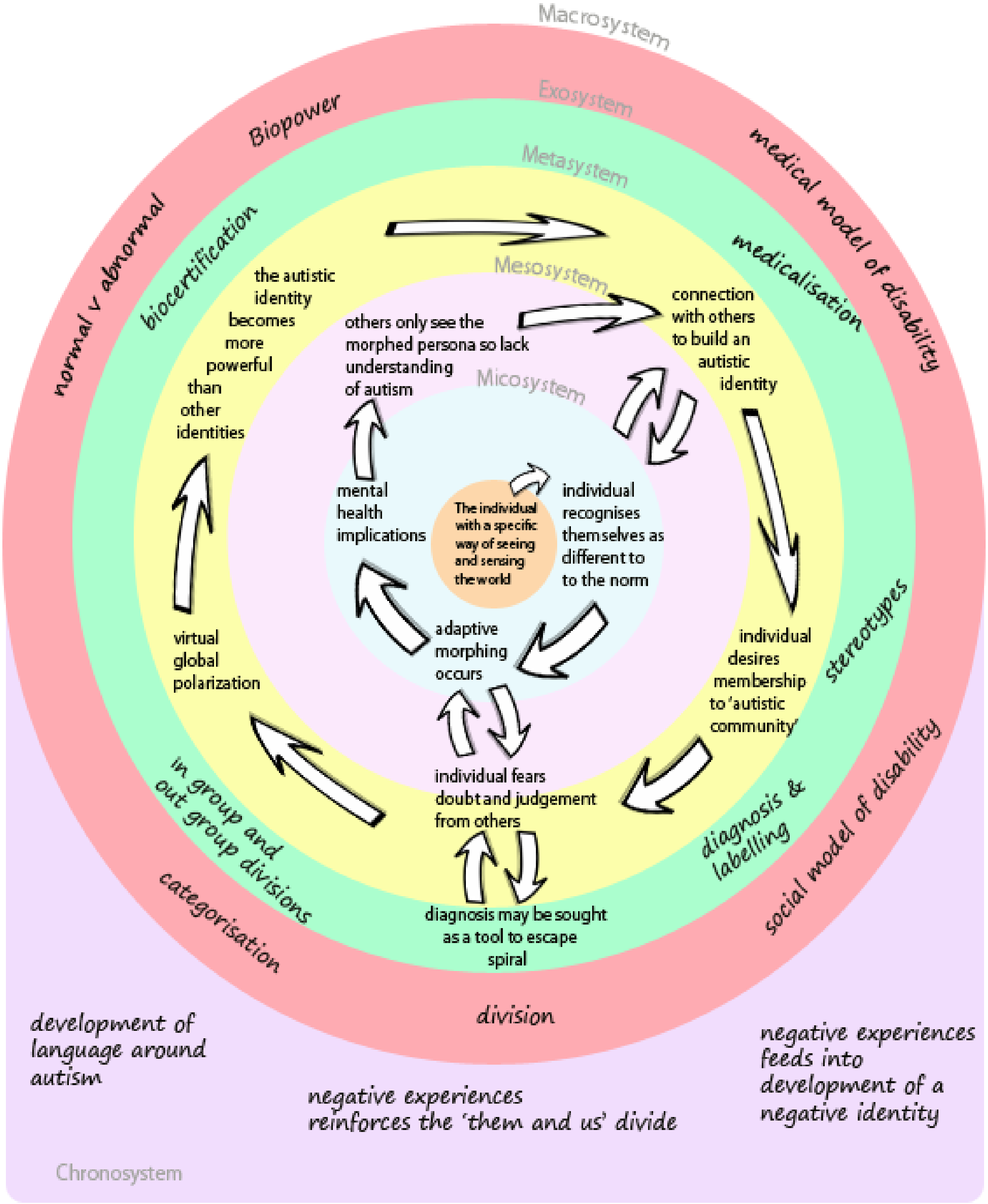


Figure 70: Spiral of self-identification

As the diagram illustrates, the processes of developing an autistic identity spiral out from the individual, across the microsystem, mesosystem and the metasystem. The spiral represents movement that may occur at any time and suggests a never-ending cycle between layers constrained by the biopower features within the macrosystem and exosystem, which effectively control the way in which the individual constructs an autistic identity. This directly reinforces the work of Hacking and his Looping Effect of Human Kinds:

> *"in the spiralling dialectical process, each element-the classification and the classified-mutually reinforce and sustain each other as they evolve jointly. There is considerable evidence of the Hacking looping effect is a genuine sociological phenomena" (Charland, 2004 page 341).*

The Chronosystem is illustrated as a 3D element of the diagram as it represents changes over time and space. It is acknowledged that this has a significant impact on all other spheres of influence. It is suggested therefore that in order to break the spiral as depicted above, change has to occur within the macro and exosystem in order to feed into the remaining systems and positively impact on the individual's concept of self.

Summary

The results of this study indicate that the purpose of self-identifying as autistic was to enable self-acceptance and self-understanding, which in turn had a positive impact on the individual's mental health. It is argued that due to the negative experiences of individuals the purpose of self-identifying is a backwards looking process, whereby past events are reviewed and reshaped through the autistic lens. The focus on looking back however, distracts the individual from developing an identity that is “ongoing and pervasive”, instead becoming static and therefore is not one of a “nexus of identities” (Wenger, 1998). To allow self-identification to become a forward-thinking process, the structure of the education system and the way in which we promote self-expression at an earlier age needs to be explored.

> *“The doorway to realising one’s true self is simply self-expression (Cook and Garnett, 2018, p.51).*

Discussion Summary

The above discussion has identified that the principles of Communities of Practice can offer us much in our understanding of the process of self-identification of autism and the way in which the term autism has become polysemic (Rhodes, Nocon, Small and Wright. 2008) and the implications of this. It is however acknowledged, that there are gaps that the theory of Communities of Practice does not address. This research has identified that some of the participants have been marginalised from the communities of practice but did not have the necessary knowledge or language to develop an appropriate outbound trajectory and inbound trajectory into other communities, they therefore become stuck morphing themselves to seek acceptance which has significant implications on their identity and mental health. It is suggested that the identification of such a cohort within the construct of Communities of Practice should be explored further. Furthermore, the process of biocertification of autism, can result in a secondary level of marginalisation of the self-identifying individual, within the autistic community, resulting in the perceived need to fight to claim the identity through the system of diagnosis to gain full entry.

The process of marginalisation was explored through consideration of Foucault's theory of power in relation to autism. This has driven the development of the concept that the purpose of self-identifying as autistic is an illusion of individual power. Bronfenbrenner's ecological systems theory was slightly altered, to demonstrate how the spiral of self-identification sat within the differing systems of influence but continuously constrained by biopower. Specifically, how the processes embedded within delayed realisation of the autistic identity, alongside the resulting priority given to the autistic identity once invested into, functions as a productive constraint that empowers subjects to act in a way that also constrains themselves (Tremain, 2001; 2002).

Based on the results of this study, one of the key societal structures to break this illusion by reducing or even eradicate the need for politicalised identities based on advocacy, is education. As such, a radical overhaul of educational policy is needed.

6.6 Educational Change

The results of this study, in line with others, has indicated that the stage of recognition of difference is from the age of four, but it does not become problematic until around the age of eleven. As it is acknowledged that at this age a significant amount of time is spent within the school, it is suggested that it is the education system from the primary years onward that requires significant change to provide a framework that values diversity, alongside supporting the understanding of our own differences, that will then ripple out into the wider societies in which the children grow up to live in. Molloy and Vasil (quoted in Limburg, p144) reinforce the importance of education in the autistic identity, when they argued that:

> *that the idea of the child with Asperger's has been created by and serves the interest of the field of special education, and was unlikely to have taken hold without it. By locating the problem-disability-in the child impairment rather than in an education system which cannot adapt to difference, dominant institutions and their normative practices can be preserved and challenged (in Limburg, 2016, page 144).*

A recognition of diversity is not proposed within the guise of accepting the ontological status of categories of human beings as a social reality or the social construct of 'normal' (O'Dell and Brownlow, 2015). Instead, directly challenging its biopower, advocating for the concept that, while individuals are shaped by the communities in which they live, the only ontological fact is that they are all human beings. Featherstone uses the work of Durkheim to argue that this would reflect the local development of our societies as they become more complex and globalised:

> *"For Durkheim, the sacredness of the person could become one of the few cultural ideals capable of providing a crucial point of unification for an increasingly differentiated, yet interdependent, world." (Featherstone. 2011. P4).*

By taking this as the very starting point of our education system, differences and similarities can be seen across the global society and positioned in the baseline that "it is difference, not homogeneity, that unites us" (Solomon, 2013).

Foucault questioned:

> *"is it surprising that prisons resemble factories, schools, barracks, hospitals, which all resemble prisons?" (Foucault, 1995, p.228).*

Similarly, Bruner viewed education as a political structure, analysing how groups of individuals come to make judgments about and for other individuals and the consequences of this (Smidt, 2013). Runswick-Cole and Hodge (2009) provide an enlightening argument on the way in which the education system is sustaining the biopower of exclusionary practice. While the basis of their report focuses on the impact of special needs terminology on children so labelled, the data of this research can be seen to extend their argument further to include children without such a label. While the participants of this study were often ‘missed’ from being labelled as having special educational needs, ninety-six participants were labelled ‘weird’, eighty-seven were labelled ‘different’ and eighty-three were labelled ‘awkward’ (it is acknowledged that these figures represent individuals who may have been identified as more than one option):

> ***“I was expelled from school for attitudinal reasons and attendance issues while achieving the highest scores” [Mark]***

Mark’s comment highlights a further point of consideration, reinforced by the survey data that eighty-nine participants reported that they had been labelled ‘intelligent’. While this can be viewed as a potentially positive label, the evidence of this research indicates that it is another way in which they may have been excluded from appropriate support:

> ***“My teachers didn't really see any need to intervene other than to try to force me to talk because my work was of a sufficient standard” [Martin]***

As Twachtman-Cullen (1996) argues that teachers become “blinded” to the needs of the student because of their strengths. Positioning my own knowledge, having worked for many years in the education sector and special educational needs (SEN), as well as having children currently at different stages of their academic careers, I can corroborate that the processes within the current UK education system, for example the restricted curriculum and the processes for gaining specialist support, limits support to students that can prove they are failing academically. Foucault's work on power structures has been used to demonstrate why these processes exist. For example, according to Foucault, the teacher's current role in education is that of authority, the producer of knowledge to be passed to the subordinate learner (Deacon and Parker, 1995). As the authoritative adult, the teacher has the power in which to produce concepts of normalisation and to categorise based on predetermined expectations. Dreyfus and Rabinow (1982) argue that normalisation occurs through the process of identifying abnormalities and the reproduction of biopower to administer them. By working with a power structure based on the belief that science can label individuals within a subordinate role, for example, as "gifted, slow, intelligent or special" (Canella, 2000, p36) this research indicates individual's needs may be missed because they do not impact explicitly on grades:

> ***"I pull out my eyelashes and have pulled out my hair or eyelashes since I was about 8….. I didn't get any help [at school]. Nobody realised that I was struggling so much with everything" [Margaret]***

Runswick-Cole and Hodge (2009) highlight the flawed use of Individual Education Plans as a tool to merely demonstrate ways a student may fail, but only for those labelled as having special educational needs, as a way of comparing against a school system in Italy that:

> *"emphasises the value of documentation of all children's experiences and learning assuming a multidimensional view of intelligence focusing on the child's strengths (Gardner, 1983. Quoted in Runswick-Cole and Hodge, 2009. p.10)."*

By constructing a system whereby the differences of all students are recognised and provided for, children such as those in my study would not be trapped between provision for the typical student and for the student with special educational needs:

> *"Learning is not simply about developing one's knowledge and practice, it also involves a process of understanding who we are and in which communities of practice we belong and are accepted." (Hadley, Sturdy, Fincham and Clark, 2006, p.664).*

In support of Runswick-Cole and Hodge (2009) as well as Mortier (2020) and Nussbaum (2013), it is believed that a complete overhaul of education systems is needed to ensure that, at its roots, is a "system that cultivates the ability to see full and equal humanity in *the other*" (Mortier, 2020, p329). This is further reinforced with reference to the Situated Learning Theory and Communities of Practice, which highlight that the current assumptions of our education systems that knowledge is passed from one person to another (teacher to pupil) is flawed. In fact, as I have outlined above, learning is a process of social transformation and not a simple matter of personal achievement. It is also thought provoking to connect this back to the curious conflict, addressed above, that the autistic identity appeared to move from global to local, rather than local-global as suggested in Communities of Practice. Archer (1991) in her argument for a 'sociology for the one world' suggests that the globalisation of the world should lead us to recognise the "fundamental unicity of humanity" (p131) and it is this process that illustrates the instruments of change are found in the multifaceted interplay between emergent structures (global) and established structures (regional), therefore mirroring the global-local interplay seen in this research.

It is suggested that by reconstructing our education system away from a 'factory model of education' (Sleeter, 2015), towards a social pedagogue (Petrie, 2005; Cameron, 2007) we can normalise the provision of specialist support to anyone that needs it and in turn challenge the status quo of the 'normal is good' dominated society:

> *"Valuing multiple intelligence (Gardner, 1983; Edwards et al 1993) and giving practitioners time to reflect on their own practice are key to the schools' inclusive approach." (Runswick-Cole and Hodge 2009,* p*10)*

With reference to Communities of Practice, and the identified three modes of belonging to a social learning system: engagement, imagination, and alignment (Wenger, 2000), we can begin to explore autistic specific challenges, especially within the early years of child development. The impact of reduced access to these modes of learning would have a consequent impact on the construction of identity (Lave and Wenger, 1991), as the evidence from this research reinforces. It is suggested that specialist systems of support should be available in schools to anyone identifying with such difficulties to enable pathways of self-exploration, reinforced by the promotion of diversity. As Kelly (2005) discovered in her study on implications of perceptions of disability on children, embracing the way each child was different, in a positive manner, was hindered by the lack of available opportunities to discuss and explore them with an adult. By providing these opportunities, we challenge directly the concept of disability. By offering such support at a younger age, and older as needed, I would reinforce the argument seen in the work of Lombardo et al, (2007) who found that "as self-memory increased, mentalizing also increased, and the endorsement of autistic traits decreased" (p9). Therefore, suggesting that the polarisation between autism and non-autism is broken down to accepted complex personhood:

> *"Living with one foot in neurotypical land and one in Aspie land, is very stressful and exhausting" (Holliday-Wiley, 2015, p131).*

One way this can be achieved is through the development of a diversity curriculum. It is proposed that by developing a curriculum that begins at the age this research suggests children begin to acknowledge differences but are more accepting of such, the principles of diversity acceptance can be nurtured and cultivated having long term impacts on wider societal acceptance.

Specific implications of a diversity curriculum, it is suggested, would be the development of supportive peer-on-peer relationships. This research has clearly illustrated that the autistic identity cannot be built in isolation, and therefore peer support is central to the development of individual wellbeing. By raising awareness of differences research indicates children become more accepting of one another:

> "Thirty-four of the interventions we reviewed showed statistically significant improvements in attitudes toward and/or acceptance of people with disabilities" *(Lindsay and Edwards, 2013, p20).*

This in term would reduce the high levels of bullying this study indicates is prevalent in schools for students as research has shown that increased awareness also increases the level of inclusion among peers. While research into the relationship between awareness and acceptance is limited, it is the agreement of this research with Humphrey and Hebron (2014) who argue that:

> *"Currently available evidence suggests that a multi-level, comprehensive approach to intervention that offers parallel foci on children and young people with ASC, their peers, teaching and support staff, and the broader school ethos and climate is warranted." (p1).*

It is acknowledged that there is a wider literature, including some evidence from this research, of broader implications on education and diversity regarding, but not exclusively, classroom structure, teacher-pupil relationships, sensory adaptations and work expectations (Goodall, 2018). It is outside of the remit of this study to explore these further, but I recognise their role in moving away from the 'factory-based school model' and suggest further exploration would be beneficial.

6.6.1 Educational Change Conclusion

The argument has been put forward that the current education system reinforces the power of authority and categorisation based on ability, which was functional during the industrial revolution but is no longer reflective of the wider societal structures of the modern era. The educational system should be viewed as a process of social transformation and not simply a mechanism for individual achievement.

To drive forward a societal transformation aimed at celebrating diversity, the development of a new mandatory curriculum is proposed. The basis of which will be developing an understanding that the only thing 'normal' about every individual is their difference. By nurturing and cultivating diversity acceptance it is argued that the autistic identity would develop as one of a nexus of identities that individuals may associate themselves with.

Furthermore, in line with the evidence of this research that the autistic identity cannot be built in isolation, the development of diversity awareness would facilitate supportive peer-on-peer relationships which would not only allow the development of secure identities but also work to prevent social isolation and bullying that this research has demonstrated occurs at a high rate with those that are labelled as ‘different’.

CHAPTER SEVEN: CONSTRUCTING A SOCIAL LEARNING SPACE

> *"we talk about a social learning space as a particular experience of engagement that takes place among people in pursuit of learning to make a difference" (Wenger-Trayner and Wenger-Trayner, 2020).*

As was outlined in the methodology chapter, the focus for my research was to provoke action, not merely describe a phenomenon. Therefore, an approach was used that did not focus on where the 'knowledge' was coming from but instead where it was going. While this in itself may not be noteworthy, there are several elements of my research which are unique and have arguably been the cause of the novel findings and has allowed me to explore the phenomenon of self-identification of autism in depth, referring to theories and developing proposals for changes in the way we interpret such knowledge and action in the future. I will take this opportunity to explore the unique factors of my methodology as a way of considering their importance in future research structures.

7.1 Positioning of the researcher and research participants

> *"there is inherent value in finding others who understand why you care to make a certain difference, who recognize the validity of your uncertainty, and who are willing to engage yours and theirs to make progress" (Wenger-Trayner and Wenger-Trayner, 2020, page 79).*

Participatory methodologies, which the principles of learning spaces are built upon, directly challenge a 'top-down' approach to research (Guldberg et al, 2021) instead incorporating a construction of active engagement with the participants from the beginning. This has been shown to produce a more socially robust and context transferable basis of knowledge (Bergold and Thomas, 2012; Milton, 2014; Gillespie-Lynch et al, 2017) as well as a higher potential for research impact (Seale, Nind and Parsons, 2014). The way in which I have structured my research has encapsulated the importance of collaboration and sensitive participation. By maintaining a qualitative primacy to the research I have been able to foster a rebalance of power between researcher and researchee (O'Connor & O'Neill, 2004), this required a significant degree of constant reflection to ensure that the voices of the participants were continuously central, rather than mine as the researcher. Karnieli-Miller, Strier and Pessach (2009) argue that in research that focuses upon biological accounts, the participant possesses the most power and control during the data collection stage. I ensured that this power remained during the data analysis stage, resisting "the interviewers monopoly of the interpretation" (Brinkmann & Kvale, 2005; Marcus & Fischer, 1986) by incorporating participant check stages and the construction of phase two questions based on the results of phase one (Cutcliffe, 2000). While Forbat and Henderson (2005) questioned the validity of engaging with participants during the analysis stage, the experiences of this research suggest that, while a small percentage of participants engaged in the process, those that did provided additional information and did so in an informed and constructive way. It is noted that the process of participant involvement in the analysis stage was not possible to the same degree in phase two of the research, however the careful wording of the questions did enable the participants to retain a level of power in the analysis. For example, by including the option of "other" alongside the opportunity to add additional detail in the question surrounding what prompted their self-identification, resulted in amended categorisation, and therefore improved data analysis. Karnieli-Miller, Strier and Pessach (2009) argued that it is the researcher's ethical obligation to include participants in data analysis by cultivating creative methods that enable them to participate. I believe this has been achieved in this research and has produced novel and exciting results.

Alongside the participatory strengths of the methodology, this research was also unique in the incorporation of autistic voice within the literature review. This will be explored subsequently to consider its impact.

Ever since autism emerged from the work of Asperger and Kanner (Asperger 1944; Kanner 1943), it has remained medicalised and therefore research and academic literature is almost exclusively the domain of clinicians and non-autistic researchers (Chown et al, 2017). Over recent years it has been argued that it is ethically problematic that the autistic voice is excluded from social scientific research that seeks to further develop knowledge of autism (Milton and Bracher, 2013). Despite such arguments and a small but tangible shift in autism participatory research, no other research, to my knowledge, acknowledges the role that the autistic voice can play in investigating prior knowledge before research construction. Milton and Bracher (2013) articulately express that:

> *"Failure to acknowledge and explore the different personal and social conditions in which autistic people live and implications for their wellbeing is therefore a significant barrier to impact in contemporary research." (p64).*

I would suggest that this assertion is important to be used to encompass autistic literature; in collaboration with academic research as a means of triangulating research assertions and arriving at valid premises on which to commence data gathering.

In their outline of sequential mixed methods, Ivanakova, Creswell and Stick (2006) state that:

> *"the mixed-methods sequential explanatory design, is highly popular among researchers and implies collecting and analyzing first quantitative and then qualitative data in two consecutive phases within one study" (p4).*

The suggestion that the qualitative element of data gathering should follow the quantitative had been my experience of opinions prior to commencing my research, however, despite this I chose to undertake a sequential mixed method design that prioritised the qualitative data, using the quantitative data as a second layer. My justification for this approach lay in the role of researcher bias and researcher arrogance, that is to say, that I did not want to impose my knowledge on the subject matter as superior to anyone else's. Aldridge and Levine (2001) write that in order to undertake a survey a researcher must engage in 'sociological imagination' (p3), putting oneself in the shoes of the phenomenon to be researched and construct surveys questions from that basis. I would argue that no-one can undertake such an act accurately and therefore any assumption based on imagination has the potential to be flawed. By undertaking semi-structured interviews as my starting point, it enabled me to present my thoughts as facilitators of conversation but allowed the experiences of the participants to add to this knowledge and in turn shape the subject discourse. The interview data, therefore, directly bypassed the need for an imagined reality, instead giving the power to the individual to express their reality. The benefit of this approach is clearly evidenced in the number of questions and consequential data gathered, that would not have been possible without the findings of the interviews. It is evident that without the qualitative primacy to the research, alongside its participatory nature, essential data may not have been gathered.

There are limitations to this approach, as there are all research approaches, it is therefore recognised that the construction of discussions from this research does not encapsulate the opinions of all. However, as I believe the discovery of ‘fact’ or ‘truth’ is not achievable in any research this does not provide any justification for lack of validity in this approach.

I believe that by providing a structure whereby autistic authors outside of the research as well as participants within the research act as co-researchers I have facilitated an effective social learning space, whereby value is created:

> *“for participants to the extent that they view engaging uncertainty and paying attention as contributing to their ability to make a difference they care to make” (Wenger-Trayner and Wenger-Trayner, 2020, p43)*

7.2 Autism central

Fletcher-Watson et al (2018) argue that one manifestation of participatory research is leadership by an autistic researcher. Much like the arguments outlined above, there has been recognition that there are few autistic academics researching autism which has a direct impact on the validity of their findings. It is important therefore to acknowledge the role my autism plays in the production of this research. In Collins and Evans (2007) *Rethinking Expertise* an argument was put forward to distinguish between *ubiquitous* expertise and *specialist* expertise. By using their categorisations, it can be argued that as an autistic academic I hold specialist expertise that others may not, however this is approached with extreme caution, as to suggest a specialist knowledge of autism experiences is to suggest an ontological truth to autism, which I do not. Therefore, I hesitantly suggest that due to my experiences of autism I may approach the subject matter differently to others. As Beauchamp (2011) argues:

> *"A disabled researcher is an 'insider', and can generally step beyond the superficial level that an outside researcher may experience" (p13).*

In this way I provide two examples to justify my assumption.

Firstly, as I have noted previously, my connection with the online autistic community facilitated my initial questions regarding self-identification. My initial literature review provided empirical evidence that this is not a subject matter that has been sufficiently researched previously, despite the numbers of people within this community. Furthermore, further exploration of the literature suggests that it is not that self-identification is a phenomenon that others were unaware of, but that they choose it was not important to explore, therefore reinforcing the power of biocertification. By pursuing such a topic, I believe I have moved against an imposed power structure that silences and constrains autistic experiences, restricts a dominance of medicalisation and cure talk (Milton and Bacher, 2013) to allow an exploration of the lived experiences of some autistic people, something that only specialists in their field can truly do.

Another key feature of participatory research is inclusivity in adapting the research environment. I believe that by building on my specialist knowledge I was able to provide a 'safe' learning space which facilitated accessibility. Similar to Taylor and Bogdan's (1998) expression that as scholars we create "a feeling of empathy for informants [that enables] people [to] open up about their feelings" (p48).

One of the ways in which this was achieved was by challenging the traditional view that interviews are based on the assumption of talking (Adams and Cox, 2008; Thomas, 2018), by focusing on a text-based system of discussion. This was based on my own communication preferences alongside the literature that suggested that the internet facilitates individuals to communicate and nurture relationships with greater ease than in face-to-face interactions (Benford & Standen, 2009).

This approach was welcomed by my participants:

> **“its just amazing to talk to person who knows what you need” [Neil]**
>
> **“I had been thinking you'd want to talk to me on video chat or something, so I just need to get my head into typing mode! Much more relaxed” [Kathy]**

By using my specialist knowledge as an autistic person and creating an effective safe learning space, I would argue that I was able to collate richer data. It is acknowledged that there are limitations in that this style of communication would not have been accessible to all and therefore while a richness of data was gathered, it would not be representative of all individuals that self-identify as autistic.

7.3 Power and Illusion

As the role of power and illusion has emerged as a central feature of this research it is important to acknowledge that as a researcher, I am not independent of such powers. Indeed, Aldridge and Levine (2001) argue that it is the process of partaking in a survey that facilitates a group identity which can be a powerful motivator.

I am forced to question my role in promoting the biopower present in our societies surrounding normal and abnormal.

As Monica during our pilot interviewed explained:

> **"I never really thought of it before, I was just autistic. Your questions made me think about it, what is it then and this is how it felt like" [pilot interview transcript, appendix 16]**

As Wenger-Trayner and Wenger-Trayner (2020) claim, there is an impact on those participants who invest their time in a social learning environment that is significant to my exploration of identity:

> *"*Caring to make a difference is an investment of identity" (p48).

Foucault, however, acknowledges that when power is illuminated, studied, and given a name to, it can be questioned and judged. Power is not a static entity, but a process of continual development. Therefore, by recognising the power at play here, Foucault would subscribe to the idea that it can be challenged and changed.

It is my hope that by recognition and positioning the role of biopower it will provide a basis to develop.

> "*Agency is not freedom from history, but the ability to engage with it to make a difference" (Wenger-Trayner and Wenger-Trayner, 2020, p59).*

7.4 Limitations

In line with the suggestion for future research, the limitations of this research are acknowledged. Primarily, while every effort has been taken to incorporate a methodology that triangulates its findings, it is acknowledged that the population of the study does not represent the entirety of the autistic population worldwide. The sample, as set out in ethical approval for the study, excluded participants under the age of eighteen and by using the methodologies I chose, it further excluded those individuals that did not have access to computer technologies. It is unclear whether communication abilities and cognition differences were represented within the research population as participants were not asked to identify this. For this reason, it cannot be assumed that they were, or were not, effectively represented.

During the discussion of the research findings it was acknowledged, and repeated here, that it was a limitation of this study that phase two of the research was not used to gather quantifiable data specifically on the number of self-identifying individuals who were seeking a diagnosis. While there was data that could be interpreted to aid my understanding, I believe it would have increased reliability of the data had this question been asked.

Much thought has been given to the experiences of the individuals who participated in this study and as a result concepts have been developed that may impact on the individual and their well-being. It is important to stress that these suggestions will not match the experiences of everyone, fundamentally, as I stress throughout, due to the complex personhood of each individual. It is also not intended to diminish the challenges and need for support that the individuals currently experience, instead I recognise this and use it as a motivator to seek change and appropriate recognition of the importance of the autistic individual.

Summary

I have outlined how I have used participatory research alongside my unique attributes as an autistic academic to construct a safe learning space which has produced relevant and unique findings. By recognising the power of history and how it has produced agency to prompt change for the benefit of others. It is hoped that the structures addressed here can be taken forward to address the limitation of this research in the diversity of autistic individuals that may not have participated. Fundamentally I believe that by pursuing the arguably unique approach of ensuring a qualitative primacy to a sequential mixed methods design alongside participatory research principles throughout both stages, has facilitated a large data set of findings that has not previously been evidenced. I would therefore recommend this approach is considered by future researchers aiming to explore the voices of participant experiences.

CHAPTER EIGHT: CONCLUSIONS

The thesis presented here set out to explore the previously under-researched area of self-identification of autism. Through a sequential mixed method approach, the lived experiences of ten participants were sought through semi-structured interviews. The transcripts of such were analysed, using Interpretive Phenomenological Analysis, to develop superordinate themes that then became the foundations of an online survey, which served to triangulate the results found. The amalgamation of the results from both phases of research were subsequently combined with the available literature, both academic and autobiographical, to arrive at original and innovative conclusions.

In total, one hundred and forty individuals participated in this study, spanning all adult age ranges, seven genders, nine ethnicities, eleven religions and twelve countries. Within the research population, thirty-eight individuals self-identified without a diagnosis, fifty-nine self-identified before then receiving a diagnosis, thirty-six were diagnosed after a third party prompted awareness and seven were diagnosed without any involvement themselves. Due to the breadth of numbers involved in this study, alongside the way in which the specific research questions explores differences and correlations of experiences between non-diagnosed and diagnosed individuals has significant impact on our understanding of a wider societal concept of autism.

Within the discussion chapter the data of this research was directly analysed to answer the questions set out as the aims of this research:

1. what is the autistic identity/ies?
    a. what facilitates the process of self-discovery of autism?

b. what is the impact of the delayed realisation of the autistic identity?

c. what is the purpose of self-identifying as autistic?

In doing so the ‘spiral of self-identification of autism’ was presented, amalgamated into Bronfenbrenner’s ecological systems theory, to represent the accumulation of knowledge developed from the experiences of the participants of this research. The diagram is presented here again for ease of reference:

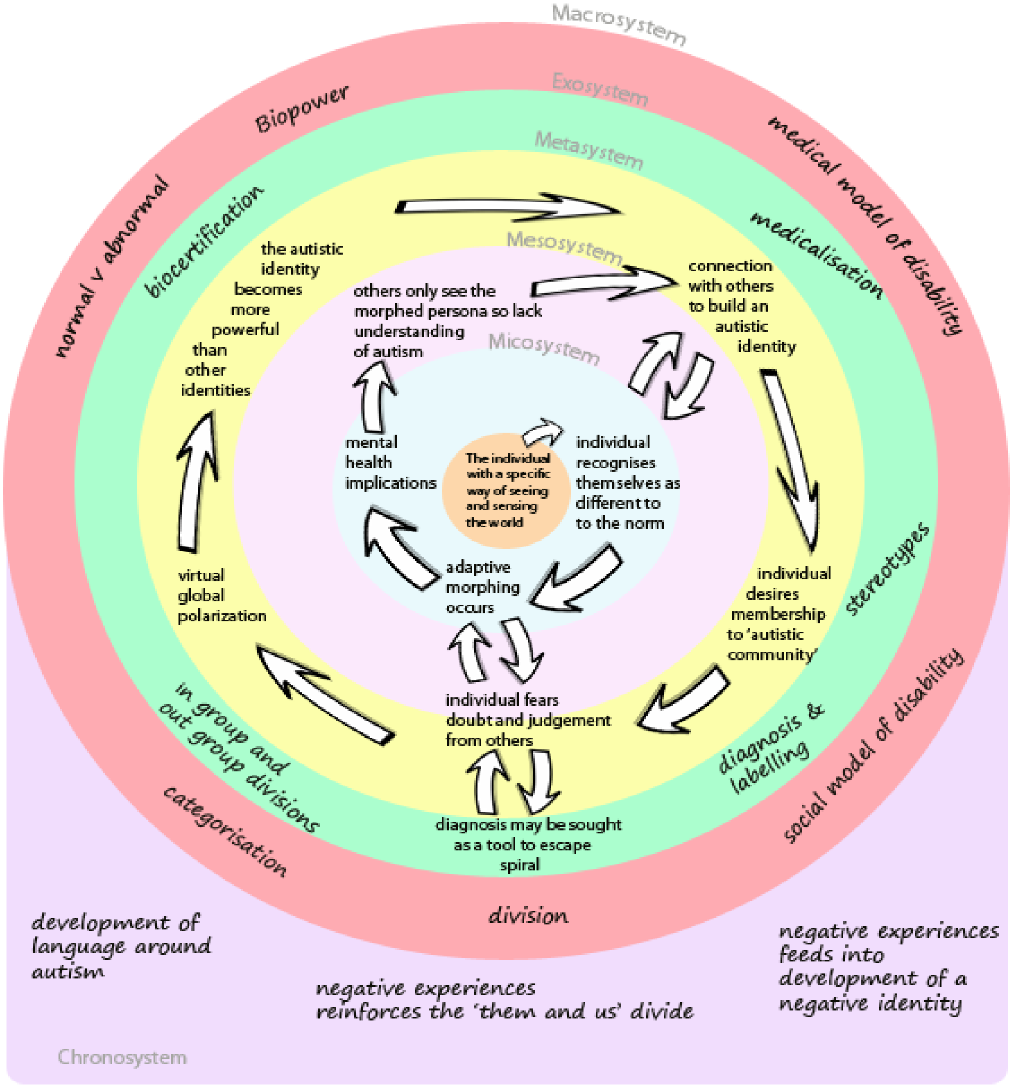


Figure 71: Spiral of Self-Identification

Taking the ‘spiral of self-identification of autism’ as an underpinning concept, several key themes evolved, that had implications for many of the research participants, regardless of diagnosis status, which will now be highlighted as key developments from my work.

8.1 BioPower

By positioning my data alongside that of biopower seen in the work of Foucault, I have argued that for the participants in this study the purpose of self-identifying lay in a desire to claim back an identity from the ‘deviant’ one placed upon them. However, the actions undertaken to do this, result in an illusion of power, which in truth only serves to reinforce the authority of categorisation and division. This in turn weakens the identity for the individual as it prevents them from embracing the ‘normalcy’ of their complex personhood.

I use the work of Foucault, and his argument that:

> *“human beings are said to be ‘made subjects’ in the sense that their ‘subjective identity’, who or what they understand themselves to be, is ‘made’ or produced by being ‘tied’ to a specific identity through a ‘conscience or self-knowledge’” (Foucault, 1982. Quoted in Roberts, 2005, Page 2).*

This argument is presented as a fundamental, interweaving theme in all developing key points of my research that follows.

8.1.1 Marginalisation

The evidence from this research has illustrated how individuals experienced marginalisation from their daily communities of practice due to a perception of being different to the social construction of normal. Furthermore, individuals have in the past been stuck in the peripherals of practice due to a lack of language to associate their experiences with others. Over 80% of the participants of this study, regardless of gender, reported 'masking' as a mechanism built out of marginalisation and fear. The term adaptive morphing (Lawson, 2020) was embraced as an effective term to explain these experiences, instead of the previously used term 'masking'. 80% of participants felt that adaptive morphing had a direct impact on their mental health, with exhaustion featuring above all else.

The positioning of individuals within the periphery of practice is reinforced by a culture that continues to dichotomise ability, therefore enabling a politicalised identity and in turn suppressing the possible exploration of autism being merely one facet in an individual's personal construct.

8.1.2 Society and Culture

The data from this research indicates that the autistic identity/ies is specific to the culture, time, and place, being the product of its histories. Participants highlighted how changes within their societies, such as media and language, had enabled their exploration and association with autism. For those individuals that self-identified, the media featured as a more central facilitator than for those that were formally diagnosed. As it is acknowledged that the media exerts a substantial power on societies, it is suggested that the ‘knowledge’ presented within such mediums, may be flawed and therefore bar individuals from beginning the process of self-discovery. Participants demonstrated that there has been an increase in opportunities to encounter language surrounding autism in recent years, which has facilitated the development of the phenomenon of self-identification. The ability to restrict and/or manipulate an individual’s self-construct by the media is suggested as further evidence of biopower within society. This is evidence therefore of a pivotal epoch in understanding autism.

The role of society in the autistic identity/ies, illustrated in this research, has reinforced the social learning theory that identities cannot be built in isolation. The marginalisation from their local communities of practice encourages individuals to seek communities on a global scale, facilitated by the internet. The data of this research reinforces the argument that there is an ‘autistic culture’ online and that this culture is used to share experiences, often of marginalisation, and therefore construct an identity. The ability to access such communities of practice however, as my data suggests, is hindered by the individual’s awareness of autism, communities are therefore not sought until the individual has begun their journey towards an autistic identity. As such it is suggested that our awareness of the numbers of people worldwide that may align themselves with the autistic identity/ies is inaccurate and vastly underestimated.

While the purpose of self-identifying as autistic can be seen as a means to gain access to the online autistic communities of practice at a global level, it is the findings of this research that the imbalance between global and local identities is reinforced and possibly exacerbated by the ‘them and us’ nature of some autistic groups online and a consequential politicisation of the autistic identity/ies.

8.2 Pieces of a Puzzle

The data of this research illustrated significant contradictions surrounding the individual’s understanding of the autistic identity/ies, especially its singularity or plurality, perpetuality or transmutability, and essential or existential nature. It was acknowledged through the principles of Communities of Practice that an identity should be “ongoing and pervasive” (Wenger, 1998), should transverse across landscapes of practice (Wenger-Trayner and Wenger-Trayner, 2000) and any identity should be only one of a nexus of identities (Wenger, 1998). Despite this, there is clear evidence, in this research, that while individuals recognised the differences in autism between people, they continued to believe that for themselves the autistic identity was static and singular, often holding superiority over all other identities. As such it is argued that the development of a perceived ontology of autism results in a reduction of the autistic identities down to a politicalised identity as individuals experience the need to validate themselves from the perspectives of doubt and prejudice of others.

Wenger (1998) talks of the plurality of identities forming “pieces of a puzzle that go together” (*p*159). However, the puzzle piece is often used to represent the singularity of autism and the confusion in understanding where it fits within the wider picture. I use this image to represent my findings that the puzzle piece, used in popular media, stands alone because the autistic identity/ies is made to overshadow all other identities/pieces of the human puzzle. Only by shrinking the autism piece down to mirror the sizes of the other pieces of the human puzzle can we enable the autistic puzzle piece to effectively aid the construction of the individual’s nexus of identities.

8.3 Power of Diagnosis

Despite this research specifically focusing on individuals without a diagnosis, the power of the medical diagnosis quickly became apparent. The inclusion of individuals at differing levels/routes to diagnosis within the online survey allowed exploration of opinions of the role of diagnosis for the individual within their experiences.

In line with the conclusions above relating to marginalisation and biopower, the view of diagnosis for those individuals that self-identified as autistic was that it would provide external validity of their identity to others. It is argued therefore that the current biopower manipulates individuals to devalue their own awareness of self, in favour of the ‘external expert’ who based on second-hand knowledge and observations provides a diagnosis if they feel it appropriate. The significant influence of this power can be seen in the fact that the neurodiversity movement which argues for the value of the autistic voice and experience, conversely, continues to argue biocertification by such professionals is more valid than a person’s own experience and knowledge.

Diagnosis therefore is viewed as the metaphorical key to acceptance and support, not held by the individual however, with the power currently held by medical professionals. As such, it is argued that the self-identifying individual is potentially marginalised from two different communities of practice, too ‘ab-normal’ for their everyday lives but not ‘ab-normal’ enough for the autistic community. This therefore results in a more significant impact on the individual and their mental health. It is therefore suggested that the biopower within society 'black-mails' the individual into diagnosis (Hodge, 2005) in order to move from the peripheral of practice and begin to develop mutual recognition.

In contrast to the current practice illustrated, my data would suggest that such a process is not necessary. Self-understanding, which it was previously believed would only be achieved through diagnosis (Bertilsdotter Rosqvist, 2012; Powell & Acker, 2016), is realized through self-identification. Furthermore, the process of self-identification would, alongside societal changes to perceptions of diversity, allow the individual to place the autistic identities within a nexus of identities rather than the label becoming more significant than the individual. As Kirby (2021c) effectively states:

> *"We obsess about diagnosis and categorization rather than considering the needs of each child or adult, but this is more about fitting into systems rather than the person fitting into a category" ([blog]).*

8.4 Role of Education

Within this study 86% of the research population lived more than 50% of their lives without language to understand the differing ways they perceive and interact with the world which resulted in associated marginalisation and mental health challenges. In line with this, evidence was provided that those without a formal diagnosis had more negative experiences at school. It is a central positioning of this study therefore that the education system needs a complete overhaul to ensure that, at its roots, is a "system that cultivates the ability to see full and equal humanity in *the other*" (Mortier, 2020, *p*329). Advocating for the concept that, while individuals are shaped by the communities in which they live, the only ontological fact is that they are all human beings. By taking this as the very starting point of our education system, differences and similarities can be seen across the global society and positioned on the baseline of 'while we are different, we are the same'.

Such an argument is reinforced by the data that over 70% of participants, not diagnosed at an early age, reported experiences of bullying at school and that experiences of marginalisation negatively impacted on the participants identity and mental health. It is suggested that by reconstructing our education system away from a 'factory model of education' (Sleeter, 2015), constructing a system whereby the differences of all students are recognised and provided for we can normalise the provision of specialist support to anyone that needs it. This would mean that for those children undergoing similar experiences to those seen in this study, would not be trapped between provision for the typical student and for the labelled student with special educational needs. In effect not only modelling but also directly teaching the necessary challenge to the status quo of the 'normal is good' dominated society.

8.5 Call for Action

It is acknowledged that the process of changing the way in which society approaches disability and autism, while vital, is not an easy or quick process. Therefore, reflection needs to occur on the more immediate impacts of the results gathered. I agree with Wenger-Trayner and Wenger-Trayner (2020) when they write:

> *“our ethical stance is one that values diversity and dialogic respect. We work in service of a world where conditions are in place for all humans to flourish, and where flourishing includes having agency: the power to make a difference” (p4).*

From reviewing the experiences of the participants, alongside the available academic and autobiographical literature, I believe there is a strong argument for improvements in post-diagnostic support and recognition of mental health needs associated with these challenges as fundamental, rather than an ‘add-on’ as they are now.

By reflecting back on figure thirty-nine, copied here for ease of reference.

	Self-diagnosed, not formally diagnosed	**Self-diagnosed and then formally diagnosed**	**Formally diagnosed after someone else thought I was autistic**	**Formally diagnosed when I was younger, so I was not involved in it**
1	feeling different to the 'norm'	*Jointly* anxiety and socially awkward	socially awkward	*Jointly* socially awkward & meltdowns/shutdowns & passionate
2	anxiety		feeling different to the 'norm'	
3	socially awkward	feeling different to the 'norm'	Anxiety	

It is evident that the autistic identity was predominantly shaped by feeling ‘ab-normal’. When viewed alongside the data that over 80% of participants, regardless of formal diagnosis, reported undertaking masking, and that the primary impact of masking was emotional exhaustion, there is significant evidence that support is required to enable individuals to feel more positive about themselves, reduce isolation and in turn manage associated mental health challenges.

I have previously detailed how contradicting beliefs regarding the autistic identity became an interweaving feature in this research. The current process whereby the autistic identity is politicalised and therefore seen as static, reflects the current societal structures, but prevents the individual from understanding the fluidity of the autistic identity and the importance of a nexus of identities (Wenger 1998). It is the recommendation of this research therefore, that the support for individuals identifying as autistic be urgently reviewed. Strategies need to be considered, and researched to ensure evidence-based practice, on how best to support individuals to not feel isolated or 'ab-normal'. Alongside my proposed changes to the education system to promote diversity acceptance, interventions need to be constructed now to target those that would be too late to benefit from such changes. In order to allow them to accept and have confidence in their autistic identity while also understanding that it is only one of a nexus of identities they possess.

The importance of peer connections has been evident in this research, with 87.7% of participants expressing they had been actively searching for people to relate to. As previously outlined, Wenger (1998) suggests that participation, the process of identifying with another person's experiences, is crucial to the formation of an identity. Therefore, the scarcity of opportunity for the autistic person to engage in this activity will negatively impact on their sense of identity and in turn their mental health. Taking this and the evidence above into account, it is recommended that opportunities for individuals to experience connections with other autistic people is a vital element of providing support, especially that relating to mental health. As well as ensuring, the positive impacts of peer support is mirrored in the individual's local environment and not merely at a global level.

This should be approached with a specific focus on reducing the 'them and us' atmosphere that has been shown to be present, especially in current online forums.

> *"Go to any autistic-only group on Facebook and you'll see discussion about the weird or confusing ways non-autistic people communicate" (Hanson, 2019 {blog}).*

It is argued, with reference to Foucault's biopower, that the current popular use of the term neurodiversity continues to serve the categorisation of those that are seen in direct comparison to 'normal'. Individuals need opportunities to experience connections with autistic people as well as a wide range of differences, in order to recognise their own strengths and weakness and how this makes them similar to others, while at the same time recognising the naturalness of how this also makes them different to others.

The principles of Foucault's biopower have been used to understand the ways in which our current societies drive our thought processes behind normal and ab-normal, it is further used to argue that while discourse maintains power, it is also through discourse that power can be challenged and changed (Sam, 2019). I have provided significant evidence throughout this research that participatory research methods have enabled power through discourse, and as such future research is needed to continue the development of understanding I have commenced.

Specific questions that I believe would benefit from exploration to continue the developments of the findings of this research, are:

- how can schools develop systems to support the effective exploration of self-identity for all students?
- What role does diagnosis play in a truly diversity valuing society?
- What impact does self-identification at an earlier age have on the individual's wellbeing?

- How can social learning theory develop to help us further understand the impacts of marginalisation on identity, especially without the necessary language to conceptualise experiences?
- How do we move away from the ‘factory-based school model’ and build a system that values, models and directly teaches the natural complex personhood of every individual?

Beyond these suggested research areas, the findings of this research suggest more immediate action is needed to support the population of individuals who self-identify as autistic. While suggestions have been made that within a diversity-promoting society, diagnosis is likely to become unnecessary, we currently do not live in such a society and therefore diagnosis is needed for the individual to receive validation for their own self-awareness and feel confident to move beyond the peripherals of the autistic community. Furthermore, the evidence indicates that mental health challenges are significant for this population and therefore action is needed to develop targeted provision to enable them to explore their own self identities, strengths, and weaknesses and to ensure that they see their autism as just one part of their individuality.

8.6 Final Statement

The thesis that has been laid out here has produced new and significant evidence that facilitates our understanding of the autistic identity/ies within a subsection of the autistic population. By exploring the experiences of this previously under-researched population, a new concept has been presented ‘the spiral of self-identification of autism’ with secure foundations in theories, such as Bronfenbrenner’s ecology systems model, Foucault’s biopower and Lave, Wenger-Trayner and Wenger-Trayner’s Landscapes of Practice. The spiral represents a metaphorical understanding of the way individuals are trapped, within an illusion of power, in a societal system that devalues their individuality. It further represents an urgent call for action to support such individuals to break free of these constraints and celebrate their complex personhood.

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Appendices

Contents

Appendix 1: - Autistic Literature sorting process

top 80 blogs of 2021 as defined by feedspot.com tps://blog.feedspot.com/autism_blogs/

Blog Name	Link	Meets inclusion criteria?	If not why not
A diary of a mom	https://adiaryofamom.com/	No	Parents
Adventures in Patience, Love, and Hope…with a side of Autism and goldfish	https://asideofgoldfish com/	Yes	
Affect Autism	https://affectautism.com/blog/	No	research
AGE OF AUTISM	https://www.ageofautism.com/	No	Organisation
Ausome Girls	https://myausomegirl.wordpress.com/	Yes	
Autisable	https://autisable.com/	Yes	
Autism Awareness	https://autismawarenesscentre.com/autism-news/	No	Parents
Autism Eye Magazine	https://www.autismeye.com/	No	Parents
Autism in Our Nest	http://www.autismfamilypower.com/	No	Parents
Autism Journey	https://autismjourney.org/blog/	No	Parents
Autism Mom | ABA Help for Professionals and Parents	https://marybarbera.com/	No	Parents
Autism Parenting Magazine	https://www.autismparentingmagazine.com/	No	Parents
Autism Plus More	https://autismplusmore.blog/blog/	No	Parents
Autism Policy and Politics	http://www.autismpolicyblog.com/	No	research
Autism Products	https://www.autism-products.com/blog/	No	Parents
Autism Resources and Community (ARC) | Stages Learning	https://blog.stageslearning.com/blog	No	Organisation
Autism Society	https://www.autism-society.org/	No	Organisation
Autism Spectrum News	https://autismspectrumnews.org/	No	research
Autism Spectrum Therapies	https://autismtherapies.com/blog/	No	Organisation
Autism with a side of fries	http://autismwithasideoffries.blogspot com/	No	Parents
Autistic & Unapologetic	https://autisticandunapologetic.com/	Yes	
Autistic Mama	https://autisticmama.com/blog/	Yes	
Awesome Super Diary	http://awesomesuperdiary.blogspot.com/	Yes	
AwesomismMom	https://awesomismmom.com/blogs/	No	Parents
Behavioral Innovations Blog	https://behavioral-innovations.com/blog/	No	Organisation
Best Practice Autism	https://bestpracticeautism.blogspot.com/	No	education
Big Abilities	https://bigabilities.com/	No	education
BlueSprig Autism	https://bluesprigautism.com/blog	No	Organisation
Carrie Cariello | Exploring the Colorful World of Autism	https://carriecariello com/mondays-blog-2/	No	Parents
ChevsLife | Blog about Aspergers Kid	https://chevslife.com/	No	Parents
Different Brains | The Neurodiversity Resource for Everyone	https://www.differentbrains.org/category/blog/	No	Organisation
edge of the Playground	https://edgeoftheplayground.com	Yes	
Embrace ASD	https://embraceasd.com/	No	Organisation
Embrace Autism	https://embrace-autism.com/blog	Yes	

Faith, Hope, and Love...With Autism	https://faithhopeloveautism.blogspot.com/	No	Parents
Fierce Autie	https://www.fierceautie.com/	Yes	
Finding Cooper's Voice	https://www.findingcoopersvoice.com/	No	Parents
From an Autistic Point of View	https://fromanautisticpointofview.wordpress.com/	Yes	
HomeSchool Special Needs Tidbits	https://homeschoolspecneedstidbits.com/	No	education
I am Candence	https://iamcandence com	Yes	
Ido In Autism Land	https://idoinautismland.com	Yes	
In the Loop About Neurodiversity	https://intheloopaboutneurodiversity.wordpress.com/	Yes	
Irabina Autism Services	https://www.irabina.com/	No	Organisation
Jewel Autism Centre	https://jewelautismcentre.com/jewel blog/	No	Organisation
Learn From Autistics	https://www.learnfromautistics com/blog/	Yes	
Madison House Autism Foundation	http://madisonhouseautism.org/blog/	No	Organisation
Mitchell's Life with Autism	https://mitchellslifewithautism.com/	Yes	
Musings of an Aspie	http://musingsofanaspie.com	Yes	
Naturally Recovering Autism	https://naturallyrecoveringautism.com/blog/	No	Parents
Neuro Clastic	https://neuroclastic.com/	Yes	
Neurodivergent Rebel	https://neurodivergentrebel com	Yes	
Not Weird, Just Autistic	https://www.notweirdjustautistic com/	Yes	
Olli Bean	https://ollibean.com	Yes	
Our Chaos | Autism Family	https://www.ourchaos.net/	No	Parents
Purple Ella | Autism and Disability	https://www.purpleella.com/category/autistic-spectrum/	Yes	
Rainbows are too beautiful	http://www.rainbowsaretoobeautiful.com/	No	Parents
Raising My Little Superheroes	https://www.raisingmylittlesuperheroes.com/	No	Parents
sarahnannery.com	https://www.sarahnannery.com/blog	Yes	
Side by Side	https://www.sidebysidetherapy.ca/blog/	No	Organisation
Speaking of Autism...	https://speakingofautismcom.wordpress com/	Yes	
Spectroomz	https://www.spectroomz.com/	No	Organisation
Spectrum | Autism Research News	https://www.spectrumnews.org/	No	research
Squidalicious	http://www.squidalicious.com/	No	Parents
Susan's Blog	http://susansenator.com/blog/	No	Parents
Teaching Autism	https://teachingautism.co.uk/	No	education
The Art of Autism	https://the-art-of-autism.com/	Yes	
The Asperger / Autism Network (AANE)	https://www.aane.org/blog/	No	Organisation
The Autism Blog - Seattle Children's	https://theautismblog.seattlechildrens.org/	No	Organisation
The Autism Cafe | Flappy hands, happy hearts	https://theautismcafe.com/	No	Parents
The Autism Dad	https://www.theautismdad.com/blog/	No	Parents
The Autism Helper	https://theautismhelper.com/	No	education
The autism site blog	https://blog.theautismsite.greatergood.com/	No	Organisation
The Autistic Me	https://theautisticme.blogspot.com/	Yes	
The Mom Kind	https://www.themomkind.com/	No	Parents
The Musical Autist Blog	https://themusicalautist.org/blog/	Yes	

The Other Autism	https://femaleautismphenotype.com/blog-2/	Yes
The Real Michael Tanzer	https://therealmichaeltanzer.wpcomstaging.com/blog/	Yes
Thinking Person's Guide to Autism	http://www.thinkingautismguide.com/	Yes
Trailblazing Autism	https://trailblazingautism.home.blog/	Yes
Undercover Autism	https://undercoverautism.org/	Yes

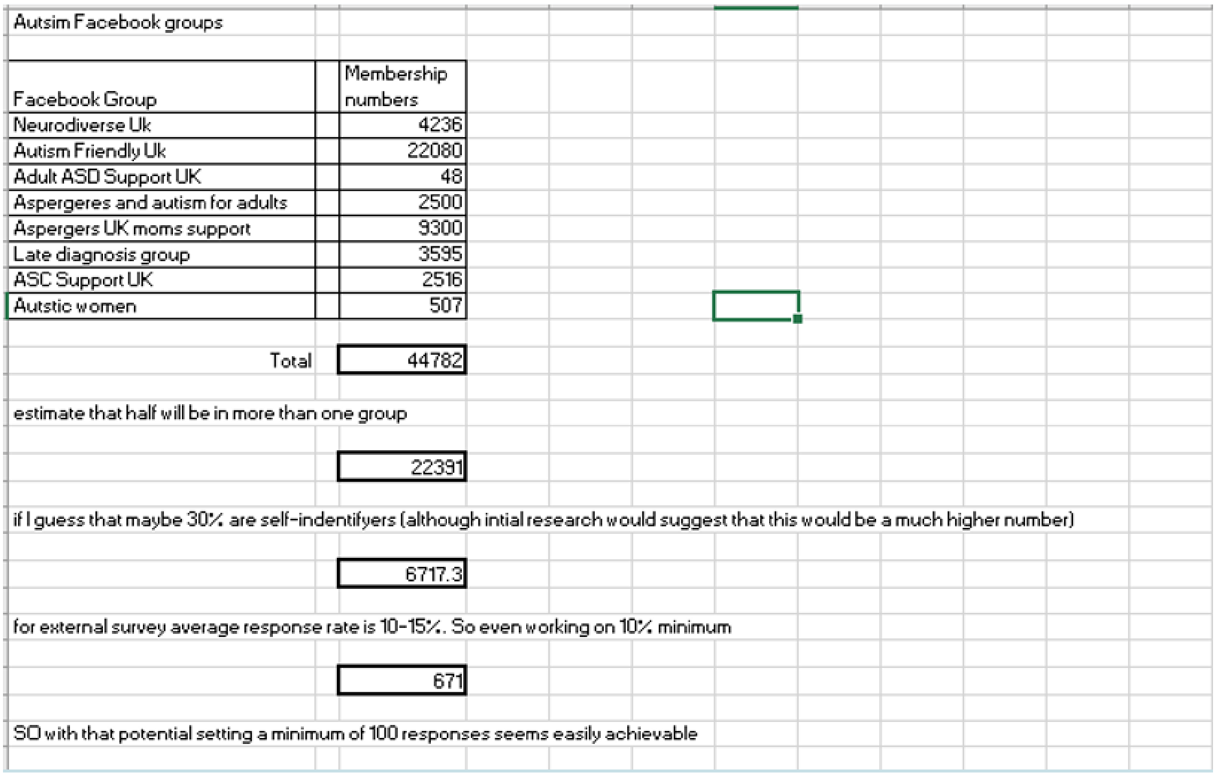
Appendix 2: - List of Autobiographical Accounts Included in 2.3

Book Title	Author
From another planet; autism from within	Dumortier, D.
Making sense of the unfeasible: My life Journey with Aspergers	Fleisher
The way I see it	Grandin, T
Asperger syndrome, the universe and everything	Hall, K
Women and Girls With Autism Spectrum Disorder	Hendrickx, S
Pretending to be Normal	Holliday-Willey, L.,
Freaks, geeks and Asperger Syndrome	Jackson, L
I think I might be Autistic; A Guide to Autism Spectrum Diagnosis and Self-Discovery for Adults	Kim, C
Life Behind Glass: A personal account of Autism Spectrum Disorder.	Lawson, W
Glass half empty, Glass half full; how Asperger's syndrome has changed my life	Mitchell, C
Beyond the Silence: My Life, the world and autism	Mukhopadhyay, T
Born on a Blue Day	Tammet, D
Nobody Nowhere	Williams, D
Spectrum Women	Cook, B., Garnett, M., Artemisia, R., Stewart, C., Lesko, A., Willey, L., Craft, S., Purkis, J. and Ross, K

Blog Title	URL
Adventures in Patience, Love, and Hope…with a side of Autism and goldfish	https://asideofgoldfish.com/ F
Ausome Girls	https://myausomegirl.wordpress.com/ Mi
Autisable	https://autisable.com/ Mi
Autistic & Unapologetic	https://autisticandunapologetic.com/ M
Autistic Mama	https://autisticmama.com/blog/ F
Awesome Super Diary	http://awesomesuperdiary.blogspot.com/ M
edge of the Playground	https://edgeoftheplayground.com F
Embrace Autism	https://embrace-autism.com/blog Mi
Fierce Autie	https://www.fierceautie.com/ F
From an Autistic Point of View	https://fromanautisticpointofview.wordpress.com/ F
I am Candence	https://iamcandence.com F
Ido In Autism Land	https://idoinautismland.com M
In the Loop About Neurodiversity	https://intheloopaboutneurodiversity.wordpress.com/
Learn From Autistics	https://www.learnfromautistics.com/blog/ Mi
Mitchell's Life with Autism	https://mitchellslifewithautism.com/ M
Musings of an Aspie	http://musingsofanaspie.com F

Neuro Clastic	https://neuroclastic.com/ Mi
Neurodivergent Rebel	https://neurodivergentrebel.com F
Not Weird, Just Autistic	https://www.notweirdjustautistic.com/ M
Olli Bean	https://ollibean.com F
Purple Ella | Autism and Disability	https://www.purpleella.com/category/autistic-spectrum/ F
sarahnannery.com	https://www.sarahnannery.com/blog F
Speaking of Autism…	https://speakingofautismcom.wordpress.com/ M
The Art of Autism	https://the-art-of-autism.com/ Mi
The Autistic Me	https://theautisticme.blogspot.com/ M
The Musical Autist Blog	https://themusicalautist.org/blog/ Mi
The Other Autism	https://femaleautismphenotype.com/blog-2/ F
The Real Michael Tanzer	https://therealmichaeltanzer.wpcomstaging.com/blog/ M
Thinking Person's Guide to Autism	http://www.thinkingautismguide.com/ Mi
Trailblazing Autism	https://trailblazingautism.home.blog/ F
Undercover Autism	https://undercoverautism.org/ F

Appendix 3: - Participant Sample Estimations



Autsim Facebook groups

Facebook Group	Membership numbers
Neurodiverse Uk	4236
Autism Friendly Uk	22080
Adult ASD Support UK	48
Aspergeres and autism for adults	2500
Aspergers UK moms support	9300
Late diagnosis group	3595
ASC Support UK	2516
Autstic women	507
Total	44782

estimate that half will be in more than one group

22391

if I guess that maybe 30% are self-indentifyers (although intial research would suggest that this would be a much higher number)

6717.3

for external survey average response rate is 10-15%. So even working on 10% minimum

671

SO with that potential setting a minimum of 100 responses seems easily achievable

Appendix 4: - Foundation Interview Questions

Pre-Interview Survey

Name?	
Age?	
Age of Self Identification of Autism?	
What Gender do you identify as?	
What county do you live in? and which area of said country?	
Ethnicity?	
Religion?	
Any diagnosed disabilities?	
Any self-identified disabilities?	
Relationship status?	
Do you have close family members that are autistic?	

Tell me 5 things that define you as a person

1
2
3
4
5

The following questions will be part of the discussion during the interview. I am sending them in advance to give you time to reflect on them and feel confident that you will be able to answer on the day. **Please remember there is no right or wrong answer, I am merely after your thoughts and experiences.**

Section 1 – Autistic Identity

1) When and how did you come to build/accept an autistic identity?
2) Do you see autism as being part of your identity? (it would be helpful here to consider what you understand the term identity to mean)
3) Do you believe you have always been autistic? And Do you think you will always be autistic?

Section 2 – Prominence of your autism

1) Is your autism always evident?
2) Are there times when you feel more or less autistic?
3) Do you think that you were a 'different person', before you identified as autistic? (by different person I mean, different characteristics/identity. For example: I was withdrawn before and I'm not now)

Section 3 – Purpose of self-identifying

1) What are the advantages and disadvantages to you of self-identifying
2) Did you contact with other autistic people on social media before or after self-identifying? What impact has this connection had? (on you and your identity)
3) Do you connect with other autistic people off-line?

Section 4 – What is the impact of self-identifying on others?

1) Do you share with others that you identify as autistic?
2) What are people's responses if/when you do share this?
3) What are your views on formal diagnosis?

Appendix 5: - Phase One Recruitment Letter

Recruitment message to be sent via private messenger to the administrators of the following closed facebook groups:

Neurodiverse Uk
Autism Friendly Uk
Adult ASD Support UK
Aspergeres and autism for adults
Aspergers UK moms support
Late diagnosis group
ASC Support UK
Autistic women

To ………………………. (administrators name)

I am a current member of your group (as an autistic individual) and a PhD student at the University of Birmingham. I am seeking your permission to advertise within the group to recruit a small number of people to participate in my research (through an individual interview). I have attached the advert for your reference. I am researching self-identification of autism and wish to gather experiences that will help me collate data on:

1. What is an autistic identity?
2. How prominently do people experience that identity?
3. What is the purpose of self-identifying as autistic?
4. What is the impact of self-identifying on others?

The research is in three stages, with the interviews being the first stage (the second stage will be an online survey which I will write to you again in the New Year to seek your approval to advertise this next stage, and the third stage a return to the interviewees). The first stage of the research now has full ethical approval (which I will attached for you). I will also attached the participant information form for your information.

It is my intention to be as supportive as possible throughout the interview process as I appreciate discussing life experiences can sometimes be emotional unsettling. There will be a de-briefing at the end of the interview and further resources available as necessary, specifically details of the National Autistic Society Helpline will be provided as an appropriately trained body with which to provide additional support and signpost to professional services if required.

If you have any further questions about my research, please do not hesitate to ask

Many Thanks

Barbara Sandland

Appendix 6: - Ethical Approval

UNIVERSITY OF BIRMINGHAM

APPLICATION FOR ETHICAL REVIEW

☒ Before submitting, please tick this box to confirm that you have consulted and understood the following information and guidance and that you have taken it into account when completing your application:

The information and guidance provided on the University's ethics webpages

UNIVERSITY OF BIRMINGHAM APPLICATION FOR ETHICAL REVIEW	*OFFICE USE ONLY:* Application No: Date Received:

TITLE OF PROJECT

What is the process of self-identification of autism, as understood by those who have experienced it?

THIS PROJECT IS:

University of Birmingham Staff Research project ☐

University of Birmingham Postgraduate Research (PGR) Student project ☒

Other ☐ (Please specify):

INVESTIGATORS

PLEASE GIVE DETAILS OF THE PRINCIPAL INVESTIGATORS OR SUPERVISORS (FOR PGR STUDENT PROJECTS)

Name: Title / first name / family name	DR ANDREA MACLEOD
Highest qualification & position held:	PhD, lecturer
School/Department	EDUCATION
Telephone:	
Email address:	

Name: Title / first name / family name	
Highest qualification & position held:	
School/Department	
Telephone:	
Email address:	

PLEASE GIVE DETAILS OF ANY CO-INVESTIGATORS OR CO-SUPERVISORS (FOR PGR STUDENT PROJECTS)

Name: Title / first name / family name	PROFESSOR KAREN GULDBERG
Highest qualification & position held:	PhD, professor
School/Department	EDUCATION
Telephone:	
Email address:	

In the case of PGR student projects, please give details of the student

Name of	BARBARA SANDLAND	Student No:	
Course of study:	PhD EDUCATION	Email	
Principal	ANDREA MACLEOD		

Name of student:		Student No:	
Course of study:		Email address:	
Principal supervisor:			

ESTIMATED START OF PROJECT Date: OCT 2019

ESTIMATED END OF PROJECT Date: JULY 2020

FUNDING

List the funding sources (including internal sources) and give the status of each source.

Funding Body	*Approved/Pending /To be submitted*
COSS	APPROVED

If you are requesting a quick turnaround on your application, please explain the reasons below (including funding-related deadlines). You should be aware that whilst effort will be made in cases of genuine urgency, it will not always be possible for the Ethics Committees to meet such requests.

N/A

SUMMARY OF PROJECT

Describe the purpose, background rationale for the proposed project, as well as the hypotheses/research questions to be examined and expected outcomes. This description should be in everyday language that is free from jargon. Please explain any technical terms or discipline-specific phrases.

THE PROJECT IS TO INVESTIGATE THE PHENOMENON OF SELF-IDENTIFICATION OF AUTISM (Autism is a lifelong developmental disability that affects how people perceive the world and interact with others. Autistic people see, hear and feel the world differently to other people (National Autistic Society)).

THE PROJECT ARISES FROM PERSONAL EXPERIENCES OF AUTISM AND PEOPLE WHO ARE NOT OFFICIALLY DIAGNOSED BUT COMMUNICATE WITHIN AN ONLINE AUTISM COMMUNITY AND LIVE THEIR LIVES AS AN AUTISTIC INDIVIDUAL. DIAGNOSIS RATES OF AUTISM ARE VARIED ACROSS THE COUNTRY, AND ACROSS GENDERS/RACE ETC AND IT IS QUESTIONED WHETHER THE PROCESS OF SELF-IDENTIFICATION IS MASKING THE NUMBERS OF AUTISTIC PEOPLE WITHIN SOCIETY AS THEY ARE FORMING A HIDDEN POPULATION.

IT IS AIMED TO UNCOVER WHY PEOPLE SELF IDENTIFY AS AUTISTIC AND WHAT IMPACT THIS HAS ON THEIR LIVES.

RESEARCH QUESTIONS TO BE COVERED WITHIN THE PROJECT

WHAT IS AN AUTISTIC IDENTITY?

HOW PROMINENTLY DO PEOPLE EXPERIENCE THAT IDENTITY?

WHAT IS THE PURPOSE OF SELF-IDENTIFYING AS AUTISTIC?

WHAT IS THE IMPACT OF SELF-IDENTIFYING ON OTHERS?

IT IS HOPED THAT BY UNDERSTANDING THE PERSONAL EXPERIENCES OF THIS POPULATION IT WILL AID OTHERS IN DEVELOPING THEIR KNOWLEDGE OF AUTISM FROM A PROFESSIONAL, ACADEMIC AND EVERYDAY VIEWPOINT.

CONDUCT OF PROJECT

Please give a description of the research methodology that will be used

METHODOLOGY WILL BE BASED UPON DEWEY'S PRAGMASTISM AND A MIXED METHODS DESIGN. IT WILL BE A SEQUENTIAL QUALITATIVE – QUANTITATIVE DESIGN USING SEMI STRUCTURED INTERVIEWS IN THE FIRST INSTANCE. THE RESULTS OF WHICH WILL FORM THE QUESTIONS FOR A LARGER SCALE QUESTIONNAIRE IN ORDER TO TRIANGULATE THE RESULTS AND BUILD GENERALISABILITY.

DATA COLLECTION

SEMI STRUCTURED INTERVIEWS WILL BE UNDERTAKEN ONLINE THROUGH INSTANT MESSENGER FACILITIES. OPPORTUNITIES FOR ONLINE FACE-TO-FACE DISCUSSION WILL BE OFFERED SHOULD THE PARTICIPANT REQUEST THIS AS AN ALTERNATIVE TO TEXT BASED COMMUNICATION. INTERVIEWS WILL BE UNDERTAKEN ON A 1 PER WEEK SCHEDULE FOR A PERIOD OF APPROXIMATELY 6 WEEKS (APPENDIX 5) TO ENSURE THAT DATA ANALYSIS CAN BE UNDERTAKEN AT THE POINT OF COLLECTION. AND PARTICIPANT CHECKING AT THIS TIME TO ENSURE THEY ARE CONFIDENT THAT THE RECORDED DATA IS AN ACCURATE REFLECTION OF THEIR EXPERIENCES.

AN ETHICS FORM AMMENDMENT WILL BE SUBMITTED IN JANUARY OF 2020 TO OUTLINE THE METHODS AND ASSOCIATED RISKS FOR THE QUANITATIVE ELEMENT OF THE PROJECT.

DOES THE PROJECT INVOLVE PARTICIPATION OF PEOPLE OTHER THAN THE

RESEARCHERS AND SUPERVISORS?

Yes ☒ No ☐

Note: 'Participation' includes both active participation (such as when participants take part in an interview) and cases where participants take part in the study without their knowledge and consent at the time (for example, in crowd behaviour research).

If you have answered NO please go to Section 18. If you have answered YES to this question please complete all the following sections.

PARTICIPANTS AS THE SUBJECTS OF THE RESEARCH

Describe the number of participants and important characteristics (such as age, gender, location, affiliation, level of fitness, intellectual ability etc.). Specify any inclusion/exclusion criteria to be used.

FOR THE QUALITATIVE ELEMENT OF THE PROJECT BETWEEN 6-10 PARTICIPANTS ARE SOUGHT.

INCLUSION CRITERIA:

18+ OF AGE

UK RESIDENCE

ONLINE USERS

SELF IDENTIFYERS OF AUTISM

LITERATE

THE PARTICIPANT INFORMATION SHEET (APPENDIX 3) PROVIDES EXAMPLES OF WHAT CLASSIFIES AS SELF-IDENTIFICATION TO ENSURE THAT THE INCLUSION/EXCLUSION CRITERIA IS MET ON THIS KEY ISSUE.

CONSIDERATION HAS BEEN GIVEN TO THE RESTRICTIONS OF THOSE WHO CAN BE INVOLVED IN THE STUDY AND THE IMPLICATIONS ON THE DATA PRODUCED. EVIDENCE IS OUTLINED IN THE THESIS AS TO WHY THESE DECISIONS HAVE BEEN MADE AND THE BENEFIT TO THE STUDY.

RECRUITMENT

Please state clearly how the participants will be identified, approached and recruited. Include any relationship between the investigator(s) and participant(s) (e.g. instructor-student).

Note: Attach a copy of any poster(s), advertisement(s) or letter(s) to be used for recruitment.

PARTICIPANTS WILL BE RECRUITED THROUGH ONLINE FACEBOOK CLOSED GROUPS (APPENDIX 2). A RECRUITMENT LETTER OUTLINING THE PROJECT AND ETHICAL APPROVAL WILL BE SENT TO GROUP ADMINISTRATORS TO SEEK THEIR CONSENT FOR ME TO ADVERTISE WITHIN SAID GROUPS (APPENDIX 1). THE ADVERTISMENT WILL BRIEFLY OUTLINE THE REQUEST FOR PARTICIPANTS AND ASK THOSE WHO MAY BE INTERESTED TO CONTACT ME VIA INSTANT MESSANGER IN ORDER TO BE SENT THE PARTICIPANT INFORMATION SHEET (APPENDIX 3) AND ASK ANY FURTHER QUESTIONS. INITIAL DECLARATIONS OF INTEREST DO NOT AMOUNT TO CONSENT AND THIS WILL BE MADE CLEAR AT THIS TIME.

THERE WILL BE NO PRIOR RELATIONSHIP WITH THOSE THAT PARTICIPANT ASIDE FROM A MUTUAL MEMBERSHIP OF CLOSED FACEBOOK GROUPS FOR PEOPLE OF THE AUTISM SPECTRUM.

CONSENT

a) Describe the process that the investigator(s) will be using to obtain valid consent. If consent is not to be obtained explain why. If the participants are minors or for other reasons are not competent to consent, describe the proposed alternate source of consent, including any permission / information letter to be provided to the person(s) providing. the consent.

INFORMED CONSTENT WILL BE OBTAINED FOLLOWING A PERIOD OF DISCUSSION WITH THE PARTICIPANTS TO ENSURE THEY ARE FULLY AWARE OF THE PROJECT AND THE IMPACT THEIR INVOLVEMENT MAY HAVE ON THEM. CONSENT WILL BE CONFIRMED THROUGH THE JOINT SIGNING OF A CONSENT FORM (APPENDIX 4).AS THE INCLUSION CRIERIA STIPULATES THAT THOSE PARTICIPATING ARE LITERATE, COMPETANCES TO READ THE CONSENT WILL NOT BE A CONCERN. DUE TO POSSIBLE LANGUAGE DIFFICULTIES IN AUTISM, I WILL ENSURE THAT EVERYONE FULLY UNDERSTANDS WHAT THEY ARE CONSENTING TOO THROUGH DISCUSSION AS NECESSARY.

Note: Attach a copy of the Participant Information Sheet (if applicable), the Consent Form (if applicable), the content of any telephone script (if applicable) and any other material that will be used in the consent process.

b) Will the participants be deceived in any way about the purpose of the study? Yes ☐ No ☒

If yes, please describe the nature and extent of the deception involved. Include how and when the deception will be revealed, and who will administer this feedback.

N/A

PARTICIPANT FEEDBACK

Explain what feedback/ information will be provided to the participants after participation in the research. (For example, a more complete description of the purpose of the research, or access to the results of the research).

PARTICIPANTS WILL BE PROVIDED WITH A TRANSCRIPT OF THE INTERVIEW FOR THEIR CONFIRMATION THAT IT IS AN ACCURATE PORTRAYAL OF THE DISCUSSION. PARTICIPANTS WILL ONLY BE ABLE TO VIEW THEIR OWN INVOLVEMENT AND NOT THAT OF OTHERS.

PARTICIPANTS WILL BE OFFERED THE OPPORTUNITY TO READ THE FULL FINDINGS OF THE RESEARCH ONCE ALL DATA IS ANONYMISED.

PARTICIPANT WITHDRAWAL

Describe how the participants will be informed of their right to withdraw from the project.

THE PARTICIPANT INFORMATION SHEET (APPENDIX 3) AND CONSENT FORM (APPENDIX 4) OUTLINES THAT EACH PARTICIPANT IS ENTITLED TO WITHDRAW PREVIOUSLY SUPPLIED INFORMATION WITHIN WEEKS OF THE INTERVIEW DATE WITHOUT GIVING A REASON. IF A PARTICIPANT WITHDRAWS AND DOES NOT WISH THEIR DATA TO BE USED THEY MUST INFORM ME AND THE DATA WILL BE DESTROYED.

b) Explain any consequences for the participant of withdrawing from the study and indicate what will be done with the participant's data if they withdraw.

UP UNTIL SEPT 2020 PARTICIPATE CAN OPT TO WITHDRAW AND FURTHER OPT IF THEY SHOULD WISH TO WITHDRAW PREVIOUSLY PROVIDED INFORMATION. SHOULD THIS OCCUR THEIR DATA WILL BE DESTROYED IN LINE WITH UNIVERSITY PROTOCOL. THERE ARE NO CONSEQUENCES TO THE PARTICIPANT FOR UNDERTAKING THESE ACTIONS. AFTER SEPT 2020, THE CONCLUDING DATA ANALYSIS WILL BE UNDERWAY AND IT WILL NOT BE FEASIBLE FOR DATA TO BE REMOVED FROM THE PROJECT AND PARTICIPANTS WILL THEREFORE BE AWARE OF THIS UPON COMMENCEMENT.

COMPENSATION

Will participants receive compensation for participation?

i) Financial Yes ☐ No ☒

ii) Non-financial Yes ☐ No ☒

If Yes to either i) or ii) above, please provide details.

N/A

If participants choose to withdraw, how will you deal with compensation?

N/A

CONFIDENTIALITY

a) Will all participants be anonymous? Yes ☐ No ☒

b) Will all data be treated as confidential? Yes ☒ No ☐

Note: Participants' identity/data will be confidential if an assigned ID code or number is used, but it will not be anonymous. Anonymous data cannot be traced back to an individual participant.

Describe the procedures to be used to ensure anonymity of participants and/or confidentiality of data both during the conduct of the research and in the release of its findings.

INFORMATION PROVIDED WILL BE STORED USING ACROYNIMS NOT TRACEABLE BACK TO THE PARTICIPANTS. HOWEVER, UNTIL THE END OF THE PROJECT A SEPARATE DOCUMENT WILL BE KEPT THAT LINKS THE ACROYNIMS TO THE PARTICIPANTS TO ENSURE THE DATA IS USED ACCURATELY. THIS DOCUMENT WILL ONLY BE ACCESSIBLE BY ME AND WILL BE DESTROYED WHEN THE WITHDRAWAL DEADLINE IS REACHED.

If participant anonymity or confidentiality is not appropriate to this research project, explain, providing details of how all participants will be advised of the fact that data will not be anonymous or confidential.

N/A

STORAGE, ACCESS AND DISPOSAL OF DATA

Describe what research data will be stored, where, for what period of time, the measures that will be put in place to ensure security of the data, who will have access to the data, and the method and timing of disposal of the data.

IN ORDER TO ENSURE COMPLIANCE WITH GDPR LAWS I WILL USE THE UNIVERSITY ENVIRONMENT FOR ACADEMIC RESEARCH (BEAR). BEAR RESEARCH DATA STORE (RDS) WILL BE USED TO STORE THE ELECTRONIC DATA. WHEN THE RESEARCH PROJECT IS COMPLETED, THE DATA WILL BE STROED IN BEAR RESEARCH DATA ARCHIVE (RDA). THE DATA WILL BE KEPT FOR A PERIOD OF 10 YEARS AND THEN DESTOYED IN LINE WITH UNIVERSITY POLICY.

ACCESS TO THE DATA WILL BE MYSELF AND MY SUPERVISORS ONLY.

*O*THER APPROVALS REQUIRED? e.g. Criminal Records Bureau (CRB) checks or NHS R&D approvals.

☐ YES ☒ NO ☐ NOT APPLICABLE

If yes, please specify.

SIGNIFICANCE/BENEFITS

Outline the potential significance and/or benefits of the research

TO SHINE A LIGHT ON A POSSIBLE HIDDEN POPULATION AND TO INCREASE AWARENESS. IN TURN TO IMPROVE THE WAY IN WHICH AUTISM IS VIEWED BY THE GENERAL POPULATION.

THE OUTCOMES ARE HOPING TO BE BENEFICAL TO ACADEMICS AND THE GENERAL PUBLIC EQUALLY.

RISKS

a) Outline any potential risks to INDIVIDUALS, including research staff, research participants, other individuals not involved in the research and the measures that will be taken to minimise any risks and the procedures to be adopted in the event of mishap

b)

AS THE RESEARCH WILL BE UNDERTAKEN THROUGH A COMPUTER WITHIN THE PARTICIPANTS OWN HOMES (AND THE RESEARCHERS OWN HOME) THERE IS NO PHYSICAL RISKS TO BE PLANNED FOR.

PSYCHOLOGICAL HARM MAY OCCUR DUE TO THE NATURE OF THE QUESTIONS AND REFLECTIONS ON PERSONAL EXPERIENCES THAT MAY NOT BE POSITIVE. SUPPORT WILL BE OFFERED THROUGHOUT TO PARTICIPANTS TO DISCUSS THESE IN MORE DETAIL, AWAY FROM THE RESEARCH, SHOULD THEY WISH. AS WELL AS SIGN POSTING TO THE MODERATORS OF THE ORIGINAL FACEBOOK GROUPS WHO OFFER EMOTIONAL SUPPORT AS PART OF THEIR ROLE.

AS AN AUTISTIC RESEARCHER I AM ALSO PLANNING TO ACCOMMODATE ANY PSYCHOLOGICAL HARM THAT MAY OCCUR AS A RESULT OF UNDERTAKING THIS PROJECT. I HAVE A SYSTEM OF MENTORSHIP AND FREQUENT MEETINGS WITH MY SUPERVISORS TO DISCUSS AND PROCESS ANY SUCH CONCERNS.

Outline any potential risks to THE ENVIRONMENT and/or SOCIETY and the measures that will be taken to minimise any risks and the procedures to be adopted in the event of mishap.

NONE

ARE THERE ANY OTHER ETHICAL ISSUES RAISED BY THE RESEARCH?

Yes ☐ No ☐

If yes, please specify

IT IS QUESTIONED AS TO WHETHER THE PARTICIPANTS WOULD FEEL THAT I WAS VALIDATING THEIR 'DIAGNOSIS' BY INVOLVING THEM IN THE STUDY WHICH MAY LEAD TO EMOTIONAL DISTRESS SHOULD THIS NOT BE VALIDATED BY OTHER PROFESSIONALS WITHIN THEIR LIFE. IN ORDER TO ADDRESS THIS, IT WILL BE MADE CLEAR FROM THE START THAT PARTICIPATION IS BASED ON THEIR OWN CONSTRUCTION OF THEIR IDENTITY AND NOT LINKED IN ANYWAY TO A MORE FORMAL DIAGNOSIS. AN INFORMATION RESOURCE SHEET WILL ALSO BE COMPILED AND BE AVAILABLE FOLLOWING A DE-BRIEFING PROCESS AT THE END OF THE INTERVIEW. SHOULD THE PARTICIPANTS RAISE CONCERNS ABOUT WANTING TO PURSUE FORMAL DIAGNOSIS THIS WILL SERVE AS A SUPPORT.

I RECOGNISE THAT AS AN AUTISTIC RESEARCHER I HAVE AN ELEMENT OF PERSONAL BIAS WITHIN THIS FIELD OF RESEARCH. HOWEVER I HAVE GIVEN A SIGNIFICANT AMOUNT OF TIME TO REVIEWING APPROPRIATE RESEARCH PHILOSOPHIES, METHODOLOGIES AND THEORIES TO ENSURE I HAVE AN ADEQUATE BASIS FOR MY RESEARCH, AWAY FROM MY INITIAL PERSONAL THOUGHTS. ALONGSIDE THIS, I HAVE CREATED A STRUCTURE WHEREBY I CAN ENSURE ALL DATA CAN BE PROVIDED, NOT MERELY THAT WHICH MAY 'PROVE MY POINT' WHICH WILL ENSURE A REDUCTION OF ANY PERSONAL BIAS IMPACT. PROCESSES OF TRIANGULATION AND PARTICIPANT CHECKING WILL ALSO ENSURE THAT THE INFORMATION I HAVE COLLATED IS AN ACCURATE REPRESENTATION OF THE DATA SET AND NOT SWAYED BY MY PERSONAL OPINIONS.

EXPERT REVIEWER/OPINION

You may be asked to nominate an expert reviewer for certain types of project, including those of an interventional nature or those involving significant risks. If you anticipate that this may apply to your work and you would like to nominate an expert reviewer at this stage, please provide details below.

Name
Contact details (including email address)
Brief explanation of reasons for nominating and/or nominee's suitability

CHECKLIST

Please mark if the study involves any of the following:

Vulnerable groups, such as children and young people aged under 18 years, those with learning disability, or cognitive impairments ☒

Research that induces or results in or causes anxiety, stress, pain or physical discomfort, or poses a risk of harm to participants (which is more than is expected from everyday life) ☒

Risk to the personal safety of the researcher ☐

Deception or research that is conducted without full and informed consent of the participants at time study is carried out ☐

Administration of a chemical agent or vaccines or other substances (including vitamins or food substances) to human participants. ☐

Production and/or use of genetically modified plants or microbes ☐

Results that may have an adverse impact on the environment or food safety ☐

Results that may be used to develop chemical or biological weapons ☐

Please check that the following documents are attached to your application.

	ATTACHED	NOT APPLICABLE
Recruitment advertisement	☒	☐
Participant information sheet	☒	☐
Consent form	☒	☐
Questionnaire	☐	☒
Interview Schedule	☒	☐

DECLARATION BY APPLICANTS

I submit this application on the basis that the information it contains is confidential and will be used by the

University of Birmingham for the purposes of ethical review and monitoring of the research project described

herein, and to satisfy reporting requirements to regulatory bodies. The information will not be used for any

other purpose without my prior consent.

I declare that:

The information in this form together with any accompanying information is complete and correct to the best of my knowledge and belief and I take full responsibility for it.

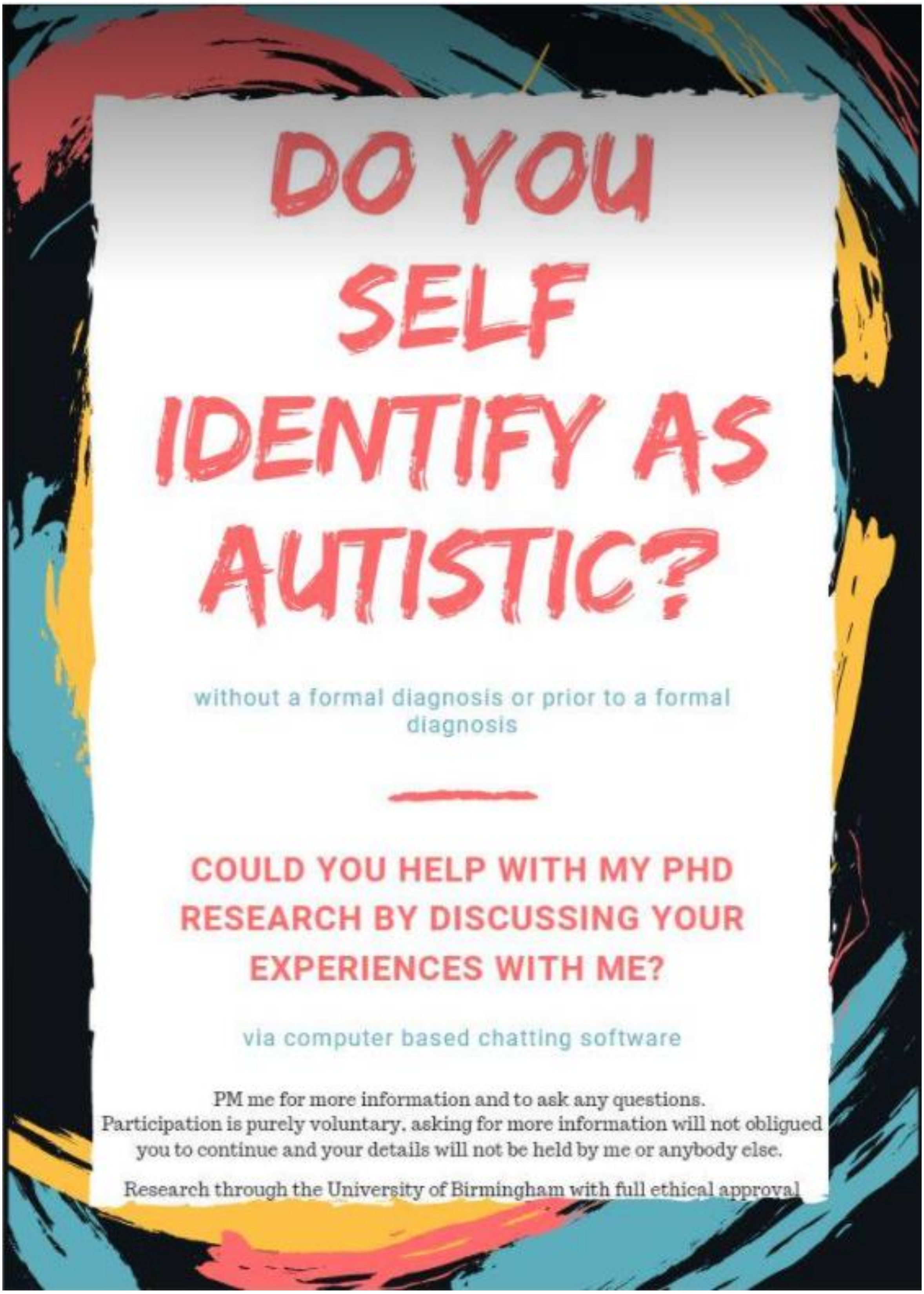
I undertake to abide by University Code of Practice for Research (http://www.as.bham.ac.uk/legislation/docs/COP_Research.pdf) alongside any other relevant professional bodies' codes of conduct and/or ethical guidelines.

I will report any changes affecting the ethical aspects of the project to the University of Birmingham Research Ethics Officer.

I will report any adverse or unforeseen events which occur to the relevant Ethics Committee via the University of Birmingham Research Ethics Officer.

Name of principal investigator/project supervisor:	Dr Andrea Macleod (School of Education)
	04/0719

Appendix 7: - Phase One; Recruitment Advert



DO YOU SELF IDENTIFY AS AUTISTIC?

without a formal diagnosis or prior to a formal diagnosis

COULD YOU HELP WITH MY PHD RESEARCH BY DISCUSSING YOUR EXPERIENCES WITH ME?

via computer based chatting software

PM me for more information and to ask any questions.
Participation is purely voluntary, asking for more information will not obligued you to continue and your details will not be held by me or anybody else.

Research through the University of Birmingham with full ethical approval

Appendix 8: - Phase One Participant Information Sheet

What is the process of self-identification of autism, as understood by those who have experienced it?

I would like to invite you to take part in a research study, conducted as a part of my doctoral thesis at the University of Birmingham. This document provides you with key relevant information about the research project, to help you decide whether you would like to participate in the study. Please feel free to ask any questions, if you require further information.

What is the research about?

The research is about understanding how and why individuals self-identify as autistic. The research aims to explore 4 key areas:

5. What is an autistic identity?
6. How prominently do people experience that identity?
7. What is the purpose of self-identifying as autistic?
8. What is the impact of self-identifying on others?

I believe that the greatest knowledge comes from those that have had first-hand experience of it and therefore the research is formatted around giving people the opportunity to share this.

It is hoped that the findings from this research will help develop the understanding of the diversity of autism and its prevalence beyond the 'official figures'. It is also hoped that the experiences shared may help other individuals who wish to pursue the same identification process and give them confidence to do so.

Who is the Researcher?

My name is Barbara Sandland and I am a post graduate researcher at the University of Birmingham. I have worked in special needs education all my professional career and only discovered I was autistic in my 30s. This discovery has awoken a desire to develop an understanding into autism from the experiences of those that have lived it. As an autistic researcher I hope that my unique perspective on the autistic world will allow me to fully understand your experiences and give you a voice to be able to express them to others.

What does participation involve?

If you agree to participate you will be asked to undertake an online semi-structured interview through instant text facilities. It is expected that the interview should last approximately 2 hours. Should text based conversation not be appropriate to your needs, opportunities for online based video chatting will be available.

The interview will form the basis of a conversation surrounding your experiences of self-identification of autism. While there will be foundation questions that I will wish to gather your views on, further discussions are expected to develop based on the content of the conversation. Interview questions will be sent to you in advance, so you do not feel under pressure on the day to 'come up with' and answer without appropriate processing time.

All comments will be transcribed in order to analyse them. You will be asked to check that the transcript is an accurate reflection of the interview. You will then have a further opportunity to view a summary of the findings of the completed study upon request.

Is it a one-off meeting?

Yes, at this stage all you would be required to agree to is a one-time interview with myself. There are 3 stages to the research, with this being stage 1. The second stage will be a survey which you are not required to participate in. In the 3rd stage I will contact you again to see whether you would be willing to discuss further any new data that has arisen from the survey. You do not have to commit to this 3rd stage at this time but need to be aware that I will contact you with the information. Following that contact you can either consent to participate again or refuse, without any impact on your involvement in the first stage.

How do I know if I'm eligible to participate?

In order to participate in the study, you need to comply with a series of criteria. This criterion is as follows:

- You are now older than 18
- You use a computer
- You can communicate effectively via word-based software, in English.
- You self-identify as autistic or you previously self-identified as autistic and this led to a formal diagnosis

How do I know I class as self-identified?

In the premise of this study, self-identification refers to the process of believing you are on the autism spectrum without the prompting from a third party. Examples are given below, but if you are unsure whether you meet this criterion please feel free to ask.

Examples of eligible self-identification:

- I saw a TV programme that I associated with the characters and this led me to believed I was autistic
- I had a family member/friend diagnosed and this led me to believe I was autistic so got diagnosed too.
- I have asked for a diagnosis. I was turned down, but I still think I'm autistic

Examples of non-eligible identification

- A family member told me they thought I was autistic and then I sought a diagnosis
- I was told I was autistic by someone else and I just never felt the need to get a diagnosis
- Someone else told me to get a diagnosis but I was turned down.

Is participation voluntary and can I change my mind?

Participation is voluntary and therefore you have the right to withdraw without giving a reason, within 4 weeks of the interview date. If you feel uncomfortable in any way, at any time during the discussions, you have the right to decline to answer any question (please just specify this with a "decline to answer" comment). Should you wish to withdraw, you have the choice whether any data you have submitted before that time is used within the study. If you do not wish your contributions to be used, your data will be removed from the study and will be destroyed. If you wish to withdraw, you should do so within 4 weeks of the interview date, as this is when the data analysis process will start, and all data will begin to be synthesised.

What will happen to the information I provide?

The information you provide will be treated as strictly confidential and will be stored on the university designed Environment for Academic Research store in order to comply with data protection regulations. This software ensures all documentation is encrypted and therefore cannot be accessed without permission. It will be used only for research purposes and will be accessed only by the researchers involved in this research. The researchers who will have access to the data are myself, Barbara Sandland and my university supervisors, Dr Andrea McLeod and Professor Karen Guldberg. As the research lead, I will be undertaking all transcription of data myself and therefore no issues concerning anonymity with 3rd parties will occur. As a participant, the information you provide will be stored anonymously under acronyms not traceable back to you. However, until the end of the study, a separate document will be kept that links the participant's codes to the participants initials in order to identify your data so you can be contacted to participate in the 3rd stage of data collection. This document will be only accessible by me and will be destroyed at the end of the study.

Upon completion of the project, the anonymised data collected could be used in; the thesis document, published (journal articles) and non-published articles, conference and seminar presentations and workshops. Reporting of the data will be only in an aggregate and or summary form as part of a qualitative and quantitative analysis. Direct quotations without personally identifying information, will be used.

What should I do next?

1. If you are confident you are sufficiently informed about the project and wish to be involved, please email me on and I will send a consent form to you which will need to be signed before participation can begin. Interviews will take place between November and January on a weekly basis, so it should be possible to agree a time that is mutually convenient.
2. If you feel you require further information, please either email me any questions you have and I will provide you with all the information you need.
3. Should you not wish to be involved in the study, you need to do no more. Thank you for taking the time to read the information. Your information will not be stored, and you will not be contacted again.

Many Thanks
Barbara Sandland

Supervisor Details:
Dr Andrea Macleod
School of Education
University of Birmingham
Edgbaston, Birmingham
B15 2TT, United Kingdom

Appendix 9: - Phase One: Consent Form

Understand the process of self-identification of autism, from those who have experienced it

Data processing statement

This information is being collected as part of a research project concerned with the understanding of self-identification in autism by Barbara Sandland at the University of Birmingham in collaboration with Dr. Andrea Macleod (University of Birmingham) and Prof. Karen Guldberg (University of Birmingham). The information which you supply and that which may be collected as part of the research project will be only accessed by the authorised personnel involved in the project. The information will be retained by the lead researcher, Barbara Sandland, and only be used for research purposes. By supplying this information, you are consenting to your information to be stored for the purposes stated above. The information will be processed in accordance with the provisions of the General Data Protection Regulations 2016. No identifiable personal data will be published. The data will be preserved and accessible for research purposes for ten years.

Consent for participation in the study

- I confirm that I have read and understand the participant information leaflet for the study. I have had the opportunity to ask questions if necessary and have had these answered satisfactorily.

- I understand that if I feel uncomfortable in any way during the interview session, I have the right to decline to answer any question or to end the interview.

- I understand that my participation is voluntary and that I am free to withdraw, within 4 weeks of the interview date, without giving any reason. If I withdraw and inform the research lead, Barbara Sandland, that I do not wish my data to be used, it will be removed from the study and will be destroyed.

- I understand that the interviews will be transcribed and will be stored anonymously under acronyms not traceable back to me. I understand that, a separate document will be kept that links my responses to my initials in order to identify my data in case I decide to withdraw. I understand that this document will be only accessible by the lead researcher and will be destroyed at the end of the study. This document will also be used following the second stage of research, for the lead researcher to contact me again and ask whether I would be willing to discuss further any data that has been identified through the surveys. I understand that I am not obliged to agree to participate in the 3rd stage.

- I understand that the researcher will not identify me by name or the name of the organisation I work for in any research pieces that use the information obtained from this interview, and that my confidentiality as a participant will remain secure. I understand that my personal data will be processed only for research purposes as explained above, as well as in the information sheet, in accordance with the General Data Protection Regulations 2016.

- I understand that upon completion of the project, the data collected could be used in; the thesis document, published (journal articles) and non-published articles, conference and seminar presentations and workshops. Reporting of the data will be only in an aggregate and or summary form as part of a qualitative and quantitative analysis. Direct quotations without personally identifying information, will be used.

Based upon the above, I agree to take part in this study.

[redacted]	[redacted]	[redacted]
Name of the participant	Signature	Date
[redacted]	_____	[redacted]
Name of the researcher	Signature	Date

Appendix 10: - Phase Two Advert

Barbara Sandland shared a link.

May 6, 2020 ·

Afternoon all, as long standing part of this group I am hoping that you will be able to help me out with my research. I am doing my PhD on Autistic Identity and looking for autistic individuals to complete an online survey. If you feel able to help (or would just like some more detail initially please follow the link below

BHAM.QUALTRICS.COM

Autistic Identity

Appendix 11: - Ethical Amendment Form

UNIVERSITY OF BIRMINGHAM **APPLICATION FOR ETHICAL REVIEW -** **REQUEST FOR AMENDMENTS**	*OFFICE USE ONLY:* Application No: Date Received:

1. **TITLE OF PROJECT**

What is the process of self-identification of autism? As understood by those who have experienced it

2. **APPROVAL DETAILS**
What is the Ethical Review Number (ERN) for the project?

ERN_19-0675

3. **THIS PROJECT IS:**
University of Birmingham Staff Research project ☐
University of Birmingham Postgraduate Research (PGR) student project ☒
Other ☐ (Please specify):

4. **INVESTIGATORS**

a) PLEASE GIVE DETAILS OF THE PRINCIPAL INVESTIGATORS OR SUPERVISORS (FOR PGR STUDENT PROJECTS)

Name: Title / first name / family name	Dr ANDREA MACLEOD
Highest qualification & position held:	
School/Department	EDUCATION
Telephone:	
Email address:	

b) PLEASE GIVE DETAILS OF ANY CO-INVESTIGATORS OR CO-SUPERVISORS (FOR PGR STUDENT PROJECTS)

Name: Title / first name / family name	Professor KAREN GULDBERG
Highest qualification & position held:	
School/Department	EDUCATION

Telephone:	
Email address:	

c) In the case of PGR student projects, please give details of the student

Name of student:	BARBARA SANDLAND	Student No:	789215
Course of study:	PhD EDUCATION		
Principal supervisor:	ANDREA MACLEOD		

Name of student:		Student No:	
Course of study:			
Principal supervisor:			

5. **ESTIMATED START OF PROJECT** Date: OCT 2019

ESTIMATED END OF PROJECT Date: JULY 2020

6. **ORIGINAL APPLICATION FOR ETHICAL REVIEW AND ANY SUBSEQUENT APPROVED AMENDMENTS:**

Please complete the table below for the original application and any subsequent amendments submitted

Title and reference number of application or amendment	**Key points of application and/or changes made by amendment (include: aims of study, participant details, how participants were recruited and methodology)**	**Ethical considerations arising from these key points (e.g. gaining consent, risks to participants and/or researcher, points raised by Ethical Review Committee during review)**	**How were the ethical considerations addressed?** **(e.g. consent form, participant information, adhering to relevant procedures/clearance required)**
Original application	the project is to investigate the phenomenon of self-identification of autism (autism is a lifelong developmental disability that affects how people perceive the world and interact with others. autistic people see, hear and feel the world differently to other people (national autistic society)). it is aimed to uncover why people self-identify as autistic and what impact this has on their lives. it is hoped that by understanding the personal experiences of this population it will aid others in developing their knowledge of autism from a professional, academic and everyday viewpoint. participant recruitment is via closed Facebook groups specifically for people on the	consent is gained through a written form which is sent to the participant to sign. this is following a discussion with me to ensure they understand the study and a participant information sheet which outlines the requirements and inclusion criteria. participation is voluntary and withdrawal is an open within 4 weeks of the interview date. all personal	consent form, participant information sheet and opportunities to answer questions all given to anyone declaring an interest. data checking scheduled for the same week as the interview so the participant is confident that i have interpreted their experiences correctly. the document will be stored in the university secure, bear software which ensures documents are encrypted and therefore, unable to be accessed without permission. I will be undertaking all

	autism spectrum. case design - 18+ participants - online users - self identifiers of autism - literate - proficient in English methodology is based on pragmatism and a mixed qualitative-quantitative research design. Semi structured interviews via internet communications software have ethical pproval.	information is anonymised and all data collated is stored on the university secure system. support is in place to ensure no psychological harm occurs due to the personal nature of the questioning. the pilot interview suggests this is not a significant concern as the participant felt that it was a positive experience.	transcript of data myself and therefore no issues concerning anonymity with 3rd parties will occur. in order to alleviate anxiety surrounding the interview process and allow appropriate processing time (which can be significantly increased in the autistic population) an outline of foundation interview questions will be given to all participates at least 1 week prior to the interview date

Title and reference number of application or amendment	**Key points of application and/or changes made by amendment (include: aims of study, participant details, how participants were recruited and methodology)**	**Ethical considerations arising from these key points (e.g. gaining consent, risks to participants and/or researcher, points raised by Ethical Review Committee during review)**	**How were the ethical considerations addressed?** **(e.g. consent form, participant information, adhering to relevant procedures/clearance required)**
Subsequent amendment 1	Phase 2 of research. Online survey (attached). The survey has been produced using the university suggested program of Qualtrics. The questions attached are copied from this program and therefore may look different to the online version). This phase fits within the original study methodology as it was always planned, however, it was decided ethical approval would be sought at this stage so specific details of questions could be supplied. Participants will be recruited through Facebook groups, with the approval of each administrative officer and through contacts who have shown an interest at recent conferences.	psychological harm due to the personal nature of the questioning Gaining informed Consent was considered as a risk Managing of personal information was considered as a risk Ability to answer questions and refuse answers as appropriate	Support continues to be in place to signpost people to support provisions such as details of the national autistic society helpline will be provided at the end of the survey, as an appropriately trained body with which to provide additional support and signpost to professional services if required. Consent will be gained through the cover sheet of the survey which outlines the project and explains that consent is given by them proceeding but they can withdraw at any time prior to submitting the survey. No names and contact details are collated so all data collected will be anonymous. The survey has been created on the university advised program and will be stored in the university supplied secure data server. Wording of the questions has been carefully considered as well as ensuring an option is always provided to state they do not know how to answer/do not want to answer. As well as providing an option in some cases to expand on their answers.
Subsequent amendment 2			
Subsequent amendment 3			

7. **DETAILS OF PROPOSED NEW AMENDMENT**
Provide details of the proposed new amendment, and clearly and explicitly state how the proposed new amendment will differ from the details of the study as already approved (see Q6 above).

Phase 2 of the research is an Online survey to be completed by autistic people and self-identifying autistics on their experiences.

8. **JUSTIFICATION FOR PROPOSED NEW AMENDMENT**

Phase 2 was always the plan for the research however, the questions for the survey came directly from the analysis of the first stage and therefore initial ethical approval could not include a copy of the survey questions and therefore it was felt it was more appropriate to submit an amendment.

9. **ETHICAL CONSIDERATIONS**
What ethical considerations, if any, are raised by the proposed new amendment?

psychological harm due to the personal nature of the questioning

Gaining informed Consent was considered as a risk

Managing of personal information was considered as a risk

Ability to answer questions and refuse answers as appropriate

All of which are accounted for and planning for them is outline in the table above as requested.

10. **DECLARATION BY APPLICANTS**

I make this application on the basis that the information it contains is confidential and will be used by the University of Birmingham for the purposes of ethical review and monitoring of the research project described herein, and to satisfy reporting requirements to regulatory bodies. The information will not be used for any other purpose without my prior consent.

I declare that:

- The information in this form together with any accompanying information is complete and correct to the best of my knowledge and belief and I take full responsibility for it.
- I undertake to abide by University Code of Conduct for Research (http://www.birmingham.ac.uk/Documents/university/legal/research.pdf) alongside any other relevant professional bodies' codes of conduct and/or ethical guidelines.
- I will report any changes affecting the ethical aspects of the project to the University of Birmingham Research Ethics Officer.
- I will report any adverse or unforeseen events which occur to the relevant Ethics Committee project to the University of Birmingham Research Ethics Officer.

Signature of Principal investigator/project supervisor:	
Date:	20th April 2020

Appendix 12: - Phase Two; Consent Form

What is the process of self-identification of autism? As understood by those who have experienced it

Dear Participant,

I invite you to participate in the above research study as part of my PhD thesis through the University of Birmingham, UK. The survey marks the second phase of research. The first stage consisted of semi-structured interviews and the questions within the survey are compiled directly from the findings of these interviews.

While the study is focusing around individuals who build their own autistic identity, the survey is open to everyone to complete as experiences from a range of people will help provide depth to the survey's findings. Where questions are not relevant to your experiences, there will be an option to mark this, with options such as "does not apply". I welcome individuals with and without formal diagnosis, all genders and from anywhere across the world. The only restrictions on participation are that you are 18 years or older and that you are able to read and understand the questions within the survey accurately.

The following questionnaire has been designed to collect information on the concept of the autistic identity, the process of developing an autistic identity, the impact of delayed realisation of the autistic identity and the societal responses to self identification.

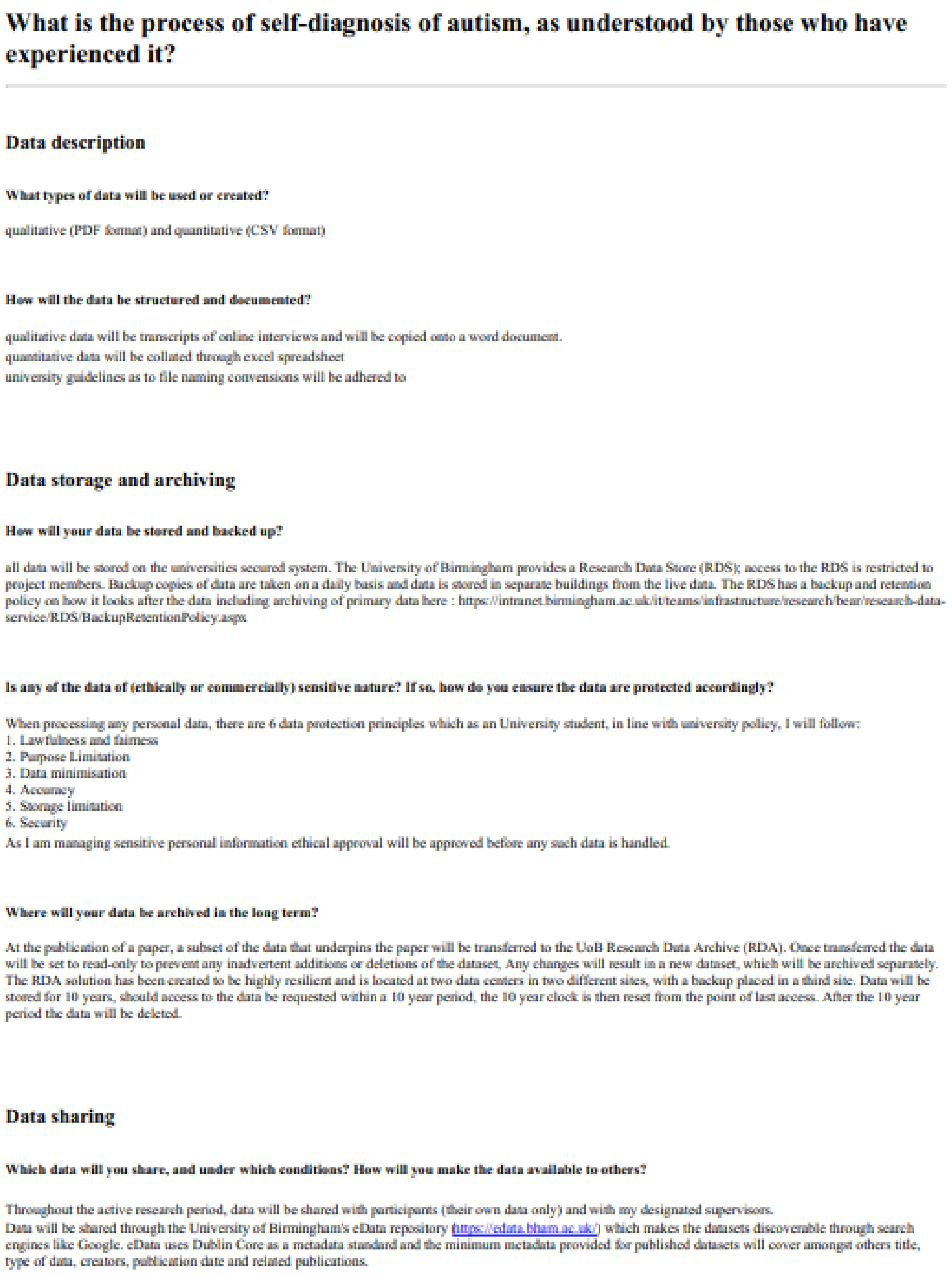
Your participation in this research project is completely voluntary. You may decline altogether should you wish to. There are no known risks to participation beyond those encountered in everyday life. Your responses will remain confidential and anonymous. Data from this research will be held on secure servers and reported only as a collective combined total. No one other than the researchers will know your individual answers to this questionnaire.

By continuing, you acknowledge that you have understood the above information and that you are happy to continue. Please answer the questions on the questionnaire as best you can. It should take approximately 30 mins to complete, dependant on the level of detail you wish to provide as well as the questions may well be thought provoking and therefore need time to consider. Each section has a description to it, it is important that you read this carefully to understand how to answer the questions within it.

If you have any questions about this project, feel free to contact
Barbara Sandland at

Thank you for your assistance in this important endeavour.
Sincerely yours,
Barbara Sandland

Appendix 13: - Data Management Plan



What is the process of self-diagnosis of autism, as understood by those who have experienced it?

Data description

What types of data will be used or created?

qualitative (PDF format) and quantitative (CSV format)

How will the data be structured and documented?

qualitative data will be transcripts of online interviews and will be copied onto a word document.
quantitative data will be collated through excel spreadsheet
university guidelines as to file naming conversions will be adhered to

Data storage and archiving

How will your data be stored and backed up?

all data will be stored on the universities secured system. The University of Birmingham provides a Research Data Store (RDS); access to the RDS is restricted to project members. Backup copies of data are taken on a daily basis and data is stored in separate buildings from the live data. The RDS has a backup and retention policy on how it looks after the data including archiving of primary data here : https://intranet.birmingham.ac.uk/it/teams/infrastructure/research/bear/research-data-service/RDS/BackupRetentionPolicy.aspx

Is any of the data of (ethically or commercially) sensitive nature? If so, how do you ensure the data are protected accordingly?

When processing any personal data, there are 6 data protection principles which as an University student, in line with university policy, I will follow:
1. Lawfulness and fairness
2. Purpose Limitation
3. Data minimisation
4. Accuracy
5. Storage limitation
6. Security
As I am managing sensitive personal information ethical approval will be approved before any such data is handled.

Where will your data be archived in the long term?

At the publication of a paper, a subset of the data that underpins the paper will be transferred to the UoB Research Data Archive (RDA). Once transferred the data will be set to read-only to prevent any inadvertent additions or deletions of the dataset, Any changes will result in a new dataset, which will be archived separately. The RDA solution has been created to be highly resilient and is located at two data centers in two different sites, with a backup placed in a third site. Data will be stored for 10 years, should access to the data be requested within a 10 year period, the 10 year clock is then reset from the point of last access. After the 10 year period the data will be deleted.

Data sharing

Which data will you share, and under which conditions? How will you make the data available to others?

Throughout the active research period, data will be shared with participants (their own data only) and with my designated supervisors.
Data will be shared through the University of Birmingham's eData repository (https://edata.bham.ac.uk/) which makes the datasets discoverable through search engines like Google. eData uses Dublin Core as a metadata standard and the minimum metadata provided for published datasets will cover amongst others title, type of data, creators, publication date and related publications.

Appendix 14: - Blank copy of Phase Two Survey

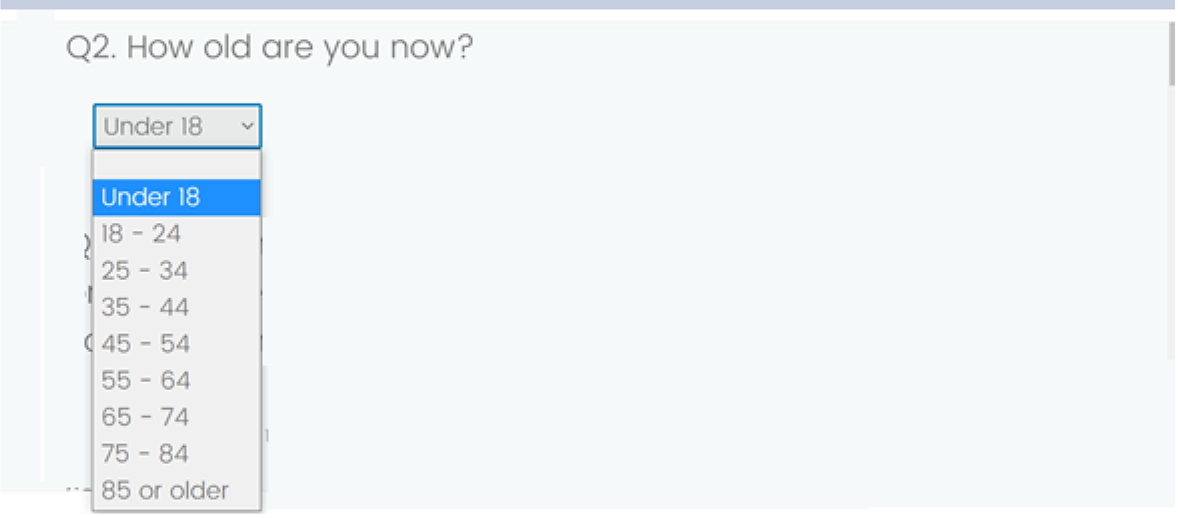
Q1. Please chose the option that describes your current position most accurately

○ Self-diagnosed, not formally diagnosed

○ Self-diagnosed and then formally diagnosed

○ Formally diagnosed after someone else thought I was autistic

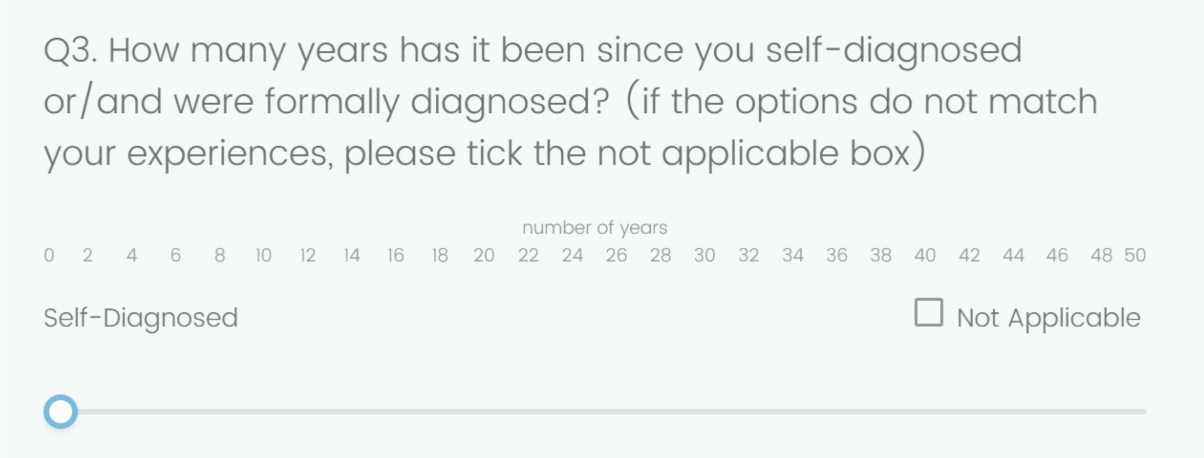
○ Formally diagnosed when I was younger, so I had no involvement in it



Q2. How old are you now?

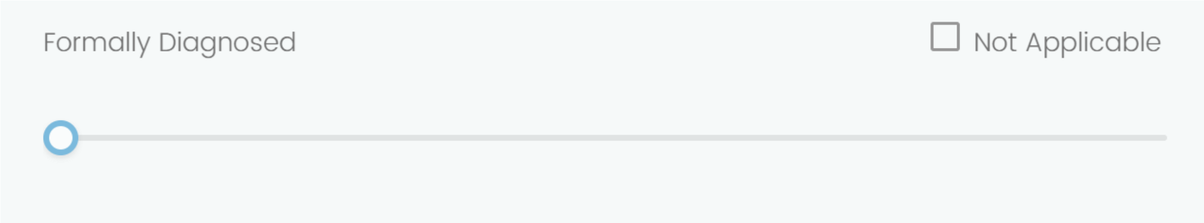
Under 18

- Under 18
- 18 - 24
- 25 - 34
- 35 - 44
- 45 - 54
- 55 - 64
- 65 - 74
- 75 - 84
- 85 or older



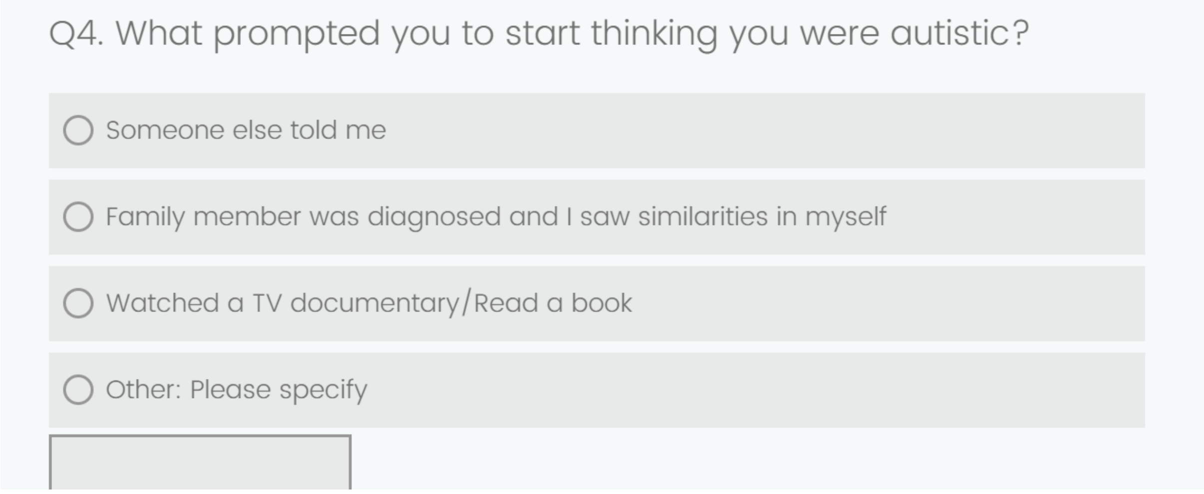
Q3. How many years has it been since you self-diagnosed or/and were formally diagnosed? (if the options do not match your experiences, please tick the not applicable box)

Self-Diagnosed ☐ Not Applicable



Formally Diagnosed

☐ Not Applicable



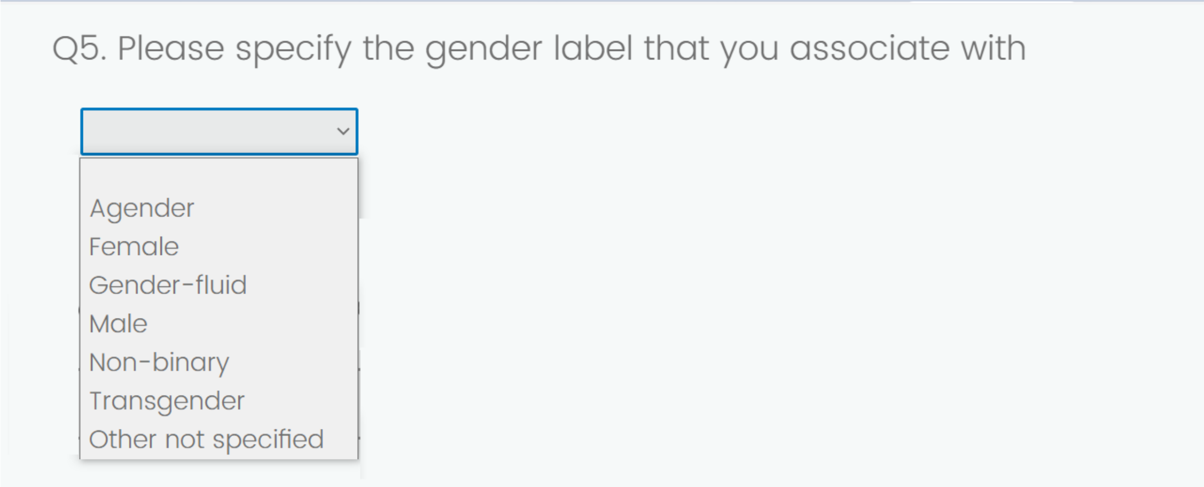
Q4. What prompted you to start thinking you were autistic?

○ Someone else told me

○ Family member was diagnosed and I saw similarities in myself

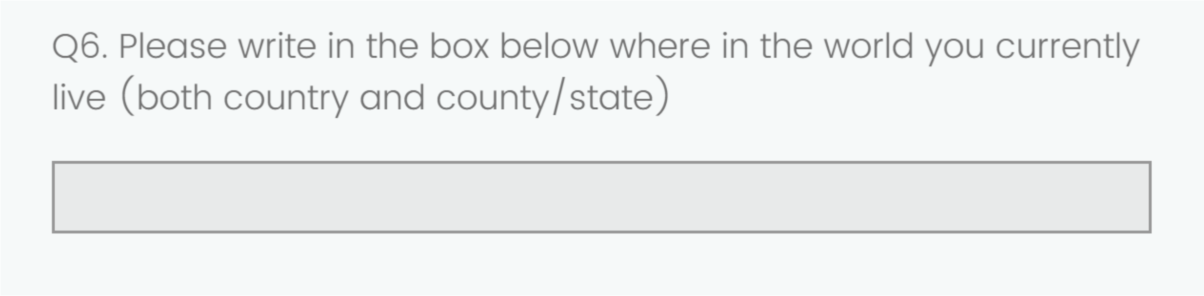
○ Watched a TV documentary/Read a book

○ Other: Please specify

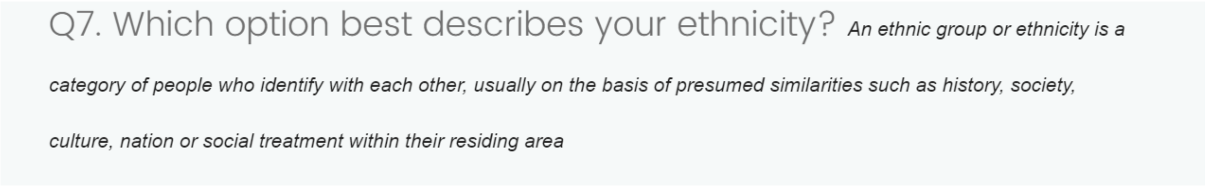


Q5. Please specify the gender label that you associate with

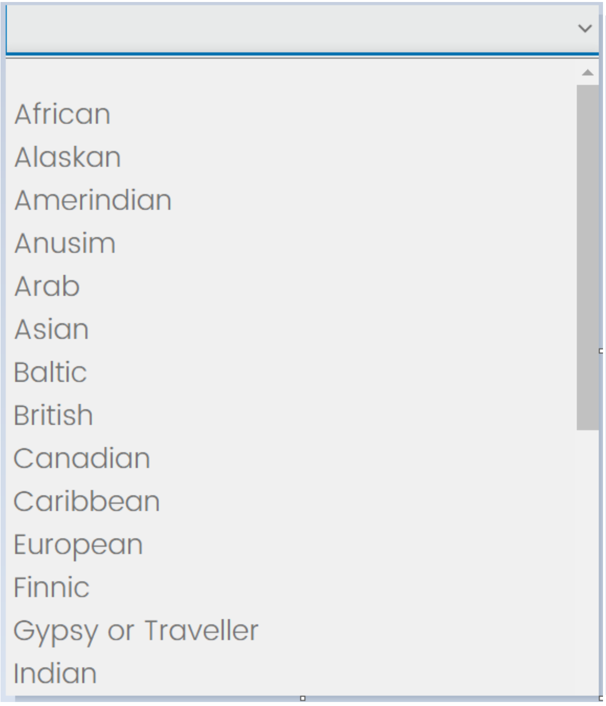
Agender
Female
Gender-fluid
Male
Non-binary
Transgender
Other not specified



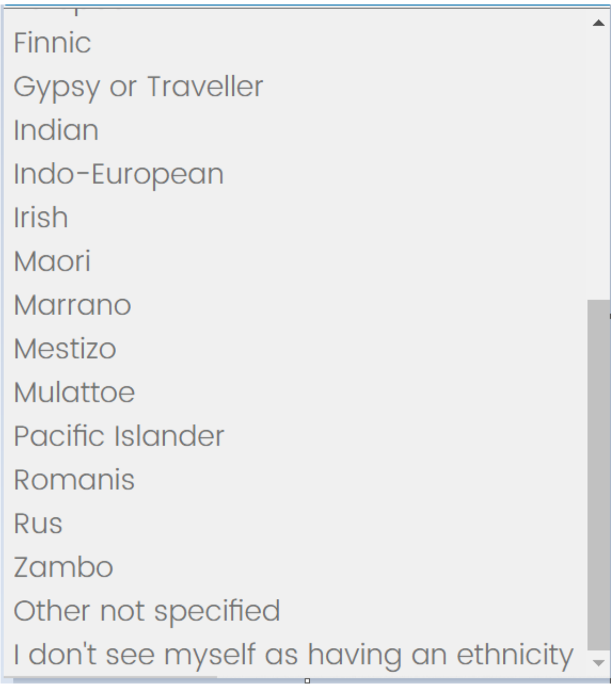
Q6. Please write in the box below where in the world you currently live (both country and county/state)



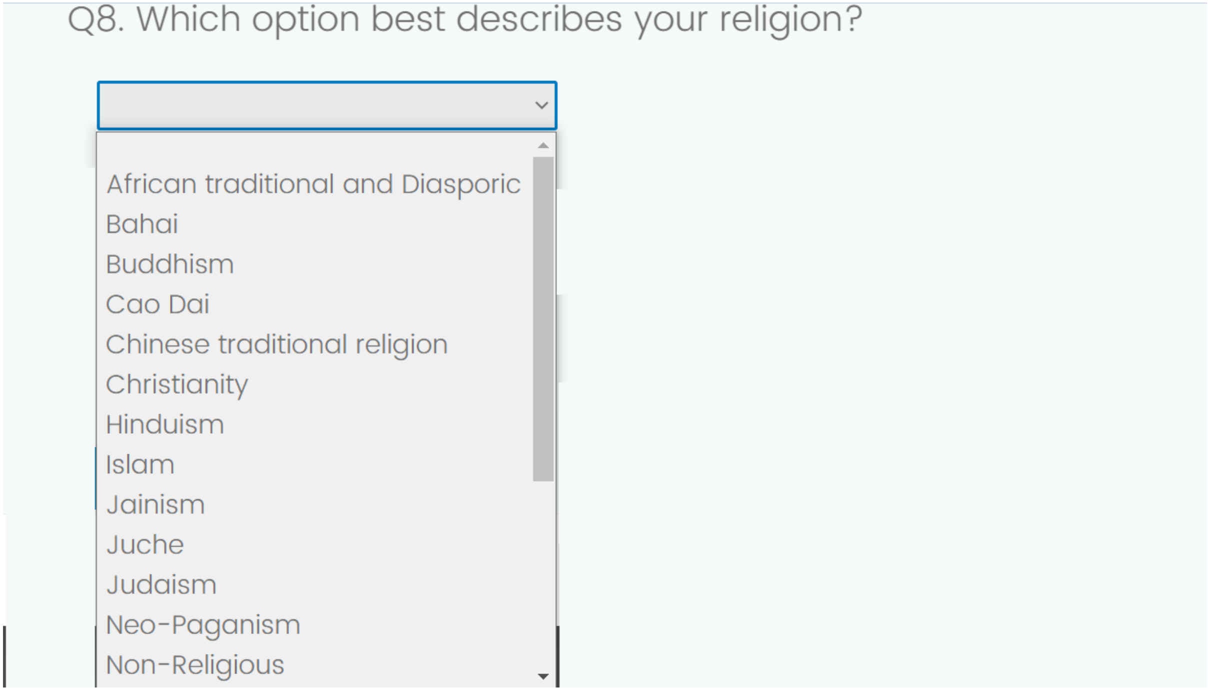
Q7. Which option best describes your ethnicity? *An ethnic group or ethnicity is a category of people who identify with each other, usually on the basis of presumed similarities such as history, society, culture, nation or social treatment within their residing area*



African
Alaskan
Amerindian
Anusim
Arab
Asian
Baltic
British
Canadian
Caribbean
European
Finnic
Gypsy or Traveller
Indian

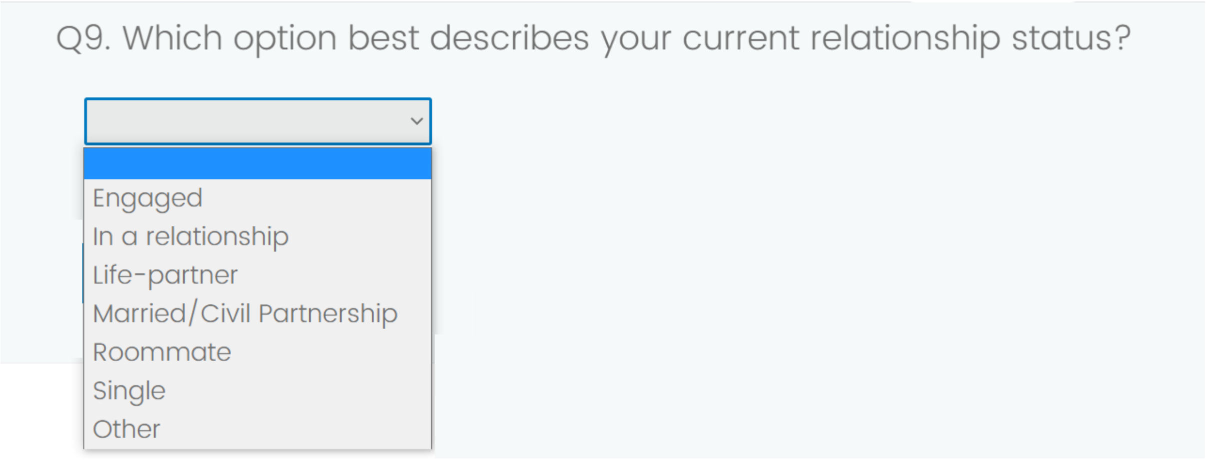


Finnic
Gypsy or Traveller
Indian
Indo-European
Irish
Maori
Marrano
Mestizo
Mulattoe
Pacific Islander
Romanis
Rus
Zambo
Other not specified
I don't see myself as having an ethnicity



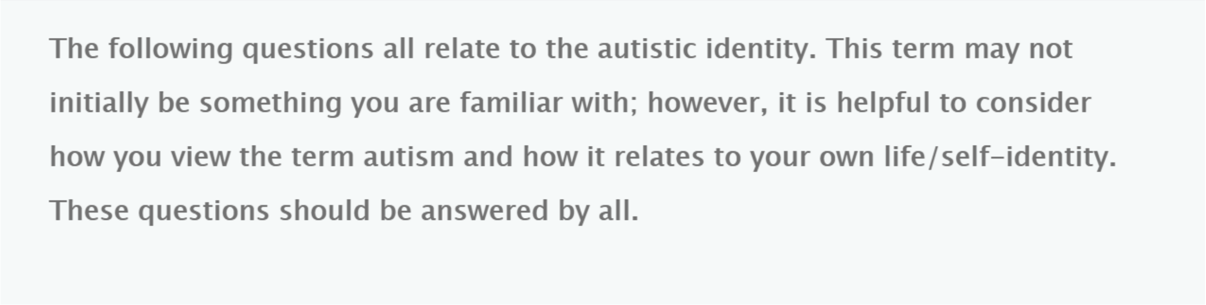
Q8. Which option best describes your religion?

African traditional and Diasporic
Bahai
Buddhism
Cao Dai
Chinese traditional religion
Christianity
Hinduism
Islam
Jainism
Juche
Judaism
Neo-Paganism
Non-Religious

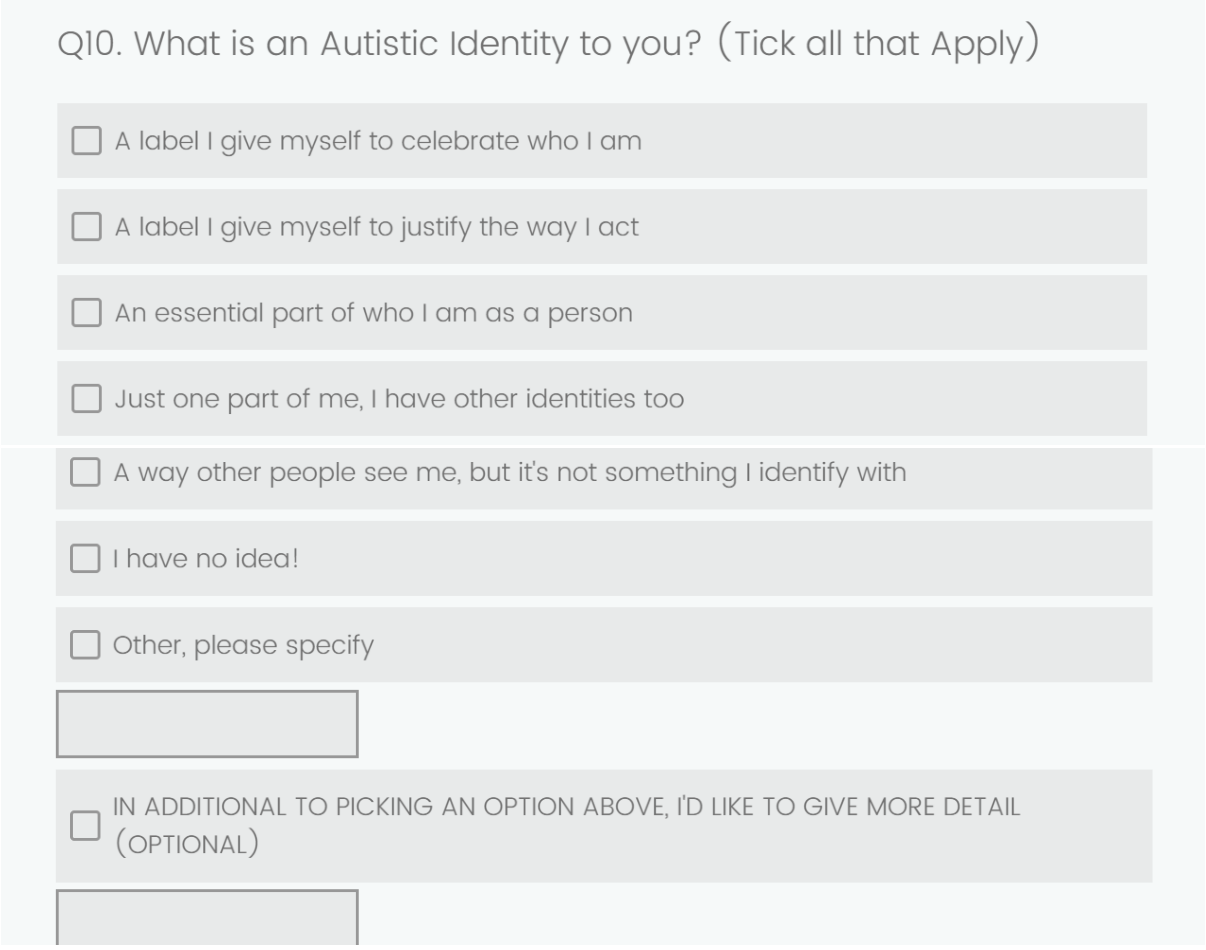


Q9. Which option best describes your current relationship status?

- Engaged
- In a relationship
- Life-partner
- Married/Civil Partnership
- Roommate
- Single
- Other



The following questions all relate to the autistic identity. This term may not initially be something you are familiar with; however, it is helpful to consider how you view the term autism and how it relates to your own life/self-identity. These questions should be answered by all.



Q10. What is an Autistic Identity to you? (Tick all that Apply)

☐ A label I give myself to celebrate who I am

☐ A label I give myself to justify the way I act

☐ An essential part of who I am as a person

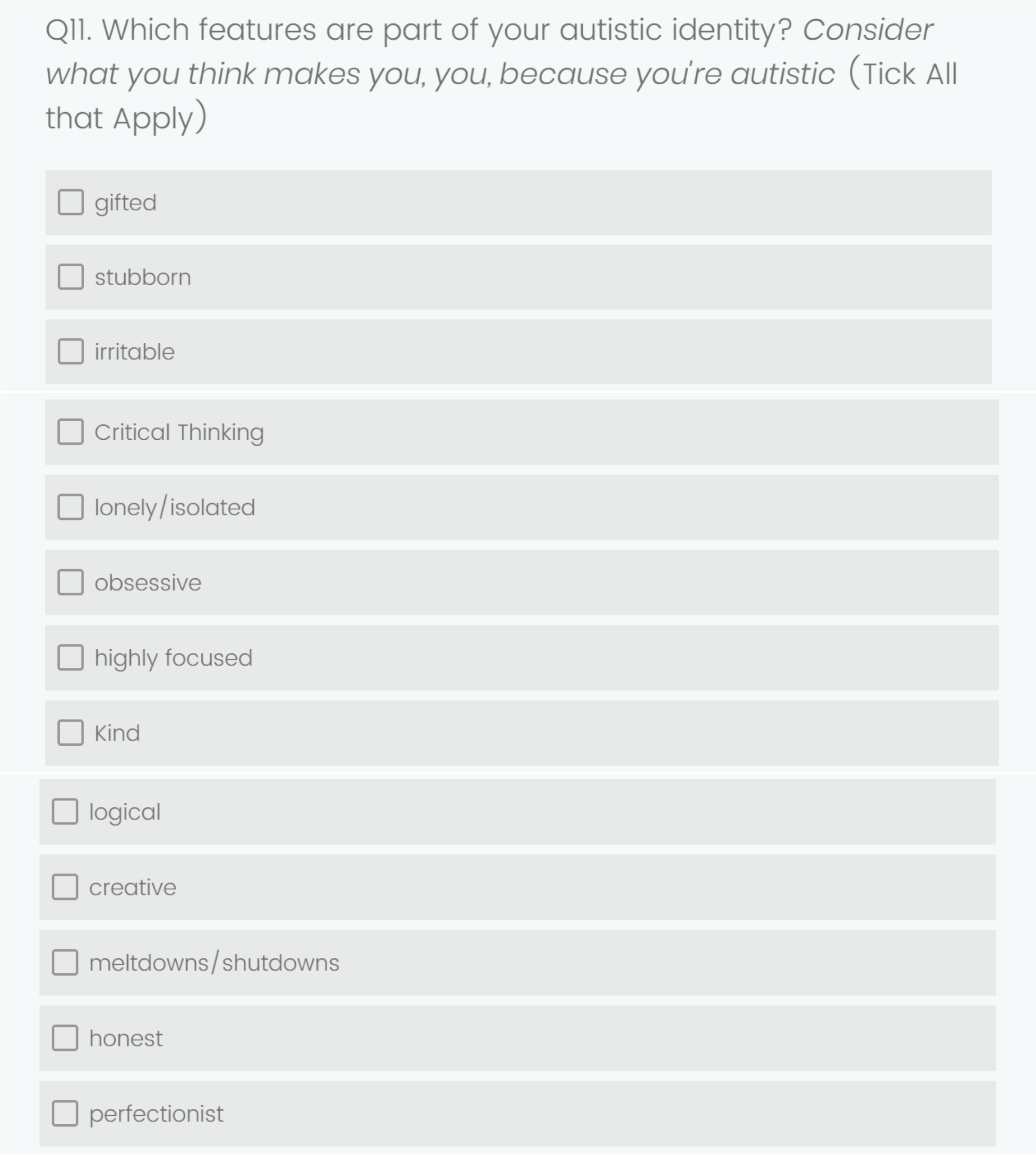
☐ Just one part of me, I have other identities too

☐ A way other people see me, but it's not something I identify with

☐ I have no idea!

☐ Other, please specify

☐ IN ADDITIONAL TO PICKING AN OPTION ABOVE, I'D LIKE TO GIVE MORE DETAIL (OPTIONAL)



Q11. Which features are part of your autistic identity? *Consider what you think makes you, you, because you're autistic* (Tick All that Apply)

☐ gifted
☐ stubborn
☐ irritable
☐ Critical Thinking
☐ lonely/isolated
☐ obsessive
☐ highly focused
☐ Kind
☐ logical
☐ creative
☐ meltdowns/shutdowns
☐ honest
☐ perfectionist

☐ anxiety

☐ intelligent

☐ socially awkward

☐ Resilient

☐ Passionate

☐ concentration issues

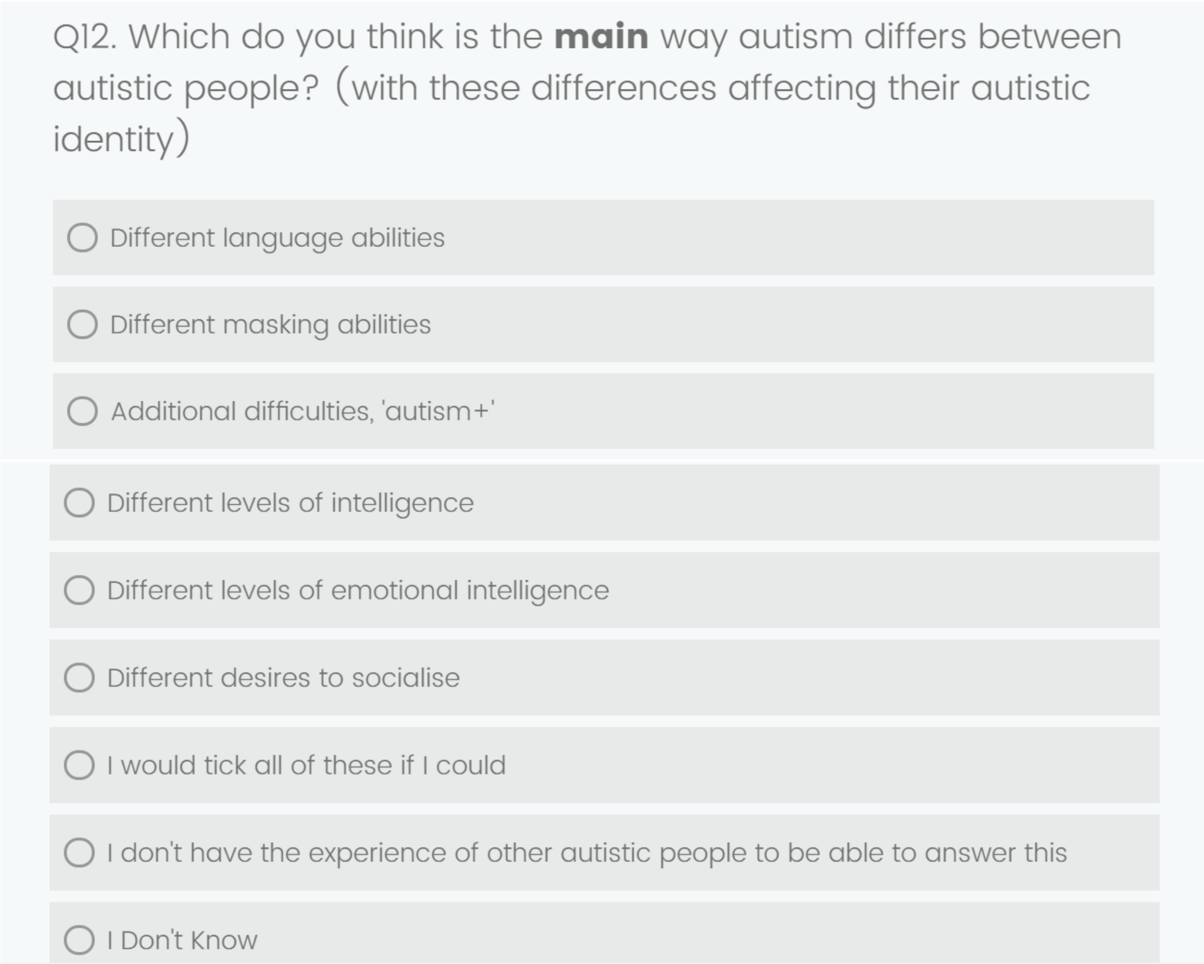
☐ Good memory

☐ hatred of dishonesty

☐ Accepting of others

☐ feeling different to the 'norm'

☐ Other, please specify



Q12. Which do you think is the **main** way autism differs between autistic people? (with these differences affecting their autistic identity)

○ Different language abilities

○ Different masking abilities

○ Additional difficulties, 'autism+'

○ Different levels of intelligence

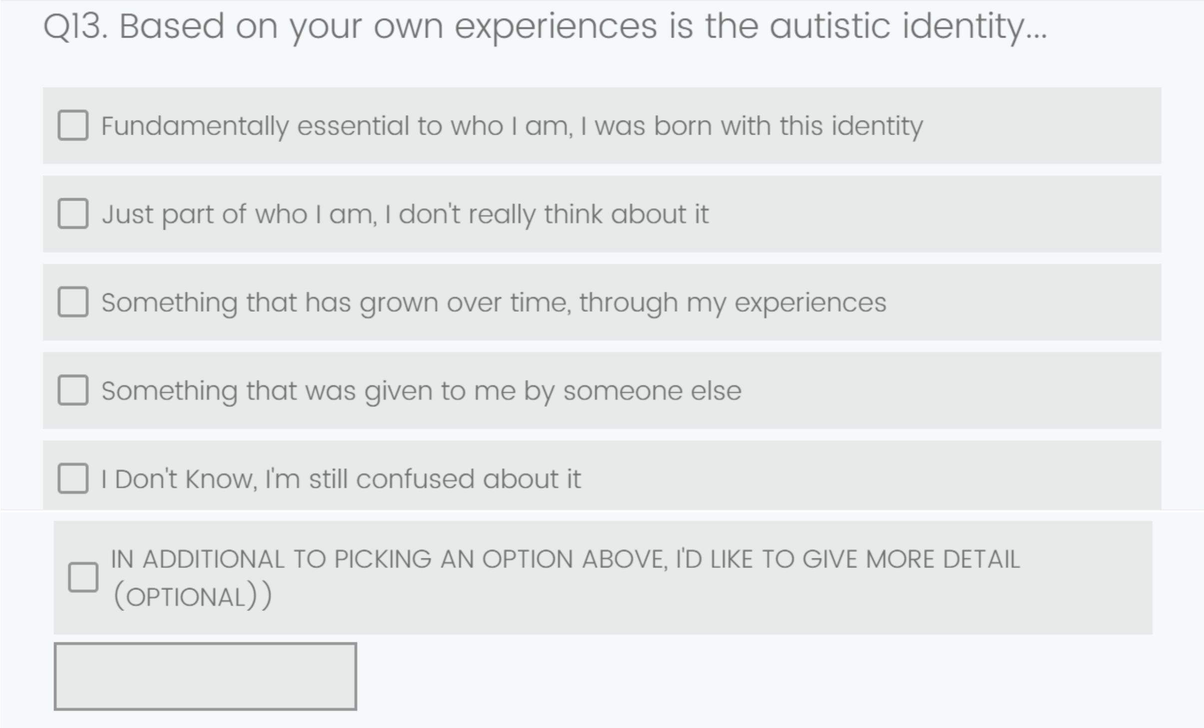
○ Different levels of emotional intelligence

○ Different desires to socialise

○ I would tick all of these if I could

○ I don't have the experience of other autistic people to be able to answer this

○ I Don't Know



Q13. Based on your own experiences is the autistic identity...

☐ Fundamentally essential to who I am, I was born with this identity

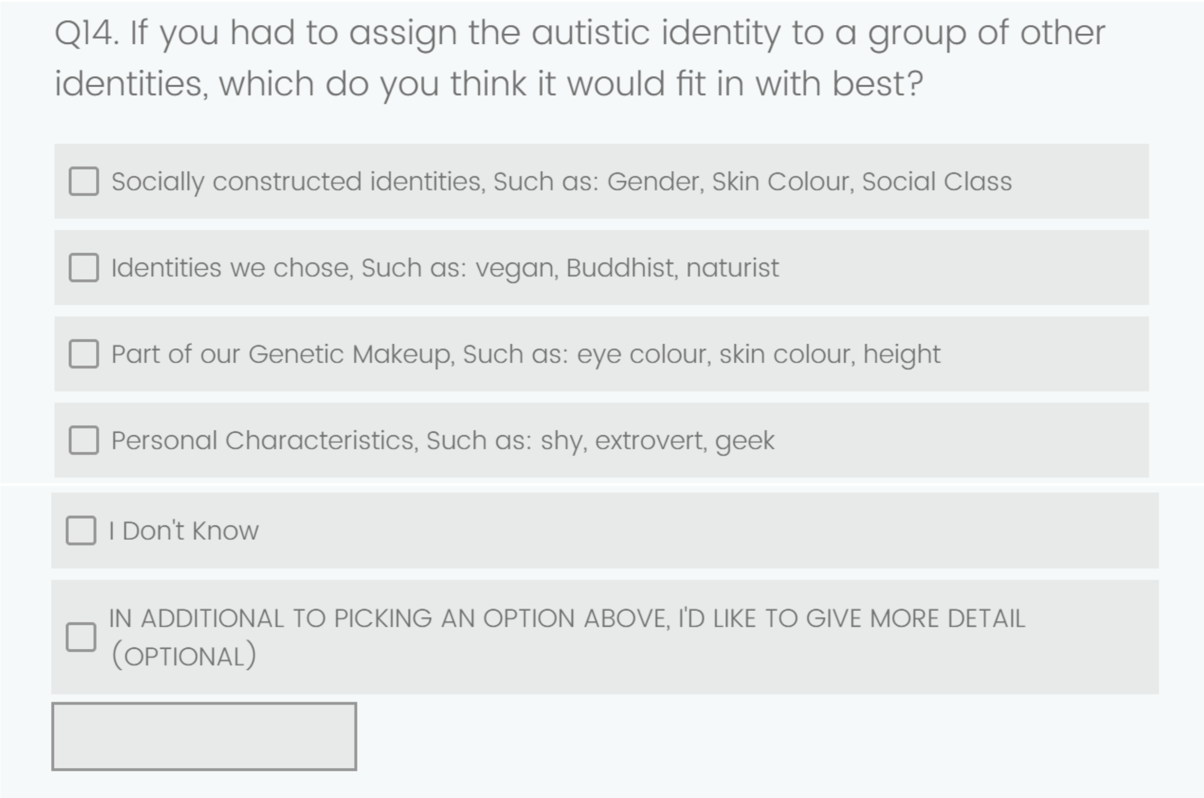
☐ Just part of who I am, I don't really think about it

☐ Something that has grown over time, through my experiences

☐ Something that was given to me by someone else

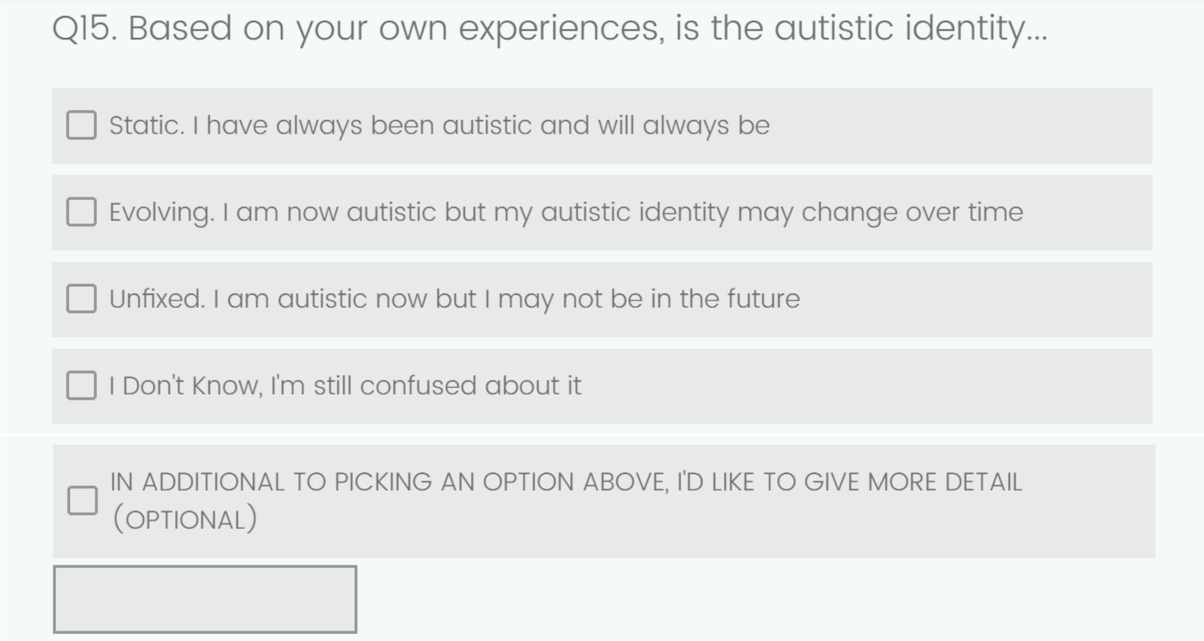
☐ I Don't Know, I'm still confused about it

☐ IN ADDITIONAL TO PICKING AN OPTION ABOVE, I'D LIKE TO GIVE MORE DETAIL (OPTIONAL))



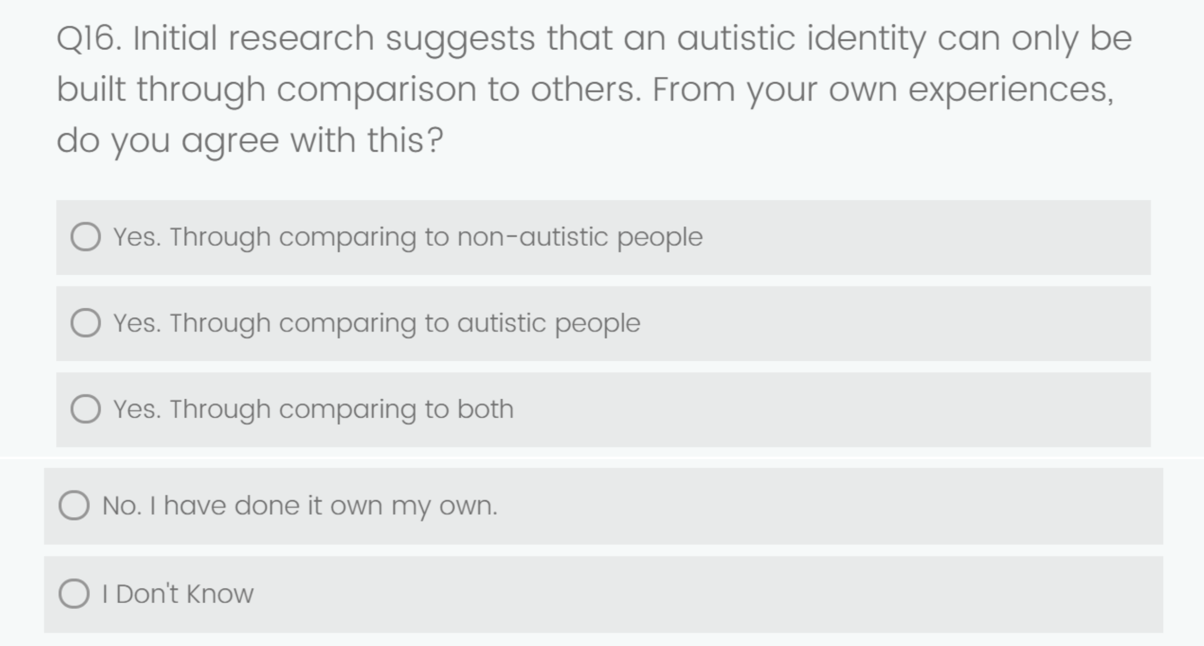
Q14. If you had to assign the autistic identity to a group of other identities, which do you think it would fit in with best?

- ☐ Socially constructed identities, Such as: Gender, Skin Colour, Social Class
- ☐ Identities we chose, Such as: vegan, Buddhist, naturist
- ☐ Part of our Genetic Makeup, Such as: eye colour, skin colour, height
- ☐ Personal Characteristics, Such as: shy, extrovert, geek
- ☐ I Don't Know
- ☐ IN ADDITIONAL TO PICKING AN OPTION ABOVE, I'D LIKE TO GIVE MORE DETAIL (OPTIONAL)



Q15. Based on your own experiences, is the autistic identity...

- ☐ Static. I have always been autistic and will always be
- ☐ Evolving. I am now autistic but my autistic identity may change over time
- ☐ Unfixed. I am autistic now but I may not be in the future
- ☐ I Don't Know, I'm still confused about it
- ☐ IN ADDITIONAL TO PICKING AN OPTION ABOVE, I'D LIKE TO GIVE MORE DETAIL (OPTIONAL)



Q16. Initial research suggests that an autistic identity can only be built through comparison to others. From your own experiences, do you agree with this?

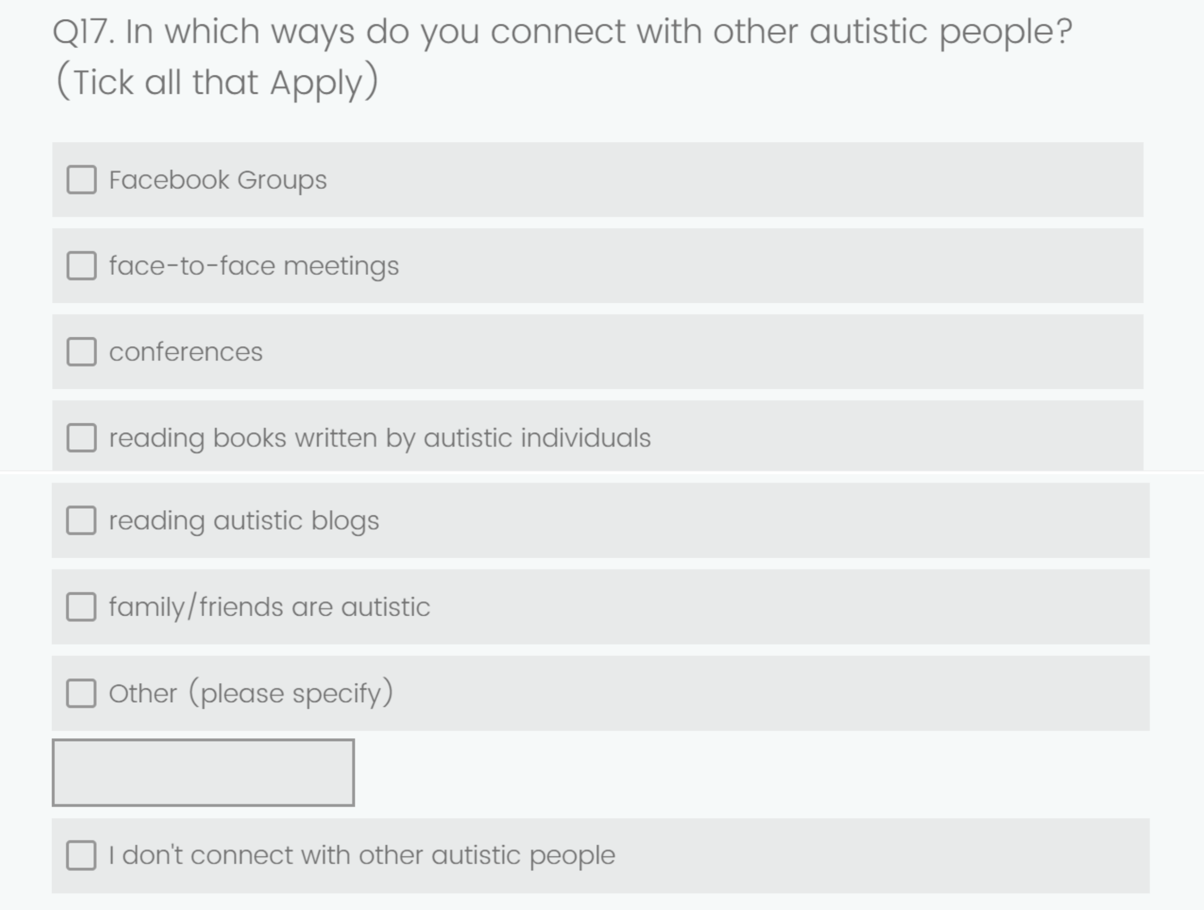
○ Yes. Through comparing to non-autistic people

○ Yes. Through comparing to autistic people

○ Yes. Through comparing to both

○ No. I have done it own my own.

○ I Don't Know



Q17. In which ways do you connect with other autistic people? (Tick all that Apply)

☐ Facebook Groups

☐ face-to-face meetings

☐ conferences

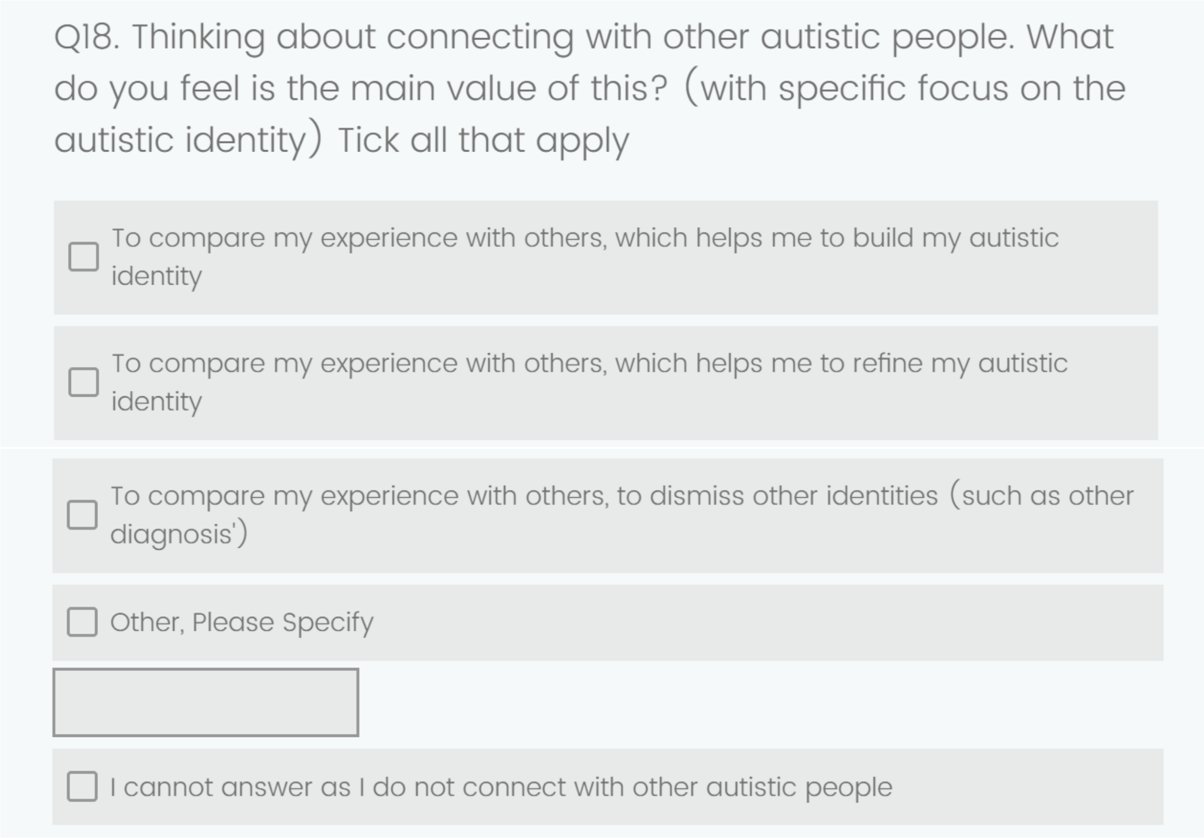
☐ reading books written by autistic individuals

☐ reading autistic blogs

☐ family/friends are autistic

☐ Other (please specify)

☐ I don't connect with other autistic people



Q18. Thinking about connecting with other autistic people. What do you feel is the main value of this? (with specific focus on the autistic identity) Tick all that apply

☐ To compare my experience with others, which helps me to build my autistic identity

☐ To compare my experience with others, which helps me to refine my autistic identity

☐ To compare my experience with others, to dismiss other identities (such as other diagnosis')

☐ Other, Please Specify

☐ I cannot answer as I do not connect with other autistic people

Q19. At what age do you think you started to notice you were 'different' to others around you?

○ 1 - 3 years

○ 4 - 10 years

○ 11 - 16 years

○ 17 - 25 years

○ 26 years +

○ I don't see myself as different

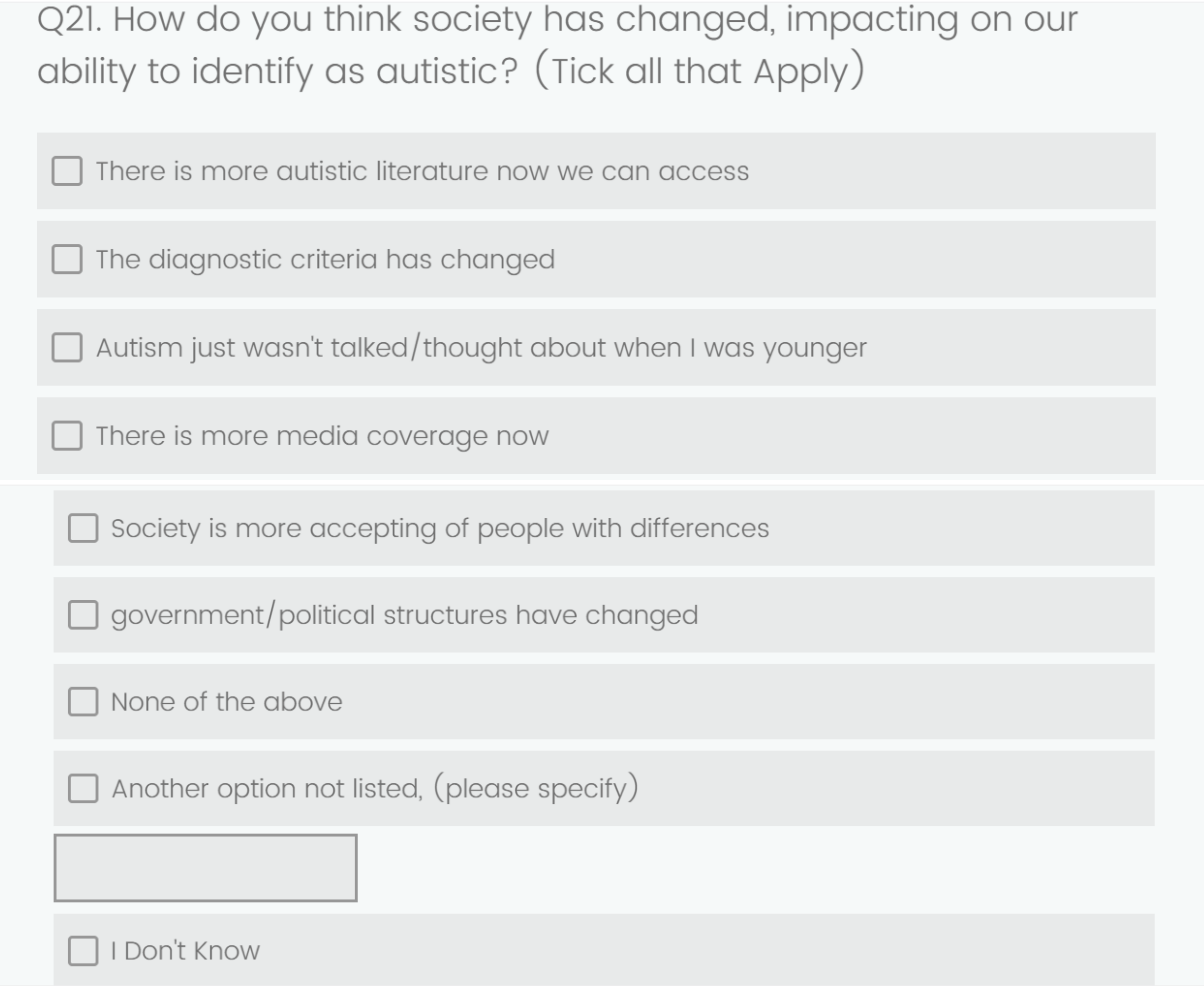
Q20. Do you think puberty changed the way you saw/interacted with the social world?

○ Yes

○ No

○ Possibly, I've never thought about it that way before

○ I Don't Know



Q21. How do you think society has changed, impacting on our ability to identify as autistic? (Tick all that Apply)

☐ There is more autistic literature now we can access

☐ The diagnostic criteria has changed

☐ Autism just wasn't talked/thought about when I was younger

☐ There is more media coverage now

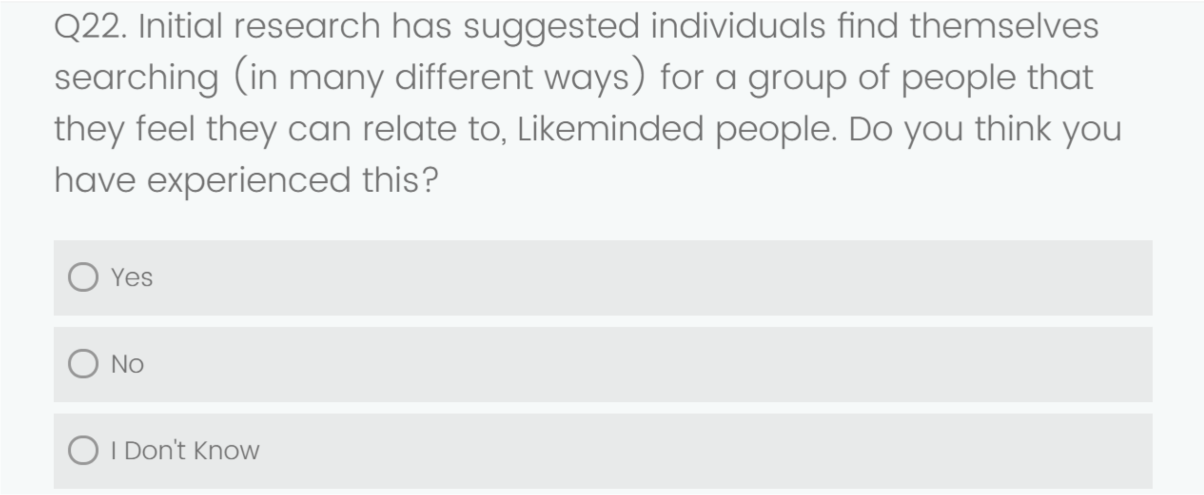
☐ Society is more accepting of people with differences

☐ government/political structures have changed

☐ None of the above

☐ Another option not listed, (please specify)

☐ I Don't Know

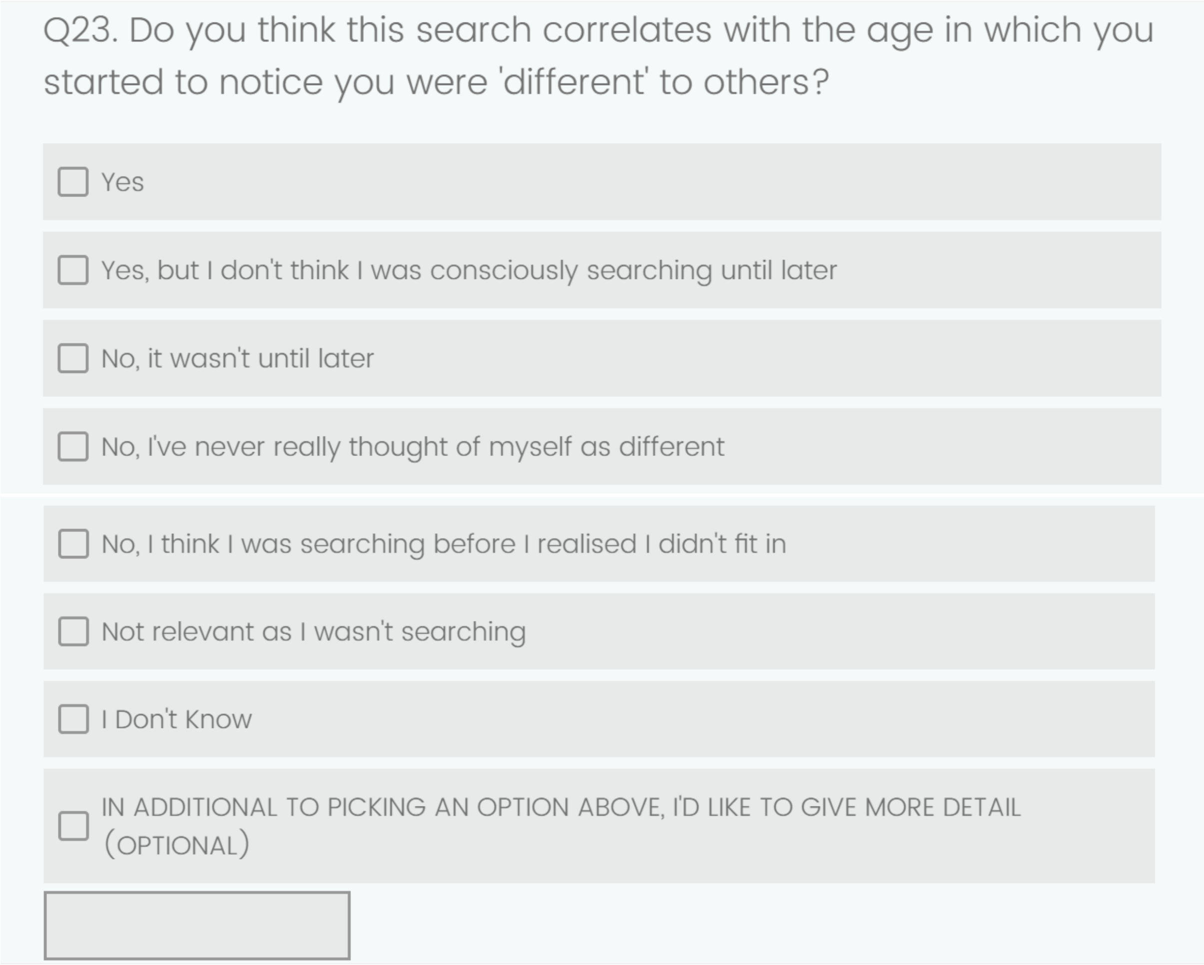


Q22. Initial research has suggested individuals find themselves searching (in many different ways) for a group of people that they feel they can relate to, Likeminded people. Do you think you have experienced this?

○ Yes

○ No

○ I Don't Know



Q23. Do you think this search correlates with the age in which you started to notice you were 'different' to others?

☐ Yes

☐ Yes, but I don't think I was consciously searching until later

☐ No, it wasn't until later

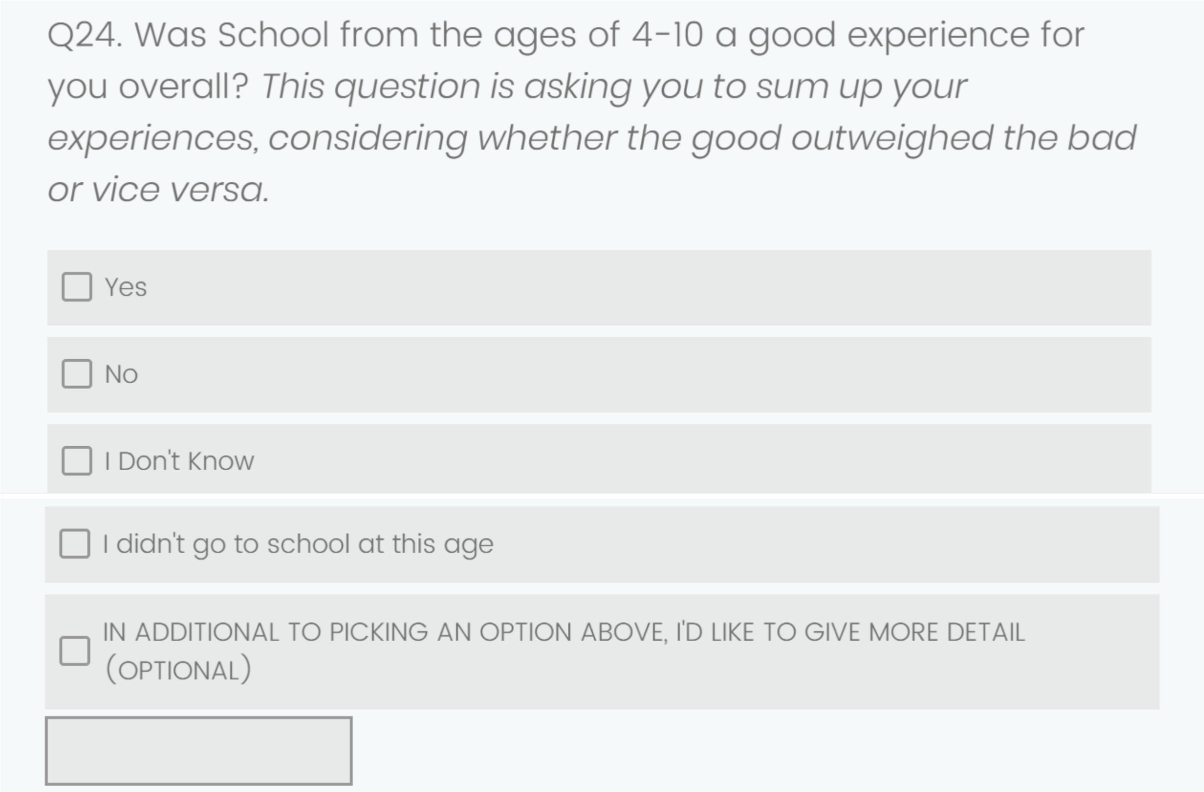
☐ No, I've never really thought of myself as different

☐ No, I think I was searching before I realised I didn't fit in

☐ Not relevant as I wasn't searching

☐ I Don't Know

☐ IN ADDITIONAL TO PICKING AN OPTION ABOVE, I'D LIKE TO GIVE MORE DETAIL (OPTIONAL)



Q24. Was School from the ages of 4-10 a good experience for you overall? *This question is asking you to sum up your experiences, considering whether the good outweighed the bad or vice versa.*

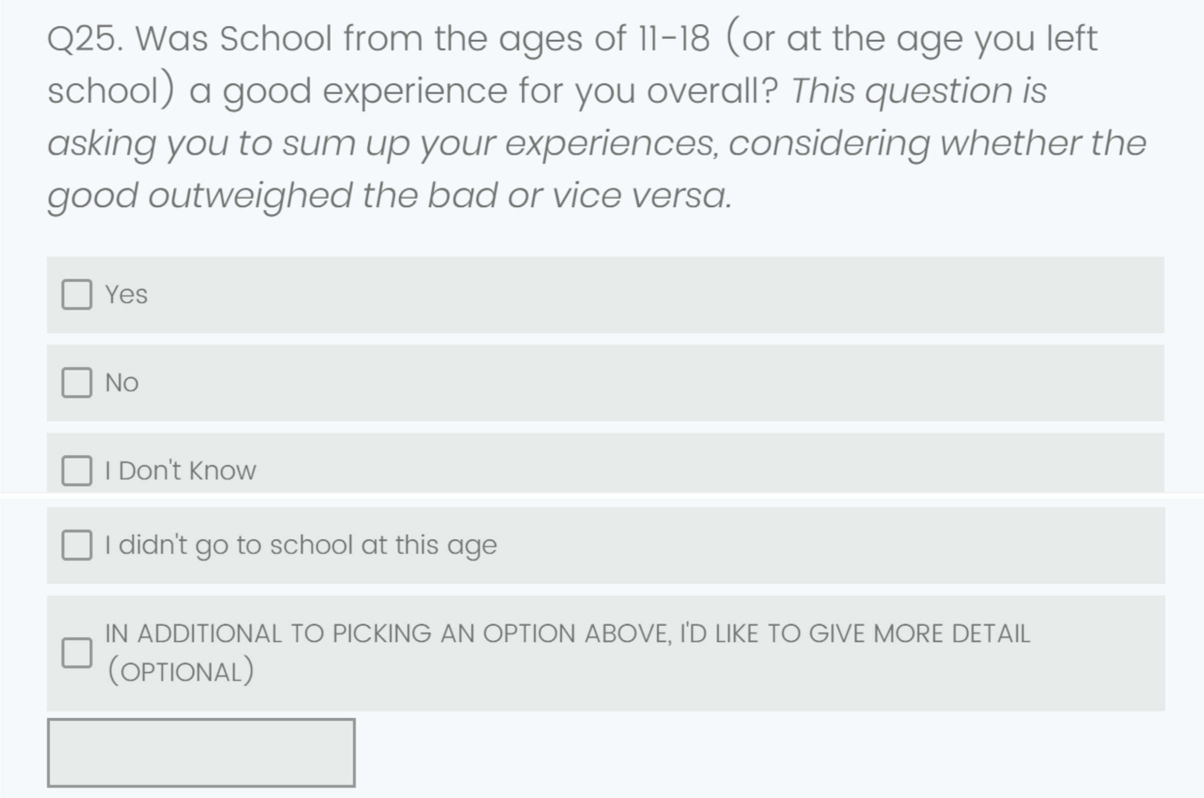
☐ Yes

☐ No

☐ I Don't Know

☐ I didn't go to school at this age

☐ IN ADDITIONAL TO PICKING AN OPTION ABOVE, I'D LIKE TO GIVE MORE DETAIL (OPTIONAL)



Q25. Was School from the ages of 11-18 (or at the age you left school) a good experience for you overall? *This question is asking you to sum up your experiences, considering whether the good outweighed the bad or vice versa.*

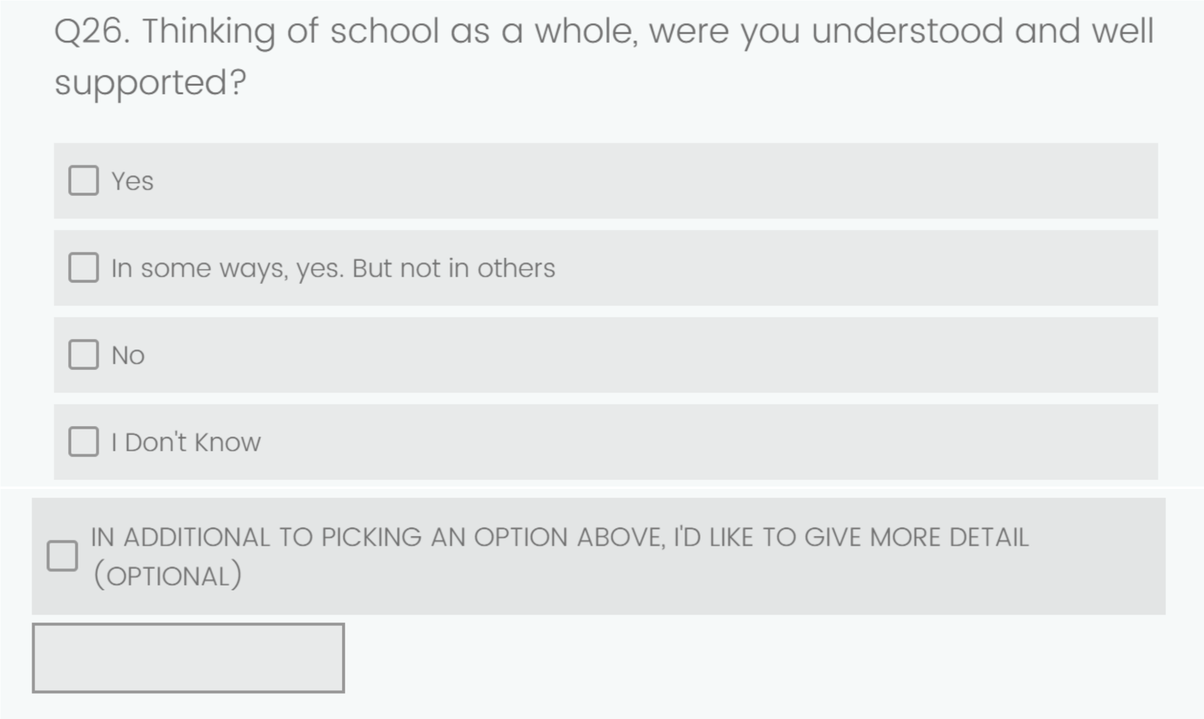
☐ Yes

☐ No

☐ I Don't Know

☐ I didn't go to school at this age

☐ IN ADDITIONAL TO PICKING AN OPTION ABOVE, I'D LIKE TO GIVE MORE DETAIL (OPTIONAL)


Q26. Thinking of school as a whole, were you understood and well supported?

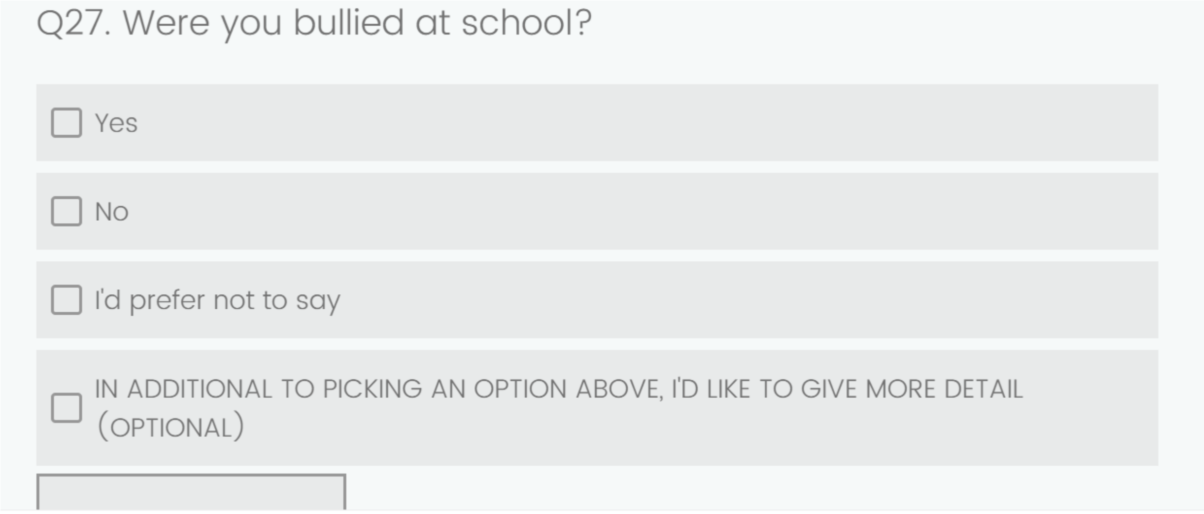
☐ Yes

☐ In some ways, yes. But not in others

☐ No

☐ I Don't Know

☐ IN ADDITIONAL TO PICKING AN OPTION ABOVE, I'D LIKE TO GIVE MORE DETAIL (OPTIONAL)

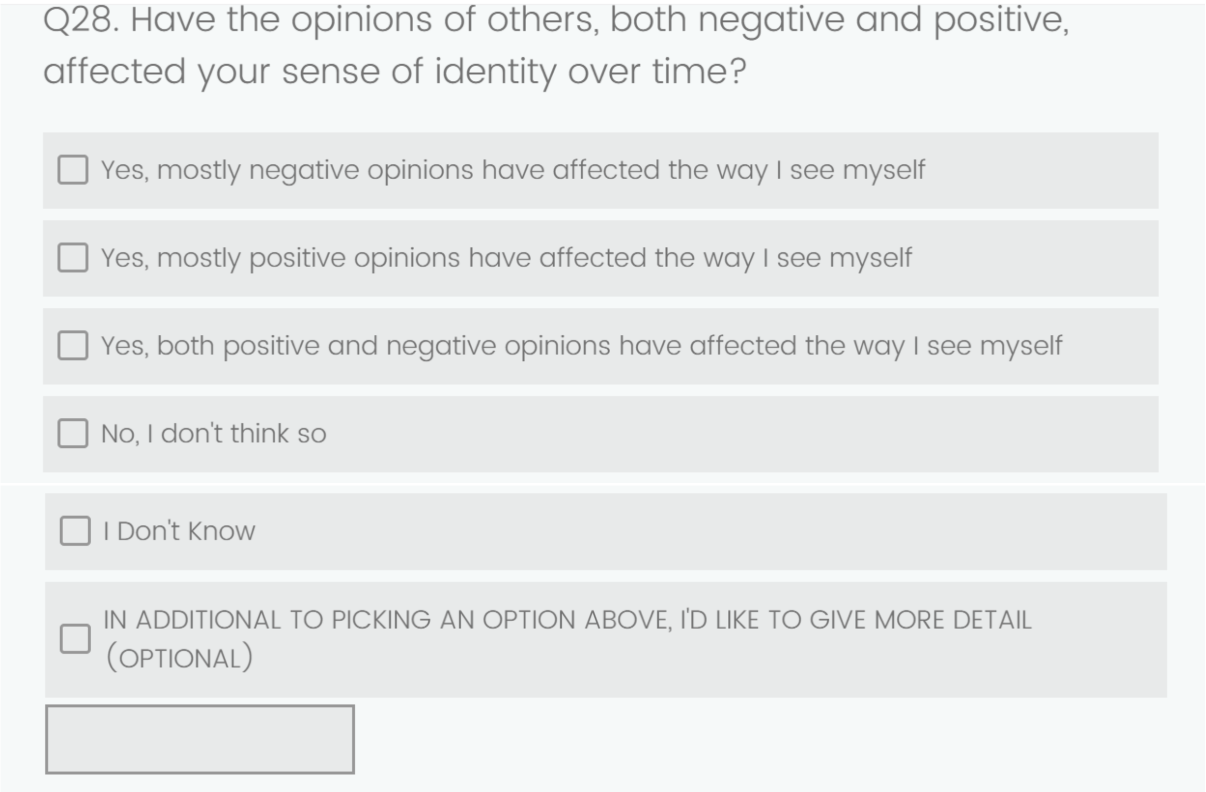

Q27. Were you bullied at school?

☐ Yes

☐ No

☐ I'd prefer not to say

☐ IN ADDITIONAL TO PICKING AN OPTION ABOVE, I'D LIKE TO GIVE MORE DETAIL (OPTIONAL)



Q28. Have the opinions of others, both negative and positive, affected your sense of identity over time?

☐ Yes, mostly negative opinions have affected the way I see myself

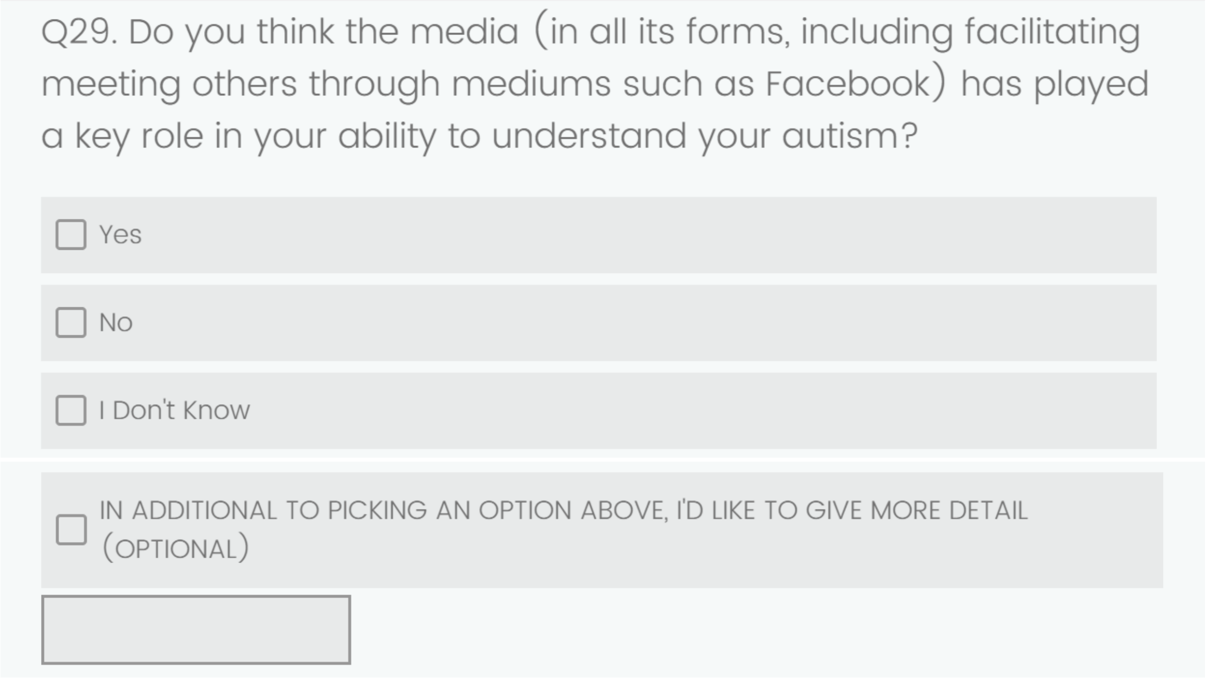
☐ Yes, mostly positive opinions have affected the way I see myself

☐ Yes, both positive and negative opinions have affected the way I see myself

☐ No, I don't think so

☐ I Don't Know

☐ IN ADDITIONAL TO PICKING AN OPTION ABOVE, I'D LIKE TO GIVE MORE DETAIL (OPTIONAL)



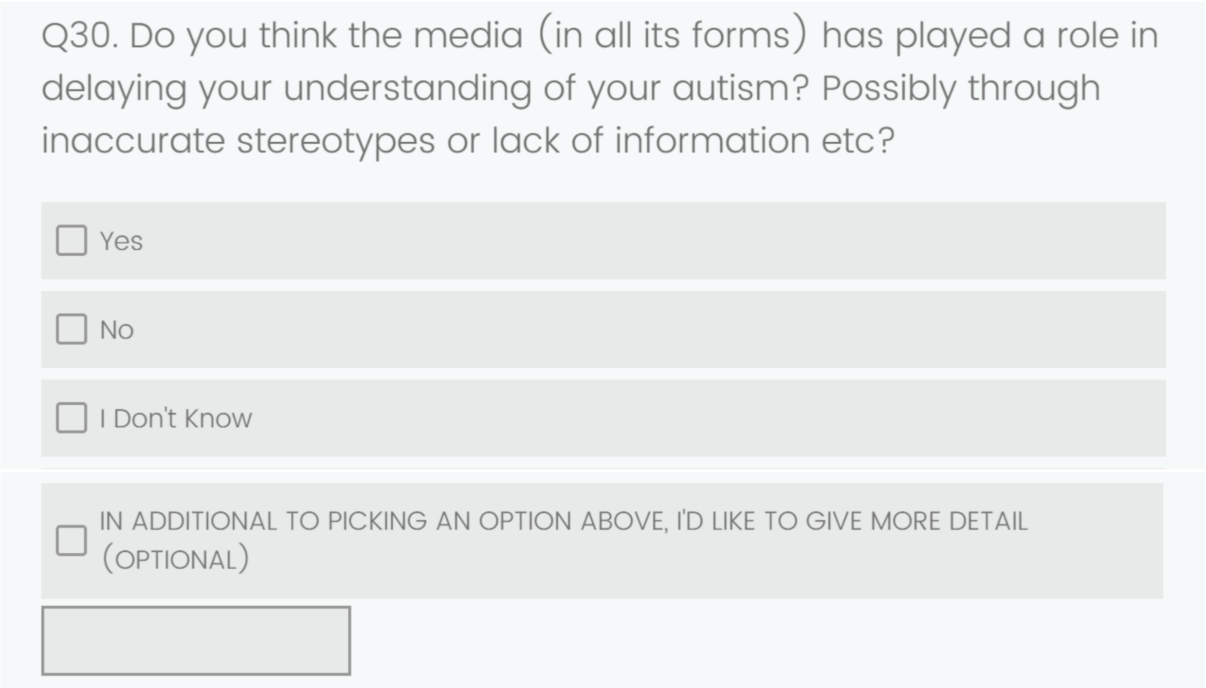
Q29. Do you think the media (in all its forms, including facilitating meeting others through mediums such as Facebook) has played a key role in your ability to understand your autism?

☐ Yes

☐ No

☐ I Don't Know

☐ IN ADDITIONAL TO PICKING AN OPTION ABOVE, I'D LIKE TO GIVE MORE DETAIL (OPTIONAL)



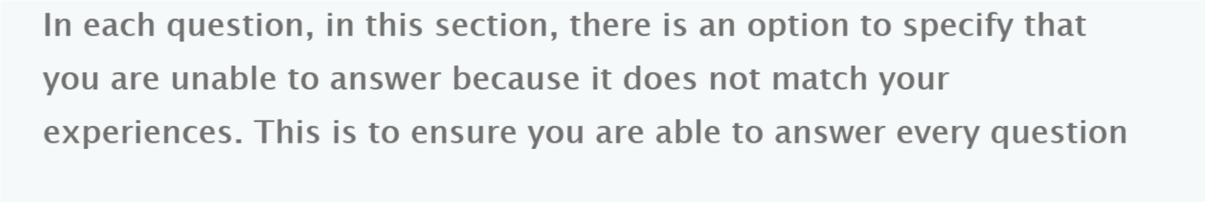
Q30. Do you think the media (in all its forms) has played a role in delaying your understanding of your autism? Possibly through inaccurate stereotypes or lack of information etc?

☐ Yes

☐ No

☐ I Don't Know

☐ IN ADDITIONAL TO PICKING AN OPTION ABOVE, I'D LIKE TO GIVE MORE DETAIL (OPTIONAL)



In each question, in this section, there is an option to specify that you are unable to answer because it does not match your experiences. This is to ensure you are able to answer every question

Q31. Do you feel that you have experienced challenges with your mental health, either presently or in the past?

○ Yes, and sought help

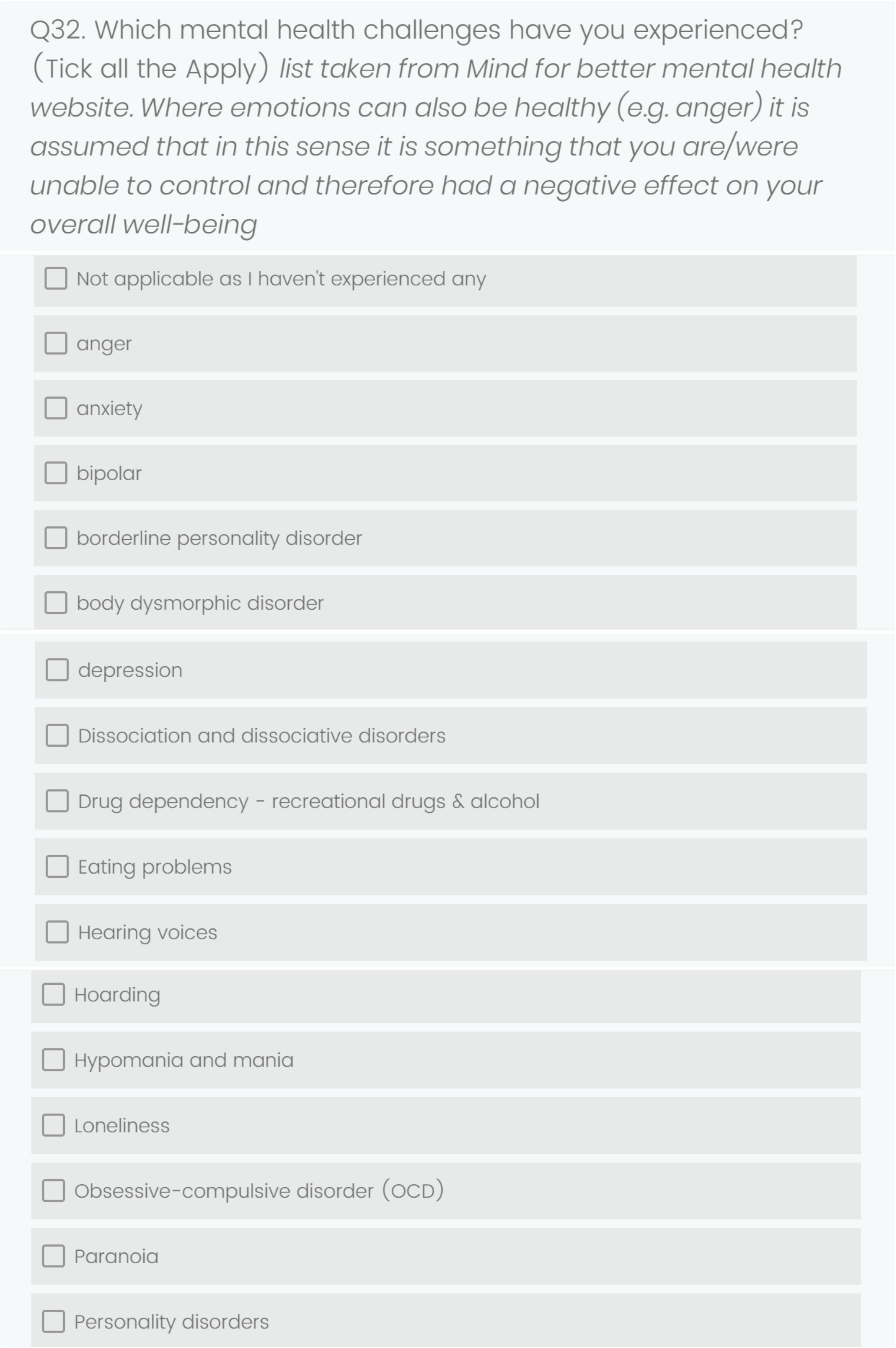
○ Yes, self managed

○ Yes, sought help sometimes and not others

○ Yes on reflection but I didn't realise at the time

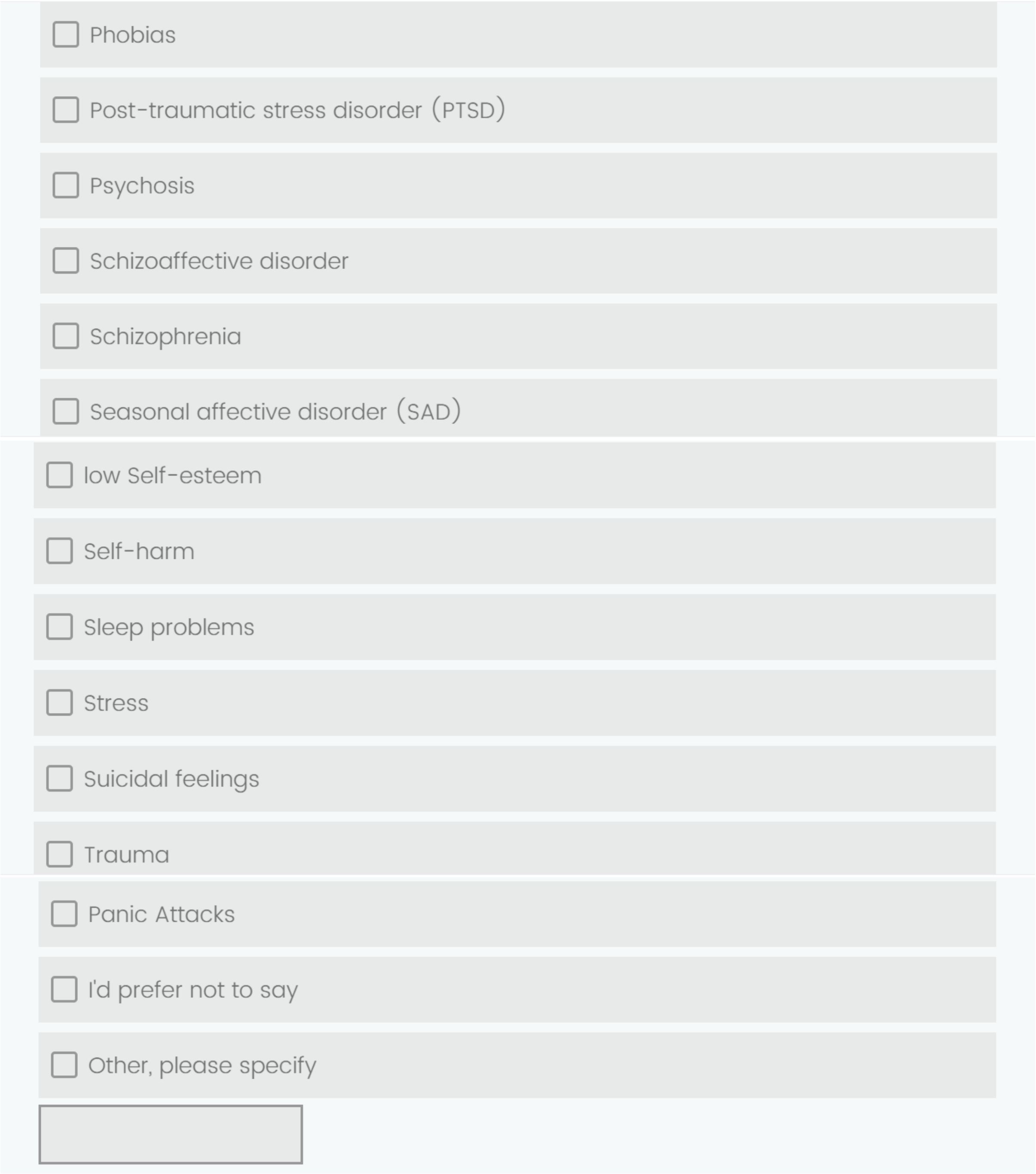
○ No

○ I'd prefer not to say



Q32. Which mental health challenges have you experienced? (Tick all the Apply) *list taken from Mind for better mental health website. Where emotions can also be healthy (e.g. anger) it is assumed that in this sense it is something that you are/were unable to control and therefore had a negative effect on your overall well-being*

- ☐ Not applicable as I haven't experienced any
- ☐ anger
- ☐ anxiety
- ☐ bipolar
- ☐ borderline personality disorder
- ☐ body dysmorphic disorder
- ☐ depression
- ☐ Dissociation and dissociative disorders
- ☐ Drug dependency - recreational drugs & alcohol
- ☐ Eating problems
- ☐ Hearing voices
- ☐ Hoarding
- ☐ Hypomania and mania
- ☐ Loneliness
- ☐ Obsessive-compulsive disorder (OCD)
- ☐ Paranoia
- ☐ Personality disorders



☐ Phobias

☐ Post-traumatic stress disorder (PTSD)

☐ Psychosis

☐ Schizoaffective disorder

☐ Schizophrenia

☐ Seasonal affective disorder (SAD)

☐ low Self-esteem

☐ Self-harm

☐ Sleep problems

☐ Stress

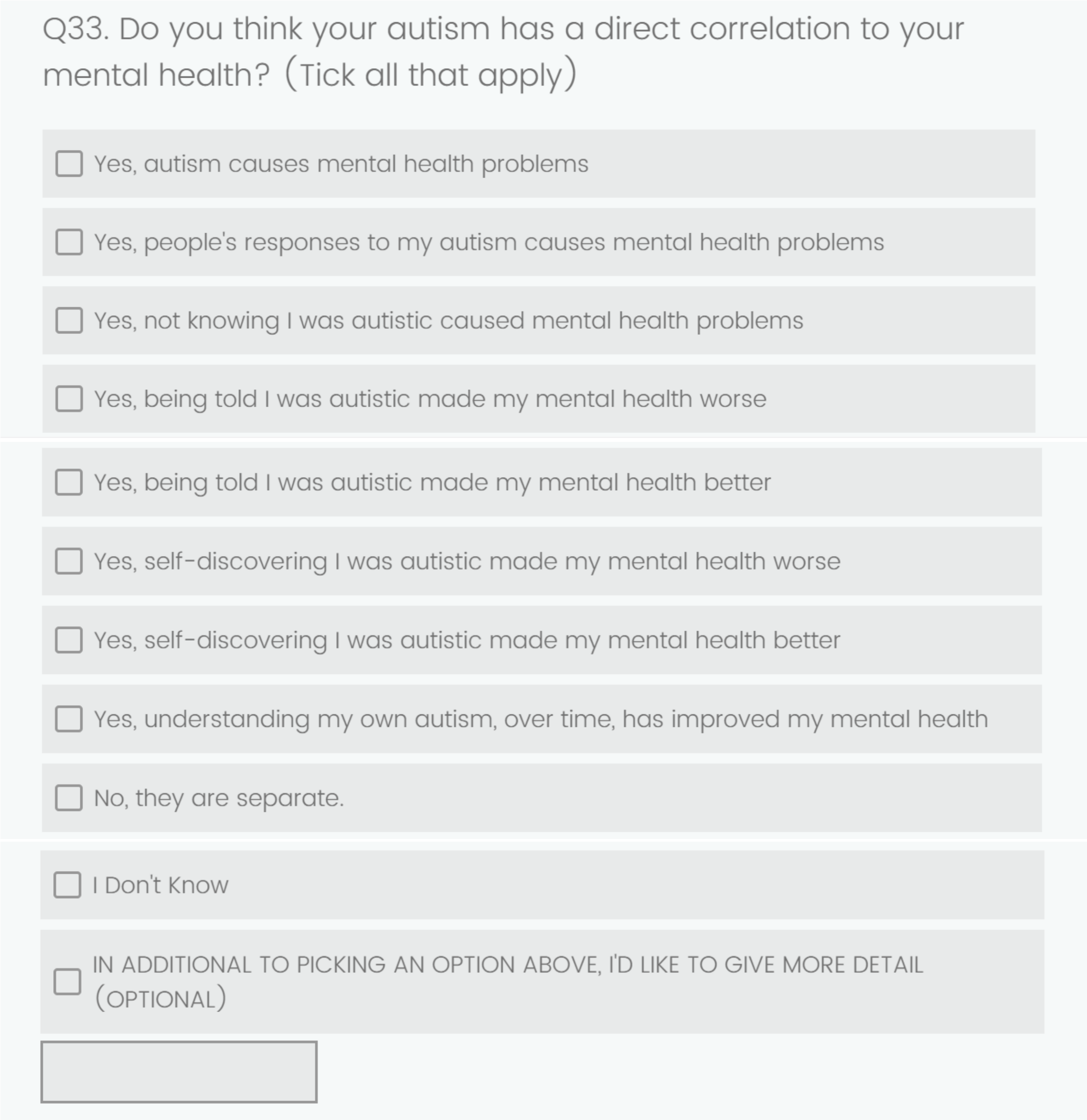
☐ Suicidal feelings

☐ Trauma

☐ Panic Attacks

☐ I'd prefer not to say

☐ Other, please specify



Q33. Do you think your autism has a direct correlation to your mental health? (Tick all that apply)

☐ Yes, autism causes mental health problems

☐ Yes, people's responses to my autism causes mental health problems

☐ Yes, not knowing I was autistic caused mental health problems

☐ Yes, being told I was autistic made my mental health worse

☐ Yes, being told I was autistic made my mental health better

☐ Yes, self-discovering I was autistic made my mental health worse

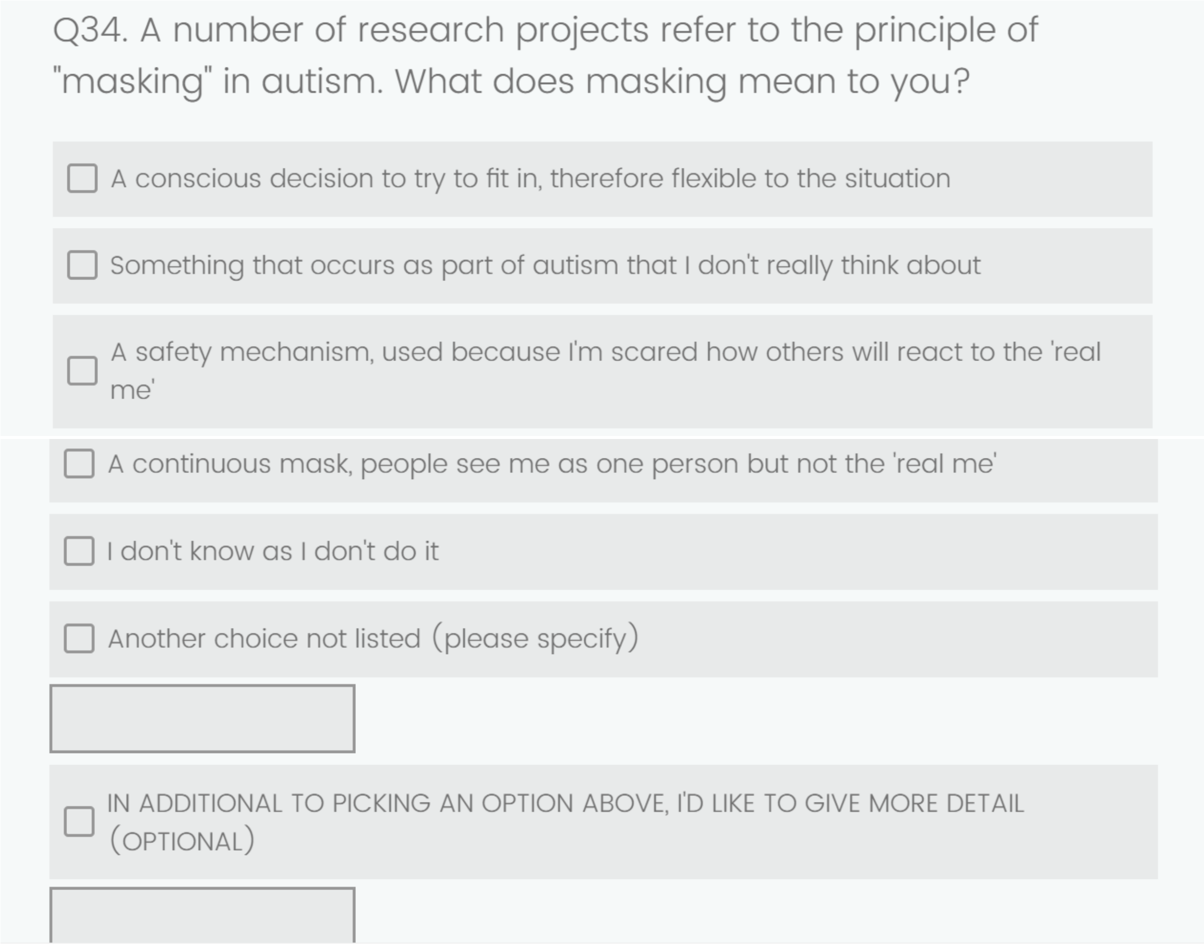
☐ Yes, self-discovering I was autistic made my mental health better

☐ Yes, understanding my own autism, over time, has improved my mental health

☐ No, they are separate.

☐ I Don't Know

☐ IN ADDITIONAL TO PICKING AN OPTION ABOVE, I'D LIKE TO GIVE MORE DETAIL (OPTIONAL)



Q34. A number of research projects refer to the principle of "masking" in autism. What does masking mean to you?

☐ A conscious decision to try to fit in, therefore flexible to the situation

☐ Something that occurs as part of autism that I don't really think about

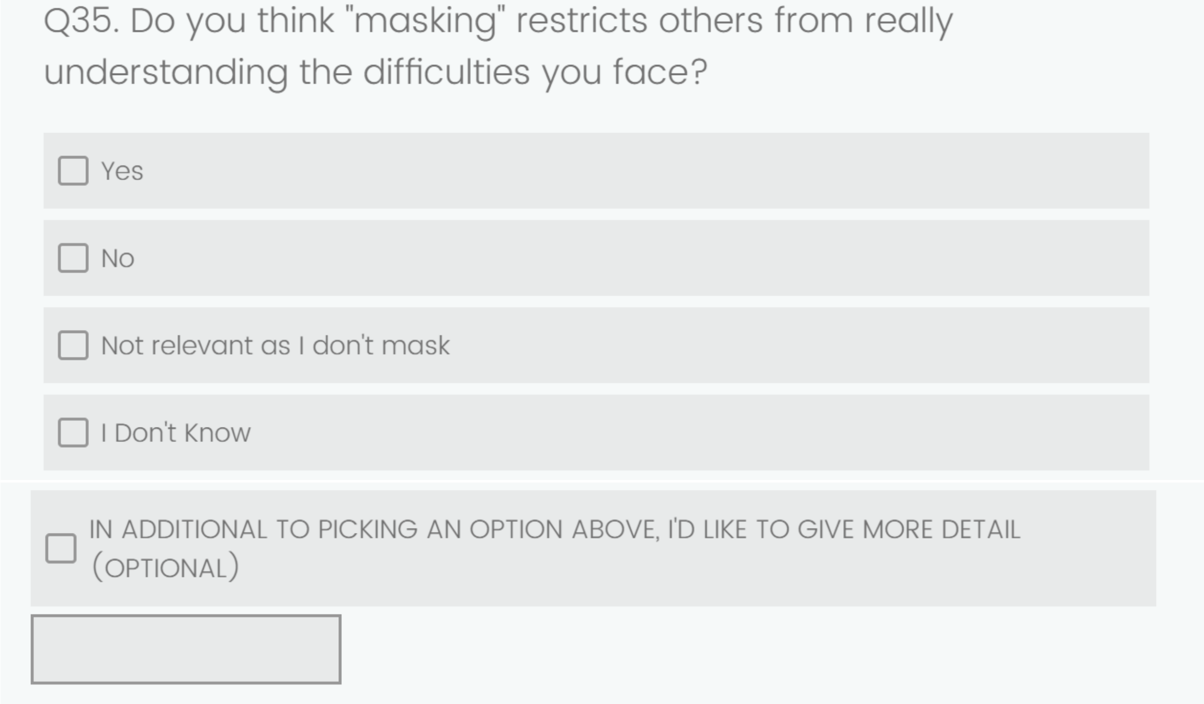
☐ A safety mechanism, used because I'm scared how others will react to the 'real me'

☐ A continuous mask, people see me as one person but not the 'real me'

☐ I don't know as I don't do it

☐ Another choice not listed (please specify)

☐ IN ADDITIONAL TO PICKING AN OPTION ABOVE, I'D LIKE TO GIVE MORE DETAIL (OPTIONAL)



Q35. Do you think "masking" restricts others from really understanding the difficulties you face?

☐ Yes

☐ No

☐ Not relevant as I don't mask

☐ I Don't Know

☐ IN ADDITIONAL TO PICKING AN OPTION ABOVE, I'D LIKE TO GIVE MORE DETAIL (OPTIONAL)

Q36. From your own experiences, what are the effects of "masking" (Tick all that Apply)

☐ I am included in situations I may otherwise not be

☐ I struggle to understand my own self identity

☐ I have reduced self-esteem

☐ It has helped me maintain my career

☐ It has helped me maintain my relationships

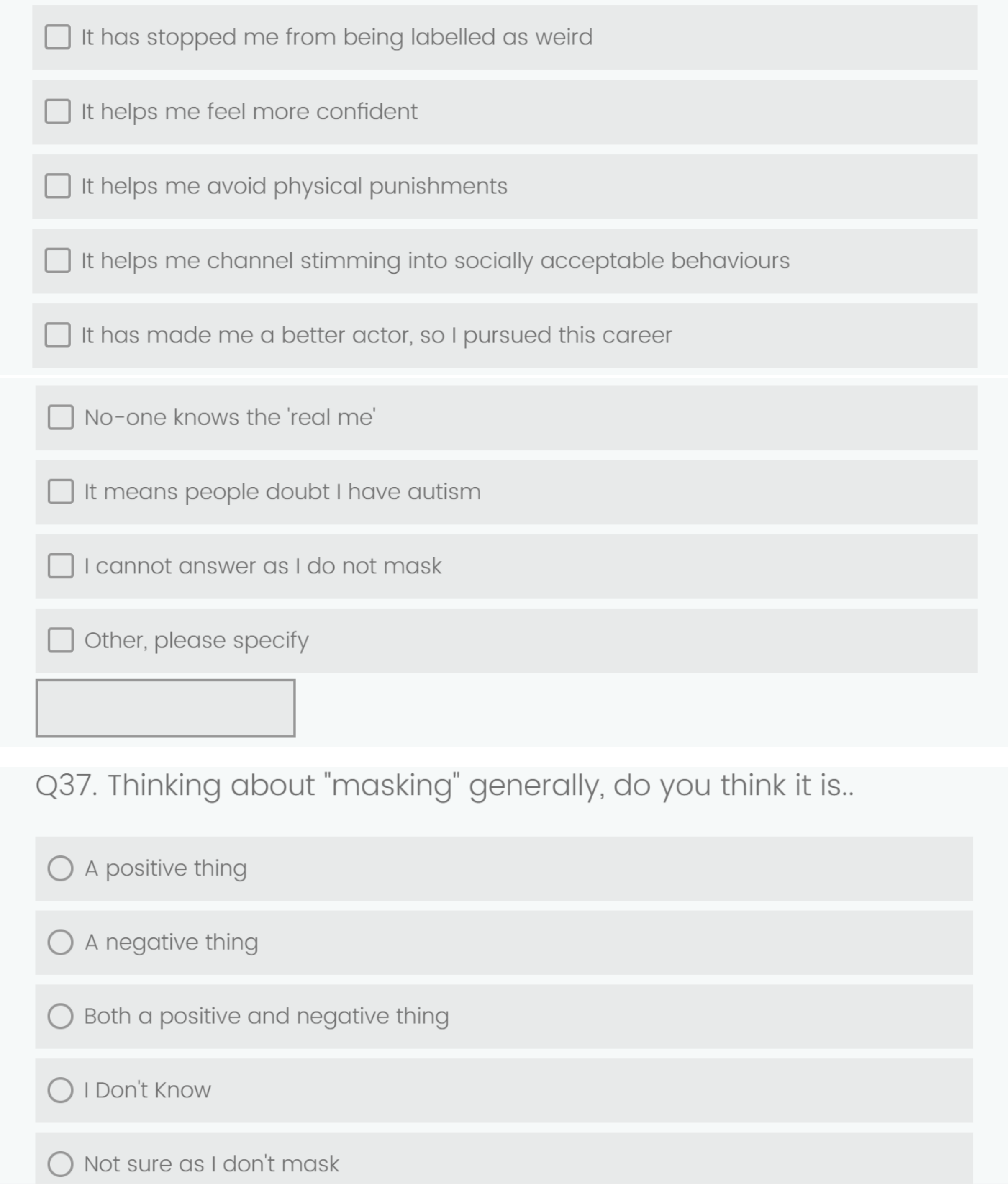
☐ It makes me feel lonely

☐ It makes me physically exhausted

☐ It makes me emotionally exhausted

☐ It makes me mentally exhausted

☐ It has helped me understand the differences in people/situations



☐ It has stopped me from being labelled as weird

☐ It helps me feel more confident

☐ It helps me avoid physical punishments

☐ It helps me channel stimming into socially acceptable behaviours

☐ It has made me a better actor, so I pursued this career

☐ No-one knows the 'real me'

☐ It means people doubt I have autism

☐ I cannot answer as I do not mask

☐ Other, please specify

Q37. Thinking about "masking" generally, do you think it is..

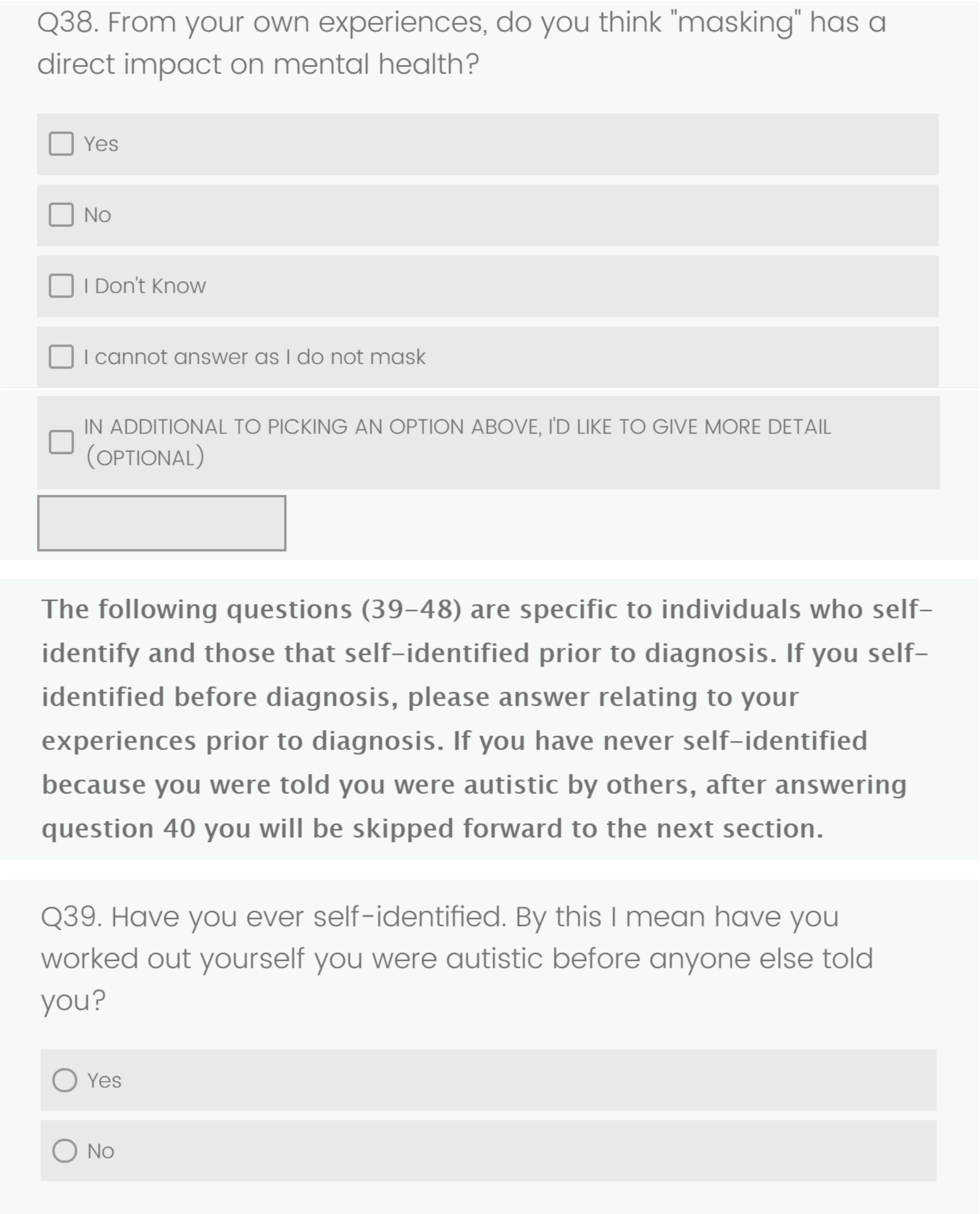
○ A positive thing

○ A negative thing

○ Both a positive and negative thing

○ I Don't Know

○ Not sure as I don't mask



Q38. From your own experiences, do you think "masking" has a direct impact on mental health?

☐ Yes

☐ No

☐ I Don't Know

☐ I cannot answer as I do not mask

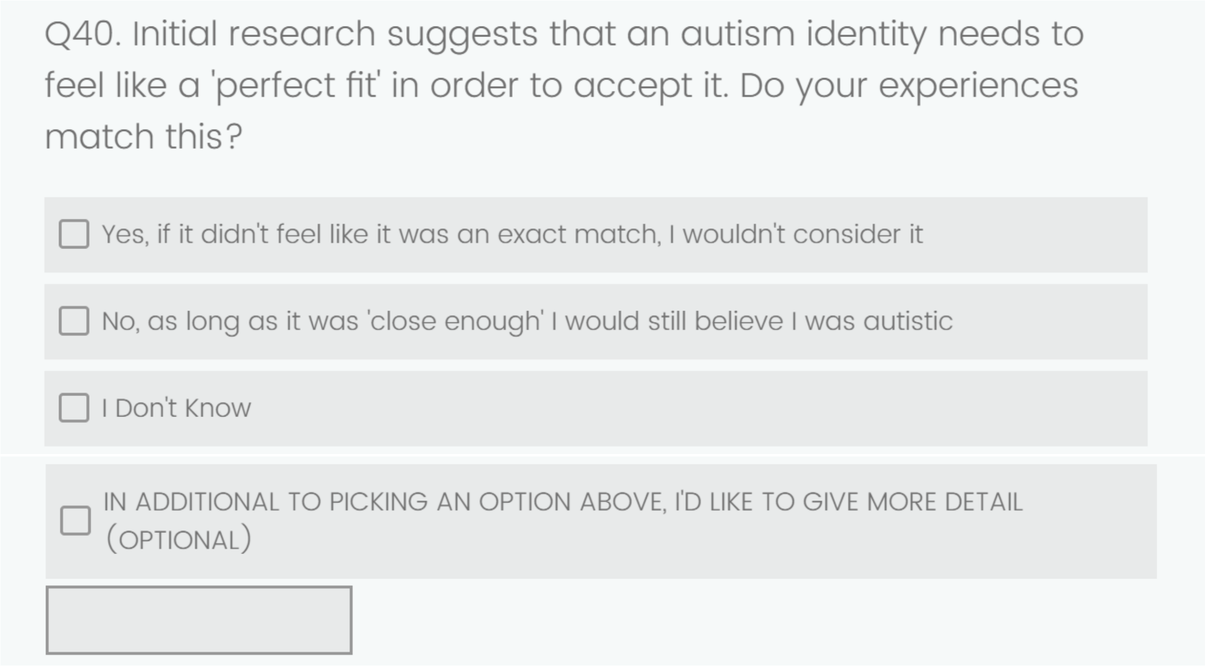
☐ IN ADDITIONAL TO PICKING AN OPTION ABOVE, I'D LIKE TO GIVE MORE DETAIL (OPTIONAL)

The following questions (39-48) are specific to individuals who self-identify and those that self-identified prior to diagnosis. If you self-identified before diagnosis, please answer relating to your experiences prior to diagnosis. If you have never self-identified because you were told you were autistic by others, after answering question 40 you will be skipped forward to the next section.

Q39. Have you ever self-identified. By this I mean have you worked out yourself you were autistic before anyone else told you?

○ Yes

○ No



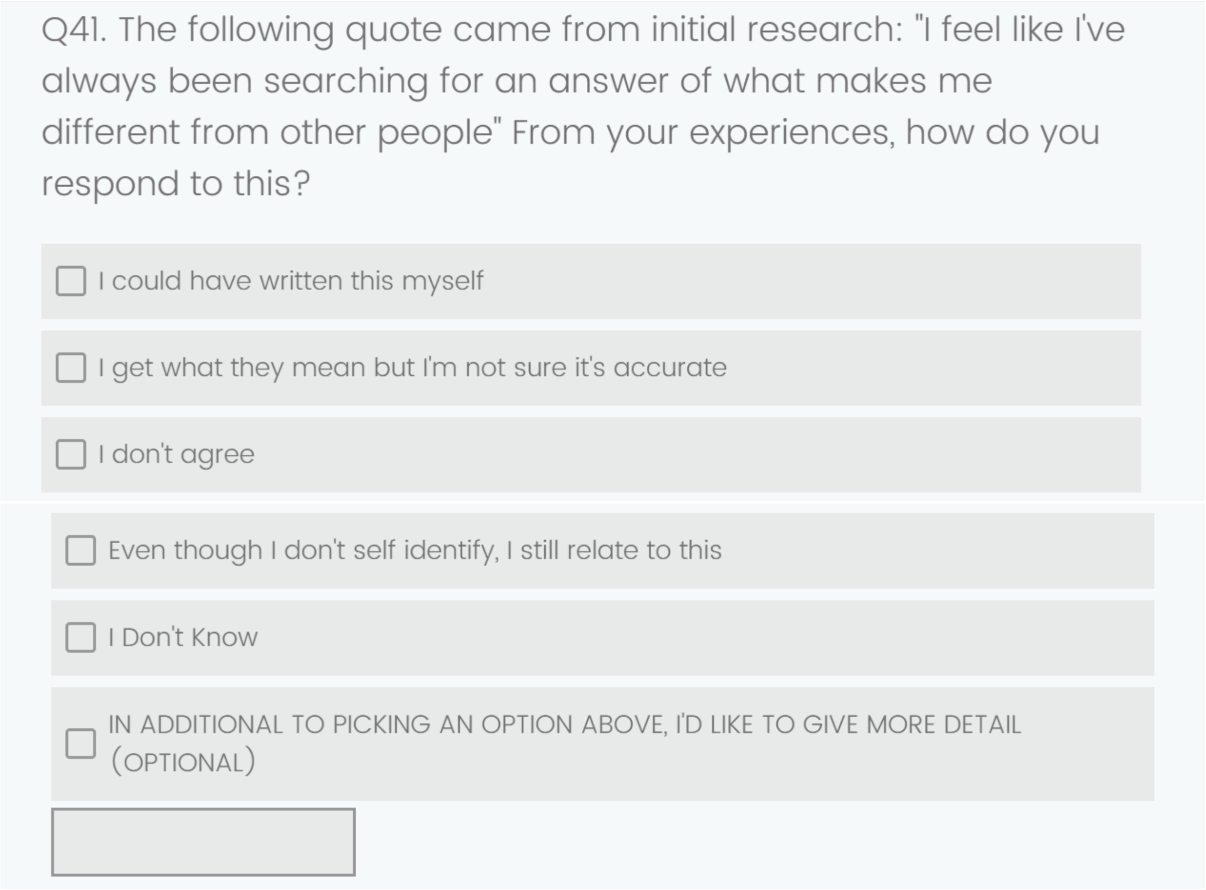
Q40. Initial research suggests that an autism identity needs to feel like a 'perfect fit' in order to accept it. Do your experiences match this?

☐ Yes, if it didn't feel like it was an exact match, I wouldn't consider it

☐ No, as long as it was 'close enough' I would still believe I was autistic

☐ I Don't Know

☐ IN ADDITIONAL TO PICKING AN OPTION ABOVE, I'D LIKE TO GIVE MORE DETAIL (OPTIONAL)



Q41. The following quote came from initial research: "I feel like I've always been searching for an answer of what makes me different from other people" From your experiences, how do you respond to this?

☐ I could have written this myself

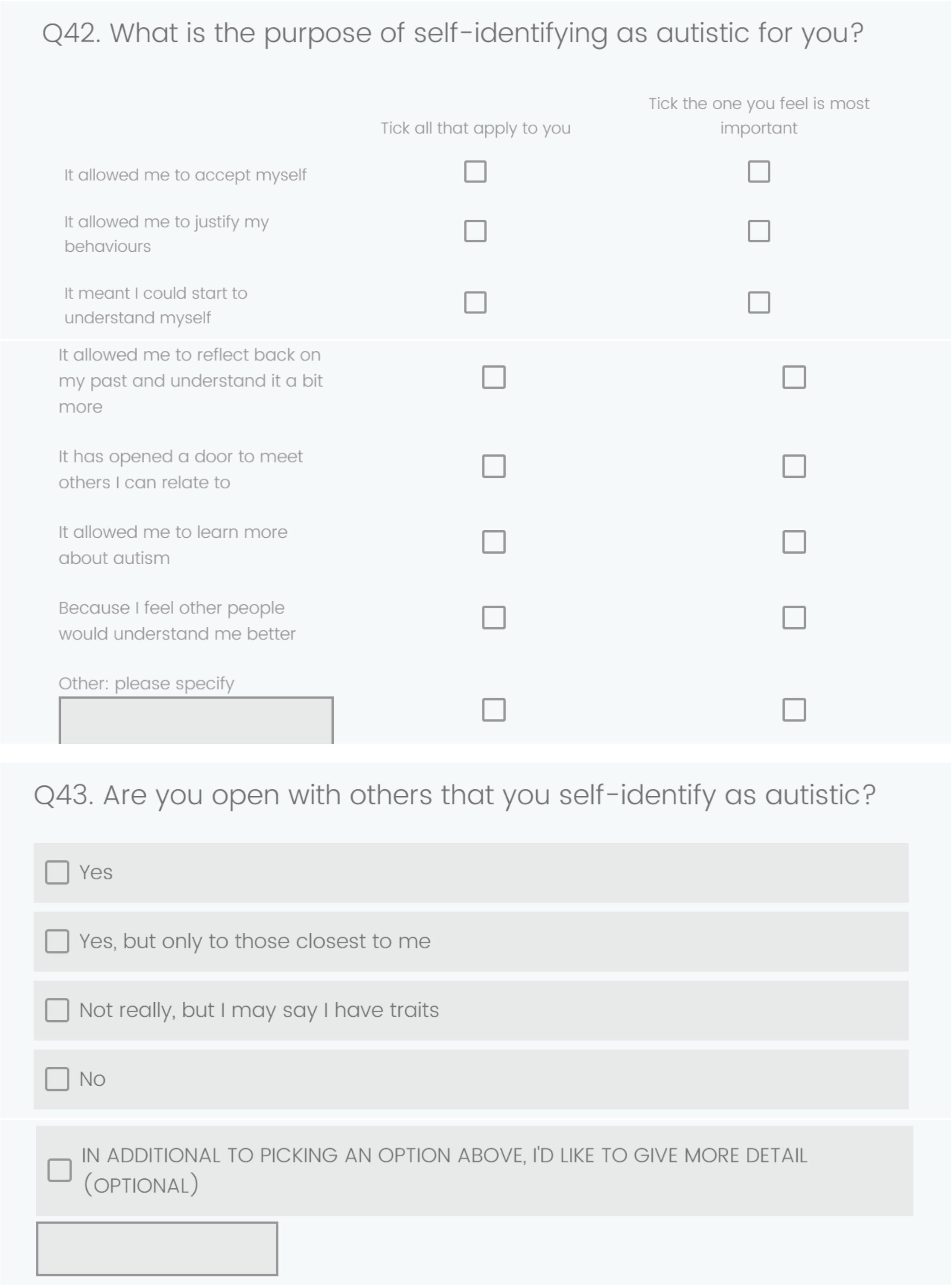
☐ I get what they mean but I'm not sure it's accurate

☐ I don't agree

☐ Even though I don't self identify, I still relate to this

☐ I Don't Know

☐ IN ADDITIONAL TO PICKING AN OPTION ABOVE, I'D LIKE TO GIVE MORE DETAIL (OPTIONAL)



Q42. What is the purpose of self-identifying as autistic for you?

	Tick all that apply to you	Tick the one you feel is most important
It allowed me to accept myself	☐	☐
It allowed me to justify my behaviours	☐	☐
It meant I could start to understand myself	☐	☐
It allowed me to reflect back on my past and understand it a bit more	☐	☐
It has opened a door to meet others I can relate to	☐	☐
It allowed me to learn more about autism	☐	☐
Because I feel other people would understand me better	☐	☐
Other: please specify	☐	☐

Q43. Are you open with others that you self-identify as autistic?

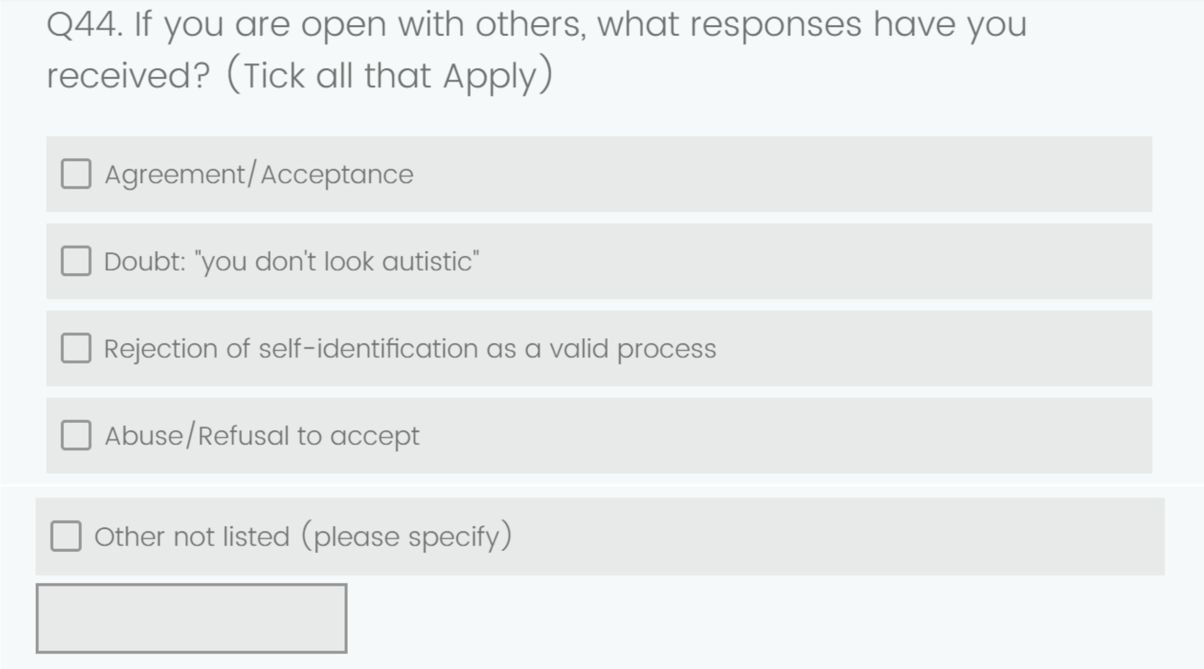
☐ Yes

☐ Yes, but only to those closest to me

☐ Not really, but I may say I have traits

☐ No

☐ IN ADDITIONAL TO PICKING AN OPTION ABOVE, I'D LIKE TO GIVE MORE DETAIL (OPTIONAL)



Q44. If you are open with others, what responses have you received? (Tick all that Apply)

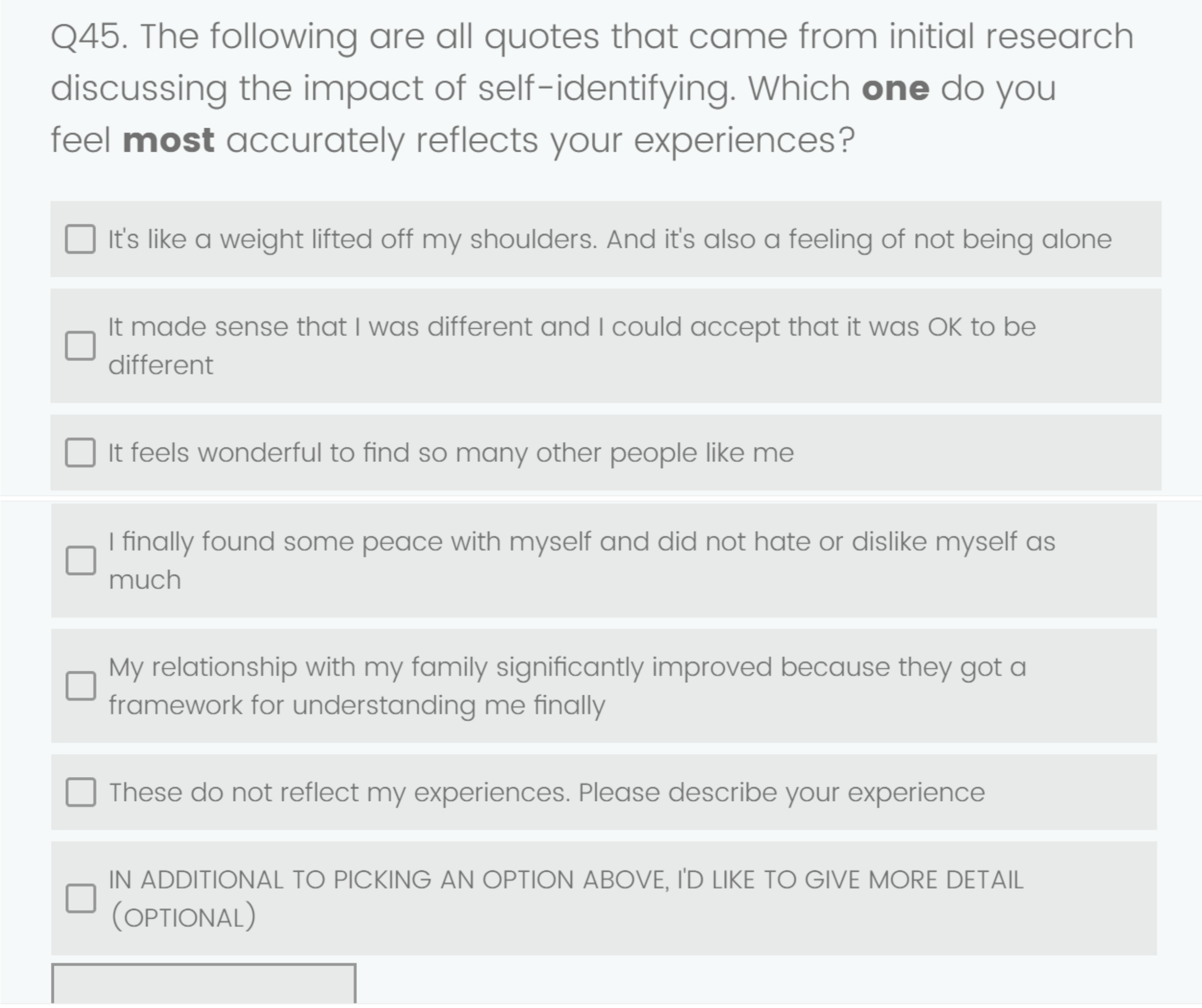
☐ Agreement/Acceptance

☐ Doubt: "you don't look autistic"

☐ Rejection of self-identification as a valid process

☐ Abuse/Refusal to accept

☐ Other not listed (please specify)



Q45. The following are all quotes that came from initial research discussing the impact of self-identifying. Which **one** do you feel **most** accurately reflects your experiences?

☐ It's like a weight lifted off my shoulders. And it's also a feeling of not being alone

☐ It made sense that I was different and I could accept that it was OK to be different

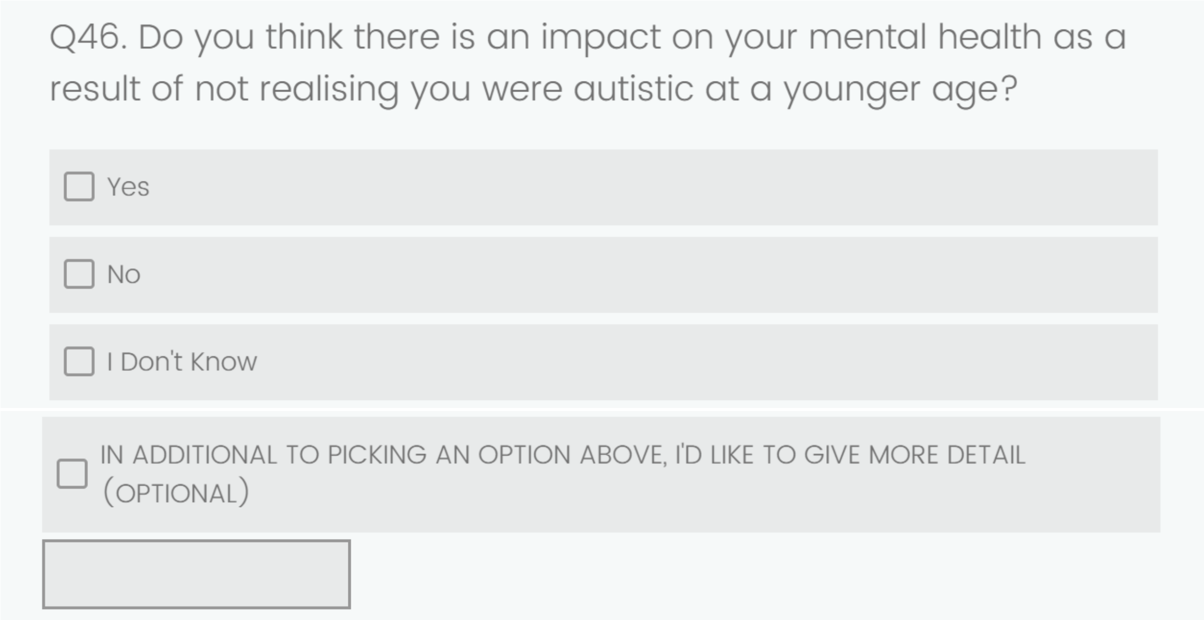
☐ It feels wonderful to find so many other people like me

☐ I finally found some peace with myself and did not hate or dislike myself as much

☐ My relationship with my family significantly improved because they got a framework for understanding me finally

☐ These do not reflect my experiences. Please describe your experience

☐ IN ADDITIONAL TO PICKING AN OPTION ABOVE, I'D LIKE TO GIVE MORE DETAIL (OPTIONAL)

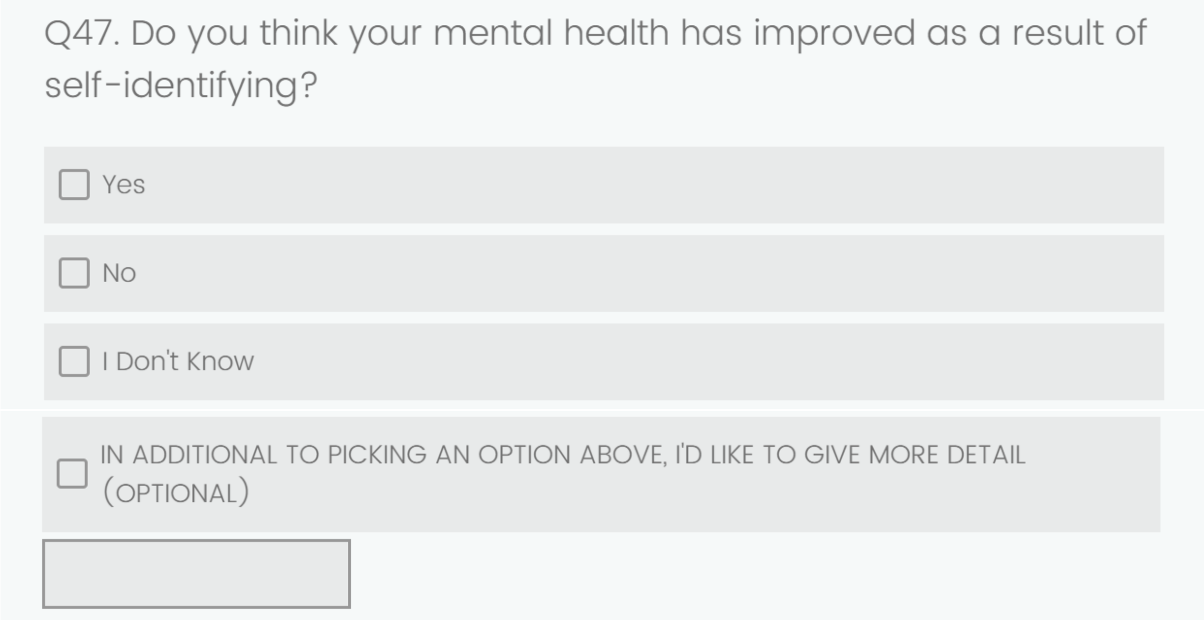

Q46. Do you think there is an impact on your mental health as a result of not realising you were autistic at a younger age?

☐ Yes

☐ No

☐ I Don't Know

☐ IN ADDITIONAL TO PICKING AN OPTION ABOVE, I'D LIKE TO GIVE MORE DETAIL (OPTIONAL)

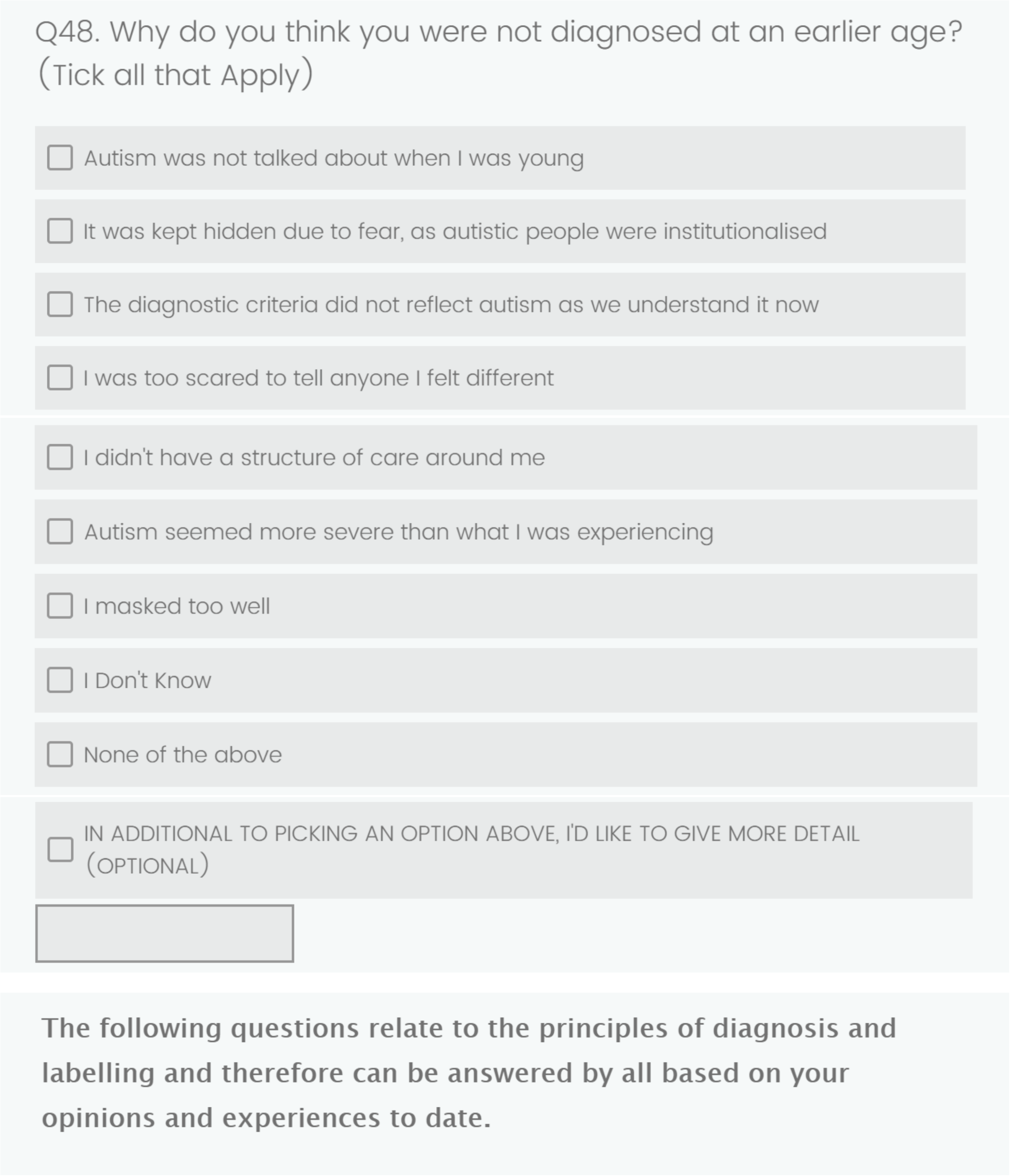

Q47. Do you think your mental health has improved as a result of self-identifying?

☐ Yes

☐ No

☐ I Don't Know

☐ IN ADDITIONAL TO PICKING AN OPTION ABOVE, I'D LIKE TO GIVE MORE DETAIL (OPTIONAL)



Q48. Why do you think you were not diagnosed at an earlier age? (Tick all that Apply)

☐ Autism was not talked about when I was young

☐ It was kept hidden due to fear, as autistic people were institutionalised

☐ The diagnostic criteria did not reflect autism as we understand it now

☐ I was too scared to tell anyone I felt different

☐ I didn't have a structure of care around me

☐ Autism seemed more severe than what I was experiencing

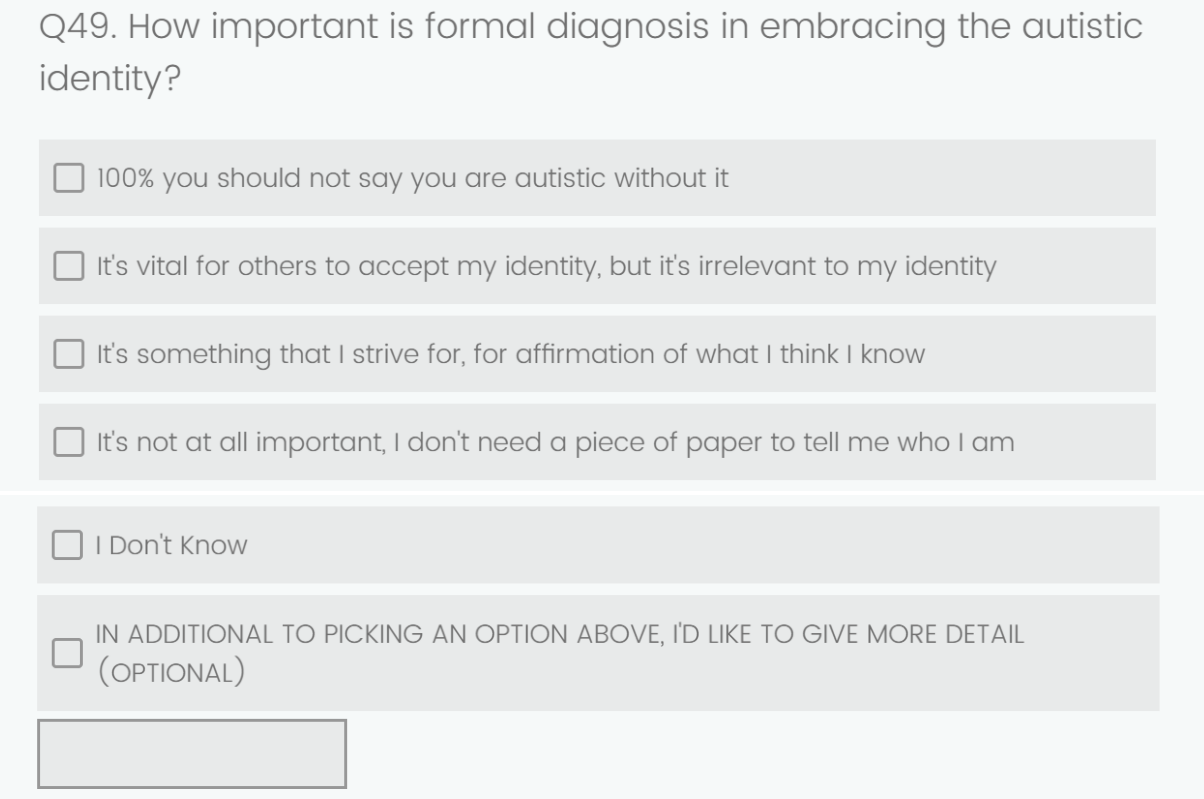
☐ I masked too well

☐ I Don't Know

☐ None of the above

☐ IN ADDITIONAL TO PICKING AN OPTION ABOVE, I'D LIKE TO GIVE MORE DETAIL (OPTIONAL)

The following questions relate to the principles of diagnosis and labelling and therefore can be answered by all based on your opinions and experiences to date.



Q49. How important is formal diagnosis in embracing the autistic identity?

☐ 100% you should not say you are autistic without it

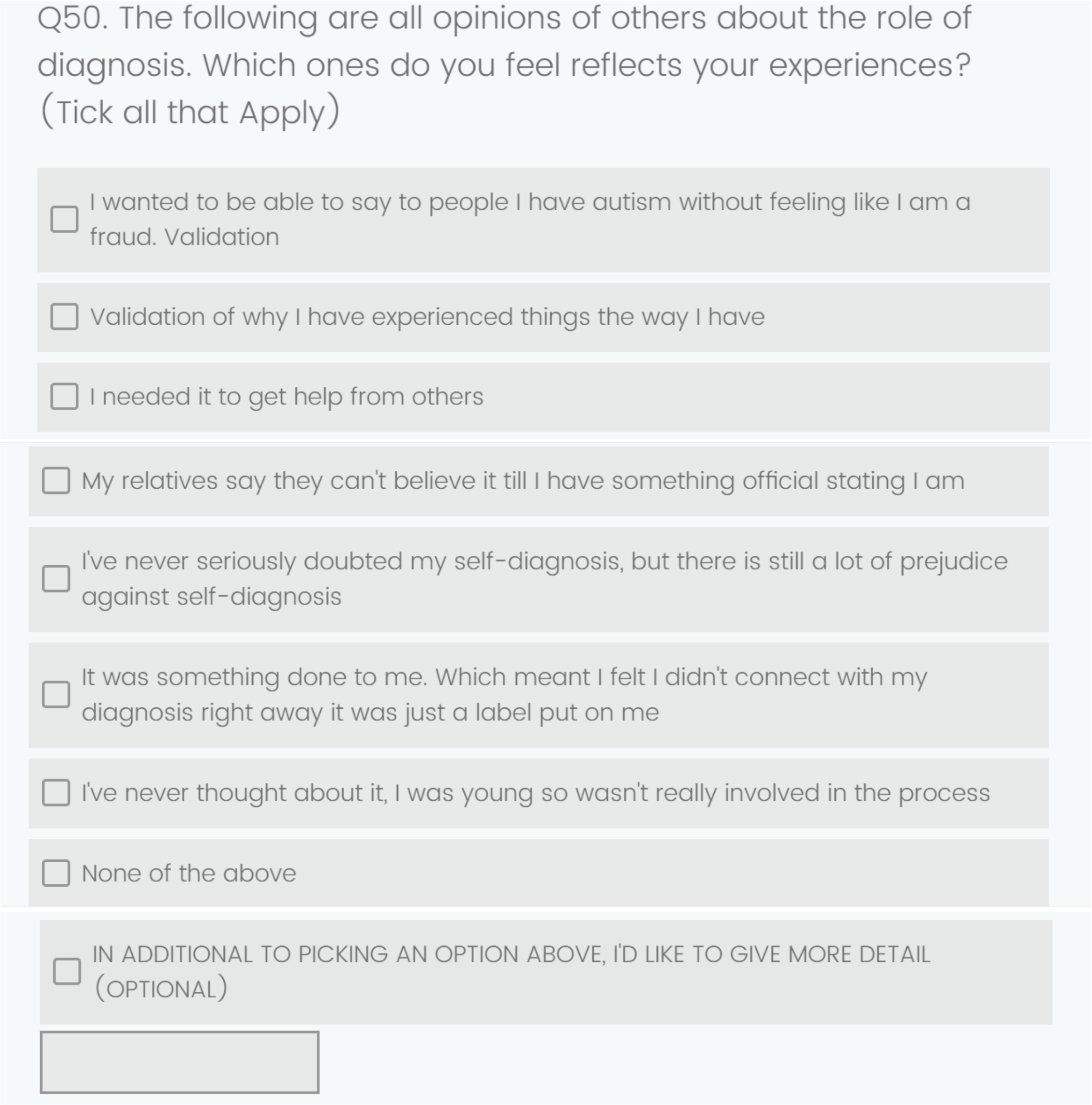
☐ It's vital for others to accept my identity, but it's irrelevant to my identity

☐ It's something that I strive for, for affirmation of what I think I know

☐ It's not at all important, I don't need a piece of paper to tell me who I am

☐ I Don't Know

☐ IN ADDITIONAL TO PICKING AN OPTION ABOVE, I'D LIKE TO GIVE MORE DETAIL (OPTIONAL)



Q50. The following are all opinions of others about the role of diagnosis. Which ones do you feel reflects your experiences? (Tick all that Apply)

☐ I wanted to be able to say to people I have autism without feeling like I am a fraud. Validation

☐ Validation of why I have experienced things the way I have

☐ I needed it to get help from others

☐ My relatives say they can't believe it till I have something official stating I am

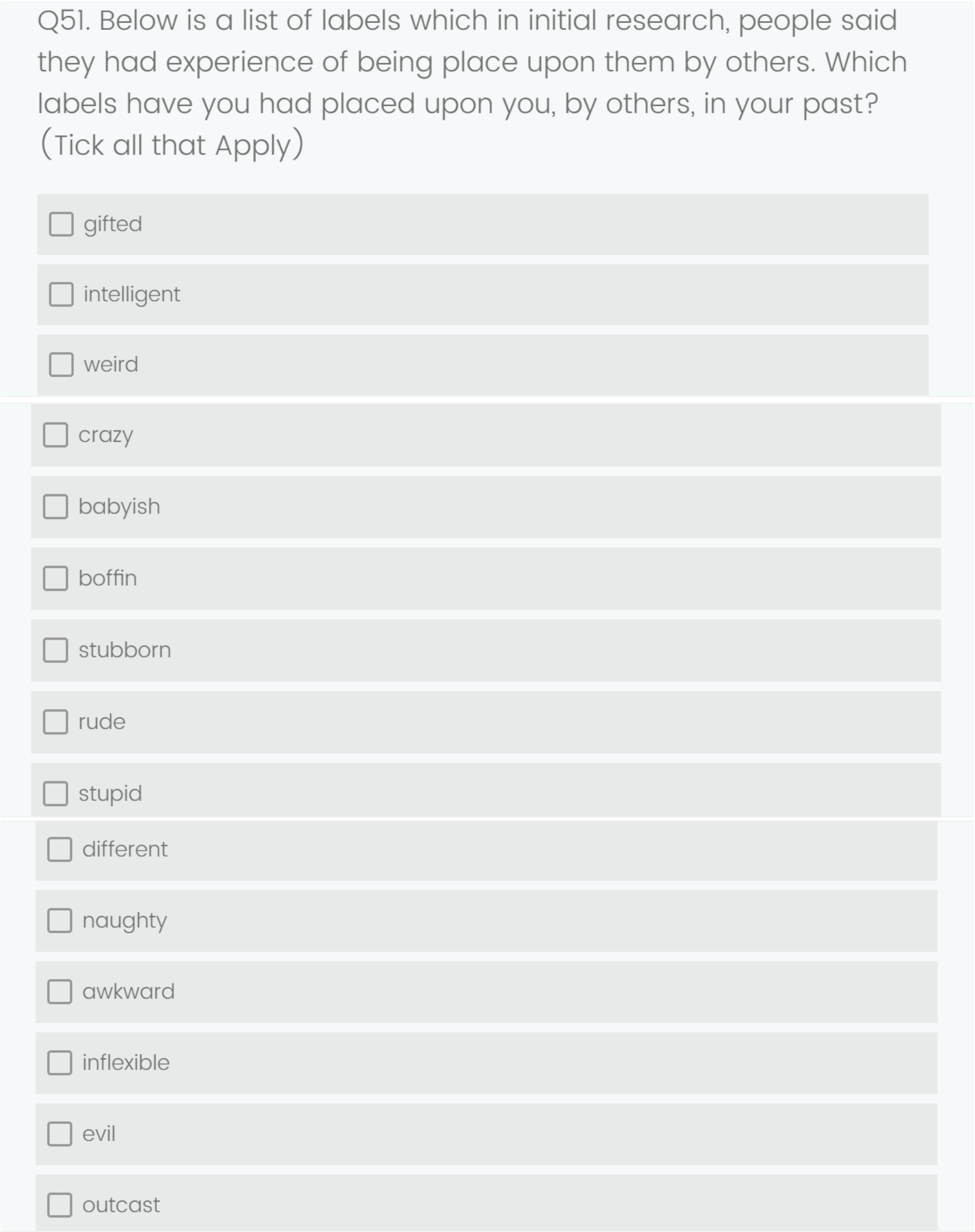
☐ I've never seriously doubted my self-diagnosis, but there is still a lot of prejudice against self-diagnosis

☐ It was something done to me. Which meant I felt I didn't connect with my diagnosis right away it was just a label put on me

☐ I've never thought about it, I was young so wasn't really involved in the process

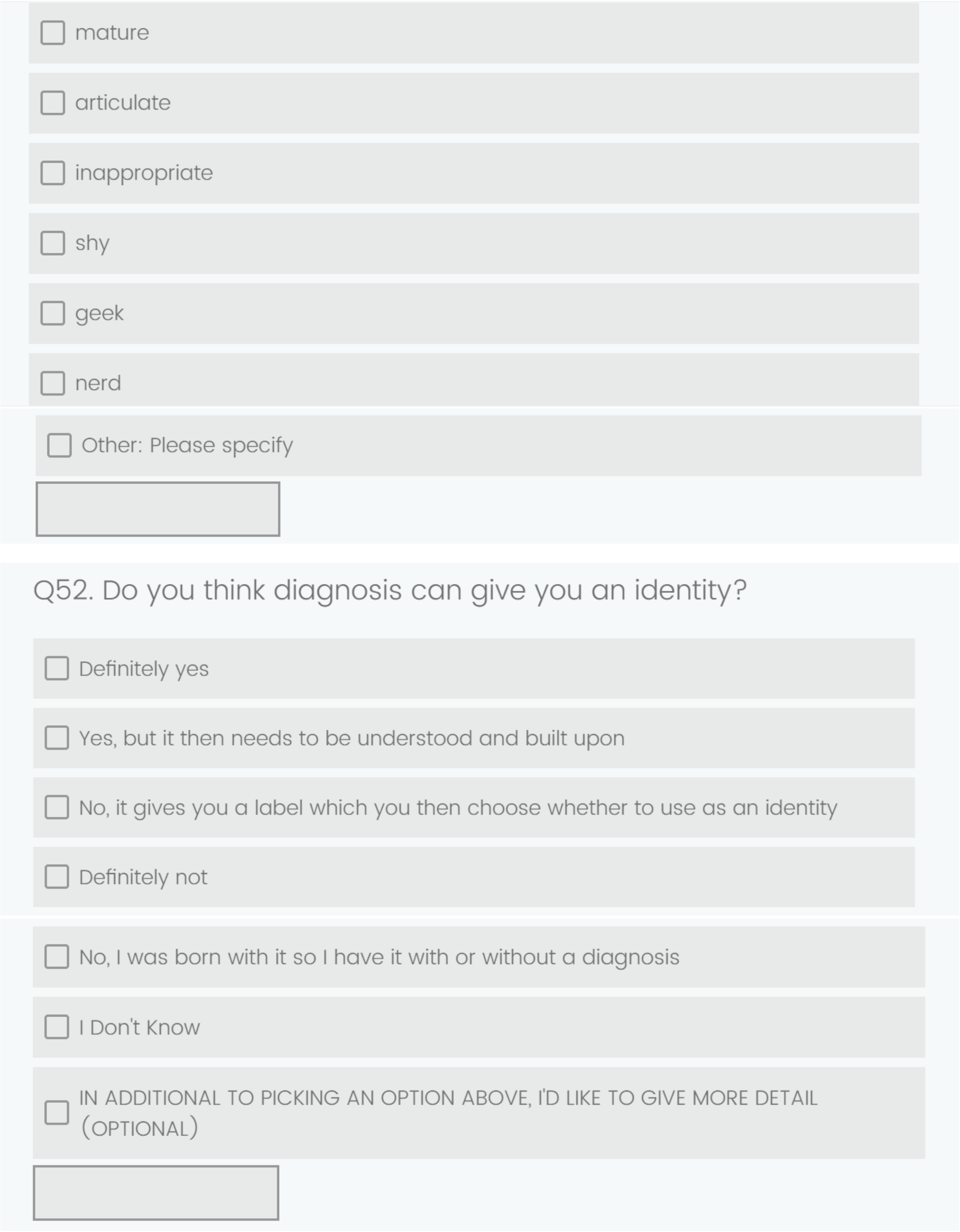
☐ None of the above

☐ IN ADDITIONAL TO PICKING AN OPTION ABOVE, I'D LIKE TO GIVE MORE DETAIL (OPTIONAL)



Q51. Below is a list of labels which in initial research, people said they had experience of being place upon them by others. Which labels have you had placed upon you, by others, in your past? (Tick all that Apply)

☐ gifted
☐ intelligent
☐ weird
☐ crazy
☐ babyish
☐ boffin
☐ stubborn
☐ rude
☐ stupid
☐ different
☐ naughty
☐ awkward
☐ inflexible
☐ evil
☐ outcast



☐ mature

☐ articulate

☐ inappropriate

☐ shy

☐ geek

☐ nerd

☐ Other: Please specify

Q52. Do you think diagnosis can give you an identity?

☐ Definitely yes

☐ Yes, but it then needs to be understood and built upon

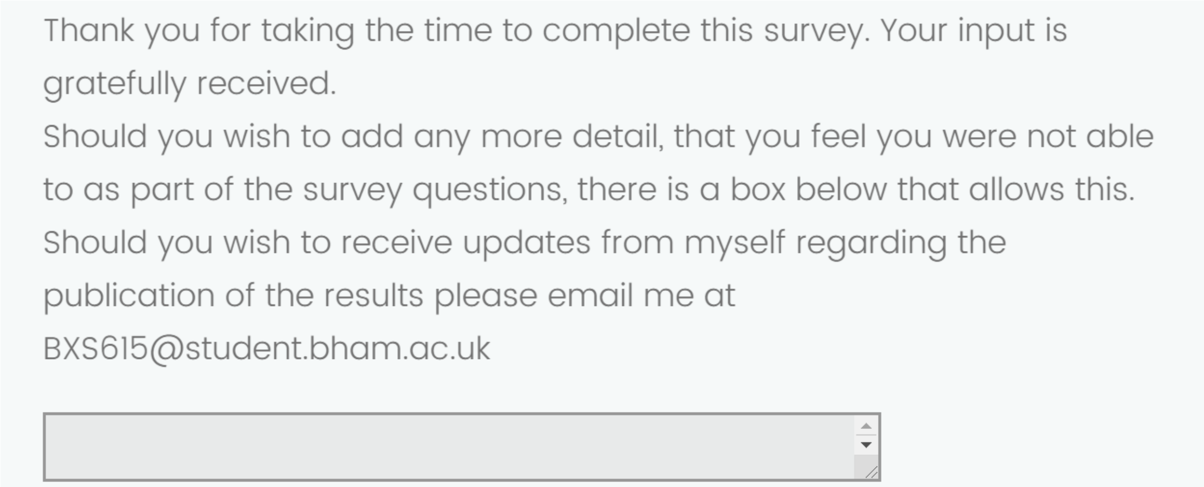
☐ No, it gives you a label which you then choose whether to use as an identity

☐ Definitely not

☐ No, I was born with it so I have it with or without a diagnosis

☐ I Don't Know

☐ IN ADDITIONAL TO PICKING AN OPTION ABOVE, I'D LIKE TO GIVE MORE DETAIL (OPTIONAL)

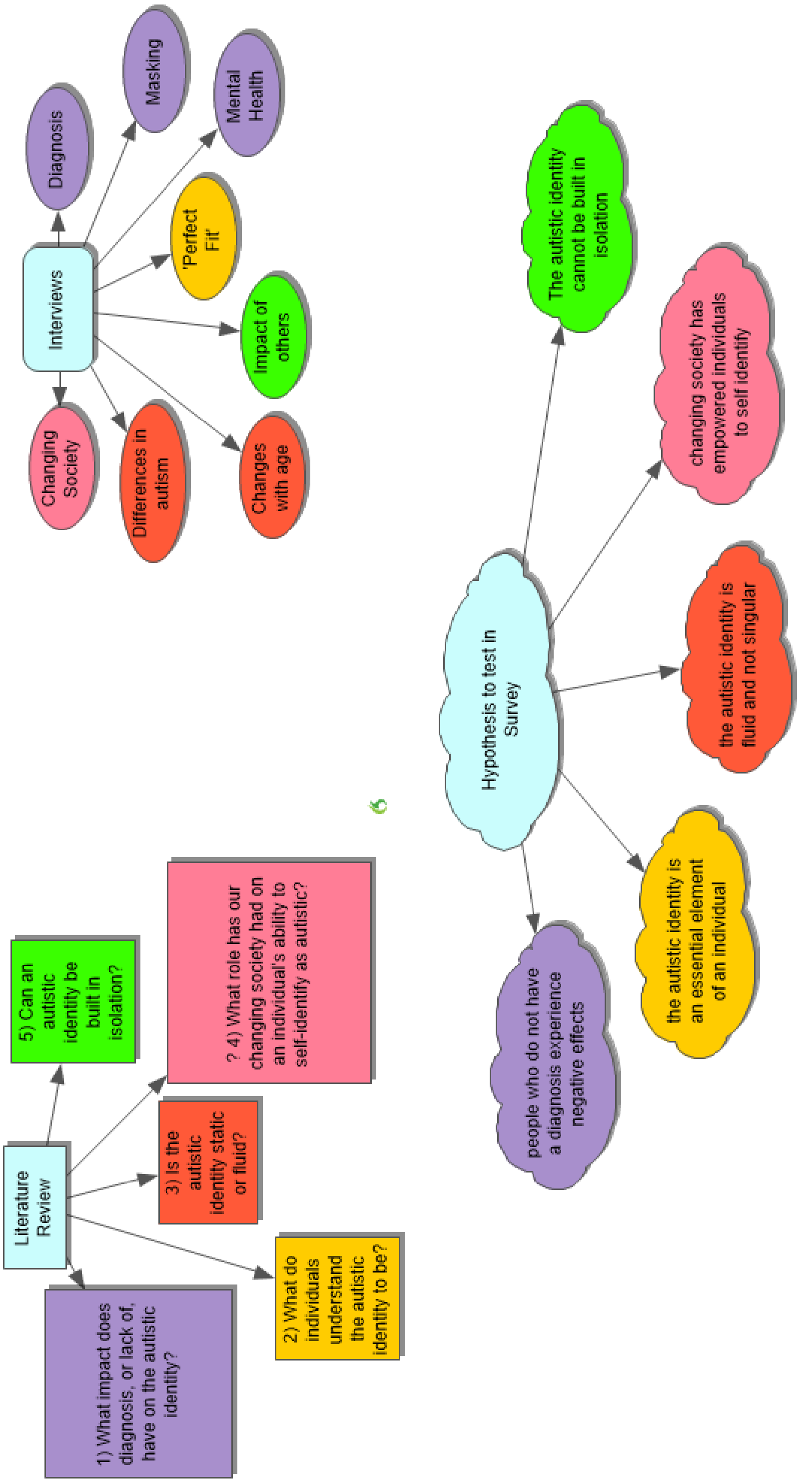


Thank you for taking the time to complete this survey. Your input is gratefully received.

Should you wish to add any more detail, that you feel you were not able to as part of the survey questions, there is a box below that allows this.

Should you wish to receive updates from myself regarding the publication of the results please email me at BXS615@student.bham.ac.uk

Appendix 15: - Copy of themes to hypothesis for Phase Two



Appendix 16: - Random example of data collected from a completed survey with demographic information retracted

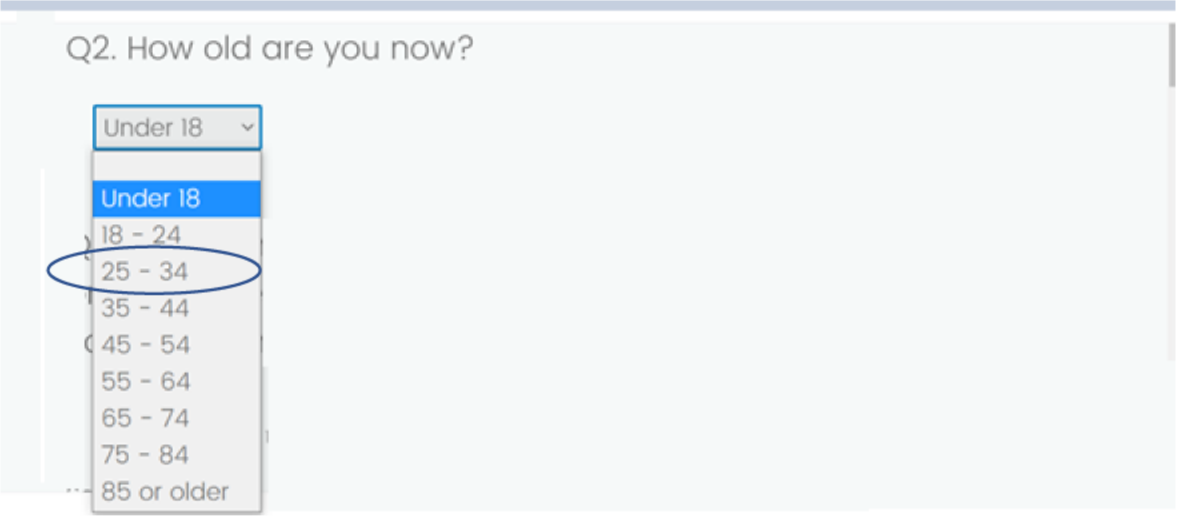
Q1. Please chose the option that describes your current position most accurately

☑ Self-diagnosed, not formally diagnosed

○ Self-diagnosed and then formally diagnosed

○ Formally diagnosed after someone else thought I was autistic

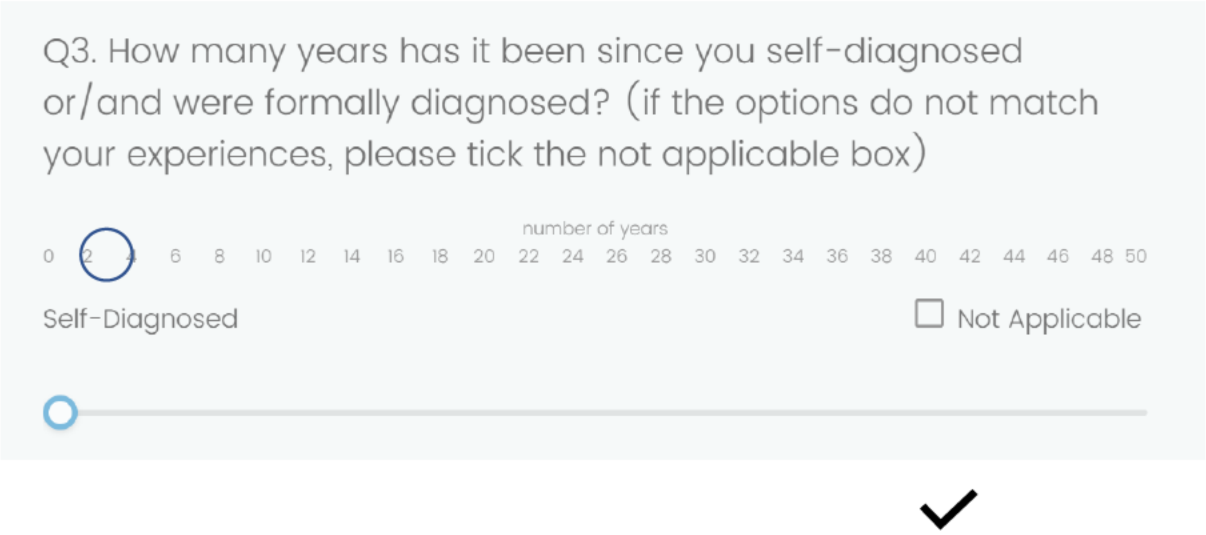
○ Formally diagnosed when I was younger, so I had no involvement in it



Q2. How old are you now?

Under 18

- Under 18
- 18 - 24
- [✓ 25 - 34]
- 35 - 44
- 45 - 54
- 55 - 64
- 65 - 74
- 75 - 84
- 85 or older



Q3. How many years has it been since you self-diagnosed or/and were formally diagnosed? (if the options do not match your experiences, please tick the not applicable box)

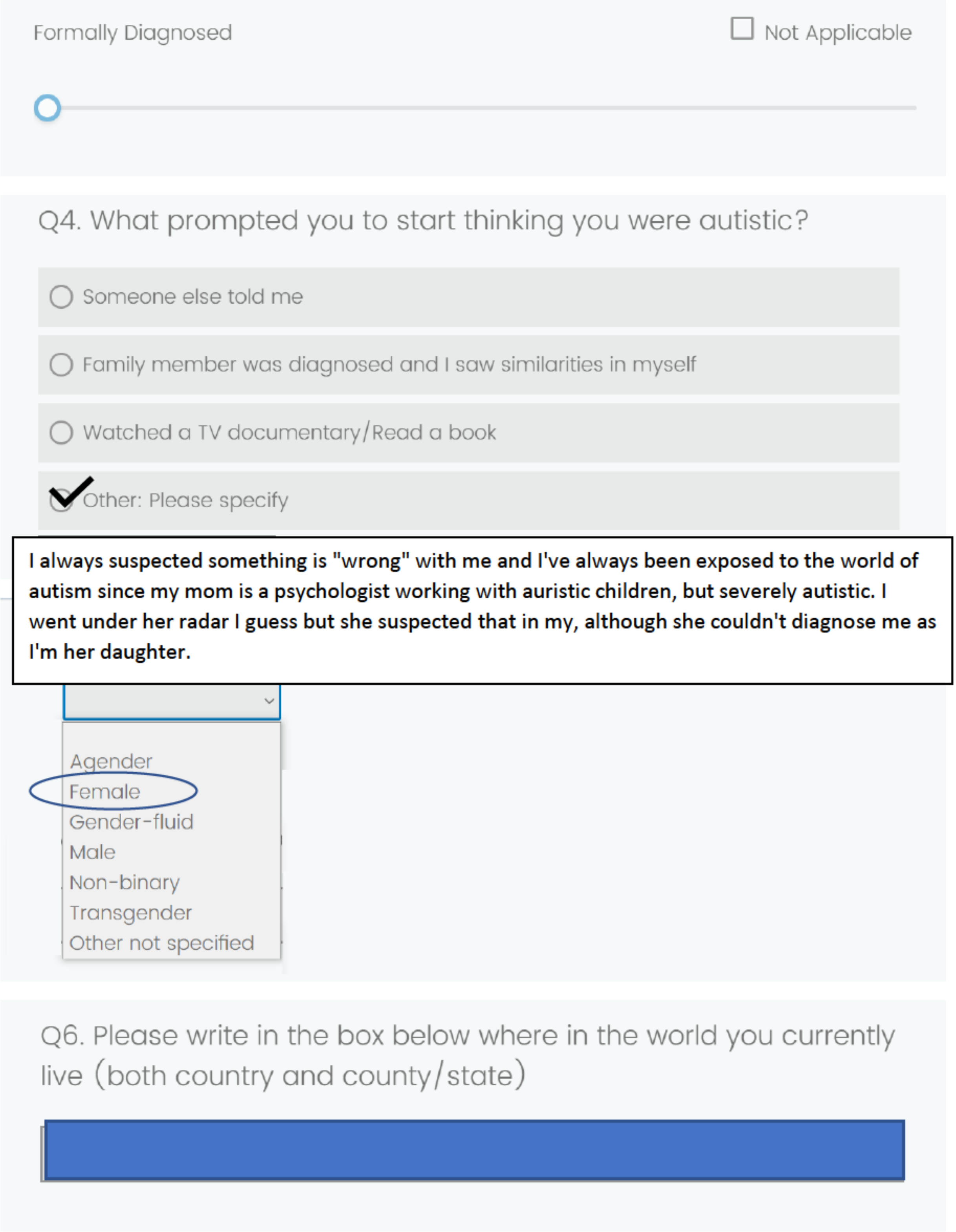
number of years

0 [✓ 2] 4 6 8 10 12 14 16 18 20 22 24 26 28 30 32 34 36 38 40 42 44 46 48 50

Self-Diagnosed

☐ Not Applicable

✓



Formally Diagnosed ☐ Not Applicable

Q4. What prompted you to start thinking you were autistic?

○ Someone else told me

○ Family member was diagnosed and I saw similarities in myself

○ Watched a TV documentary/Read a book

☑ Other: Please specify

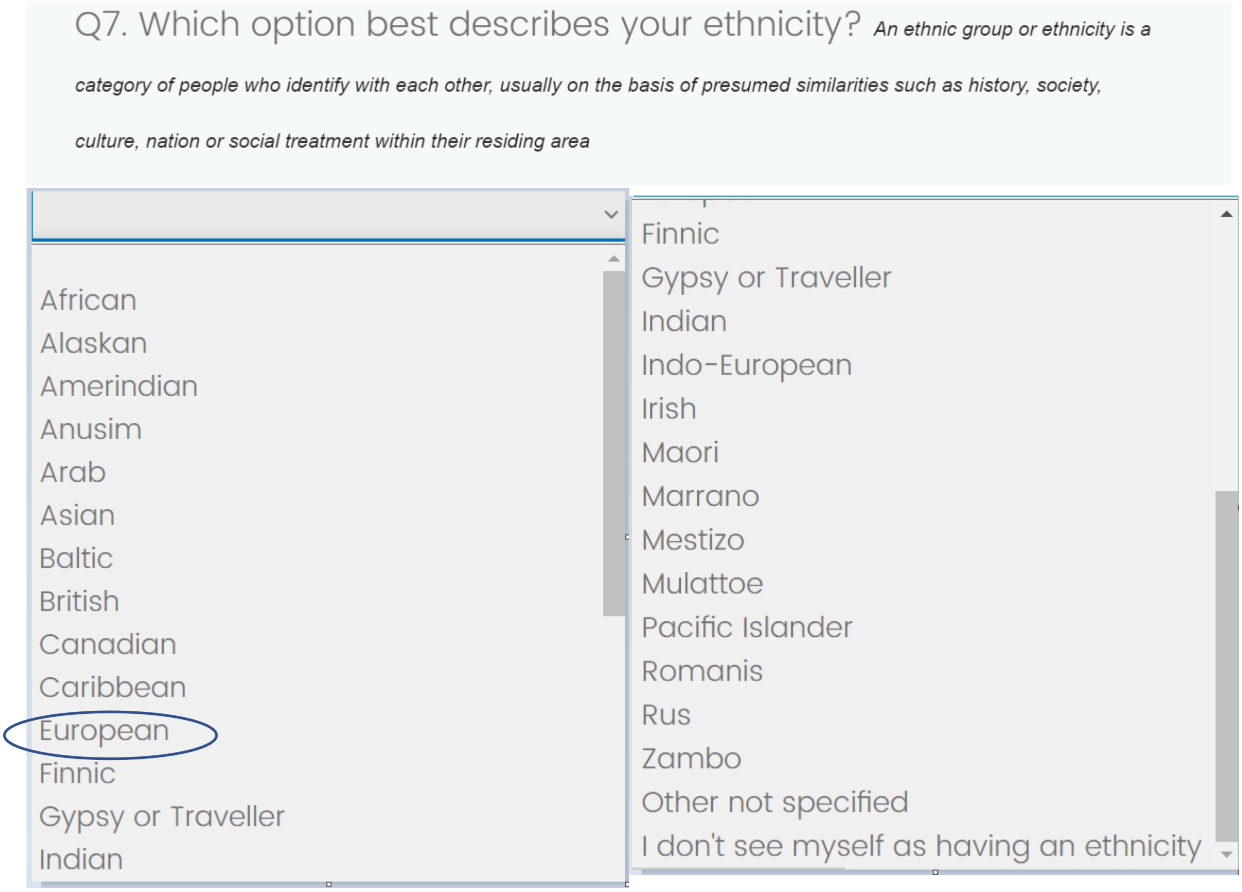
I always suspected something is "wrong" with me and I've always been exposed to the world of autism since my mom is a psychologist working with auristic children, but severely autistic. I went under her radar I guess but she suspected that in my, although she couldn't diagnose me as I'm her daughter.

- Agender
- [✓ Female]
- Gender-fluid
- Male
- Non-binary
- Transgender
- Other not specified

Q6. Please write in the box below where in the world you currently live (both country and county/state)

[redacted]

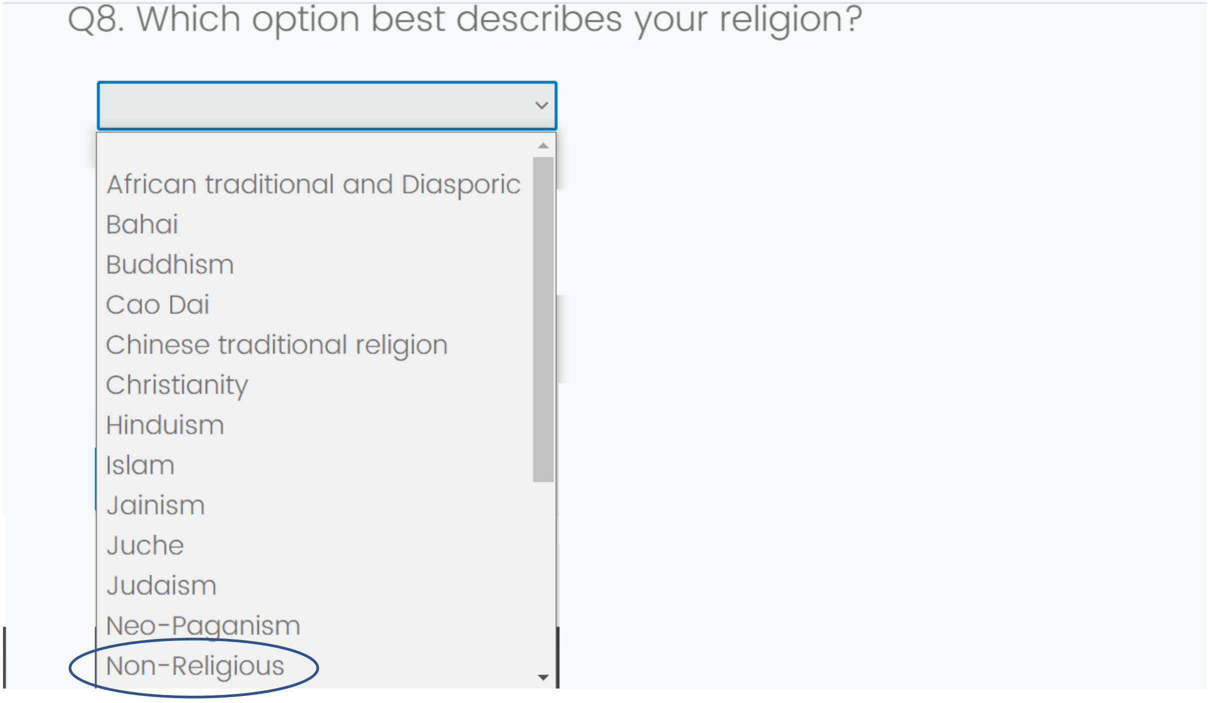
Information redacted to ensure anonymity is maintained



Q7. Which option best describes your ethnicity? *An ethnic group or ethnicity is a category of people who identify with each other, usually on the basis of presumed similarities such as history, society, culture, nation or social treatment within their residing area*

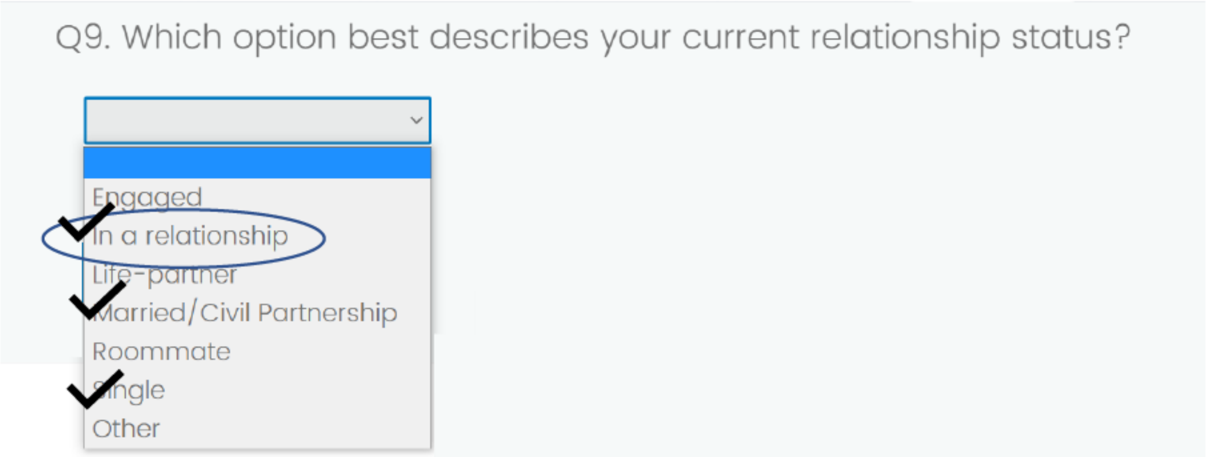
African
Alaskan
Amerindian
Anusim
Arab
Asian
Baltic
British
Canadian
Caribbean
[✓ European]
Finnic
Gypsy or Traveller
Indian

Finnic
Gypsy or Traveller
Indian
Indo-European
Irish
Maori
Marrano
Mestizo
Mulattoe
Pacific Islander
Romanis
Rus
Zambo
Other not specified
I don't see myself as having an ethnicity



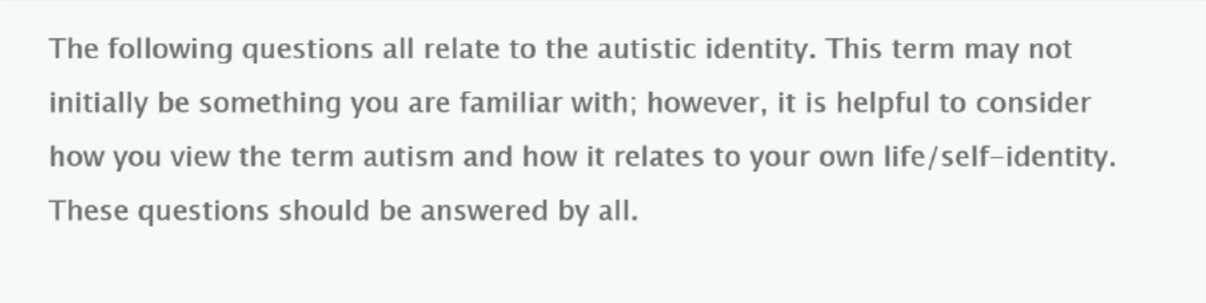
Q8. Which option best describes your religion?

African traditional and Diasporic
Bahai
Buddhism
Cao Dai
Chinese traditional religion
Christianity
Hinduism
Islam
Jainism
Juche
Judaism
Neo-Paganism
[✓ Non-Religious]

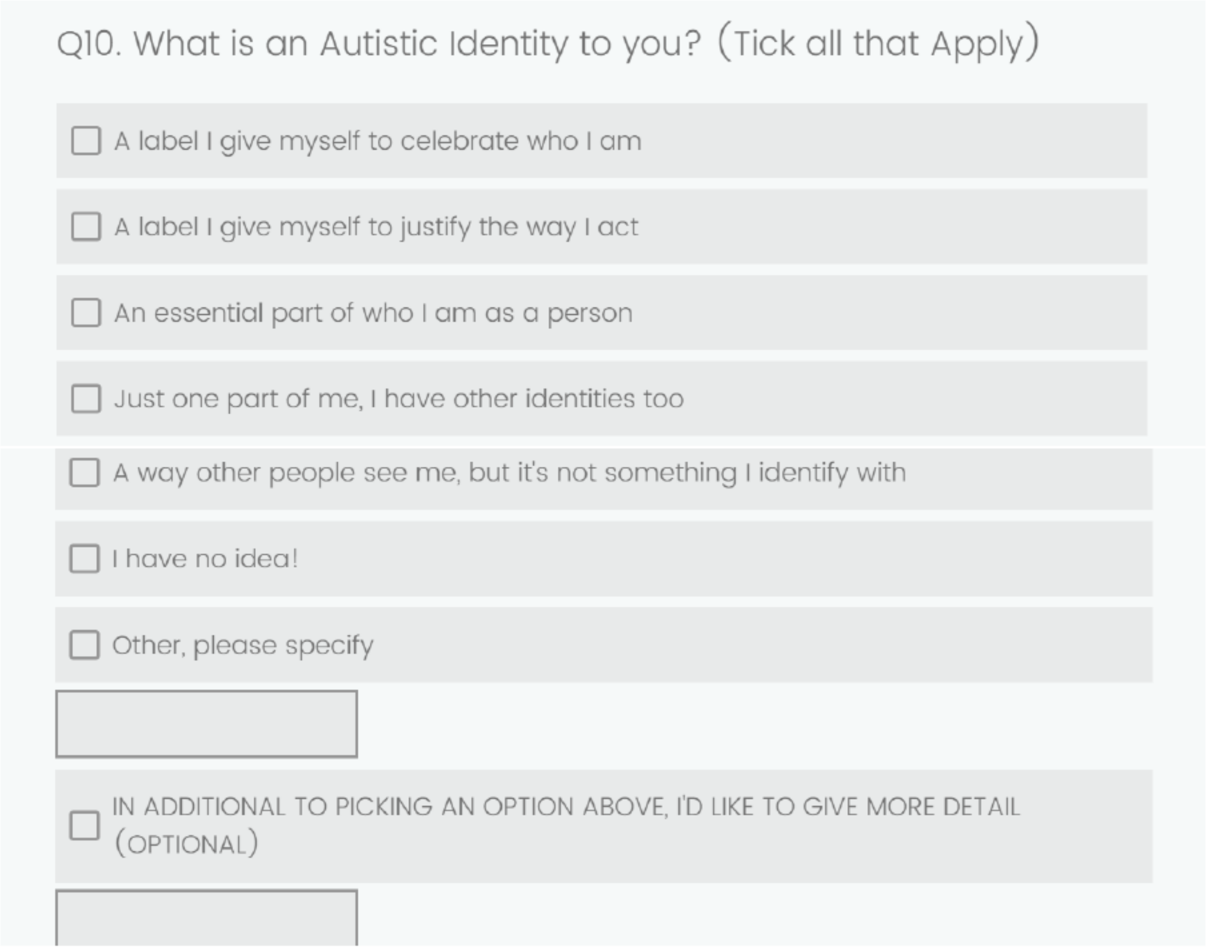


Q9. Which option best describes your current relationship status?

Engaged
✓ [✓ In a relationship]
Life-partner
✓ Married/Civil Partnership
Roommate
✓ Single
Other

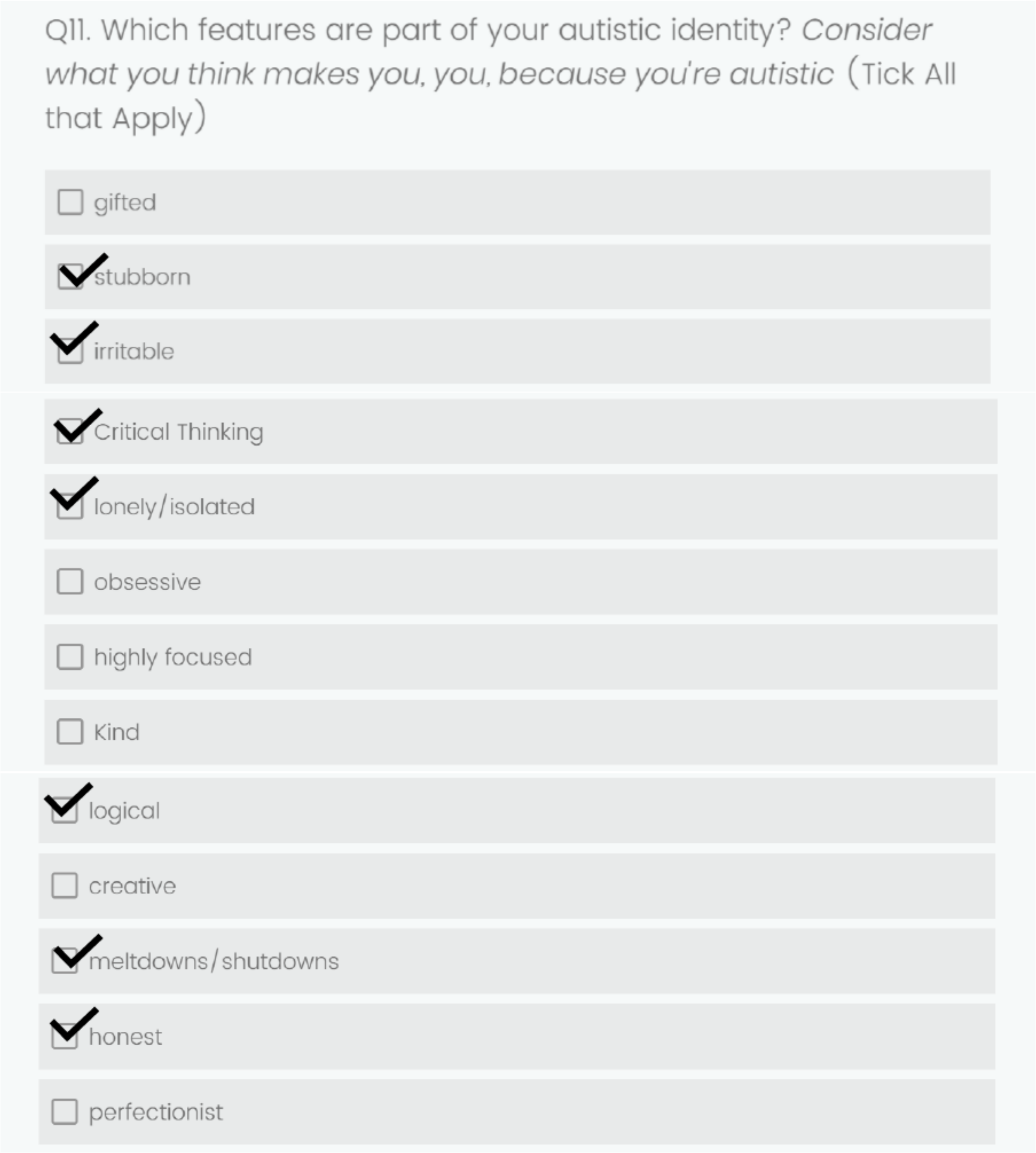


The following questions all relate to the autistic identity. This term may not initially be something you are familiar with; however, it is helpful to consider how you view the term autism and how it relates to your own life/self-identity. These questions should be answered by all.



Q10. What is an Autistic Identity to you? (Tick all that Apply)

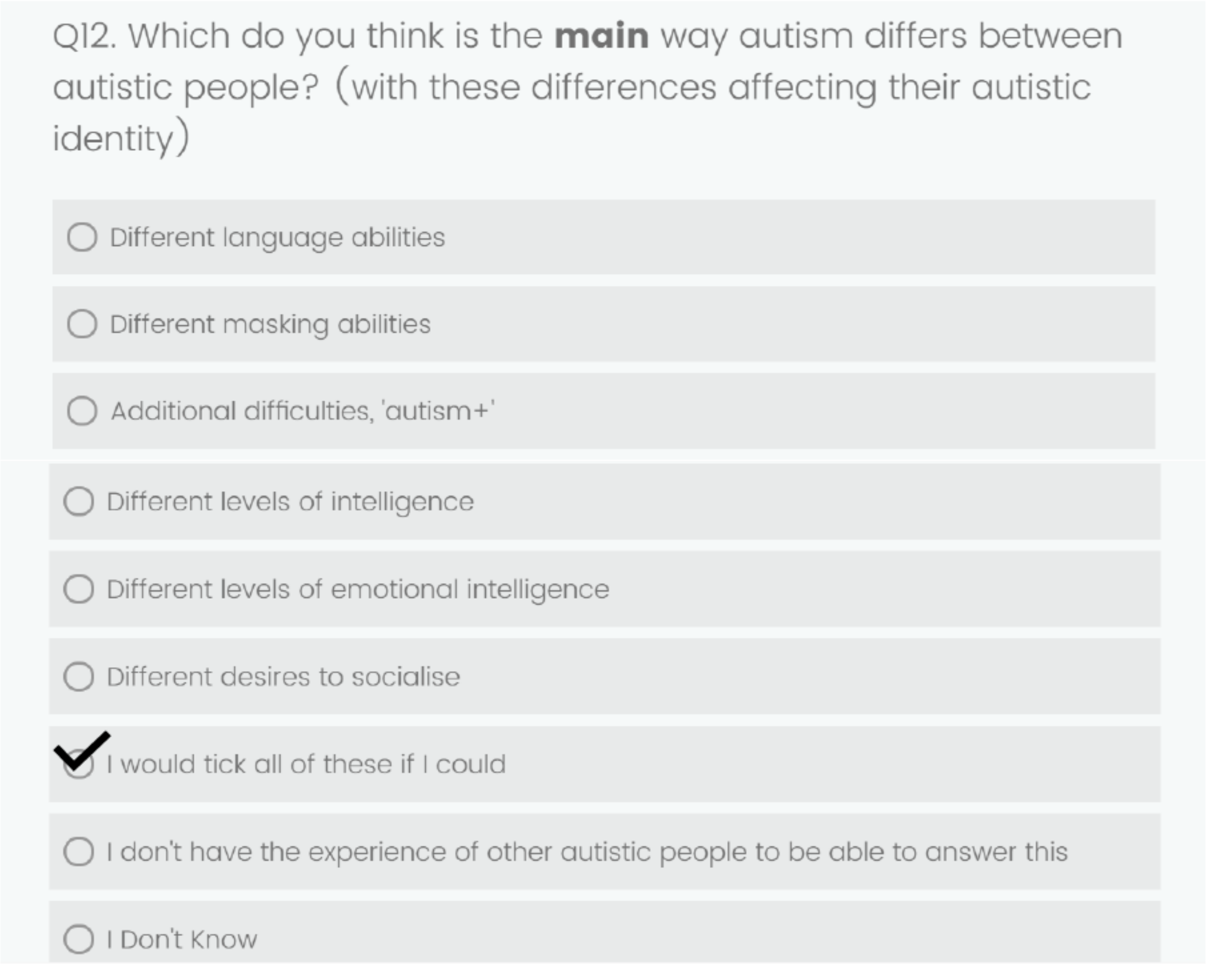
☐ A label I give myself to celebrate who I am
☐ A label I give myself to justify the way I act
☐ An essential part of who I am as a person
☐ Just one part of me, I have other identities too
☐ A way other people see me, but it's not something I identify with
☐ I have no idea!
☐ Other, please specify
☐ IN ADDITIONAL TO PICKING AN OPTION ABOVE, I'D LIKE TO GIVE MORE DETAIL (OPTIONAL)



Q11. Which features are part of your autistic identity? *Consider what you think makes you, you, because you're autistic* (Tick All that Apply)

☐ gifted
☑ stubborn
☑ irritable
☑ Critical Thinking
☑ lonely/isolated
☐ obsessive
☐ highly focused
☐ Kind
☑ logical
☐ creative
☑ meltdowns/shutdowns
☑ honest
☐ perfectionist

- ☑ anxiety
- ☐ intelligent
- ☑ socially awkward
- ☑ Resilient
- ☐ Passionate
- ☐ concentration issues
- ☑ Good memory
- ☑ hatred of dishonesty
- ☑ Accepting of others
- ☑ feeling different to the 'norm'
- ☐ Other, please specify



Q12. Which do you think is the **main** way autism differs between autistic people? (with these differences affecting their autistic identity)

○ Different language abilities

○ Different masking abilities

○ Additional difficulties, 'autism+'

○ Different levels of intelligence

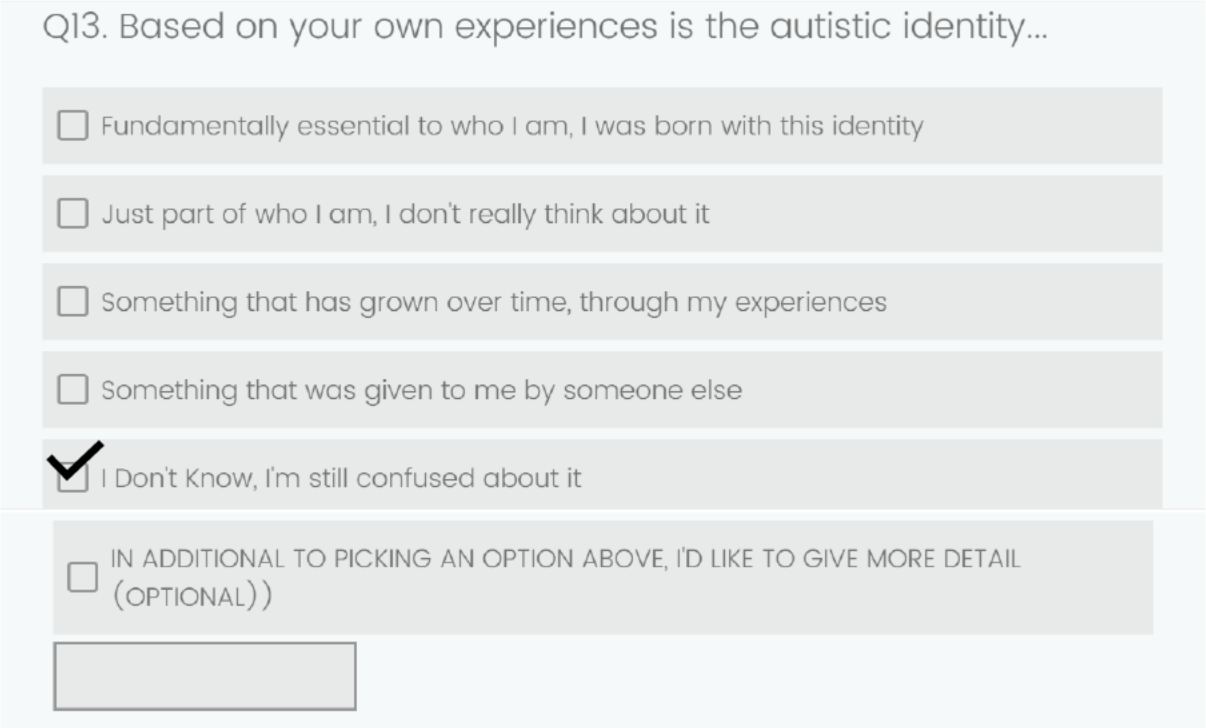
○ Different levels of emotional intelligence

○ Different desires to socialise

● I would tick all of these if I could

○ I don't have the experience of other autistic people to be able to answer this

○ I Don't Know



Q13. Based on your own experiences is the autistic identity...

☐ Fundamentally essential to who I am, I was born with this identity

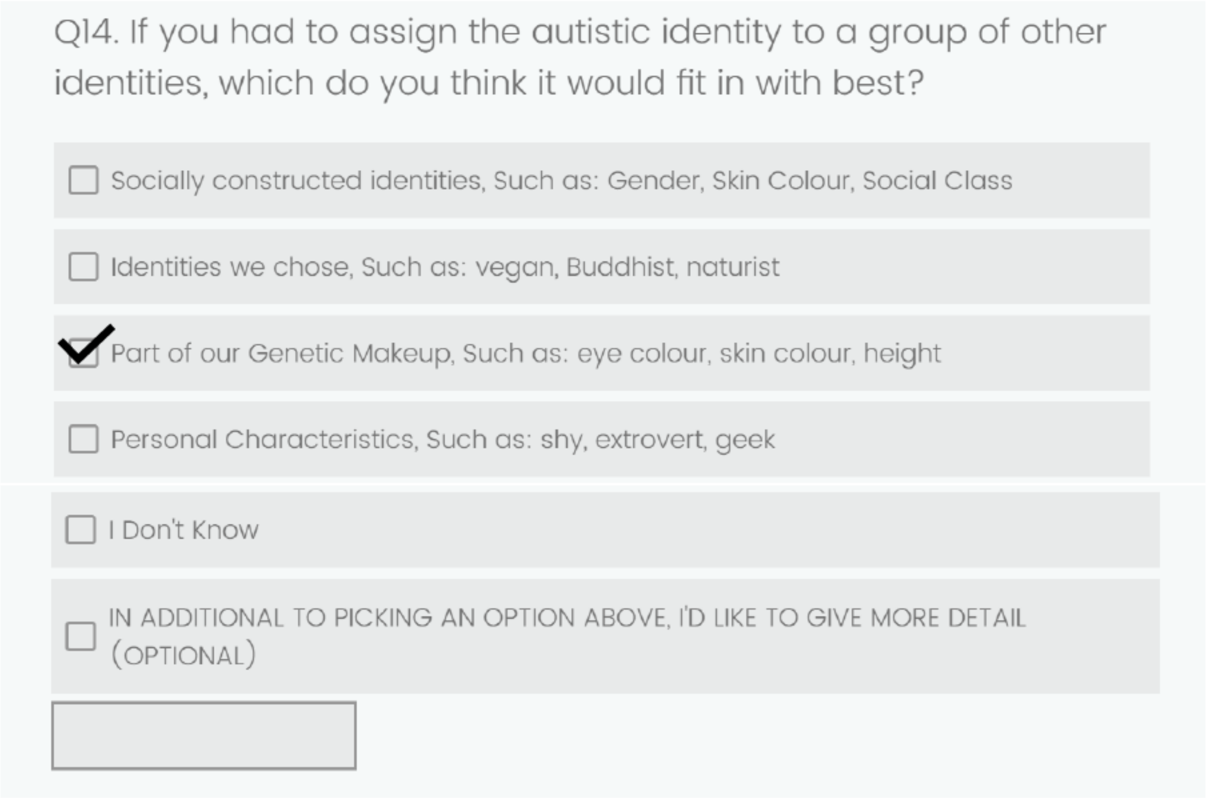
☐ Just part of who I am, I don't really think about it

☐ Something that has grown over time, through my experiences

☐ Something that was given to me by someone else

☑ I Don't Know, I'm still confused about it

☐ IN ADDITIONAL TO PICKING AN OPTION ABOVE, I'D LIKE TO GIVE MORE DETAIL (OPTIONAL))



Q14. If you had to assign the autistic identity to a group of other identities, which do you think it would fit in with best?

☐ Socially constructed identities, Such as: Gender, Skin Colour, Social Class

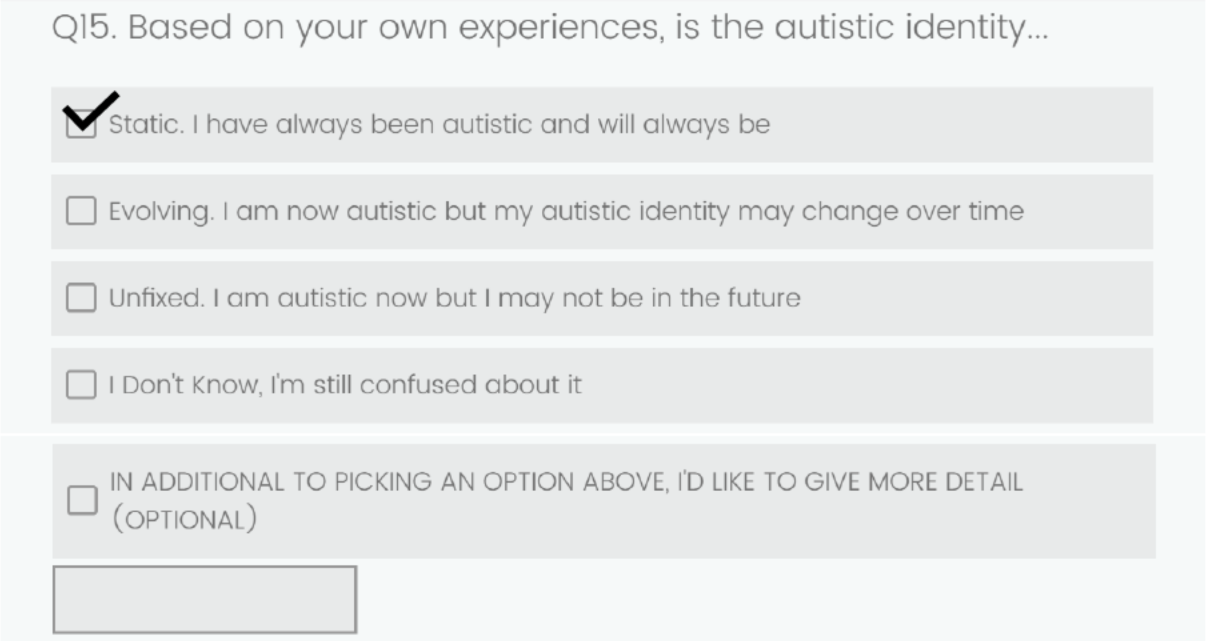
☐ Identities we chose, Such as: vegan, Buddhist, naturist

☑ Part of our Genetic Makeup, Such as: eye colour, skin colour, height

☐ Personal Characteristics, Such as: shy, extrovert, geek

☐ I Don't Know

☐ IN ADDITIONAL TO PICKING AN OPTION ABOVE, I'D LIKE TO GIVE MORE DETAIL (OPTIONAL)



Q15. Based on your own experiences, is the autistic identity...

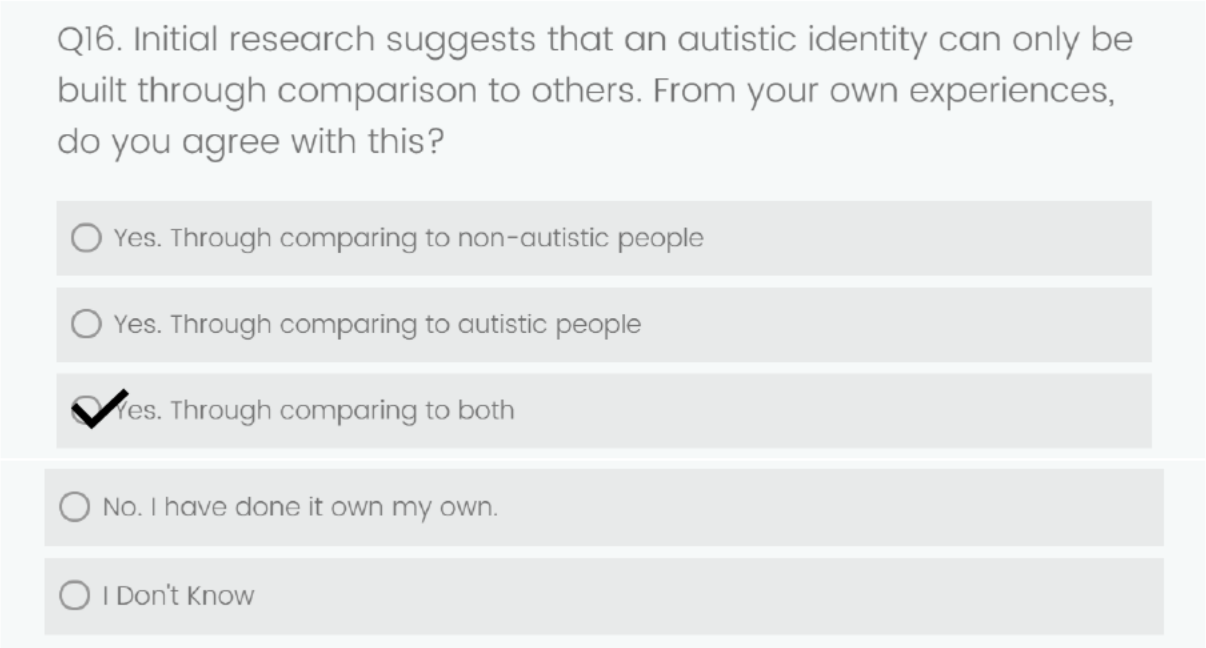
☑ Static. I have always been autistic and will always be

☐ Evolving. I am now autistic but my autistic identity may change over time

☐ Unfixed. I am autistic now but I may not be in the future

☐ I Don't Know, I'm still confused about it

☐ IN ADDITIONAL TO PICKING AN OPTION ABOVE, I'D LIKE TO GIVE MORE DETAIL (OPTIONAL)



Q16. Initial research suggests that an autistic identity can only be built through comparison to others. From your own experiences, do you agree with this?

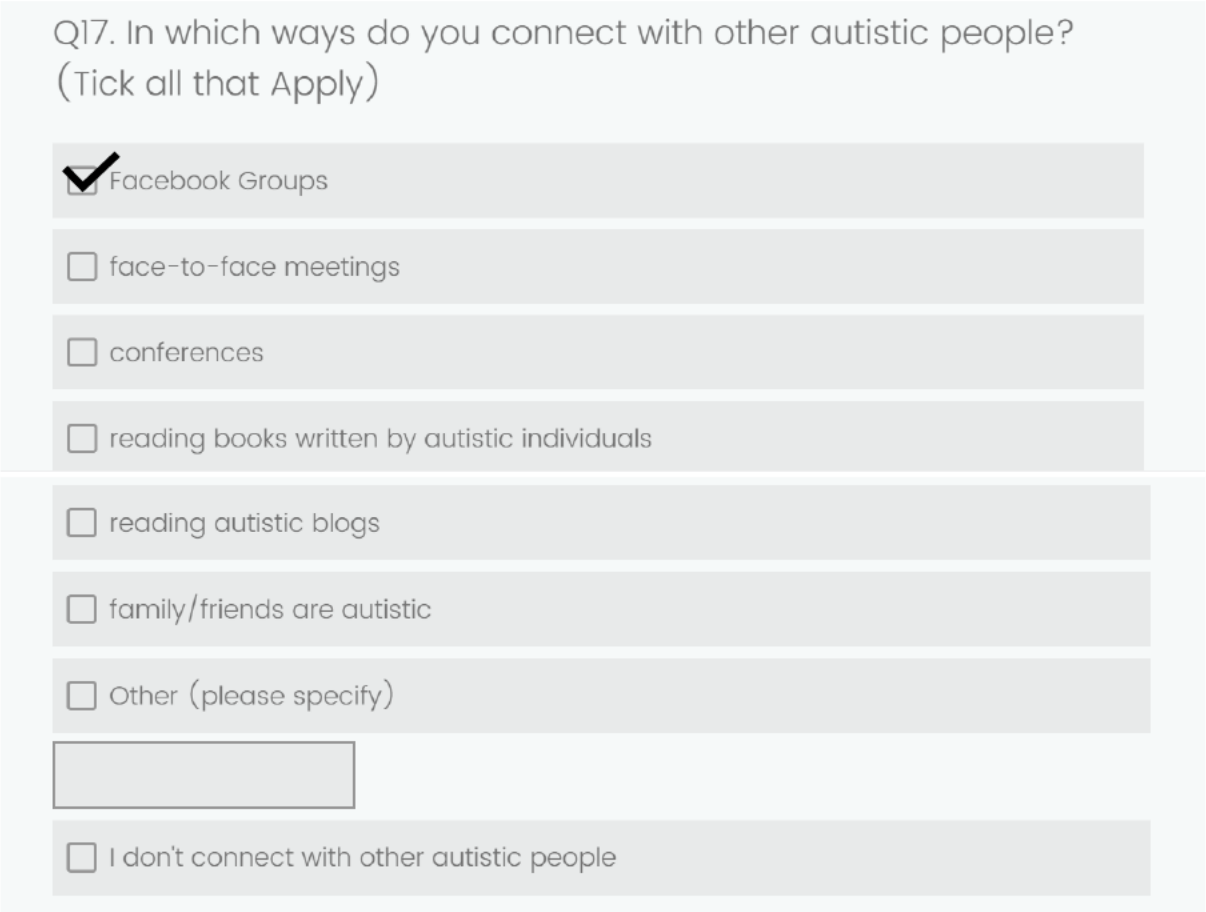
○ Yes. Through comparing to non-autistic people

○ Yes. Through comparing to autistic people

● Yes. Through comparing to both

○ No. I have done it own my own.

○ I Don't Know



Q17. In which ways do you connect with other autistic people? (Tick all that Apply)

☑ Facebook Groups

☐ face-to-face meetings

☐ conferences

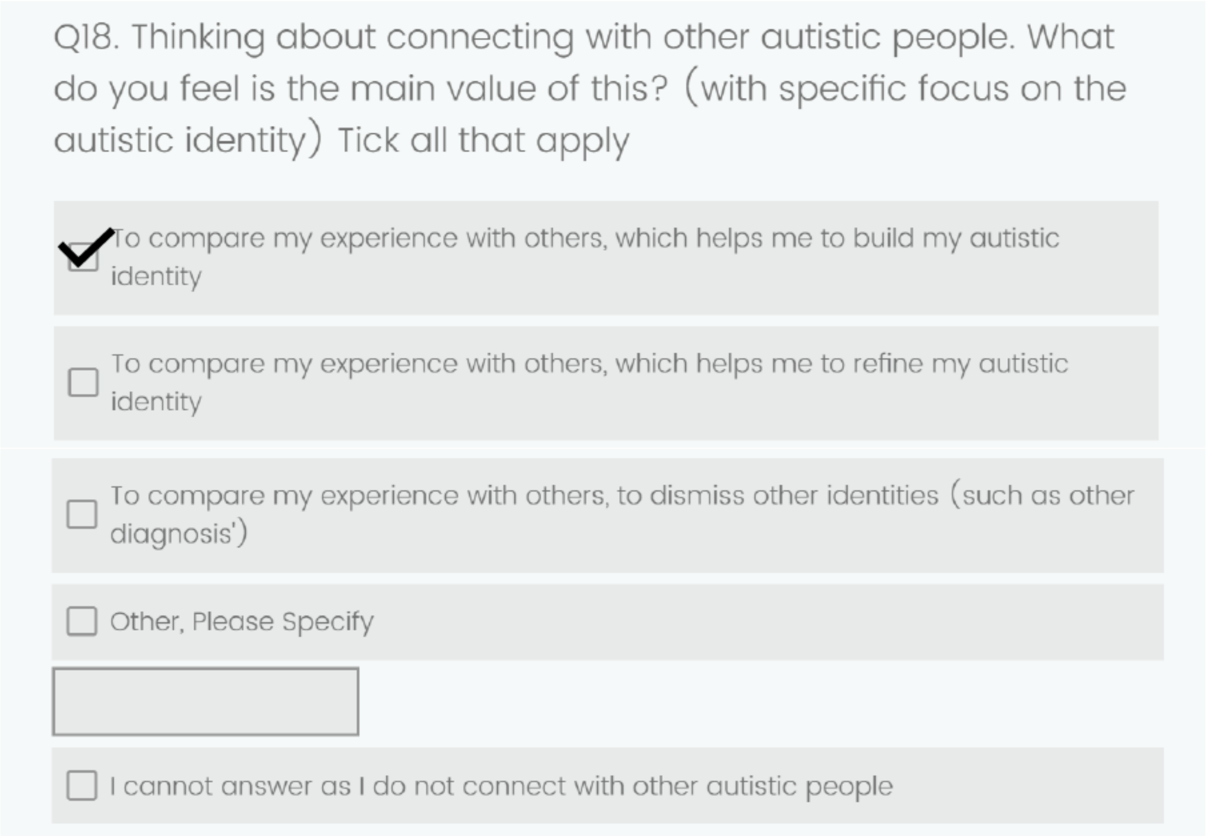
☐ reading books written by autistic individuals

☐ reading autistic blogs

☐ family/friends are autistic

☐ Other (please specify)

☐ I don't connect with other autistic people



Q18. Thinking about connecting with other autistic people. What do you feel is the main value of this? (with specific focus on the autistic identity) Tick all that apply

☑ To compare my experience with others, which helps me to build my autistic identity

☐ To compare my experience with others, which helps me to refine my autistic identity

☐ To compare my experience with others, to dismiss other identities (such as other diagnosis')

☐ Other, Please Specify

☐ I cannot answer as I do not connect with other autistic people

Q19. At what age do you think you started to notice you were 'different' to others around you?

○ 1 - 3 years

● 4 - 10 years

○ 11 - 16 years

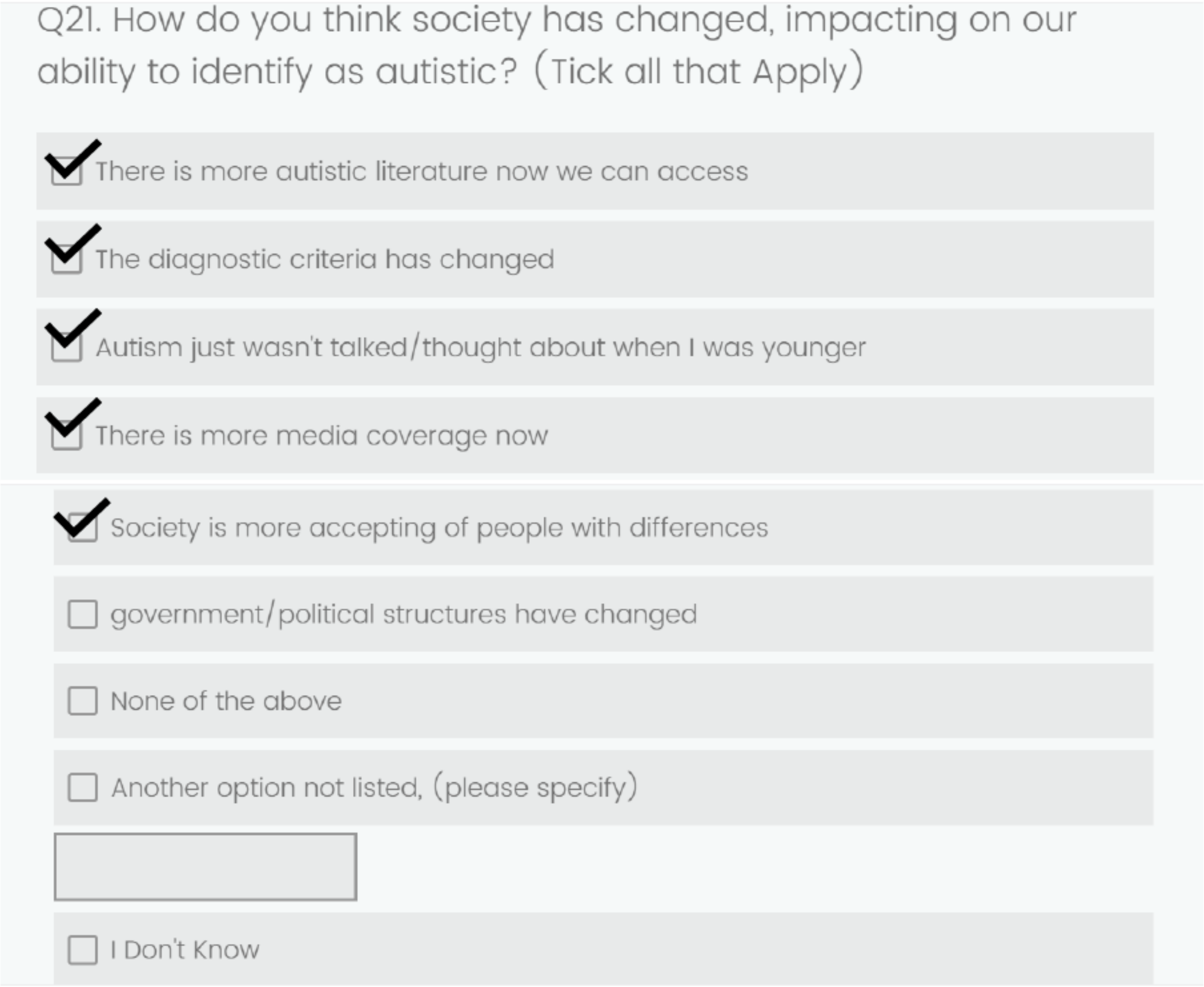
○ 17 - 25 years

○ 26 years +

○ I don't see myself as different

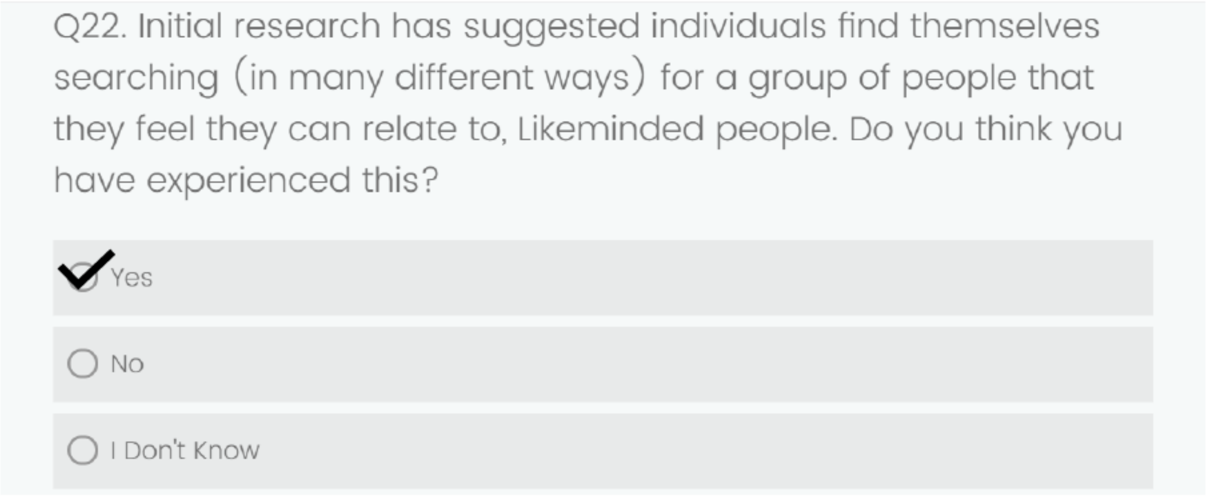
Q20. Do you think puberty changed the way you saw/interacted with the social world?

- ● Yes
- ○ No
- ○ Possibly, I've never thought about it that way before
- ○ I Don't Know



Q21. How do you think society has changed, impacting on our ability to identify as autistic? (Tick all that Apply)

- ☑ There is more autistic literature now we can access
- ☑ The diagnostic criteria has changed
- ☑ Autism just wasn't talked/thought about when I was younger
- ☑ There is more media coverage now
- ☑ Society is more accepting of people with differences
- ☐ government/political structures have changed
- ☐ None of the above
- ☐ Another option not listed, (please specify)
- ☐ I Don't Know

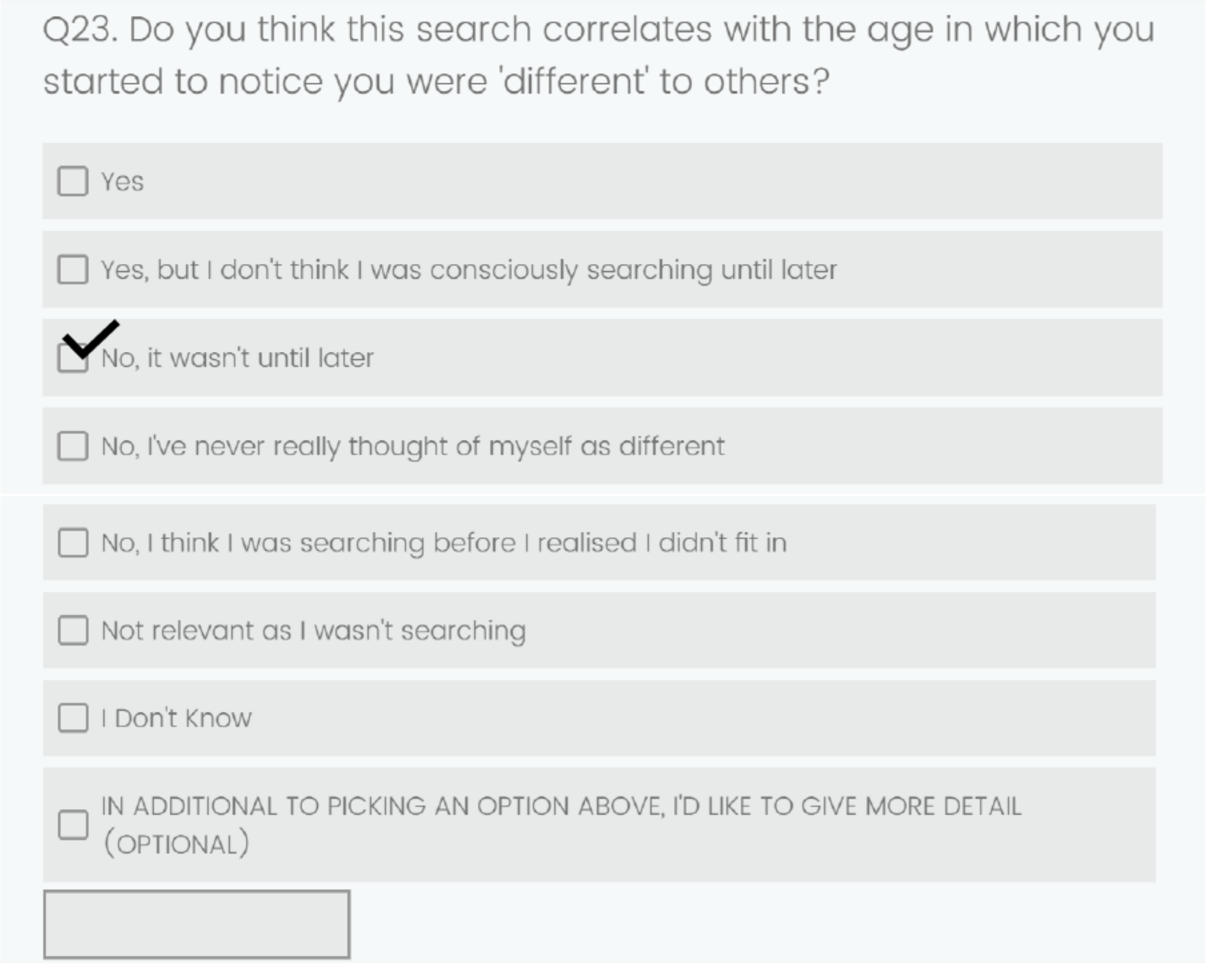


Q22. Initial research has suggested individuals find themselves searching (in many different ways) for a group of people that they feel they can relate to, Likeminded people. Do you think you have experienced this?

● Yes

○ No

○ I Don't Know



Q23. Do you think this search correlates with the age in which you started to notice you were 'different' to others?

☐ Yes

☐ Yes, but I don't think I was consciously searching until later

☑ No, it wasn't until later

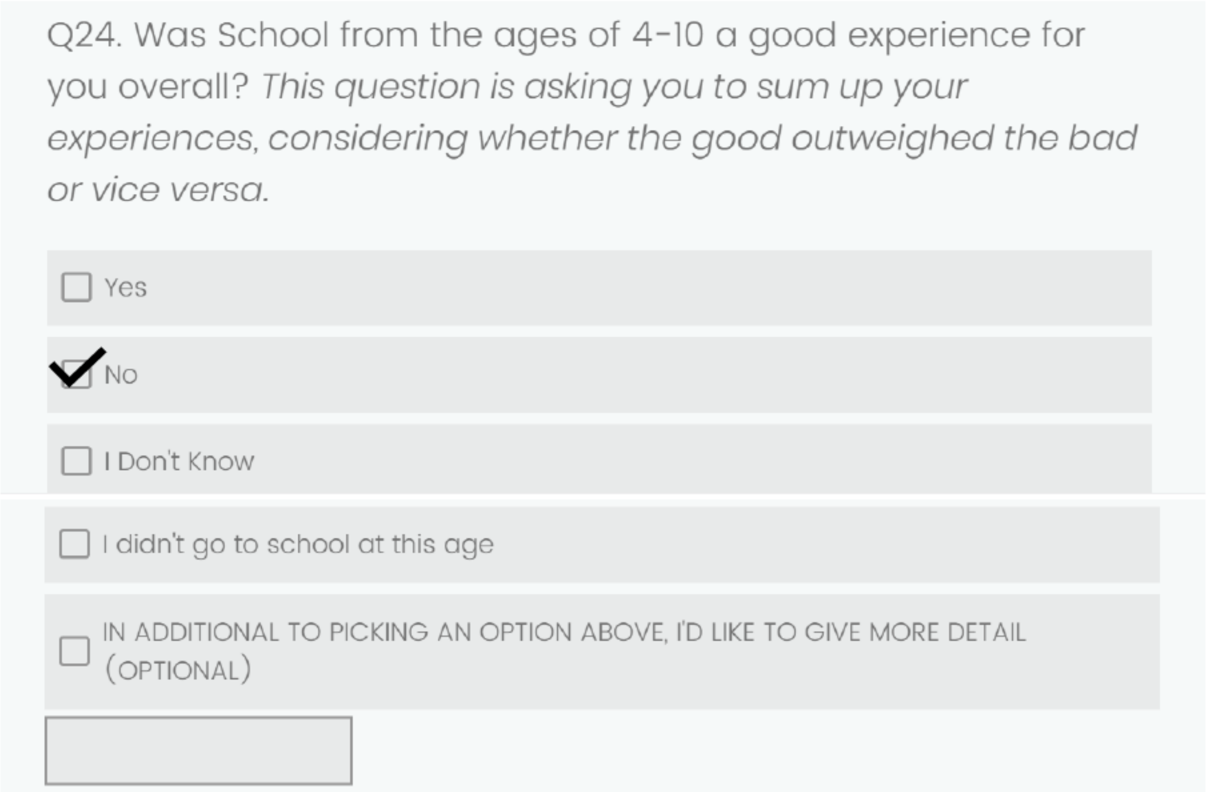
☐ No, I've never really thought of myself as different

☐ No, I think I was searching before I realised I didn't fit in

☐ Not relevant as I wasn't searching

☐ I Don't Know

☐ IN ADDITIONAL TO PICKING AN OPTION ABOVE, I'D LIKE TO GIVE MORE DETAIL (OPTIONAL)



Q24. Was School from the ages of 4-10 a good experience for you overall? *This question is asking you to sum up your experiences, considering whether the good outweighed the bad or vice versa.*

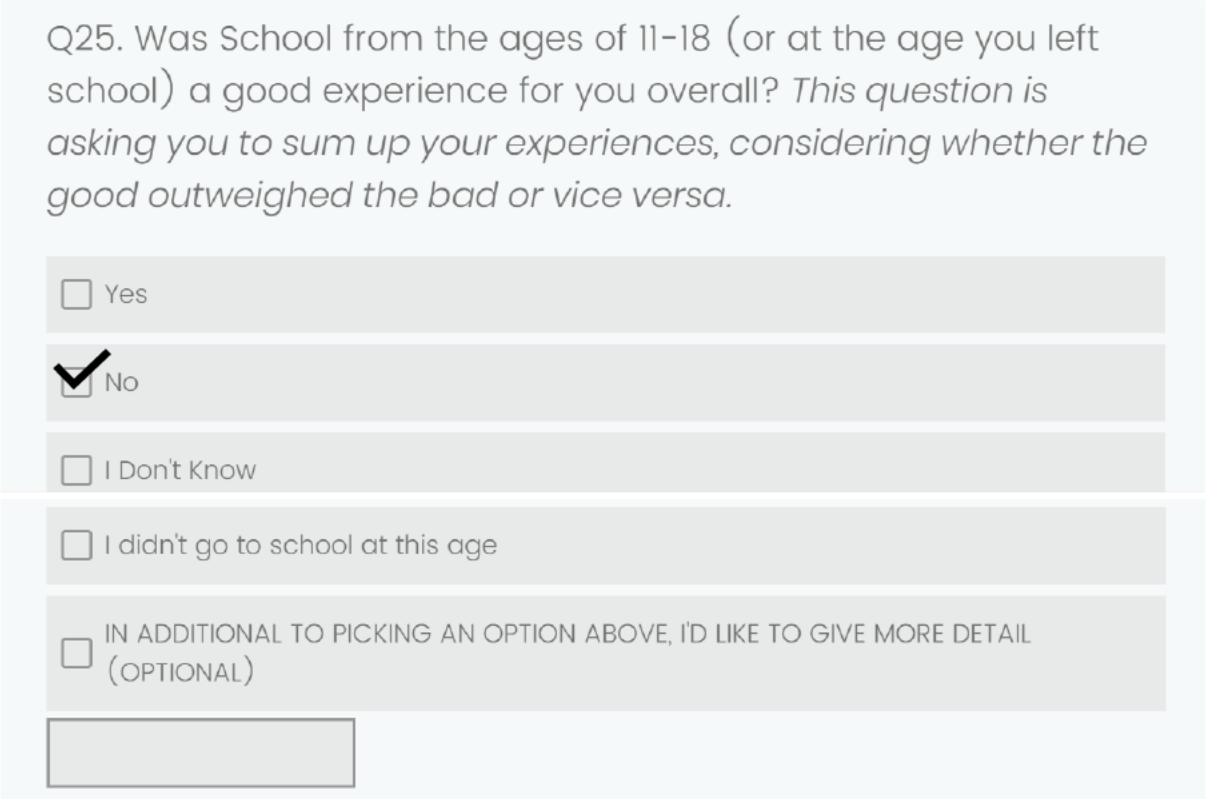
☐ Yes

☑ No

☐ I Don't Know

☐ I didn't go to school at this age

☐ IN ADDITIONAL TO PICKING AN OPTION ABOVE, I'D LIKE TO GIVE MORE DETAIL (OPTIONAL)



Q25. Was School from the ages of 11-18 (or at the age you left school) a good experience for you overall? *This question is asking you to sum up your experiences, considering whether the good outweighed the bad or vice versa.*

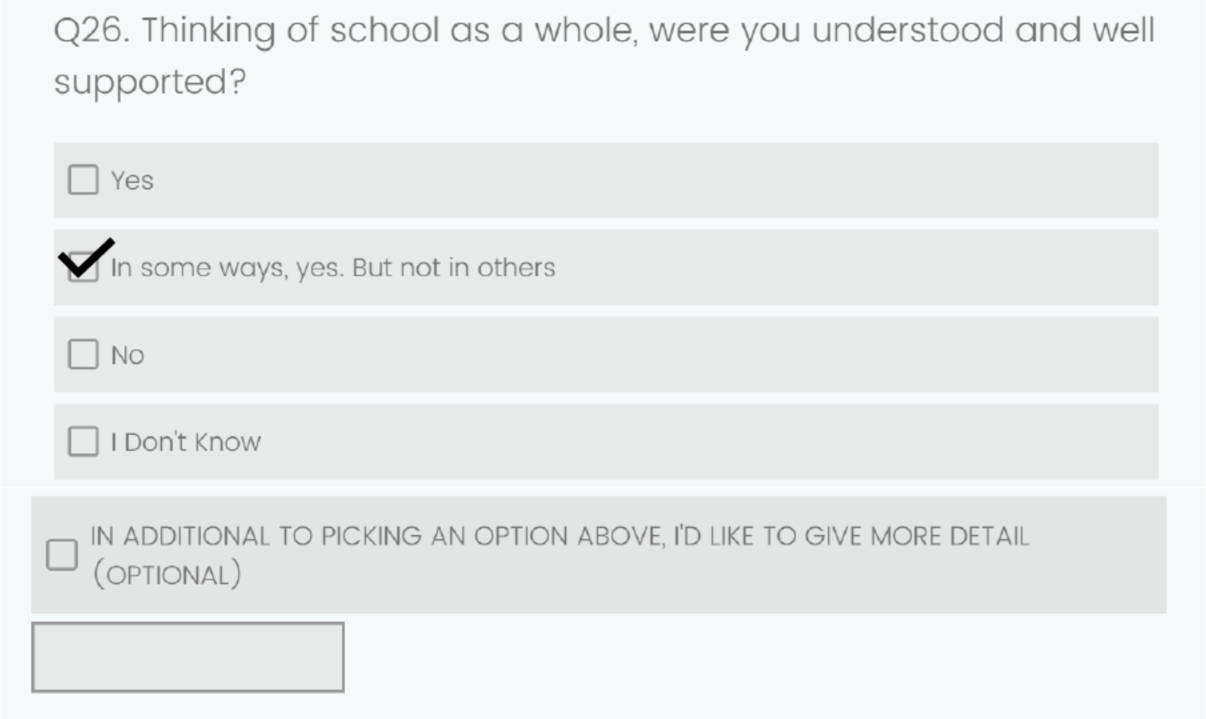
☐ Yes

☑ No

☐ I Don't Know

☐ I didn't go to school at this age

☐ IN ADDITIONAL TO PICKING AN OPTION ABOVE, I'D LIKE TO GIVE MORE DETAIL (OPTIONAL)



Q26. Thinking of school as a whole, were you understood and well supported?

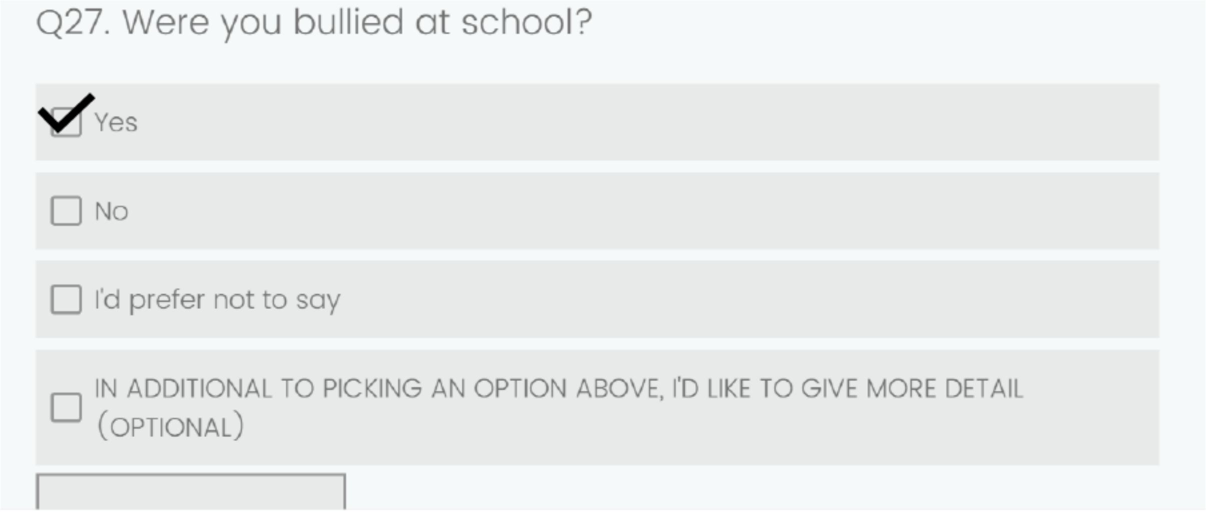
☐ Yes

☑ In some ways, yes. But not in others

☐ No

☐ I Don't Know

☐ IN ADDITIONAL TO PICKING AN OPTION ABOVE, I'D LIKE TO GIVE MORE DETAIL (OPTIONAL)



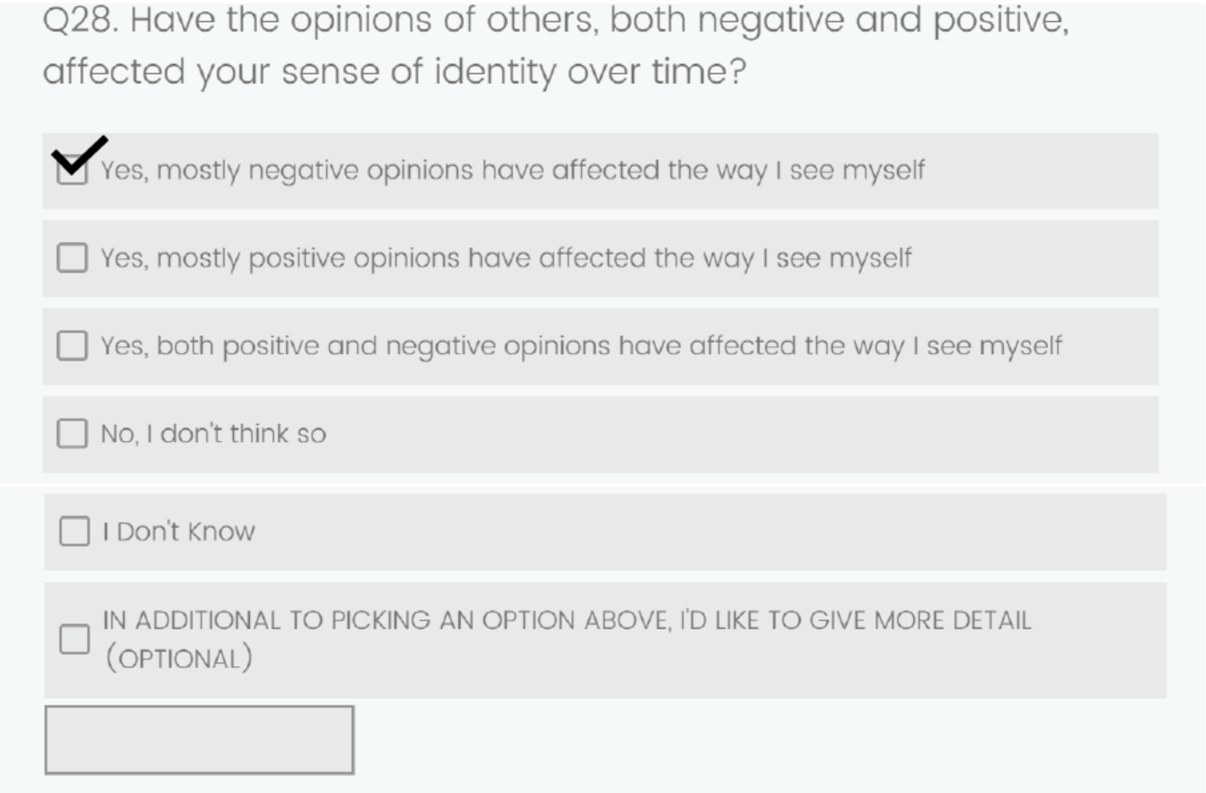
Q27. Were you bullied at school?

☑ Yes

☐ No

☐ I'd prefer not to say

☐ IN ADDITIONAL TO PICKING AN OPTION ABOVE, I'D LIKE TO GIVE MORE DETAIL (OPTIONAL)



Q28. Have the opinions of others, both negative and positive, affected your sense of identity over time?

☑ Yes, mostly negative opinions have affected the way I see myself

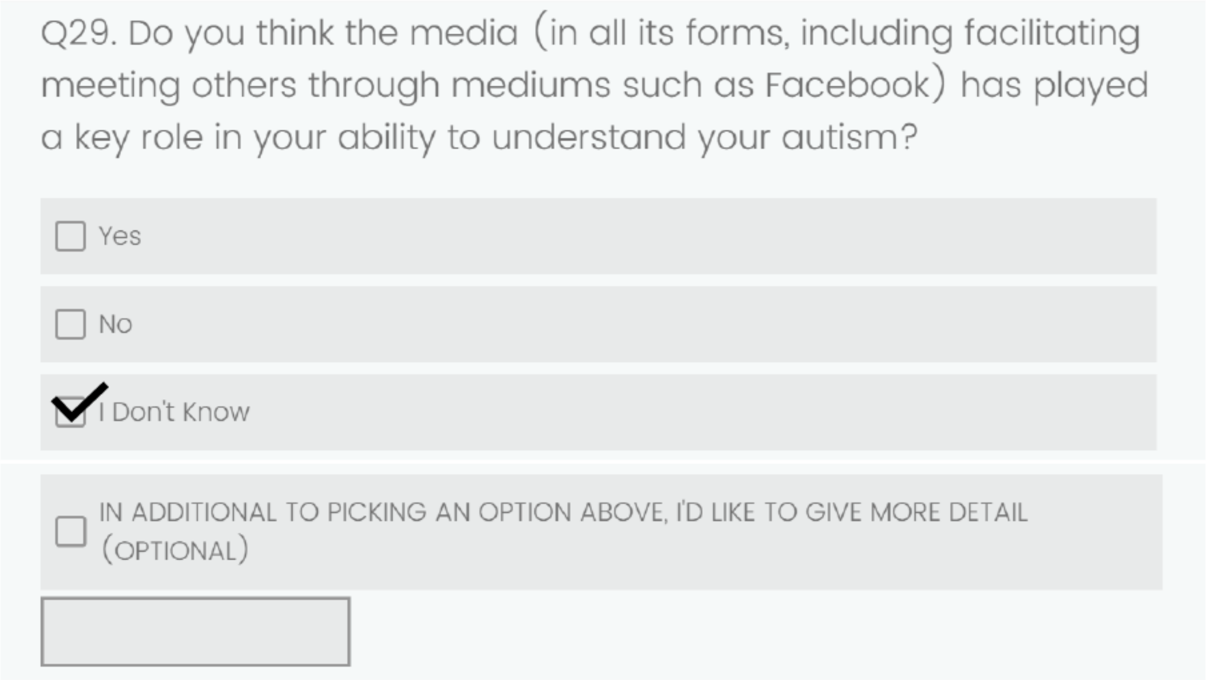
☐ Yes, mostly positive opinions have affected the way I see myself

☐ Yes, both positive and negative opinions have affected the way I see myself

☐ No, I don't think so

☐ I Don't Know

☐ IN ADDITIONAL TO PICKING AN OPTION ABOVE, I'D LIKE TO GIVE MORE DETAIL (OPTIONAL)



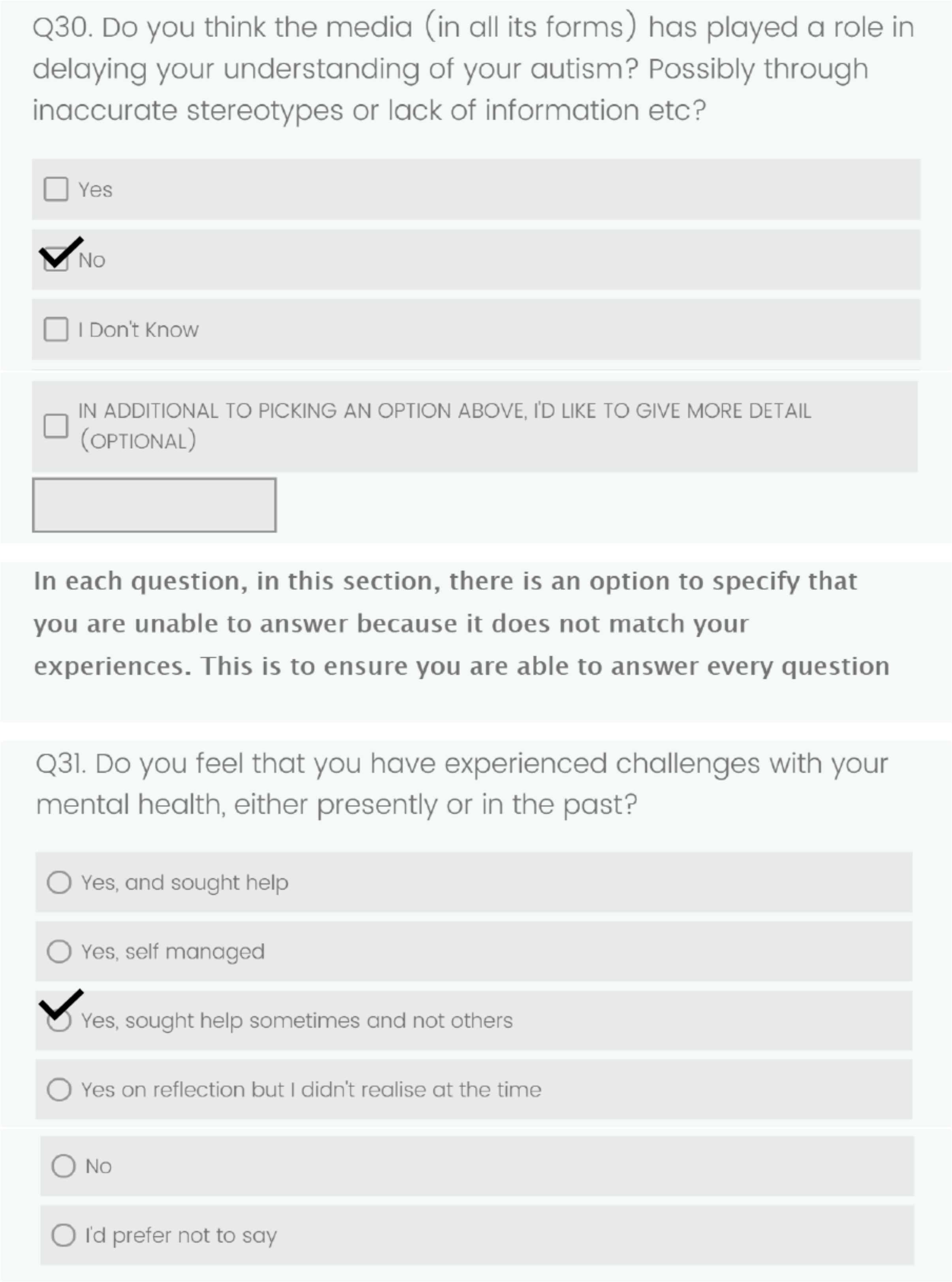
Q29. Do you think the media (in all its forms, including facilitating meeting others through mediums such as Facebook) has played a key role in your ability to understand your autism?

☐ Yes

☐ No

☑ I Don't Know

☐ IN ADDITIONAL TO PICKING AN OPTION ABOVE, I'D LIKE TO GIVE MORE DETAIL (OPTIONAL)



Q30. Do you think the media (in all its forms) has played a role in delaying your understanding of your autism? Possibly through inaccurate stereotypes or lack of information etc?

☐ Yes

☑ No

☐ I Don't Know

☐ IN ADDITIONAL TO PICKING AN OPTION ABOVE, I'D LIKE TO GIVE MORE DETAIL (OPTIONAL)

In each question, in this section, there is an option to specify that you are unable to answer because it does not match your experiences. This is to ensure you are able to answer every question

Q31. Do you feel that you have experienced challenges with your mental health, either presently or in the past?

○ Yes, and sought help

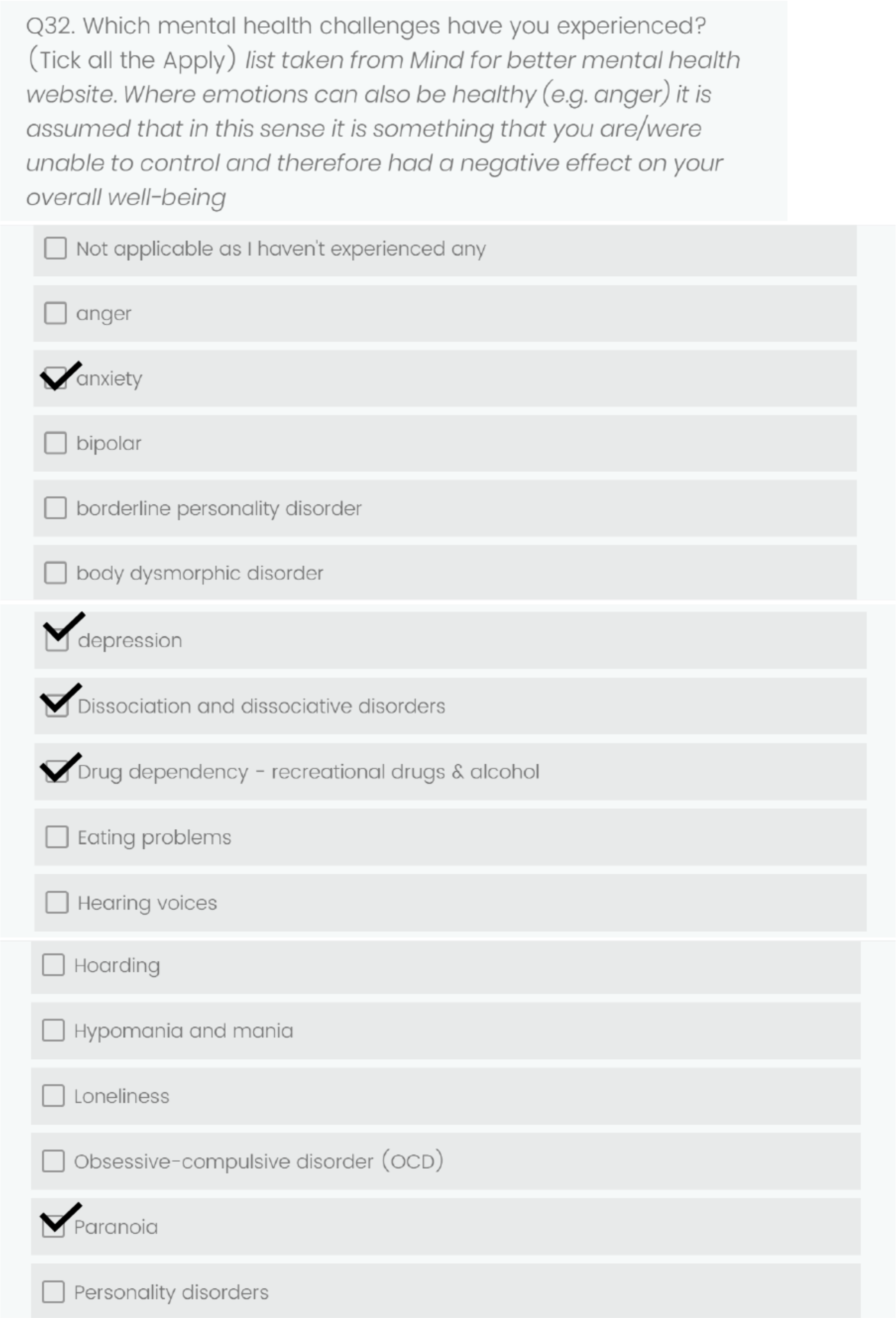
○ Yes, self managed

● Yes, sought help sometimes and not others

○ Yes on reflection but I didn't realise at the time

○ No

○ I'd prefer not to say



Q32. Which mental health challenges have you experienced? (Tick all the Apply) *list taken from Mind for better mental health website. Where emotions can also be healthy (e.g. anger) it is assumed that in this sense it is something that you are/were unable to control and therefore had a negative effect on your overall well-being*

☐ Not applicable as I haven't experienced any

☐ anger

☑ anxiety

☐ bipolar

☐ borderline personality disorder

☐ body dysmorphic disorder

☑ depression

☑ Dissociation and dissociative disorders

☑ Drug dependency - recreational drugs & alcohol

☐ Eating problems

☐ Hearing voices

☐ Hoarding

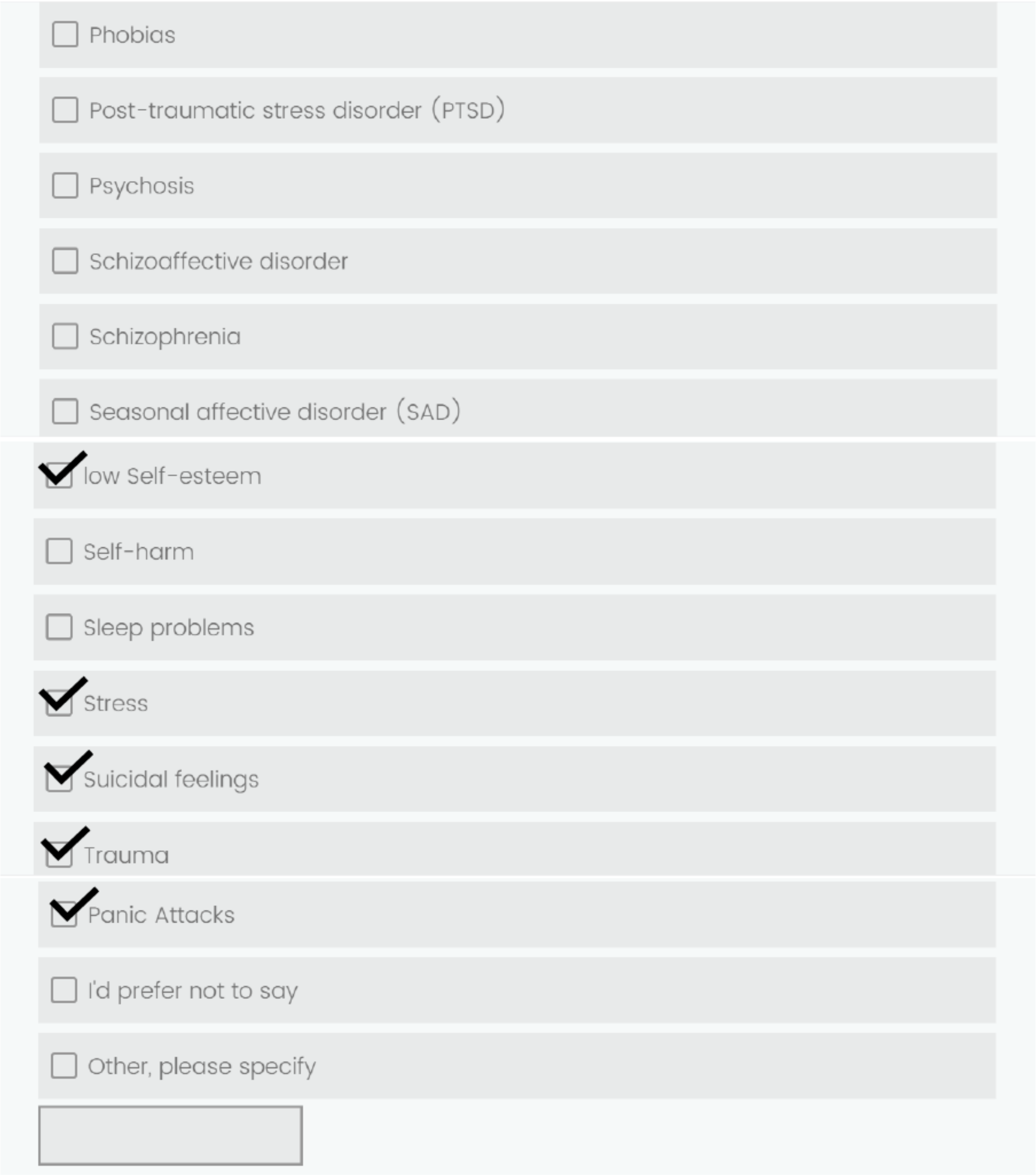
☐ Hypomania and mania

☐ Loneliness

☐ Obsessive-compulsive disorder (OCD)

☑ Paranoia

☐ Personality disorders



☐ Phobias

☐ Post-traumatic stress disorder (PTSD)

☐ Psychosis

☐ Schizoaffective disorder

☐ Schizophrenia

☐ Seasonal affective disorder (SAD)

☑ low Self-esteem

☐ Self-harm

☐ Sleep problems

☑ Stress

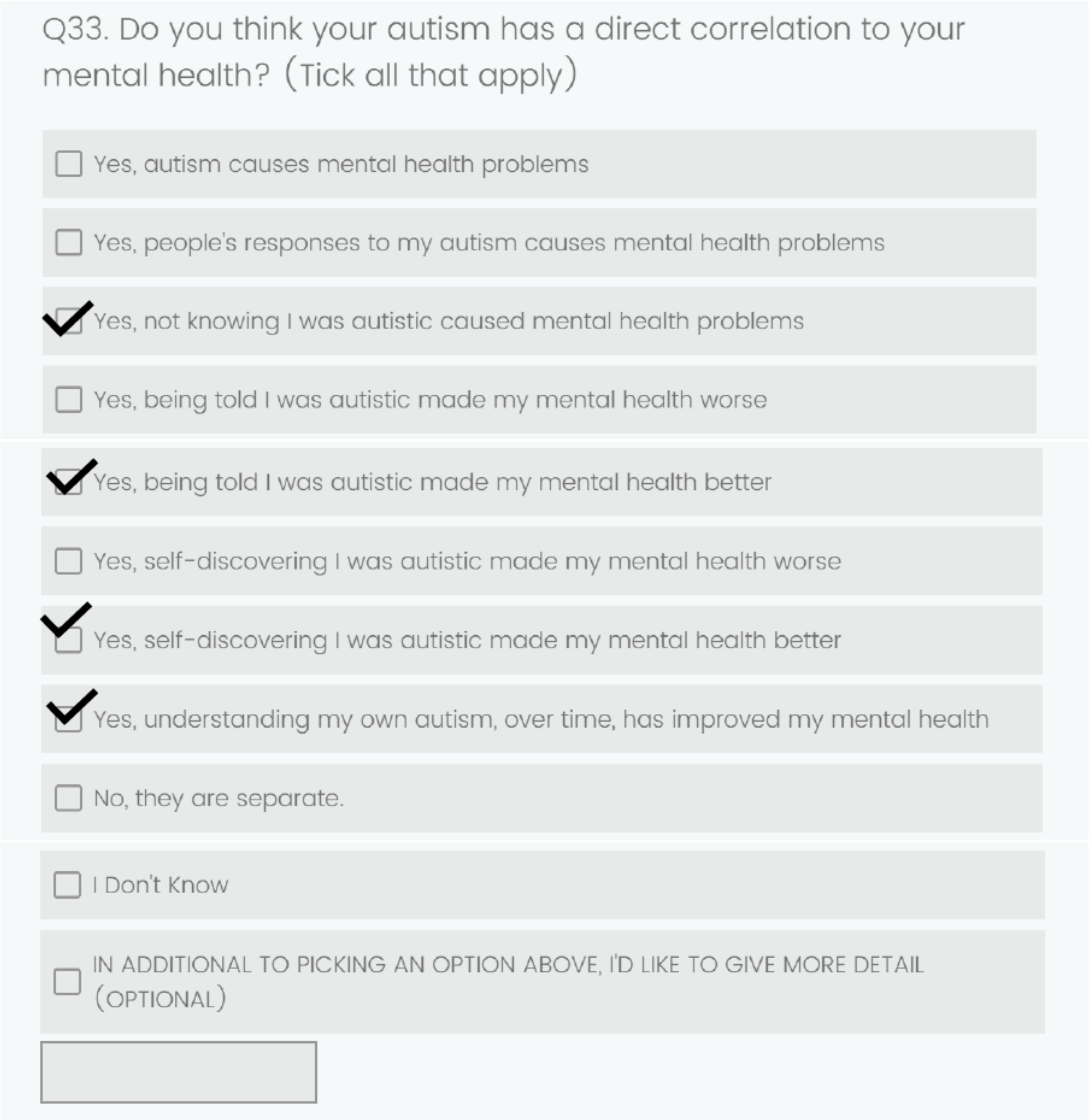
☑ Suicidal feelings

☑ Trauma

☑ Panic Attacks

☐ I'd prefer not to say

☐ Other, please specify



Q33. Do you think your autism has a direct correlation to your mental health? (Tick all that apply)

☐ Yes, autism causes mental health problems

☐ Yes, people's responses to my autism causes mental health problems

☑ Yes, not knowing I was autistic caused mental health problems

☐ Yes, being told I was autistic made my mental health worse

☑ Yes, being told I was autistic made my mental health better

☐ Yes, self-discovering I was autistic made my mental health worse

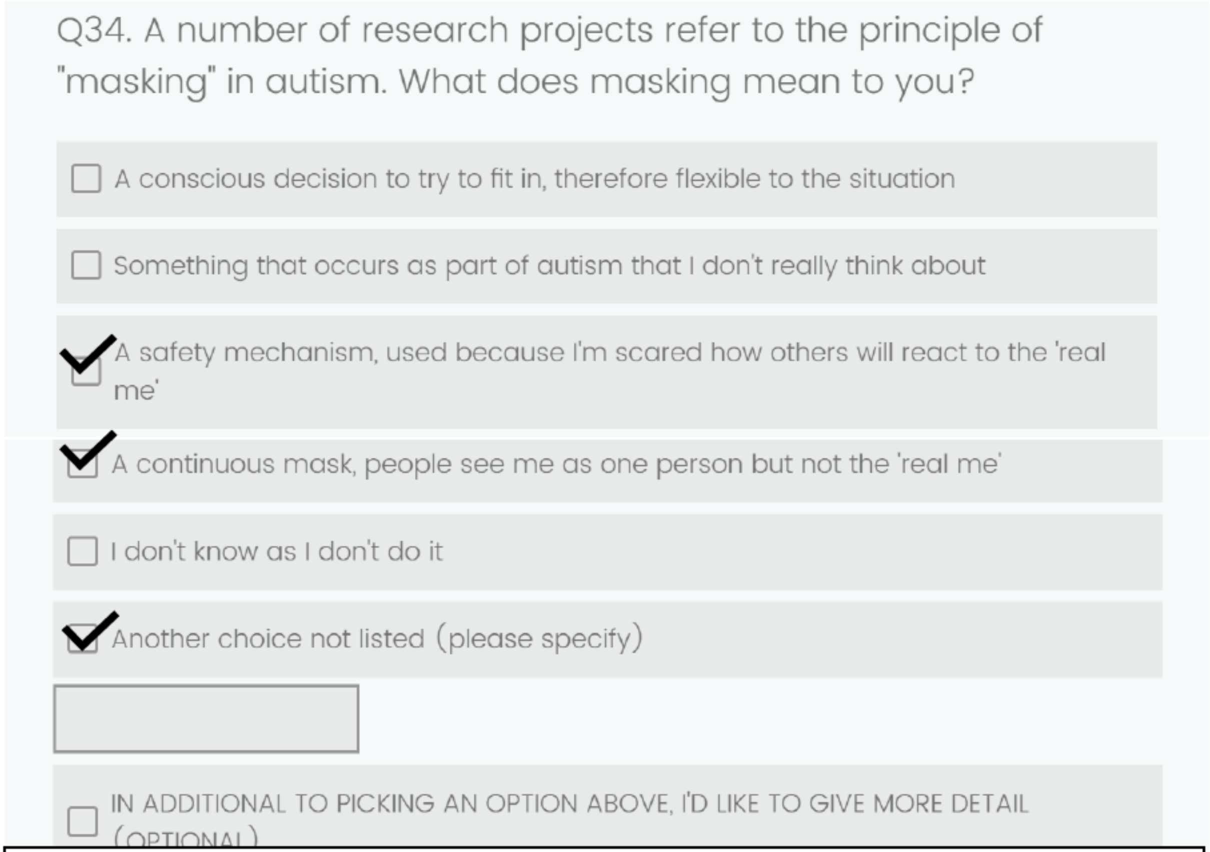
☑ Yes, self-discovering I was autistic made my mental health better

☑ Yes, understanding my own autism, over time, has improved my mental health

☐ No, they are separate.

☐ I Don't Know

☐ IN ADDITIONAL TO PICKING AN OPTION ABOVE, I'D LIKE TO GIVE MORE DETAIL (OPTIONAL)



Q34. A number of research projects refer to the principle of "masking" in autism. What does masking mean to you?

☐ A conscious decision to try to fit in, therefore flexible to the situation

☐ Something that occurs as part of autism that I don't really think about

☑ A safety mechanism, used because I'm scared how others will react to the 'real me'

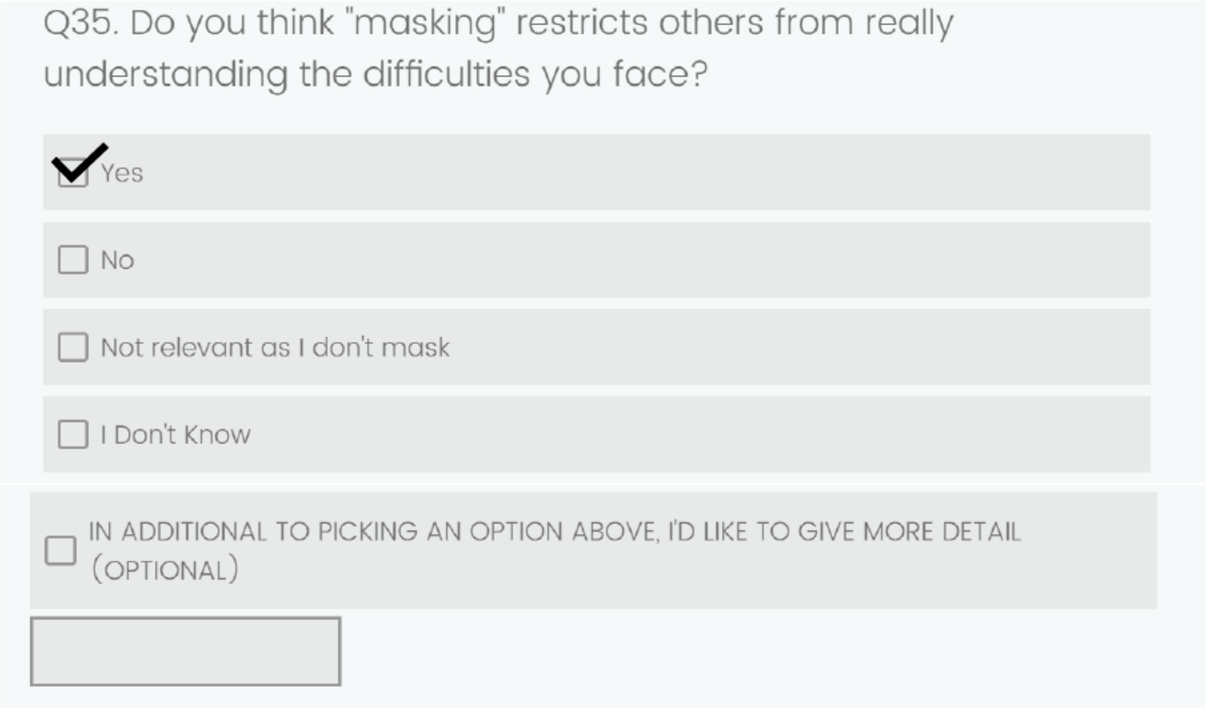
☑ A continuous mask, people see me as one person but not the 'real me'

☐ I don't know as I don't do it

☑ Another choice not listed (please specify)

☐ IN ADDITIONAL TO PICKING AN OPTION ABOVE, I'D LIKE TO GIVE MORE DETAIL (OPTIONAL)

Something like the first answer but it's not really a conscious decision. It's like trying to fit in by observing what's being rewarded for other people. But I didn't do it consciously.



Q35. Do you think "masking" restricts others from really understanding the difficulties you face?

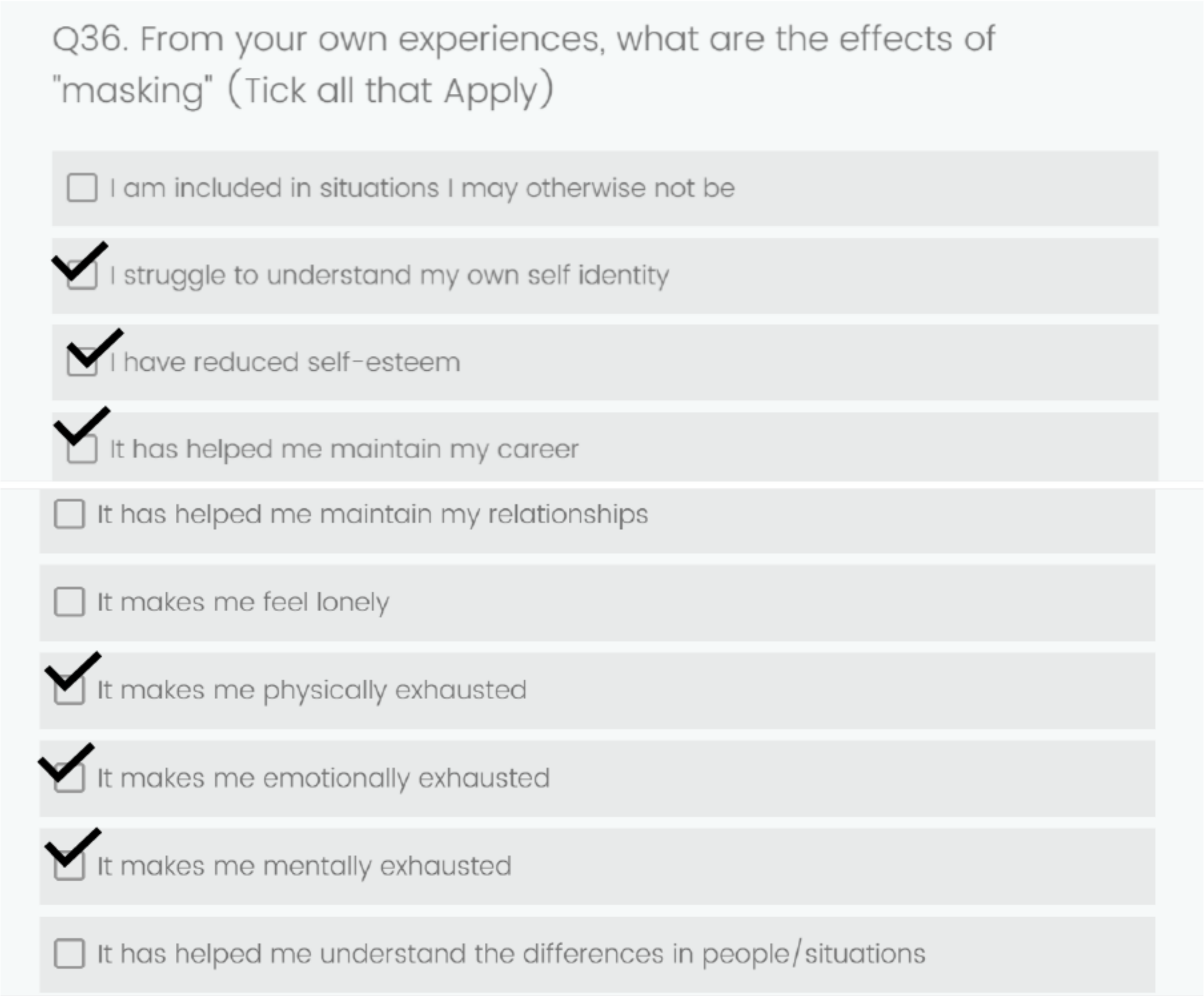
☑ Yes

☐ No

☐ Not relevant as I don't mask

☐ I Don't Know

☐ IN ADDITIONAL TO PICKING AN OPTION ABOVE, I'D LIKE TO GIVE MORE DETAIL (OPTIONAL)



Q36. From your own experiences, what are the effects of "masking" (Tick all that Apply)

☐ I am included in situations I may otherwise not be

☑ I struggle to understand my own self identity

☑ I have reduced self-esteem

☑ It has helped me maintain my career

☐ It has helped me maintain my relationships

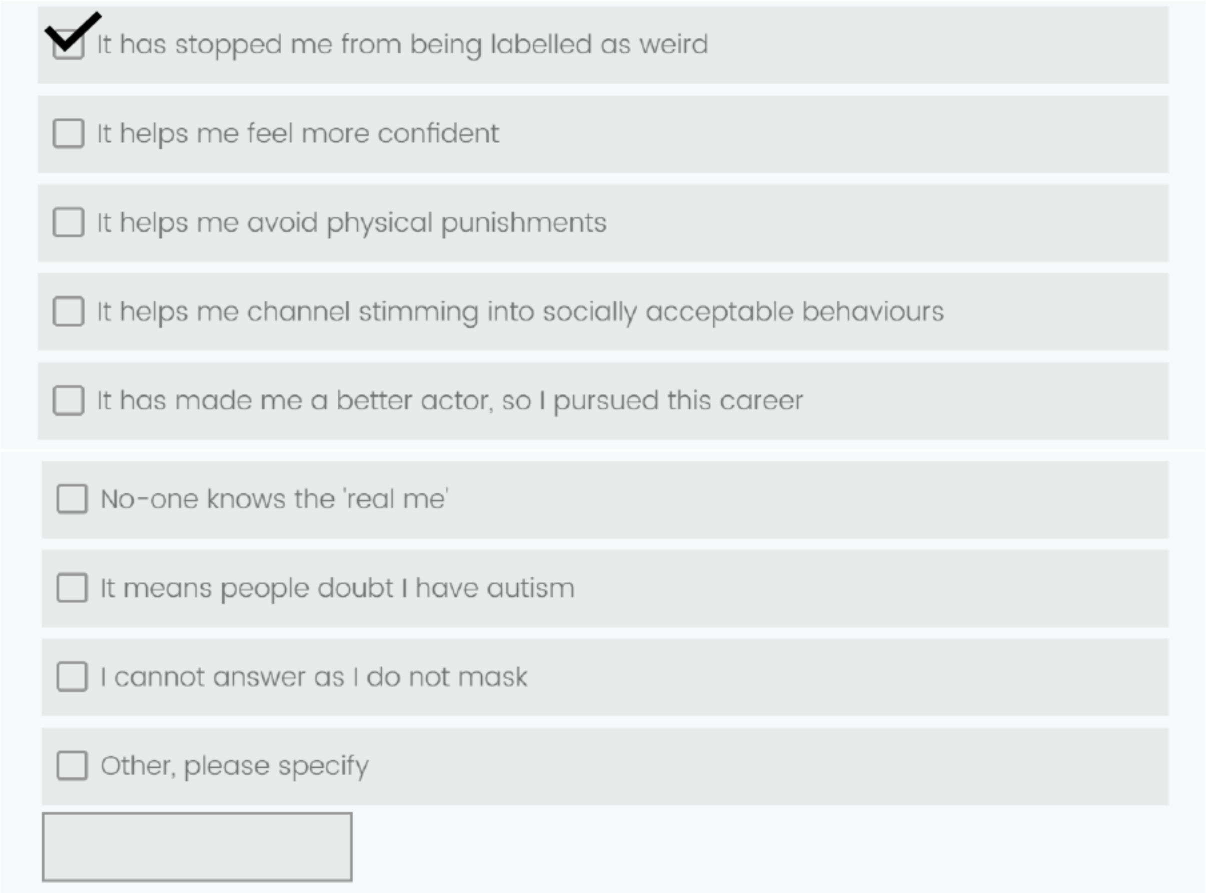
☐ It makes me feel lonely

☑ It makes me physically exhausted

☑ It makes me emotionally exhausted

☑ It makes me mentally exhausted

☐ It has helped me understand the differences in people/situations



☑ It has stopped me from being labelled as weird

☐ It helps me feel more confident

☐ It helps me avoid physical punishments

☐ It helps me channel stimming into socially acceptable behaviours

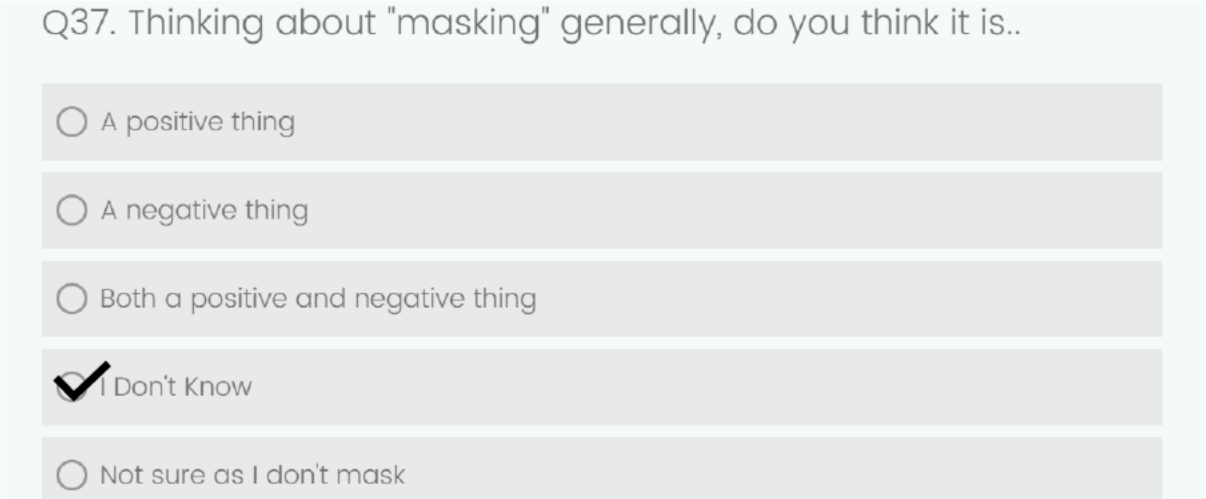
☐ It has made me a better actor, so I pursued this career

☐ No-one knows the 'real me'

☐ It means people doubt I have autism

☐ I cannot answer as I do not mask

☐ Other, please specify



Q37. Thinking about "masking" generally, do you think it is..

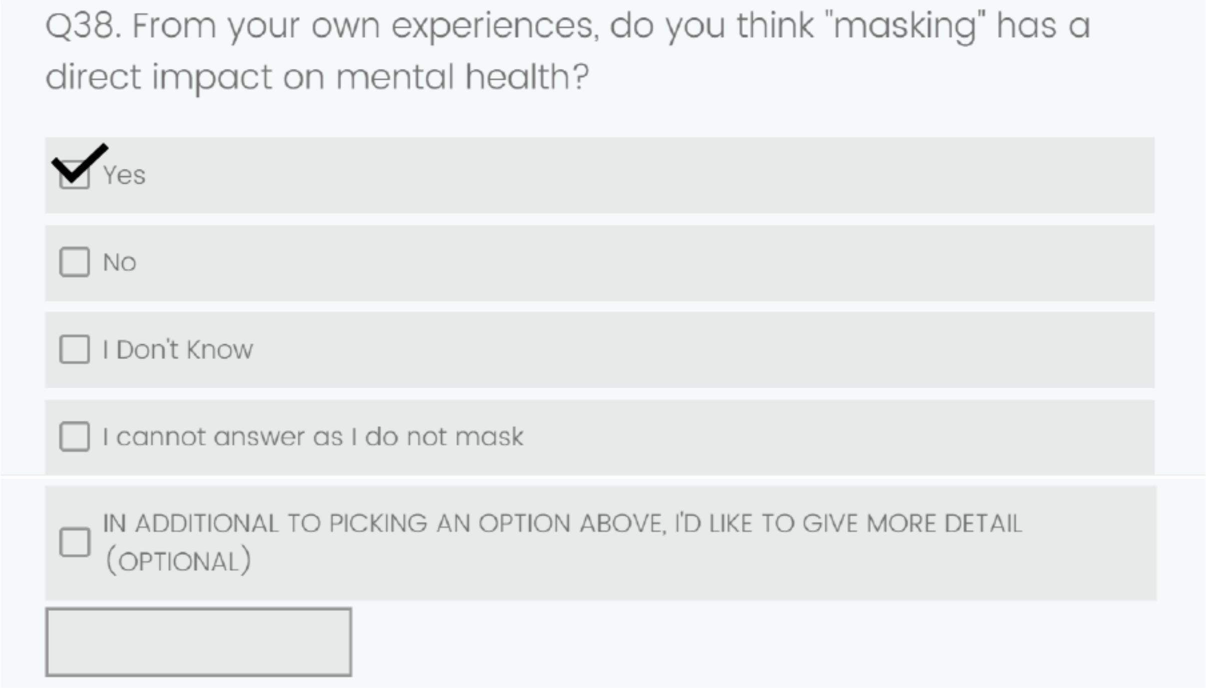
○ A positive thing

○ A negative thing

○ Both a positive and negative thing

● I Don't Know

○ Not sure as I don't mask



Q38. From your own experiences, do you think "masking" has a direct impact on mental health?

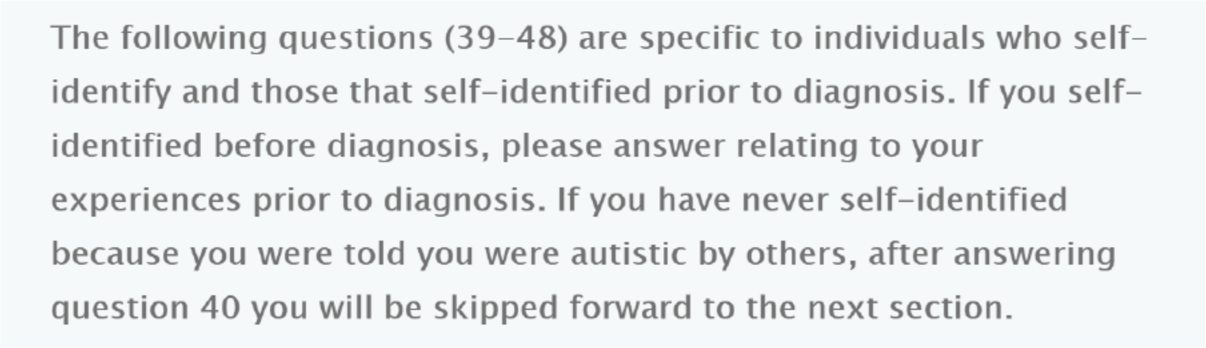
☑ Yes

☐ No

☐ I Don't Know

☐ I cannot answer as I do not mask

☐ IN ADDITIONAL TO PICKING AN OPTION ABOVE, I'D LIKE TO GIVE MORE DETAIL (OPTIONAL)

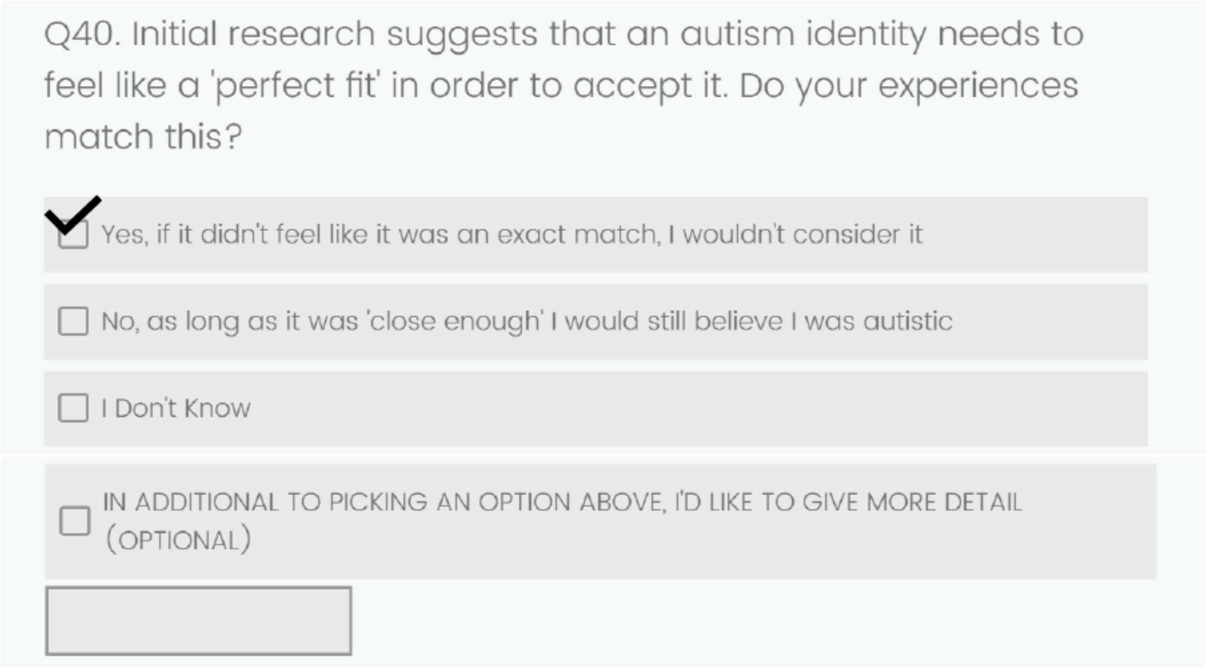


The following questions (39-48) are specific to individuals who self-identify and those that self-identified prior to diagnosis. If you self-identified before diagnosis, please answer relating to your experiences prior to diagnosis. If you have never self-identified because you were told you were autistic by others, after answering question 40 you will be skipped forward to the next section.

Q39. Have you ever self-identified. By this I mean have you worked out yourself you were autistic before anyone else told you?

● Yes

○ No



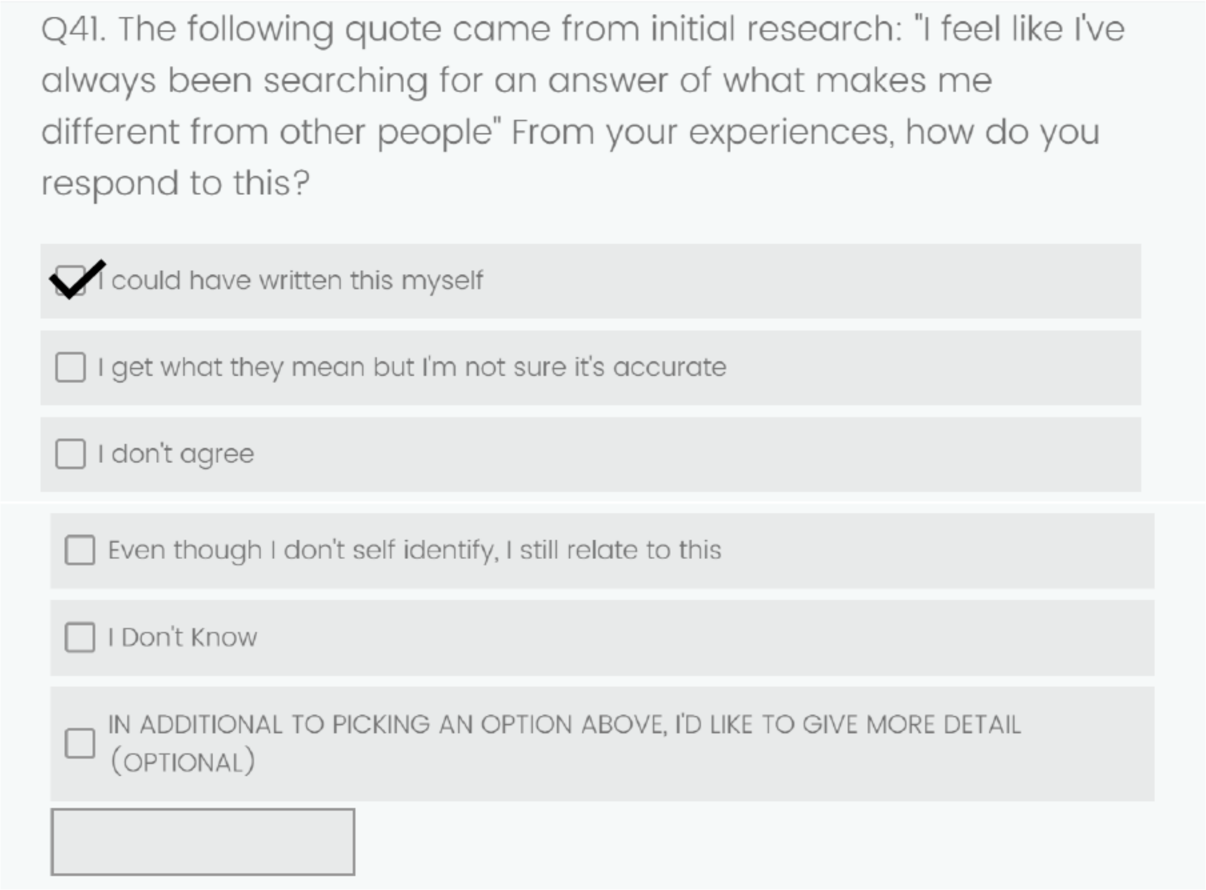
Q40. Initial research suggests that an autism identity needs to feel like a 'perfect fit' in order to accept it. Do your experiences match this?

☑ Yes, if it didn't feel like it was an exact match, I wouldn't consider it

☐ No, as long as it was 'close enough' I would still believe I was autistic

☐ I Don't Know

☐ IN ADDITIONAL TO PICKING AN OPTION ABOVE, I'D LIKE TO GIVE MORE DETAIL (OPTIONAL)



Q41. The following quote came from initial research: "I feel like I've always been searching for an answer of what makes me different from other people" From your experiences, how do you respond to this?

☑ I could have written this myself

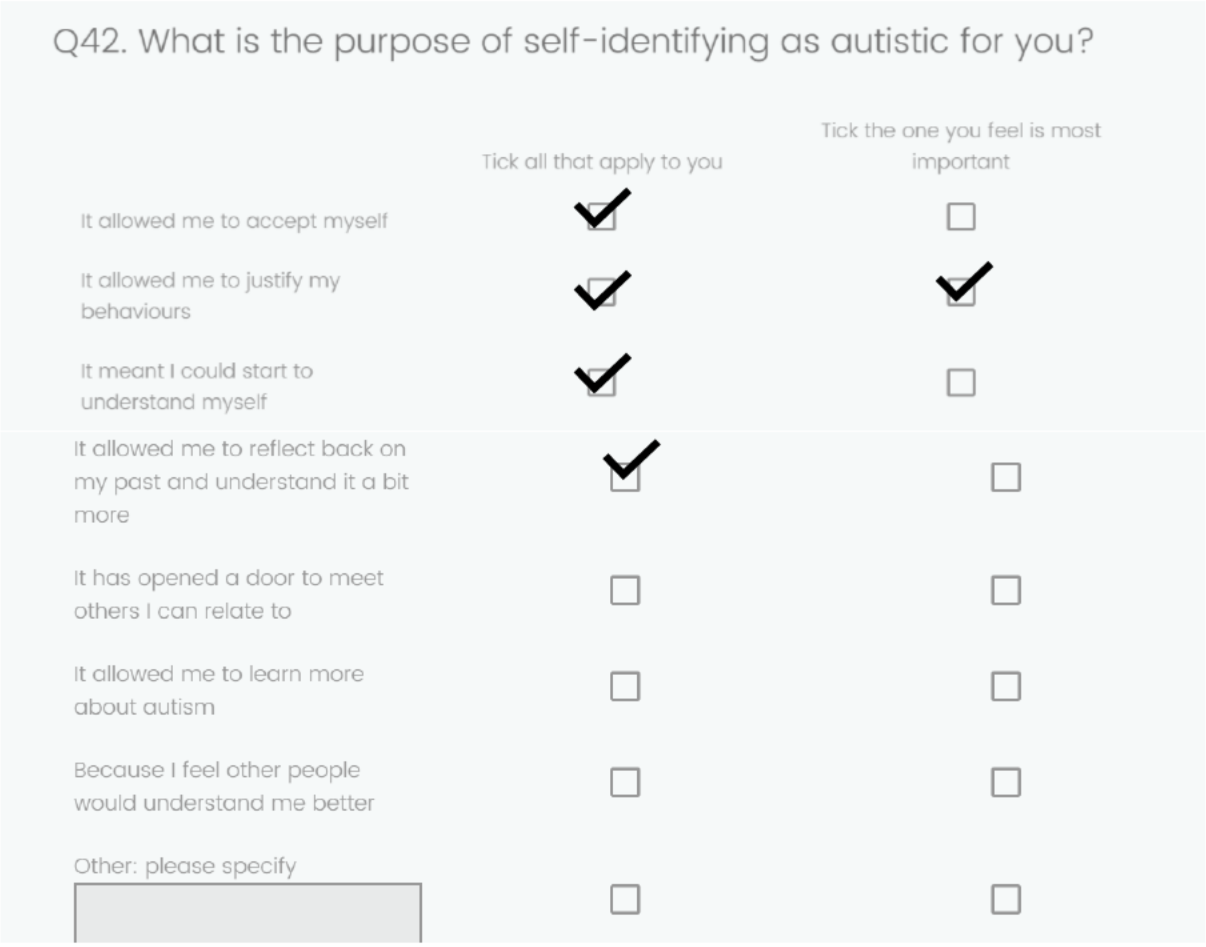
☐ I get what they mean but I'm not sure it's accurate

☐ I don't agree

☐ Even though I don't self identify, I still relate to this

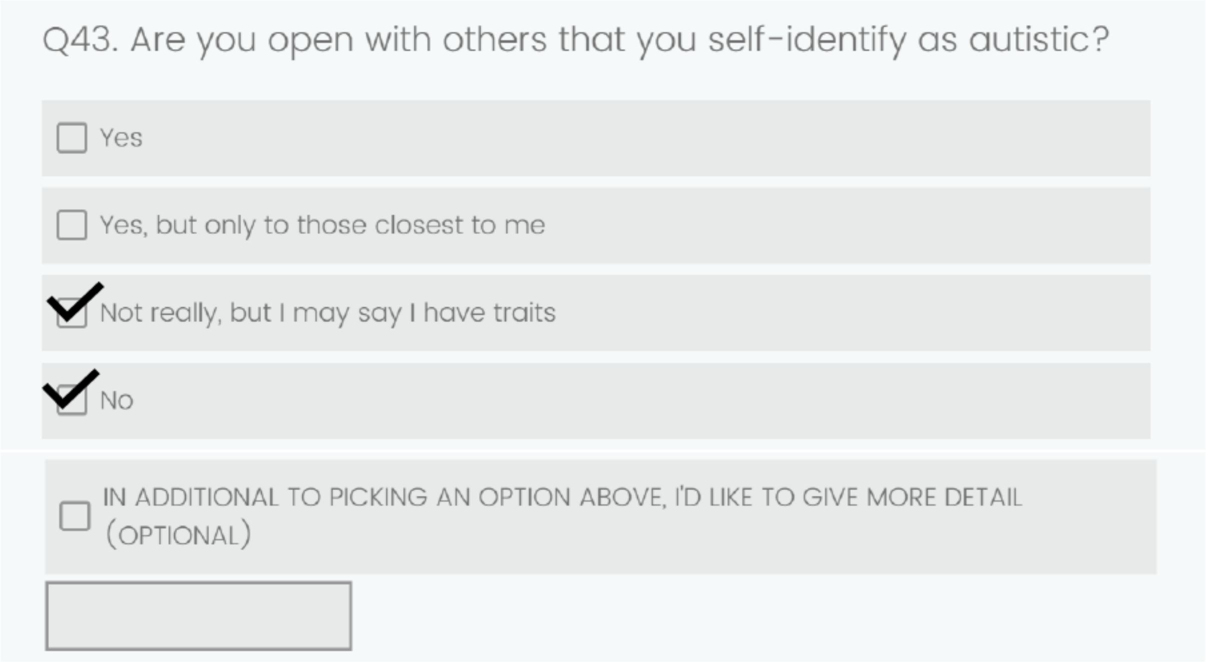
☐ I Don't Know

☐ IN ADDITIONAL TO PICKING AN OPTION ABOVE, I'D LIKE TO GIVE MORE DETAIL (OPTIONAL)



Q42. What is the purpose of self-identifying as autistic for you?

	Tick all that apply to you	Tick the one you feel is most important
It allowed me to accept myself	☑	☐
It allowed me to justify my behaviours	☑	☑
It meant I could start to understand myself	☑	☐
It allowed me to reflect back on my past and understand it a bit more	☑	☐
It has opened a door to meet others I can relate to	☐	☐
It allowed me to learn more about autism	☐	☐
Because I feel other people would understand me better	☐	☐
Other: please specify	☐	☐



Q43. Are you open with others that you self-identify as autistic?

☐ Yes

☐ Yes, but only to those closest to me

☑ Not really, but I may say I have traits

☑ No

☐ IN ADDITIONAL TO PICKING AN OPTION ABOVE, I'D LIKE TO GIVE MORE DETAIL (OPTIONAL)

Q44. If you are open with others, what responses have you received? (Tick all that Apply)

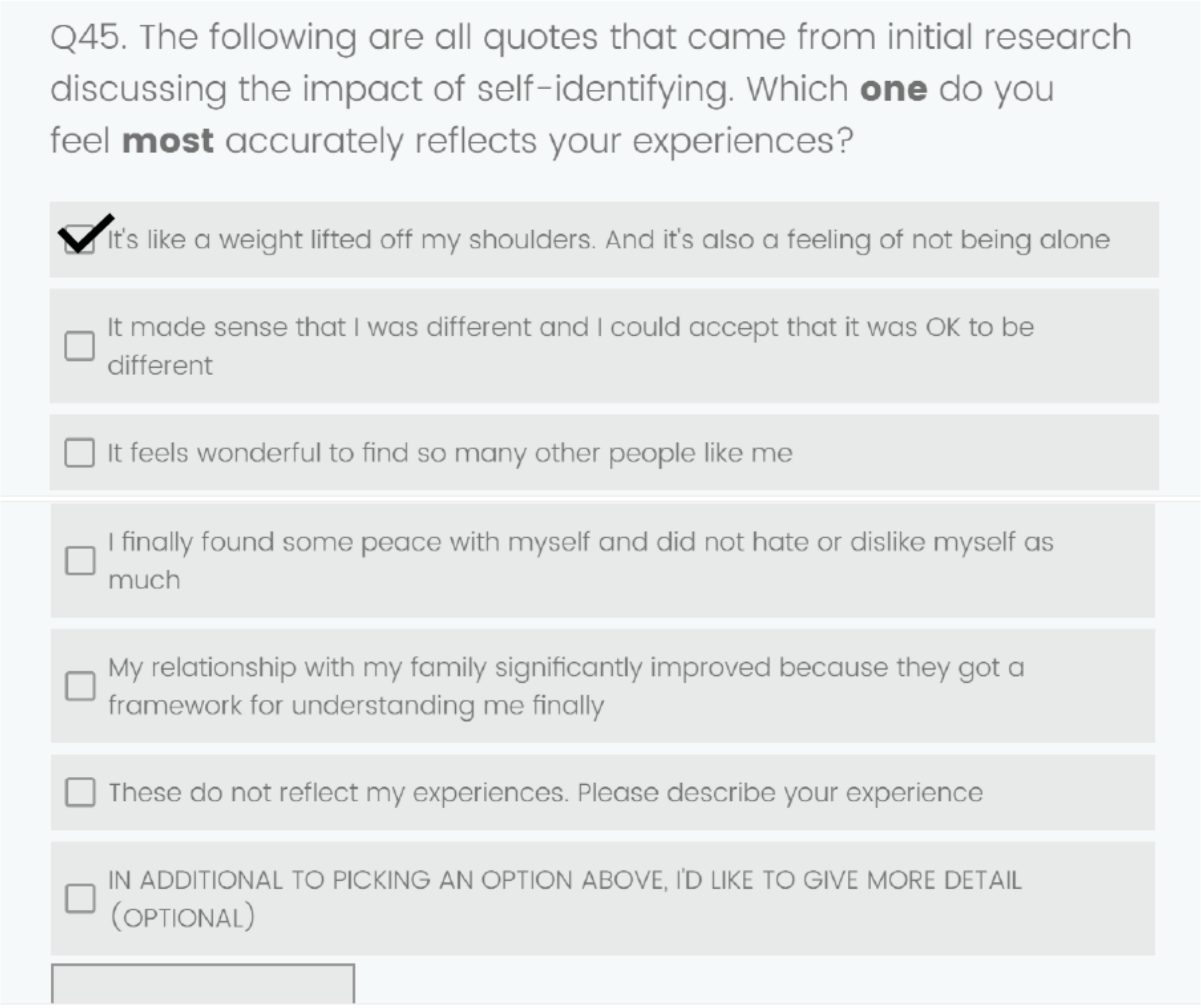
☑ Agreement/Acceptance

☐ Doubt: "you don't look autistic"

☐ Rejection of self-identification as a valid process

☐ Abuse/Refusal to accept

☐ Other not listed (please specify)



Q45. The following are all quotes that came from initial research discussing the impact of self-identifying. Which **one** do you feel **most** accurately reflects your experiences?

☑ It's like a weight lifted off my shoulders. And it's also a feeling of not being alone

☐ It made sense that I was different and I could accept that it was OK to be different

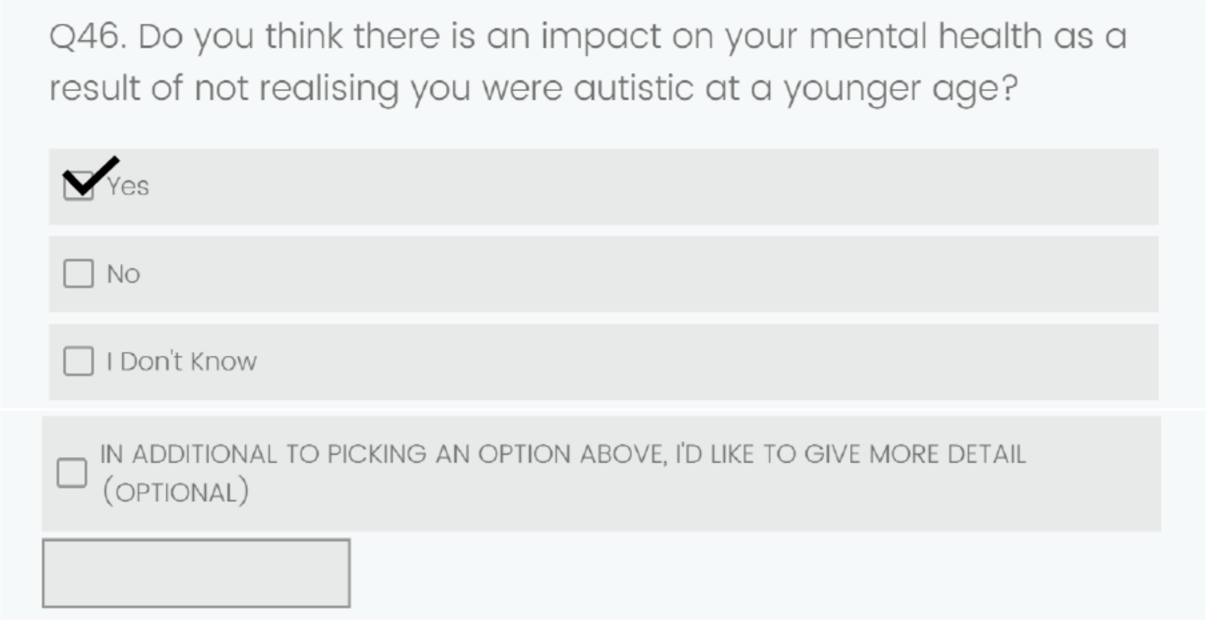
☐ It feels wonderful to find so many other people like me

☐ I finally found some peace with myself and did not hate or dislike myself as much

☐ My relationship with my family significantly improved because they got a framework for understanding me finally

☐ These do not reflect my experiences. Please describe your experience

☐ IN ADDITIONAL TO PICKING AN OPTION ABOVE, I'D LIKE TO GIVE MORE DETAIL (OPTIONAL)



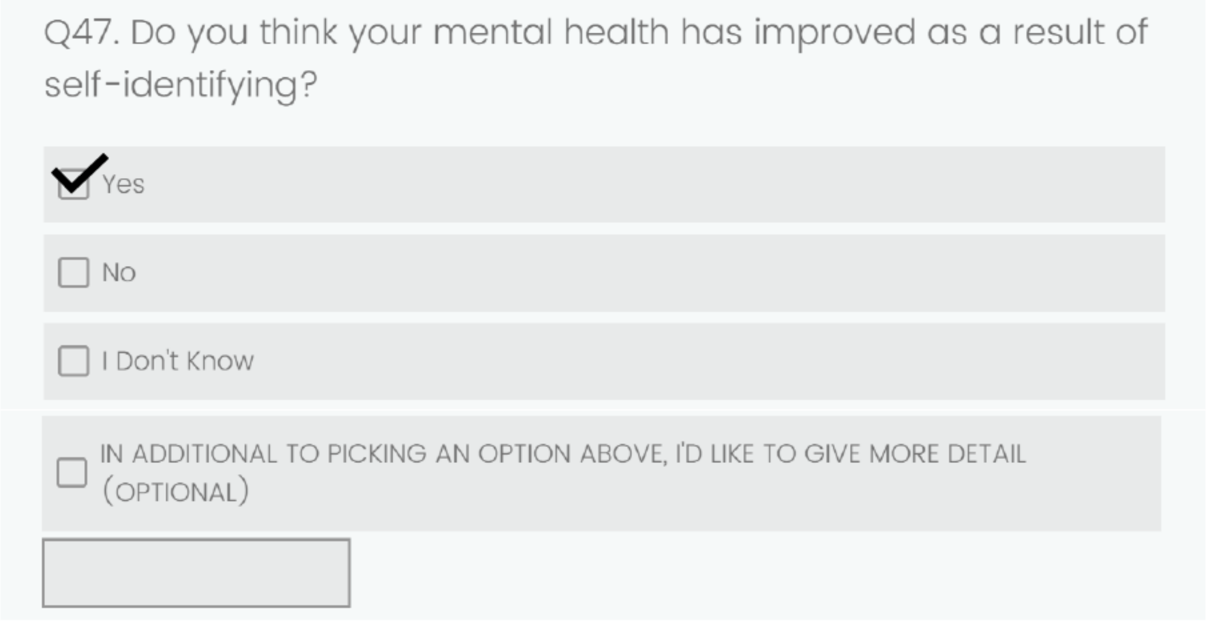
Q46. Do you think there is an impact on your mental health as a result of not realising you were autistic at a younger age?

☑ Yes

☐ No

☐ I Don't Know

☐ IN ADDITIONAL TO PICKING AN OPTION ABOVE, I'D LIKE TO GIVE MORE DETAIL (OPTIONAL)



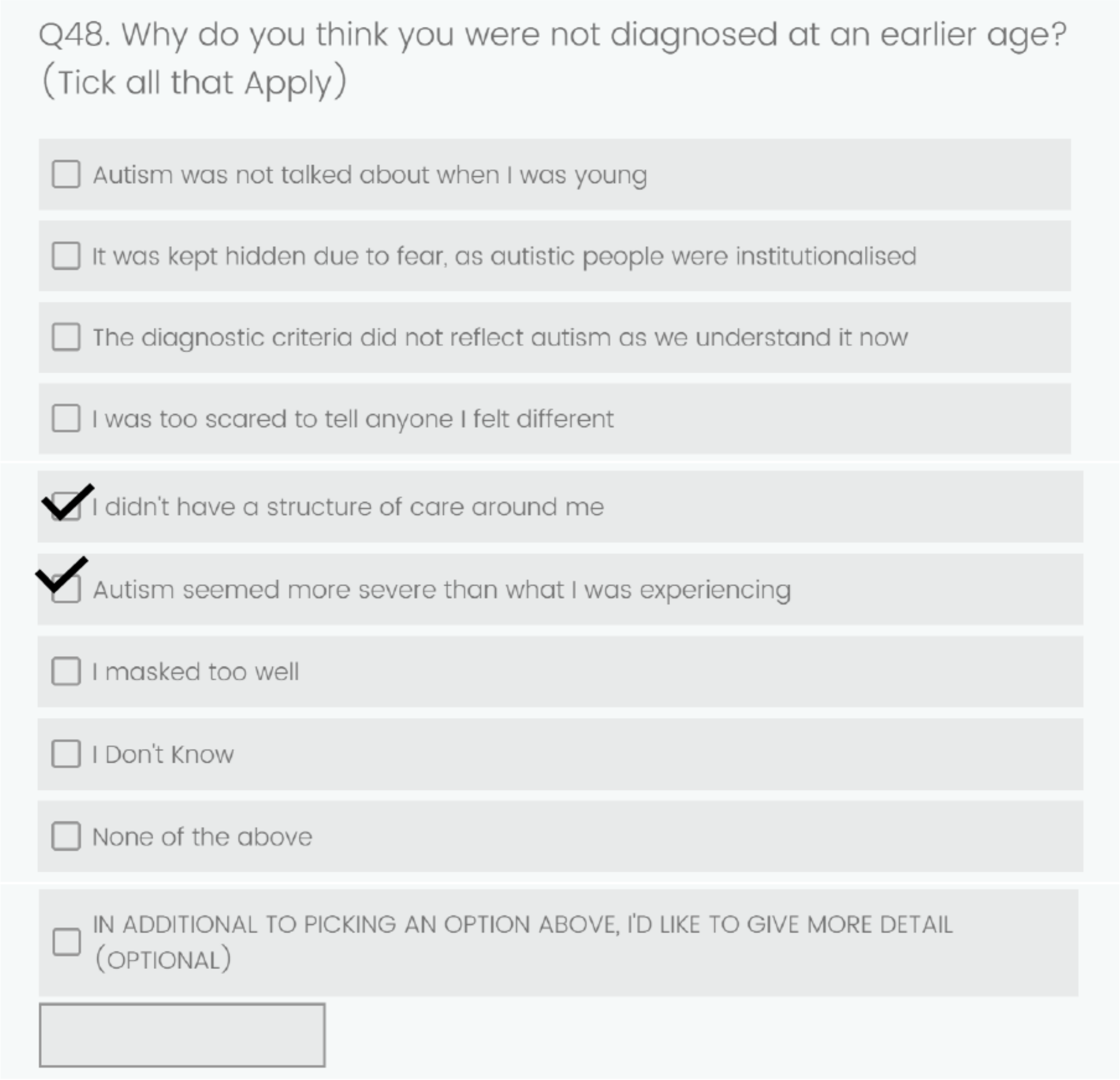
Q47. Do you think your mental health has improved as a result of self-identifying?

☑ Yes

☐ No

☐ I Don't Know

☐ IN ADDITIONAL TO PICKING AN OPTION ABOVE, I'D LIKE TO GIVE MORE DETAIL (OPTIONAL)



Q48. Why do you think you were not diagnosed at an earlier age? (Tick all that Apply)

☐ Autism was not talked about when I was young

☐ It was kept hidden due to fear, as autistic people were institutionalised

☐ The diagnostic criteria did not reflect autism as we understand it now

☐ I was too scared to tell anyone I felt different

☑ I didn't have a structure of care around me

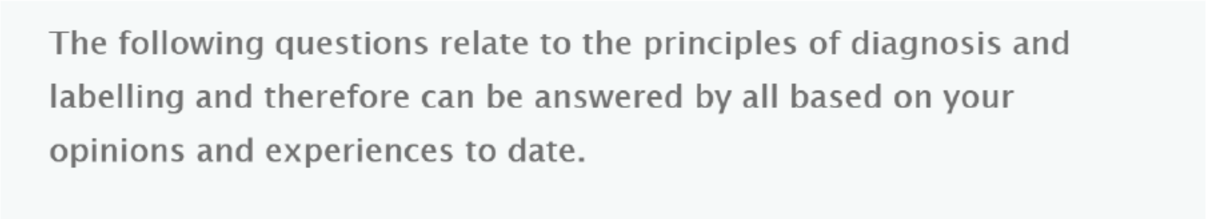
☑ Autism seemed more severe than what I was experiencing

☐ I masked too well

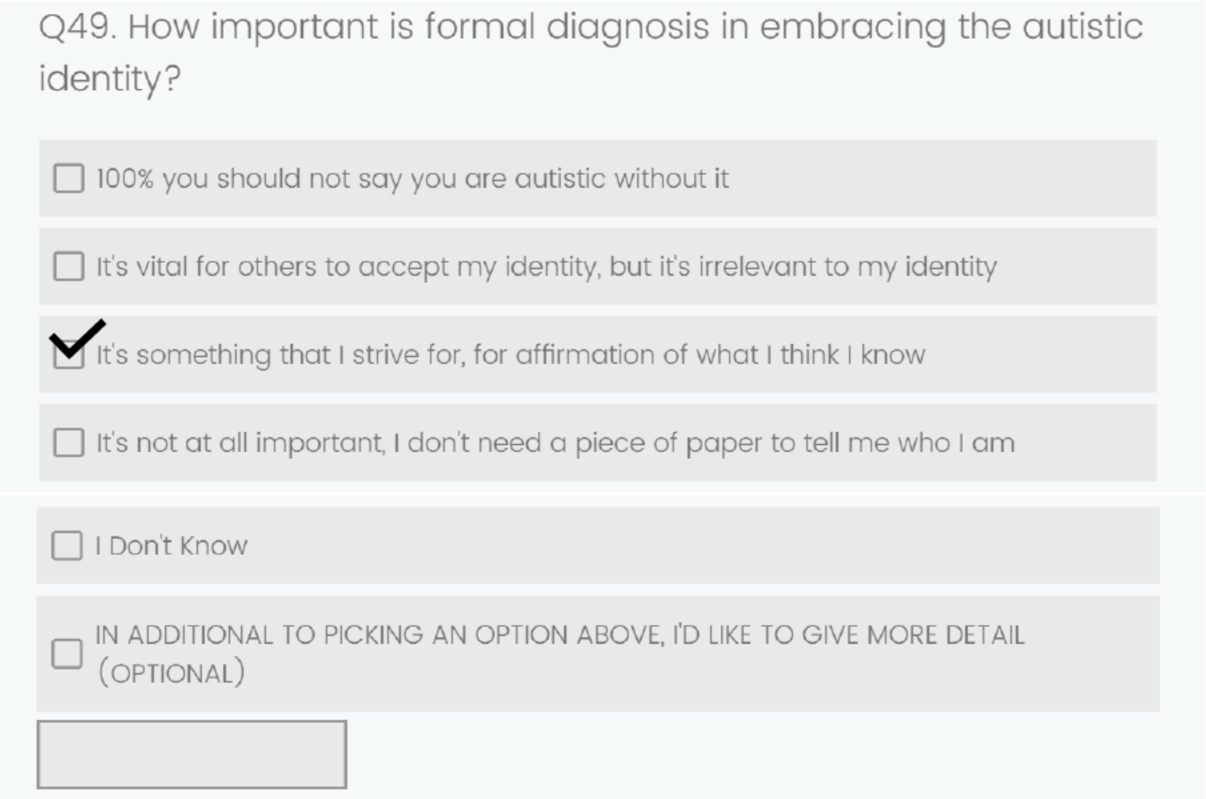
☐ I Don't Know

☐ None of the above

☐ IN ADDITIONAL TO PICKING AN OPTION ABOVE, I'D LIKE TO GIVE MORE DETAIL (OPTIONAL)



The following questions relate to the principles of diagnosis and labelling and therefore can be answered by all based on your opinions and experiences to date.



Q49. How important is formal diagnosis in embracing the autistic identity?

☐ 100% you should not say you are autistic without it

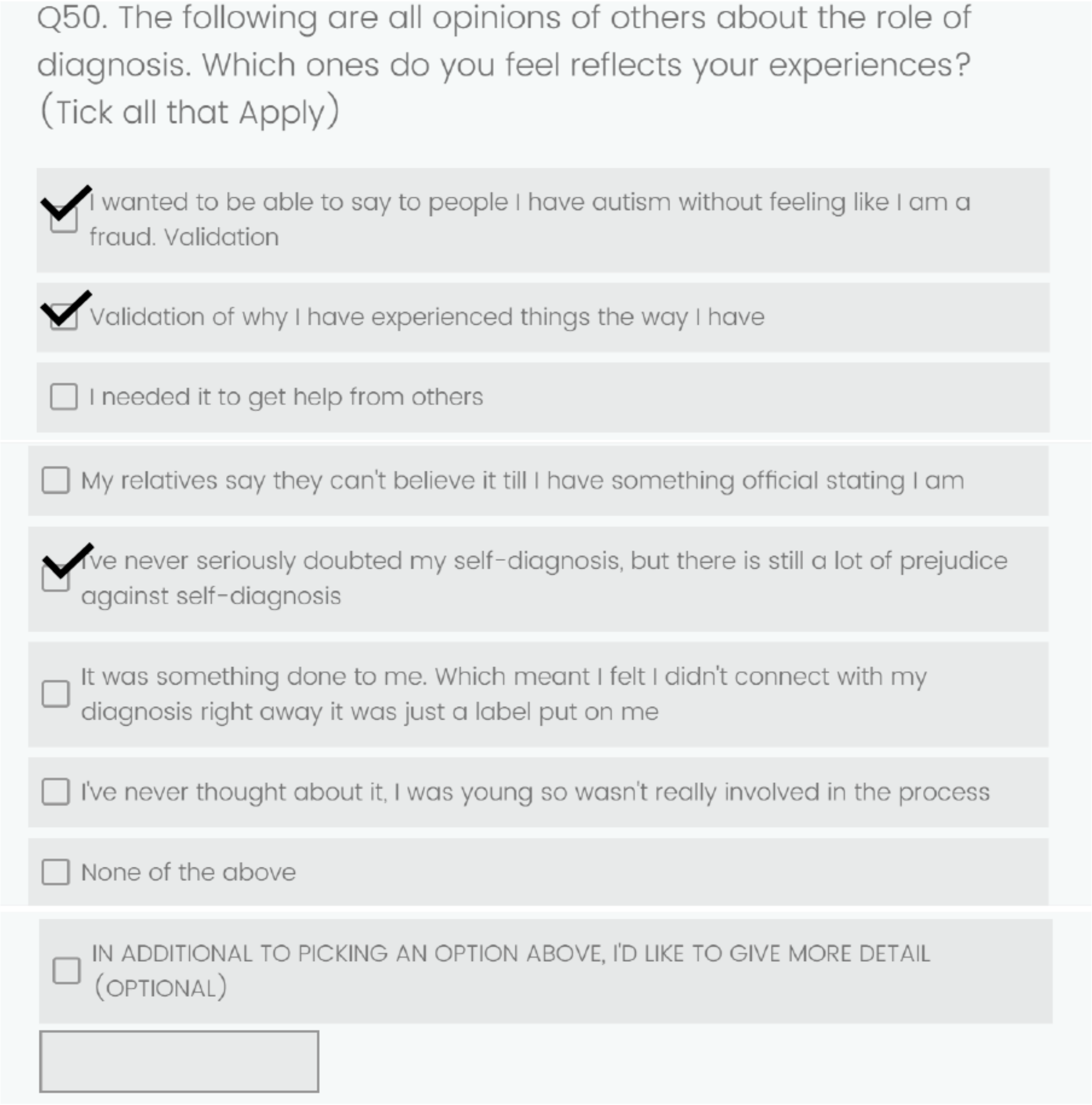
☐ It's vital for others to accept my identity, but it's irrelevant to my identity

☑ It's something that I strive for, for affirmation of what I think I know

☐ It's not at all important, I don't need a piece of paper to tell me who I am

☐ I Don't Know

☐ IN ADDITIONAL TO PICKING AN OPTION ABOVE, I'D LIKE TO GIVE MORE DETAIL (OPTIONAL)



Q50. The following are all opinions of others about the role of diagnosis. Which ones do you feel reflects your experiences? (Tick all that Apply)

☑ I wanted to be able to say to people I have autism without feeling like I am a fraud. Validation

☑ Validation of why I have experienced things the way I have

☐ I needed it to get help from others

☐ My relatives say they can't believe it till I have something official stating I am

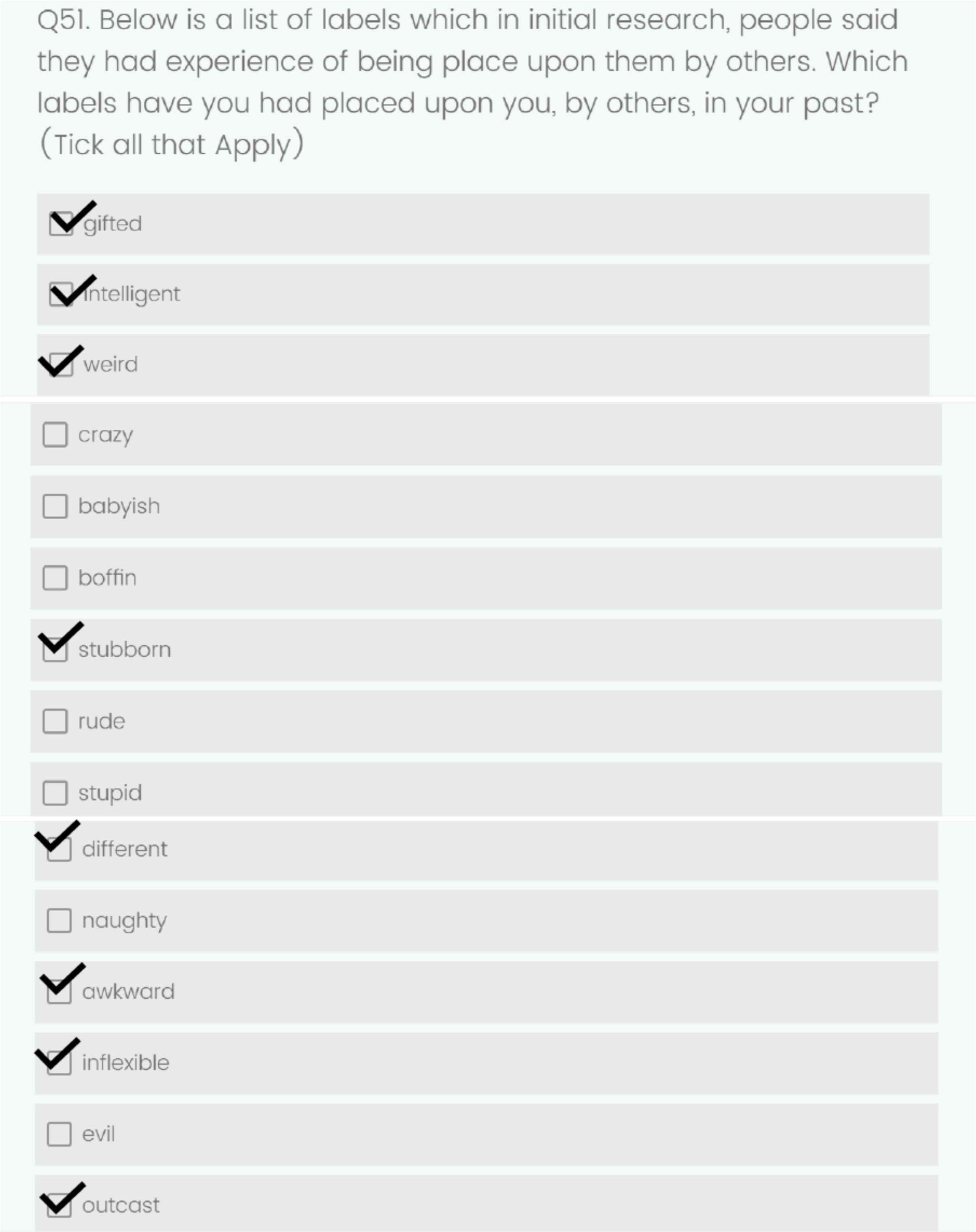
☑ I've never seriously doubted my self-diagnosis, but there is still a lot of prejudice against self-diagnosis

☐ It was something done to me. Which meant I felt I didn't connect with my diagnosis right away it was just a label put on me

☐ I've never thought about it, I was young so wasn't really involved in the process

☐ None of the above

☐ IN ADDITIONAL TO PICKING AN OPTION ABOVE, I'D LIKE TO GIVE MORE DETAIL (OPTIONAL)



Q51. Below is a list of labels which in initial research, people said they had experience of being place upon them by others. Which labels have you had placed upon you, by others, in your past? (Tick all that Apply)

☑ gifted

☑ intelligent

☑ weird

☐ crazy

☐ babyish

☐ boffin

☑ stubborn

☐ rude

☐ stupid

☑ different

☐ naughty

☑ awkward

☑ inflexible

☐ evil

☑ outcast

☑ mature

☐ articulate

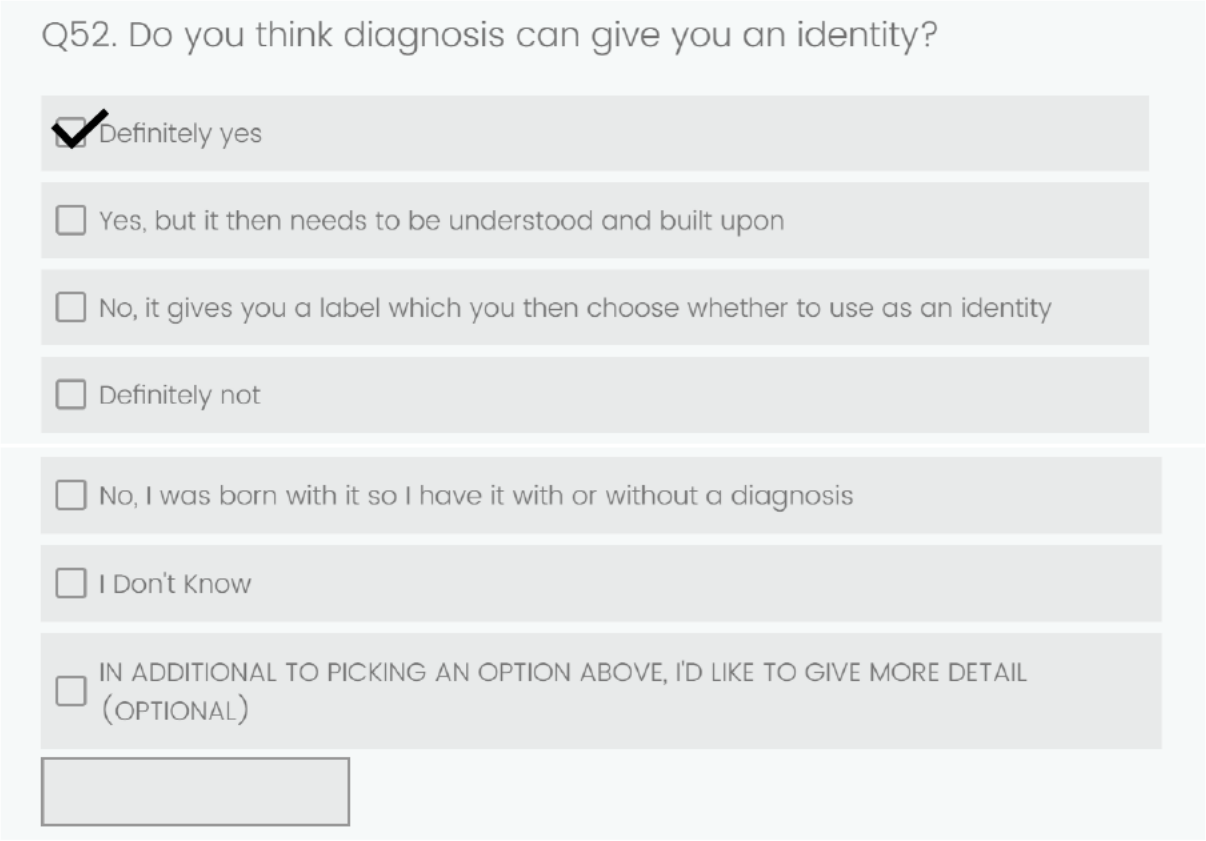
☐ inappropriate

☑ shy

☑ geek

☐ nerd

☐ Other: Please specify



Q52. Do you think diagnosis can give you an identity?

☑ Definitely yes

☐ Yes, but it then needs to be understood and built upon

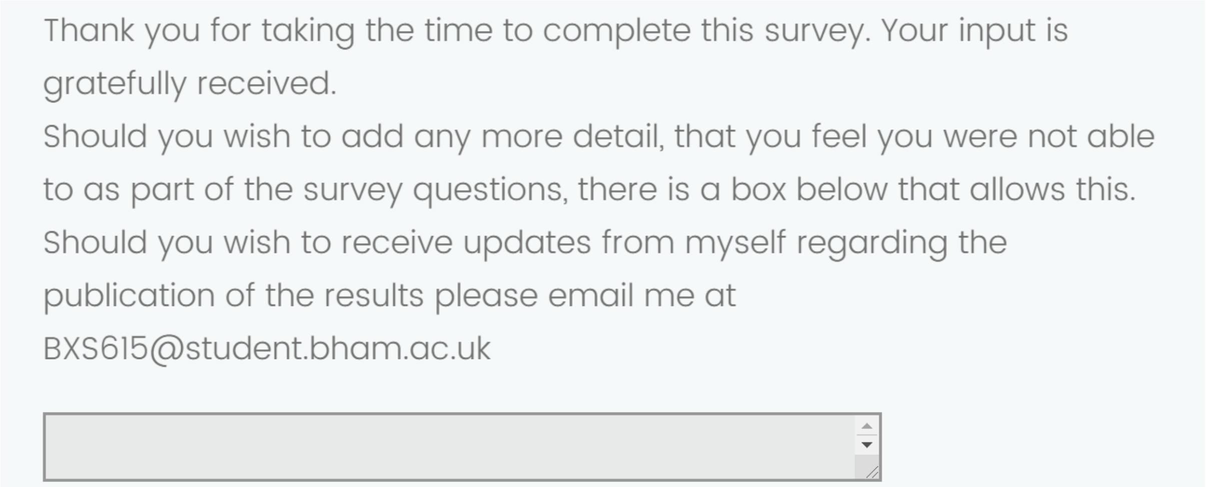
☐ No, it gives you a label which you then choose whether to use as an identity

☐ Definitely not

☐ No, I was born with it so I have it with or without a diagnosis

☐ I Don't Know

☐ IN ADDITIONAL TO PICKING AN OPTION ABOVE, I'D LIKE TO GIVE MORE DETAIL (OPTIONAL)



Thank you for taking the time to complete this survey. Your input is gratefully received.

Should you wish to add any more detail, that you feel you were not able to as part of the survey questions, there is a box below that allows this.

Should you wish to receive updates from myself regarding the publication of the results please email me at BXS615@student.bham.ac.uk

Appendix 16: - Masking Implications table

	Self-diagnosed, not formally diagnosed	Self-diagnosed and then formally diagnosed	Formally diagnosed after someone else thought I was autistic	Formally diagnosed when I was younger, so I was not involved in it
Most chosen impact of Masking	It makes me emotionally exhausted	It makes me emotionally exhausted	It makes me emotionally exhausted	It makes me emotionally exhausted
		It makes me mentally exhausted		
Second Most chosen impact of Masking	It makes me mentally exhausted	It means people doubt I have autism	It makes me mentally exhausted	It makes me mentally exhausted
	It means people doubt I have autism			It has helped me maintain my relationships
				It means people doubt I have autism
Third Most chosen impact of Masking	It has helped me maintain my career	I have reduced self-esteem	It makes me physically exhausted	It makes me physically exhausted
			It means people doubt I have autism	It has helped me understand the differences in people/situations
				It has stopped me from being labelled as weird
				It helps me channel stimming into socially acceptable behaviours
				It has made me a better actor, so I pursued this career

Appendix 17: - Pilot Interview Transcript

12:09

the best way I have found to do this is, everytime we have finished typing what we want to say is you put 2 // then I will know I'm not interrupting your thoughts/typing :)

//

12:09

okay, so we are typing? not talking outloud?

12:10

yeah, typing is the way I think I will do the other interviews and it means I have an accurate record of what is said. Is that ok? //

12:11

sure. i just have to switch a knob in my head. or how do you say that. commute, adjust. :-D //

12:11

hehe! how did you find the initial questions. Where they easy enough to understand? //

12:13

the questions were great. it made me be aware of a few things.

i struggled with the word identity. though. autistic identity. i was like: what even IS that? //

12:14

thats a really interesting point and kinda at the core of what I am looking at. Did you come to an answer? //

12:22

what i feel is that i am me. and then there is this autistic thing as some kind of layer put over me. not over all of me but over most of me. as some kind of filter i see the world through and i perceive the world. not that it IS me, not that autism IS me but that it's some extra thing that can change in different situations too. sometimes it's thicker and bigger than at other times. //

jeez, my internetconnection went down. i created a hotspot with my phone so i am back. will try to fix this in the mean time. this never happens, lol, just now that we are in the middle of an interview. my kind of puppy interruption :-| //

12:23

haha I was wondering if you were just typing a really long reply :)

Your perspective is really interesting though. When did you come to believe this? By this I mean have you always though that autism was the "extra thing" of you? //

12:29

no, i never really thought of it before, i was just autistic. your questions made me think about, what is it then and this is how it felt like :-) //

12:30

Ok I understand. So when did you first realise you were autistic? //

12:33

i was in a course with someone i did more courses with. she did it in a way that i thought, i could do this to you know... with other course presenters i always was more like, how on earth do they DO that, reading questions and comments in a facebook live, or answering questions live in a call, telling their story, being interrupted, continuing where they had left their story, it would be HELL for me to do all that. if you interrupt me i am lost. i've lost the whole conversation. and then the client contact... to keep up with clients in between courses or classes, HOW do they DO that.

this woman didn't. she focussed on one question at the time and gave a crystal clear answer. then she let go of the people completely, till the next call or course.

at one point she answered the question in my head how she did that: i am highly functoning autistic, if you want to know what that is, google temple grandin.

i did not like temple grandin much but that was the start of my search. i googled and read and googled and read, and read and that evening i knew i was autistic.

that was in november 2016. almost 3 years ago now. //

12:36

wow, so did you know she was autistic before the course or was it through conversation about her different skill at managing people that led to this awareness? //

12:37

moment, my daughter has some questions

12:49

i had no clue :-)

i did not even know what highly functioning autism was. i had never heard of it.

in my searchi came across the term aspergers. i had heard of that but had had no idea what that was either.

i only knew a few mentally handicapped people (if that's the correct term these days) who were autistic too. my uncle was one and some of his friends are/were, jasper my partner is a psychiatric nurse and he knows a lot of them too. and i had seen the movie rainman, so knew about the savant verion. and i knew quite some boys who were diagnosed with pdd-nos. and i knew some other guys. and that was it. that was it really.

it was quite disturbing for me to think of myself as possibly autistic too. it was weird. jasper could not believe it at first either. but i read there was so much more about it.

there were women with autism too!

and so many of them!

and not just the mentally handicapped but women with high iq's too!!

in my search i quickly came across tony attwood who in one presentation said he thought Hermione in harry potter series was an aspie.

then i was reassured. hermione is my hero. (i read the whole harry potter series every autumn hahaha) if she is an autie, it's okay for me to be one too.

then i found forums and the aspiegirls book by rudy simone. it was like coming home. //

12:51

that's a really inspiring way of putting it, and makes me feel really happy. I guess I have 2 questions from that. What did you feel was missing before this awareness? and what did you associate with in what you read that made you feel so connected to the term HFA? //

12:53

sidenote, some more info:

the teacher said something like: some of you might have questions on how i present this course. i read your question, then laser sharp focus on that and on you and your world, then i answer from what comes up from deep inside and then i let go. i let completely go, it's up to you then what you do with my answer. i do it like that because my brain is wired differently than most peoples' brains. it's called highly functioning autism. if you want to know more about that, look up temple grandin.

and barbara, i think I might have been the only person in the group who hear her say all this. it was not relevant for the others, they might have let that information pass right away, maybe don't remember she ever said this.

it felt like, this was for me. and i am so grateful to her. she just read my mind i think, lol. this information was for me. my life changed. //

back to your questions.

13:01

1. i felt that i was an alien all my life. that the spaceship dropped me off of the wrong planet. i looked up to the sky many many times, pleaaaase pick me up again, i am LOST here, this can't be right, i don't get them, they don't get me, i am alooonnnneeeeee!!!

i have been looking for answers to that all my life.

why was it that i was not functioning, not really, can give examples later, why was it that i seem to do it all wrong, overshare or not opening my mouth, being weird with people, that i was so fucking intelligent and made such stupid choices, or that my choices seemed clever at the time i chose them but all turned out so badly.

and allll the other things.

i'd come across the term highly sensitive person about 10 years earlier. (and i found jasper and a few other good friends on a forum for hsps.) but i was the elephant i a china shop there. i was wayyyyy to blunt for all these sensitive souls. i always had to explain what i meant, that i was coming from a warm well meaning heart, that i ment well, that it was a joke, just a joke, nothing to offend you. jeeez. so tiring. i left that forum, i just couldn't anymore. so there was something that did not fit completely.

a friend found out she had add. when i looked that up i was like, hmmm i can say i have that too. but i don't like all those labels, and i did not adopt that one.

i was just me, but blundering in life, trying to find my way, but never succeeding really.

2. the term highly functioning autism reminded me of this highly sensitive thing. i did not like the word highly in that term, nor do i in this one. but i thought, that could be a language thing. in my

language it kind of applies better than the rest and i am not a fan of that. we have highly intelligent too. as if those peeps are gods. but maybe in english it has a different feel to it.

when i heard the term aspergers was used more often i loved to adopt that one.

then the whole story about hans aspergers came out, that's quite an ugly one. the dsm stopped making the differences, they now have level 1 or 2 or whatever. i do like the term aspie very much. on a forum for women i soon joined i quickly learned there is a difference, a huge difference between classic autists and aspies.

i was missing connection with other people. somehow they don't get me. somehow we speak across each other, a different language.

I felt the intense search and diving into things i have s sudden interest in is soooo me. drowning on and on about something, i don't mind doing that, i love doing that, but i hear from others it's boring and anti social if i do it. lol.

being clumsy, i can't wear white. at the end of the day you can read my clothes and see what my meals that day were.

the intellectual approach of things. i can feel, i can deeply feel. way too deep often and then i go out of it and look for the practical solution. not flopping on the floor with you and cry with you, i will say okay, what can we do here, what can we do about this to make you feel better? people find that heartless. people who know me know how good i am at that and how well i mean and how well that helps, if they let me help them my way :-)

being overwhelmed so easy. i once saw a clip made by someone to show how autism is for a little boy who was taken to the mall by his mum.

that's years ago and i was like, yeah, duh, that's how malls ARE aren't they? that's just how it is visiting a mall, what is autistic about THAT?

i did not get it. lol.

other friends who saw that clip were like, but that's horrible!!!! to perceive the world this intense, god... that poor kid!

rambling on here. please interrupt :D

//

13:13

there is so much there for me to really process which is amazing thank you. One of the questions I asked you to consider was whether you felt that autism was part of your identity. How do you feel about this. I'm especially interested bearing in mind your comment of not liking labels much and not wanting to associate yourself with the add label. //

13:25

i feel it helps.

it helps to think about myself as autistic, it is such a huge relief.

it helps to give all those quirks and problems a place. we, jasper and i both, are still digesting what it means and come across sooooo many things we can now understand and find a way to deal with.

oh, that's you being autistic. oh, that's an autism thing.

oh that's not because you won't or can't, it's an autism think you struggle with it, maybe you can learn it in steps.

it helps me being patient with myself, and with understanding my brilliance at the same time,

answers questions around that too. :-D

how can someone this highly intelligent be soooo stupid at times?

funnily stupid, like not knowing how to trow out a pizza box when the dustbin is round and the nox just does not fit.

like, running into the garden on socks to do something quickly, and being all annoyed when coming back with completely wet socks and ice cold feet. it has been RAINING all day. you should have put on some shoes!! eh, oh.

like sitting in the cold all day till jasper comes home asking why i did not turn on the heater. well, i had no energy to get out of bed to open the hatch to let some fresh air in.

but that does not prevent you from turning on the heat? eh yes, i can only turn on the heater after i have let in some fresh air, otherwise the rooms gets so stuffy.

that sort of things and much more i can now understand, we can laugh about it. Hell YES to the label autistic for personal use!1

but i feel it's only wise to share it with people who know what autism is. there are so many people who just have no clue, (just as i did not have a clue, and i consider myself quite educated on all kinds of things.) they will misunderstand quickly. they start speaking very slowly and loud to you all of a sudden. or they will feeeeeel for you, poor you, as if you have something incurable you will soon die of.

so i am very happy with all advocates who bring more awareness in the world. //

13:27

Some great examples there. Do you think your autism is always evident? or is there times when you feel more or less autistic? //

13:29

(oh and there is the not being formally diagnosed thing too. at one hand i don't want it, at the other i deeply long for it. i don't dare to declare myself autistic because i have no proof in doctor's writing. don't want to try to be interesting here, or anything. but i know i am autistic. i so know i am. that's a bit weird.)

when i am with people i feel confident with, who get me, who are autistic too or just get it, i can be me. with everything that comes to that.

when i am in bigger groups, when it comes to interacting with NTs or coping with the world outside my ship i can feel SO autistic. in supermarkets, malls, just walking through streets, being in traffic, trying to make conversation... mostly in terms of easily overwhelmed and misunderstood.

13:32

I'm really interested by the comment about not being formally diagnosed and therefore holding back your self-acceptance with others. What impact (if any) does that have on your own sense of 'self' and mental wellbeing? //

13:36

like i might be faking it all along :-|

feeling i might be an imposter :-|

however i would never do that, this asperger thing fits me like a glove. why should i pretend to be one? it's not a status i long to achieve or anything.

yes, it feels like i don't really belong yet. i am autistic with this tiny reservation.

what if i am not? what if i don't get my form signed and stamped?

i know it's bullshit, but actually, that though is eating me. i am not official, i am not for real.

strange huh?

maybe that idea was ingrained by that first forum i entered. it was top secret and difficult to get onto. they wanted me to be officially diagnosed. i was not. i got a year to get my diagnoses. 9but i have some insurance trouble, due to lack of money i could not pay it for a long time, and i can't afford to pay for the diagnosis trajectory myself) so i needed more time to sort that out. and after my first year i was kicked out of the forum.

at one hand i into rebellion state, like I KNOW THIS ABOUT ME! I don't need some doctor guy telling me. and at the other hand i want to beloooonnnngggggg. i want the official status. then it's loud and clear and no one can doubt it anymore. here i have it, black on white. done deal, now what? how to deal with it.

but i am already dealing with it :-)

it's a strange dance. impacting though. //

13:42

that sounds really challenging and I'm really grateful for you sharing that with me. So was it after you realise you were autistic that you started searched for others the same via the internet? did you do any offline? //

13:49

yes. for there was not much official information about women with autism i searched high and low to find real women who live with it. i wanted to hear/read their stories, about their experiences. i wanted to know them. i wanted to compare notes.

i wanted to hear from them what their hiccups and challenges were (and if they overcame some and if so how) and i wanted to check if what they experience sounded a bit like the same of what i experience.

before daring to go to a doctor and making a fool out of myself asking this question (you think i can be autistic?) i wanted to self diagnose more less.

knowing if there indeed was this possibility.

i found all my contacts online. all my aspie peeps are online. in real life i know nobody but the said young pdd nos guys and some older guys who i think are autistic. //

13:50

what impact has the connection via social media had on you and your sense of identity/acceptance of autism? //

14:05

A HUGE one. i consider some of the people i met online as my best friends these days :-|

even though we never met.

(i did meet other people irl i know that's not an issue, meeting irl will be great after chatting with cameras about everything for years, you just know eachother already, only meet in 3d for the first time) i feel so at home in the autism facebook groups i am in. and i read some of the articles the advocates wrote.

i did not plunge in it completely, the autistic thing mentally did not take over my whole life. i know this now and i live my life and at times i connect with my autie peers. they are my hub. that's a bit how it is. i don't follow all the news, some of them inform me about the latest stuff, they taught me what autism speaks is and i decided to stay far away from that.

knowing these fellow autistics and knowing where to find them is a huge contribution to my life. i would NEVER be able to find them in my real life. first of all, due to physical handicaps i am quite bed/boat bound, i can't go out much, so if i were not online i would not meet much people, and then again, how could i find a collection of such great people in my neighbourhood? they won't be there.

the ones i really like are a rare species i think. we are all over the world and through the internet we are able to find each other.

i never felt attracted to go to a common meeting for autistic people here to just meet other autistics. i feel i'd need to have more in common with people than just autism to make it make sense to meet. i feel just meeting other autistics because they are autistic would be sooooo awkward and clumsy. there would be mainly men and i already see a lot of guys clinging on to me, i can be very open and sociable and make everyone feel comfortable, but i won't be the bartender there, i would be there to just meet like minded people. and i just don't think i'd meet them there. :-)

when i was on this first women's forum they were talking about some conference some of them were going to, some of them were speaking at. i thought about going there, (however huge anxiety moods flared up when only thinking about just going there)

but the atmosphere on that forum was harsh and cold and bitchy and when i got kicked out i decided to not invest in any of those people anymore, and completely forgot about going to things like that.

i now have signed up with a thing i like so much better. i'll go to a conference with tony, the big old tony, the one who taught me so much in the beginning of my search. not here in the netherlands but internationally, in london. i would like that so much more. and i will meet some of my aspie friends there!!! //

(so i am def, interested in meeting people live, only not randomly i think. not the unexpected, going to a thing (a big thing)and then see who is there too.

i suddenly remember a guy who i was friends with for years, he must have been very autistic, i understood him very well, and we could get along, and he has all these quirks. his name was frank. he was always looking for the perfect girl. he was 35-40 years old at the time, 5 years older than i was then, and never had had a girl into his life, i was the first who could get along with him. we had no relationship or anything.

i think that going to an autism thing, like attending some local casual meeting, would be entering a room full of franks. younger and older. on the other forum i am on, not much anymore, there are lots and lots of them too. and i am not really interested in really meeting them in real life, i must say. :-))

14:08

Amazing, we are nearing the end. But to finish off I wonder if we could just reflect back on what you said right at the beginning "what i feel is that i am me. and then there is this autistic thing as some kind of layer put over me" when i read this I felt that there was a you and then the autism was separate. But then listening to all you have shared it felt that discovering autism was like understanding yourself. So I guess what I am wondering is, is autism a separate thing to you and your feeling of self? or is it a indistinguishable part of it? //

14:19

i think that at times that i can really be me, as i can with you guys, talking the way i talk, choosing the subjects i like to talk about, and drone on about it till someone else takes over the droning hahahaha, this autism thing is a bit less there. like, not prominent at all, i am just me.

at those times the cloud kind of clears up. it's light and shiny and no handicap at all. we can even use the brilliance of it.

when with other people, people who don't get me, it often becomes very dense and dark and present. then it's SO there.

it's not just around me though, it's in me too. but i can't think of it not being there either. who would i be if the cloud would leave- no it can't leave. it is there. it is always there. it is only quite bright and light at comfortable times and at less comfortable times quite dark and heavy. or anxious and the whole lot.

hah, so i do think it's part of me. //

(it can function as a shield too, i realise. it's up when stupids are around me, helps me feel something like: i am autistic i don't have to deal with them. :-D)

14:20

haha love that end sentence!!

14:21

hahahahahaa you know the muggles i am talking about right? Hahahaha

14:21

M, that has been absolutely amazing. And I wish I could use your answers in my research as they are so insightful!

How did you find it?

14:21

fantastic

really cool to just think about it and just type and then have you ask me even more wonderful questions

14:22

Do you have any suggestions of what I didn't ask? or any ways to improve?

14:23

you were so patient. if you feel you have what you need you did a great job! i can't think of anything that i skipped or that needs to be said to complete the story...

no you do a great job. your presence is so soothing and calm and interested, i feel i can tell you anything.