A Mixed Methods Investigation into Autism Plus and the Impact of Co-Occurring Conditions on the Outcomes and Support Needs amongst Adults with Autism Spectrum Conditions

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Declaration of Authenticity

This thesis is the result of the author's original research. It has been composed by the author and has not been previously submitted for examination which has led to the award of a degree.

Signed: Michael Connally

Date: 02/02/2021

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Abstract

‘Autism Plus’ is a concept which relates to individuals with Autism Spectrum Condition (ASC) and co-occurring conditions (Gillberg & Fernell, 2014). Three studies reported in this thesis examined evidence for a key premise of Autism Plus, namely that individuals with Autism Plus experience poorer social and independent living outcomes and greater support needs compared to those with ‘Autism Only’ (i.e. those with ASC but no co-occurring diagnoses).

Study One was a secondary analysis of survey data from secondary data analysis of 404 adults with autistic disorder (n = 82), Asperger’s/High-Functioning Autism (n = 236) and other ASCs (n = 86). A series of chi-square analyses comparing employment, relationship, residential and independent travel outcomes and service pattern use between those with Autism Plus and Autism Only. No group differences were found in employment or travel outcomes, though contrary to the premise of interest here, those with Autism Plus were found to be more likely to live independently and to be in long-term relationships. However, in line with the premise, those with Autism Plus were more likely to have used support services in the six months prior to data collection. In Study Two, logistic regression analyses focusing on the same sample explored whether Autism Plus may better predict poorer adult outcomes as part of a larger model accounting for age and autistic symptom severity. Findings indicated that Autism Plus was not a useful predictor of employment or independent travel outcomes as part of this model, though again indicated that those with Autism Plus were more likely to live independently and to be in long-term relationships. Other key findings indicated that outcomes were better amongst older individuals and those with milder autistic symptoms.

Study Three aimed to gain greater insight into the ways in which co-occurring diagnoses could influence the lives of those with ASC through interviews with adults with Autism Plus.

Analysis of accounts of lived experience using Interpretative Phenomenological Analysis (IPA) supported the view that the participants' co-occurring symptoms added considerable disruption and difficulty to their lives, and at times could have a greater impact than their ASC symptoms. There was also evidence that within the context of Autism Plus, the severity of a co-occurring condition may be as important as its presence.

Overall, the evidence reported here indicates that current conceptualisation of Autism Plus is limited in the extent to which it can predict those with ASC most likely to experience poor outcomes, though may be helpful in establishing those most likely to require support. Given the findings from Study Two and Three, it is recommended that a modified version of Autism Plus, which considers Autism Plus as an important component of a larger model and acknowledges co-occurring symptom severity, should be explored further.

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Glossary

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Glossary

AD	Autistic Disorder
CA	Childhood Autism
HFA	High Functioning Autism
AS	Asperger’s Syndrome
PDDNOS	Pervasive Developmental Disorder Not Otherwise Specified
ASD	Autism Spectrum Disorder
ASC	Autism Spectrum Condition
ID	Intellectual Disability
DSM	DSM is an abbreviation for the Diagnostic and Statistical Manual of Mental Disorders, which is one of the two main sets of guidelines (along with the ICD) used by clinicians and researchers to diagnose and describe psychiatric and developmental conditions. The manual is published by the American Psychiatric Association (APA), and several editions have been released to reflect changes in the knowledge and understanding of these conditions over time. The first four volumes are commonly referenced using roman numerals (e.g. DSM-IV), while the latest version is referred to as DSM-5.
ICD	ICD is an abbreviation for the International Statistical Classification of Diseases and Related Health Problems, the second main set of guidelines used in the diagnosis and description of psychiatric and developmental conditions. The ICD is published by the World Health Organisation (WHO) and includes guidelines for diagnosing physical health conditions as well as mental and psychiatric conditions. Several editions of the ICD have been published, with the latest version, ICD-11 due to officially replace ICD-10 in 2022.
IPA	Interpretative Phenomenological Analysis

Terminology Used in this Thesis

The focus of this thesis is Autism Spectrum Conditions (ASC). Historically these conditions have been described using a number of different terms in the research literature, though at times similar terms have been associated with different meanings. For clarity, the list below introduces some of these terms along with a description of what they refer to within the context of this thesis.

Table ii

Terminology Used in this Thesis

Term	Definition
Autistic	Autistic is a term used to describe a combination of social, communication and behavioural symptoms associated with impairments in social understanding, interaction and communication. This term can also be used to refer to those presenting these symptoms, who can be described as ‘autistic individuals’.
Autism spectrum / Autistic spectrum	The autism spectrum is a conceptualisation of autistic symptoms which indicates that they can be considered to exist on a spectrum ranging from severe to mild. Any individual presenting clinically significant levels of autistic symptoms can be considered to be ‘on the autistic spectrum’.
Autism spectrum condition (ASC)	‘Autism spectrum condition (ASC) is a term which can be used to refer to any diagnosis featured in the DSM or ICD which is primarily defined by the presence of autistic symptoms. This term can be seen as distinct from the term ‘Autism Spectrum Disorder’ (see below) which in this thesis has been used to refer specifically to those diagnosed according to DSM-5 or ICD-11 criteria.’

(continued)

Term	Definition
Autistic disorder	Autistic disorder (AD) is a diagnosis which featured in the third and fourth editions of the DSM and seventh, eighth and ninth versions of the ICD. This was originally the only diagnosis associated with autistic symptoms, but over time became the diagnosis given to those presenting more severe autistic symptoms. As with AS below, this term has been superseded by more modern diagnostic terms but continues to feature in the research literature given its personal significance to those on the autism spectrum and its continuing utility as a term which can differentiate those with more severe presentations of autistic symptoms (these points are discussed further in Section 2.1.4.).
Asperger's syndrome	Asperger's Syndrome (AS; also known as Asperger's Disorder) is a term which featured in the third and fourth editions of the DSM and seventh, eighth and ninth versions of the ICD. This diagnosis was given to individuals who presented milder symptoms and typically these individuals were of average and above average intellectual abilities. As with AD, this term has been superseded by more modern diagnostic terms though, as discussed in Section 2.1.4, continues to have personal and research significance.
Pervasive Developmental Disorders Not Otherwise Specified (PDDNOS)	PDDNOS is a term used featured in the third and fourth editions of the DSM and seventh, eighth and ninth versions of the ICD. It was originally given to individuals whose autistic symptoms did not clearly fit with the criteria for AD or AS, though has now been superseded by more modern diagnoses, and unlike AD or AS is less regularly referenced in the modern research literature.
Autism Spectrum Disorder	Autism Spectrum Disorder (ASD) is the current diagnosis recommended by DSM-5 and ICD-11 for individuals presenting autistic symptoms and is intended to replace all of the diagnoses previously associated with autistic symptomology. As discussed in Section 2.1.4, this conceptualisation of the condition has received a great deal of scrutiny and critique, which is why the term ASC is preferred in this thesis for discussions relating to anyone with a diagnosis primarily defined by the presence of autistic symptoms.

(continued)

Term	Definition
Autism Spectrum Disorder	‘Autism Spectrum Disorder’ (ASD) is the current diagnosis recommended by DSM-5 and ICD-11 for individuals presenting autistic symptoms and is intended to replace all of the diagnoses previously associated with autistic symptomology. As discussed in Chapter 2, this conceptualisation of the condition has received a great deal of scrutiny and critique, which is why the term ASC is preferred in this thesis for discussions relating to anyone on the autism spectrum.
High functioning / Low functioning	High-functioning (HF) and Low-Functioning (LF) are terms used in the research literature to differentiate between individuals on the autism spectrum with and without intellectual disability (ID). HF refers to individuals with ASC who have average or above average intellectual abilities, while LF refers to individuals with an ASC and co-occurring ID.
Autism Plus	A term coined by Gillberg and Fernell (2014) to describe individuals with an ASC diagnosis and at least one co-occurring diagnosis.
Autism Only	A term used by Gillberg and Fernell (2014) but no co-occurring conditions

Chapter 1

Introduction

1.1. Introduction to Autism Spectrum Conditions: Definition and Impact on Social and Independent Living Outcomes

Autism spectrum conditions (ASC) are characterised by persistent social and communication impairments, and rigid, repetitive patterns of behaviour, (American Psychiatric Association, 2013; World Health Organisation, 2018). The estimated prevalence of ASC is 103.5 per 10,000 (1 in 97; MacKay et al., 2018), though the research literature strongly indicates that this is a condition which impacts more than just the individual who experiences the symptoms (Karst & Van Hecke, 2012; LeBlanc et al., 2008; Lin, 2011; MacKay et al., 2018; Wong et al., 2012). Family members and carers often have to adjust their day to day lives, give up on employment or struggle financially in order to care for an individual with ASC (Gray, 2002; Hare et al., 2004; Pisula, 2007). More broadly, the condition is associated with a considerable economic cost, with estimates indicating that the annual cost of ASCs in Scotland is £2.3 billion (MacKay et al., 2018).

Though historically a large portion of research within the field of ASC has focused on children and adolescents (Jang et al., 2014)[1], studies indicate that adult life can also be greatly impacted by the presence of autistic symptoms (Howlin & Magiati, 2017; Levy & Perry, 2011; Steinhausen et al., 2016). The core social, communication and behavioural characteristics associated with ASC have the potential to profoundly influence many different aspects of adult life with evidence to suggest that overall adults with an ASC are less likely to

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[1] This review of two decades of the ASC research literature (from 1990 – 2010) indicated that 96% of research focused on children and adolescents, based on an analysis of 3,635 research articles.

develop social relationships, gain employment or live independently in comparison to those in the typically developing population (Bishop-Fitzpatrick et al., 2016; Holwerda et al., 2012; Howlin & Magiati, 2017; Matson et al., 2009; Müller et al., 2008; Orsmond et al., 2004; Shattuck et al., 2012). While overall outcomes in the ASC population compare unfavourably to those in the typically developing population, there is also evidence that these outcomes also vary considerably within the ASC population (Howlin & Magiati, 2017; Steinhausen et al., 2016). This means that while some adults with ASC rely heavily on the support of family members and carers for many aspects of everyday life, others can live with some degree of independence, and a small portion of those with ASC may be capable of achieving outcomes comparable to those found in the typically developing population (in the ASC literature, this is known as achieveiving 'optimal outcomes'; Fein et al., 2013; Suh et al., 2014). The severity of ASC can vary, as too can the presentation of the core social, communication and behavioural symptoms which accompany the condition, however previous research has indicated that this heterogeneity in symptom severity and presentation cannot account for the considerable variance in outcomes described above (Chiang & Wineman, 2014; Farley et al., 2009; Magiati et al., 2014; Renty & Roeyers, 2006; Steinhausen et al., 2016; Strunz et al., 2017). While other research has indicated that age, gender and the presence of intellectual disability (ID) diagnoses may also be useful in disentangling this variance, outcomes have still been found to vary greatly within groups of the same age, gender or intellectual ability (Chiang & Wineman, 2014; Gotham et al., 2015; Howlin & Magiati, 2017; Howlin et al., 2013; Khanna et al., 2014).

At present, the lack of understanding about what differentiates more positive and negative outcomes in this population presents challenges in terms of planning and providing support for this population as a whole (MacKay et al., 2018; Roberts, 2010). The majority of individuals in this population are reported to experience stress and discomfort on a daily basis, and on average individuals with ASC report lower levels of life satisfaction and experience a poorer quality of life in comparison to those in the typically developing population (Barneveld et al., 2014; Billstedt et al., 2005; Renty & Roeyers, 2006; van Heijst & Geurts, 2014). These findings are supported by results from other studies which indicate that individuals in this population desire friendships and close relationships but often experience isolation (Mazurek, 2013; Orsmond et al., 2013), desire to be engaged in employment but remain unemployed (Hendricks, 2010; Hendricks & Wehman, 2009), and desire greater independence but are unable to live on their own (Anderson, Roux, et al., 2018; Billstedt et al., 2011; Cederlund et al., 2008). There are a variety of services and support which aim to assist individuals with ASC achieve a better quality of life and improve their social and independent living outcomes (Hedley, Uljarević, Cameron, et al., 2017; Howlin et al., 2005; Spain & Blainey, 2015; Turcotte et al., 2016). However, the research literature has consistently indicated that adults in this population struggle to access these services which may be unavailable in particular regions, at full capacity, or only cater to individuals within a particular age group or with specific presentations and severities of ASC (Anderson & Butt, 2018; Anderson, Lupfer, et al., 2018; Iemmi et al., 2017; MacKay et al., 2018; Tint et al., 2017). While the availability of funding and resources is likely to have contributed to these findings, they also raise questions about whether there is a disconnect between the services and support made available, and the needs of individuals with different presentations and severities of ASC (Underwood et al., 2017).

Considerable advances have been made in establishing the cause of autistic symptoms since the existence of the condition was first proposed, though to date researchers have yet to pinpoint specific genes or variables which autistic symptoms can be attributed to (Amaral et al., 2008; Ecker et al., 2015; Martins, 2017). The current understanding of autistic symptoms is that they are a product of atypical brain development, given that atypical brain structure and brain connectivity are particularly common amongst individuals who present these symptoms (Dajani & Uddin, 2016; Martins, 2017; O'Reilly et al., 2017). Research has also indicated that autistic traits and characteristics are to some extent inherited, given that parents of children diagnosed with ASC are more likely than other parents to present some autistic traits (Hallmayer et al., 2011; Scheeren & Stauder, 2007; Wheelwright et al., 2010). However, research involving monozygotic (identical) twins indicates that at most, autistic symptoms only appear in both twins around 50% of the time, indicating that environmental factors also play a role (Gaugler et al., 2014). So far, some of the environmental factors proposed to increase the likelihood of ASC are prenatal exposure to toxins or use of selective serotonin reuptake inhibitor medication, and poor caregiver interactions in early childhood, though researchers in this area have been keen to stress that these factors only appear to account for proportion of ASC diagnoses (Mandy & Lai, 2016). This has led many researchers to argue that ASC may have multiple etiologies, though this understanding of ASC remains in development (Anderson, 2015; Kim & Leventhal, 2015; Mandy & Lai, 2016).

Without a complete understanding of the etiology of ASC, researchers have struggled to develop effective interventions which can be used to overcome or reduce the impact of autistic symptoms on everyday life as well as important adult outcomes (Havlicek et al., 2016; Helles et al., 2016; Murphy et al., 2016; Ospina et al., 2008; Raymaker et al., 2016; Turcotte et al., 2016; Vohra et al., 2016). As such, it is important that research strives to identify more reliable predictors of outcomes and needs amongst individuals with ASC, which can be used by government, charities and health organisations to develop and budget for better ASC service provision and support in the shorter term (Iemmi et al., 2017; MacKay et al., 2018).

While the impact of ID on the lives of those with ASC has received considerable attention, relatively few studies have examined the potential of other co-occurring conditions such as depression and anxiety to impact outcomes such as employment, social relationships and daily living within the ASC population. Co-occurring conditions are highly prevalent amongst those with ASC, with more than half of this population reported to have at least one psychiatric or medical condition in addition to their core ASC diagnosis (Croen et al., 2015; Lever & Geurts, 2016; Lugo-Marín et al., 2019; Simonoff et al., 2008; Vohra et al., 2016). Given that autistic symptom severity and other demographic and diagnostic factors have been found to be inconsistent predictors of the experiences of adults with ASC, Gillberg and Fernell (2014) propose that co-occurring conditions may be a more appropriate indicator of potential outcomes and support needs within this population. A small but significant number of studies have set out to test this theory, with results suggesting that those with ASC and at least one other co-occurring condition – referred to Gillberg and Fernell as Autism 'Plus' – are more likely to experience a poorer outcomes and a poorer quality of life (Gillberg et al., 2016; Helles et al., 2016)[2]. However, further research is required in order to establish the utility of the Autism Plus as an indicator of needs and outcomes within the adult ASC population.

1.2. Overview and Aims of this Thesis

The aim of this thesis is to explore the impact of co-occurring conditions on outcomes and support needs in the adult ASC population, and more specifically to establish whether there is evidence that Autism Plus can be a useful predictor of poorer outcomes and greater needs in this population. The rationale for this research, the methodological approach adopted and the

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[2] The concept of Autism Plus and the research relating to this conceptualisation of ASC are discussed in more detail in Section 2.3

findings are discussed across seven chapters, and an overview of these chapters is provided below.

Chapter Two introduces and explains the diagnosis and conceptualisation of ASC, which has consistently evolved since it was first recognised as a distinct diagnosis. In recent years the research literature has featured articles which advocate (1) a return to older conceptualisations of ASC (given their potential utility from a research perspective and their personal significance to individuals who experience the symptoms), (2) a modification of the current conceptualisation of ASC, and (3) a disbandment of the current conceptualisation of the condition, and the development of a completely new approach to conceptualising the condition entirely (Kenny et al., 2016; Lombardo et al., 2019; Waterhouse & Gillberg, 2014; Waterhouse et al., 2016). In light of this, Chapter Two provides an overview of how the conceptualisation of ASC has changed over time, the debate surrounding the current conceptualisation of the condition and the merits of Autism Plus (which differentiates those in the ASC population with and without co-occurring diagnoses) as an alternative conceptualisation of the condition.

Chapter Three presents an overview of the current literature relating to social and independent living outcomes in the adult ASC population and focuses on four main outcomes considered to be of particular significance to individuals in the ASC population, namely; social relationships, employment, independent living and independent travel. This review of literature discusses what is currently known about these outcomes, the methodological issues which are prevalent across this research literature and the gaps in this literature which research should aim to address in the future.

Chapter Four introduces the main research questions investigated in this thesis, which aim to address the limitations of the current research literature discussed in Chapter 2 and 3. This chapter also provides and overview of the methodological approach and methods used to investigate these research questions, and outlines the rationale for using these methods to explore the concept of Autism Plus and examine social and independent living outcomes and needs in the adult ASC population.

Chapter Five (Study 1) presents the first of two secondary data analyses, aimed at exploring the utility of Autism Plus as an indicator of outcomes and needs within the adult ASC population. This first analysis compared outcomes and service-use patterns between those with Autism Plus and Autism Only in a large sample of Scottish adults with ASC.

Chapter Six (Study 2) reports a further secondary analysis informed by the findings from Study 1. In this case the aim was to establish whether Autism Plus was a more useful predictor of outcomes and needs when other factors, such as autistic symptom severity, were also accounted for.

Chapter Seven (Study 3) aimed to further explore the utility of the Autism Plus conceptualisation of outcomes and needs within the ASC population by conducting interviews with adults with ASC and at least one co-occurring diagnosis. Findings from Study 1 and 2 provided limited support for the utility of the Autism Plus conceptualisation of ASC, and as such, Study 3 aimed to use qualitative methods to better understand the impact of co-occurring conditions on the lives of adults with ASC and in doing so was intended to explore whether the relationship between co-occurring conditions and outcomes is more complex than has previously been suggested.

Chapter Eight synthesises findings from the three studies as part of a general discussion, and highlights what this research can contribute to the pre-existing ASC research literature. Importantly, this Chapter also provides conclusions on the usefulness of Autism Plus as a concept for differentiating between adults with ASC who experience different outcomes and have different needs.

1.3. Framework for this Thesis

There are a number of frameworks in which medical, psychiatric and developmental conditions may be examined, each which offers an alternative explanation of the way in which particular symptoms and behaviours impact an individual's life. The vast majority of research within this field has been conducted within the medical model framework (Anderson-Chavarria , 2021) which is an impairment-focused model wherein autistic symptoms and behaviours are considered accountable for their difficulties that individuals on the autism spectrum experience (e.g. within the context of the medical model, the difficulties that individuals with ASC experience when forming and maintaining friendships can be attributed to their social and communication impairments; Kapp, 2019). In recent years, this approach to studying ASC has come under increasing scrutiny, for defining autistic individuals only by their symptoms and failing to recognise the other factors which may contribute to the outcomes that an individual experiences throughout life, leading some to propose that the condition is best explored from a different perspective (Anderson-Chavarria , 2021).

One alternative framework in which ASC may be examined is the social model of disability, in which the difficulties that individuals on the spectrum experience are attributed to the way in which society can exclude or marginalise individuals who behave differently (Anderson-Chavarria , 2021; Kapp, 2019). As part of this perspective, it is proposed that some autistic symptoms (e.g. repetitive rocking back and forth or unusual patterns of speech) only cause difficulties because society refuses to accept less common behaviours and as such discriminates against those who display them (Bagatell, 2007). According to this model, individuals with ASC may struggle to gain or maintain employment because workplaces are unwilling to accept individuals those who are different, rather than because they lack the skills our ability to work well (Woods, 2007). However, this approach to studying ASC has also been criticised, in particular because it prioritises the critique of societal norms over advancement in the understanding of symptoms which can make life more difficult for some (Peters, 2000).

The power threat framework has recently emerged as a further approach which can be used to examine ASC and can in some ways can be considered a midpoint between the medical and social models (Johnstone & Boyle, 2018). This approach recommends that conditions and their impact may best be understood by exploring an individual's entire story, ranging from their biology and mental health, to how they make sense of their condition and the personal qualities and resources (including support from others) which they can draw upon to help them cope with their symptoms (Read & Harper 2020). In this case, the experiences which individuals with ASC have with friendships or in gaining employment may be attributed to a combination of the severity of their ASC symptoms, the support or services available to them, and the personal qualities which may make them more or less employable (Johnstone & Boyle, 2018; Read & Harper, 2020). While potentially the most well-rounded method of studying ASC, and something which should be aimed for, from a research perspective this approach may be considered the most labour and resource intensive, given that it involves data to be collected across many different aspects of an individual's life.

The research in this Thesis is grounded within the medical model, given that it is intended to develop a better understanding of how diagnoses defined by the DSM may be useful in predicting outcomes across the ASC population. However, in taking this approach, the analysis in this Thesis can be seen to overcome some of the critique highlighted above (particularly in Study 3, a qualitative investigation into the lives of individuals with Autism Plus), by acknowledging that (1) at times, individuals on the spectrum may experience difficulties simply because they have different interests and preferences than those around them, and (2) that an autistic individual’s experiences are often influenced by a broad range of factors (e.g. personal characteristics and qualities or the availability of social support) rather than just the nature and severity of their symptoms.

Chapter 2

Historical and Conceptual Overview of Autism Spectrum Conditions

2.1. History of the Conceptualisation of Autism Spectrum Conditions

2.1.1. Early History

The conceptualisation of ASC and the terms used to describe autistic symptoms and behaviours have consistently evolved since the condition was first proposed by Leo Kanner in 1943. Kanner was the first to recognise the existence of a distinct condition defined by the presence of social and communication impairments, repetitive patterns of behaviour, a strong desire for consistency and high levels of discomfort in response to changes in environment or established routines (Kanner, 1943; Volkmar & McPartland, 2014). The term originally used to describe the symptoms was ‘Infantile Autism’ (IA), for although Kanner’s description of the condition did not specifically exclude adults, he first observed the symptoms amongst children attending his psychiatric clinic. Over the next two decades, researchers developed a broader understanding of the nature and impact of the condition, though the perception that the condition only affected children persisted for some time (Volkmar & McPartland, 2014).

As research focusing on IA progressed, more details emerged about the specific difficulties which the condition could cause. For example, it was found that those with IA had impairments in social understanding, meaning that they could experience difficulties identifying and responding to social cues and body language, and struggled to perceive situations from the perspective of others (Eisenberg & Kanner, 1963; Rutter & Bartak, 1971). These impairments were often accompanied by language impairments and together these symptoms could make it difficult for those with IA to develop interpersonal relationships (DeMyer et al., 1973; Kanner, 1968; Rimland & Ney, 1974; Rutter, 1978). Much of this research also indicated that those with IA were disinterested in others and would avoid social interactions if possible (Kolvin, 1972; Rimland & Ney, 1974; Rutter, 1978), though importantly this was a perspective of autistic individuals which would gradually change with time (Mattys et al., 2017; Stokes et al., 2007). In addition to social interaction impairments, the condition was also found to be associated with hypersensitivities or hyposensitivities to uncommon sounds or events, strong attachments to inanimate objects, highly specific interests and a tendency to avoid making eye contact with others (Kolvin, 1972; Rutter & Bartak, 1971). Finally, children with IA were also found to engage in repetitive, restricted patterns of behaviours wherein they could become fixated with repeating a particular action such as organising and re-organising their toys (Baron-Cohen, 1989; Kanner, 1968; Rutter, 1978; Rutter & Bartak, 1971).

Autistic symptoms were first officially recognised in clinical and diagnostic guidelines in the eighth edition of the ICD in 1968 and the third edition of the DSM in 1980, under the heading of Autistic Disorder (AD). While the term used to describe the condition changed, the perception of the symptoms and behaviours was unchanged, and in line with this both diagnostic manuals indicated that this diagnosis should be given to individuals presenting (a) a lack of interest in interacting with others, (b) significant language impairments, (c) unusual or repetitive patterns of speech and (d) a resistance to change and an unusual attachment everyday inanimate objects (American Psychiatric Association, 1980; World Health Organisation, 1968).

In the seventies and eighties, a number of studies investigated the experiences of children diagnosed with AD as they grew older, finding that autistic symptoms consistently persisted into adulthood. (DeMyer et al., 1973; Lotter, 1978; Volkmar et al., 1986). In adulthood, the symptoms presented additional challenges, as there was evidence to suggest that in addition to experiencing social difficulties, those with AD were less likely to be in employment or live independently (Gillberg & Steffenburg, 1987; Lotter, 1974a, 1974b). These findings were associated with a major change in the conceptualisation of the condition, which were acknowledged in the revised diagnostic criteria for AD in DSM-III-TR (American Psychiatric Association, 1987), where guidelines indicated for the first time that both children and adults could be diagnosed with the condition. Around the same time, a second major conceptual shift occurred, in this case in relation to the perception of intellectual ability within the AD population. Until this point, research focusing on AD had primarily captured the experiences of individuals with lower intellectual abilities, in part because prior to 1987, DSM and ICD criteria for the condition indicated that it should be given only to individuals with significant language impairments, which were more prevalent amongst individuals with lower intellectual abilities (Volkmar & McPartland, 2014). However this changed with the publication of a number of studies which found the symptoms to also be present amongst individuals with average and above average intelligence (Kolvin, 1972; Rimland, 1968; Rimland & Ney, 1974). Significantly, social communication and behaviour symptoms were found to be milder amongst those with greater intellectual abilities but were still associated with difficulties in social understanding, interacting with others and forming relationships (Ozonoff et al., 1991a; Yirmiya & Sigman, 1991). However, compared to others with AD, those with milder autisitic symptoms tended to experience better outcomes in adulthood, for example individuals meeting this criteria were more likely to be employed and live independently (Ozonoff et al., 1991a). In light of these findings, interest began to develop in the existence of separate but linked presentations of autistic symptoms.

2.1.2. The Autism Spectrum and Categorical Understandings of Autistic Symptomology

Growing interest in different sub-groups of autistic symptoms coincided with two publications which played a pivotal role in the perception and diagnosis of autistic symptoms going forward (Volkmar & McPartland, 2014; Wolff, 2004). The first published by Wing and Gould (1979) investigated patterns in symptomology as part of a larger investigation into the prevalence of AD across a large section of London, England. From their analysis, Wing and Gould reported that all of the symptoms they assessed across a sample of 132 children, could be sub-categorised into distinct levels of severity. For example, social and communication impairments across the sample could be categorised into ‘aloof’, ‘passive’ and ‘odd’, while repetitive patterns of behaviour could be categorised as ‘repetitive only’ and ‘repetitive constructive’. This was one of the first instances in which researchers had clearly indicated that different sub-types of AD may exist.

The second significant publication at this time was the translation of a German article originally published in 1944, one year after Kanner’s original paper on autistic symptoms (Wing, 1981). The paper was originally published by Austrian-based psychiatrist Hans Asperger, though as it was published in German, it was less widely read than Kanner’s English-language paper published around the same time. The translation of the paper by Wing (1981) revealed that Asperger’s paper had provided a detailed account of individuals of with average and above average levels of intellectual ability, aged between 5 and 34 years who showed the signs of ‘autistic psychopathy’. While the nature of the sample described by Asperger differed, the symptoms and behaviours he described closely reflected those described in Kanner’s original paper on IA. For example, impairments in social understanding, difficulties perceiving and responding to body language and facial cues, repetitive patterns of behaviour, and a strong desire for consistency were all prevalent across the group. While many in Asperger’s group were aware of their impairments, few were able to adjust their behaviours, and as a result struggled to develop and maintain friendships or closer relationships. Furthermore, while some had been able to gain employment in jobs involving a high level of accuracy and precision, others struggled to maintain employment as a result of their unusual routines and behaviours.

The translation of these findings and Wing and Gould’s description of different levels of symptom severity prompted a new understanding of autistic traits and characteristics which advocated that they be perceived as existing across a ‘spectrum’, where symptom severity could range from severe to mild (Wing, 2005). As part of this conceptualisation of autistic symptoms, it was proposed that any individual could be considered to exist somewhere on the autistic spectrum, in line with findings which had identified very mild autistic traits within the general population (Rutter et al., 1988). The term spectrum was used rather than ‘continuum’, to indicate that there was not a ‘smooth transition’ between different presentations of autistic symptoms, but instead that there existed multiple types of autistic condition which were underpinned by shared commonalities (Wing, 2005). While this understanding of the condition discouraged the treatment of different presentations of autistic symptoms as completely distinct conditions, it did encourage the use of labels or sub-categories (described in more detail below) to describe individuals at different points on this spectrum (Wing, 2005). Finally, as part of this new understanding of autistic symptoms, the existence of a ‘broader autism phenotype’ was proposed, to describe individuals (often parents of individuals with and IA diagnosis) who presented a number of sub-clinical but clearly autistic characteristics across various aspects of life (Folstein & Rutter, 1978).

In response to these findings, diagnostic guidelines in ICD-10 and DSM-IV for the first time recommended a multi-categorical approach to diagnosing autistic symptoms (American Psychiatric Association, 1994; World Health Organisation, 1990). Both manuals proposed that three main diagnostic categories be used to differentiate between different presentations of autistic symptoms going forward. Two of these categories were associated with distinct levels of symptom severity, while the third (which in itself was associated with three sub-categories in ICD-10) was intended capture all other individuals who presented a combination of social, communication and behavioural symptoms but whose symptoms and behaviours did not clearly fit with one of the first two diagnostic categories[3] (Matson & Boisjoli, 2007; Njardvik et al., 1999). Table 2.1 presents three main levels of sub-diagnoses which featured in DSM-IV and ICD-10, along with the severity of autistic symptoms that these diagnostic categories were intended to capture. While diagnostic labels differed across DSM-IV and ICD-10, research indicated that there were no significant differences in the populations captured by each set of guidelines, both overall and at the sub-diagnosis level (Sponheim, 1996; Volkmar, 1998).

Table 2.1

DSM-IV and ICD-10 diagnostic categories and associated symptomology

DSM-IV	ICD-10	Autistic Symptom Severity
Autistic Disorder (299.00)	Childhood Autism [1] (F84.0)	Severe
Asperger’s Disorder (299.80)	Asperger’s Syndrome (F84.5)	Moderate/Mild
Pervasive Developmental Disorders Not Otherwise Specified (PDDNOS; 299.80)	Atypical Autism (F84.1)[2] Other Pervasive Developmental Disorder (F84.8) Pervasive Developmental Disorder (F84.9)	Mixed; autistic symptoms are clearly present, but do not fit with the diagnostic criteria for one of the above sub-diagnoses

[1] The traits of Childhood Autism were broadly considered to continue into adulthood, as such, the population that this diagnosis was intended to capture was no different than that captured by Autistic Disorder (Sponheim, 1996; Volkmar, 1998). [2] Atypical Autism has a number of sub-diagnoses including Atypicality in Age of Onset (F84.10), Atypicality in Symptomology (F84.11), Atypicality in both Age of Onset and Symptomology (F84.12). For simplicity, the term Atypical Autism (AA) will be used to cover all of these in this thesis.

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[3] DSM-IV and ICD-10 also included a number of other diagnoses including childhood disintegrative disorder and Rett’s syndrome which have not been discussed here given that they have since been shown to be distinct conditions, not associated with autistic spectrum conditions (Lai, Lombardo, Chakrabarti & Baron-Cohen, 2013; McPartland, Reichow & Volkmar, 2012).

This change in the conceptualisation of the condition saw the terms Autistic Disorder (AD) and Childhood Autism (CA) become the diagnoses given to those experiencing the most severe autistic symptoms and those whose autistic symptoms were accompanied by intellectual disabilities or below average levels of IQ. Asperger’s Syndrome (AS) and Asperger’s Disorder (AD) were the diagnoses recommended for individuals who presented moderately severe or mild autistic symptoms and who were of average or above average intelligence. Finally, PDDNOS, Atypical Autism, Other Pervasive Developmental Disorder and Pervasive Developmental Disorder were introduced as ‘catch-all’ diagnoses for individuals who presented autistic symptoms but did not clearly fit the diagnostic criteria for AD/CA or AS/AD. This final diagnostic category primarily existed as a means of ensuring that individuals presenting less typical forms of autistic symptoms and behaviour could be given a diagnosis which would allow them to access appropriate services and support (Volkmar, 1998).

With this new conceptualisation of autistic symptoms in place, research continued to find evidence to support the existence of distinct presentations of autistic symptoms. A large number of studies reported findings indicating that in comparison to others with autistic symptoms, those with AD/CA experienced more profound social and communication impairments, meaning that they were more likely to experience difficulties interacting with others and forming friendships and closer relationships as a result of their social and communication impairments (Billstedt et al., 2007; Howlin, 2003; Orsmond et al., 2004). Individuals with AD/CA also had a more intense attachment to consistency and routine in their life, and could become extremely distressed when this consistency was disrupted or in response to changes in their environment (Bennett et al., 2008; Constantino et al., 2009; Howlin & Moss, 2012; Orsmond et al., 2004; Szatmari et al., 1995). This need for consistency was also associated with highly repetitive and stereotyped (including selfinjurious) patterns of behaviour, and oversensitivity to changes in environment (Leekam et al., 2007; Leekam et al., 2011). Finally, in comparison to others with autistic symptoms, individuals with AD/CA were consistently found to experience the greatest difficulties living independently, particularly with respect to everyday tasks such as preparing food, picking up groceries, cleaning and travelling to and from places (Matson, Dempsey & Fodstad, 2009; Smith, Maenner, Mailick & Seltzer, 2012; Njardvik, Matson & Cherry, 1999).

In comparison to others on the autism spectrum, individuals with Asperger's Syndrome (AS)[4] were generally considered to experience milder autistic symptoms, and were also characterised by average or above average intellectual abilities (American Psychiatric Association, 2013; World Health Organisation, 1990). While DSM-IV and ICD-10 criteria indicated that those with AD/CA and AS could experience similar social difficulties, research consistently showed that the level of these difficulties varied, and that those with AS tended to differ socially from others with autistic symptoms (Ariella Ritvo et al., 2008; Cederlund et al., 2008; Sharma et al., 2012). More specifically, individuals with AS typically demonstrated a greater desire to interact with others and were also more likely to initiate social interactions (Billstedt et al., 2005; Cederlund et al., 2008). Despite this, individuals with AS still compared poorly to their typically developing peers in terms of their social understanding, their ability to identify and respond to relevant body language or social cues and forming social relationships (Baez & Ibanez, 2014; Baldwin et al., 2014; Barnhill, 2007; Cederlund et al., 2008; Holdnack et al., 2011; Howlin, 2000, 2003; Howlin & Magiati, 2017; Magiati et al., 2014). In addition to milder social and communication impairments, individuals with AS typically also tended to have a less intense dependency on consistency and routine (Gilchrist

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[4] From this point onwards, the terms Asperger's Syndrome (AS) will be used to refer to those with diagnoses of Asperger's Syndrome (ICD; F84.5) and Asperger's Diagnosis (DSM 299.80) to clearly differentiate these diagnoses from Autistic Disorder (AD) when abbreviations are used.

et al., 2001; Starr et al., 2003). However, many with AS still reported that the level of consistency and routine they required in order to feel comfortable could be still be disruptive to their everyday life, as could the hypersensitivities and hyposensitivies they experienced in response to sudden environmental changes (Baldwin et al., 2014; Falkmer et al., 2015; Jennes-Coussens et al., 2006; Müller et al., 2008).

PDDNOS, Atypical Autism, Other Pervasive Developmental Disorder and Pervasive Developmental Disorder were by their nature less well defined diagnostic categories, and this is reflected in the fact that these diagnoses are rarely used within the modern research literature, while other diagnoses from this time, specifically AD and AS, continue to have research and personal value (Kenny et al., 2016; Lai et al., 2013; Linton et al., 2013; Smith & Jones, 2020). Given the intended 'catch-all' nature of this last sub-category of autistic diagnoses, they came to be associated with a group of individuals who varied greatly in terms of their symptom severity and presentation, as well as their outcomes, experiences and needs (Matson & Boisjoli, 2007; Volkmar & McPartland, 2014). Therefore, while the research literature developed a well-rounded understanding of the lives and experiences of those with AD and AS, the specific nature and impact of the symptoms associated with PDDNOS, Atypical Autism, Other Pervasive Developmental Disorder and Pervasive Developmental Disorder were never fully refined (Volkmar & McPartland, 2014).

Along with the three main sub-diagnoses described above, interest in an additional 'High Functioning Autism' (HFA) diagnosis also emerged (Ghaziuddin et al., 1995; Gillberg, 1998; Ozonoff et al., 1991b). A number of clinicians and researchers proposed that HFA should be seen as a midpoint between those with AD and AS, and that this diagnosis should be given to those whose symptoms and characteristics closely resembled those found amongst individuals with AD, but who did not have a co-occurring intellectual disability (Ghaziuddin et al., 1995; Ozonoff et al., 1991b). While HFA was never officially recognised as a diagnosis in the DSM or ICD, some professionals and clinicians adopted this term and used it to diagnose individuals meeting the criteria above (Gillberg, 1998). While some research focusing on those with HFA found evidence to suggest that the intellectual ability of those with HFA was higher than those with AD and lower than those with AS (Ghaziuddin & Mountain-Kimchi, 2004; Macintosh & Dissanayake, 2004), other research found less pronounced differences (de Giambattista et al., 2019). Furthermore, as research progressed there was evidence to suggest that those with HFA and AS were not significantly different in terms of social and communication abilities, repetitive behaviours, sensory difficulties, outcomes or support needs (de Giambattista et al., 2019; Gillberg, 1998). Therefore, while many individuals on the spectrum have historically described themselves, or been described, as having HFA, the modern research literature typically groups those with HFA with individuals with AS for the purposes of analysis (Baldwin et al., 2014; Khor et al., 2014; Mitchell & Beresford, 2014; Orum et al., 2018; Strunz et al., 2017; Wilson et al., 2014).

Research around this time also made a number of advances in understanding the difficulties experienced by those with ASC. For example, a number of studies explored the ability of individuals with autistic conditions to perceive situations and experiences from the perspective of others (Frith, 1989a; Happé & Frith, 1995). This ability, also known as ‘Theory of Mind’, was found to be greatly impaired in autistic individuals, which led many to hypothesise that it could be responsible for the difficulties individuals in this population experienced with developing social skills, empathising with others, identifying and perceiving social cues as well as limited social understanding (Baron-Cohen, 2000; Frith, 1994; Happé, 1994; Rajendran & Mitchell, 2007). Other theories at this time attributed the presence of the symptoms to impairments in executive function, a group of cognitive abilities used to perceive and interact with the world which include memory, inhibition, planning and decision making (Christ et al., 2007; De Martino et al., 2008; Sinzig et al., 2008).

Impairments across these abilities were highly prevalent in the autistic population, leading many to argue that they could be responsible for the difficulties individuals with autistic conditions experienced with learning how to socialise with others, and also be linked to the need for consistency and routine in this population (Leung et al., 2016). A final account of autistic symptoms and behaviours presented at this time related to the concept of ‘coherence’, which can be considered an individual’s ability to integrate different information, often gathered in different ways (e.g. visually or audibly), to generate an overall understanding of an event, experience or environment (Beaumont & Newcombe, 2006; Frith, 1989b; Jolliffe & Baron-Cohen, 2001). The ‘weak central coherence’ account of autistic symptoms and behaviours proposed that individuals with autistic conditions primarily focus on very specific aspects of a situation at the expense of combining information to generate a more well-rounded understanding of an event or matter (Frith, 1989b; Happé, 2005). It was proposed that this way of thinking could explain why individuals in the autistic population could overlook subtle social cues such as facial expressions or body language, and become absorbed by highly specific interests and repetitive patterns of behaviours despite other things going on around them (Beaumont & Newcombe, 2006; Berger et al., 2003; Happé, 2005; Loth et al., 2008).

2.1.3. Modern Conceptualisations of Autistic Symptomology: DSM-5 and ICD-11

In research terms, the categorical understanding of autistic symptoms and traits was greatly beneficial to the knowledge and understanding of the autistic population, their experiences and their needs (de Giambattista et al., 2019; Volkmar et al., 2014). However, a number of researchers and clinicians raised questions about the clinical utility and accuracy of the diagnostic criteria featured in DSM-IV and ICD-10. A major concern was that individuals could present autistic symptoms which had a profound influence on their life, but fail to acquire a diagnosis because they did not meet the specific criteria associated with AD/CA, AS, PDDNOS, Atypical Autism, Other Pervasive Developmental Disorder or Pervasive Developmental Disorder, often because they presented other symptoms or behaviours which excluded them from receiving an autistic diagnosis (Lord & Bishop, 2015; McPartland et al., 2012). This was an issue of particular concern given that it could result in an individual being excluded from services and support which were only open to individuals with confirmed autistic diagnoses (Bennett et al., 2008; Kamp-Becker et al., 2010; Lord & Bishop, 2015; South et al., 2005; Szatmari et al., 2009; Woodbury-Smith et al., 2005). Furthermore, evidence from the research literature indicated that there were inconsistencies in those who were given diagnoses of AS and PDDNOS across different diagnostic clinics, and different periods of time (Lord et al., 2012; Lord & Spence, 2006).

Ultimately these issues resulted in a further reconceptualisation of the condition which first featured in DSM-5 and saw the introduction of a new diagnostic category, ‘Autism Spectrum Disorder’ (ASD), intended to replace all pre-existing autistic diagnoses (American Psychiatric Association, 2013). Significantly, this reconceptualisation was not intended to adjust the symptoms and behaviours associated with the autistic diagnoses in DSM-IV and ICD-10, but instead to collapse pre-existing autistic diagnoses into one single category. The diagnostic criteria for ASD was also accompanied by diagnostic specifiers which clinicians and researchers were encouraged to use as a means of differentiating between those with different severities of the condition, as well as those with co-occurring conditions such as intellectual difficulties or language disorder (Volkmar & McPartland, 2014). Similar diagnostic recommendations have also been published in the draft criteria for ICD-11 (the final version is due to officially replace ICD-10 in 2022), with guidelines recommending the use of the Autism Spectrum Disorder diagnosis, and the use of sub-diagnoses to differentiate between those with and without ID and language impairments (World Health Organisation, 2018).

The introduction of this range of diagnostic specifiers across DSM-5 and ICD-11 reflected a growing awareness that autistic symptoms could not be perceived to neatly exist on a linear spectrum ranging from mild to severe (Fletcher-Watson & Happé, 2019). This perspective was informed by research which highlighted that different types of autistic symptoms (e.g., social and communication impairments, repetitive, restrictive patterns of behaviour or sensory issues) often not clearly aligned in terms of their severity (for example, and individual with ASC may have poor language abilities but no sensory issues or an extremely strong need for routine and consistency in their lives but relatively mild social and communication difficulties; Lombardo, Lai & Baron-Cohen, 2019; Wolfers et al., 2019). Ultimately, this evidence suggested that autistic symptoms severity should be viewed as multi-dimensional, and that the nature and impact of these symptoms could be amplified and further complicated by the presence of co-occurring conditions (Fletcher-Watson & Happé, 2019).

Including the testing period, the DSM-5 criteria for ASD have now been in use for around ten years, and while the intention was that this conceptualisation of the condition would be more inclusive and help disentangle the heterogenous nature of the condition through the use of diagnostic specifiers, research indicates that this has not been the case (Fein & Helt, 2017; Lai et al., 2013). A number of researchers raised concerns before the criteria was officially released in 2013, with early field tests for the criteria indicating that at least 10% of those with AS and PDD-NOS diagnoses would no longer meet the diagnostic criteria associated with ASD (Frazier et al., 2012; Kim et al., 2014; McPartland et al., 2012) and research continues to indicate that this is the case (Mazurek et al., 2017). Importantly, DSM-5 guidelines recommend that any individual who previously received one of the autistic diagnoses included in DSM-IV or ICD-10 would automatically qualify for an ASD diagnosis. However, the evidence above does at least suggest that the population captured by DSM-5 will differ from that captured by DSM-IV, and possibly excludes a significant number of individuals with autistic symptoms.

A further issue is that since the official introduction of the DSM-5 criteria, there is evidence to suggest that the recommended diagnostic specifiers are not useful predictors of experiences and needs in this population (Bal et al., 2017; Ellison et al., 2019), have been applied inconsistently within diagnostic and clinical settings (Mazurek et al., 2018) and that when they are applied they are typically more reflective of an individual's intellectual ability than their core autistic symptoms (Mazurek et al., 2018; Weitlauf et al., 2014). Finally, these specifiers have rarely been used in the research literature, with a large number of studies instead reporting findings which relate to any individual with ASD, without an indication of the severity of symptoms experienced by those involved in the research (Howlin & Magiati, 2017; Underwood et al., 2019; Underwood et al., 2017). This can be seen as in contrast to research which in the past may have focused exclusively on those with AD/CA or AS, or made comparisons between those with different DSM-IV diagnoses, and in doing so reported findings which better acknowledged the influence of autistic symptoms severity on the lives and experiences of those with ASC (de Giambattista et al., 2019; Underwood et al., 2019; Volkmar & McPartland, 2014).

This evidence suggests that while the diagnostic criteria laid out in DSM-5 was intended to result in a more accurate and inclusive conceptualisation of autistic conditions, this has not been the case. With ICD-11 set to recommend similar criteria in the coming years, there is concern within the research literature that continuing to perceive and diagnose autistic symptoms in this way could be to the detriment of the long-term understanding of impact of these symptoms and how best to support those who experience them (Lombardo et al., 2019; Waterhouse & Gillberg, 2014). As a result, a number of researchers have advocated the return to categorical conceptualisation of autistic conditions, which better acknowledges differences in symptom severity, experiences and needs (Fein & Helt, 2017; Lombardo et al., 2019; Müller & Amaral, 2017), while others have argued that the concept of the autism spectrum lacks validity and as a result should be disbanded entirely (Waterhouse & Gillberg, 2014; Waterhouse et al., 2016).

2.1.4. Validity of the Autism Spectrum

Calls for an alternative means of classifying and diagnosing autistic symptoms and behaviours since the publication of the DSM-5 have largely been based upon the perspective that the heterogeneity that exists across the autism spectrum is too great to be represented by one single diagnosis or condition (Happé et al., 2006; London, 2014; Smith et al., 2015; Waterhouse & Gillberg, 2014; Waterhouse et al., 2016; Wolfers et al., 2019). A review of the various strands of this argument by Waterhouse et al. (2016) indicates that the main objections to the current approach to diagnosing ASC are that: (1) there is increasing evidence that social and communication impairments often occur without the presence of restrictive patterns of behaviour, and as such ASD lacks construct validity; (2) the exceptionally high prevalence of co-occurring conditions amongst those with ASD makes it difficult to establish which symptoms are autistic and which are a product of other conditions; (3) ASD overlaps too greatly with other conditions such as ADHD and OCD and as such cannot be seen as a distinct diagnosis; (4) ASD is not associated with a single developmental course; and (5) there is too much heterogeneity amongst the proposed sub-categories of ASD.

While it is important that going forward researchers are considerate of the issues raised by Waterhouse et al., there are a number of reason these issues should not be considered sufficient justification for disbanding autistic diagnoses. Firstly, and in response to point two, although there are studies which have reported that more than 90% of their adult ASC sample have at least one co-occurring diagnosis (Anckarsäter et al., 2008; Gillberg et al.,2016), these rates can be affected by a number of different factors including sample size, the representativeness of the sample and whether studies have reported lifetime or current diagnoses (which is significant as the prevalence conditions such as ADHD, Depression and Anxiety have previously been shown to fluctuate with age in the ASC population; this has been discussed further in section 2.4.1). These methodological differences may also be able to account for some of the very high rates of co-occurring conditions reported in the ASC population, included those cited above. For example, Anckarsäter et al. (2008) based their analysis only 22 individuals and recruited their participants from a psychiatric hospital, a forensic psychiatry department and an instituion for adolescents, where it would be expected that rates of co-occurring diagnosis would be higher than average. Similarly, the rates of co-occurring conditions reported by Gillberg et al. (2016) were based upon a sample of 50 individuals, and while they reported that 94% of participants had experienced an additional diagnosis at some point in life, only 54% of participants reported co-occurring conditions at the time of the study, at which point participants were aged between 23 and 43. It should also be noted that neither Anckarsäter et al. (2008) nor Gillberg et al. (2016) set out to specifically report on the prevalence of co-occurring conditions, but instead reported information on this matter as part of studies focusing on broader research issues.

A recent meta-analysis of the literature by Lugo-Marin et al. (2019) attempted to synthesise findings across the literature focusing on co-occurring conditions amongst individuals with ASC, by weighting reported rates according to the sample size of each study, and reported that the proportion of adult with at least one co-occurring condition in this population may be closer to 55%. However, this analysis did not differentiate between lifetime and current rates of co-occurring conditions in the ASC population and as such it is possible that this may still represent an overestimate of additional diagnoses in this population. Nevertheless, there is some evidence here to suggest that that there is a large population of individuals with only an

ASC diagnosis, who may be considered to share similar experiences and have similar levels of ability and needs.

Secondly, and in response to point 3 above, while there is clear evidence that autistic conditions overlap with conditions such as ADHD and OCD, and research should aim to better differentiate these conditions going forward, there is also evidence to suggest that ADHD, OCD and ASD follow distinct trajectories and experience different challenges and experiences throughout their life (Agnew-Blais et al., 2018; Coluccia et al., 2016; Kanai et al., 2017; Roy et al., 2017; Solberg et al., 2019).

Thirdly, and in relation to the three remaining points made by Waterhouse et al., disbanding autistic conditions and the idea of the autism spectrum has the potential to result in stress and uncertainty amongst those with ASC and their families and to be disruptive to research progress rather than being of benefit to the long-term understanding of autistic symptoms (Chambers et al., 2020; Müller & Amaral, 2017). Instead, a number of researchers argue that autistic symptoms should continue to be viewed as existing across a spectrum, but that research aims to better identify homogenous and clearly defined sub-diagnoses which can be used to identify individuals with different symptoms (including co-occurring/non-autistic symptoms), experiences and needs (Ellison et al., 2019; Lai et al., 2013; Lombardo et al., 2019; Underwood et al., 2019). Some have argued that previous diagnostic categories represent a useful starting point in this respect, with many proposing that differentiating between those with AS and other types of ASC continues to be clinically useful (de Giambattista et al., 2019; Kite et al., 2013; Linton et al., 2013; Volkmar et al., 2014). In particular, the continuing utility of the Asperger’s diagnostic category is clear from the fact that it continues to be used and referenced in the research literature many years after the introduction of the more modern ASD diagnosis (Camodeca et al., 2020; Cebreros-Paniagua et al., 2020; Hartwell et al., 2020; Rubido et al., 2020; Shtayermman, 2020; Smith & Jones, 2020; Vincent et al., 2020). A return to a categorical conceptualisation of the condition is also likely to be welcomed by the autistic community, given that many individuals with ASC and their families have expressed a preference for terms such as ‘Asperger’s’ which are an indicator of an individual’s level of ability and needs (Chambers et al., 2020; Huynh et al., 2020; Kenny et al., 2016; Linton et al., 2013).

However, if research is to return to dividing the spectrum to account for the existence of different sub-types, it is important that this is also accompanied by a change in the methods used to examine differences across this population (Lai et al., 2013; Lombardo et al., 2019). As will be discussed further in Chapter 3, a large proportion of research in the ASC literature has been based upon relatively small, poorly defined samples, which makes it difficult to learn more about possible sub-types of ASC which do exist. Therefore it is important that going forward, research bases analysis on larger samples which allows these sub-types to emerge, and consistently stratifies findings to account for any factors (e.g. autistic symptom severity) which could potentially differentiate experiences, outcomes and needs across the spectrum (Lombardo et al., 2019; Müller & Amaral, 2017).

As indicated above, one of the main criticisms of the current conceptualisation of ASC is that the prevalence of co-occurring conditions in the population make it too difficult to untangle the heterogeneity in experiences, outcomes and needs in the ASC population (Waterhouse et al., 2016). However, as outlined in Chapter 1, it has been proposed that rather than further complicating the diagnosis and support of those on the spectrum, co-occurring conditions may be a useful indicator of outcomes and needs within the ASC population (Gillberg & Fernell, 2014). Despite this, co-occurring diagnoses other than ID or language disorder have received relatively little attention within the ASC research literature (Gillberg & Fernell, 2014; Howlin & Magiati, 2017; Lever & Geurts, 2016; Rosen et al., 2018; Underwood et al., 2017).

2.2. Co-occurring conditions in the ASC Population

The core symptoms of ASC are often further complicated by the presence of co-occurring psychiatric and medical conditions (Kohane et al., 2012; Sharma et al., 2018), with evidence to suggest that co-occurring diagnoses are prevalent 70% or more of children and adolescents with ASC (Leyfer et al., 2006; Simonoff et al., 2008; Supekar et al., 2017), and around 55% of adults in this population (Lugo-Marín et al., 2019). It is also common for individuals in this population to experience more than one co-occurring condition, with a study by Joshi et al. (2013) indicating that on average, individuals with ASC have three additional diagnoses. A review by Sharma et al. (2018) indicates that there are at least 16 diagnoses which can be considered to frequently co-occur with ASC, though along with other reviews in this literature indicate that anxiety disorder, depression, epilepsy, ADHD and ID are the most prevalent co-occurring conditions within this population (Levy & Perry, 2011; Rosen et al., 2018; Simonoff et al., 2008).

While a broad range of conditions are known to co-occur with ASC, the majority of research exploring the impact of co-occurring conditions within this population has focused specifically on ID (Howlin & Magiati, 2017; Underwood et al., 2017), with estimates indicating that approximately 20% of those with ASC have moderate to severe ID and a further 10% have mild ID[5] (MacKay et al., 2018). ID is associated with a broad range of difficulties which can make it difficult for an individual to develop skills essential to everyday life such as reading, writing and arithmetic and in turn reduce an individual's ability

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[5] The severity of ID is typically described using labels associated with specific sub-categories of intellectual ability (APA, 2013; WHO, 2018). These labels include mild ID (associated with an IQ of 52–69), moderate (IQ: 36–51), severe (IQ: 20–35) and profound (IQ: 19 and below). These IQ values are acquired through the use of standardised intelligence tests such as the Weschler Adult Intelligence Scale (WAIS; Psychological Corporation, 1997).

to gain employment, live independently and complete tasks such as collecting groceries, preparing food or paying bills (Bouck & Chamberlain, 2017; Grigal et al., 2011; Kampert & Goreczny, 2007; Mansell & Beadle-Brown, 2009; Nota et al., 2007; Schwartz & Rabinovitz, 2003; Wehmeyer & Garner, 2003). These difficulties have prompted a large number of studies to explore the impact of ID on outcomes within the ASC population, though findings have been inconsistent with some research indicating that outcomes are poorest amongst those with ID, and others indicating that ID is a less useful predictor of outcomes when other key factors such as age and autistic symptom severity are controlled for (Alvares et al., 2020; Billstedt et al., 2011; Kamp-Becker et al., 2010; Magiati et al., 2014; Poon et al., 2013; Woodman, Smith, et al., 2016; this is an issue which has been discussed further throughout Chapter 3). Despite these inconsistencies, many studies focusing on outcomes amongst individuals with ASC continue to differentiate between those with ID in their sample, focus specifically on those with or without ID or else account for the specific impact of ID within their analysis (Bishop-Fitzpatrick et al., 2016; Chiang et al., 2013b; Howlin et al., 2013; Ohl et al., 2017; Renty & Roeyers, 2006).

Research from the general population indicates that conditions such as depression, anxiety, epilepsy, ADHD and language disorder[6] can also impact social, employment and independent living outcomes, albeit for different reasons (Geerlings et al., 2019; LeMoult & Gotlib, 2019; Lensing et al., 2015; Michielsen et al., 2015; Rosen et al., 2018; Taylor & Seltzer, 2011; Thomson et al., 2014). For example, there is evidence to suggest that the low levels of confidence and self-esteem and physical exhaustion reported by individuals with depression and anxiety can prevent individuals from socialising with others or going outside

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[6] Several other terms have been recommended as an alternative to language disorder including ‘specific language impairment’, ‘pragmatic language disorder’ and ‘developmental language disorder’ (Bishop, 2017). However, the term language disorder will be used in this thesis as it has most commonly been used to describe language difficulties across the ASC literature.

and can make it difficult to find or maintain employment or go about everyday tasks such as preparing food or cleaning (Ben-Zeev et al., 2012; Craske et al., 2011; Davidson et al., 2011; LeMoult & Gotlib, 2019; Oquendo et al., 2007; Sareen et al., 2005). Despite this evidence from the typically developing population, the impact of these other co-occurring conditions has been less frequently accounted for in research focusing on adult outcomes in the ASC population, and has less regularly been acknowledged as a factor which may be helpful in explaining the considerable heterogeneity in social, employment and independent living outcomes across the autistic spectrum (Smith et al., 2019; Uljarević et al., 2019). This is despite proposals that symptoms such as anxiety could potentially moderate the relationship between autistic symptom severity and outcomes in this population (Smith et al., 2019; Wood & Gadow, 2010).

While overall the ASC research literature has overlooked the potential impact of co-occurring conditions other than ID, a small group of researchers have produced a number of papers and studies which propose that co-occurring diagnoses may be central to differentiating between those on the spectrum with more positive and negative outcomes and greater and lower levels of required support (Gillberg & Fernell, 2014; Gillberg et al., 2016; Helles et al., 2016; Posserud et al., 2018).

2.3. Autism Plus

Autism Plus is a term first used by (Gillberg & Fernell, 2014) to describe any individuals with ASC who also have an additional neurodevelopmental, cognitive or psychiatric diagnosis (e.g. ADHD, epilepsy, depression or anxiety). Gillberg and Fernell’s proposal suggests that outcomes, needs and experiences may significantly differ between those with Autism Plus and those with ‘Autism Only’, and that potentially co-occurring conditions may be a better indicator of outcomes and needs than an individual’s core autistic symptoms. This hypothesis was partly inspired by two other lines of enquiry within the ASC literature. The first focused on the factors associated with the early diagnosis of ASC, which had produced findings to suggest that children with co-occurring conditions were typically diagnosed earlier in life than those with ASC only (Carlsson et al., 2013; Gillberg et al., 2014). The second, was research which had focused on the presence of 'marked' autistic symptoms amongst the family members of individuals with ASC (Eriksson et al., 2013; Gillberg & Cederlund, 2005). Gillberg and Fernell pointed out that if parents and sibling could achieve outcomes comparable to others in the typically developing population despite the clear presence of autistic symptoms, this indicated that autistic symptoms alone could not be solely responsible for the difficulties of those given ASC diagnoses. While Gillberg and Fernell (2014) originally proposed that this understanding of the condition may be most relevant to younger individuals, subsequent research has shown that it may also be helpful in understanding differences in the experiences and needs of adults with ASC. Two studies have specifically set out to compare experiences, outcomes and needs across adults with Autism Plus and Autism Only[7], though both have published analysis focusing on the same sample (Gillberg et al., 2016; Helles et al., 2016).

The first of these studies conducted by Gillberg et al. (2016) carried out a follow-up analysis of 39 males without intellectual disability, with an average age of 30 years at follow-up. At the time of the study, 54% of the sample had a co-occurring diagnosis, with the most prevalent conditions including depression and ADHD, both of which affected 28% of the sample, and anxiety disorders which affected 22% of the sample. However, 94% of the sample indicated that they either had a co-occurring condition at the time of the study or else had previously experienced a co-occurring condition, with the lifetime prevalence of

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[7] Two additional studies have examined differences in those with Autism Plus and Autism Only and found evidence of differences between these groups. However these are not considered to be directly relevant to the research in this thesis or the aims of this literature review given that one focused on personality differences across these groups (Helles et al., 2016) and one focused on service-use differences between 5-6 year old children (Posserud et al., 2018)

depression in the sample 58%, 50% of individuals indicating that they had previously had a tic disorder and 70% indicating that they had experienced a co-ordination disorder at some point in life. Individuals included in the sample were originally diagnosed between 1985 and 1999 at a diagnostic child neuropsychiatric clinic in Gothenburg by experienced clinicians, who made the diagnosis using the Gillberg criteria for AS[8], and the Weschler Intelligence Scale-Revised (WISC-R) or the Weschler Intelligence Scale-III (WISC-III).

At follow-up, participants were once again assessed by experienced clinicians and psychiatrists according to the Gillberg Criteria, though on this occasion were also assessed according to DSM-IV and DSM-5 criteria. At the follow-up, 11 individuals were found to no longer met the criteria for AS according to the Gillberg, DSM-IV or DSM-5 criteria, in that the autistic symptoms these individuals presented could not be considered disruptive to their social life or ability to live independently, and that significantly none of these individuals had experienced co-occurring conditions in their lives. Gillberg et al's (2016) follow-up also assessed participants using the Global Assessment of Functioning (GAF), and found that social and cognitive functioning was poorest amongst those with a co-occurring diagnoses. Together, these findings led Gillberg et al. (2016) to conclude that co-occurring conditions are an important determinant of lifetime prognosis in this population.

Helles et al. (2016) carried out a second analysis on the sample described above, on this occasion examining differences in objective and subjective quality of life across those with Autism Plus and Autism Only. Objective quality of life was assessed using a questionnaire developed by the researchers which captured a number of participant outcomes relating to

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[8] The Gillberg criteria for Asperger's Syndrome (AS) is an alternative diagnosis for AS which was developed as an alternative to the DSM-IV criteria for the condition. This diagnostic criteria was intended to more closely map onto Hans Asperger's original description of the condition than the DSM-IV criteria for the condition. As such was closer to the DSM-IV criteria for AD than the DSM-IV criteria for AS (Leekam, Libby, Wing, Gould & Gillberg, 2000). The Gillberg criteria has been used across a broad range of studies involving individuals with ASC.

friendships, relationships, employment, educational experiences, and residential status. Subjective quality of life was captured using the Sense of Coherence (SOC) measure (Bowman, 1996), which assesses the extent to which a person feels in control of their life and feels live is worthwhile, and the Medical Outcome Study Short-Form Health Survey (Sullivan, Karlsson & Taft, 2002), intended to measure health-related quality of life. No significant differences were found in outcomes experienced by participants, however differences in subjective quality of life were identified. More specifically, those with Autism Only reported feeling in more control of their lives and having a better understanding of other people and the world around them. Helles et al. concluded that it was possible that factors such as autistic symptom severity could be better predictors of specific objective outcomes such as employment or independent living, while co-occurring conditions are a better predictor of how an individual's feel about their life.

While the two studies described above provide preliminary evidence to suggest that outcomes and subjective quality of life may vary between those with Autism Plus and Autism Only, there are three important factors which should be taken into consideration in reviewing these findings. Firstly, these analyses were based upon a relatively small sample (n = 39), meaning that it is difficult to establish to what extent these findings would be generalisable in the larger ASC population. Secondly, the sample included only individuals with Asperger's Syndrome (AS), and as such findings from these studies may only be relevant to those with less severe autistic symptoms rather than anyone on the spectrum. Thirdly, in the sample examined by both studies depression, anxiety and ADHD were far more prevalent than any other co-occurring condition, with lifetime rates for these additional diagnoses, 58%, 22% and 28% respectively, and all other co-occurring conditions affecting less than 10% of the sample. As such, it is difficult to establish to what extent differences across these groups can be attributed to all co-occurring conditions or are more relevant to specific co-occurring conditions. Further assessment of the utility of Autism Plus as a predictor of outcomes and needs in this population is therefore required, however evidence thus far suggests that this is a concept that may be useful in untangling some of the considerable heterogeneity in outcomes and needs which exists across the ASC population.

A further major limitation of the studies which have so far focused on Autism Plus is that they have primarily described the outcomes and experiences of those with Autism Plus and Autism Only at a descriptive level. That is, neither of these studies has considered the role of other factors which may influence outcomes amongst those with ASC alongside co-occurring conditions. Throughout Chapter 1 and Chapter 2 of this thesis, the difference which symptom severity can make to outcomes across the spectrum has already been outlined. However, as will be discussed further in Chapter 3, research also indicates that demographic factors can also play a key role in the experiences of those on the spectrum (Howlin & Magiati, 2017; Steinhausen et al., 2016) and as such should be taken into consideration in any research aiming to better understand the nature and impact of autistic symptoms. It is therefore unclear whether Autism Plus will continue to be a useful predictor of needs and outcomes within this population when these other key variables have been accounted for.

Beyond the studies described above, the research focusing on the specific impact of co-occurring conditions on the outcomes, experiences and service use needs of adults on the spectrum is limited, however a small number of studies have focused specifically on the impact of anxiety on adult outcomes. One of these studies, conducted by Robertson et al., (2018) interviewed 7 adults with ASC about their experiences with co-occurring anxiety. Findings indicated that the severity of anxiety varied across participants, meaning that for some these co-occurring symptoms added an extra level of stress to their everyday life, while for others the symptoms prevented them from leaving their house and having a social life and could make their worklife exhausting. Importantly, these findings also indicated that the impact these symptoms could vary across life, as while at the time of interview some participants indicated their co-occurring symptoms only affected some aspects of their day, the same participants reported that their anxiety had profoundly affected their ability to live independently earlier in life. Similarly, Farley et al. (2009) in a study focusing more broadly on outcomes reported that some of the participants involved in their study (n = 141, aged 22 to 46) were unable to gain employment and avoided engaging in closer social relationships as a result of their anxiety disorder, though the specific of number of people who experienced this difficulty was not indicated.

A further study by (Smith et al., 2019) also focused on the impact of anxiety, this time in relation to the broader concept of quality of life, assessed using the WHOQOL-BREF (WHOQOL-Group, 1998), in a sample of 160 adults with ASC aged between 18 and 27. Smith and colleagues conducted regression analyses, which showed that as part of a larger model accounting for language ability, medication taken and autistic symptom severity, anxiety moderated the relationship between the autistic symptom severity and social domain of the WHOQOL-BREF (this domain included questions which related to how satisfied individuals were with their personal relationships and the support that these relationships provided them with). However, given the data collected, it was not possible to determine whether the presence of anxiety was associated with fewer friendships or a lower likelihood of being involved in a long-term relationship.

Other studies in this area have also explored influence of co-occurring conditions on employment. Schaller and Yang (2005), analysed the impact of having any co-occurring condition on employment in a sample of over 1,000 individuals with ASC living in the United States. As part of the study, a logistic regression analysis with age and years of education as covariates indicated that those with a co-occurring condition were more than two times less likely to be in employment. However, this analysis did not account for differences in symptom severity, nor did the authors differentiate between the impact of ID and other neuropsychological and mental health diagnoses. In similar research Ohl (2017) found that in subsamples of those with ASC and co-occurring ADHD, OCD, depression or anxiety, more individuals were unemployed that employed. Though, this study found that the presence of a co-occurring condition could not significantly predict employment outcomes in a model which also included factors such as years of education, gender and age.

Overall, while generally research focusing on co-occurring conditions has been limited, there is at least evidence to suggest that additional diagnoses need to be better accounted for in ASC research, particularly in studies which aim to better understand the heterogeneity across the autistic spectrum or develop a better understanding of the outcomes and needs of those with ASC.

2.4. Other Influences on the Lives and Experiences of Individuals with ASC

Up to this point, this chapter has focused on the way in which autistic and co-occurring symptoms can influence the lives of those with ASC. However, the ASC research literature has consistently highlighted two other factors which have the potential to shape the lives of those on the spectrum, with evidence to suggest that the outcomes and needs of individuals in this population may also vary according to their age and their gender/sex[9].

2.4.1. Age

ASC is often described as having a lifelong impact, though there is evidence to suggest that the nature of the symptoms and their impact can change with age (Billstedt et al., 2007;

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[9] In line with previous research in this field (Hull, Mandy & Petrides, 2017, Lai, Lombardo, Auyeung, Chakrabarti & Baron-Cohen, 2015; Mandy & Lai, 2017; Shuck, Flores & Fung, 2019) the term ‘sex/gender’ has been used here as a means of acknowledging that sex and gender are not easily separated (Hull et al., 2017) and the inevitable overlap between research focusing on these factors (Lai et al., 2015; Springer, Stellman & Jordan-Young, 2012).

Chowdhury et al., 2010; de Giambattista et al., 2019; Fein et al., 2013; Levy & Perry, 2011; Seltzer et al., 2004; Shattuck et al., 2007; Steinhausen et al., 2016; Woodman, Mailick, et al., 2016). However, the research literature has produced contrasting accounts of the relationship between age and autistic symptomology. A number of studies have provided evidence to suggest that changes in autistic symptomology occur up the end of adolescence, though other research suggests that symptoms may continue to change as individuals reach their fifties and sixties (Lever & Geurts, 2016; Schonauer et al., 2001). Also disputed is the nature of these changes as some have found that symptoms become more severe with time (Billstedt et al., 2007; Gillespie-Lynch et al., 2012), while others have indicated that the intensity and frequency of autistic behaviours decreases with age (Chowdhury et al., 2010; Matson & Dempsey, 2008; Richler et al., 2010).

In support of the case that autistic symptoms decline with time are a number of reports focusing on individuals with ASC who are described as achieving ‘optimal outcomes’, a term used to describe individuals whose outcomes can be considered comparable to those commonly found amongst their typically developing peers. One of the most widely cited of these studies was carried out by Fein et al. (2013) who reported on 34 individuals previously diagnosed with ASD before the age of 5 years old, who in adulthood were found not only to have better outcomes than others on the spectrum, but also to experience comparable social and independence outcomes (in terms of friendships, close relationships, employment and independent living) in comparison to a control group of typically developing individuals. Upon re-assessing the 34 individuals using the Autism Diagnostic Observation Schedule (ADOS), a tool used to assess autistic symptom severity (Lord et al., 2000), the authors concluded that they no longer met the clinical criteria for ASD, in that the symptoms these participants experienced no longer significantly impacted their ability to live independently or interact with others. Several other studies have also reported on individuals with ASC who met the criteria for optimal outcome when followed up in adulthood (Anderson, Liang, et al., 2014; Cederlund et al., 2008; Farley et al., 2009; Helles et al., 2016), with a review of work in this area indicating that between 10 and 20% of individuals with ASC are capable of achieving optimal outcome later in life (Seltzer et al., 2004).

One reason that the findings relating to symptom severity and age may be inconsistent is that different presentations of ASC may be associated with different symptom trajectories. For example, research has shown that symptom trajectories are more consistent amongst those whose initial level of symptom severity are milder, with symptoms more likely to improve over time amongst this subsection of the ASC population (Fountain et al., 2012; Seltzer et al., 2004; Sigman & McGovern, 2005). Similar research has shown that those with ASC and ID are more likely to see symptoms intensify with age, while the severity of autistic symptoms appears to decline with age amongst those in this population without ID (Gray et al., 2012; Lord & Bishop, 2015; Shattuck et al., 2007; Woodman, Mailick, et al., 2016).

2.4.2. Sex/Gender

An increasing number of studies have acknowledged that there may be sex/gender differences in the prevalence and presentation of autistic symptoms (Hull, Mandy, et al., 2017). Research indicates that ASC is four times more common in males than females, a rate which increases to 8:1 amongst those with ASC and no ID (Fombonne, 2009; Loomes et al., 2017). However, a number of researchers have argued that in reality these differences are less pronounced, and that these rates are reflective of a different presentation of ASC amongst females which is less commonly identified at diagnostic assessments (Allely, 2019; Dworzynski et al., 2012; Lai et al., 2017; Lehnhardt et al., 2016). This line of argument also suggests that females are better at ‘camouflaging’ their autistic symptoms, so that instead of being seen as having social or communication impairments they may instead be perceived as ‘shy’ (Allely, 2019; Hull, Mandy, et al., 2017). Support for this hypothesis has been produced by studies which have found large discrepancies between clinician and self-reported ratings of autistic symptoms in females and evidence to suggest that females often fail to meet the diagnostic criteria for ASC despite performing poorly on theory of mind tasks (intended to test an individual's ability to perceive other individuals perspectives on a situation or experience; Hull, Mandy, et al., 2017; Kanfiszer et al., 2017; Lai et al., 2013; Schuck et al., 2019). In line with these findings, there is evidence to suggest that females are more likely to receive their diagnosis later in life than males (Hartley & Sikora, 2009). Importantly, other research has found no evidence of sex/gender differences in symptom presentation or that females are less likely to be diagnosed in comparison to males (Harrop et al., 2015; Lai et al., 2013; Wilson et al., 2016). However, one potential explanation for the inconsistencies in these findings is that ASC studies tend to involve a very small number of female participants, and such analyses aimed at establishing differences in symptomology may be underpowered (Hull, Mandy, et al., 2017; Mandy et al., 2012).

There is also some evidence to suggest that males and females with ASC may differ in terms of their co-occurring symptoms and diagnoses, though again findings relating to this matter have been mixed. For example, some studies have reported that females with ASC are more likely to experience the symptoms of depression and anxiety in line with the sex/gender differences in the prevalence of these conditions also found in the typically developing population (May et al., 2014; Oswald et al., 2016). Similarly, in line with research from the typically developing population, epilepsy has been found to be more prevalent amongst males with ASC (Amiet et al., 2008). However, several other studies have also have found no evidence of such differences (Tsakanikos et al., 2011; Wilson et al., 2016).

2.5. Summary of Chapter 2

The knowledge and understanding of autistic symptoms and conditions has advanced considerably since they were first proposed by Kanner in 1943, though there is still some way to go before the nature and impact of ASC are fully understood. While calls for the disbandment of the current conceptualisation of the condition may be considered a step too far, they do highlight the lack of confidence in the current understanding of ASC and the difficulties which come with diagnosing and researching a highly heterogenous population using a single diagnosis. These issues also highlight that the value in returning to a conceptualisation of ASC which acknowledges sub-types of autistic symptoms, which can be used to parse the considerable heterogeneity in the experiences, outcomes and needs of the ASC population.

Co-occurring conditions are highly prevalent within the autistic population, and according to the Autism Plus theory may be a useful way of moving forward and explaining some of the heterogeneity across this population. In particular, differentiating between those with and without co-occurring conditions may be helpful in better understanding differences in the social and independent living outcomes and needs across this population. Further research is required to establish to what extent the theory of Autism Plus may be useful in this respect, given that that a better understanding of outcomes and needs is a crucial component of being able to support individuals on the spectrum. Furthermore, it is important that this research is also considerate of whether Autism Plus can be considered a useful predictor of other outcomes in this population. While findings relating to the impact of age and sex/gender on the lives of those with ASC may be inconsistent, there is at least sufficient evidence to suggest that these are factors which should be taken into consideration in any research focusing on issues such as outcomes and needs within this population. The following chapter provides an overview of the research which has so far investigated the impact of these demographic variables, as well as other factors such as autistic symptom severity, on the outcomes and needs of those with ASC, as part of a broader discussion focused on the importance of employment, relationships, independent living and independent travel to individuals on the autism spectrum.

Chapter 3

Social, Employment and Independent Living Outcomes in the Adult Autism Spectrum Condition Population

Independent living, employment and involvement in friendships and closer relationships are closely associated with life satisfaction and psychological well-being amongst those with ASC as well as the typically developing population (Arnett, 2004; Cohen, 2004; Fryer, 1986; Hurlbutt & Chalmers, 2002; Jahoda, 1981; Mattys et al., 2017; Sosnowy et al., 2019). Parents and carers of individuals with ASC also report social, employment and independent living outcomes as of central importance, given the potential impact on their children but also on family life as a whole (Eremin, 2011; Mattys et al., 2017; Poon et al., 2013; Sosnowy et al., 2018). Those who look after individuals with ASC often take on considerable care responsibilities, including financial support, social support or support with everyday aspects of life such as preparing food or travelling to and from places (Pisula & Porębowicz-Dörsmann, 2017), therefore independent levels of functioning across these aspects of life can offer parents and carers some form of relief in this respect. However, parents and carers also indicate that their concerns about these issues are also informed by an awareness that there will come a time when they are no longer able to provide or look after their children (MacKay et al., 2018; Mattys et al., 2017).

The aim of this chapter is to outline why these outcomes may be of particular significance to those with ASC, as well as their family members and carers, and to provide an overview of the positive and negative adult outcomes reported amongst those with ASC and the factors previously explored as predictors of these outcomes. Throughout this chapter comparisons are drawn across studies reporting employment, residential, independent living, independent travel and overall outcome rates in this population – the rates reported by these studies are presented in Tables 3.1–3.4 and 3.7–3.9. Sample characteristics (including the age of participants, the autistic diagnoses present in the sample and the intellectual ability of participants) for each of these studies have been presented in Tables A1–A3 in the Appendices. This review of the literature focuses only on studies published since the year 2000. The turn of the century has been used as a cut-off here as by this point in time the changes made in DSM-IV would have been embraced by the vast majority of clinicians and researchers. As such, studies published since 2000 are more likely to be representative of the experiences of the current ASC population than those published before this date.

3.1. Employment

Evidence from the typically developing and autistic literature indicates that there is a strong, positive association between employment and psychological well-being and a number of psychological theories indicate why this may be the case (Dooley, 2003; García-Villamisar et al., 2002; Liu et al., 2013; Schall & McDonough, 2010; Stodden & Mruzek, 2010; Winefield & Tiggemann, 1990). Jahoda (1981) suggests that employment provides life structure, social contact, status and activity, each of which can have a positive impact on life satisfaction and well-being. Similarly, Warr (1987) proposed that employment offers opportunities relating to skill utilisation and variety, social support, income and task significance, and that these opportunities should be perceived like ‘vitamins’, in that humans require just the right amount in order to maintain well-being. A third theory by Fryer (1986) approaches the issues from an alternative perspective and suggests that poor well-being amongst those who are unemployed can be attributed to financial difficulties and the restrictions which these place on an individual’s ability to achieve a good quality of life.

While these theories have not been specifically tested amongst individuals with ASC, evidence to date suggests that they have relevance to individuals in this population. For example, research focusing on individuals with ASC indicates that being in employment is associated with more frequent and better quality social interactions (Billstedt et al., 2011), improvements in cognitive abilities and social skills (Billstedt et al., 2011; García-Villamisar & Hughes, 2007; García-Villamisar et al., 2002; Liu et al., 2013), increased levels of independence (Brooke et al., 2018) and improvements in quality of life (Stodden & Mruzek, 2010). Conversely, findings relating to unemployment in the ASC population indicate that it is associated with a poorer quality of life (Billstedt et al., 2011; Cassidy et al., 2018). Both quantitative and qualitative research have shown that individuals with ASC have a strong desire to work, and that employment outcomes are a major concern for both those on the autistic spectrum and the parents and carers of individuals with ASC (Bennett & Dukes, 2013; Hendricks, 2010; Herrema et al., 2017; Pellicano et al., 2014; Perkins & Berkman, 2012; Turcotte et al., 2015).

There is evidence to suggest that individuals with ASC can be highly effective employees, particularly given the number of highly intelligent individuals in this population (Krieger et al., 2012; Müller et al., 2003). Several studies have also highlighted that autistic traits can be advantageous in the workplace, in particular close attention to detail and precise technical abilities (Baldwin et al., 2014; Griffith et al., 2011; Smith & Sharp, 2013). Despite this, the majority of employment estimates reported in the ASC literature indicate that fewer than 40% of individuals in this population are in employment (see Table 3.1 for an overview of findings). These statistics suggest that employment rates of individuals on the spectrum are poorer than those found amongst individuals in the typically developing population, those with ID (not including those with ASC and co-occurring ID), and individuals with other psychiatric, neurodevelopmental or cognitive diagnoses (Henninger & Taylor, 2013; Roux et al., 2013; Shattuck et al., 2012). Furthermore, individuals in this population who do gain employment report difficulties holding onto their jobs, difficulties interacting with colleagues and difficulties adapting to subtle workplace social rules often cited as a common cause of this (Baldwin et al., 2014; Chiang et al., 2013a; Griffith et al., 2011; Holwerda et al., 2012; Hurlbutt & Chalmers, 2004; Patterson & Rafferty, 2001).

3.1.1. Factors associated with Employment and Unemployment in the ASC Population

Autistic Symptom Severity and Intellectual Ability

As indicated above, qualitative research has found that individuals with ASC often report that they can experience difficulties within the workplace as a result of their communication and social impairments and this is a view reflected in interviews with individuals who have employed individuals on the spectrum (Hagner & Cooney, 2005). However, quantitative research in the same field has failed to substantiate these findings, with a review of this literature indicating that overall there is little evidence to indicate that social ability and functioning alone can predict employment outcomes in this population (Holwerda et al., 2012). These inconsistencies have been reflected in research more broadly examining the link between autistic symptom severity, with some evidence to suggest that employment rates vary across those with AD and AS/HFA and others suggesting that there is considerable overlap in the employment experiences of those with AD and AS/HFA (see Table 3.1). The presence of ID has also been proposed as a useful predictor of employment outcomes in this population, with some of the poorest employment rates in this population reported in studies including a high proportion of individuals with ID in their sample [10] (Cederlund et al., 2008a; Esbensen et al., 2010; Sung et al., 2015; Taylor & Seltzer, 2011, 2012). However, significantly, two papers have found evidence to indicate that individuals with ASC and co-occurring ID are more likely to be in employment than those with ASC only (Cimera & Cowan, 2009; Taylor & Seltzer, 2012). In each of these cases the authors concluded that these findings could be attributed to individuals with ID having greater opportunities

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[10] Further details of the studies described in this chapter are provided in Tables A.1–A.3. in Appendix A

Table 3.1

Studies Reporting Employment Rates for Adults with ASC Published Since the Year 2000

Study No.[1]	Study First Author and Date	% of Sample Achieving Each Employment Outcome			
		Employed or Student	Supported Employment	Unemployed	Other[2]
Studies including individuals with AD					
2	Bush 2017	29	0	71	0
3	Cedurland 2008a[3]	< 1	0	26	73
5	Farley 2009	54	7	10	29
6	Gillespie-Lynch 2012	35	30	35	0
7	Taylor 2011a	6	12	8	74
Studies including individuals with AS or HFA					
9	Cedurland 2008b[4]	28	0	48	24
11	Engstöm 2003	12.5	19	37.5	31
12	Helles 2017	26	44	30	0
13	Ohl 2017	61	←	39	→
14	Roy 2015	46	←	54	→
15	Taylor 2011b	58	12	24	6
Studies including individuals with any ASC diagnoses					
16	Barneveld 2014	49	0	36	15
18	Billstedt 2011	28	6	18	48
22	Gray 2014[5]	18	←	82	→
24	Hofvander 2009	43	0	57[6]	0
25	Howlin 2004	27	7	41	25
26	Howlin 2013	30	15	55	0
28	Kamp-Becker 2010	← 27[7]	→	73	0
29	Kirby 2016	31	←	69	→
30	Mason 2018	36.5	0	63.5	0
33	Sung 2015	8	0	92	0
34	Taylor 2012	9	27	21	43

←→Arrows indicate categories were combined in the paper [1] Study numbers correspond with those in Tables A.1–A.3 in Appendix A which present further details of the studies included in this table [2] Includes volunteering and structured daily activities [3] Employment data only provided for 51/70 participants in this sample [4] Employment data only provided for 25/66 participants in this sample [5] It was not possible to differentiate those who were students and training in this study [6] This includes some individuals who were on long-term sick-leave and a medical pension. [7] 14% of this sample were students, though given the age range of this sample, it's likely that some of these individuals were at high school rather than attending higher education. As such, these individuals have not been included in the 'in employment' category here.

to access services which help individuals into employment.

Early research focusing on the ASC population frequently highlighted language ability and language impairments as important predictors of employment outcomes in the ASC population (e.g. Rumsey 1985; Wolf and Goldberg, 1986). However, more recently few studies have investigated the extent to which this factor can predict employment outcomes in this population, and those doing so have only found differences at a descriptive level (e.g. Whitehouse, 2009). A review of this research by Holwerda et al. (2012) suggested that this change can be attributed to the fact that oral language skills are highly correlated with IQ, and that in the modern ASC research literature the presence of ID is more commonly used as a way of differentiating between those of different abilities, including language.

A number of studies have considered the impact of education on employment, with some evidence to suggest that individuals who have completed more years of education are in turn more likely to be in employment (Howlin, 2000; Ohl et al., 2017; Schaller & Yang, 2005). However, there is also evidence to suggest that educational achievements are associated with greater intellectual ability, fewer language difficulties and fewer ritualistic and repetitive patterns of behaviour (Howlin et al., 2004). As such, it may be the case that the link between educational attainment and employment in this population is strongly influenced by differences in symptom severity and intellectual ability amongst those with greater and fewer years of education.

Several large scale reviews of the ASC employment literature (Chen et al., 2015; Holwerda et al., 2012; Scott et al., 2019) have failed to identify any studies which have investigated the impact of age on employment, despite evidence to suggest that autistic symptoms may change with time (see Section 2.4.1). Of the studies featured in Table 3.1, there was no evidence to indicate that higher or lower rates of employment were associated with the age of the sample[11]. Similarly, few studies have investigated gender/sex differences in employment across the spectrum, though (Chiang et al., 2013b) found that males were three times less likely to be in employment than females and Taylor et al. (2019) found that females were more likely to stay in employment for a longer period of time than males in this population. However, notably Taylor et al. (2019) did not find significant differences in the overall rate of employment across males and females.

Finally, a number of more specific factors may also be considered to influence employment rates amongst the ASC population, though it is likely that these factors will affect some more than others. For example, the social stigma associated with ASC may mean that some employers are reluctant to hire those on the spectrum (Gerhardt et al., 2014), though it is likely that this is an attitude that is gradually declining along with an increase in the awareness and acceptance of ASC within the last two decades. Others have also suggested that because of their social and communication impairments, some with ASC may struggle in the application or interview processes which are key to gaining employment (Scott et al., 2019).

3.2. Relationships

Research indicates that having a close group of friends and being in a good quality, long-term relationship is positively associated with psychological well-being and higher reported rates of life satisfaction (Cacioppo & Cacioppo, 2014; Clark & Lemay, 2010; Cohen & Wills, 1985; Demir, 2010; Hendrick et al., 1988; Oishi et al., 2010; Uchino et al., 1996). Theoretical accounts of social relationships, such as the stress-buffering hypothesis (Cohen & Wills, 1985) and the communal strength account of relationships (Clark & Mills, 1979), indicate

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[11] Further details of the studies described in this chapter are provided in Tables A.1–A.3. in Appendix A

that this positive relationship exists because social relationships provide a sense of belonging, which in turn can improve confidence and self-esteem and can provide an opportunity to combine skills and resources which can make many aspects of life much easier (Cohen, 2004; Cohen & Wills, 1985; Mills et al., 2004; Reis & Patrick, 1996). Furthermore, it has also been proposed that the emotional support that social relationships offer can provide a buffer to the stresses of everyday life as well as to the more major life events associated with high levels of stress (Cohen, 2004; Cohen & Wills, 1985). More specifically, this research indicates that such relationships provide the opportunity to discuss challenging experiences which can help individuals cope with the stresses of everyday life in a way which would be less possible for an individual living on their own (Gable & Reis, 2006).

The ‘buffer’ that social support provides may be of particular significance to individuals in the ASC population, who as a result of their symptoms often find life more difficult and stressful than those in the typically developing population, and often have co-occurring diagnoses of anxiety and depression (Bruggink et al., 2016; Maddox & White, 2015). For example, one study in this field indicated that individuals with ASC who report receiving tangible social support (i.e. the kind of support which relates to the assisting others with practical aspects of life either through providing advice or helping someone complete a task), are less prone to the development of depression compared to others on the spectrum (Hedley, Uljarević, Wilmot, et al., 2017).

However, as a result of their social and communication impairments, individuals on the spectrum typically struggle to form friendships and closer relationships which can provide this form of support (Mazurek, 2013; Müller et al., 2008; Orsmond et al., 2004; Orsmond et al., 2013; Stokes et al., 2007). Historically, the low rates of friendships and closer relationships within this population led to an assumption that individuals on the spectrum were uninterested in interacting with others, however this perception has gradually declined in light of evidence to suggest that a large portion of adults with ASC strongly desire better quality social relationships as well as more intimate longer-term relationships (Mattys et al., 2017; Stokes et al., 2007).

Experiences with friendships and closer relationships vary considerably amongst adults with ASC. Estimates indicate that around 40% of individuals on the spectrum do not have an individual who they would consider a close friend (i.e. someone with whom they would meet or speak on a regular basis; Gillespie-Lynch et al., 2012; Mazurek, 2013; Orsmond et al., 2013). Similar research indicates that those with ASC are more likely to rely on parents or carers for social support than friends (Howlin et al., 2004) and that amongst those who do have friends, friendship quality is typically poorer than that found in the typically developing population. (Baron-Cohen & Wheelwright, 2003).

Findings relating to close, long-term relationships in this population (see Table 3.2) indicate that fewer than 40% of individuals are married or involved in close and long-term relationship (Byers et al., 2013; Koegel et al., 2014; Pecora et al., 2016; Strunz et al., 2017). However, there is also evidence to suggest that this rate rises considerably when previous relationships are taken into consideration. Strunz et al (2017), for example, reported that 73% of their sample of over 200 individuals with high functioning ASC reported being in a relationship at some point in the past. This is in line with findings that indicate that individuals on the spectrum who are not currently involved in a long-term relationship show a strong desire to be involved in this kind of relationship in the future (Hellemans et al., 2007; Kamp Dush et al., 2008; Lau & Peterson, 2011; Renty & Roeyers, 2006).

A qualitative study by Müller et al. (2008) provided insight into the specific reasons why individuals with ASC struggle to form and maintain social relationships (beyond the core social and communication impairments which are typically considered to hamper positive outcomes

Table 3.2

Studies Reporting Long-Term Relationship Rates for Adults with ASC Published Since the Year 2000

Study No.[1]	Study First Author and Date	% of Males in Sample	Relationship Status (%)	
			Married or in LT/ Close Relationship	Not involved in LT/Close Relationship
Samples primarily including individuals with AD				
3	Cedurland 2008a	100	1	99
5	Farley 2009	92	20	80
Samples primarily including individuals with AS or HFA				
8	Byers 2013	47	41	59
9	Cedurland 2008b	100	4	96
11	Engström 2003	56	38	62
12	Helles 2017	100	28	72
13	Ohl 2017 [2]	55	25	75
Samples including individuals with any ASC diagnoses				
16	Barneveld 2014	83	12	88
19	Eaves 2008	77	33	67
24	Hofvander 2009	67	16	84
31	Renty 2006	74	28	72
32	Strunz 2017	40	44	56

[1] Study numbers correspond with those in Tables A.1–A.3 in Appendix A which present further details of the studies included in this table [2] Data missing for three individuals, it was not possible to differentiate those who were widowed from those not involved in a relationship.

within this aspect of life) in a sample of 18 individuals with ASC (including 13 males and 5 females, aged 18–62). Though some within the sample were married, all but one of the participants reported feeling socially isolated, and participants indicated that their lack of friendships was in part due to social anxiety and difficulties initiating social interactions with others. On the idea of closer, longer term relationships, some participants raised concerns that these could be too exhausting, and half indicated they were unsure of how a closer or romantic relationship might work. Other research in this area indicates that individuals in this population may avoid close interpersonal relationships, as they have experienced too many negative social interactions in the past (Barnhill, 2007) or because of a lack of emotional flexibility and emotional dysregulation (Urbano et al., 2013).

3.2.1. Factors associated with Friendships, Close and Long-Term Relationship Status

A small number of studies have explored differences in the nature and quality of friendships experienced by males and females with ASC, indicating that while overall individuals with ASC experience poorer quality and few friendships compared to their peers, autistic girls are more likely than autistic boys to report having friendships which are supportive, close and involve lower levels of conflict (Sedgewick et al., 2019; Sedgewick et al., 2016). However, to the best of the author’s knowledge, similar issues have not been explored within the adult population, nor has research explored whether the likelihood of having friends is associated with sex/gender. Furthermore, other than the findings mentioned above, the research literature has not provided evidence to suggest that other factors may predict the likelihood that those with ASC form friendships or are socially isolated.

Alongside the reported rates of close, long-term relationships presented in Table 3.2, the proportion of males in each sample is also reported given that there is also evidence to suggest that males and females may differ in their experiences of longer-term and close relationships. For example, Byers et al. (2013) explored long-term relationships involvement in a sample of 141 individuals with ASC (without co-occurring intellectual disability) and found that individuals in the sample with relationship experience were more likely to be older and twice as likely to be female. Furthermore, the analyses reported by Byers et al. indicated that those in employment, with more severe ASC symptoms and co-occurring symptoms (such as depression and anxiety but excluding ID) were no more or less likely to be in relationships compared to others in the sample.

Further evidence of a sex/gender difference in close and long-term relationship involvement in this population can be found in Table 3.2. The lowest rates of close and long-term relationship involvement were reported by two of the three samples involving males only (Cedurland et al., 2008a and Cedurland 2008b) and the three highest rates of relationship involvement were reported by three of the four samples in which at least 40% of participants or more were female (Byers et al., 2013; Engström et al., 2003; Strunz et al., 2017). Few other studies have provided evidence relating to the factors which might predict relationship involvement in this population, though findings by Strunz et al. (2017), who based their analysis on over 200 individuals with ASC, indicated that involvement in a close long-term relationship was not significantly associated with autistic symptom severity.

Though no study known to the author has commented on the association between relationship status and age in this population, there is some evidence to suggest that long-term relationships may be more common amongst older individuals in this sample. Of the studies featured in Table 3.2 the lowest rates of relationship involvement (Cedurland 2008a; Cedurland 2008b; Barneveld 2014) involved individuals aged between 16 and 36 with a mean age of 23, while the highest rates reported (Byers, 2013; Engstrom, 2003; Strunz 2017) involved individuals aged between 18 and 73 with an average age of 33[12].

Importantly, it must be noted that in the case of close and long-term relationships, poor or unhealthy dynamics can be associated with more negative consequences than not being in a relationship at all (Holt-Lunstad et al., 2008; McCabe et al., 1996), and recent evidence has

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[12] Further details of the studies described in this chapter are provided in Tables A.1–A.3. in Appendix A

indicated that a significant percentage of individuals in the ASC population experience significant difficulties within relationships. Griffiths et al. (2019) indicated that between 20 and 40% of individuals with ASC had suffered abuse from their partner or spouse. Therefore, while not a factor taken into consideration in the analysis in this thesis, it is important to acknowledge that low rates of relationships in this population could be partly influenced by negative experiences in the past.

3.3. Residential Independence

Residential independence is considered to be an important indicator of an individual's transition to adulthood within the general populations and amongst those with ASC (Ivey, 2004; Pellicano et al., 2014; Stone et al., 2014). Qualitative research indicates that this is an outcome which may be of particular importance to individuals with ASC as well as their families and carers. Krauss et al. (2005) carried out interviews with parents and carers of 133 individuals with ASC whose child (a) continued to live in the family home or (b) was living independently (children in the study were an average of 32 years old and 60% were either non-verbal or communicated using single words or phrases). The findings from this study indicated that parents of ASC children who were living independently felt that the family dynamic was better overall, and that this living situation gave the child an opportunity to develop new skills, confidences, a greater level of independence, a better social life, and a more age-appropriate lifestyle. The same study indicated that the parents of ASC children who had stayed at home were happy to know that their child was receiving the correct level of support and care, but also expressed concerns that the living situation might limit their child's freedom or social opportunities, and restrict some aspects of the family's day-to-day lives.

A number of other studies have reported similar results, indicating that residential independence can be of benefit to both individuals on the spectrum and their families. For example, Orsmond et al. (2013) reported that individuals with ASC who lived independently were more likely to make friends and see their friends in comparison to those with similar presentations of ASC who continued to live in their family home. Furthermore, Billstedt et al. (2011) report that amongst the parents and carers of individuals with autism, quality of life was better when the individuals with ASC lived independently, than when they continued to live in the family home. However, while there is evidence to suggest that many of those with ASC desire to live more independently, research also indicates that a large portion of these individuals may be unsure of the steps towards living more autonomously (Hurlbutt & Chalmers, 2002; Müller et al., 2008).

Research involving individuals with ASC suggest that while many individuals prefer to continue living with their parents until later in life as a result of their symptoms, a sizeable proportion of this population live independently, or aspire to live independently in the future (Anderson, Roux, et al., 2018). Despite this, the research literature has consistently indicated that the rates of residential independence in this population are much lower than those found in the typically developing population (see Table 3.3 for an overview of findings).

3.3.1. Factors associated with Independent Living amongst Adults with ASC

The low rates of residential independence reported in the ASC literature have previously been attributed to a number of factors, including poor adaptive living skills, which are highly prevalent in the ASC population and can cause difficulties with the practical aspects of life including meal preparation, planning and going grocery shopping or keeping a basic hygiene routine (Bishop-Fitzpatrick et al., 2016; Matson et al., 2009; Smith & Shinebourne, 2012a). However, as shown in Table 3.3, there is evidence to suggest that rates of residential independence vary according to level of autistic symptom severity, with studies focusing on those with AS reporting higher rates of independence than those focusing on individuals with

Table 3.3

Studies Reporting Independent Living Rates Amongst Adults with ASC Published Since the Year 2000

Study No.[1]	Study First Author and Date	% of Individuals in Each Residential Outcome			
		Independent [2]	Supported Accommodation	Living with Parents	In Residential Care
Studies including individuals with AD					
1	Billstedt 2005a[3]	4	◄———	96	———►
3	Cedurland 2008a[3]	4	◄———	96	———►
5	Farley 2009	17	17	61	5
6	Gillespie-Lynch 2012	5	10	50	35
Studies including individuals with AS or HFA					
9	Cedurland 2008b	28	◄———	72	———►
13	Ohl 2017[4]	63	0	37	0
Studies including individuals with any ASC diagnoses					
16	Barneveld 2014	34	0	45	21
18	Billstedt 2011	5	57	38	0
19	Eaves 2008	9	35	56	0
22	Gray 2014	9	2	61	28
23	Hewitt 2017	8	4	53	35
25	Howlin 2004	4	5	34	57
26	Howlin 2013	13	5	26	56
29	Kirby 2016 [3]	8	◄———	92	———►
31	Renty 2006	19	0	55	26

◄– –► Arrows indicate categories were combined in the paper [1] Study numbers correspond with those in Tables A.1–A.3 in Appendix A which present further details of the studies included in this table [2] Indicates individual lived alone, with a partner or shared accommodation with another (e.g. lives with a flatmate). Individuals in this situation may still have been dependent upon family member or others for support with some aspects of life. [3] Studies only differentiated between those who were independent and non-independent, for this reason non-independent categories are collapsed here. [4] Data missing for ten individuals in sample

AD (Billstedt et al., 2005; Cederlund et al., 2008; Gillespie-Lynch et al., 2012; Ohl et al., 2017).

There is also evidence to indicate that ID may also be a useful predictor of residential independence outcomes given that some of the highest rates of independence reported in Table 3.3 relate to samples with no ID[13] (Barneveld, 2014; Cedurland 2008b, Farley 2007). However, other studies with a low rate of ID have also found the rate of residential independence to be low (e.g. Howlin 2004).

Research in this literature has also reported evidence to suggest that residential independence is associated with age in this population. For example, Hewitt et al. (2017) reported that older individuals with ASC were less likely to live in the family home, but also acknowledged that this may not always be as a result of increased independence given that many of these individuals were living in residential care. An additional study focusing on this matter by Anderson, Shattuck, et al. (2014) also reported on the relationship between residential outcomes and a broad range of demographic and diagnostic factors in a sample of 620 adults with ASC (mean age 23 years). Findings from this study indicated that household income, higher adaptive living skills and stronger conversational abilities were all associated with residential independence.

One broader issue of relevance here is that research from the general population indicates that children are increasingly leaving their family home at a later age for financial reasons or because it allows them to pursue personal goals (e.g. attending further or higher education) which may be more difficult if living independently (Berrington, Stone, and Falkingham 2010, Billari and Liefbroer 2010). This is an additional factor which should be taken into

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[13] Further details of the studies described in this chapter are provided in Tables A.1–A.3. in Appendix A

consideration in any research focusing on adult outcomes in the ASC population, as it may be the case that some individuals chose to stay at home despite being capable of living independently.

3.4. Independent Travel

Mobility is another aspect of independent living which can present challenges for individuals with ASC (Chee et al., 2015; Deka et al., 2016; Falkmer et al., 2015). Driving is often not an option for many individuals on the spectrum due to general cognitive impairments as well as more specific impairments in working memory, eye gaze and attention (Classen et al., 2013; Cox et al., 2016; Reimer et al., 2013). This is reflected in research which has indicated that a lower percentage of individuals on the spectrum have a driving licence compared to their peers in the general population (Curry et al., 2018). A large proportion of individuals with ASC are therefore dependent upon others or public transport as a means of getting around. However, public transport comes with its own challenges for ASC individuals, as impairments in social understanding, social anxiety and sensory issues can mean that being seated close to others for long periods of time on buses or trains can be a source of stress (Lubin & Feeley, 2016). Reliance on others for transportation can also be problematic as parents of individuals with ASC have reported that being solely responsible for transporting an autistic child can have a significant impact on life, and in some cases may force them to adjust their career in order to help their child access important opportunities and support services (Kersten et al., 2020; Lubin & Feeley, 2016). Furthermore, research indicates that there is little support available for individuals on the spectrum aiming to develop their ability to travel more independently (Lubin & Feeley, 2016).

Relatively few studies have reported upon the rate of individuals with ASC who are able to travel independently, with a broad number of studies only reporting on the percentage of individuals who are able to drive. Three studies which have reported on this matter indicate that between 43 and 65% of individuals with ASC are able to travel independently (see Table 3.4).

Falkmer et al. (2015) reported that amongst a sample of 54 individuals with high functioning variations of ASC, most reported that it was important to them to be able to be able to use public transport, that they felt safe using it, and most importantly that being able to use public transport allowed them to participate in more activities out of their home. In line with this, Lubin and Feeley (2016) collected information on barriers to using public transport from individuals with ASC and the parents and carers of those with ASC and highlighted that some of the greatest concerns related to practical aspects of public transport, such as fears of alighting at the incorrect station. Importantly, Lubin and Feely reported that amongst the 45 individuals with ASC in their sample, all of those who were unable to travel independently, expressed an interest in being able to do so in the future.

While transport issues are frequently acknowledged in the ASC literature, the specific impact of these issues is less well documented. However, a large-scale study conducted by Deka et al. (2016) involving over 1,000 individuals with ASC found that almost 50% of their sample reported requiring transport to travel to work, to attend educational or training facilities, to go shopping, complete other daily errands, to attend healthcare appointments and to visit family and friends. These findings, combined with difficulties which those on the spectrum experience with driving and public transport, indicate that difficulties travelling to and from places may be an issue which adds an additional level of complexity and stress to the lives of those with ASC.

While the literature relating to independent travel and public transport is limited, it has identified two important findings. Firstly, while it might be expected that the symptoms of ASC could limit independent travel in this population, findings suggest that a significant proportion are able to travel independently, and many of those who are unable to, desire to do so in the future. Secondly, the analysis conducted by Falkmer et al. (2015) indicates that being able to travel independently allowed those with ASC to access and engage in more opportunities. Together these findings suggest that more positive mobility outcomes may be achievable across the ASC population, and that such outcomes could also have a positive impact on other aspects of life, and emphasise the importance of supporting more individuals on the spectrum travel independently.

Table 3.4

Studies Reporting Independent Travel Rates Amongst Adults with ASC Published Since the Year 2000

<table>
<tr><th rowspan="2">Study No.[1]</th><th rowspan="2">Study First Author and Date</th><th colspan="3">% of Individuals Able to Travel Independently</th></tr>
<tr><th>Able to Drive or Use Public Transport</th><th>Able to Travel Using Special Transport Services</th><th>Unable to Travel Independently</th></tr>
<tr><td>19</td><td>Eaves 2008</td><td>43</td><td colspan="2">57</td></tr>
<tr><td>5</td><td>Farley 2009</td><td>65</td><td>12</td><td>23</td></tr>
<tr><td>21</td><td>Falkmer 2015</td><td>48[1]</td><td colspan="2">← 52 →</td></tr>
</table>

← → Arrows indicate categories were combined in the paper [1] Study numbers correspond with those in Tables A.1–A.3 in Appendix A which present further details of the studies included in this table [2] This rate is based upon the rate of individuals who reported that they were comfortable using public transport combined with those who indicated that they preferred to drive rather than use public transport

3.4.1. Factors Associated with Independent Travel amongst Adults with ASC

To the best of the author's knowledge, no studies have previously investigated the factors which predict independent travel within this population. However, the broader research does provide some evidence to suggest that ID, which are prevalent amongst one third of the ASC population (MacKay et al., 2018), are associated with difficulties in driving and using public transport (Friedman & Rizzolo, 2016; McCausland et al., 2020). For example, McCausland et al. (2020) reported that in a sample of 708 individuals with ID aged 50 and above, 30% were unable to travel via car or public transport as a result of cognitive impairments. It is possible that the presence of ID in the ASC population may have a similar impact on mobility, though whether it has the potential to differentiate between those who can and cannot travel independently in this population is currently unclear.

3.5. Overall Outcomes

Historically, one of the main ways in which outcomes have been analysed and reported outcomes in the adult ASC population has been through the use of overall outcome ratings (OOR; Henninger & Taylor, 2013; Steinhausen et al., 2016). Studies adopting this approach generate an overall score outcomes within an individual’s life numerically according to whether they are objectively more positive or negative (see Table 3.5 for an example of the rating system used to generate these scores), and scores from each outcome are then combined to generate a total score which can be used to make a general evaluation about an individual’s quality of life or needs (see Table 3.6). The majority of studies adopting this approach to analysing outcomes use ratings of employment, social relationships and independent living (Henninger & Taylor, 2013; Howlin & Moss, 2012; Steinhausen et al., 2016), though a small number have also used ratings of communication abilities, co-occurring conditions and the need for support (Billstedt et al., 2005; Cederlund et al., 2008; Chamak et al., 2008).

Estimates across OOR studies have varied considerably with estimates of the percentage of individuals experiencing poor or very poor outcomes ranging from 0–93% (Cederlund et al., 2008; Chamak & Bonniau, 2016). There is evidence to suggest that the rates of OOR are more homogenous amongst studies focusing on those with similar levels of autistic symptom for example, studies which primarily include individuals with AD have typically reported a higher rate of poor and very poor outcomes compared to studies with samples which only include individuals with AS or HFA (see Table 3.7). However, there are also important exceptions to this trend, particularly from Farley et al. (2009) who reported that only 17% of participants experienced poor or very poor outcomes, in a sample of 41 individuals aged

Table 3.5

Example of Overall Outcome Rating (OOR) guidelines, taken from Eaves & Ho (2008, p. 741)

Outcome	Scoring	
Employment	0	Employed or self-employed
	1	Engaged in voluntary work, job training or low-paid work
	2	In supported or sheltered employment
	3	No occupation or in specialised residential centre
Friendships[1]	0	Engaged in close friendships involving sharing, exchange of confidences and a range of different activities
	3	No friends and no joint activities
Residential Status	0	Living independently
	1	In semi-sheltered accommodation or still at home but with a high degree of autonomy
	2	Living with parents but with a high degree of autonomy
	3	In residential accommodation with some limited autonomy
	4	In residential accommodation with little or no autonomy
	5	Hospital institution.

[1] The authors indicated that scores for this outcome could range between 0 and 3, though no specific criteria were provided for scores of 1 and 2.

Table 3.6

Example of Overall Outcome Rating (OOR) Score Interpretation Guidelines (taken from Eaves and Ho (2008, p.741)

Score	Categorical Label for Outcome	Description
0 – 2	Very Good	Achieving a high level of independence, some friends and a job
3 – 4	Good	Generally in work, and some friends/acquaintances, but requiring some support in daily living
5 – 7	Fair	Some degree of independence, no close friends but some acquaintances, requires support and supervision but does not require specialise residential provision
8 – 10	Poor	Requiring special residential provision, or a high level of support, and has no friends outside of residence
11	Very Poor	Needing high level of care, with no friends or autonomy

Table 3.7

Proportion of Individuals Experiencing Different Levels of Outcomes Published Since the Year 2000

Study No.[1]	Study First Author and Date	% of Sample Experiencing Outcomes			
		Poor & Very Poor	Fair	Good	Very Good
Studies including individuals with AD					
1	Billstedt 2005a[2]	91	9	0	0
3	Cedurland 2008a[3]	93	7	0	0
4	Chamak 2016a	90	0	10	0
5	Farley 2009	18	34	24	24
6	Gillespie-Lynch 2012	50	20	10	20
Studies including individuals with AS or HFA[4]					
9	Cedurland 2008b[5]	26	47	27	0
10	Chamak 2016b	0	0	100	0
11	Engström 2003	12.5	75	12.5	0
Studies including individuals with any ASC diagnosis					
17	Billstedt 2005b	92	8	0	0
19	Eaves 2008	46	33	17	4
20	Esbensen 2010	61	28	9	2
25	Howlin 2004	58	20	10	12
26	Howlin 2013[6]	60	23	10	7

[1] Study numbers correspond with those in Tables A.1–A.3 in Appendix A which present further details of the studies included in this table [2] Outcome data missing for 5 individuals, and intellectual ability data was missing for a very small proportion (< 3%) of individuals [2] Individuals reported as having ‘restricted’ outcomes in this study closely mapped onto the criteria for poor/very poor outcomes in other studies. As such, these categories have been combined here [3] Participants were only described according to 3 levels of outcome; good, poor and very poor [4] Engström 2003 included 6 individuals with High-Functioning Autism in their sample, other studies in this table included only individuals with AS diagnoses [5] Outcome data was missing for 8 individuals [6] This study followed up the sample previously assess in the Howlin 2004 study

between 22 and 46. One factor which may be able to account for this inconsistency in findings is intellectual ability, given that none of the participants in Farley et al.'s sample had co-occurring ID[14], while ID was present at least 50% of the samples from other OOR studies focusing on those with AD (Billstedt et al., 2005; Cederlund et al., 2008a). Furthermore, of the studies which have acknowledged differences in intellectual ability across their sample, poor and very poor OOR tend to be more prevalent samples with higher rates of severe, moderate or mild ID (see Table 3.8).

However, these differences in OOR may also be reflective of age differences in samples, with some of the highest rates of poor and very poor OOR found amongst studies focusing on individuals with an average age of 24 years (Study 3 and 17 in Table 3.7) and higher rates of fair and good OOR reported amongst three studies where the average age of participants ranged between 33 and 44 years (Study 19 and 20, 25 in Table 3.7).

3.5.1. Factors Associated with Overall Outcome Ratings in the Adult Autism Spectrum Condition Population

A small number of studies have investigated the factors which predict OOR within the adult ASC population. The most notable finding in this area was produced by (Howlin et al., 2013) who reported that together, reciprocal social interaction, language ability, restrictive repetitive patterns of behaviour (all determined by the Autism Diagnostic Interview-Revised [ADI-R], a gold standard measure of autistic symptom severity; Rutter et al., 2003), and IQ could account for 76% in the variance in overall outcomes in a sample of adults with ASC and mixed intellectual ability. Though importantly, this analysis was based upon a relatively small sample of 58 participants and used a measure of overall outcomes which combined historical and current outcomes (e.g. an individual could be rated as having a positive

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[14] Further details of the studies described in this chapter are provided in Tables A.1–A.3. in Appendix A

outcome, if they were currently employed or had been employed in the past). As such, it is difficult to establish to what extent these factors would be able to predict current outcomes as successfully.

Table 3.8

Percentage of Individuals Experiencing Poor and Very Poor Overall Outcome Ratings (OOR) According to Proportion of Individuals with Severe, Moderate or Mild ID

Study No.[1]	Study First Author and Date	Percentage of Sample with Intellectual Disability[2]		Percentage of Sample Experiencing Poor/ Very Poor Rates
		Severe/Moderate	Mild	
3	Cedurland 2008a	72	21	93
17	Billstedt 2005b	77	20	92
19	Eaves 2008	48	31	46
20	Esbensen 2010	71	26	61
25	Howlin 2004	16	20	59

[1] Study numbers correspond with those in Tables A.1–A.3 in Appendix A which present further details of the studies included in this table [2] The proportion of individuals with IQ ≥ 70 is not reported here

A further study which aimed to predict OOR in this population was conducted by Esbensen et al. (2010), who indicated that physical health, functional abilities (relating to being able to carry out practical everyday tasks), literacy, behaviour problems and services received accounted for 21% of the variance in overall outcomes, however noted that only functional ability was significantly associated with OOR. Finally, two other studies have reported on the extent to which OOR may be predicted by data collected earlier in the lives of those with ASC. For example, Farley et al. (2009) reported that the current age of participants combined with their childhood IQ could account for 23% of the variance in outcomes in a sample of 41 individuals with ASC, and Eaves and Ho (2008) reported that 61% of the variance in adult OOR could be accounted for by IQ and autistic symptom severity (as determined by the childhood autism rating scale).

A review of the OOR literature conducted by Steinhausen et al. (2016) synthesised findings from OOR studies published between 1967–2014 (including all of the papers mentioned in Table 3.7 and an additional six papers published before 2000). The final estimate was based upon 12 samples including a total of 828 individuals and indicated that 48% (95% CI 37–59) of individuals on the spectrum experience poor or very poor outcomes but that this rate increased to 68% (95% CI 51 – 72) amongst individuals with autistic disorder or childhood autism diagnoses, and fell to 26% (95% CI 12–49) for those with other ASC diagnoses. However, Steinhausen et al. (2016) stressed that the broad confidence intervals associated with these rates were indicative of the highly heterogenous nature of the OOR reported as well as the samples these analyses were based upon. This meta-analysis also considered the influence of age on outcomes and though finding that outcomes varied across different age bands, there was no evidence that of a general improvement or decline in OOR with age. Steinhausen et al. (2016) made no comment on the impact of ID upon OOR.

3.5.2. Critique of the Overall Outcome Rating Approach to Assessing Outcomes in the ASC Population

While the OOR approach to describing adult outcomes has proven popular in the ASC literature, it can be argued that the approach is problematic for understanding outcomes for two main reasons. Firstly, studies taking this approach typically equate outcomes across different aspects of life (e.g. positive relationship and employment outcomes will be scored equally) and in doing so risk overlooking differences in the objective or subjective importance of these outcomes. The broader issue with this is that it can result in individuals being classed as having good OOR, despite experiencing poor outcomes within an aspect of life that matters to them most. For example, the criteria used by Eaves & Ho (see Table 3.5 and 3.6) allows for an individual with no friends to be described as experiencing good outcomes, going against evidence from the broader psychological and ASC research literature which indicates that friendships are a desirable and important part of life.

A second issue with this approach is that it risks overlooking important differences in the factors which influence individual outcomes. For example, research cited in Section 3.1 indicated that employment rates did not consistently differ across those with different levels of autistic symptom severity or intellectual ability, while there was no evidence to suggest that these factors may be associated with residential independence (see Table 3.1 and Table 3.3).

3.6. Critique of the ASC Adult Outcome Literature

Reviews of the ASC adult outcome literature have identified a number of problems with research within this field, with one of the most common criticisms that studies in this literature have based analyses upon relatively small sample sizes (Zimmerman et al., 2018). This review of the literature has also found evidence of this, in that of the 34 samples which have been referenced here as reporting rates of social, independent living or employment or travel outcomes, 21 based analyses on less than 100 individuals, and 10 based analyses on 50 or fewer individuals (for specific sample sizes see Tables A.1–A.3 in Appendix A). Research within this literature has also been criticised for basing analyses on poorly defined samples (Steinhausen et al., 2016; Underwood et al., 2017). The consequence of this is that studies may describe analyses as relating to the entire ASC spectrum, with no indication of to what extent this sample is representative of the ASC population or may be skewed towards individuals with more or less severe autistic symptoms or individuals with higher or lower intellectual abilities. Other reviews of the literature have raised questions about the validity of findings produced by univariate analyses (i.e. those which account for one or fewer influential factors when reporting outcomes in this population), arguing that by failing to account for key factors such as age, symptom severity or the presence of ID, analyses risk misrepresenting the social and independent living outcomes in this population (Magiati et al., 2014; Underwood et al., 2019).

Aside from issues associated with study design, a number of researchers have also raised concerns about how adult outcomes are conceptualised in the ASC population. For example, Magiati et al. (2014) highlight that a large portion of this literature makes assumptions about what constitutes positive and negative outcomes (for example being in employment and involved in a long-term relationship are typically perceived as a positive outcomes), which may be inaccurate due to the difficulties and impairments experienced by those on the spectrum. Bishop-Fitzpatrick et al. (2016) also reported concerns about this conceptualisation of outcomes highlighting that while employment can bring many benefits, for some on with ASC it may represent a negative outcome in that it can lead to an increase stress and anxiety. Evidence in favour of this critique comes from studies which have found differences between self and other reported measures of quality of life amongst individuals with ASC (Clark et al., 2015; Egilson et al., 2017; Ikeda et al., 2014). While this issue does not invalidate previous research in this area, it does serve as a warning that research focusing on adult outcomes in this population must also be considerate of individual differences, and how the symptoms and behaviours associated with ASC may affect the desires and goals of those on the spectrum.

3.7. Support and Service-Use

One issue not so far covered in this Chapter is the provision of services and support and the impact of that these can have on adult outcomes within the ASC population. Service use and support can be considered closely associated with the adult outcomes on the spectrum given that many adults on the spectrum use employment services to help them develop skills which can be useful in the workplace, may use ASC-specific support groups to meet others and may rely on small amounts of regular support (i.e. help with groceries or money management) to help them live more independently overall (Shattuck et al., 2020). However, qualitative research within this field indicates that both individuals with ASC, and the parents and carers of those with ASC, report that there is inadequate support for individuals in this population, and that the support that is available is often difficult to access. Furthermore, this is a finding which has been reported across studies from a number of countries including the United States (Bianco et al., 2009), Canada (Eaves & Ho, 2008) and the United Kingdom (Crane et al., 2019; Herrema et al., 2017). Research has indicated that this is an issue which affects adults with ASC more, with qualitative studies with the ASC community indicate that there is often a decrease in the level of support available after leaving secondary education, and again once an individual reaches their mid-twenties (Howlin & Moss, 2012; Perkins & Berkman, 2012 Turcotte, 2015). Furthermore, interviews with individuals with ASC and their caregivers indicate that a primary concern is how the individuals with ASC will cope when a caregiver is no longer able to provide them with support (Glasberg, 2006; Herrema, 2017).

A key component of ensuring that adequate support is provided is a knowledge and understanding of the factors which influence service and support needs, however, to date the evidence base to inform this knowledge and understanding is limited (Płatos & Pisula, 2019; Turcotte et al., 2016; Vogan et al., 2017). As highlighted by a recent review of this literature, few psychological studies have investigated the consistency and variability in service use and needs and explored the broader impact which such services can have on the outcomes or needs of those on the spectrum (Shattuck et al., 2020). This can be considered a significant oversight by the ASC literature, given a better understanding of those who may require additional needs compared to others on the spectrum (for example individuals with Autism Plus) would make it easier to provide care and support packages more specific to an individual’s needs.

One aspect of service use and support which has received more attention in the research literature is the use of employment services and training programmes, aimed at improving employability of individuals in the spectrum, though findings suggest that the success of these programmes varies (Scott et al., 2019). However, while some research has provided evidence to suggest that such schemes and programmes increase the likelihood of gaining employment in the future (Alverson & Yamamoto, 2017; Cimera et al., 2012), most studies indicate that engaging in these services does not guarantee subsequent employment, and many who use them are reported to be unemployed when followed up later in life (Hillier et al., 2007; Lawer et al., 2009; Nicholas et al., 2015). Furthermore, a longitudinal study following 161 individuals with ASC over 10 years found evidence to suggest that there was a decrease in the number of individuals employed and the average number of hours worked by individuals with ASC, regardless of the use of support services earlier in life (Taylor & Mailick, 2014). There is also limited evidence to suggest that interventions specifically targeting skills associated with employability significantly improve employment outcomes across this population (Hedley, Uljarević, Cameron, et al., 2017; Scott et al., 2019). Finally, it should be acknowledged that the more positive findings above relate to individuals who have been able to access appropriate levels of support, though as previously indicated, this is only the case for a small proportion of individuals on the autistic spectrum (Baldwin et al., 2014; Turcotte et al., 2016).

3.8. Summary of the Autism Spectrum Condition Adult Outcome Literature

The review of the literature presented in this chapter highlights that positive employment, long-term relationship and independent living outcomes are strongly desired by a large portion of the ASC population and that overall these have the potential to greatly improve the lives of individuals on the spectrum as well as their parents. Research has explored to what extent a number of factors can predict outcomes in this population, though the literature has overwhelming focused on the role of autistic symptom severity and intellectual abilities. While there is some evidence to suggest that each of these factors can impact outcomes such as employment, social relationships and independent living, findings focusing on this relationship have also been inconsistent. This suggests that while these factors should be considered and accounted for in any research involving this population, these factors alone cannot be considered to determine outcomes amongst adults with ASC. Similarly, findings relating to age, gender may be inconsistent across this research, but there is still sufficient evidence to suggest that they should be recognised as factors which may be able to explain some of the variance in outcomes across this population (Howlin & Magiati, 2017; Steinhausen et al., 2016; Underwood et al., 2017).

It is important that research strives to better understand the factors and mechanisms which underpin positive and negative outcomes in this population for a number of different reasons. Firstly, a better knowledge and understanding of these issues can produce important context for individuals on the spectrum as well as their parents and carers about what can be expected in adult life. Individuals with ASC have previously reported that they feel unsure of what they should expect from their lives given their difficulties and impairments and mixed messages about what they are capable of (Cribb et al., 2019; Hurlbutt & Chalmers, 2002; Kirby, 2016). This is also a concern of parents and carers is that they struggle to find a balance between supporting their child’s needs and encouraging them to be more independent for their own benefit (Mattys et al., 2017). As experiences vary greatly from person to person across the spectrum, it would be inappropriate to use this knowledge to indicate what should be expected of individuals on the spectrum or to suggest what individuals on the spectrum are and are not capable of. Instead, this research could be used as means of identifying which type and level of support may be particularly advantageous to individuals with particular traits and characteristics.

Secondly, and as discussed in Chapter 1 and 2, if more reliable and accurate predictors of outcomes and needs in this population can be identified, this can be useful in budgeting for, planning and providing more appropriate levels of support for individuals across the spectrum (Iemmi et al., 2017; MacKay et al., 2018; McCarthy et al., 2015; Nicolaidis et al., 2015; Turcotte et al., 2016). This is crucial, given that as discussed in Section 3.7, a large proportion of individuals with ASC report experiencing difficulties accessing support which is reflective of their abilities and needs. A better understanding of the factors associated with different adult outcomes may therefore be helpful in developing a model of service provision which better accounts for differences in service needs across the spectrum.

Thirdly, identifying predictors of outcomes and experiences may also be useful to the development of a more appropriate conceptual understanding of ASC. As discussed in Chapter 2, the current conceptualisation of autistic symptoms has received a great deal of scrutiny for capturing a highly heterogenous population. A better understanding of what differentiates outcomes and needs across this population may therefore also be helpful in developing more homogenous sub-categories of ASC which would be beneficial from both a clinical and research perspective (Fein & Helt, 2017; Lombardo et al., 2019; Müller & Amaral, 2017; Smith et al., 2015).

More research which focuses on understanding adult outcomes in the ASC population and the factors which influence them is therefore required (Howlin & Taylor, 2015; Long et al., 2020; Michael, 2016; Ruggieri et al., 2019). However, it is important that this research aims to address some of the issues associated with research previously published in this field.

More specifically, this research should involve larger and better-defined samples and also aim to better acknowledge the perspectives of individuals with ASC regarding outcomes relating to employment, long-term relationships and independence. It is also particularly important that these outcomes are explored separately rather than as part of a composite, given the concerns raised in Section 3.5.2 that this approach risks equating aspects of life which should not be equated and may overlook important differences in the factors which affect different types of outcomes.

Chapter 4

Methodology and Methods

4.1. Introduction

In Chapter 2, it was proposed that the Autism Plus conceptualisation of ASC has the potential to differentiate between those with greater and less severe needs across the autistic spectrum and may also be useful in predicting different outcomes and experiences within this population. It is therefore important that this conceptualisation of the condition is further explored, particularly given the potential benefits to planning and providing support for individuals on the spectrum and their families (as discussed in Chapter 3). This thesis takes a three-study approach to exploring the validity and utility of Autism Plus as a concept and in doing so aims to also address previous issues within the ASC outcome literature, such as ensuring that analyses are based upon a larger and better-defined sample and being more considerate of the perspectives of those with ASC.

4.2. Research Questions

The following five research questions were developed with the intention of achieving the objectives described above and responding to some of the gaps in the literature raised in Chapter 2 and Chapter 3.

(1) Do individuals with Autism Plus and Autism Only differ in their employment, long-term relationship, independent living and independent travel outcomes?

(2) Do individuals with Autism Plus receive greater levels of support than those with Autism Only?

(3) Can the Autism Plus conceptualisation of ASC differentiate between social and independent living outcomes when key demographic and diagnostic factors are also controlled for?

(4) What are the perceptions of a sample of adults with Autism Plus of the impact of co-occurring conditions on their social and independent living outcomes?

(5) On the basis of lived experience, to what extent might the Autism Plus conceptualisation of ASC be useful in differentiating needs and outcomes of adults across the spectrum?'

The remainder of this chapter describes the methodological approach which will be used to investigate these research questions as well as a rationale for the methodology and methods adopted in this thesis.

4.3. Methodology

While often used interchangeably, many researchers propose that 'methodology' and 'methods' are distinct components of a research project, and that the understanding of a phenomenon is more likely be accurate when both of these components are fully thought through (Cresswell, 2003; Robson, 2011; Valsiner, 2017). In this respect, methodology can be seen as the philosophical principles which underpin the overall approach to investigating a phenomenon, while methods are the techniques used to collect data which can answer research questions (Hughes & Sharrock, 2007; Roberts, 2014). However, it should also be noted that both method and methodology are typically also underpinned and shaped by the rationale for investigating a particular concept or phenomena of interest (Roberts, 2014; Robson, 2011).

The term research paradigm is commonly used to describe different combinations of research methodologies and methods within the research literature, and in the psychological literature studies tend to align with one of five main paradigms; positivism, post-positivism, interpretivism, pragmatism and critical realism (Camic et al., 2003). Each of these paradigms is associated with a specific ontological stance – which relates to how reality is defined – and an epistemological stance – which relates to how reality is best measured (see Table 4.1).

Ontological perspectives exist across a spectrum which ranges from realist to idealist, where realist perspectives propose that there is a single reality which exists independent of human perception, and idealist perspective propose that reality is defined by individual and group perceptions and that as such there are multiple realities (Burkitt, 2003; Lundh, 2018; Sullivan, 2010). Epistemological stances range from more objective to more subjective, where objective perspectives advocate that anything in our reality can be accurately measured if the correct method or methods are employed, and subjective perspectives propose that an accurate interpretation of reality is gained from examining how society interacts with reality and by asking individuals about their experiences and perspectives (Cresswell, 2003). Table 4.1 outlines the ontological and epistemological approach associated with each of the five main research paradigms mentioned above, as well as the methods typically associated with each of these paradigms.

Table 4.1

Types of Research Paradigms commonly followed in the Psychological Research Literature and the associated methods, advantages and limitations

Paradigm	Ontology	Epistemology	Associated Methods	Advantages	Limitations
Positivism	Realist – there is a single reality which is directly observable	Reality can be directly measured if the appropriate tools are used	(Primarily quantitative, though some qualitative) Data collected through methods such as questionnaires, structured interviews or behaviour observations, analysed using statistical analysis to search for causal relationships	Encourages the use of standardised measures, to increase consistency across research.	Overlooks biases which may influence the perception of reality, and as such the authenticity of findings can be questioned.
Post-Positivism	Post-Realist – there is a single reality which exists, but observations of this reality are fallible.	Reality can be directly measured, but findings must viewed in the context of potential observer biases, or methodological weaknesses. Potential methods must therefore be scrutinised.	(Primarily quantitative, though some qualitative). Similar techniques to positivism, though efforts are made to overcome potential biases (e.g. efforts are made to recruit a representative sample, and assure samples recruited are appropriate for the planned statistical analysis)	Encourages the reliability of findings to be consistently questioned, in order to develop a more accurate understanding of reality in the long-term	Focuses on observable factors, and as such may overlook factors which may be unseen but of equal importance (e.g. an individual's perception of reality) which in some instances may be more import in answering a research question

(continued.)

Paradigm	Ontology	Epistemology	Associated Methods	Advantages	Limitations
Interpretivism (Constructionism)	Idealism – reality is what individuals (or a group of individuals) perceive it to be, and as such there are multiple realities.	Reality is best understood by questioning individuals or groups of individuals about their perception of the world, as individual interpretations of reality are more important than the directly observable reality	(Primarily qualitative) Data collected through methods such as open-ended interviews and focus groups are used to identify reoccurring themes or topics which can illuminate underlying causal relationships which influence an outcome or event	Generates a deep understanding of concepts which may not be directly observable through typical quantitative approaches	The methods required to generate this understanding of reality are highly work-intensive, and as such, studies of this nature tend to involve smaller sample sizes often involving 30 or fewer participants (Vasileiou et al., 2018). This makes it less likely that findings are able to be generalised.

Paradigm	Ontology	Epistemology	Associated Methods	Advantages	Limitations
Pragmatism	Rejects the need for ontology and encourages the use of different research strategies for different problems.	For each research question, a researcher must decide if concepts or events are best understood through direct observation, individual perceptions of a matter, or a combination of these two approaches.	Either qualitative or quantitative, including any of the techniques mentioned above.	Highly flexible, and not restricted by the limitations associated with single methodology reports	Researchers must determine the most appropriate methods for an investigation, and method-selection guidelines are limited. This leaves research taking this approach open to critique regarding their data collection techniques

(continued.)

Paradigm	Ontology	Epistemology	Associated Methods	Advantages	Limitations
Critical Realism	Between realist and idealist – holds that there is a directly observable version of reality, which can be influenced by underlying, unseen mechanisms, and the perception of this reality can vary from person to person.	The different layers of reality – directly observable, actual reality and the underlying mechanisms and structures which underpin these – are equally important, and a complete understanding of a concept or event can only be understood by investigating each of these layers and synthesising findings.	A combination of qualitative and quantitative methods (including any of those mentioned above) are recommended, as a means of capturing a well-rounded understanding of reality	Examining concepts or events from using multiple different approaches allows for the cross-validation of findings, and a more robust understanding of a concept or event.	Findings from different strands of an investigation may be contradictory, leaving a researcher without a concrete conclusion on an issue.

Note: Definitions and descriptions in this table are adapted from Cresswell (2003), Krauss (2005) and Ponterotto (2005).

4.3.1. Research Paradigms within ASC and Broader Psychological Literature

A large proportion of the research focusing on outcomes in the ASC population, and the psychological literature more broadly, employs a positivist or post-positivist approach to research wherein findings are based upon primarily quantitative methods (e.g. questionnaires) or systematic observations (Anderson, Roux, et al., 2018; Camic et al., 2003; Scott et al., 2019; Zimmerman et al., 2018). The advantage of this approach is that allows for theories and concepts to be tested across a large representative population and the strength of relationships between factors to be assessed through the use of statistical analysis (Castro et al., 2010; Robson, 2011). Positivist and post-positivist may therefore be useful when researchers intend to test candidate or pre-existing theories involving variables known or suspected to be influential (Krauss, 2005).

Critics of this approach argue that while there are positive elements of the positivist and post-positivist approach, their major failing is that they are prone to overlooking important or highly influential variables as a consequence of focusing too closely on factors involved in theories of interest, factors which intuitively seem most relevant or which have previously been highlighted in the research literature (Collier, 1994; Danermark, 2002). There is some evidence of this within the ASC adult outcome literature given that the vast majority of studies have revisited autistic symptom severity and the presence of intellectual ability as predictors despite their limitations as predictors of outcomes, with few studies examining the role of other potential predictors (as discussed in Chapter 3). More generally, positivist and post-positivist approaches methodologies have also been criticised for encouraging researchers to believe they ‘know best’ about a particular matter (Brown et al., 2002; Fletcher, 2017).

In contrast, interpretivist approaches to research encourage researchers to base findings primarily on the perspectives of those who directly experience or are impacted by a phenomenon, and to allow participant voices to inform the development of theory, rather than looking to find evidence for pre-existing theories or concepts within a participants responses (Cresswell, 2003; Krauss, 2005). Typically, this type of approach involves qualitative methods such as interviews or analyses of written perspectives or opinions, which discourage researchers from allowing pre-existing theory to guide their research questions an analysis and encourages the development of theories and hypotheses based upon what is learned from participants (Ponterotto, 2005; Schwandt, 1994). This approach to research is becoming more prevalent within the ASC literature, with a number of researchers calling for more research which involves the voice and expertise of autistic individuals, though still continues to be vastly outweighed by research taking a positivist and post-positivist approach (Milton, 2014; Nicolaidis et al., 2011). Interpretivist research published to date has been hugely important in that it has given voice to individuals in the autistic population and recognised the value of autistic accounts in the development of knowledge and theory relating to the condition (Griffith et al., 2011; Mattys et al., 2017). However, more broadly speaking, the interpretivist approach to research in turn may be criticised for failing to adequately acknowledge the biases which may influence subjective perspectives on matters or concepts (Danermark, 2002; Fletcher, 2017; Roberts, 2014). For example, perspectives of adults with ASC on what influences their ability to gain employment or live independently may be influenced by advice they may have been given by professionals and family members, what they have learned from doing their own research on the condition and a broad range of individual differences (Cribb et al., 2019; Hurlbutt & Chalmers, 2002; Kirby, 2016).

Positivism and post-positivism interpretivism have historically been the research paradigms of choice in the psychological literature, encouraging researchers to prioritise either the expertise of the researcher or the perspectives of participants. By contrast, critical realism (CR) is a research paradigm which positions itself between post-positivist and interpretivist approaches to research, combining the most positive aspects of each approach (Bhaskar, 2016; Brown et al., 2002; Kelly, 2016; Robson, 2011).

4.3.2. Critical Realism

Generally speaking, a CR approach to research can be described as one which (1) acknowledges the existence and importance of different levels and perspectives of reality and (2) recognises the advantages, limitations and suitability (given the research questions) of each of these levels and perspectives (Collier, 1994; Fleetwood, 2014). Ontologically, CR hold that there are three levels of reality (Fleetwood, 2014). The first is ‘empirical’ reality, which can be described as the version of reality which is directly observed by a researcher or an individual affected by a particular phenomenon. Perception of this reality can be influenced by biases (from both those who experience a phenomenon as well as those who observe the phenomena being experienced) relating to pre-existing knowledge, hypotheses and understandings of the world. The second level is ‘actual’ reality, which can be considered as the reality which exists independent of human perception (e.g. an event or outcome that occurs, regardless of whether it is observed). The final level is described as the ‘real’ (underlying) level of reality, and involves the underlying frameworks, mechanisms and factors which interact to produce a particular event or outcome. Table 4.2 provides a hypothetical example of what conclusions may reached at different levels of reality relating to outcomes experienced by adults with ASC.

As a research approach, the core principles of CR advocate that a more reliable, valid and trustworthy understanding of a phenomena or the applicability of a theory can only be gained by examining a matter across each of these levels of reality and comparing and contrasting findings relating to each level (Ackroyd & Karlsson, 2014; Danermark, 2002; Patomäki & Wight, 2000).

This approach acknowledges that all observations are fallible regardless of actions taken to avoid misinterpretation or bias, but argues that by revisiting and reassessing a concept in different ways researchers are encouraged to question and scrutinise pre-existing conceptions and theories which in the long-term is more likely to produce a more accurate representation of reality (Fleetwood, 2014). According to this understanding, if a concept or theory makes sense at each level then it can be considered to be relevant and useful, otherwise it may be considered redundant or in need of modifications before it can be considered an accurate representation of phenomena, outcomes or events (Cruickshank, 2007) .

Table 4.2

Levels of Reality in the Critical Realism Paradigm, their Definition and Examples of Possible (Hypothetical) Conclusions

Level of Reality	Definition	Possible Conclusions (Hypothetical)
Actual	What really happens regardless of how it is perceived by researchers or those who experience an event or outcome	An individual with ASC is unemployed
Empirical	How an event or outcome is perceived by either a researcher or an individual affected by the event or outcome	An individual with ASC is unemployed as a result of their autistic symptoms
Real (Underlying)	The underlying mechanisms and structures which may contribute to an event or outcome occurring	An individual has difficulty gaining employment in part because of their autistic symptoms but also as a result of co-occurring depression symptoms which together make it difficult to for them to motivate themselves to pursue employment. These difficulties could also be influenced by external factors such as employer concerns about hiring individuals with ASC.

4.3.1. Critical Realism as a Methodology

In line with the above, CR is not associated with a specific set of methods but instead encourages combining different methods to generate alternative understandings of a matter, which can later be contrasted and combined to develop a more complete and accurate understanding of a matter (Fletcher, 2017; McEvoy & Richards, 2006; Zachariadis et al., 2013). As such, mixed method approaches, which combine qualitative and quantitative methods, are highly prevalent amongst researchers working within the critical realist framework (Bryman 2006; Cresswell et al., 2011; Venkatesh et al., 2013).

Explanatory Sequential Approach

One way in which the mixed methods approach can be applied is using an exploratory sequential approach, which typically involves a large-scale quantitative investigation, followed up by a smaller qualitative investigation which aims to provide a more detailed understanding of the concepts and relationships which emerged from the quantitative analysis (Fetters, Curry & Cresswell; Ivankova, Cresswell & Stick, 2006). The benefit of this approach is that it provides an opportunity to triangulate findings, a process which involves of comparing and contrasting findings gained through different methods as a means of critically assessing and validating results (Bowen et al., 2017; Ivankova et al., 2006). This process of triangulation can be seen to complement the key principles of critical realism, in that it aims to reduce the likelihood that researchers will misrepresent the data and increase the credibility of conclusions researched by the research. While mixed method approaches and the processes of triangulation may result in a researcher reporting inconsistencies in their findings, Robson (2011) argues that this is a helpful outcome as it can force researchers to reconsider the validity of a concept or theory or highlight the complexity of an issue. A mixed method approach may therefore be considered ideal for investigating Autism Plus, given that this is an emerging concept which has yet to be fully scrutinised.

4.4. Methods Used in this Thesis

As indicated in Chapter 3, there is a need for research which (1) analyses differences in outcomes and needs across the ASC population according to key demographic and diagnostic characteristics and (2) better acknowledges the perspectives of those with ASC on the factors which affect their outcomes and needs. With this in mind, the research in this thesis was conducted within a critical realist framework, which allowed for findings from more objective, large scale analyses of group differences in adult outcomes stratified to account for key demographic and diagnostic variables, to be contrasted with more in-depth participant accounts of life with Autism Plus.

The five research questions introduced in Section 4.2 were explored within this critical realist, mixed method framework using an explanatory sequential approach and Table 4.3 provides an indication of the methods which be used to gather data and respond to each of these questions. Research questions 1–3 were investigated using quantitative techniques, which allow for the applicability of Autism Plus to be tested in a large sample of adults with ASC while also accounting for the role of other potentially key factors such as age and autistic symptom severity. Following this, research questions 4 and 5 were intended to follow-up on the previous studies using qualitative techniques and establish whether personal accounts living with ASC and co-occurring diagnoses provided support for the utility of Autism Plus as a useful predictor of outcomes and needs. Given that the pre-existing literature has also raised questions about the conceptualisation of positive and negative outcomes in the ASC population being heavily influenced by typically developing perspectives on outcomes, research questions 4 and 5 were also intended to gain greater insight into how outcomes such as employment, independent living and relationships are perceived by adults on the spectrum.

Table 4.3

Studies Featured in this Thesis, Research Questions and Methods Employed

Study No.	Research Questions	Methods
1	1. Do individuals with Autism Plus and Autism Only[1] differ in their employment, long-term relationship, independent living and independent travel outcomes? 2. Do individuals with Autism Plus receive greater levels of support than those with Autism Only?	Quantitative; secondary data analyses, including group comparisons conducted using chi-square analyses
2	3. Can the Autism Plus conceptualisation of ASC differentiate between social and independent living outcomes when key demographic and diagnostic factors are also controlled for?	Quantitative; secondary data analyses involving logistic regression modelling exercises
3	4. What are the perceptions of a sample of adults with Autism Plus of the impact of co-occurring conditions on their social and independent living outcomes? 5. On the basis of lived experience, to what extent might the Autism Plus conceptualisation of ASC be useful in differentiating needs and outcomes of adults across the spectrum?	Qualitative; Semi-structured interviews involving individuals with Autism Plus

[1] Autism Plus = Individuals with ASC and at least one co-occurring condition, Autism Only = Individuals with ASC and no co-occurring conditions

Ultimately, this research project aims to capture an understanding of the impact of co-occurring conditions and the validity of the Autism Plus conceptualisation of ASC which can (1) provide an indicator of how useful Autism Plus is as a concept for differentiating those with different outcomes and needs across the spectrum; (2) capture the extent to which, if any, those with Autism Plus and Autism Only differ in terms of their needs and experiences; (3) provide an indication of whether the concept of Autism Plus continues to be useful when other factors known to influence outcomes in this population are also taken into consideration; (4) explore to what extent those on the spectrum perceive co-occurring conditions as making life more difficult; and (5) capture the value placed on different adult outcomes by those on the autism spectrum. As such, final conclusions on the concept of Autism Plus will be based on a combination of these findings, and these conclusions will be used to inform future recommendations for research and policy. The remaining sections of this Chapter provide a detailed account of the methods used to explore these research questions.

4.4.1. Quantitative Research Methods

Secondary Data Analysis

Secondary Data Analysis is a popular technique within the psychological literature which uses pre-existing datasets to conduct unique analyses which can be used to re-evaluate pre-existing data or use this data for a new purpose (Hinde, 1991; Johnston, 2017). Two of the studies presented in this thesis used such an approach using a pre-existing dataset which was constructed as part of the Scottish Autism Microsegmentation Study (SAMS; MacKay et al., 2018).

This thesis is the product of a linked research scholarship between Scottish Autism and the University of Strathclyde. As part of this joint project, the author of this thesis made a significant contribution to the design and data analysis of the SAMS, and was one of six researchers involved in the data collection (including the development of the questionnaire used to collect data), analysis and write up of this study which focused on the link establishing the outcomes and economic cost associated with ASC in Scotland. The secondary data analyses which features in this thesis is based upon data originally collected as part of this SAMS project.

Scottish Autism Microsegmentation Dataset

The aim of the SAMS was to develop a better understanding of the outcomes and economic cost associated with ASC in Scotland, and to achieve this, a questionnaire was distributed to individuals with ASC, as well as parents, carers and professionals to gather information which could inform this analysis. The survey gathered data relating to demographics, ASC diagnoses, the presence of co-occurring conditions, social and independent living outcomes and the familial impact of ASC. The final dataset included information relating to 950 individuals with ASC, 404 of whom were adults aged 16 years and older. Of this adult sub-sample, 24% had autistic disorder, 52% had Asperger's syndrome and 24% had another form of ASC. These figures are in line with previously reported rates of different variations of ASC, indicating that this sample is relatively representative of the ASC population (Macintosh & Dissanayake, 2004). Importantly, close to 50% of this population also had at least one co-occurring condition. Additional details on this dataset are included in Section 5.2.

While there is some overlap in the matters discussed in this thesis and the SAMS, analyses in the original study took a broader, exploratory approach to examining outcomes in the general ASC population, while the research reported in this thesis tested a pre-existing conceptualisation (Autism Plus) which may prove useful in better understanding how outcomes vary across the adult ASC population. The new analyses reported here were designed and carried out by the author, and with their focus on the theory of Autism Plus are distinct from those presented in the SAMS report.

Advantages of a Secondary Data Analysis

A secondary data analysis of the SAMS dataset was seen as highly beneficial for two main reasons. Firstly, the size of the sample included within this dataset was larger and more representative than those which had previously focused on adult outcomes within the ASC literature (as discussed in Chapter 3). It therefore presented an opportunity to investigate concepts and theories which would be less appropriate in smaller, less representative samples (Trzesniewski et al., 2011). Furthermore, this dataset offered the opportunity to conduct complex multi-variate analyses, which is essential in this project given that aims to assess the validity of Autism Plus as a predictor, while ensuring that outcomes for adults with ASC are not better predicted by other factors.

Secondly, this secondary analysis allowed for the research in this thesis to build upon and reassess findings produced as part of the SAMS. From this perspective, secondary data analysis allowed for alternative research questions, not considered as part of the original research project, to be explored (Greenhoot & Dowsett, 2012; Hinde, 1991).

Statistical Analysis and Modelling

This thesis aimed to quantitatively examine the utility of Autism Plus at two levels. Firstly, the conceptualisation was tested as it was originally proposed by Gillberg and Fernell (2014). This analysis is presented in Study 1 (Chapter 5) and featured statistical comparisons between those with Autism Plus (ASC and a co-occurring condition) and Autism Only (those with ASC but no co-occurring diagnoses). These comparisons were made at both the descriptive level and the inferential level through the use of chi-square analyses.

Following this, Study 2 conducted further data modelling using multiple regression analyses which aimed to establish 1) whether Gillberg and Fernell's original proposal would prove a useful predictor when other potentially influential factors such as age and autistic symptom severity were taken into consideration or 2) if models including co-occurring conditions alongside other key factors such as autistic symptom severity and age could be seen to better account for the variance in adult ASC outcomes better than the concept of Autism Plus can alone. This second set of analyses therefore went beyond Gillberg and Fernell's conceptualisation but in doing so tested the robustness of this concept and assessed whether this conceptualisation of the ASC could benefit from modification.

Using Diagnostic Categories in ASC Research

Study 1 and 2 explore to what extent diagnostic categories (relating to both autistic symptoms and co-occurring symptoms) could be useful in predicting the outcomes and support use of individuals with ASC, however it is important to recognise the limitations of this approach. More specifically, it is important to acknowledge that it is possible for some individuals to receive the wrong type of diagnosis, particularly in cases where a standardised diagnostic procedure is not followed, where the most appropriate assessment tools are not employed, or when the diagnosis is made by individuals without the necessary level of training (Pilowsky, Yirmiya, Shulman & Dover, 1998; Stewart, Vigil, Ryst & Yang, 2014; Wilson et al., 2013). It should also be acknowledged that even when assessments are of a high standard, it is still possible for there to be inconsistencies or mistakes in the diagnostic process due to the fact that there is an element of judgement and interpretation involved in each diagnostic assessment (Saulnier & Ventola, 2012). Therefore, studies such as this one, which do not include diagnostic assessments as part of the methodology, cannot guarantee the accuracy of the diagnosis reported by participants, and it is important to acknowledge that in some instances these diagnoses may be inaccurate.

Similarly, due to overlap between the symptoms associated with ASC and other diagnoses (e.g. the repetitive patterns of behaviour observed amongst individuals with ASC are similar to the traits and routines followed by some individuals with obsessive-compulsive disorder; Cath, Ran, Smit, Van Balkom & Comijs, 2008), it is possible for co-occurring conditions to perceived as being part of an individual's autistic traits and behaviours rather than an additional diagnosis (Antshel & Russo, 2019; Bauman, 2010). Furthermore, though co-occurring conditions and their interactions are currently a topic of considerable interest within the clinical and research world, historically this has not always been the case. For example, according to DSM-III, individuals were typically considered to have one primary diagnosis (often defined as their main reason for initially being referred for a diagnosis), while additional symptoms were considered complications of this primary diagnosis and so not always recorded (Clark, Cuthbert, Lewis-Fernández, Narrow & Reed, 2017). As such, the under-diagnosis of co-occurring conditions may be a particular issue for adults in the ASC population who were diagnosed according to DSM-III criteria and who have not since been involved in further clinical or mental health assessments.

Given the resources of this project, it was not possible to verify diagnoses. Instead, the final results and conclusions from this Thesis must be viewed in the context of these issues relating to the accuracy of ASC diagnoses and the potential under-diagnosis of co-occurring conditions within this population. This issue is further discussed in the General Discussion (Chapter 8).

4.4.2. Qualitative Research Methods

Qualitative research typically involves collecting data through methods such as interviews, focus groups or analysing detailed text responses to questions (Robson, 2011). The data collected through these different methods tends to be similar in nature, given that it typically results in the analysis of transcripts which involve participant's perspectives on a particular matter (Camic et al., 2003). However, despite similarities in the nature of the data collected, different approaches to qualitative research exist and can be differentiated by the size and type of population they gather data from, the purpose of data collection (e.g. to explore an issue for the first time or to explore the validity of a pre-existing theory), and the procedures used to analyse the data collected (Guba & Lincoln, 1994; Sullivan, 2010). While there are a wide range of approaches to qualitative research, three of these approaches could be used to explore the link between co-occurring conditions and social and independent living outcomes in the adult ASC population: thematic analysis, grounded theory and phenomenology. (Aspers, 2009; Braun & Clarke, 2012; Strauss & Corbin, 1994). In developing the design of Study 3, the advantages and disadvantages of each approach were considered and a summary of these considerations is presented below.

Thematic Analysis

Thematic analysis (TA) is a flexible approach to analysing qualitative data which can be used to analyse transcript data, generated through any of the data collection approaches mentioned above (Braun & Clarke, 2012). TA involves searching transcripts to identify points of potential interest, including ideas and opinions which are frequently returned to throughout a transcript, all of which may be considered themes (Braun & Clarke, 2006). Researchers can take one of two approaches to identifying and coding themes within a transcript; either they can analyse the transcript with an open mind and look for themes which emerge naturally, or else they can aim to identify themes which relate to a particular concept of theory of interest (Braun & Clarke, 2012; Joffe, 2012).

TA is generally considered to be the most flexible and easily applied approach to qualitative analysis, and as such it is a popular method when aiming to generate an understanding about the opinions and experiences of a large number of individuals (Braun & Clarke, 2006; Gavin, 2008). It can also be helpful in identifying concepts and relationships to be investigated in future research projects or as means of findings supporting evidence for pre-existing theories and hypotheses (Braun & Clarke, 2006). However, critics of this approach highlight that given that the main guiding principles of TA are relatively simple, it can lead researchers to accept the perspectives of respondents as an accurate reflection of reality rather than scrutinising the data collected, and may also discourage researchers for conducting a deeper exploration of the data in search of more subtle and complex relationships between the matters being discussed (Javadi & Zarea, 2016). Furthermore, while TA encourages researchers to look for links and associations between themes, this is not an essential part of the research process, and as such research employing TA may result in primarily descriptive findings (Terry et al., 2017).

Grounded Theory

Grounded theory (GT) takes a similar approach to analysing data to TA, though is most appropriate when a researcher aims to develop a theory about a specific matter or the relationship between different concepts (Robson, 2011). GT also recommends that researchers code the data and in doing so aim to identify re-occurring themes and patterns, however this approach places the greatest importance on explaining or accounting for patterns in the data (Strauss & Corbin, 1994).

This approach to qualitative analysis is ideal when a researcher aims to add structure to an area of research where standardised conceptualisations of theories are lacking (Birks & Mills, 2015). However, as an approach it has also been criticised for a number of reasons, given that it can encourage researchers to report associations between factors based on limited evidence (Robson, 2011). Others have accused this approach of undermining the benefits of gathering subjective accounts of a phenomenon or experience given that the final outcome a grounded theory project will be heavily influenced by the researcher's interpretation of the data (Allan, 2003). Furthermore, given that the final goal of this approach is to produce evidence of theoretical links and structures, this approach to research may be considered vulnerable to misrepresentations of the data in pursuit of this goal (Clarke, 2007).

Phenomenology

Phenomenological approaches to qualitative research share similarities with TA and GT in that in it involves coding and identifying re-occurring themes and patterns across a transcript (Robson, 2011). However, the key difference of this approach is that requires researchers to scrutinise the influence that they may have on both data collection and data analysis and acknowledges that the findings of qualitative research may be influenced by both participant and researcher biases (Smith & Shinebourne, 2012a). Phenomenological approaches are therefore not associated with a strict set of guidelines about how to code and analyse data, nor are they associated with a specific intended outcome (e.g. the development of theory) but instead are most concerned with understanding the perspectives of participant's, how participant's developed these perspectives of their experiences and how a researcher's pre-existing knowledge, understanding and perspectives may influence their interpretation of a participant's account of their experiences (Tuffour, 2017). A phenomenological approach therefore places as much importance on how findings were arrived at as it does on what these findings might indicate about a particular phenomenon, concept or theory (Smith, 1996). The approach therefore aims to provide clear context for any findings, and to be specific about the biases which may have influenced the final results of a research project (Smith, 1996; Smith & Shinebourne, 2012a).

Compared to TA and GT, phenomenological approaches to research can be highly labour-intensive, given that they recommend researchers consistently reassess and scrutinise their findings in order to ensure that they have not unintentionally misrepresented the data

(Robson, 2011). As a result, samples involved in phenomenological studies are often smaller as a result of the length of time it takes to analyse data from one individual. Furthermore, in line with the aim of providing an accurate representation of reality, a widely used approach to phenomenological analysis, interpretative phenomenological analysis (IPA), discourages researchers from limiting questions asked during data collection, and codes and themes developed during analysis, to specific theories of interest. This has led some to argue that this approach lacks structure and as a result is vulnerable to gathering too little information about a particular topic of interest (Giorgi, 2011). Phenomenological analysis has also been accused of placing too much importance on the subjective views of participants and in doing so limiting the extent to which researchers can use their expertise and research knowledge to produce accurate findings (Sousa, 2014). Finally, critics have proposed that in prioritising the views of the participants, researchers employing a phenomenological approach are at risk of providing only a descriptive account of a phenomena rather than one which involves a deeper level of analysis (Brocki & Wearden, 2006).

Qualitative Analytic Approach Taken in this Thesis

In considering the advantages and disadvantages to each qualitative approach it was decided that this thesis would employ a phenomenological approach to qualitative analysis. This approach was selected as though the process can be more time intensive (and as a result often involves fewer participants), it allows findings to focus a representation of reality which is informed primarily by participant accounts of their experiences. While phenomenological approaches place great importance on the subjective views of participants, this can be seen as highly compatible within the critical realist stance taken in this thesis, which encourages researchers to challenge their own preconceptions and beliefs and to actively search participant’s accounts of their experiences for key concepts or relationships not covered by pre-existing literature or theory (Smith, 1996; Smith & Shinebourne, 2012a). This is of particular relevance in a thesis which aims to test to what extent the Autism Plus conceptualisation of ASC can be helpful in differentiating needs and outcomes across this population, as it allows for this theory to be explored, while allowing alternative theories (including possible modifications to Autism Plus or entirely different theories) to emerge from the data (i.e. participant's accounts of their experiences). This thesis can also be seen to overcome the critique that phenomenological analysis risks being too descriptive, since as part of the critical realist approach of this thesis, findings from the phenomenological component of this thesis will be compared, contrasted and triangulated with the analyses featured in Study 1 and Study 2 of this thesis.

Finally, an phenomenological approach can be considered particularly appropriate here given that it prioritises the subjective perspectives of individuals with the greatest experience of a phenomenon over the expertise of the researcher (Fletcher, 2017). Individuals with ASC have consistently been described as experts of their own condition, though an extremely small proportion of the published ASC research literature has taken advantage of this (Fletcher-Watson et al., 2019; Goodman, 2006; MacLeod, 2019). Therefore, including a phenomenological component to this research not only offers the opportunity to triangulate findings, but will also contribute to the presence of ASC voices in the research literature.

Phenomenological approaches to data collection typically fall into one of two categories; descriptive and interpretative (Mayoh & Onwuegbuzie, 2015). Broadly speaking, descriptive phenomenological analyses can be considered to place greater trust in participant's accounts of their experiences, while interpretative phenomenological analyses (IPA) encourages researchers to think more critically about whether these accounts may have been influenced by bias (Englander, 2012; Giorgi, 2009; Smith & Osborn, 2009; Smith & Shinebourne, 2012a; Sousa, 2014). In line with this an IPA approach was taken to conducting qualitative research in this thesis, given that the critical analysis of participant accounts which it encourages was seen as more in line with the critical realist stance adopted by this thesis.

Interpretative Phenomenological Analysis (IPA)

IPA is a method first proposed by Smith (1996) and while it developed out of the health psychology research literature, it has been used to examine a broad range of psychological issues. As with other forms of phenomenological analysis, IPA prioritises participant perspectives on phenomena and aims to base findings primarily on direct quotes from participants, though as alluded to above findings are always reported within the context of potential participant and researcher biases (Smith, 2009).

A key aspect of the IPA approach is that it acknowledges what is known as the ‘double hermeneutic’ (Smith, 1996). The term hermeneutic refers to an individual’s attempts to make sense of the world around them and make sense of their experience, and double hermeneutic is a term which refers to the fact that when analysing a transcript a researcher can be seen to be trying to make sense of an individual’s account of their lives, while at the same time that individual may be trying to make sense of their own experiences (Smith & Osbourne, 2003). A major component of the IPA process is therefore to identify instances where participants themselves may be unsure of the relationship between different factors and experiences, or instances where perspectives may be biased or lack an evidence base, and to acknowledge and account for this in any conclusions made from the research. These issues are typically highlighted as part of the ‘reflexive’ component of the IPA process.

Reflexivity

Reflexivity is a component of the IPA process which focuses more on the factors which may have influenced the process of data collection and the interpretation of data, rather than the association between the specific factors which a researcher is interested in learning about

(Lazard & McAvoy, 2020). Importantly, it can be seen as distinct from ‘reflection’ in that it encourages researchers to not only review the research which has taken place but also to actively scrutinise the methodology and methods use as a means of understanding how they may have impacted the research outcomes (Corlett & Mavin, 2018).

One of the main aims of reflexivity is to ensure that the potential biases and limitations of the approach taken towards studying a particular phenomenon are fully acknowledged (Berger, 2015; Finlay & Gough, 2003; Lazard & McAvoy, 2020). While it may not always be possible to completely eliminate such biases, by scrutinising the ways in which researcher and participant views and experiences may influence the interpretation of the data, researchers can reduce the impact of such biases and in turn are more likely to report a more accurate understanding of reality (Fade, 2004). As part of this reflexive process, Berger (2015) recommends that researchers are considerate of their age, gender, personal experiences, and theoretical stances as well as how they perceive participants.

Lazard and McAvoy (2020) highlight how easy it may be for the process of reflexivity to ‘fall short’, as often researchers describe themselves and experiences but fail to fully explain how they could have influenced the research process. These authors therefore recommend going beyond Berger’s (2015) recommendations and ensuring that the reflexive process is considerate of how a researcher’s epistemological and ontological stance may also impact the outcomes of a researcher project. As such, it is important that researchers are also considerate of the extent to which their research aims and objectives may have influenced the questions asked during the data collection process and how this may have shaped the direction of the conversation between researcher and participant as well as participant responses (Corlett & Mavin, 2018). Similarly, researchers are encouraged to indicate whether they can be considered an ‘insider’ or ‘outsider’ relative to participants and the experiences being examined as part of the research process, given that this perspective may also have the potential to shape data analysis and conclusions (Finlay & Gough, 2003). Finally, while the aim of this reflexive process is to be critical, it should not undermine the research project and finding and instead this process should aim to make the research credible by providing a clear and complete context for the findings (Corlett & Mavin, 2018; Lazard & McAvoy, 2020).

Interpretative Phenomenological Analysis in this Thesis

For this research project, IPA was used to analyse data generated by interviews with adults with ASC. These semi-structured interviews included questions relating to autistic symptoms, co-occurring symptoms, social and independent living outcomes and the day-to-day impact of living with ASC. A detailed account of the specific process adopted to collect and analyse data in line with IPA guidelines is provided in the Method section of Chapter 7, which directly precedes findings from the IPA conducted as part of this thesis.

4.4.3. Summary of Methodological Approach and Methods Used in this Thesis

The methodology and methods adopted in this thesis were chosen with the intention of generating an assessment of the validity and utility of Autism Plus as concept which can incorporate and contrast more objective analytical techniques with participant-centered understandings of living with ASC and co-occurring diagnoses. The research was conducted within a critical realist framework, and so combined and synthesised quantitative and qualitative findings as a means of generating a well-rounded understanding this conceptualisation of ASC. Secondary data analysis of the SAMS questionnaire survey data and primary data analysis of interviews using IPA were selected as appropriate methods, given that they allowed this conceptualisation to be explored firstly by making group comparisons in a large population of adults with ASC, and secondly in a more in-depth manner which prioritised the experience and expertise of a small sample of adults with ASC. By approaching this issue from two different perspectives, and by incorporating the scrutiny of methods and findings encouraged by the critical realist and interpretative phenomenological approach analysis, this research aimed to provide a more well-rounded account of the influence of co-occurring conditions on the experiences of adults with ASC.

4.4.4. Studies and Research Questions in this Thesis

To conclude, a summary of the research questions addressed by each of the three studies is shown below:

Study 1

(1) Do individuals with Autism Plus and Autism Only differ in their employment, long-term relationship, independent living and independent travel outcomes?

(2) Do individuals with Autism Plus receive greater levels of support than those with Autism Only?

Study 2

(3) Can the Autism Plus conceptualisation of ASC differentiate between social and independent living outcomes when key demographic and diagnostic factors are also controlled for?

Study 3

(4) What are the perceptions of a sample of adults with Autism Plus of the impact of co-occurring conditions on their social and independent living outcomes?

(5) On the basis of lived experience, to what extent might the Autism Plus conceptualisation of ASC be useful in differentiating needs and outcomes of adults across the spectrum?

In the next chapter, Study 1 presents a comparison between adults with Autism Plus and Autism Only of independent living outcomes, relationship outcomes, and service use.

Using Diagnostic Categories in ASC Research

Section 2.1.4 of this Thesis proposed that from a research perspective, a return to the use of DSM-IV categorical diagnoses may be more helpful in better understanding the heterogeneity across the autism spectrum, than the more modern DSM-5 conceptualisation of autistic symptoms and behaviours. However, it is important to recognise that regardless of the specific diagnostic criteria used, it is possible for some individuals to receive the wrong type of diagnosis, particularly in cases where the diagnosis was made without following a standardised procedure, failed to employ the most appropriate assessment tools, or did not involve professionals with the necessary level of training (Pilowsky, Yirmiya, Shulman & Dover, 1998; Stewart, Vigil, Ryst & Yang, 2014; Wilson et al., 2013). It should also be acknowledged that even when assessments are of a high standard, it is still possible for there to be inconsistencies or mistakes in the diagnostic process due to the fact that there is an element of judgement and interpretation involved in each diagnostic assessment (Saulnier & Ventola, 2012). Therefore, studies such as this one, which do not include diagnostic assessments as part of the methodology, cannot guarantee the accuracy of the diagnosis reported by participants, and it is important to acknowledge that in some instances these diagnoses may be inaccurate.

Similarly, due to overlap between the symptoms associated with ASC and other diagnoses (e.g. there are similarities between the repetitive patterns of behaviour presented by individuals with ASC and the rituals and routines followed by individuals with obsessive-compulsive disorder; Cath, Ran, Smit, Van Balkom & Comijs, 2008), it is possible for co-occurring conditions to go unrecognised in the ASC population, because these additional symptoms are perceived to be part of an individual’s autistic traits and behaviours (Antshel & Russo, 2019; Bauman, 2010). It may therefore also be the case that some of those in the

Autism Only group described in Study 1 and Study 2, may have undiagnosed co-occurring conditions, and would be better placed within the Autism Plus group.

Given the resources of this project, it was not possible to verify diagnoses, therefore instead this issue is something which much be taken into consideration when examining the final results and conclusions from this Thesis. This is matter has been discussed further in the General Discussion (Chapter 8).

Chapter 5

Study 1: Adult Outcomes and Service Use amongst Individuals with Autism Plus and Autism Only

5.1. Introduction

There is a consensus within the literature that the lives of adults with ASC have generally been under-researched, with a review of 20 years of ASC research indicating that 94% of studies focused exclusively on children or adolescents (Jang et al., 2014). This is an issue which has been consistently highlighted by members of the ASC community, who have in recent years called for more research which focuses on the everyday lives of adults in this population (Gotham et al., 2015; Howlin & Magiati, 2017; Magiati et al., 2014; Pellicano et al., 2014; Steinhausen et al., 2016). As discussed in Chapter 3, positive outcomes relating to employment, independent living, independent travel and relationships are not only desirable in the adult ASC population, but also have the potential to positively impact other aspects of life such as psychological well-being and skill development (Billstedt et al., 2011; García-Villamisar & Hughes, 2007; García-Villamisar et al., 2002; Liu et al., 2013). However, the majority of individuals with ASC experience poor outcomes across these aspects of life, and though a large number of studies have previously focused on these matters, a reliable, accurate model of what differentiates those who experience poorer and better outcomes in this population has still to be developed (Anderson, Roux, et al., 2018; Magiati et al., 2014; Steinhausen et al., 2016).

Previous research focusing on outcomes has been criticised for basing analyses on small samples, failing to stratify findings to account for important factors such as autistic symptom severity, and for overlooking subtle differences in the factors which influence an outcome by examining outcomes collectively (i.e. using the overall outcome approach) rather than independently (Magiati et al., 2014; Underwood et al., 2017). Furthermore, few studies have examined the factors which predict these outcomes, and those which have primarily focus on the influence of autistic symptom severity and the role of intellectual disability; both of which have been found to be associated with outcomes in this population, but unable to consistently and accurately differentiate between individuals who experience poorer and better outcomes (Magiati et al., 2014; Steinhausen et al., 2016; Zimmerman et al., 2018). There is therefore a need for research which better acknowledges the heterogeneity which exists in the ASC population and investigates the extent to which a broader range of factors may influence employment, independent living and relationship outcomes are influenced by a broader range of factors.

As discussed in Chapter 3, some adults with ASC engage with support services to help them live with a greater degree of independence, however research indicates that individuals with ASC, as well as their parents and carers, have concerns about the availability and accessibility of this support (Bianco et al., 2009; Eaves & Ho, 2008 Herrema et al., 2017). Furthermore, to date research has provided little insight into the factors which may increase the need for this kind of support or associated with the uptake of this kind of support (Płatos & Pisula, 2019; Turcotte et al., 2016; Vogan et al., 2017). As indicated in Chapter 3, these are issues which should also explored, given the potential for such research to underpin more appropriate support packages which can account for individual differences in abilities and needs across the autistic spectrum (Anderson, Lupfer, et al., 2018; Kuo et al., 2018).

Gillberg and Fernell’s (2014) conceptualisation of Autism Plus indicates that outcomes and support needs in the ASC population may be influenced more by an individual’s co-occurring conditions than their core autistic symptoms. If valid, this conceptualisation of the condition suggests that those with Autism Plus (i.e. individuals with at least one co-occurring condition in addition to their core ASC diagnosis) will experience poorer outcomes than others on the spectrum and require higher levels of support than those with Autism Only (i.e. those with an ASC diagnosis and no co-occurring conditions). While a small but significant number of studies have shown support for this concept, these have focused on small samples of individuals with autistic diagnoses and no intellectual disability (Gillberg & Fernell, 2014; Gillberg et al., 2016; Helles et al., 2016; Posserud et al., 2018).

This study aimed to further explore this conceptualisation of the autism spectrum in a larger sample of individuals with any level of intellectual ability and in doing so aimed to answer the following research questions:

(1) Do individuals with Autism Only and Autism Plus differ in their employment, long-term relationship, independent living and independent travel outcomes?

(2) Do individuals with Autism Plus receive greater levels of support than those with Autism Only?

5.2. Method

As discussed in Chapter 4, analyses in this study were informed by a secondary data analysis of data originally collected as part of the Scottish Autism Microsegmentation Study (SAMS; MacKay et al., 2018). The Recruitment and Measures sections below therefore describe the processes involved in the original study. As previously discussed in Section 4.4.1, the author of this thesis made a significant contribution to devising these procedures which is acknowledged in the published report and the statistical analyses reported here was unique to this study and was designed and carried out by the author.

5.2.1. Participants

Recruitment

The strategy for the SAMS combined convenience and snowball sampling approaches to recruitment, targeting any individuals with a formal ASC diagnosis, the parents and carers of individuals with ASC, and any others who knew an individual with ASC well enough to comment on their everyday life and experiences. The study was promoted on the websites and social media pages of relevant support groups including Scottish Autism, Autism Network Scotland and the National Autistic Society. These groups in turn circulated information about the survey with other relevant organisations and support groups. Members of the research team who worked on the original study also used their own networks to construct a mailing list of other potential participants, including individuals with ASC and their parents and carers, who were contacted by post.

Scottish Autism Microsegmentation Study Sample

This recruitment strategy originally yielded in 1604 responses, though following a process of data cleaning to identify responses failing to provide key information on diagnoses and outcomes (n = 612) and duplicate responses (i.e. cases where two responses related to one individual, n = 42), the final sample for this study included 950 individuals, an estimated 1% of the ASC population living in Scotland [15].

Participants in this Study

Analyses reported in this study were based upon a sub-sample of adults aged 16 years and older from of the SAMS sample[16]. This sub-sample included 404 individuals and data about these individuals was provided by the individuals (n = 108), parents and family carers (n = 238), non-related carers (n = 29), professionals (n = 23), voluntary workers (n = 1) or close friends and family members other than parents or carers (n = 5). From this point onwards, the

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[15] This estimate is based upon previous estimates of the prevalence of ASC which indicate that it affects 1.32% of the total population (MacKay et al., 2018). The latest census data indicates that the population of Scotland is around 5,296,000, and in line with prevalence estimate indicated above this would suggest that around 69,900 individuals in Scotland have an ASC diagnosis.

[16] For the purposes of this analysis, adults were defined as individuals aged 16 and older, this was in line with the Age of Legal Capacity (Scotland) Act (1991), which indicates that in Scotland, individuals of this age should be considered adults.

terms ‘sample’ and ‘participants’ will be used to refer to the individuals with ASC, rather than those who provided the data.

Five types of diagnoses were reported which included diagnostic categories from DSM-IV (American Psychiatric Association, 1994), DSM-5 (American Psychiatric Association, 2013) and ICD-10 (World Health Organisation, 2018). These diagnoses included autistic disorder and childhood autism (AD/CA; n = 82), high functioning autism (HFA; n = 35), Asperger’s syndrome (AS; n = 201), PDDNOS (n = 7) and ASD (n = 79) diagnoses. As discussed in Section 2.1.2, individuals with HFA and AS have consistently been shown to present similar symptoms and behaviours and experience similar outcomes in life and as such these diagnostic categories were collapsed for the purposes of the analyses presented here.

Appendix B2 provides more detail on the rationale for collapsing these diagnostic categories. Similarly, given that ASD and PDDNOS diagnoses have the potential to include individuals with any severity or presentation of autistic symptoms (as discussed in Section 2.1.3 and 2.1.4), these categories were also collapsed in order to simplify analysis. While the diagnostic terms AD/CA, AS/HFA and PDDNOS have been superseded in official diagnostic guidelines by the term ASD (see Section 2.1.3 for a complete account of this change), their continued utility within research and their significance to individuals within the ASC population has previously been established in Section 2.1.4.

Participants were aged between 16 and 85, with a mean age of 29.88 years (SD = 13.20). Analysis of the summarised age data (see Figure 1) indicated that the sample was skewed towards younger individuals. Follow-up analysis confirmed that the age of participants was not normally distributed and was negatively skewed, with a skewness statistic of 1.15 (SD = .12) and kurtosis statistic of .40 (SD = .24). Of the 404 participants, 71% were male (n = 288) and 29% were female (n = 116), representing a gender ratio in the sample of 2.5:1. As indicated in Section 2.4.1, research has previously indicated that ASC is four times more

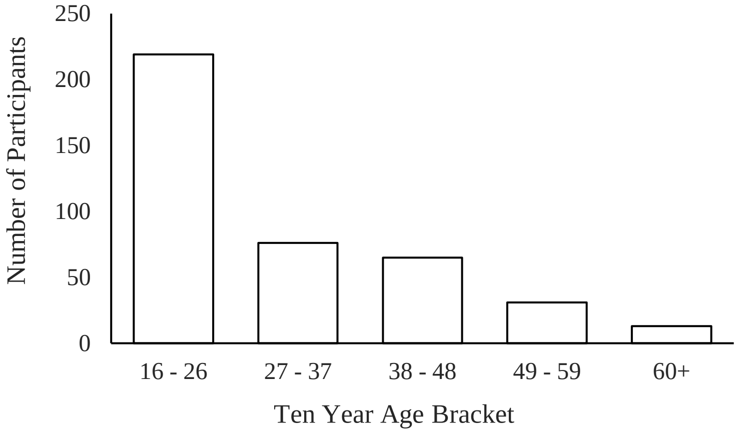

Figure 5.1 *Distribution of Participant Age according to ten-year age brackets*

Table 5.1

Number and Percentage of Individuals with each Type of Co-Occurring Conditions [1]

Co-Occurring	n	%
Anxiety	97	24
ADHD	30	7
Bipolar Disorder	9	2
Challenging Behaviour	3	2
Depression	91	23
Down Syndrome	3	1
Epilepsy	29	7
Fragile X	2	1
Intellectual Disability	68	19
Severe	62	15
Mild	15	4
OCD	30	7
Schizophrenia	4	1
Tourette’s	6	2
Tuberous Sclerosis	1	0

[1] Participants may appear in more than one category.

common in males (Fombonne, 2009) and in this respect, this study may be considered to include an over-representation of females with ASC.

The presence of co-occurring conditions across the sample is presented in Table 5.1. In total, 48% of the sample had at least one co-occurring diagnosis (n = 196), 16% had 2 co-occurring diagnoses (n = 65), and 5% had 3 or more co-occurring diagnoses (n =20). The most prevalent co-occurring conditions within the sample were anxiety, depression and intellectual disabilities (ID).

5.2.2. Materials

As noted above, data for this project and the SAMS was collected through the use of an online survey, which was also posted to a small number of participants by mail. A copy of this survey has been included in Appendix B1. The original aim of the Scottish Autism survey was to collect information which could inform an economic analysis of the cost of ASC in Scotland; the analyses presented here, however focus on the parts of the survey which generated data relating to demographics, diagnoses, outcomes and service-use. These sections included questions which asked about the specific type of autistic diagnoses that participants had, as well as about their ability to travel independently, their employment status and their residential status. For example, participants were asked '*Can the individual with [with ASD] travel independently by public transport or their own car?*', '*Where is the individual with ASD currently living?*' and '*What is the current employment status of the individual with ASD?*'. Questions relating to service-use asked about the type of educational, psychological, health and social support services used, as well as how frequently these services had been used in the past six months.

Key Outcome Variables of Interest

Outcome analyses in line with the research questions of the thesis focused on four key dependent variables; employment, long-term relationship status, residential status and ability to travel independently. In this survey, long-term relationships were defined a ‘stable relationship of over 2 years duration’.

Participants could select one of a number of categories from multiple-choice questions focusing on employment and residential status. The analyses here were intended to compare only those who were independent and dependent upon others, and as such the full range of categories used by participants to describe their employment and residential status were collapsed into one of two categories. This step was taken to simplify analysis, given that several of these categories were associated with a low *n*. Appendix B3 provides full details of the original categories that were converted for analysis.

5.2.3. Statistical Analysis

Analyses focused on establishing whether social and independent living outcomes (including independent travel, employment, residential status and long-term relationships) and service-use patterns varied according to whether individuals had Autism Plus or Autism Only. Preliminary analyses were also carried out to provide additional context for the main findings of this study and to assess whether those with Autism Plus and Autism Only differed in their demographics or the severity of their autistic symptom severity (as determined by the type of ASC diagnosis they had). Group differences between those with Autism Plus and Autism Only presented here are reported firstly at the descriptive level, with the significance and strength of differences assessed using chi-square analyses. Square, cube root and logarithmic transformations were carried out on the age data given that it was found to be skewed, however these did not result in a significant improvement in the skewness of the data. As such, the data was left in its original form, and non-parametric two-tailed Mann-Whitney U tests were used to conduct analyses which involved age as a variable.

Missing Data

In the original dataset constructed as part of the SAMS more than 5% of data was missing for a number of variables of interest, and this was addressed as part of the original study through the use of imputation using the multiple imputation by chained equation method[17] (MICE; Azur et al., 2011; Sterne et al., 2009). As part of this process, missing values are predicted through regression analyses which are informed by other theoretically or intuitively relevant variables within the dataset. This approach is used to impute one variable at a time. In cases, where variables intended to inform these regression analyses are also missing data, these missing values are temporarily replaced with placeholder mean imputations, and these placeholder imputations are later replaced using the chained equation approach.

As part of the chained equation approach, the process above (which can be described as a cycle) was repeated multiple times, and each of these cycles produces a new dataset (known as imputation blocks) in which the values imputed slightly vary. This variance occurs as each regression analyses used to inform missing values are accompanied by a confidence interval and the statistical simulations run as part of the multiple imputation process select a different value within this confidence interval each time a cycle is completed and a new dataset is generated.

The secondary data analyses reported in this thesis are informed by a dataset which included 20 imputation blocks and this number of imputations was selected in line with the proportion

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[17] Notably, none of the four key variables (employment status, long-term relationship status, residential independence and ability to travel independently), nor service-use variables were subject to imputation given that one of the inclusion criterion for inclusion in the final dataset analysed in the SAMS, was that participants must have provided data for questions relating to these outcomes.

of missing data across the 1604 participants included in the complete dataset rather than the subsample analysed here (Jakobsen et al., 2017; White et al., 2011). The analyses reported in Study 1 and Study 2 of this thesis are therefore pooled results, which can be seen as average results from across the 20 multiple imputation datasets.

Corrections for Multiple Testing

This study aimed to make a large number of statistical comparisons to explore how adult outcomes and service use were associated with demographic and diagnostic variables. When testing multiple hypotheses, the likelihood of a type I error (i.e. incorrectly rejecting the null hypothesis) increases, and as such it is recommended that measures are taken to correct for this (Jafari & Ansari-Pour, 2019; Vickerstaff et al., 2019). This is considered particularly important when multiple hypotheses have a variable in common or when the variables of primary interest across these hypotheses are not clearly distinct (Streiner & Norman, 2011). One approach to addressing this issue is through the use of the Bonferroni correction, which uses the number of comparisons made, to calculate a new p-value which analyses should meet in order to be considered indicative of a statistically significant relationship or difference (this new p-value is arrived at by dividing the standardised significance cut-off of .05 by the number of comparisons made; Dunn, 1961). However, it has also been proposed that when such corrections are applied in studies involving a high number of comparisons (as is the case in this study), the revised p-value can become too conservative, thus increasing the likelihood of a type II error (i.e. incorrectly accepting the null hypotheses; Perneger, 1998).

In this study, with 39 exploratory comparisons, analyses would have been required to produce a significance value of < .0012 in order to be considered indicative of a significant relationship or difference. In line with the above, this adjusted cut-off was considered too conservative, as while it would reduce the likelihood of a Type I error it may also increase the likelihood of a type II error. As such, it was determined that a more appropriate alpha significance cut-off value would be .01, as this would allow for a better balance between controlling for multiple comparisons and reducing the risk of a Type II error.

Comparisons involving Autistic Symptom Severity

Diagnoses of ASD and PDDNOS are not associated with a specific level of severity, but instead can be given to individuals whose autistic symptoms are considered clinically significant (American Psychiatric Association, 2013; World Health Organisation, 2018). It was not possible to conduct an analysis involving all 404 participants which could establish whether individuals with mild or more severe symptoms were more likely to meet the criteria for Autism Only or Autism Plus. Therefore, to gain a better understanding of this, some of the analyses presented in the following section focused only on the 318 individuals in the sample with AD/CA or AS/HFA (i.e. diagnoses associated with a more specific level of symptom severity). While focusing on 79% of the complete sample, these analyses were intended to give an indication of the extent to which autistic symptom severity may also be associated with outcomes and service-use in this population.

5.3. Results

5.3.1. Autism Only and Autism Plus Groups

Table 5.2 summarises the demographic and diagnostic characteristics of those in the Autism Only and Autism Plus sub-groups. Preliminary analyses focusing on these characteristics were conducted to provide context for results of the main analyses focusing on social and independent living outcomes.

Table 5.2

Subsample characteristics for individuals with Autism Only and Autism Plus

Demographic and Diagnostic Characteristics	Group n (%)[1]		Total n (%)
	Autism Only	Autism Plus	
n	208 (51)	196 (49)	404 (100)
Age			
Range	16–85	16–70	
Mean	27.90	31.97	
Median	22.00	28.00	
Gender			
Female	54 (46)	63 (54)	117 (29)
Male	154 (54)	133 (46)	287 (71)
ASC Diagnoses			
AD/CA	48 (23)	34 (17)	82 (20)
AS/HFA	117 (56)	119 (61)	236 (58)
ASD	43 (21)	43 (22)	86 (22)

[1] Percentages relate to the proportion of individuals of within each column within the Autism Only (n = 208) and Autism Plus (n = 196) subgroups and the total sample (n = 404)

A two-tailed Mann Whitney-U analyses confirmed that there were significant age differences in those with Autism Only (Mdn = 22.00) and Autism Plus (Mdn = 28.00), U = 16027.50, *p* < .001, though chi-square analyses indicated that there were no differences in the proportion of males and females in each group, χ^2 [1, n = 404] = 1.73, *p* = .189. Findings also indicated that there were no significant differences in the number of individuals with each type of ASC diagnosis across the Autism Plus and Autism Only groups, χ^2 [1, n = 404] = 1.64, *p* = .281.

5.3.2. Social and Independent Living Outcomes

Preliminary Analyses

As shown in the final column of Table 5.3, the majority of the sample lived with their parents or in residential care (59%), were unemployed (55%) and were not involved in a long-term or close relationship (82%).

Table 5.3

Percentage of Residential, Employment, Long-Term Relationship (LTR) and Travel Outcomes Experienced according to Type of ASC diagnosis[1]

Outcome	Type of ASC Diagnosis (%)			Total (%)
	AD/CA	AS/HFA	ASD	
Residential Status				
Non-Independent [2]	57 (70)	122 (49)	60 (70)	238 (59)
Independent [3]	25 (30)	114 (51)	26 (30)	166 (41)
Employment Status [3]				
Unemployed	54 (66)	115 (49)	53 (62)	222 (55)
Employed	28 (34)	121 (51)	33 (38)	182 (45)
LTR Status				
No LTR	78 (95)	173 (73)	81 (94)	332 (82)
Involved in LTR	4 (5)	63 (27)	5 (6)	72 (18)
Independent Travel				
Non-Independent	66 (80)	64 (27)	54 (63)	184 (46)
Independent	16 (20)	172 (73)	32 (37)	220 (54)

[1] Percentages represent the number of individuals with each diagnosis (AD, n = 82, AS, n = 236 and ASD, n =86) and across the entire sample (n = 404), to have reported each outcome [2] Includes individuals living with parents or in residential accommodation [3] Includes individuals living alone, with a flatmate/housemate, with a partner or in supported living accommodation.

However, the rate of those who could travel independently by car or public transport (54%) was higher than those who could not. Further preliminary analyses considered whether those achieving more positive and negative outcomes differed in age or gender. Significant age differences were found between those who were involved in long-term relationships (Mdn = 41.55) and those who were not (Mdn = 23.00), U = 18600.73, $p < .001$, those living independently (Mdn = 34.55) and those not living independently (20.53), U = 32157.68, $p < .001$, those who could travel independently (Mdn = 30.45) and those who could not (Mdn = 22), U = 27587.1, $p < .001$. However, no significant age differences were found between those were employed (Mdn = 26.25) and unemployed (Mdn = 24.23), U = 21029.08, $p = .357$. Chi-square analyses indicated that gender was not significantly associated at the $p < .01$ level with any of the four social and independent living outcomes (independent living: χ^2 [1, n = 404] = .98, $p = .342$, employment: χ^2 [1, n = 404] = .87, $p = .563$, long-term relationship status: χ^2 [1, n = 404] = 3.62, $p = .062$, ability to travel independently: χ^2 [1, n = 404] = .77, $p = .397$).

Comparisons of outcomes according to autistic symptom severity focused on a sub-sample of individuals with AD/CA and AS/HFA (n = 318). A higher proportion of those with AS/HFA were found to be in employment compared to those with AD/CA, but these differences were not found to be significant at the $p < .01$ level, χ^2 [1, n = 318] = 7.20, $p = .018$. Further chi-square analyses did however indicate that those with AS/HFA were significantly more likely to be in a long-term relationship (χ^2 [1, n = 318] = 16.31, $p < .001$), to be able to travel independently (χ^2 [1, n = 318] = 71.91, $p < .001$), and to be living independently (χ^2 [1, n = 318] = 7.40, $p < .009$).

Autism Plus and Social and Independent Living Outcomes

The number and proportion of those with Autism Only and Autism Plus who reported each type of social and independent living outcome are reported in Table 5.4. Chi-square analyses indicated that there were no significant differences in the proportion of individuals with Autism Plus and Autism Only who were in employment (χ^2 [1, n = 404] = 1.60, $p = .272$) or who were able to travel independently (χ^2 [1, n = 404] = .75, $p = .395$). Significant group differences were found in the rates of long-term relationship involvement (χ^2 [1, n = 404] = 11.66, $p < .001$) and residential status (χ^2 [1, n = 404] = 17.11, $p < .001$), indicating that those with Autism Plus were more likely to be involved in long-term relationships and more likely to be living independently compared to those with Autism Only.

Table 5.4

Number and Percentage of individuals experiencing each type of residential, employment, long-term relationship and independent travel outcomes according to presence of co-occurring conditions[1]

Outcome	Group n (%)		Total n (%)
	Autism Only	Autism Plus	
Residential Status			
Non-Independent [2]	143 (69)	95 (48)	238 (59)
Independent [3]	65 (31)	101 (52)	166 (41)
Employment Status			
Unemployed	120 (58)	102 (52)	222 (55)
Employed	88 (42)	94 (48)	182 (45)
LTR Status			
No LTR	184 (88)	148 (76)	332 (82)
Involved in LTR	24 (12)	48 (24)	72 (18)
Independent Travel			
Non-Independent	99 (48)	85 (43)	184 (46)
Independent	109 (52)	111 (57)	220 (54)

[1] Percentages represent the number of individuals with Autism Only (n = 208) and Autism Plus (n = 196) subgroups and the total sample (n = 404) to have reported each outcome [2] Includes individuals living with parents or in residential accommodation [3] Includes individuals living alone, with a flatmate/housemate, with a partner or in supported living accommodation.

Outcomes According to Co-occurring Condition

Table 5.5 reports the rates of outcomes according to the presence of each kind of co-occurring conditions. Statistical comparisons of the outcomes experienced by those with each

Table 5.5

Residential, Employment, LTR and Independent Travel Outcomes according to type of Co-Occurring Condition [1]

Outcome	Group n (%)							
	ADHD	Anxiety	Bipolar	Depression	Epilepsy	ID	OCD	Tourette's Syndrome
Residential Status								
Non-Independent	18 (60)	41 (42)	1 (11)	32 (35)	20 (69)	54 (71)	18 (60)	5 (83)
Independent	12 (40)	56 (58)	8 (89)	58 (65)	9 (31)	22 (29)	12 (40)	1 (17)
Employment Status								
Unemployed	12 (40)	52 (54)	5 (56)	41 (45)	20 (69)	54 (71)	13 (43)	3 (50)
Employed	18 (60)	45 (46)	4 (44)	50 (55)	9 (31)	22 (29)	17 (57)	3 (50)
LTR Status								
No LTR	21 (70)	72 (74)	5 (56)	56 (62)	26 (90)	75 (99)	26 (87)	5 (83)
Involved in LTR	9 (30)	25 (26)	4 (44)	35 (38)	3 (10)	1 (1)	4 (13)	1 (17)
Independent Travel								
Non-Independent	11 (37)	36 (37)	6 (56)	20 (22)	22 (76)	71 (93)	11 (37)	5 (83)
Independent	19 (63)	61 (63)	3 (34)	71 (78)	7 (24)	6 (7)	19 (63)	1 (17)

[1] Table does not include outcome rates according to the presence of co-occurring conditions reported by fewer than 5 individuals (this includes Challenging Behaviour, Down Syndrome, Fragile X, Schizophrenia and Tuberous Sclerosis)

type of co-occurring condition were not possible, given that many individuals had more than one co-occurring condition. However, notable here is that a higher proportion of those with depression and anxiety diagnoses experienced more positive outcomes than those with other conditions, and that overall outcomes appeared poorest amongst individuals with ID.

5.3.3. Service-Use and Support

Table 5.6 presents the service-use patterns of individuals in the sample from the six months prior to data collection. Of the 404 participants, 45% of individuals in the sample had used at least one of the services listed in Table 5.6 in the six months prior to data collection. In terms of the types of services and support used, 30% reported using psychiatric or psychological support, 7% reported using cognitive or physical support services, 1% had used employment services, 3% had used befriender services, 4% had used home help services and 22% had received support from social workers or community/district nurses.

Preliminary Analyses

Further preliminary analyses investigated whether the types of services used varied according to the age and gender of participants or the type of ASC diagnosis which they reported. Potential differences in the use of employment, social engagement and care and respite services could not be tested due to the low number of individuals who reported using these services.

No significant age differences were found at the $p < .01$ level between those using at least one type of service and those who had used no services in the six months prior to data collection, U = 19302.50, $p = .462$. Nor were significant age differences found in the age of those using and not using different subcategories of support (all p-values > .02; see Appendix B4 for full details). Gender was also not found to be significantly associated with whether or not a participant had used support services, or the specific type of support that they used (all χ^2 values < 2, all p-values > .1; see Section Appendix B5 for full details). Again, analyses

Table 5.6

Number and Percentage of Services Used in the Six Months Prior to Data Collection according to Type of ASC Diagnosis[1]

Service	Type of ASC Diagnosis n (%)			Total n (%)
	AD/CA	AS/HFA	ASD	
Psychiatric and Psychological Services				
Psychiatrist	16 (20)	44 (19)	15 (17)	75 (19)
Psychologist	12 (15)	35 (15)	12 (14)	59 (15)
Individual Counselling	5 (6)	19 (8)	0 (0)	24 (6)
Group Counselling	0 (0)	3 (1)	3 (3)	6 (1)
Any Psychiatric or Psychological Service	27 (33)	73 (31)	23 (27)	123 (30)
Cognitive or Physical Support Services				
Speech Therapist	7 (9)	3 (1)	8 (9)	18 (4)
Physiotherapist	3 (4)	4 (2)	2 (2)	9 (2)
Occupational Therapist	4 (5)	8 (3)	4 (5)	16 (4)
Any Cognitive or Physical Support Service	9 (11)	10 (4)	11 (13)	30 (7)
Employment Services				
Individual Placement	2 (2)	0 (0)	3 (3)	5 (1)
Sheltered Workshop	0 (0)	0 (0)	2 (2)	2 (0)
Any Employment Service	2 (2)	0 (0)	3 (3)	5 (1)
Social Engagement Services				
Befriender	3 (4)	6 (3)	3 (3)	12 (3)
Care and Respite Services				
Home Help	7 (9)	7 (3)	1 (1)	15 (4)
General Support				
Social Worker	27 (33)	32 (14)	23 (27)	82 (20)
Community/District Nurse	22 (27)	8 (3)	15 (17)	45 (11)
Any General Support Service	30 (37)	36 (15)	24 (28)	24 (22)

[1] Percentages represent the number of individuals with each diagnosis (AD, n = 82, AS, n = 236 and ASD, n =86) and across the entire sample (n = 404),

Table 5.7

Number and Percentage of Services Used according to Presence of Co-occurring Conditions [1]

Service	Subgroup n (%)		Total n (%)
	Autism Only	Autism Plus	
Psychiatric and Psychological Services			
Psychiatrist	19 (9)	56 (29)	75 (19)
Psychologist	20 (10)	39 (20)	59 (15)
Individual Counselling	12 (6)	12 (6)	24 (6)
Group Counselling	1 (< 1)	5 (3)	6 (1)
Any Psychiatric or Psychological Service	41 (20)	82 (42)	123 (30)
Cognitive or Physical Support Services			
Speech Therapist	8 (4)	10 (5)	18 (4)
Physiotherapist	4 (2)	5 (3)	9 (2)
Occupational Therapist	7 (3)	9 (5)	16 (4)
Any Cognitive or Physical Support Service	11 (5)	19 (10)	30 (7)
Employment Services			
Individual Placement	4 (2)	1 (< 1)	5 (< 1)
Sheltered Workshop	1 (< 1)	1 (< 1)	2 (< 1)
Any Employment Service	4 (2)	1 (< 1)	5 (< 1)
Social Engagement Services			
Befriender	7 (3)	5 (3)	12 (3)
Care and Respite Services			
Home Help	6 (3)	9 (5)	15 (4)
General Support			
Social Worker	44 (21)	38 (19)	82 (20)
Community/District Nurse	16 (8)	19 (10)	35 (9)
Any General Support Service	46 (22)	44 (22)	90 (22)

[1] Percentages represent the number of individuals with Autism Only (n = 208) and Autism Plus (n = 196) subgroups and the total sample (n = 404) to have reported each outcome

relating to autistic symptom severity focused on the subsample of individuals with AD/CA and AS/HFA diagnoses (n = 318). These analyses indicated that symptom severity was not associated with whether or not an individual had or had not used a support service in the previous six months (χ^2 [1, n = 318] = 3.68, $p = .055$), nor the use of psychiatric and psychological services (χ^2 [1, n = 318] = .11, $p = .738$), services providing cognitive and physical support (χ^2 [1, n = 318] = 4.92, $p = .027$) or employment services (χ^2 [1, n = 318] = 5.80 , $p = .016$). However, a significantly greater number of those with AD/CA reported visiting (or receiving visits from) social workers and community/district nurses, χ^2 [1, n = 318] = 16.84, $p < .001$.

Autism Plus and Social and Service Use

Table 5.7 presents the number and proportion of individuals who reported using services in the six months prior to data collection according to the presence of co-occurring conditions. Amongst individuals with Autism Plus, 35% had received support from at least one service, compared to 54% in the Autism Only group, and chi-square analysis indicated that these differences were significant, χ^2 [1, n = 404] = 15.52, $p < .001$. Individuals with Autism Plus were also found to be significantly more likely to find psychological or psychiatric support, χ^2 [1, n = 404] = 23.33, $p < .001$. Comparisons were also made across the use of employment, social engagement, care and respite and general support services by those with Autism Plus and Autism Only, though no significant differences were identified (all $\chi^2 < 3$, all p-values > .09).

Summary of Findings

Table 5.8 highlights the significant relationships identified in the above analyses, indicating those which were significant at the $p < .01$ level.

Table 5.8

Matrix Showing Significant Relationships Identified in this Study

Variable	Age	Gender	Autistic Symptom Severity	Autism Only/ Autism Plus
Autism Only/Plus	•			N/A
Employment Status				
Long-term Relationship Status	•		•	•
Residential Status	•		•	•
Independent Travel	•		•	
Overall Outcomes				•
Any Form of Support				•
Psychological and Psychiatric Services				•
Cognitive and Physical Support Services				
General Help Services			•	

• = Significant relationship at the corrected $p < .01$ level, empty cell = no relationship identified

5.4. Discussion

This is the first study known to the author to explore the validity of the Autism Plus conceptualisation of ASC in a large sample of adults with ASC with milder and more severe autistic symptoms and in a sample of mixed intellectual ability. While there was evidence to suggest that those with Autism Plus and Autism Only differed in terms of their outcomes, these findings were not in line with Gillberg and Fernell’s proposal on the impact of co-occurring conditions on outcomes. More specifically, those with Autism Plus were found to be more likely to live independently and more likely to be in a long-term relationship compared to those with Autism Only. No significant differences were found in the employment or independent travel outcomes across the groups. In the analyses focusing on service use, those with Autism Plus were significantly more likely to have used at least one support service in the six months prior to data collection compared to those with Autism Only, and similar significant differences were found in the use of psychiatric and psychological services. These findings suggest that if Gillberg and Fernell’s proposals relating to the level of support required by those with Autism Plus are accurate, then there is at least evidence to suggest that the greater need for support in this population is being met.

These findings above raise questions about the utility of Autism Plus as a factor which may be able to account for the considerable heterogeneity in the adult outcomes of individuals on the spectrum. However, a number of other analyses reported here indicate the relationship between other important factors and outcomes, which may need to be accounted for in any research focusing on outcomes in this population.

Other Influences on Social and Independent Living Outcomes

Additional analyses reported here focused on assessing to what extent outcome and service use patterns were associated with other potentially relevant factors including age, gender and type of ASC diagnosis. A small number of studies have previously highlighted the importance of age which is associated with changes in autistic symptoms and their impact and which is also associated with outcomes in this population (Billstedt et al., 2011; Seltzer et al., 2004; Shattuck et al., 2007; Steinhausen et al., 2016). The findings of this study indicate that this is a factor which was associated with three of the four outcomes of interest (residential status, long-term relationships and independent travel), with the median age of individuals experiencing positive outcomes across these aspects of life 30 years or older. This indicates that within this population more positive outcomes may not occur until later in life, and that this is something which should be taken into consideration in research focusing on ASC outcomes in the future. Notably, no such age differences were found in the service-use patterns of participants. Furthermore, despite evidence from the pre-existing literature to suggest that outcomes, in particular those relating to relationships, may differ between males and females with ASC (discussed in Section 2.4.2 and 3.2.1), there was no evidence from this study to suggest that such differences existed.

Previous research has indicated that autistic symptom severity (as indicated by type of ASC diagnosis) is associated with outcomes in this population but cannot account entirely for differences in needs and outcomes (Howlin & Magiati, 2017; Magiati et al., 2014; Steinhausen et al., 2016). Analyses reported here on a sub-sample of those with AD/CA and HFA/AS (n = 318) are in line with this research and indicated that long-term relationship status and independent travel outcomes were better amongst those with AS/HFA (i.e. those with less severe autistic symptoms). However, type of ASC diagnosis was not associated with employment or residential outcomes, nor service-use patterns, with the exception of visits to/from social workers and community/district nurses. These findings therefore indicate that the type of ASC diagnosis that an individual has, and the severity of their ASC symptoms are factors which should be considered in research focusing on adult outcomes, but as evidenced here, diagnostic sub-categories alone cannot differentiate those with better and poorer outcomes within this population and it may not have relevance to all of these adult outcomes.

Finally, there was some evidence to suggest that the outcomes experienced across the Autism Plus subgroup varied according to type of co-occurring condition. As stated earlier, this can only be considered preliminary evidence, given that many individuals had more than one co-occurring condition and it was not possible to conduct analyses which could establish the impact of each co-occurring condition. However, this preliminary evidence did suggest that those with depression and anxiety may experience better outcomes that those with other co-occurring conditions, and that those with ID may experience the poorest outcomes compared to others with Autism Plus. This in turn suggests that if Autism Plus was to be a useful indicator of outcomes and needs in this population, the concept may need to better acknowledge that some co-occurring conditions can be more impactful than others.

Together, the analyses conducted here indicate that Autism Plus alone may not be an effective predictor of the outcomes of those with ASC but do raise questions about whether a modified version of this conceptualisation which better accounts for factors such as age, autistic symptom severity or different sub-diagnoses of ASC could be more useful.

5.4.1. Strengths and Limitations

The research presented in this chapter can be considered to have a number of strengths. Firstly, and as indicated above, and to the best of the author’s knowledge, this study is one of the first to examine the concept of Autism Plus in a sample representing individuals with both milder and more severe autistic symptoms, and as such be considered to make a unique contribution to the research literature. Secondly, as indicated in Chapter 3, previous research in the adult outcome literature has often been based upon samples including fewer than 100 participants and failed to stratify findings according to the severity of autistic symptom severity within the sample. In this respect, this study which based analysis on 404 adults and compared adult outcomes across those with milder and more severe autistic symptoms, can also be considered to make a useful contribution to the broader adult outcome literature. Thirdly, this study can be seen to highlight the merits in investigating adult outcomes separately in the ASC population, as opposed to the overall outcome rating (OOR) approach which has commonly been adopted within this field (the OOR approach to investigating adult outcomes has previously been discussed in Section 3.5). This is based upon evidence presented here to suggest that factors such as age and autistic symptom severity may influence some outcomes (e.g. residential independence, independent travel and social relationships) more than others (e.g. employment).

There were also a number of limitations to this research which should be taken into consideration while interpreting the findings above. Firstly, the sample upon which data analysis in this study was based was generated by a combination of convenience and snowball sampling, and it is important to acknowledge that this could be considered to influence the extent to which the individuals described here were representative of Scottish individuals with ASC. Secondly, ASC and co-occurring diagnoses reported here were reported by individuals with ASC, or family members, friends and professionals commenting on their behalf. As such, it is possible that there are inaccuracies in the diagnoses reported here which would have not been an issue had proof of clinical diagnoses been obtained. However, requiring participants to provide such information could have reduced the number of participants taking part in the original survey and prevented the analyses presented here from being conducted. Therefore, while this is recognised as a limitation, it is also accepted that the particular approach take to data collection has most likely contributed to the large size of sample available for analyses.

A third related issue is that close to one quarter of the sample reported having an ASD diagnosis, which is the current recommended DSM-5 and ICD-10 diagnosis for individuals.

While those with AS/CD and HFA/AS diagnoses are associated with a specific level of symptom severity, outcomes and needs (and this was confirmed by the analyses reported here), the more modern ASD diagnosis can be given to individuals who vary considerably in the severity of their autistic symptoms (this issue has previously been discussed as part of Section 2.1.4). As such, it was not possible to estimate the autistic symptom severity of individuals in this group or establish individuals in this group which may have skewed the overall nature of the sample towards those with milder or more severe autistic symptoms. The analyses focusing on the sub-sample of individuals with AD/CA and HFA/AS were intended in part to overcome this limitation, and the significant group differences established by these findings re-emphasise the need for ASC research which includes well-defined samples, which allow analyses to stratify findings according to factors such as symptom severity.

Fourthly, it is important to acknowledge that these findings reflect the lives of the individuals at the time of data collection and that previous research has indicated that outcomes relating to employment in particular can fluctuate considerably for individuals in the ASC population (Howlin et al., 2004; Taylor, Henninger & Mailick, 2015). Therefore, while not possible as part of this project, the ASC adult outcome literature would benefit from more research which takes a longitudinal approach to examining outcomes and examining to what extent the influence of particular factors is consistent or inconsistent.

A final factor which should be taken into consideration in interpreting these results is the nature of the Autism Plus sample, which was predominately made up of individuals with co-occurring ID, Depression and Anxiety. The original concept of Autism Plus indicates that outcomes will be poorer and needs greater for individuals who have ASC and co-occurring diagnoses, and as such the analysis in this study did not set out to specifically test the impact of different co-occurring diagnoses. However, some evidence was reported here to indicate that outcomes did vary according to type of co-occurring condition. Importantly, analyses here could not explore these differences fully, as multiple individuals had multiple co-occurring conditions and it was not possible to separate the impact of each condition. However, in the future this is an issue which could be addressed by studies using much larger sample sizes or which take a more in-depth qualitative approach to exploring this issue.

5.4.2. Conclusion and Link to Study 2 and 3

This study has provided evidence to suggest that while those with Autism Plus may use a greater level of support services compared to others on the spectrum, they do not necessarily experience poorer adult outcomes. The findings here indicate that if Autism Plus is to have utility as a predictor of both outcomes and needs in this population, it may need to be considered as part of a larger model which acknowledges and accounts for the impact of other important factors. This is an issue that was further explored in Study 2 in the following chapter.

The findings relating to service use in this Study can be seen to make a significant contribution to the research relating to those with Autism Plus, in that they suggest individuals with co-occurring conditions are indeed more likely to use support services than others on the spectrum. However, while analyses in this study was based on a sample of 404 individuals, the level of information available on service-use was limited given that only a small percentage of this sample reported using support services. In line with this, Study 2, which aimed to establish the predictive ability of Autism Plus as part of a larger model, focused on outcomes only, given that any modelling analyses focusing on service-use would have risked being under-powered due to the small number of those who reported using services. The issue of service use and support was however re-visited as part of Study 3 in Chapter 7.

The early chapters of the thesis highlighted the importance of considering gender/sex in any research focusing on outcomes and needs in this population, however as indicated above, no significant differences were found in the rates of outcomes or the types of services used by the males and females within this sample. With this in mind, gender/sex was also not reconsidered as part of the modelling analyses presented in the following study. This is an issue which has been discussed further in the General Discussion presented in Chapter 8.

Chapter 6

Study 2: Predicting Adult Independent Living and Relationship Outcomes in the Autism Spectrum Condition Population

6.1. Introduction

Findings from Study 1 (Chapter 5) provided evidence to suggest that Autism Plus was not a useful indicator of poorer outcomes in the adult ASC population. However, supplementary analyses raised questions about whether Autism Plus could prove a useful concept if other influential factors can be accounted for and controlled for. Within the research literature, the term ‘multivariate’ is used to describe analyses or models which aim to account for the simultaneous impact of multiple factors on an outcome, while the term ‘univariate’ is used to describe approaches which account for only one factor at a time (Field, 2013). Previous research focusing on the concept of Autism Plus, including the analyses featured in the previous chapter, has taken a univariate approach to understanding outcomes and needs in the ASC population (Gillberg et al., 2016; Helles et al., 2016), as have many of the studies within the broader ASC adult outcome literature (Magiati et al., 2014; Underwood et al., 2019).

As discussed in Chapter 3, studies which have previously investigated the factors associated with independent living, relationship, employment and travel outcomes in the adult ASC population have reported inconsistent findings, both in terms of the factors found to be associated with these outcomes, and the strength of associations identified. It is possible that these inconsistencies are in part due to the large number of studies which have taken a univariate approach towards analyses, and in doing so overlooked factors previously shown to influence outcomes in this population such as autistic symptom severity (Lombardo et al., 2019; Steinhausen et al., 2016; Underwood et al., 2017). To the best of the author’s knowledge, only three studies within the ASC literature have previously taken a multivariate approach to examining outcomes within the adult ASC population though two of these focused exclusively on employment outcomes (Chiang et al., 2013b; Howlin et al., 2013; Ohl et al., 2017). Two additional studies used a multivariate approach to examine the related concept of quality of life (which combines information relating to adult outcomes with other information relating to other concepts such as life satisfaction) in the adult ASC population, in which quality of life was determined by a combination of factors including independent living, employment and social outcomes check this is the actual factors (Bishop-Fitzpatrick et al., 2016; Renty & Roeyers, 2006). Key details from these studies are presented in Table 6.1.

Findings across these five studies mentioned above have been inconsistent. Renty and Roeyers (2006) focused their multivariate analyses on overall quality of life, meaning that outcomes including employment and relationship status were examined as part of a larger quality of life outcome which also included life satisfaction. Renty and Roeyers (2006) reported that in a hierarchical multiple regression analysis, age, gender, intellectual ability (as indicated by full-scale IQ) and autistic symptom severity (determined by the Autism Quotient [AQ; Baron-Cohen, Wheelwright, Skinner, Martin & Clubley, 2001] measure – a standardised measure of autistic symptom severity), were not predictive of overall quality of life, but could predict the level and type of support and individual received. However, though this study included participants with milder and more severe autistic symptoms, analyses was based on only 58 individuals. These findings must therefore be viewed within the context that analyses in this study would have been more vulnerable to type II errors (i.e. incorrectly rejecting null hypotheses) which are a greater risk in analyses involving a small number of participants (Banerjee et al., 2009).

By contrast, Chiang et al. (2013b) based their analysis on over 4,000 individuals in a study focusing on employment outcomes amongst recent high school leavers (mean age = 21). This analysis was based upon data previously collected as part of a national longitudinal

Table 6.1

Studies reporting multivariate analyses relating to outcomes amongst adults with ASC

Study Author and Date	Dependent (Outcome) Variable	Sample Size	Diagnoses in Sample	Predictors Tested	
				Significantly Associated with Outcome Variable	Not Significantly Associated with Outcome Variable
Renty & Roeyers (2006a)	QoL determined by life satisfaction, employment, independence and relationships	58	21% AD, 34% AS, 9% PDDNOS, 36% Other ASC	-	Age, Gender, Intellectual Ability, Autistic Symptom Severity
Chiang et al (2013)	Employment Status	4,167	ASC	Higher Income Background, Social Skills, Intellectual Ability, Use of Counselling Services, Employment Support from High School	-
Ohl et al (2017)	Employment Status	256	AS	Not declaring diagnosis, More Years of Education	Age, Gender, Co-Occurring Conditions
Howlin et al (2013)	Overall Outcomes (a single outcome variable which combined data relating to independent living, employment, friendships and relationship outcomes)	58	ASC	Autistic Symptom Severity, Language Disorder Intellectual Disability Status	
Bishop-Fitzpatrick et al. (2016)	Composite Outcome Variable based on Overall Independence, Mental Health and Physical Health	406	95% AD 5% Other ASC	IQ (but not Intellectual Disability status), Executive Functioning	Age, Autistic Symptom Severity,

study conducted by the U.S. Department of Education (NSLT2; Newman et al., 2011) and the data analysed had originally been collected using self-report and parent report surveys. This analysis found a number of factors to significantly predict participation in employment since leaving high school, including coming from a higher income background, the educational level of the participant and their parents, having higher levels of socials skills (differences were found between those with high and low social skills but not those with high and medium social skills), the presence of an intellectual disability, use of counselling services and support gaining employment provided by the participant's school. However, beyond self/parent ratings of social skills, this study did not control for the influence of autistic symptom severity, and the sample consisted of individuals who had been labelled as having 'autism' in their educational records (in this instance autism was used as a catch-all term for anyone with an ASC). It is therefore not possible to establish to what extent this sample was skewed towards those with milder or more severe needs and to what extent results may have been influenced by this. Furthermore, this analysis focused on those with any previous employment, with no indication of what constituted employment, and the authors acknowledged that since leaving high school, only a small percentage of the sample had been in full-time employment. This indicates that while this study highlights factors which may need to be better accounted for in research focusing on employment, questions can be raised about the extent to which the factors highlighted as useful predictors can genuinely be considered to differentiate those with better and poorer employment outcomes in this population.

A further study focusing on employment outcomes was conducted by Ohl et al. (2017) who based their analysis on a sample of 256 individuals with Asperger's Syndrome (AS what extent a number of factors predicted employment status at the time of data collection. Individuals who had who had not mentioned their diagnosis to employers and those with more years of education of significantly more likely to be in employment compared to others in the sample. However, as part of the same regression analysis, age, gender and the presence of co-occurring symptoms were not found to be significantly associated with employment status.

As previously discussed in Section 3.5, Howlin et al. (2013) conducted one of the most comprehensive multivariate analyses of adult outcomes in this population, and focused analyses on overall outcomes which combined participant responses relating to independent living, employment, friendships and relationships (the overall outcome approach to analysing outcomes in this population has previously been discussed in Section 3.5. of this thesis). Findings from this study indicated that as much as 76% of variance in overall outcomes could be explained by a combination) of reciprocal social interaction, language ability, restrictive repetitive patterns of behaviour and IQ, though as indicated in Chapter 3, some questions can be raised about size of the sample upon which this analysis was based (n = 58) and the use of a measure of overall outcomes which combined historical and current outcomes, making it difficult to establish to what extent these factors could predict current outcomes.

A final study of interest here was conducted by Bishop-Fitzpatrick et al. (2016) focused on 406 individuals, 95% of whom met the criteria for Autistic Disorder (AD), and the remainder of whom had another form of ASC. This study conducted a latent class analysis aimed at establishing subgroups of individuals within their sample, and this class analyses was informed by data on broad range of factors including, physical health, mental health, quality of neighbourhood, contact with family, employment, independent living and social engagement. This analysis revealed three subgroups; those who were more dependent, those who had good physical and mental health though relied on others for support with some aspects of life (e.g. they continued to live in their family home), and those who were independent and experienced generally positive outcomes and good physical and mental health. The authors reported that individuals in these groups differed in terms of their IQ (though notably intellectual disability status was not significantly associated with group membership) and executive functioning. Notably, group differences were not found in the age or autistic symptom severity of individuals within these groups. These findings should however be interpreted in the context that they focus primarily on individuals with autistic disorder (i.e. more severe autistic symptoms), they treated mental health diagnoses such as anxiety and depression as outcomes rather than co-occurring symptoms which could influence outcomes, and that outcomes were grouped together rather than analysed separately.

Together, the studies above have considered the impact of a broad range of factors on outcomes in this population, with autistic symptom severity and intellectual ability the most consistently revisited factors. While each study has provided evidence to suggest that a multivariate approach to analysing outcomes in this population is important, findings from each study must be examined within the context of methodological limitations. For example, two studies based analyses on a sample involving fewer than 60 individuals (Howlin et al., 2013; Renty & Roeyers, 2006), three grouped outcomes together rather than analysing them independently (Bishop-Fitzpatrick et al., 2016; Howlin et al., 2013; Renty & Roeyers, 2006) and one involved a sample of mixed autistic symptom severity without accounting for this factor in analysis (Chiang et al., 2013a).

In order to contribute further to the literature focusing on Autism Plus, and also the research which has aimed to develop models which can predict outcomes within the ASC population, this analysis also aimed to model outcomes in the ASC literature and in doing so overcome some of the methodological issues associated with these studies, in particular those relating to the need to base analyses on a larger sample, to recognise that different factors may affect each type of adult outcome and in line with findings from Study 1, to better account for the impact of age and autistic symptom severity on outcomes. More specifically, this study aimed to assess whether the Autism Plus conceptualisation of ASC differentiate between social and independent living outcomes when other key demographic and diagnostic factors are also controlled for?

6.2. Method

Analyses for this study involved a further secondary data analysis of the SAMS dataset and participants described in 5.2.1. In this case analyses aimed to establish to what extent outcomes in this population could be predicted by demographic and diagnostic factors.

6.2.1. Participants

While analysis for this study was based upon the same dataset described in Study 1, it was decided that analysis here would be based on the subset of individuals with AD/CA and AS/HFA (i.e. diagnoses associated with a specific level of severity; n = 318) described as part of Study 1, and to exclude those with ASD and PDDNOS, given that the latter are not associated with a specific level of autistic symptom severity (this issue has previously been discussed in Section 2.1.3, 2.1.4 and 5.2.3). This decision was taken given that there was evidence from Study 1 to suggest that autistic symptom severity was associated with some of the adult outcomes analysed. As such, it was considered beneficial to include a smaller but better-defined sample in this follow-up analysis.

6.2.2. Statistical Analysis

Dependent and Independent Variables

The aim of this study was to carry out four separate logistic regression analyses, with dependent variables of (1) relationship status, (2) employment status, (3) residential status and (4) ability to travel independently. Data relating to these outcomes were previously collapsed into binary outcomes as part of Study 1 and this process is described in Appendix

B3. The same independent variables were used in each of the four analyses. The main independent variable of interest was membership of the Autism Plus or Autism Only group (i.e. whether or not participants had at least one co-occurring condition). In each analysis, membership of the Autism Plus group was represented by a '1' and membership of the ASC Only group was represented by a '0'. In line with the findings from Study 1 (Chapter 5), age and autistic symptom severity (as indicated by the type of ASC diagnosis an individual had) were included as independent predictors. Finally, the potential interaction effects of age and Autism Plus and age and autistic symptom severity (as defined by type of diagnosis) were tested in each model. However, preliminary analyses investigating the models indicated that none of these interactions were significantly associated with any of the four adult outcomes dependent variables (all *p*-values > .623) or improved the variance explained by the model by greater than 1% (all Nagelkerke R^2 values < .01). These interactions were therefore not included as part of the final logistic regression models presented in this chapter.

Throughout the procedures described above, all statistical analyses were conducted using SPSS version 26. The analyses reported here were again based upon a dataset previously subject to multiple imputation. This process has previously been described and explained as part of 5.2.

Procedure for Logistic Regression Analyses

Preliminary Checks

Before each of the four main analyses was conducted, checks were carried out to ensure that results would be based upon an adequate sample size. These checks were based upon guidelines from Peduzzi, Concato, Kemper, Holford and Feinstein (1996), which assess the appropriateness of sample size by comparing event rate to the number of independent variables involved in the analysis. According to these guidelines, the sample size is adequate when the number of independent variables included in a model, is less than the *n* of the least frequently occurring event in a binary dependant variable divided by 10. For example, in a regression model where a binary dependent variables represent outcomes experienced by 40 and 60 individuals, the number of recommended independent variables would be calculated by dividing 40 (the least frequently occurring event) by 10, to arrive at a recommended 4 independent variables. Each of the regression analyses reported here were intended to include three independent variables, and using the guidance reported above, it was confirmed that this was a suitable number of independent variables in each model relative to the dependent variable.

Multicollinearity checks were also carried out prior to analysis. This kind of check is not available as part of the SPSS logistic regression function, but the relevant statistics were obtained using SPSS by using a method recommended by Field (2013). This method advocates including independent and dependent variables associated with a model of interest in a linear regression model, for which SPSS version 26 does provide multicollinearity checks, and using these statistics to assess the relationships between factors. Given that multicollinearity analyses relate to the relationship between independent variables within the context of a dependent variable, rather than the influence of independent variables *on* dependent variables, it can be assumed that multicollinearity statistics for an independent variable will be the same regardless of whether logistic or linear regression is being conducted.

Using the approach above, multicollinearity was assessed according to the variance inflation factors (VIF) statistics. A VIF value of 1 indicates that independent variables are not correlated, with scores above this indicating that independent variables are closely associated. VIF scores of around 5 are considered to indicate a moderately strong associated of variables, and scores of 10 and above indicated that variables are very closely associated and as such cannot be considered independent (Field, 2013). These checks were conducted for each of the analyses reported as part of this study, though no issues with multicollinearity were identified.,

Finally, outlier analyses were also conducted for each logistic regression analysis, in order to establish whether any data points could potentially skew results. These checks focused on identifying data points with a Cook's distance of > 1 (indicating that a data point has a higher than expected influence on the fit of the model) or studentised residuals > 3 (indicating that a data point greatly deviates from the model found to best explain the variance in the data). No outliers were identified as part of these checks, and as such the results presented in this Chapter are based upon the 318 individuals with AD/CA or AS/HFA.

Main Analyses

Output from the logistic regressions was assessed in three ways. Firstly, the Hosmer and Lemeshow (HL) goodness of fit tests were assessed to establish the extent to which each model fitted with the data provided by the sample. Secondly, the variance in the dependent variable explained by each independent variable was assessed by the Nagelkerke R^2 value associated with each block of the model. The Nagelkerke statistic was preferred here to the Cox and Snell R^2, (which SPSS also offers as an indicator of variance explained) as it has a maximum value of 1, making it easier to interpret the percentage of variance explained compared to the Cox and Snell statistics which has a maximum value of less than 1. Finally, the predictive ability of each independent variable was interpreted by the odds ratio statistics produced by the logistic regression model (Expβ), as well as the 95% confidence intervals (95% CI) which provided an indicator of the reliability of these findings.

Given its more exploratory nature, and the number of large of comparisons made, Study 1 adjusted p-values to reduce the likelihood of a type I error. However, it has been proposed that this kind of correction is less appropriate when: 1) fewer hypotheses are tested (i.e. the risk of a type I error is lower); 2) when studies are less exploratory in nature; 3) when hypotheses are informed by previous analyses; and 4) when dependent variables are independent of one another (Perneger, 1998; Streiner & Norman, 2011). These points have relevance to the analysis presented in this study, given that each logistic regression analysis focused on a distinct aspect of life and the independent variables included in each model had been selected in line with findings from Study 1. Therefore, in contrast to Study 1, results in this study were interpreted according to the conventional indicator of significance, $p < .05$.

6.3. Results

6.3.1. Testing the Influence of ASC Plus on Social and Health Outcome

Tables 6.2– 6.5 provide the results of four hierarchical logistic regression analyses testing the ability of age, ASC diagnosis severity and ASC Plus to predict relationship, residential, travel and employment outcomes. Each of these models is discussed separately below. Goodness of fit across these models was assessed using Hosmer and Lemeshow test, with findings indicating that each model was associated with a good level of fit (all χ^2 values > 15.60, all p-values > .05).

Residential Outcomes

Table 6.2 presents the results of a hierarchical logistic regression analyses focusing on residential status. The first step of regression analysis entered age into the model, which was found to account for 30% of the variance in residential outcomes in this sample, and subsequent steps indicated that the type of ASC diagnosis an individual had, and the presence of co-occurring conditions could only account for a further 3% of the variance in this outcome. In the final block of the model, once all independent variables of interest had been included, age was found to be significantly associated with residential status ($p < .001$), with findings indicating that individuals were 4% more likely to be living independently (i.e. on their own, with a partner or with flatmates/housemates) for every year old they were. The type of ASC diagnosis that an individual had was not significantly associated with residential outcomes, however, there was evidence to suggest that those with at least one co-occurring condition were 1.74 times more likely to be living independently, $p = .042$.

Table 6.2

Hierarchical Logistic Regression Model Testing Age, Autistic Diagnosis Severity and ASC Plus as Predictors of Independent Residential Status

Model	β	Std. Error	Sig. [1]	Exp (β)	95% CI		Block R^2
					Lower	Upper	
Block 1							
Age	.09	.01	< **.001**	1.10	1.07	1.12	.30
Block 2							
Age	.09	.01	< **.001**	1.09	1.07	1.12	.32
Type of ASC Diagnosis [2]	-.49	.32	.129	.61	.32	1.15	
Block 3							
Age	.09	.01	< **.001**	1.04	1.02	1.06	.33
Type of ASC Diagnosis [2]	-.47	.33	.156	.63	.33	1.19	
Autism Plus[3]	.56	.27	**.042**	1.74	1.02	2.98	

[1] Statistically significant relationships in **bold** [2] Autistic Symptom Severity as indicated by type of diagnosis. This compares individuals with AD/CA (0) and AS/HFA diagnoses (1), where AS/HFA is the reference category. [3] This compares those with Autism Only (0) and Autism Plus (1), where Autism Only is the reference category.

Employment Outcomes

Table 6.3 shows the findings from the second hierarchical logistic regression analysis which focused on employment outcomes in the sample. Overall, findings indicated that the independent variables included in the model could only account for 3% of the variance in employment outcomes in this sample. However, while neither age nor the presence of at least one co-occurring condition was significantly associated with employment status, compared to those with AD/CA (i.e. more severe autistic symptoms), those with AS/HFA were twice as likely to be employed.

Table 6.3

Hierarchical Logistic Regression Model Testing Age, Autistic Diagnosis Severity and ASC Plus as Predictors of Being in Employment

Model	β	Std. Error	Sig. [1]	Exp (β)	95% CI		Block R^2
					Lower	Upper	
Block 1							
Age	- .01	.01	.780	1.00	.99	1.02	<.01
Block 2							
Age	- .01	.01	.937	.99	.98	1.01	.03
Type of ASC Diagnosis [2]	-.70	.30	**.021**	.50	.27	.90	
Block 3							
Age	- .01	.01	.853	.99	.27	1.02	.03
Type of ASC Diagnosis [2]	-.70	.31	**.023**	.50	.27	.91	
Autism Plus[3]	.15	.27	.564	1.17	.69	1.96	

[1] Statistically significant relationships in **bold** [2] Autistic Symptom Severity as indicated by type of diagnosis. This compares individuals with AD/CA (0) and AS/HFA diagnoses (1), where AS/HFA is the reference category. [3] This compares those with Autism Only (0) and Autism Plus (1), where Autism Only is the reference category.

Long-Term Relationship Outcomes

Table 6.4 presents findings from a logistic regression analysis focusing on long-term relationship status. In the first block of the model, age could account for 22% of the variance in relationship outcomes, in block 2, the type of ASC diagnosis an individual had was found to account for a further 6% in the variance and in block 3, the presence of co-occurring symptoms was able to explain a further 2% of the variance. In the final block of the model, once all variables had been entered, all three variables were found to be associated with long-term relationship status. More specifically, these findings indicated that those for every year older an individual was, they were 7% more likely to be involved in a long-term relationship

($p < .001$), and that compared to those with AD/CA, those with AS/HFA diagnoses were more than five times less likely to be involved in a long-term relationship ($p = .002$). Individuals with co-occurring conditions were also found to be twice as likely to be in a long-term relationship ($p = .019$).

Table 6.4

Hierarchical Logistic Regression Model Testing Age, Autistic Diagnosis Severity and ASC Plus as Predictors of Long-Term Relationship Status

Model	β	Std. Error	Sig.[1]	Exp (β)	95% CI		Block R^2
					Lower	Upper	
Block 1							
Age	.07	.01	**< .001**	1.07	1.05	1.09	.22
Block 2							
Age	.07	.01	**< .001**	1.07	1.05	1.10	.28
Type of ASC Diagnosis [2]	-1.71	.56	**.002**	.18	.06	.56	
Block 3							
Age	.07	.01	**< .001**	1.07	1.04	1.09	.30
Type of ASC Diagnosis [2]	-1.71	.56	**.002**	.18	.06	.54	
Autism Plus[3]	.76	.32	**.019**	2.13	1.13	4.03	

[1] Statistically significant relationships in **bold** [2] Autistic Symptom Severity as indicated by type of diagnosis. This compares individuals with AD/CA (0) and AS/HFA diagnoses (1), where AS/HFA is the reference category. [3] This compares those with Autism Only (0) and Autism Plus (1), where Autism Only is the reference category.

Independent Travel Outcomes

Table 6.5 presents findings from a logistic regression analysis focusing on long-term relationship status. In the first block of the model, age could account for 13% of the variance in relationship outcomes, in block 2, the type of ASC diagnosis was found to account for a further 31% but that the presence of co-occurring conditions was not able to explain any additional variance in this outcome. In the final block of the model, once all variables had been entered, both age and autistic symptom severity were significantly associated with the ability to travel independently. More specifically, these findings indicated that those for every year older an individual was, they were 6% more likely to able to travel independently ($p < .001$), and that compared to those with AD/CA, those with AS/HFA diagnoses were more than 11 times less likely to be involved in a long-term relationship ($p < .001$). The presence of at least one co-occurring condition was not found to be associated with independent travel ability.

Table 6.5

Hierarchical Logistic Regression Model Testing Age, Autistic Diagnosis Severity and ASC Plus as Predictors of Independent Travel

Model	β	Std. Error	Sig.	Exp (β)	95% CI Lower	95% CI Upper	Block R^2
Block 1							
Age	.05	.01	**< .001**	1.06	1.03	1.08	.13
Block 2							
Age	.05	.01	**< .001**	1.06	1.03	1.08	.31
Type of ASC Diagnosis [2]	-2.40	.34	**< .001**	.09	.05	.18	
Block 3							
Age	.06	.01	**< .001**	1.06	1.03	1.08	.31
Type of ASC Diagnosis [2]	-2.43	.35	**< .001**	.09	.05	.17	
Autism Plus[3]	-.31	.28	.266	.73	.42	1.27	

[1] Statistically significant relationships in **bold** [2] Autistic Symptom Severity as indicated by type of diagnosis. This compares individuals with AD/CA (0) and AS/HFA diagnoses (1), where AS/HFA is the reference category. [3] This compares those with Autism Only (0) and Autism Plus (1), where Autism Only is the reference category.

6.4. Discussion

6.4.1. ASC Plus and Adult Outcomes in the ASC Population

The aim of this study was to examine whether ASC Plus could predict residential, relationship, employment and independent travel outcomes, when the important factors of age and severity of ASC were controlled for. The results of four logistic regression analyses suggested that even in larger models where age and type of ASC diagnosis are controlled for, Autism Plus cannot be considered a reliable indicator of poorer outcomes within the adult ASC population. This was based on the findings that in models also accounting for age and type of ASC diagnosis, Autism plus was not significantly associated with employment or travel outcomes, and contrary to the premise of interest here, evidence to suggest that both relationship and residential outcomes were better amongst those with at least one co-occurring condition. It was hypothesised that the utility of the ASC Plus approach could be revealed if the severity of an individual's autistic symptoms was also accounted for, however for the most part, these results indicate that the relationship between co-occurring conditions and adult outcomes may be more complex than previously proposed. This research has therefore failed to find support for Gillberg and Fernell's (2014) conceptualisation of the ASC population. These findings can also be seen to be in line with one additional study in this literature which found Autism Plus to be associated with differences in life satisfaction but not adult outcomes (Helles et al., 2016).

6.4.2. Age, ASC Severity and Adult Outcomes in the ASC Population

Of the two control variables included in each logistic regression analysis, age was found to be significantly associated with residential status, relationship status and ability to travel independently, while autistic symptom severity was found to significantly predict employment status, long-term relationship status and ability to travel independently. In each of these cases, better outcomes were found amongst those who were older and had less severe autistic symptoms (as indicated by whether they had an AD/CA or AS/HFA diagnosis).

While a number of studies have previously focused on the way in which the symptoms of ASC may change with age, few have focused on the way in which this may affect adult outcomes. The findings of this study therefore emphasise the need to be more considerate of age in research focusing on outcomes, particularly given that this factor was able to account for 12% of the variance in independent travel outcomes, 22% of the variance in long-term relationship outcomes and 30% of variance in residential outcomes. These findings may also be considered relevant to the literature focusing on the relationship between age and autistic symptom severity. As discussed in Section 2.4.1, the research literature has produced findings to suggest impact of autistic symptom severity may either decline or improve with age (Billstedt et al., 2007; Chowdhury et al., 2010; Gillespie-Lynch et al., 2012; Matson & Dempsey, 2008; Richler et al., 2010). Given that there was a significant positive relationship between age and three of the outcomes analysed here, this may be considered further evidence that the impact of autistic symptoms may decline with age.

As already indicated throughout this thesis, the type of ASC diagnosis that an individual has is another factor which it is important to account for in analyses focusing on outcomes in this population (Howlin & Magiati, 2017; Underwood et al., 2019), however as highlighted in Chapter 2 of this thesis, findings relating to the relationship between autistic symptom severity and outcomes have been inconsistent. The findings here clearly indicate that outcomes were better amongst those with AS/HFA and as such may also be seen to reinforce the need to account for different sub-diagnoses of ASC in research focusing on outcomes. Furthermore, at a time when there is uncertainty around the utility and appropriateness of the DSM-5 ASD diagnosis given the considerable heterogeneity of the population which this diagnosis can relate to (see Section 2.1.4 for a full discussion of this issue), these findings may be considered to contribute to the evidence which suggests that there is still value to differentiating those with AS/HFA from others with ASC (de Giambattista et al., 2019; Kite et al., 2013; Linton et al., 2013; Volkmar et al., 2014).

6.4.3. Strengths and Limitations

There are a number of strengths to the research presented in this chapter. Firstly, this study can be considered to have assessed the utility of Autism Plus more thoroughly than previous research, given that it took a multivariate rather than univariate approach to exploring this issue. Secondly, this research can be seen to expand upon the previous adult outcome literature which has acknowledged that adult outcomes in this population may best be predicted by a combination of factors, rather than single variables. For example, the models focusing on long-term relationship involvement and independent travel ability presented here showed that age and autistic symptom severity could each account for a unique proportion of the variance in these outcomes. Thirdly, the multivariate analyses presented here were based on an appropriate sample size, in contrast to some of the previous research which has focused on adult outcomes amongst the ASC population (as discussed in Section 6.1, see Table 6.1 for further details).

However, there are also a number of limitations to this study which must be taken into consideration when interpreting the results of the analyses presented here, some of which have already been discussed as part of Study 1 (see Section 5.4.1). One further limitation that could account for the unexpected findings here is that while the severity of participants' autistic symptoms was accounted for in the analysis reported here, the severity of co-occurring conditions was not.. It is therefore possible, that if this factor had also been taken into consideration, it may have resulted in a clearer link between Autism Plus and the outcomes analysed in this study. Finally, it is important to acknowledge, as previously discussed in Section 3.6, that while desirable in the typically developing population, being employed, living independently, being involved in a long-term relationship and being able to travel independently, may not be desirable amongst some members of the ASC population (Bishop-Fitzpatrick et al., 2016; Magiati et al., 2014).

6.4.4. Future Recommendations

The results of this study reinforce the need to be considerate of the broad range of factors which can affect social and independent living in the adult ASC population. While the overall findings from Study 1 and 2 of this thesis raise questions about the validity of ASC Plus as a predictor of outcomes in this population, as highlighted above, it may be the case that the severity of an individual's co-occurring condition may also have an impact on an individual's outcomes. It is therefore important that future research explores how co-occurring symptom severity in the ASC population is linked to social and independent living outcomes in this population.

6.4.5. Conclusions

Overall, findings from this study suggest that Autism Plus, as it was initially proposed by Gillberg and Fernell (2014) may not be considered helpful in predicting poorer outcomes within the ASC population even when considered as part of a larger model accounting for other important and influential factors such as age and autistic symptom severity. The findings from Study 1 and Study 2 suggest that the relationship between co-occurring conditions and adult outcomes may be more complex than proposed by Gillberg and Fernell. However, as indicated in Chapter 2 and 3 of this thesis, there is considerable evidence to suggest that the presence of diagnoses such as depression, anxiety, ID, ADHD and epilepsy can have a considerable impact on many different areas of life. It is therefore of some interest that in the first two studies of this thesis, there was no evidence to suggest that the presence of these additional conditions had little impact on the adult outcomes of individuals with ASC (Geerlings et al., 2019; LeMoult & Gotlib, 2019; Lensing et al., 2015; Michielsen et al., 2015; Rosen et al., 2018; Taylor & Seltzer, 2011; Thomson et al., 2014).

As previously discussed in Chapter 2, Section 2.3, one study focusing on Autism Plus found evidence to suggest that life satisfaction, but not adult outcomes, may be influenced by the presence of co-occurring conditions in this population (Helles et al., 2016). It is therefore possible that while the presence of co-occurring conditions in this sample did not prevent individuals from forming relationships, gaining employment and living independently, they may have complicated these aspects of life, added an additional level of stress to life or affected other aspects of life not covered here. In line with this, and following the findings from Study 1 and 2, it was therefore considered beneficial to explore the experiences of those with Autism Plus more broadly in order to gain a greater sense of the impact of co-occurring conditions on the lives of those with ASC. This was the aim and focus of Study 3, presented in the following Chapter.

Chapter 7

Study 3: The Lived in Experience of ‘Autism Plus’ amongst Adults with Autism Spectrum Conditions

7.1. Introduction

Previous research has shown that individuals on the autism spectrum are well-informed about their condition and can provide detailed accounts of the impact which ASC may have on their lives (Gillespie-Lynch et al., 2017; Milton, 2014). Qualitative research, which typically takes a more open and less-structured approach to data collection, can therefore be particularly useful in gaining insight into the specific aspects of life which those on the spectrum find difficult, in comparison to more structured approaches which limit the topics upon which those with ASC can comment upon (MacLeod, 2019; van Schalkwyk & Dewinter, 2020).

With this in mind, the present study aimed to further explore the lives and experiences of those on the spectrum with co-occurring conditions through the use of interviews informed and analysed using Interpretative Phenomenological Analysis (IPA). This is an approach which has successfully been used to generate a better understanding of the lives of those with ASC before, though a large portion of this research has focused on younger individuals and covered topics relating to identity and educational experiences (Howard et al., 2019; MacLeod, 2019). However, two IPA studies have previously focused on issues of more direct relevance to this thesis.

In the first of these, Griffith et al. (2011) interviewed 11 adults with AS (aged 37–57) to learn more about the impact of the condition on everyday life and the support experiences of individuals within this population. One of the most frequently discussed topics raised within these interviews was employment, with participants describing difficulties gaining and maintaining employment and attributing these difficulties to the social aspects of employment and the workplace. Those who were able to better cope with these aspects of employment indicated that they still found the workplace a particularly difficult stressful environment and that this stress was something they took home with them at the end of each working day (Griffith et al., 2011, p. 539). Availability and access to support was also a key concern of participants, with a number of individuals indicating that they had ‘fallen through the gaps’(Griffith et al., 2011, p. 540) because they were too high functioning, and as such struggled to find support which met their needs. Finally, some participants briefly commented on co-occurring conditions, with some believing that the symptoms which came as part of their AS diagnoses also made them more vulnerable to the development of anxiety and depression.

A second IPA study from this literature by Mattys et al. (2017) interviewed individuals on the spectrum (n = 14, aged 17 – 25 years), parents (n = 14) and professionals (n = 12), and similarly aimed to gain insight into the everyday difficulties experienced by those on the spectrum. A recurring theme was that those on the spectrum felt they had difficulties meeting societal expectations and understanding what they should expect from life given their abilities and needs. Furthermore, these individuals explained that as a result of this uncertainty, they often found themselves “getting stuck” (p. 325) and experienced difficulties understanding what they should aim for in life. Parents and professionals both commented on the difficulties which those with ASC had forming social relationships with others and attributed this in part to lower levels of social needs. However, a contrasting perspective was put forward by participants on the spectrum who indicated that the main barrier to social relationships was social anxiety which prevented them from reaching out to others and initiating closer relationships.

In addition to these IPA studies, a small number of other qualitative studies have explored the everyday impact of the symptoms on ASC. The majority of these have based analyses upon interviews with individuals on the spectrum, and as part of these interviews, one of the most regularly discussed topics was the social impact of the condition. While quantitative research has made a considerable contribution to the understanding of the social difficulties which those on the spectrum face, qualitative research has been able to better capture the specific implications of these social impairments associated with ASC. For example, a number of qualitative studies have highlighted that many individuals on the spectrum are self-conscious of how they differ socially from individuals without ASC, and as a result try to mask or 'camouflage' autistic behaviours by limiting the amount of personal perspectives they share, mirroring the actions of others, and consciously maintaining a balance between they amount of talking and listening that they engage in (Cook et al., 2020; Hull, Petrides, et al., 2017; Lai et al., 2017; Mandy, 2019). Awareness of camouflaging has grown steadily within the research literature, and qualitative research has indicated that while this can in some ways be considered a coping mechanism, it can also be an exhausting and stressful for individuals with ASC (Crompton et al., 2020; Hull, Petrides, et al., 2017; Livingston et al., 2019; Müller et al., 2008). Furthermore, while there is some evidence to suggest that individuals on the spectrum can become more comfortable with social situations as they age, interviews conducted by Müller et al. (2008) indicated that participants also become aware of how greatly they differ from others as they grow older and that this can become an additional source of stress.

Qualitative research has also highlighted that social difficulties are not the only reason why those on the spectrum may find it difficult to interact with others and form relationships, with evidence to suggest that the locations in which social interactions typically take place also plays an important role. For example, Crompton et al. (2020) indicated that those with ASC would often feel excluded, or exclude themselves, from social opportunities and activities because they took place in environments such as pubs or cafes which could overwhelm their senses as a result of the noise or lighting. Similarly, Cummins et al (2020) reported that social activities involving large groups could be a source of sensory overload for individuals with ASC and make it difficult to engage with others as a result of the intensity of the situation. In line with these findings, Vincent et al. (2017) reported that their participants more often avoided social situations because of social discomfort rather than social anxiety, in that it was often environmental factors which discouraged them from socialising rather than social impairment.

Other research in this field has also been able to capture the desire that individuals on the spectrum have for engaging with others, though it suggests that those on the spectrum may prefer to socialise with others who share their values and needs. This was highlighted in interviews conducted by Crompton et al. (2020) in which participants indicated that being friends with others on the spectrum allowed those with ASC to be themselves, provided them with a sense of belonging and gave them a social group with which they could better relate. Further evidence that those on the spectrum are keen to engage with those around them was provided by Müller et al. (2008) who reported that participants showed a strong desire to contribute to their community, reporting that a number of individuals who they interviewed were involved in voluntary work, discussed the pleasure they took in supporting others and commented on their desire to support others on the spectrum by increasing the awareness of the condition, raising money for research focusing on ASC and organising support for others.

A second issue commonly discussed by research in this area is support. While difficulties accessing support have regularly been captured by quantitative research within this field, qualitative research has highlighted that these difficulties may be even greater for those on the spectrum with co-occurring conditions. For example, Adamson et al. (2020) interviewed the carers of individuals with ASC and co-occurring eating disorders, and found that carers felt that the support available to individuals with this combination of symptoms was limited.

More specifically, participants commented that professionals specialising in eating disorders would overlook autistic symptoms in communicating guidance or developing treatment plans. Carers reported this being a particular frustration, as often typical treatment plans were not compatible with the presence of autistic symptoms and behaviours. However, importantly, an earlier study by (Kinnaird et al., 2017) interviewed professionals working in the same field and reported that while many participants indicated that they had limited experience working with individuals on the spectrum, they always ensured that they took additional symptoms into consideration when developing a treatment plan for the symptoms of eating disorders. This inconsistency in the perspectives of professionals and service-users is therefore an issue which must be taken into consideration in any research focusing on the appropriateness of support available to those with ASC.

Similar findings relating to service availability and the nature of support available were also reported by (Crane et al., 2019), who as part of their research interviewed 21 individuals with ASC aged between 16 and 25, with a broad range of co-occurring diagnoses including anxiety, depression, ADHD and OCD. Participants in this study indicated that they found it difficult to identify or access services which were appropriate for their mental health needs, and indicated that there was a need for more support services which better acknowledged the way in which the presence of autistic symptoms could complicate the experience of having mental health condition. Participants also highlighted that autistic symptoms could complicate the treatment of mental health conditions, and in line with this highlighted the need for more professionals in mental health support services with an expertise of autistic symptoms and their impact.

A further qualitative study by Muller et al. (2008) explored the issue of support more broadly has also highlighted that those on the spectrum often feel they are only provided support aimed at specifically addressing their symptoms, even though many other forms of support could also be beneficial. Participants in this study indicated that it was important that they were also able to access opportunities to engage in creative, physical and outdoor activities, given that such opportunities could help reduce the stress and impact which accompanied ASC, but that such opportunities are rarely appropriate for those on the spectrum and their needs. Therefore, it is possible that professionals and individuals on the spectrum may also be considered to differ in terms of the type of support they consider to necessary. In line with this, Crane et al. (2020), suggest that there is a need to further explore alternative, short-term forms of support for individuals with ASC, given that financial restrictions mean it is not possible to provide long-term support programmes for most adults on the autism spectrum.

A final recurring theme amongst interviews with participants on the spectrum is co-occurring anxiety symptoms, which as discussed in Chapter 2 are highly prevalent amongst individuals on the spectrum. By speaking to individuals with ASC, researchers have found that those on the spectrum experience anxiety in response to a broad range of social and environmental situations including meeting new people, speaking by phone (given that this can make it easier to overlook social cues), being in groups or crowds or visiting new places (Halim et al., 2018; Spain et al., 2020; Trembath et al., 2012). There is also evidence to suggest that symptoms of anxiety may develop in situations where those with ASC feel the values of others do not align with their own (for example, values relating to timekeeping/lateness), in that their anxiety would be provoked by a desire to comment on these issues but an uncertainty regarding whether this was socially acceptable (Robertson et al., 2018; Spain et al., 2020). Finally, attempts to control behaviours so that they better align with social conventions (e.g. restraining from engaging in restrictive, repetitive patterns of behaviour such as fidgeting or going along with inconsistent or ever-changing plans despite a strong need for consistency and routine) have also been cited as a source of anxiety in this population, (Halim et al., 2018; Spain et al., 2020). Other interviews with individuals with

ASC have also indicated that the presence of anxiety can exacerbate or further complicate social and communication difficulties and at times prevent individuals in this population from interacting with others entirely (Cummins et al., 2020).

Other research has found that the anxiety experienced by those on the spectrum can have a broad ranging impact within this population (Robertson et al., 2018). For example, some research has indicated that these symptoms can have a physical consequences such as stomach problems, headaches and an increased sensitivity to the environment (Halim et al., 2018; Robertson et al., 2018; Spain et al., 2020; Trembath et al., 2012). However, there is also evidence to suggest that the presence of more severe anxiety symptoms in the ASC population can prevent individuals from leaving their homes or maintaining a social life (Robertson et al., 2018). Importantly, Robertson et al., (2018) also indicated that the severity and impact of anxiety could not only vary between individuals, but also within the same individual across their lifetime.

Findings from studies employing IPA as well as quantitative techniques more broadly have therefore provided some additional insight into the difficulties experienced by individuals on the spectrum in their everyday lives. However, while several studies have focused on the presence and impact of anxiety symptoms within this population, very few qualitative studies have investigated the impact of other co-occurring conditions on the lives of those with ASC. With this in mind, the aim of this study was to investigate what impact co-occurring conditions could have on the social and independent living outcomes and support needs of adults with ASC. More specifically, this study aimed to establish whether co-occurring symptoms could be seen to create greater challenges in life beyond those associated with the presence of ASC symptoms. In line with this, this study aimed to investigate:

(1) What are the perceptions of a sample of adults with Autism Plus on the impact of their co-occurring conditions on their social and independent living outcomes?

(2) On the basis of lived experience, to what extent might the Autism Plus conceptualisation of ASC be useful in differentiating needs and outcomes of adults across the spectrum?’

7.2. Method

Data was collected for this study through semi-structured interviews with adults with Autism Plus (i.e. individuals with an ASC diagnosis and at least one co-occurring condition) and it was decided early in the development of this study that any data collected would be analysed using IPA. This decision in turn informed the recruitment strategy for this research and the development of the interview schedule used to collect data in this study. Section 4.4 provides full details of the selection of IPA over other qualitative approaches to collecting and analysing data. Ethical approval or this study was granted by the University of Strathclyde.

7.2.1. Recruitment

In line with recommendations from the IPA research literature (Pietkiewicz & Smith, 2014; Smith & Osborn, 2009), this study set out to recruit between six and eight participants. A full rationale for this sample size has been discussed in Appendix C1.

Participant Criteria

Only those who had a pre-existing ASC diagnosis (including autistic disorder, atypical autism, high functioning autism, Asperger’s syndrome, PDDNOS or Autism Spectrum Disorder) and at least one other neurodevelopmental, cognitive or psychiatric diagnoses were asked to take part in the study. As part of the recruitment strategy (see following section for more details), individuals who expressed an interest in the study were asked to confirm that their diagnosis had been confirmed by a professional, though were not required to provide proof of this. Given that the aim of the study was to learn about the personal experiences of those living with ASC and co-occurring conditions, only individuals who could verbally communicate using English were recruited. This requirement only existed as time and budget constraints meant it was not possible to hire a translator to help conduct the interview.

The study also targeted only individuals with Autism Plus who were aged 25 years and older. This was in line with previous research, discussed in Chapter 3, which has indicated that individuals on the spectrum tend to achieve social and independent living outcomes later than their peers in the typically developing population (Fein et al., 2013; Suh et al., 2014) and that service-provision and support for individuals on the spectrum gradually declines from the point where individuals in this population leave secondary school (Chiang & Wineman, 2014; Farley et al., 2009; Renty & Roeyers, 2006). The cut-off age of 25 years used was therefore intended to reduce the likelihood that participants achieved poorer outcomes as a product of their age rather than other factors, and that the sample was not skewed towards younger individuals who could potentially recieve greater levels of support than other adults on the spectrum.

Recruitment Strategy

Ethical approval for this study allowed for interviews to be conducted on the University of Strathclyde campus, given that this was considered to be the in the best interests of the health and safety of both the researcher and participant. Given the location of interviews, recruitment targeted individuals living within 1-hour commuting distance of the University of Strathclyde campus.

Recruitment of these individuals comprised a two-stage approach. Firstly, ASC organisations and online communities were approached and asked to display an advertisement for their study on their website and social media pages. Organisations and support groups who agreed to advertise the study were provided with a form of words which could be used (see Appendix C2), and this included a hyperlink which allowed potential participants to read an information sheet providing further details about the study and allowing participants to express an interest in the study by providing their email address (this information sheet is provided in Appendix C3). One participant expressed an interest in taking part in research at this stage of the recruitment strategy, though failed to respond to a follow-up email about taking part in the research.

Following this, a second stage of recruitment involved contacting individuals on a pre-existing mailing list. This mailing list had previously been generated as part of data collection for the Scottish Autism Survey (see Section 4.4.1 for more details on this survey and the associated project), and all individuals included on the mailing list had previously consented to being contacted about similar research in the future. Permission to contact individuals on this mailing list was granted by the principal investigator of the original project. A total of 32 individuals on the mailing list who met the criteria for this study, and each was assigned an ID number ranging from 1–32. A random number generator was used to develop a list of values ranging from 1-32, which could then be used to inform the order in which participants were contacted. A new set of six participants were emailed every four days to reduce the likelihood of over-recruitment and avoid a situation where participants who had expressed an interest in the study had to be turned down. Individuals who expressed an interest in taking part in the research were contacted by email and asked to specify a date and time when they could take part in the study. Given that this was the way in which participants involved in the final sample were recruited, the interviews presented here involved individuals who had previously contributed to the SAMS dataset, upon which analyses in Study One and Study Two are based.

Factors Influencing Recruitment

Two interviews were completed before data collection was interrupted by the outbreak of the COVID-19 pandemic, which prevented further interviews from taking place due to the closure of the University of Strathclyde and UK Government advice on social distancing (a copy of the guidance provided by the University of Strathclyde regarding research during this time has been provided in Appendix C4). Prior to this, a further three individuals had indicated that they were willing to take part in the research, however, a final date and time for interviews had not been confirmed at the point where the University of Strathclyde announced its closure.

Online video calls were considered as a potential alternative to face-to-face interviews given the situation. However, ultimately this approach was not adopted given concerns for the health and safety of participants and the potential impact of this methodology on data collection amongst a population known to experience social and communication impairments and within a sample which could include individuals with co-occurring mental health difficulties. A full discussion of the reasons for deciding against this methodological approach is presented in Appendix C5.

With the concerns above in mind, the decision was made to base the analysis presented in this chapter upon data collected before the COVD-19 outbreak. To ensure anonymity, each of the participants interviewed was provided with a pseudonym used throughout analysis and throughout this chapter. Key characteristics and details relating to each participant are provided below.

Participant One: 'David'

Participant one was a 70-year-old male, with a diagnosis of Asperger's and co-occurring depression and anxiety. At the time of the interview, the participant was married, had one child, and was retired, though had been in full-time employment for most of his life.

Participant Two: 'John'

Participant two was a 47-year-old, with a diagnosis of Asperger's and co-occurring diagnoses of depression, anxiety and post-traumatic stress disorder (PTSD). At the time the interview was conducted the participant lived on their own (having previously been married),and was unemployed but had previously worked in a number of different roles.

7.2.2. Materials

Demographic and Diagnostic Questionnaire

Both participants who attended the University to take part in interviews were asked to complete a paper version of a short questionnaire which collected demographic and diagnostic information. A copy of this is presented as part of the complete participant questionnaire presented in Appendix C6. The questionnaire asked participants to state the age, gender/sex and the confirmed diagnosis that they had (including both their ASC and co-occurring diagnoses). Finally, participants were asked to indicate whether there were any terms that they preferred to use when discussing their diagnosis, as previous research has indicated that this is something that is important to individuals with ASC, and can vary from person to person (Kenny, 2016). However, neither participant indicated that they had specific preferences in this respect.

Adult Social Behaviour Scale (Horwitz et al., 2016)

The ASBQ is an English-language 44-point measure aimed at capturing the severity of an individual's autistic symptoms. Details of how this scale was originally constructed by (Horwitz et al., 2016) have been included in Appendix C7. Items on measure were responded to on a 3-point scale indicating whether a particular behaviour 'does not apply', 'somewhat applies' or 'clearly applies'. Items on the scale can be sub-divided into six subscales – (1) Reduced Contact, (2) Reduced Empathy, (3) Reduced Interpersonal Insight, (4) Violations of

Social Conventions, (5) Insistence on Sameness and (6) Sensory and Motor Stereotypes – and each of these subscales was informed by between 6 and 8 statements. As such, the ASBQ allows researchers to calculate a total score, indicating the presence and severity of autistic symptoms overall, and scores for each sub-scale which indicate the presence and severity of more specific symptoms. Examples of the statements include ‘You panic when things turn out differently than you are used to.’ and ‘You want to do certain things in exactly the same way every time.’

Total scores on the measure are associated with good levels of internal consistency (> .7, Horwitz et al., 2016). Internal consistency has also been found to be good for each of the subscales with the exception of the violations of social conventions sub-scale, which has previously been found to have ‘fair’ levels of internal consistency in the self-report version of the questionnaire (Horwitz et al, 2016). Reliability checks were not conducted for the data collected as part of this study given that previous research has raised concerns about the accuracy of these analyses on samples involving less than 30 individuals (Bujang, Omar & Baharum, 2018; Yurdugül, 2008). However, this was not of concern here given that these measures were intended to be used as a general indicator of the differences in ASC symptom severity and presentation amongst participants rather than a precise diagnostic tool. A copy of the ASBQ is presented as part of the complete participants questionnaire in Appendix C6.

Data was gathered using the ASBQ scale to establish differences in the nature and severity of symptoms across participants which could provide some additional context for findings and was not intended to in anyway validate participant’s diagnoses or provide clinical judgement on the nature of their symptoms. Given that the final sample for this study included 2 individuals, instead of the intended 8-10 participants, it was more likely that participants could recognise themselves from the information presented in this study (which may have been less likely when data was presented in relation to an entire group). With this possibility in mind, specific ASBQ scores are not reported here, in order to prevent any concern amongst participants who may read this study that their ASBQ scores did not reflect their current understanding of their diagnosis. Instead, the Results section of this study includes a brief description of only the key differences in participant responses to the ASBQ.

Interview Schedule

Data for this study were collected using a semi-structured interview, given that this approach allows participants to discuss at length about issues they feel are of particular importance, while still giving the interviewer the opportunity to steer the discussion if the conversation begins to focus too heavily on discuss topics which are less relevant. While IPA can be used with different forms of data, semi-structured interviews are typically considered to best method for capturing the rich data which is most ideal for IPA (Chiang & Wineman, 2014; Strunz et al., 2017).

Prior to data collection, an interview schedule was developed to guide the conversation with participants. However, given that the aim of IPA is to allow for an open, free-flowing conversation about a topic, the researcher was not required to ask these questions in a particular order, but instead questions were asked when they best fitted with the direction in which the conversation flowed. The exception to this was that each interview began with two open questions about the impact of autistic symptoms and the impact of co-occurring symptoms, in line with recommendations that semi-structured interviews should always begin with the broadest and most open questions of interest (Pietkiewicz & Smith, 2014). Not all questions on the schedule were asked during each interview, given that in some cases participants provided detailed responses to questions which covered number of topics of interest, and the aim of minimising repetition within the interviews. The interview schedule was therefore developed as a tool which could guide and frame the conversation, rather than something which was followed word-for-word during the interview.

The final interview schedule interview schedule featured 17 main questions, some of which were accompanied by potential follow up questions, and covered topics ranging from the impact of autistic and other symptoms, to independent living, relationships and employment Questions were developed to introduce a topic into the conversation and were intended to avoid alignment with a particular theory or research question. In line with recommendations for IPA research, these questions were also intended to encourage participants to focus on how and why experiences had occurred rather than simply describing what happened encourage an individual to speak about a topic with as little prompting as possible, as a way of establishing what a participant really thinks about an issue, rather than having their comments influenced too much by the comments asked (Howlin & Magiati, 2017; Howlin et al., 2013). A copy of the final interview transcript is included as part of the Participant Information sheet and may be found in Appendix C3.

7.2.3. Procedure

Prior to the interviews taking place, a protocol was developed for any instances in which the researcher was concerned about the participant or their own wellbeing. This has been detailed in Appendix C8.

On the day of the interview, participants were asked to read a copy of the participant information sheet and sign a consent form to confirm their agreement with taking part in the study. Before the study began, participants were reminded that they were not obliged to complete the study and were free to withdraw without consequences at any time.

Participants were then asked to complete a brief demographic and diagnostic questionnaire and to complete the ASBQ (previously discussed in Section 7.2.2), and following this interviews commenced. Each interview was recorded using a digital recorded placed on the table close to participants. Prior to start of the interview, participants were reminded that they were not obliged to answer any of the questions and could decline to answer any questions asked. Participants were also encouraged to take their time when answering questions and were informed that they could request a break at any time of the interview. Interview one lasted approximately one hour and ten minutes and interview two lasted for approximately one hour. Finally, participants were provided with a debrief sheet (provided in Section C9) and offered the opportunity to ask any additional questions about the research.

7.2.4. Data Analysis

As discussed in Section 4.4, IPA is not associated with a standardised process but several guidelines have been published which make best practice recommendations for conducting this kind of analysis (e.g. Croen et al., 2015; Howlin & Magiati, 2017; Khanna et al., 2014; Lever & Geurts, 2016; Simonoff et al., 2008). These guidelines were consistently referred to in the development of the seven-step approach to data analysis that was adopted in this study and is presented in Table 7.1. The process was also designed to be meet the requirements of Smith's (2011) for 'acceptable' IPA studies (a set of criteria also used to guide the write up of analysis in this study) and a copy of this criteria has been included in Appendix C10. Throughout this process, NVivo version 12 was used to code and label themes, though eventually this information was converted to tables in a word processor to simplify the analysis of findings later in the analysis process.

Once the approach described in Table 7.1 had been applied to each transcript, the themes, sub-themes and associations identified for each participant were compared and contrasted. The final response to the research questions and conclusions to this study, were therefore based not only on responses from participants, but also the extent to what extent participant accounts of their experiences with Autism Plus overlapped and differed.

Table 7.1

Steps involved in Analysing Interview Data

Step	Description
1	The transcript was read without any form of analysis in order to generate an overall sense of the content and key issues discussed as part of the interviews.
2	The transcript was reread, and initial notes were made about the experiences discussed and the way in which they were described. This step was repeated several times, until no additional notes could be added.
3	Notes made as part of Step 2 were reviewed to establish key themes and links between these themes. This step was intended to highlight any themes raised multiple times across the interview (i.e. recurring themes). Findings from this step were written up as part of tables which captured main themes and associated sub-themes. These tables were annotated to indicate the link between themes.
4	Tables from Step 3 and the notes which informed them were reviewed to establish whether the themes (and links between these themes) identified could be provide support for the concept of Autism Plus and could be used to answer research questions for this study.
5	The transcript was read over again from a more objective perspective, in contrast to previous steps which had fully accepted the participants account of reality as

accurate. The aim of this step was to highlight inconsistencies in the discussion which could have a bearing on the final results reported.

6 With a clear understanding of the key and recurring themes, the links between these themes and any inconsistencies in the data, the interview was read again in order to identify further of evidence of previously established themes which had been overlooked as part of previous steps. Theme tables were then updated with these findings from this step.

7 Analysis was written up to reflect the findings from each of the steps above, with a focus on the themes, sub-themes and associations which could provide clear responses to the research questions for this study. Though the main focus of the write up was the participants’ accounts of their experiences, these were contrasted with any inconsistencies in the data and more objective analyses of their experiences.

7.3. Results

7.3.1. Responses to the ASBQ (Autistic Symptom Severity Measure)

As explained in Section 7.2.2, full details of participant ASBQ scores will not be reported here. However, results from the ASBQ scores did indicate that there were some differences in ASC symptom severity and presentation across the two participants. More specifically, John scored higher across each of the subscales of ASC, and notably David did not report any symptoms relating to sensory stimulation or motor stereotypes.

7.3.2. Interpretative Phenomenological Analysis

Transcripts from the two interviews were analysed separately, with independent codings and themes developed for each interview. Emerging themes and associations between these are presented in Figure 1 and Figure 2, and these were scrutinised in order to identify those most useful in addressing key research questions relating to social and independent living outcomes and the factors which influence these outcomes.

Analyses of participant transcripts identified four main themes which consistently emerged across the interviews with both participants. These included (1) the impact of autistic symptoms; (2) the impact of symptoms of anxiety and depression; (3) support experiences; and (4) positive aspects of life. This final theme could be further divided into two sub-Themes: (4A) participant strengths; and (4B) positive social and independent living outcomes. In addition to these main themes, two additional unique themes (i.e. themes only of relevance to one participant) are also reported here, given their ability to provide useful context for other findings in this section.

Main Theme 1: Impact of Autistic Symptoms

Both participants consistently referred to the difficulties caused by their autistic symptoms throughout the interviews, with the majority of these references relating to the social

Figure 7.1 *Emerging Themes from Participant One (David)*

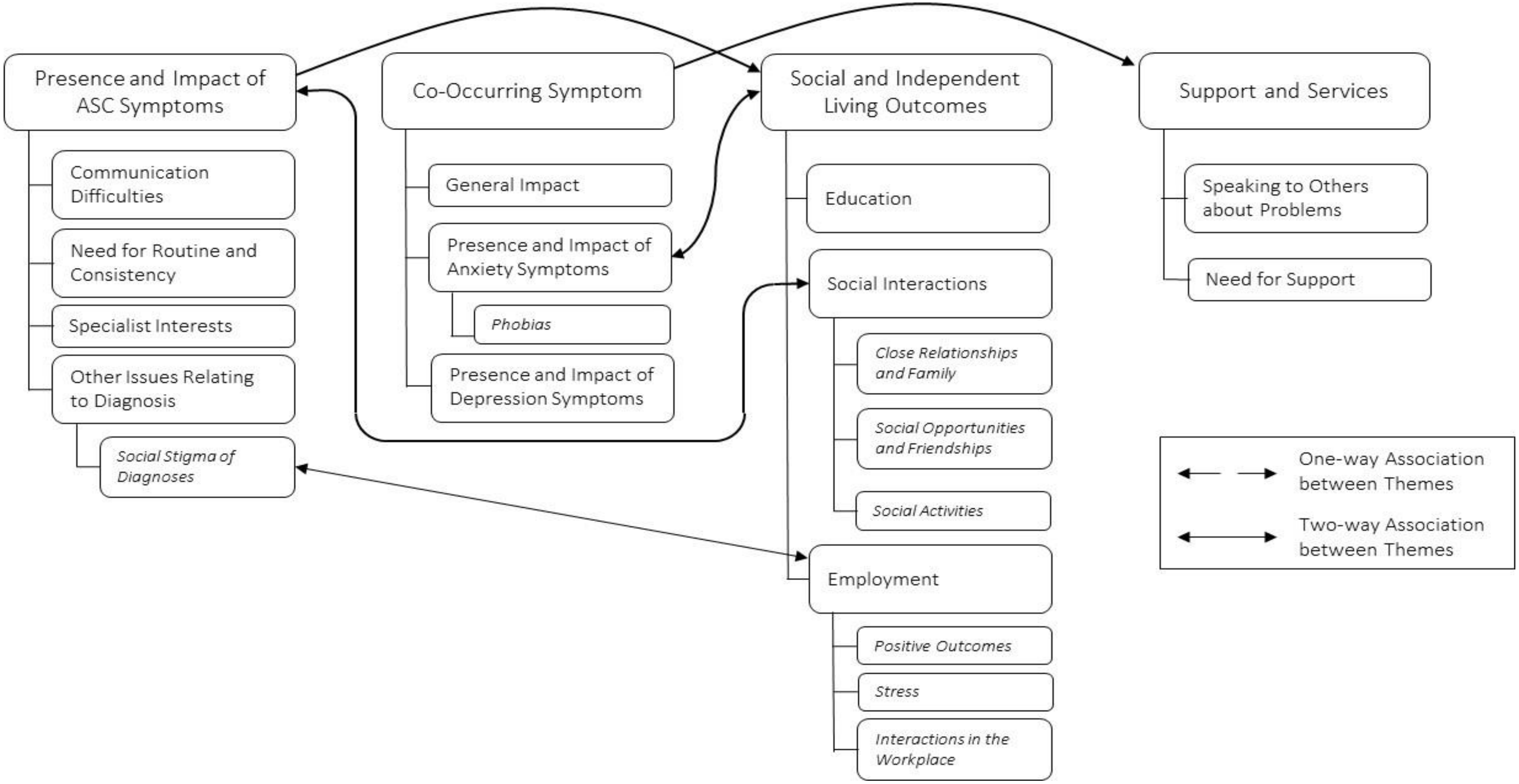
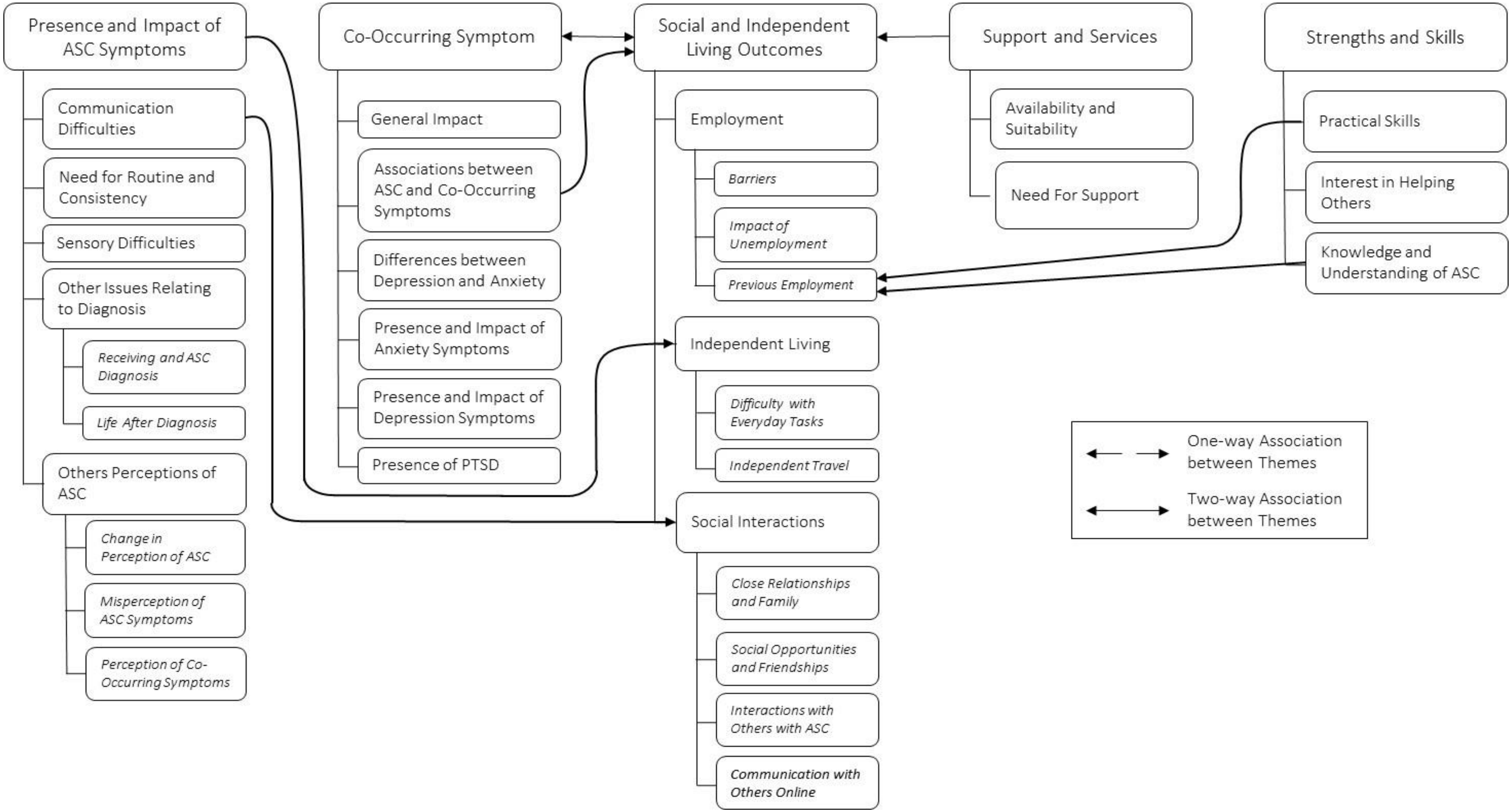


Figure 7.2 *Emerging Themes From Participant Two (John)*



challenges which these symptoms could create. David indicated that he had "*some difficulties making social contacts" (line 50)* from a young age, and his use of the term 'social contact' rather than relationship or friendship gave some early insight into the relatively detached way in which he described friendships with others. Throughout the interview, David indicated that he could sometime struggle as a result of his social difficulties, though he also gave the impression that he was not especially interested in forming close social connections with others. This appeared to have been a feature of his life from a young age:

> *David: Right back to primary school I can remember being on the fringe of classroom activities and being told off by teachers for…just for not joining in…or not playing with other kids and not sharing equipment and so on (line 209–2010)*

This detachment from those around him, and a lack of interest in social connections, was something which appeared to have persisted throughout David's life, as in discussing some of the friendships which he had formed later in life he indicated:

> *David: I'm not sure you could call them all friends…they're people I see…and I'm not particularly into…we don't have those sorts of conversations…I mean the chap I see once a month…because he's been through redundancies and stuff and has been married as well …we'll maybe talk about bigger issues in life (line 503–507)*

David's friendships appeared to centre around practical discussions and his description of these individuals as "people I see" suggested that these were not relationships that he was emotionally invested in or from which he received a great deal of enjoyment. In line with David's earlier comments, it may have been more appropriate to describe these individuals as social contacts rather than friends.

Of some interest was that at the time of the interview, David was continuing to place himself within social environments, albeit because they involved activities which interested him, or he felt he could benefit from. Within these situations David continued to find it difficult to engage with others and as a result he found it uncomfortable to be part of a social group. Commenting on an outdoor activity group which he had joined within the previous year David indicated that he was *"aware of not really getting on with anybody" (line 524–529).* However, this experience appeared to have left David feeling awkward rather than disappointed, because he was concerned about whether this would make it less appropriate to attend the group given that he was not socially engaging with others. A similar situation had also occurred in another social activity which David had attended in the recent past, and on both of these activities commented:

> *David: ...I want both of these to keep going. I'm not sure whether I'm going to be able to face up to going back to it in the autumn (line 547 – 549).*

Despite this, David was keen to remain part of his outdoor activity group, as he felt it was safer to take part in this kind of activity as part of a group rather than alone, and so indicated that he might *"dip in and out of different groups" (line 557)* which centered around similar activities as a means of avoiding the awkwardness he felt. These comments provided further evidence to suggest that though David did not feel he had close connections with others, this was not something that upset him or left him feeling greatly disappointed. However, there were also some comments throughout the interview which raised questions as to whether David's lack of interest in friendships could have been a result of him recognising that he rarely connected with others and that this was something he had come to accept as normal.

> *David: I don't take part in sports, I don't eh have any sort of social interests like that…so having conversations with other men is a bit difficult… there's a whole sort of social dimension that I'm not good at (line 231–234)*

> *David (on the outdoor activity group): it's an activity I'd like to take part in but socially I feel I'm not doing well with…and that's something I guess I'm used to (line 567–569)*

In line with comments presented earlier in this section, these extracts indicated that David's social connections often revolved around practical matters. It is therefore possible that the lack of desire David showed for friendships was something that he had acquired as historically he had struggled to connect with others.

Though David had generally struggled to form friendships throughout his life, he described having more success with romantic relationships, and having a number of girlfriends when he was younger. In his thirties, he had married his wife with whom he had a son, however there was further evidence that David would keep some distance socially, even within this family dynamic, particularly when having to deal with more complex situations. On describing a difficult situation his son was experiencing, David commented:

> *David: I think because I'm on the spectrum I'm not good at…either offering advice, or trying to find out about how he's really feeling about things…I tend to use his mother as an intermediary on that (line 63–65)*

David's tendency to avoid stressful or difficult social interactions was a theme which recurred across the interview, for example he indicated that there were parallels between his family life and work-life in this respect:

> *David:…similarly when I was working I relied on a manager or another team manger to sort out some of the politics, or what I saw as the politics of the situation (line 66–67)*

It is possible that in both of the cases above, these situations were avoided as David had an awareness that he could sometimes be misinterpreted and more generally could have difficulties communicating with others. Significantly, this awareness appeared to have also led David to avoid promotions within the workplace for fear of being placed in a situation where communication was of central importance.

> *David: I…seemed to discover that I could do the thing of upsetting people but without really realising it (line 31–32)*

> *David: Well, I'm not good at meeting people, I'm not good at talking to people, I'm not good at persuading people or trying to manage people, which is another thing at work, y'know various times I had the opportunity to move into management or at least promotions and I never felt comfortable (line 184–187)*

John had also experienced difficulties interacting with others and as with David, these difficulties had often been highlighted within the workplace. John clearly differed from those he worked with in terms of his views on when social interactions were appropriate and to what extent social interactions were necessary in the workplace and he indicated that this could *"continuously"* (line 152) cause difficulties. In particular, he indicated that he could become particularly frustrated with what he considered unnecessary social interactions:

> *John: I can't deal with the social stuff that goes on at work… that thing where you work into the office where you have to say hello to that person, hello to that person, hello to this person, y'know…drove me mad…uhm…and then people would come and sit at my desk and they would bitch about other people in the office and then and this other person would come in and they would go 'hi, how you doing, how you doing?' and it used to just drive me absolutely insane (line 161–171)*

John acknowledged that this frustration was in part a reflection of the difficulties he experienced communicating and interacting with others. However, he also felt it was unfair that he was judged on this social aspect of work, when he was capable of completing any tasks which were given to him.

> *John: I just didn't know how to communicate with anybody, so then if I didn't communicate with people, then I was called aloof (line 171 – 173)*

> *John: …when I’m in the work place, if you just let me do my work, I’ll do my work, don’t ask me to socialise, tell me the time to come in and the time to leave, and the work to do and it’ll get done.*
>
> *Interviewer: I think that’s fair enough.*
>
> *John: Yeah. But you can’t do that because people have this huge need to be social and you feel if you’re not social back to them, you’re the one that’s broken (line 245 – 250)*

John’s comments on this matter also indicated that he felt there was very little support or acceptance of his needs and preferences in the workplace and that this in itself was a source of frustration. Importantly, while many people might share John’s beliefs about unnecessary workplace interactions, it may be the case that his autistic symptoms (in particular a need for consistency and routine) may have been the reason he particularly struggled with the incongruence between his own beliefs and the way that those around him acted. Significantly, these social difficulties had created difficulties in the workplace as John indicated that when he struggled with others in this way his reactions would often be perceived as aggressive and on one job this led to him being referred to the human resources department as a result of his behaviour. Notably, John also indicated this discomfort in social situations could also affect other aspects of life, for example he found travelling on buses particularly uncomfortable for this reason and so chose to cycle wherever he could instead of using public transport (*line 487–489).*

John had previously been married. However, he had separated from his wife and in addition to this, he indicated that though he had previously considered himself to have a number of friendships, there was nobody who he considered to be a friend at the time of the interview. Furthermore, he indicated he had little optimism about this situation changing in the future.

> *John: It’s the first time in my life I’ve actually been alone and it’s really impacting me and that’s making me feel really depressed because I know I’m autistic, so I know the chances of me going out there at this age and making a new circle of friends…is…is minimal. Whereas when I was younger I had to do it, cause I had to*

> *go to school, I had to go to university, I had to go to college or I had to go to work, so I was pushed into social things where…uh…I might meet a hundred people and actually one or two of those people might actually like me and decide they want to be my friend but now I'm not meeting anybody at all (line 43–50)*

While it was clear that John saw his autistic symptoms as something which could make it more difficult for him to form friendships, the extracts above indicate that John's pessimism about the future of his social life and a lack of motivation to make friends, could have also contributed to the status of John's social life at the time of the interview. It is possible this was an instance in which John's autistic and co-occurring conditions interacted, as this pessimism and lack of motivation could have been a product of the co-occurring symptoms of depression and anxiety which John experienced. Further evidence for this came from the fact that John indicated that what he was particularly missing at the time of the interview was somebody who could provide him with a sense of social support. John's comments here also highlighted that his opportunities to form friendships often came from the workplace and other places in which he was naturally surrounded by others. It's therefore possible that the lack of social life John described could in part be attributed to the fact that he was unemployed at the time of the interview.

As noted above, John had previously enjoyed a fuller social life, and talked with particularly great warmth about his previous experiences interacting with others with Asperger's:

> *John: I remember going to my very first Christmas Asperger's party… and everybody that was in there had Asperger's or mild autism or whatever you want to call those all. And I uh…went up to the bar, got a pint, sat at a table and just ignored everybody [laughs] it was great – it was absolutely fantastic. There was no social expectation at all! And it was fabulous, it was great. And then after that we went to a pub together for a meal, went to a snooker hall and everybody could just be Aspie…it was wonderful, it was great (line 565–571)*

Most of all this kind of social opportunity offered John the opportunity to be himself and to be surrounded by others who had similar social values and principles to his own. Notably in the two extracts featured above, John clearly acknowledged his awareness that he differed socially from others, though importantly his comments here indicate that he was uninterested in changing his behaviour to fit with what was more socially acceptable, but instead strongly desired to be accepted for who he was. In line with this, John expressed a strong desire for greater opportunities to interact with others on the spectrum in the future:

> *John: I would love just to have a load of Aspie's together [laughs] hanging out together…it'd be wonderful (line 587–588).*

Therefore, in contrast to David, John showed a strong desire to be closer to others, however from the responses he provided, there was some evidence that friends within the Asperger's community may be of particular benefit to him.

In addition to the social difficulties caused by his autistic symptoms and behaviours, John also indicated that he could experience difficulties with the more practical aspects of life. For example, he could struggle with financial issues such as managing money and paying bills. He also discussed the profound impact which sensory symptoms which could have on his life, indicating that his hearing, smell and vision could all become hypersensitive at times. For example, John indicated that these difficulties had made him uncomfortable about attending an Asperger's support group within a coffee shop because of the noise *(line 585–590).* He also described how these sensory issues had also impacted the more practical aspects of life as shown in the extract below:

> *John: I mean yesterday I had to go shopping … and it was horrendous…it was just too much…well, I managed to get myself a salad together to try and eat healthy but it was just too many people…people bumping into you and the noise, it-it was just…so I just went down to the freezer and grabbed like ten uhm microwave meals…(line 455–459)*

In contrast to John, David indicated that sensory issues were not something which affected him, and talked about a number of responsibilities he had, such as managing the maintenance of a second property he owned, which indicated that he struggled less than John with these more practical aspects of life. While both participants clearly experienced difficulties as a result of their autistic symptoms, there was evidence from the interview that John's symptoms had a much wider ranging impact on his life. This was best captured by a comment from John early in the interview, where he indicated that his autistic symptoms affected him "*from the moment I wake up till I don't go to sleep" (Line 16 – 17).*

Main Theme 2: Impact of Anxiety and Depression

Both participants described experiencing depression and anxiety throughout their lives. John had experienced the symptoms of a depression for the majority of his life, though indicated that in the months prior to the he was in a period of life where these symptoms were affecting him more than usual and in which he was *"really depressed" (line 31)*. John also discussed feeling suicidal at different points in life and indicated that sometimes these suicidal thoughts returned. Importantly, John explained that his current mental health symptoms persisted despite a number of exciting creative opportunities in his life at the time of the interview:

> *John: ... I don't know if I'm gonna wake up tomorrow…I was going to kill myself last year…and uhm…y'know, it could happen again, and that's what I'm struggling to get through at the moment...just to actually uhm keep going (line 274 –279).*

There was also clear evidence throughout the discussion with John that his co-occurring symptoms had a considerable influence on many different aspects of life. As discussed in relation to Theme 1, John felt as though he didn't feel as though he had any close friends at the time of the interview was conducted. Though in addition to difficulties meeting others he felt comfortable around, John also discussed concerns that his experiences with depression and anxiety could be too much for potential friends.

> *Interviewer: Do you find…uh…you struggle to find opportunities to make friends?*

> *John: I don't want to….I want to ….I don't want to…I want to…I don't want to…Umm I'd love to have friends, I'd love to have somebody to talk to but how can I meet a new friend just now and…and…have all this to burden with…y'know…how can…I'd love to contact my friends but I want to talk to someone about all these problems I have and so I don't want to make friends because I've got all these problems…that feels really unfair to burden other people cause they've got problems, so I don't talk to anybody about it (line 530–540).*

In addition to this, there were times when John felt his depression and anxiety prevented him from going out and interacting with others, which is something he had done more frequently in the past, even with the difficulties caused by his core autistic symptoms and traits.

> *John: …socially I know my whole life I've had social issues but I've gone out, I've tried to go to parties…uhm…but now because [of] the anxiety and depression…uhm it's stopping me doing that…it's actually really stopping me leading a normal life…(line 56–58)*

> *John: I'm supposed to be going to an event tonight…not gonna go to it…*
>
> *Interviewer: And is that anxiety you're feeling…*
>
> *John: Yeah…yeah. I've always been autistic, I've always gone to events but this anxiety is different – it's stopping me from…it's stopping me going to the event (line 687 – 690)*

There was therefore some acknowledgement from John that while his autistic symptoms had always created some difficulties, depression and particularly anxiety were creating additional challenges in his life at the time of the interview and were potentially the main barrier to him engaging in a more sociable lifestyle.

David was diagnosed with depression and anxiety later in his life though there was evidence throughout the interview to suggest that these symptoms had affected him for a large portion of his life.

> *David: …even when I think back to when I was at school…there are odd episodes that I don't think were particularly traumatic but they still stick in my mind that I was on the edge of this…going to school was really difficult (line 201–204)*

> *David: Before that…I mean even at university when I dropped out…I suspect I probably had anxiety, but I wasn't given a diagnosis at that point (line 153–154)*

David often referred to periods of stress within his life, though on closer inspection it is possible that many of these instances could better be described as periods of anxiety rather than stress. This was something that David acknowledged that he had realised when discussing his experiences with others at a support group

> *David: …there's an over fourties group…I think I was about the oldest one in it… anxiety seems to be there in all of them and I'm coming to recognise it in myself, whereas before I thought it was just stress or whatever (line 575-577).*

There appeared to be a number of consequences to the stress that David described. For example, the reason David eventually received his diagnoses for depression and anxiety was because he initially visited his doctor with stomach complaints

> *David: I think I was describing stomach pains and I said…and I think they'd done some sort of test to rule out gallstones…and he said 'are you perhaps a bit depressed?' and I said 'yes of course', cause he could see from my history I'd had a couple of instances of work-place stress and so on back in the 2000s and he gave us this HADS-2 questionnaire to fill out and said that I was depressed and wonderfully anxious as well (line 142 – l46).*

The extracts above provide further evidence to suggest that David had potentially mislabelled his mental health problems as stress in the past and, as discussed later in this section, this may in part have been tied to the social stigma of receiving an official diagnosis (see Unique Theme 2). There was also evidence throughout the interview to suggest that the long-term anxiety and depression which David had experienced had also influenced his confidence and self-esteem. Throughout the interview David described himself in quite negative terms and minimised his achievements.

> *David: I was a but…y'know of a failure in the family if you like…I sort of bumped about and so on…I dropped out of Uni….I got to uni…I went to university and I dropped out and I went back and things like this (line 22–23)*
>
> *David: I went back and got a not very good honours degree which was not very good as well (line 167–168)*

Furthermore, and as illustrated below, when David did comment on more positive outcomes in his life relating to his relationships and his career, he frequently used the term '*managed to*' indicating that there was some kind of chance involved in these outcomes, rather than them being something, he achieved through merit.

> *...so I managed to keep working (line 28)*
>
> *...I managed to get back into full time employment because employment practices changed a bit again (line 40)*
>
> *…in other personal relationships I managed to get married (line 48–49)*

Main Theme 3: Support Experiences

Both participants commented on their experiences with support and services, in particular the lack of support services which they were able to access. John discussed a number of barriers to accessing support and highlighted that he believed one of these to be that there were few services which could cater to his presentation and severity of autistic symptoms. On his recent experiences searching for support John commented:

> *John: I don't fit…I mean I contacted the [support service redacted] and I just don't fit into their demographic…I'm either too old…or too capable they think….y'know, they want people with support workers, I don't fit into that demographic (line 605–607)*

As part of the larger discussion about support, John was asked whether he felt his co-occurring symptoms were recognised enough, to which he responded, *"I don't see them recognised at all" (line 851)*. Furthermore, John also commented on the type of support he felt would be greatly beneficial to those on the spectrum and this related to the stress and anxiety which could come with the conditions:

> *John: For ourselves, that would make us be able to be more cognitive in our behaviours, because all this stress and anxiety cuts down our cognitive abilities. Y'know, like not having enough sleep, how can you…how can you learn…if you've got all this stress and anxiety…how can you sit at school and learn? So if you can do something to make us aware of whether stress is going up, so we can do something to reduce it (line 781–785)*

David had also received limited support for his co-occurring symptoms, though in this case it possible that that was in part because he received his diagnoses later in life. David briefly mentioned receiving individual and group therapy for a short period of time at University after he had experienced a period of stress and indicated that he had felt the benefit of discussing his problems within these sessions. However, he talked far more enthusiastically about visiting a life coach:

> *David: it was always with a practical focus…y'know, she wasn't trying to develop any great y'know emotional understanding or anything like that…but that she was able to give a sort of outsiders view or some of the things I was worrying about…and I felt a bit of that with some of the…individual therapy I was talking about at university…that was an older woman therapist, or psychologist or psychiatrist, about the difficulties of my course and one thing or another and there was some relief in just being able to talk about these things and put labels on them… (line 423–429).*

In some ways, David's experience with the life coach could be considered comparable to the type of therapy that the counselling or therapy which might be offered to some individuals on the spectrum, in that it allowed him to discuss difficult aspects of life and also came with some degree of structure.

> *David: and if I would find myself getting frustrated or nervous, I found talking this through with this woman helped (line 404–405)*

> *David: I maybe seen her like once a month…I used to keep like a diary…part of the technique would be I would keep a diary of the sort of issues I was talking to her about (line 414–415)*

However, a question about the type of support which may be useful to those on the spectrum prompted David to discuss areas in which he felt he could have benefited from some additional support in life.

> *David: …I've seen discussions talking about transitions and I think I've always had difficulty with those as I've already mentioned…and another thing…I get the impression people are maybe focusing on transitions from school and perhaps from school to work and not thinking about transitions later in life that people will continue to have with marriage if they get married, redundancy…because they're likely to become redundant at some point these days, retirement and possible ill health, ill health in partners and relatives and all the rest of it but I think those things keep happening and I'm not sure how people can deal with it. I mean everyone has those life events…but I think people on the spectrum are gonna come at them from a different background and maybe with a different way of going about it and dealing with it (line 581–590).*

This response raised questions about whether David desired greater support earlier in life felt uncomfortable reaching out to support services as it would have meant acknowledging his ASC and co-occurring symptoms, which appeared to be something he was unwilling to do. Importantly, these comments also highlight that in addition to any struggles that individuals on the spectrum experience as a result of their core or co-occurring symptoms, those on the spectrum can also experience the same difficult life events that any individual can experience, and may require greater support that others with these life events.

Main Theme 4: Positive Outcomes and Qualities

Sub-Theme 4A: Strengths and Abilities

Though both participants experienced difficulties with some aspects of life, they also both discussed having skills and abilities which had served them well. John discussed having a passion for helping others and had previously been involved in projects aimed at improving the lives of others with ASC. At one point, John became heavily involved in a project aimed at supporting autistic children. John's account of working on this project aligned with his earlier comments about work, that it was the social aspects of employment that he struggled with in the workplace, rather than workload or task difficulty.

This passion was something that John continued to show an interest in, as he indicated that he was *"always searching for places" (line 90)* to do support work. John's ability to help others was also boosted by a passion for learning more about ASC. John had tried to develop his understanding of the condition from a young age and also enrolled in a course focused specifically on ASC. Furthermore, John indicated that he wanted to continue using this knowledge and understanding.

> *John: I just studied more and more and more and more and more about autism, so there's very little about autism I don't know now (line 399–400)*

> *John: I've got a huge knowledge about autism…um which I don't want to waste…which I want to do something with (line 407–408)*

For David, a clear strength was perseverance. David had avoided receiving an ASC diagnosis for a fear that meant it might have an impact on his career, meaning that throughout the majority of his life he was not given any special dispensation, advice or support in relation to his symptoms. Despite this, David worked full-time for most of his life until he retired, though indicated that large parts of his working career had been difficult and stressful.

> *David: …the second job after that was in an organisation that really placed a lot of stress on personal relationships, people had been in the business for a long time… I managed to fall out with a few people and that was unpleasant…I should…I was tempted to resign but I stayed on to keep my pension topped up and just stuck it out until I left…the last ten years of my working life were really uncomfortable (line 42–47)*

> *David: ...So I think I'm probably not particularly satisfied or fulfilled or anything y'know, again you hear these sort of things from people in the 2000s and I've never thought I'd be able to do that so I've just gone along with what I think I can do (line 304–307)*

Overall, there was a clear sense from David that he had always pushed himself to achieve the best he could despite his symptoms, even if this wasn't always the best thing for his psychological well-being.

Sub-Theme 4B: Positive Social and Independent Living Outcomes

While a lot of what is written here relates to the difficulties that both participants experienced throughout their lives, there were also comments throughout the interviews which indicated that they had also experienced some more positive outcomes. Though recently separated, John had previously been in a long-term relationship and had two sons from this relationship. He was also well travelled, and this was something that he appeared to take particular pride in.

> *John: I'll do a lot of travelling round...not that many people can say that at this age....so pft...at least I can say I done that for ten years (line 554–555)*

David had been happily married for a large part of his life, and despite the workplace difficulties described above, David indicated that he enjoyed the field in which he had worked for most of his career and explained that by staying in this area for so long he felt he was 'indulging his interests' *(line 302)*. David also discussed other work from earlier in his life working in public transport which he had described as comfortable, and from the way in which he described this work, it's possible he would have enjoyed remaining in this line of employment longer, particularly in that it appeared to provide a level of social interaction which suited David's preferences.

> *David: ….that was comfortable, as it was sort of shift working and you were pretty much working by yourself, with, probably with different drivers most of the time…and you could have some contact with your passengers if you wanted to but you didn't have to, so it was…I made some friends with the passengers and so on but not eh….yeah it wasn't a big social environment (line 171–178*)

David's difficulties in the workplace have been clearly outlined earlier in this section, though his experiences above indicate that he was able to find suitable work and enjoyed aspects of his work-life.

Unique Themes

Unique Theme 1: Differentiating the Symptoms of ASC from Depression and Anxiety

Throughout the interview, John provided a number of comments which related to the different ways in which his ASC and anxiety/depression symptoms impacted his life, something which David mentioned far less frequently. John felt he could clearly differentiate between the type of anxiety which accompanied his ASC symptoms, and other types of anxiety which occurred independently of his ASC symptoms (at times John referred to this as his 'depression anxiety').

> *John: I'm totally used to it. So I can differentiate between the depression anxiety because I haven't had that the whole time. Y'know? So at the moment I'm actually feeling quite happy but I know my stress and anxiety is quite high…I'm autistic…of course it is (line 653–656).*

Significantly, John indicated that his autistic symptoms were something that he felt he could clearly understand, and therefore while they could still interfere with his life at times, he felt he could cope with them. By comparison, John indicated that the symptoms of anxiety and depression were something he understood far less clearly, and which he was much less capable of coping with.

> *John: …my anxiety I can't explain…it just happens, whereas if you want to me explain autism I can…quite in depth (line 28–29).*

There was evidence to suggest that each type of anxiety affected different aspects of life, as while the ASC-related anxiety was linked to the need for consistency and routine and situations where he felt his senses were overloaded, other types of anxiety appeared to be connected to social situations. John also indicated that when his mental health was poorer, this could 'exacerbate' his ASC symptoms, and he was keen to stress that the symptoms could interlink in terms of the impact that they had on his life.

> *John: when things are going well for me…I'm like a regimented machine…everything just…everything's done perfectly. You'll come and go 'oh, there's nothing you need to do' but at the moment…uhm… because my anxiety and my depression and basically my mental health…it just exacerbates some of my autistic conditions and uhm it's just…really bad (line 448–449)* .

> *John: there's lots of other comorbid things that are going on with people with* autism*…but when you say 'comorbid'*[18]*, I don't like that term because that means it's autism plus*[19]*…but they're all separate entities (line 881–883)*

These comments from John indicate not only that he had a clear understanding of his symptoms and the way in which they co-existed, but also his use of the term 'comorbid' (a term more commonly used within academia or amongst professionals) acts a reminder here that John is someone who had spent a great time familiarising himself with the research relating to ASC. These comments from John therefore

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[18] This was not a term used by the Interviewer, but instead the participant was speaking generally here

[19] This was not a reference to the Fernell and Gillberg (2014) conceptualisation of Autism Plus discussed throughout this thesis, instead the participant confirmed that this was simply his way of describing the interaction between his autistic and co-occurring symptoms.

represent his awareness that co-occurring conditions are often discussed in a way which does not reflect his own experiences.

Unique Theme 2: Social Stigma of ASC Diagnosis

Both participants commented to some extent on how their diagnosis was perceived by others, however from the comments made by David it appeared that he had been more cautious of being labelled as different throughout his life. Furthermore, there was some evidence to suggest that he had in the past adjusted his some of his ASC-related behaviours due to concerns that they would not be good for him and how he was perceived.

> *David: I come out with the odd words and things that don't make sense, and I'll occasionally talk nonsense to myself and I'm quite interested in cars… and when I was young…I come from [CITY IN UK REDACTED] originally you see, a big railway town, so I was really into train-spotting and things…and somewhere along the line I thought that's not a good idea to get too involved in that…so it's things like that, I have what I've described as special interests and sometimes I've supressed them…I stopped stamp-collecting when I was a teenager, it wasn't so much a social pressure thing, so much as it can be quite absorbing and expensive so I stopped (line 115 – 122)*

David also indicated that the fact that he had received his diagnoses later in life was also because this was something he had avoided, despite several professionals previously suggesting that he may have Asperger's:

> *David:… I didn't actively pursue a diagnosis until I'd retired, partly because of the social stigma, partly because of the continued working security (line 112–113)*

In addition to a general aversion to medication, David also indicated that social stigma was a further reason he chose not to take medication as a means of alleviating some of his mental health symptoms.

> *David: I felt it would dull your intellectual edge if you like…and you know when I got into these office politics, it made me think it would maybe make me look less employable if I was taking a lot of medication and just sitting in a trance sort of thing (line 342–343)*

Throughout the interview, David consistently turned the conversation to employment, and while it is clear that while experienced difficulties in the workplace, employment was something he considered to be of great importance. It may therefore be the case that David's reluctance to seek help and be assessed for his symptoms was out of a perception that this could be a threat to the employment which he placed such importance on.

7.4. Discussion

It has been proposed that amongst other uses the concept of Autism Plus may prove useful in differentiating individuals on the spectrum in terms of their social and independent living outcomes and support needs (Gillberg & Fernell, 2014). To the best of the author's knowledge this study is the first to employ IPA to explore the validity of this claim and, as discussed in the Introduction to this chapter, is also one of a small number of qualitative studies which have spoken to adults on the spectrum about the presence and impact of co-occurring symptoms. Findings from this study can therefore be considered to contribute to the evidence base for Autism Plus and also be seen as a response to calls for the voices of those with ASC to be better represented within the research literature (Bölte, 2014; Fletcher-Watson et al., 2019; Goodman, 2006; MacLeod, 2019)

As discussed in Chapter 3, previous research has consistently shown that there is considerable variance in the outcomes, experiences and support needs on the spectrum, and research has yet to establish factors which can consistently and accurately account for this variance (Barneveld et al., 2014; Billstedt et al., 2005; Chiang & Wineman, 2014; Renty & Roeyers, 2006; Roberts, 2010; Strunz et al., 2017; van Heijst & Geurts, 2014). The four major themes which emerged from the IPA in this study can be considered to provide some insight into why factors such as autistic symptom severity have been found to only account portion of the variance in outcomes and support needs in this population, as they suggest that the presence of co-occurring conditions can create additional, distinct challenges which can make it more difficult for those on the spectrum to interact with others, form friendships, succeed in the workplace and carry out everyday tasks.

7.4.1. Impact of ASC Symptoms

Both participants provided evidence to suggest that the social impairments associated with ASC had a relatively broad impact on their lives, with evidence to suggest that these difficulties were most pronounced within their work-lives. John cited his difficulties aligning with social norms in the workplace as a source of great stress and explained that the way in which he communicated with others had often been misperceived and resulted in him being spoken to about his behaviour. Similarly, David described an awareness that he could unintentionally cause upset, commented that he could experience difficulties when interacting with others and explained that there were instances in which he had turned down opportunities to progress in his career for fear that it would lead to more frequent and stressful interactions with others.

Despite both participants experiencing difficulties across similar aspects of life, there was also evidence from across the interview to suggest that in comparison to David, John’s ASC symptoms were more severe and more frequently impacted his life, and this was a pattern reflected in the participant's ASBQ scores. John indicated that beyond the social impact of the condition, his life could also be disrupted by the sensory issues which accompanied his ASC diagnosis, though interestingly, his scores for component of the ASBQ were not significantly higher than the average score reported by Horowitz et al. in the paper which first described this measure. He reported that these sensory symptoms were both stressful and restrictive, in that they could prevent him from carrying out important everyday tasks (e.g. visiting the supermarket) or attending social events because of his strong discomfort around bright lights and loud noises. By contrast, David indicated that he did not experience any sensory issues and that is was primarily the social and communication issues associated with ASC which could make life difficult.

There was also evidence to suggest that the participants differed in terms of their desire to interact with others. At the time of the interview, John was living a fairly isolated life, though described previously being more socially engaged and benefiting greatly from previous interactions with others on the spectrum. In line with this, John also indicated that he desired to develop friendships and closer relationships again in the future and there was some evidence to suggest that John may particularly benefit from greater opportunity to interact with others on the autistic spectrum. By contrast, David's comments on friendships and interactions with others suggested that he was not greatly interested in forming strong connections with others, beyond those he had with his wife and son. While John's feelings on this matter aligned with findings from a large proportion of the studies which have previously reported the perspectives of those on the spectrum (Henninger & Taylor, 2013; Mazurek, 2013; Müller et al., 2008; Renty & Roeyers, 2006; Sosnowy et al., 2019), David's comments reflect findings from a small number of studies which have shown that a portion of those on the spetrum have low levels of interest in social interaction (Chevallier et al., 2012; Chevallier et al., 2015; Kohls et al., 2012). These differences in the desire for social interaction can be considered to have broader implications for research focusing on social and independent living outcomes within this population, particularly as historically a large number of studies in this area have based analyses of adult outcomes partly upon the number quality of social relationships that an individual is engaged in (see Section 3.5 for a review of this literature). These findings therefore raise questions about the appropriateness of using social relationships as an indicator of quality of life in this population, given that the perceived importance of this outcome may vary across the spectrum.

In contrast to the majority of individuals on the spectrum, John and David had been involved in long-term social relationships and in regular employment throughout their lives. Both participants showed an awareness and understanding of the aspects of life which their ASC symptoms could affect most, and there was evidence to suggest that John and David had used this awareness to minimise the impact of these symptoms. For example, both participants indicated that they avoided situations which would be most likely cause them difficulty of stress (John chose to cycle rather than use public transport and David described avoiding complex social interactions in his work and family life). By comparison, the participants appeared to have struggled more to understand and overcome their co-occurring symptoms.

7.4.2. Impact of the Symptoms of Depression and Anxiety

Both participants indicated that they had experienced with depression and anxiety for a large part of their life, with John’s symptoms beginning in childhood and David’s first emerging while attending university in his early twenties. However, there was evidence to suggest that John’s co-occurring symptoms were more severe and impactful than David’s. John described his anxiety and depression as hugely restrictive, indicating that at the time of the interview he was going through a particularly bad period of depression and anxiety, which had coincided with him being unemployed and feeling socially isolated. John recognised that gaining employment and meeting others would be good for him but explained that because of his co-occurring symptoms he lacked the motivation to do so. Furthermore, he indicated that he had some reluctance to form friendships at a time when life was difficult, as he felt it was unfair to burden others with the difficulties he was experiencing. John also explained that while he understood his ASC symptoms and had learned to adjust life to account for them, he struggled to comprehend and respond to his symptoms of depression and anxiety. In line with this, John indicated that he struggled more with his co-occurring symptoms than the symptoms associated with ASC. This was also evidenced by the fact that in the past John had been involved in a long-term relationship, had friends and worked in hugely demanding roles, despite the presence of his autistic symptoms. This was in contrast to his experiences at the time of the interview, where he indicated that he lacked the motivation to socially engage with others or find a new job after a period of unemployment.

While at the time of the interview David's depression and anxiety affected his life less profoundly, there was evidence that they been a source of discomfort and disruption in the past. David explained that his co-occurring symptoms were associated with physical symptoms, had led him to drop out of university when younger, and from his responses throughout the interview there was also evidence to suggest over the course of his life appeared to have impacted his confidence and self-esteem. It seemed possible that earlier in life, this anxiety had also made David reluctant to reach out for support for the symptoms he experienced, given that he appeared greatly concerned about the social stigma that would be associated with such support. In this sense, David's co-occurring symptoms could be seen to make various aspects of life more difficult, but also discouraged him from accessing support which would have improved his quality of life overall. Previous research in the general population has indicated that many individuals with depression and anxiety will avoid accessing support because of the social stigma (Boerema et al., 2016), and these findings raise questions about whether those with ASC and co-occurring depression or anxiety may also be less likely to reach out for support more generally.

7.4.3. Support Experiences

Previous research involving the perspectives of adults with ASC indicates that individuals in this population struggle to find support which is appropriate to their ability and needs and similar findings have been reported as part of this study. Notably, some of John's comments indicated that he desired greater opportunity to interact with others on the spectrum, reflecting Muller et al's (2008) finding that for individuals with ASC, opportunities to socialise and be themselves were often as important as receiving support which specifically targeted the symptoms and behaviours associated with ASC. He also indicated that his co-occurring symptoms were rarely acknowledged, which was of some concern given that these were the symptoms he indicated had caused him the greatest difficulties in life. David had some limited positive experiences with support, through individual and group therapy as well as visits to a life coach, and described feeling a sense of relief in discussing the difficulties he experienced with the more practical aspects of life. Revising this topic later in the interview, David commented that there was a need for support for individuals on the spectrum for when they encountered experiences or events which could be difficult for anyone to cope with, but which could be further complicated by the presence of ASC symptoms (e.g. redundancies or ill health amongst relatives). Again, these comments raise questions about the kind of support which may be most valued by those on the autism spectrum, particularly those of average and above average intellectual ability.

7.4.4. Broader Implications for the concept of Autism Plus

The findings from this study indicate that co-occurring conditions can create unique challenges for those on the spectrum, which at times can have a greater impact on life than their core ASC symptoms. This suggests that there is a need to better account for the presence of co-occurring conditions in research focusing on adult outcomes, quality of life and service use and support within this population. There is also some evidence here to suggest that such research should aim to better account for the severity of co-occurring symptoms, given that there John’s symptoms of anxiety and depression appeared to have a much more restrictive impact than David’s. However, while these findings do suggest that the participant’s co-occurring symptoms complicated their lives, they cannot be considered to completely align with Gillberg and Fernell’s original 2014 conceptualisation Autism Plus. As part of this, Gillberg and Fernell proposed that those with Autism Plus would be more likely to experience poorer outcomes and require greater support needs. While participants were not directly asked to provide their views on Autism Plus as a construct, their accounts of their lives and experiences suggested that while they may have benefited from some additional support in life, they had also achieved positive outcomes in their social lives and career. This suggests that the relationship between co-occurring symptoms, outcomes and needs may be more complex than originally proposed. However, this conclusion must be considered within the context that this study only focused on two co-occurring conditions (depression and anxiety), an issue which has been discussed in further detail below.

7.4.5. Limitations

There are a number of limitations to this research which must be taken into consideration in examining the findings and their broader implications on research within this field. Firstly, it should be acknowledged that findings here relate only to individuals without intellectual disability, and as such may be less relevant to individuals on other points of the spectrum. Secondly, the age of participants (47 and 70 years) must be taken into consideration in interpreting the findings reported here, particularly those which indicated that participants had to some extent learned to overcome their ASC symptoms – as discussed in Section 2.4.1, some research has indicated that the severity and impact of ASC declines with age. As such, it is possible that the experiences of ASC described here may not be considered reflective of younger individuals on the spectrum. It should also be recognised that the perception of ASC has also changed within the lifetime of both individuals, with awareness of the condition, and efforts to support those on the spectrum greater than ever (Ahmed et al., 2018; DeVilbiss & Lee, 2014; Kenny et al., 2016; Tipton & Blacher, 2014). Therefore, it is important to acknowledge that some of the difficulties (e.g. fear of social stigma and difficulties in the workplace) and stresses reported here, may be apply less to those of a younger generation of individuals on the spectrum. However, the opportunity to hear the perspectives of older individuals with ASC should also be valued, given that this is a part of the ASC population which is rarely acknowledged within the ASC literature (Bishop-Fitzpatrick & Rubenstein, 2019; Perkins & Berkman, 2012; Roestorf et al., 2019; Wise et al., 2020), and that this provided some insight into how outcomes and experiences can change across the lives of those with ASC. This is particularly relevant given that participants both provided some evidence to suggest that the impact of their co-occurring symptoms had varied across their lifetime, in line with some previous research in this area (Robertson et al., 2018).

A third issue here is that analysis here is based on a small sample which only included individuals with co-occurring depression and anxiety, an issue largely determined by the COVID-19 pandemic. Gillberg and Fernell’s original concept of Autism Plus indicated that it could include anyone on the spectrum with co-occurring neurodevelopmental, cognitive or psychiatric diagnoses, therefore ideally a broader range of co-occurring conditions would have been covered as part of this research. With this in mind, this study can only be considered to provide preliminary evidence that co-occurring symptoms can at times have a greater impact on life than an individual’s ASC symptoms. However, the evidence presented here does suggest that this is an issue worth exploring in a larger sample including a more diverse range of co-occurring symptoms. In addition to the size of the sample, a further limitation was that the sample only included males. While Study One and Study Two of this thesis found no evidence of the outcomes of males and females on the spectrum, previous research (discussed in Section 3.2.1) has previously indicated that in particular experiences of social relationships may differ across males and females with ASC.

A final limitation of this study was that one of the participants reported having a co-occurring diagnosis which was not discussed in detail as part of the interview. On the participant questionnaire completed as part of the study, John indicated that in addition to anxiety and depression he had a diagnoses of PTSD. During the interview John indicated that his PTSD could make him to over-react to certain situations, though did not provide specific examples of this. It is therefore possible that some of the difficulties John described, including difficulties interacting with others, were also influenced by these co-occurring symptoms. While this is something that should be taken into consideration when interpreting these results, it is important to also acknowledge that John also provided sufficient evidence to suggest that it was specifically his symptoms of anxiety and depression which he considered responsible for many of the difficulties he faced.

7.4.6. Recommendations for Future Research

While historically a large portion of the ASC literature has stratified analyses to account for the presence of intellectual disability, few other co-occurring conditions have been acknowledged in this way. The findings from this research illustrate the importance of also acknowledging the presence of co-occurring depression and anxiety in any research focusing on the outcomes and needs of those on the spectrum. However, there is also evidence here to suggest that the severity of co-occurring conditions may also be an important factor which needs to be considered, as while both participants in this study had co-occurring anxiety and depression, there was evidence to suggest that these symptoms had a more restrictive impact on one participant than the other. Therefore, while co-occurring symptom severity was not a matter acknowledged by Gillberg and Fernell's original proposal for Autism Plus, the evidence here suggests that it is something which needs to be acknowledged when examining the link between co-occurring symptoms, outcomes and needs within this population in the future.

7.4.7. Reflexive Statement

In any IPA study, researchers are encouraged to acknowledge any factors which may have had the potential to influence analysis and the interpretation of participants comments. The author of this research was specifically interested in how the lives of those with ASC are influenced by co-occurring conditions. While steps (described in Section 7.2.4) were taken to prevent the analysis process from being influenced by pre-existing knowledge of the Autism Plus theory, which is of central interest to this thesis, it is possible that this pre-existing knowledge shaped the way in which participants perspectives were analysed and reported on.

IPA guidelines also encourage researchers to be conscious of the double hermeneutic in their analysis – i.e. the concept of researcher trying to make sense of a participant's experiences who is in turn trying to make sense of these experiences themselves. Therefore, in this study, it is also important to acknowledge that the findings here are rooted in the participant's perspectives of the factors which create the greatest difficulties in life and that these perspectives may be inaccurate. One measure taken to address this matter was Step 5 of the IPA process (described in Section 7.2.4), as this was intended to establish inconsistencies in participants accounts. However, no evidence was found as part of this step to suggest that there were inconsistencies in the participant's descriptions of their experiences.

It is also important to acknowledge that the author of this thesis is not on the autistic spectrum and as such it is important to acknowledge that the analysis and interpretation of the interviews has been written by someone with no direct experience living with ASC. In line with this, efforts were made to ensure that analyses did not assume the preferences and needs of those on the spectrum aligned with those not on the spectrum (e.g. the desire for friendships), given that this has been highlighted as an issue with previous research in this field (Bishop-Fitzpatrick et al., 2016; Magiati et al., 2014).

Finally, the author of this thesis was 17 years younger than the youngest participant, and this too may have had an impact on the accounts the participants gave of their lives, and the way in which the data was collected was analysed. It is therefore possible that the data collection and analysis here prioritised topics of greater significance to younger individuals and in doing so overlooked other issues which may become more important with age. However, the data collected suggests that participants gave an open, honest and detailed account of their lives, and with this in mind the age difference between researcher and participant's is only of minor concern.

7.4.8. Conclusion

This study provided evidence to suggest that within the adult ASC population, co-occurring conditions may at times have a greater influence on aspects of life such as employment, friendships and support needs than an individual's ASC symptoms. However, accounts from two individuals with Autism Plus raise questions about the validity of Gillberg and Fernell's proposal about those with ASC and co-occurring conditions, given that both participants had also experienced some positive outcomes within their social lives and careers, despite their co-occurring symptoms. Ultimately, the evidence from this study suggests that in order to better understand variance in the outcomes and needs of those on the spectrum, there is a need to consider both the presence of co-occurring symptoms and the severity of these co-occurring symptoms.

Chapter 8

General Discussion

As discussed in Chapter 3, outcomes relating to employment, long-term relationships and independent living vary considerably amongst adults with ASC as do support needs across this population (Anderson, Lupfer, et al., 2018; Broad et al., 2017; Hewitt et al., 2017; Howlin & Magiati, 2017; Murphy et al., 2016; Steinhausen et al., 2016). Furthermore, as discussed throughout this thesis, previous research has been unable to establish a reliable model which can consistently and accurately differentiate between those with more positive and negative outcomes and need for different levels and types of support (Magiati et al., 2014; Underwood et al., 2019). However, it is important that research continues to pursue a better understanding of these matters, given that as noted in Chapter 3 positive outcomes across employment, long-term relationships and independent living have been found to be highly beneficial to individuals with ASC and their families (Billstedt et al., 2011; Orsmond et al., 2013). Furthermore, with a better understanding of what influences outcomes in this population, it may be possible to develop and provide more specific forms of support for individuals across the spectrum, which is more considerate of the highly heterogenous ASC population (MacKay et al., 2018; McCarthy et al., 2015; Nicolaidis et al., 2015; Turcotte et al., 2015).

The review of the literature in Chapter 2 highlighted that the influence of co-occurring conditions on outcomes and needs in this population has been under-researched, despite the high prevalence of co-occurring conditions such as ADHD, epilepsy, anxiety and depression within this population (Amr et al., 2012; de Bruin et al., 2007; Mannion & Leader, 2013; Mattila et al., 2010; Simonoff et al., 2008). Given the need for more research within this area, this thesis set out to investigate a proposal made by Gillberg and Fernell (2014) that outcomes and needs in the ASC population may be determined more by and individual’s co-occurring conditions and symptoms, than their core autistic symptoms, traits and behaviours. More specifically, Gillberg and Fernell (2014) proposed that they would expect outcomes to be poorest amongst those with one or more neurodevelopmental, cognitive or co-occurring condition (also known as those with Autism Plus) compared to those with ASC but no co-occurring conditions (also known as those with Autism Only).

Two studies have previously explored the concept of Autism Plus, with one providing evidence to suggesting that optimal outcomes in this population (i.e. social and independent living outcomes comparable to those found in the typically developing population), were more likely to occur amongst individuals without co-occurring diagnoses (Gillberg et al., 2016), and the other indicating that Autism Plus may be more indicative of subjective quality of life, while autistic symptoms and traits may be more predictive of objective aspects quality of life (Helles et al., 2016). While other research in this field has also considered the impact of co-occurring conditions on the lives of adults with ASC, this literature has been dominated by studies focusing on the impact of intellectual disability (ID), though as discussed in Chapter 3, findings relating to the impact of ID on the lives of those with ASC have been inconsistent. As discussed in Section 2.3 and 7.1, a small number of qualitative studies have been helpful in highlighting the potential impact of other co-occurring diagnoses, and suggest that there is a need to further the explore the ways in which conditions such as anxiety and depression, may also affect that abilities of those with ASC to form and maintain social relationships or gain and maintain employment (Cummins et al., 2020; Robertson et al., 2018). The motivation for the research in this thesis was therefore to explore the utility of the Autism Plus as an indicator of poorer outcomes and greater support needs across the autism spectrum, but also to contribute to the broader knowledge and understanding of how co-occurring conditions impact the lives of those with ASC.

8.1. Summary of Findings from this Thesis

Three studies presented in Chapters 5–7 were conducted to investigate the utility of Autism Plus in differentiating the outcomes and needs of adults with ASC. The first examined the concept as it was first proposed by Gillberg and Fernell, by comparing the outcomes and service-use patterns of those with Autism Plus and Autism Only as part of a secondary data analysis. As part of this study the influence of other known influences on outcomes in the ASC population, including age and the type of ASC diagnosis that an individual had, were also examined as a means of establishing to what extent these other factors may also influence outcomes in this population. Results from this study went against Gillberg and Fernell’s proposal given that for two of the outcomes (long-term relationship status and residential independence) outcomes were better for those with Autism Plus compared to those with Autism Only, and that no group differences were found in the other adult outcomes examined. Those with Autism Plus were however found to differ from those with Autism Only in terms of their service use in that they were significantly more likely to have used at least one service in the 6 months prior to data collection, and to have used a psychiatric or psychological support service within this time. This suggested that while Autism Plus may have limited utility as a predictor of poorer outcomes within this population, Gillberg and Fernell may have been correct to propose that support needs would differ amongst those with Autism Plus.

Study 2 explored the possibility that the concept of Autism Plus might be more useful as a component in a larger model which could account for other potentially influential factors, given that findings from Study 1 indicated that age and autistic symptom severity were significantly associated with a number of adult outcomes. This was explored by conducting a further secondary data analysis, in this case using four logistic regression models (with employment status, long-term relationship status, residential status and ability to travel independently as dependent variables). Each model examined the extent to which Autism Plus could predict outcomes when age and type of ASC diagnosis were controlled for, though again results raised questions about the utility of Autism Plus as a predictor of adult outcomes in this population. Findings indicated that neither employment status nor independent travel ability could be predicted by Autism Plus in models which also accounted for the influence of age and autistic symptom severity, but that again there was evidence to suggest that long-term relationship status and residential outcomes were better amongst those with at least one co-occurring condition in this sample. While there was little support for the utility of Autism Plus, findings again emphasised the importance of accounting for the impact of age and autistic symptom severity (in this case indicated by the type of ASC diagnosis an individual had) in research within this area. More specifically, findings indicated that individuals with AS/HFA were more likely to be in employment and long-term relationships and more likely to be able to travel independently and that residential, long-term relationship and travel outcomes improved were better amongst older individuals in this sample. Also of note here was that age was able to account for 13% of the variance in independent travel outcomes, 22% of the variance in long-term relationship outcomes and 30% of variance in residential outcomes.

Results from the first two studies suggested that while Autism Plus may be a useful indicator of support needs, it could not be considered a variable which could differentiate those in the ASC population with better and poorer adult outcomes. These findings not only showed a lack of support for Gillberg and Fernell's proposals on the impact of co-occurring conditions within the ASC population, but also contrasted with findings involving the typically developing population which suggest that conditions such as depression, anxiety, ID, ADHD and epilepsy can have a profound influence on adult outcomes (Geerlings et al., 2019; LeMoult & Gotlib, 2019; Lensing et al., 2015; Michielsen et al., 2015; Rosen et al., 2018;

Taylor & Seltzer, 2011; Thomson et al., 2014). Study 3 (presented in Chapter 7) therefore set out to learn more about what impact co-occurring conditions could have on the lives of those with ASC, and took a qualitative approach to exploring whether co-occurring symptoms could make it more difficult or stressful to achieve more positive outcomes in adulthood, even if they did not prevent individuals from achieving these outcomes entirely.

Data analysis in Study 3 focused on interviews conducted with two adults with ASC, both of whom had co-occurring depression and anxiety. The participant's accounts of these symptoms indicated that one participant, John, experienced more severe depression and anxiety than the other, David. In line with this, there was evidence to suggest that John's co-occurring symptoms had a more profound influence on his daily life compared to David (e.g. while David indicated that his co-occurring symptoms had caused him to drop out of university while younger, John indicated that at the time of the interview his co-occurring symptoms had at times prevented him from leaving the house or socially engaging with others), and this led to the conclusion that the presence of a co-occurring condition may only result in poorer outcomes when symptoms are more severe. There was again evidence to suggest that co-occurring conditions had a greater influence on some aspects of life more than others. For example, John indicated that he could clearly differentiate the impact of his autistic symptoms, which could make it more difficult to get on with others in a workplace, from his co-occurring depression and anxiety, which could make it more difficult to seek new work when unemployed and to have the motivation to go out and interact with others. On a similar note, both participants also commented that while they felt they could understand and manage their autistic symptoms, they indicated that they experienced greater difficulties in understanding and overcoming the symptoms of anxiety and depression. As such, this study suggested that support for mental health, and possibly other co-occurring conditions, may be as important for individuals on the autistic spectrum as support aimed linked to autistic symptoms and behaviours. This finding can be seen as in line with previous research in this area which has highlighted the need for support for individuals on the autistic spectrum which targets other symptoms and aspects of life rather than only focusing only an individual's autistic symptoms (Crane et al., 2019; Müller et al., 2008).

8.2. Synthesising Findings within a Critical Realist Framework

As discussed in Chapter 4, this thesis adopted a critical realist approach to examining Autism Plus, in that it aimed to investigate to investigate the link between co-occurring conditions, outcomes and needs using a combination of approaches intended to explore this matter from different perspectives. The critical realist philosophy advocates comparing, contrasting and triangulating findings across these different approaches as a means of establishing whether findings relating to a particular matter are consistent, regardless of the methods used (Ackroyd & Karlsson, 2014; Danermark, 2002; Fletcher, 2017; Patomäki & Wight, 2000). This thesis employed a sequential explanatory approach, where a qualitative investigation was conducted in order to provide more insight into findings identified as part of a larger quantitative study (Fetters et al., 2013), and the use of this approach was useful in establishing three key findings from this thesis.

Firstly, while the quantitative methods employed here provided findings which indicated that Autism Plus was not associated with significantly poorer adult outcomes, the qualitative analysis which followed provided a more nuanced understanding of the relationship between co-occurring conditions and outcomes in this population. More specifically, findings from the interviews conducted with two individuals with Autism Plus indicated that though they had both previously achieved positive employment, social relationships, and independent living outcomes, at other times in life, the depression and anxiety they had experienced had prevented them from living a normal life and caused them a considerable level of stress. Ultimately, there was therefore evidence to suggest that co-occurring conditions can make life more difficult for individuals with ASC and are an area in which additional support may be required, even in cases where individuals appear to be living with a good level of independence.

Secondly, the qualitative analyses reported in Study 3 focused on two older individuals and as such provided insight into the extent to which outcomes, experiences and needs may change over the course of life. Both participants provided examples of times in their life when these outcomes had been better or worse, in line with previous research in this field which suggests that adult outcomes in this population often fluctuate (Howlin et al., 2004; Taylor, Henninger & Mailick, 2015). The findings from Study 1 and Study 2, must therefore be viewed in the context that they provide a ‘snapshot’ of reality, and as highlighted in the Discussion section of Study 1, this raises questions about whether longitudinal analyses which can better account for these fluctuations in outcomes, may find a greater level of support for the Autism Plus conceptualisation of ASC.

Thirdly, the qualitative analyses reported here also offers insight into an additional factor which may be able to explain the findings from Study 1 and 2. While the participants who took part in interviews both had co-occurring depression and anxiety, there was evidence to suggest that the severity of these co-occurring symptoms was greater for one participant (John) than the other (David). Significantly, these differences in co-occurring symptom severity were also reflected in the experiences described by each participant, with John’s symptoms of depression and anxiety appearing to have a more profound and widespread influence on his life (as discussed in Section 7.4). This therefore raises questions as to whether Autism Plus may have emerged as a better predictor of poor outcomes across both Study 1 and 2, had the severity of co-occurring conditions been accounted for. As discussed further below, it is recommended that both the presence and severity of co-occurring conditions are better controlled for in future research focusing on the adult outcomes of individuals with ASC.

8.3. Implications for the Concept of Autism Plus

The evidence presented here indicates that the concept of Autism Plus, as it was originally proposed by Gillberg and Fernell (2014), may not be a useful predictor of poorer adult outcomes within the ASC population but could have some utility as an indicator of support needs. In line with the above, it is recommended that this conceptualisation continues to be explored as part of a larger model which better accounts for the role which factors including age and autistic symptom severity may have in determining adult outcomes in this population, and in research which can better acknowledge and account for the fluctuations in adult outcomes which may occur across the lives of those with ASC.

Findings from the qualitative component of the research indicated that even in times where participants experienced more positive social, independent living and employment outcomes, their co-occurring conditions still added an additional level of stress and difficulty to their lives. This finding may be considered in line with previous research in this area by Helles et al. (2016) who indicated that those with co-occurring did not differ in the outcomes they experienced but did report lower levels of life satisfaction. As such, it is recommended that future research is also more considerate of the extent to which Autism Plus may be associated with a lower quality of life and lower life satisfaction in this population, even amongst individuals with ASC who experience more positive social and independent living outcomes.

8.4. Broader Implications and Contributions to the Research Literature

In addition to the findings reported here in relation to Autism Plus, this research can also be considered to make several contributions to the broader research literature focusing on social and independent living outcomes and service use. For example, the findings here emphasise the importance of studying adult outcomes separately rather than as part of a composite (as recommended by the overall outcome rating approach discussed in Section 5.3), given that analyses here, discussed in Section 5.4 and 6.4, indicated that each adult outcome may be associated with a different set of demographic or diagnostic factors.

This research also highlights the importance of examining adult outcomes in this population using both a quantitative and qualitative approaches. The manner in which interviews were conducted as part of Study Three encouraged participants to freely discuss the impact of co-occurring conditions and led to important findings (e.g. the potential importance of co-occurring symptom severity in determining adult outcomes) which would have been more difficult to acquire through the use of questionnaires or other quantitative approaches to data collection.

Thirdly, this study raised questions about the availability and uptake of support services for adults with ASC. Previous research has highlighted that that individuals with ASC, as well as the parents and carers of ASC, feel there is inadequate support for individuals on the autism spectrum (Bianco et al., 2009; Crane et al., 2019; Eaves & Ho, 2008; Herrema et al., 2017), and in particular it has been suggested that there is a need for greater support for the mental health challenges faced by individuals with ASC (Crane et al., 2019). In line with this, findings from Study 1 highlighted that only a small proportion of the sample were engaged with support services, and in Study 3 both participants indicated that they would have benefited from mental health support, given that they found it more difficult to understand and manage their symptoms of depression and anxiety in comparison to their autistic symptoms and behaviours. These findings may therefore be considered to support previous calls for support which can specifically target the mental health difficulties that those with ASC experience, particularly given the high prevalence of both conditions within this population (Crane et al., 2019; Hollocks et al., 2019).

Finally, this research highlights the progress which still needs to be made in developing a better understanding of the outcomes and support needs within this population. As indicated earlier in this chapter, positive outcomes and appropriate levels of support are key to psychological well-being of individuals with ASC. Further support for this was found as part of Study Three, where one of the participants explained that the experiences of living alone, being socially isolated and being unemployed were magnifying the symptoms and depression which he already experienced. This reinforces the importance of trying to better understand the mechanisms and processes which influence outcomes and the type of support required in this population, given the broader impact which social and independent living outcomes can have on other aspects of life.

8.5. Strengths, Limitations and Recommendations for Future Research

There are a number of strengths to this research. Firstly, as already discussed in some detail above, this research can be considered to have examined the concept of Autism Plus from a number of different perspectives and in doing so provided a more well-rounded account of this concept than could have been achieved by a single study a single approach (e.g. a solely quantitative approach or an approach which only considers the concept as it was originally proposed). The nature of the sample on which analyses were based can also be considered a strength of this research for two main reasons. Firstly, Study 1 and 2 present analyses based on a sample size that exceeds the number of individuals analysed in the majority studies within this literature (see Tables A1–A3 in Appendix A). Secondly, the analyses reported in Study 3 provided insight into the experiences of older individuals with ASC which, as previously discussed in Section 7.4, (1) gave voice to an under-represented sub-section of the autistic population and (2) it allowed for unique insight into how the impact of autistic and co-occurring symptoms had changed over time.

A further strength of the research presented here, is that the statistical analyses conducted as part of Study 1 and 2 stratified findings to differentiate between those with milder and more severe autistic symptoms. The significance of this is that within the pre-existing research literature, a large proportion of studies present analyses only in relation to a specific portion of the ASC population (e.g. individuals with high functioning ASC), or else do not account for differences in symptom severity (Magiati et al., 2014; Underwood et al., 2019). As indicated above, the findings reported here can be considered to reemphasise the importance of accounting for autistic symptom severity in research focusing on adult outcomes in this population.

The limitations of each study have previously been discussed in Sections 5.4, 6.4 and 7.4, though some of these limitations are worth revisiting here given that they may be helpful in guiding future research in this area. Firstly, the nature of the samples featured in all three studies meant that it was not possible to make direct comparisons between the impact of different co-occurring conditions, despite some evidence in Study 1 to suggest that adult outcomes may be influenced differently by different types of co-occurring condition. In this particular case, such comparisons could not be made as a large portion of the sample had more than one co-occurring condition and in these cases, it was not possible to separate the impact of each diagnosis through statistical analysis. However, it is recommended that the impact of individual co-occurring conditions on adult outcomes is explored further as part of future research, though it is possible that this issue may best be explored in research which focuses on individuals with ASC who only have one co-occurring diagnosis.

On a related note, the representativeness of the samples analysed in three studies presented here may also be questioned, given that the sample analysed in Study 1 and 2 was generated using convenience and snowball sampling, and the sample for Study 3 included only two male participants. However, in the case of Study 1 and 2, it should be noted that this approach to sampling also allowed for analysis to be conducted upon 404 individuals with ASC, which can be considered a large sample size within this research literature, and in the case of Study 3, the size and nature of the sample were impacted by the COVID-19 pandemic (as discussed in Section 7.2.1).

Findings reported here should be considered within the context that they were based data provided in the majority of cases by individuals with ASC and their parents or carers (the dataset upon which data analyses in Study 1 and 2 were based also included a small number of responses provided by professionals or individuals who knew someone with ASC well enough to comment on their diagnoses and outcomes). It is therefore important to acknowledge that this data may be considered less reliable compared to a study where participant’s accounts of their lives and experiences are validated by medical records and other forms of proof.

A further limitation, and an issue already discussed in some detail above, studies in this thesis did not control for co-occurring symptom severity. In the case of Study 1 and 2, this was not possible as such information was not available as part of the dataset upon which secondary data analysis was conducted. This is a factor which it would have been helpful to control for as part of Study 3, however, this would have required far greater resources than were available as part of this research project, given that to achieve this it would have been necessary to acquire an appropriate reliable and valid measure for each possible co-occurring condition that a participant could have. Not only was this not an option given the resources and scale of the project, but this was also not an issue of central importance to the premise which this thesis set out to investigate. With this in mind, and to generate a better understanding of this more specific issue in the future, it may more appropriate and feasible for separate research projects to investigate specific groups of co-occurring conditions (e.g. only co-occurring mental health diagnoses).

A final limitation is that in Study 1 and Study 2 of this thesis autistic symptom severity was determined by DSM-IV diagnostic criteria. The use of these older diagnostic categories was considered appropriate given that (1) anyone meeting the DSM-IV/ICD-10 diagnostic criteria for AD or AS also meet the criteria for the DSM-5 and ICD-11 diagnostic criteria for Autism Spectrum Disorder (ASD); (2) these are the diagnostic terms which continue to be used by a large portion of the ASC population, while the severity indicators recommended by DSM-5 are rarely used amongst this community; (3) these terms featured in the Scottish Autism Dataset (on which secondary data analyses was conducted), while no participant described their diagnosis using the severity indicators recommended by DSM-5; and (4) there is evidence that the severity indicators recommended as part of DSM-5 are not a clear improvement on AD and AS in terms of their ability to clearly differentiate those with different severities and presentations of autistic symptoms and those with different support needs (this issue was discussed in more detail in Section 2.1.2). However, while these diagnostic categories were considered useful indicators of autistic symptom severity, ideally data relating to the severity and nature of participant's autistic symptoms in Study 1 and 2 would have been captured through the use of a standardised measure of autistic symptom severity, as was the case in Study 3. This would have been particularly helpful given that previous research has consistently highlight that the ASC population is highly heterogenous, and that stratifying findings according to two levels of symptom severity, as was the case in Study 1 and 2, can only be considered to go so far in terms of accounting for this heterogeneity. It is therefore recommended that future research not only aims to account for differences in symptoms severity and presentation across the ASC sample, but does so using a measure which can capture the considerable variance which exists across this population.

8.6. Final Conclusions

The final conclusion from this thesis is that there is insufficient evidence to suggest that the concept of Autism Plus can successfully predict outcomes within the adult ASC population, but that it could be useful in determining the support needs of individuals on the spectrum. However, it is proposed that this is an area in which more research is required, particularly in light of evidence to suggest that the impact of co-occurring conditions on adult outcomes may be determined by the severity of these additional symptoms. This thesis also reinforces the need to account for differences in age and autistic symptom severity in any research focusing on outcomes and support needs in this population, particularly as this is something which in recent years has been less commonly accounted for in research involving individuals on the autistic spectrum (Underwood et al., 2019). Finally, this thesis has highlighted the potential importance of mental health support for individuals on the autism spectrum, given the high prevalence of anxiety and depression in this population, and findings from Study 3 which indicated that in some cases these symptoms can have a greater impact on life than an individual’s core autistic symptoms, traits and behaviours.

Appendices

Appendix A: Additional Details of Studies Featured in Chapter 3 Literature Review

A1 Sample Characteristics of Studies Reporting on Employment, Long-Term Relationship, Independent Living, Travel or Overall Outcomes

Table A.1

Study Details and Sample Characteristics of Studies Reporting Employment, Relationship, Independent Living or Overall Outcomes focusing on individuals with autistic disorder

Study No.	Study First Author and Date	Age (years)	Sample Size (n)	Intellectual Ability (% of sample)			Type of Outcome Data Reported
				Moderate, Severe or Profound ID	Mild ID	IQ ≥ 70	
1	Billstedt 2005a	m = 25.5, r: 17–40	78	68	25	7	IL, OOR
2	Bush 2017	m = 34.5 r: 18–87	2174	71	29	0	E
3	Cedurland 2008a	m = 24.5, r: 16–36	70	72	21	7	E, R, IL, OOR
4	Chamak 2016a	r: 18–54	59	*not reported*			OOR
5	Farley 2009	m = 32.5 r: 22–46	41			100	E, R, IL, T, OOR
6	Gillespie-Lynch 2012	m = 26.6	20	*not reported*			E, IL, OOR
7	Taylor 2011a	r: 19–26	49	100		0	E

Table A.2

Study Details and Sample Characteristics of Studies Reporting Employment, Relationship, Independent Living or Overall Outcomes primarily focusing on individuals with high-functioning autism (HFA) or Asperger's Syndrome (AS)and no ID [1]

Study No.	Study First Author and Date	Age (years)	Sample Size (n)	Intellectual Ability (% of sample)			Type of Outcome Data Reported
				Moderate, Severe or Profound ID	Mild ID	IQ ≥ 70	
8	Byers 2013	m = 35.3 r: 21–73	141			100	R
9	Cedurland 2008b	m = 21.5, r: 16–34	66		2	98	E, R, IL, OOR
10	Chamak 2016b	r: 18–36	17			100	OOR
11	Engström 2003	m = 30.8, r: 18–49	16			100	E, R, OOR
12	Helles 2017	m = 30.7	39			100	E, IL, R
13	Ohl 2017	m = 38.11	254		*not reported*		E, IL, R
14	Roy 2015	m = 36 r: 20–62	50			100	E, IL, R
15	Taylor 2011b	r: 19–26	17			100	E

[1] The majority of studies in Table A2 only included individuals with AS in their sample. The exception to this was Engström 2003 who included 6 individuals with HFA,

Table A.3

Study Details and Sample Characteristics of Studies Reporting Employment, Relationship, Independent Living or Overall Outcomes for individuals with any ASC diagnoses

Study No.	Study First Author and Date	Age (years)	Sample Size (n)	Intellectual Ability (% of sample)			Type of Outcome Data Reported	Notes
				Moderate, Severe or Profound ID	Mild ID	IQ ≥ 70		
16	Barneveld 2014	m = 24 r: 19–30	165			100	E, IL, R	Diagnoses in sample; AD=20, AS=18, PDDNOS=131. Outcome data was missing for a small proportion of individuals (<5%), though the percentage data missing varied across each outcome
17	Billstedt 2005b	m = 25.5, r: 17–40	37	77	20	3	IL, OOR	AA diagnoses only. Intellectual ability data missing for small portion (≤ 3%) of sample
18	Billstedt 2011	m =25.5 r: 17–40	120	46	35	19	E, IL	Diagnoses in sample; AD = 73, Other ASC = 35
19	Eaves 2008	m = 24 r: 19–31	48		*not reported*		R, IL, T, OOR	Diagnoses in sample; AD = 27, AS = 5, PDDNOS = 12.
20	Esbensen 2010	m = 38, r: 22–53	70	71	26	3	OOR	ASD diagnoses only
21	Falkmer 2015	m = 24.6	54		*not reported*		T	ASD diagnoses only
22	Gray 2014	m = 24.8 r: 17–35	89	55	21	24	E, R, IL,	All participants had ASC, specific diagnoses not specified

E = Employment IL = Independent Living R = Residential Status T = Travel OOR = Overall Outcome Rating, m = mean, r = range *(Continued)*

Study No.	Study First Author and Date	Age (years)	Sample Size (n)	Intellectual Ability (% of sample)			Type of Outcome Data Reported	Notes
				Moderate, Severe or Profound ID	Mild ID	IQ ≥ 70		
23	Hewitt 2017	m = 33 r: 18–60	1250	60	24.5	15.5	R	All participants had ASC, specific diagnoses not specified
24	Hofvander 2009	m = 29 r: 16–60	122		*not reported*		E, R, IL,	Diagnoses in sample; AD = 5, AS =67, PDDNOS = 50. No intellectual ability data provided
25	Howlin 2004	m = 33.5	67	16	20	64	E, IL, OOR	ASD diagnoses only
26	Howlin 2013	m = 44	58		*not reported*		E, IL, OOR	Followed-up participants from Howlin 2013. ASD diagnoses only, mean IQ = 88.2 (range: 50–135)
27	Hutton 2008	m = 34.9 r: 21–57	135		*not reported*		E, IL, R	ASD diagnoses only.
28	Kamp-Becker 2010	m = 21.6 r: 17–28	26		*not reported*		E, IL, R	Diagnoses in sample; AS = 14, HFA = 8, AA = 4. Mean IQ = 99.3 (SD=17.1)

E = Employment IL = Independent Living R = Residential Status T = Travel OOR = Overall Outcome Rating, m = mean, r = range *(Continued)*

Study No.	Study First Author and Date	Age (years)	Sample Size (n)	Intellectual Ability (% of sample)			Type of Outcome Data Reported	Notes
				Moderate, Severe or Profound ID	Mild ID	IQ ≥ 70		
29	Kirby 2016	r: 21–25	770	*not reported*			E, IL	All participants had ASC, specific diagnoses not specified. Employment data missing for 30 individuals
30	Mason 2018	m = 41.61 r: 17–80	370	*not reported*			E	All participants had ASC, specific diagnoses not specified.
31	Renty 2006	m = 28.34 r: 18–53	58	*not reported*			R, IL	Diagnoses in sample; AD = 12, AS = 20, PDDNOS = 5, ASD = 21; No intellectual ability data reported
32	Strunz 2017	m = 34.9 r: 18–58	229			100	R	All individuals had ASD diagnoses
33	Sung, 2015	r: 16–25	1696	89		11	E	All participants had ASC, specific diagnoses not specified.
34	Taylor 2012	r: 22–52	343	71		29	E	All individuals had ASD diagnoses. Employment data provided for 239/343 individuals. Rates of ID were combined in this study

Appendix B: Study 2 Appendices

B1 Scottish Autism Microsegmentation Study Survey

Before proceeding, please read the items listed below and tick below to confirm that you consent to taking part in the research.

I confirm that I understand the purpose of the research and what is being asked of me

I understand that my participation is voluntary and that I am free to withdraw from the project at any time without having to give reason and without consequence

I understand that any information recorded in the investigation will remain confidential.

I am ready to take part and consent to taking part in the investigation ○

In what capacity are you completing this questionnaire?

If you are an individual with ASD and also a parent or carer of someone with ASD, please complete a separate questionnaire for yourself and for the individual/s of whom you are parent/carer. Similarly if you care for more than one individual with ASD please complete a separate questionnaire for each individual.

An individual with ASD	○
A parent or family carer of someone with ASD	○
A carer for someone with ASD (not a family member)	○
Other (please specify)	○

PERSONAL DETAILS OF THE INDIVIDUAL WITH ASD

Age (in completed years)

Is the individual with ASD:

Male ○

Female ○

Ethnic group:

White ○

Mixed/Multiple ethnic groups ○

Asian/Asian Scottish or Asian British ○

African ○

Caribbean or Black ○

Other (please specify) ○

Please enter the full home postcode of the individual with ASD

Is the individual currently in a long-term stable relationship of over 2 years duration?

(Please complete only for individuals age 16 and over who have left school)

Yes ○

No ○

Can the individual travel independently by public transport or their own car?

(Please complete only for individuals age 16 and over who have left school)

Yes ○

No ○

DIAGNOSIS OF ASD

Please tell us the specific diagnosis

Autism/Childhood Autism/Autistic Disorder ○

Asperger's Syndrome/Asperger's Disorder ○

High Functioning Autism (HFA) ○

ASD/Autism Spectrum Disorder/Autistic Spectrum Disorder ○

Atypical Autism/PDD-NOS ○

Other ASD Diagnosis (please specify) ○

OTHER DIAGNOSED CONDITIONS

Has the individual received any other diagnoses? (Please tick all that apply)

ADHD (Attention Deficit Hyperactivity Disorder)	○
OCD (Obsessive Compulsive Disorder)	○
Epilepsy	○
Fragile X	○
Tuberous Sclerosis	○
Down Syndrome	○
Tourette Syndrome	○
Schizophrenia	○
Bipolar Disorder	○
Depression	○
Anxiety Disorder	○
Learning Disability/Intellectual Disability (mild/moderate/severe/profound); Learning Difficulties (moderate/severe/profound or complex). Please specify.	○
Challenging Behaviour	○
Other Diagnosis (Please specify)	○

UNDIAGNOSED CONDITIONS

Do you believe there should have been diagnosis for any of the conditions mentioned on the previous page?

No ○

Yes ○

If yes please, specify below the diagnoses you believe should have been given and the reasons why

EDUCATIONAL HISTORY

Please tick all types of educational establishment attended, now or in the past

	Preschool/Nursery	Primary	Secondary
Mainstream School	○	○	○
Special Unit/Resource in Mainstream School	○	○	○
Special Day School (General)	○	○	○
Special Day School for ASD	○	○	○
Special Residential School (General) - 38 weeks	○	○	○
Special Residential School (General) - 52 weeks	○	○	○
Special Residential School for ASD - 38 weeks	○	○	○
Special Residential School for ASD - 52 weeks	○	○	○
Other (Please specify) ☐	○	○	○
Other (Please specify) ☐	○	○	○

After leaving school (Please tick all types of educational establishment attended, now or in the past)

None ○
Further education college ○
University ○
Other (Please specify) ○

Highest level of educational qualification achieved

Access 1 or 2/National 1 or 2 ○
Access 3 or Standard Grade (Foundation)/National 3 ○
Standard Grade (General)/Intermediate 1/ National 4 ○
Standard Grade (Credit)/Intermediate 2/National 5 ○
Highers/Certificate of Sixth Year Studies/Advanced Highers ○
Higher National or Higher Education Certificate or Diploma ○
Bachelors/Masters Degree ○
Bachelors/Masters Degree with Honours ○
Masters Degree (post-graduate) ○
Doctoral Degree ○
Other (please specify) ○

Has the individual with ASD ever completed an intelligence test?

No ○

Yes ○

If yes, and you have reports detailing the findings, please specify the age of the individual at the time of the test, the name of test completed, and the results of the test (if known). If more than one intelligence test has been completed, include the details of all of these in the space below.

Examples of common intelligence tests include: Wechsler tests (WISC, WPPSI, WAIS, WASI), Stanford-Binet, Raven's Matrices, British Ability Scales (BAS), Bailey Scales.

LIVING ACCOMMODATION

Where is the individual with ASD currently living (please tick all that apply)

In a private household with parents or relatives ○

In a private household with friends/flatmates ○

In a private household with a partner ○

In a private household alone ○

In a B&B/hotel ○

In a hostel ○

In formal foster care ○

In supported living accomodation ○

In residential school ○

In residential care ○

In prison/young offenders' institution/secure unit

Other (please specify) ○

Please complete only for individuals age 16 and over who have left school

What is the current employment status of the individual with ASD? (please tick all that apply)

Employment (paid, including apprenticeship/internship or other training)	○
Employment (unpaid, including apprenticeship/internship, other training or voluntary work)	○
Supported employment	○
Unemployed - but available to work	○
Unemployed - and not available to work	○
Retired/pensioned – and not in employment	○
Housewife/husband - and not in employment	○
Full time student - and not in employment	○
Other (please specify)	○

If employed (paid, including supported employment), how many hours per week does the individual with ASD work in paid employment?

If employed (unpaid), how many hours per week does the individual with ASD work in unpaid employment?

EDUCATIONAL SERVICES IN THE LAST 6 MONTHS

Please complete only for individuals who have not left education.

Please tick all those attended in the last 6 months

None ○
Mainstream school ○
Further education college ○
University ○
Special Unit/Resource in mainstream school ○
Special day school (general) ○
Special day school for ASD ○
Special residential school (general) - 38 weeks ○
Special residential school (general) - 52 weeks ○
Special residential school for ASD - 38 weeks ○
Special residential school for ASD - 52 weeks ○
Home education (as an alternative to school) ○
Other (please specify) ○

Which professionals working at a school, college or university has the individual with ASD seen in the last 6 months?

None ○
Educational psychologist ○
School family worker/ESW ○
Classroom assistant ○
Specialist teacher ○
Speech and language therapist (at school/college/university) ○
Occupational therapist (at school/college/university) ○
Physiotherapist (at school/college/university) ○
Disability service advisor (at college/university) ○
Other (please specify the type of service) ○

TUITION/TUTORIAL SUPPORT

Has the individual with ASD received any type of tuition/tutorial support in the last 6 months?

No ○

Yes ○

If yes, what type of tuition/tutorial support has the individual with ASD received in the last 6 months? If the carer or individual paid for any of these services direct (whether with personal funds or supported by a benefit or allowance) please indicate the cost if known.

	Hours per week	Paid for direct by carer/ individual (Yes/No)	If yes, how much did it cost
Individual tuition at home			
Individual tuition elsewhere (e.g. school/college/university)			
Tuition in a small group (e.g. school/college/university)			
Other (please specify)			

Has the individual with ASD been excluded from school (or other educational establishment) in the last 6 months?

No ○

Yes ○

If the answer to the previous question was yes, please specify the number of times the individual has been excluded and the length of time they were excluded on each occasion

HEALTH AND SOCIAL CARE SERVICE PROVISION

Has the individual with ASD received any residential respite care services in the last 6 months?

No ○
Yes ○

If yes, please provide information on all that apply

	Number of days spent in residential respite care
Residential care-home for children/adolescents	☐
Residential care-home for adults	☐
Foster care	☐
Other (please state the type of facility)	☐

Has the individual with ASD received any inpatient hospital care in the last 6 months?

No ○
Yes ○

If the answer to the previous question was yes, please provide information on all that apply

	Number of days attended in the last 6 months
Psychiatric hospital	
Psychiatric ward in a general hospital	
General medical ward	
Hospital care in prison/ secure/semi-secure unit	
Other (please specify)	

Has the individual with ASD received any outpatient hospital care in the last 6 months?

No ○

Yes ○

If the answer to the previous question was yes, please provide information on all that apply

	Number of times services were used in the last 6 months
Psychiatric outpatient visit	
A & E	
Other hospital out-patient visit (excluding A & E, please specify)	

Please specify whether the individual with ASD has received any of the following forms of support in the last 6 months by completing the relevant sections of the table below. Please do not include services received in school/college/university or in a residential facility where the individual lives. If the carer or individual paid for any of these services direct (whether with personal funds or supported by benefit or allowance) please indicate the cost if known.

	Visits in the last 6 months	Average length of visit (if known)	Paid for direct by carer or individual (Yes/No)	If yes, how much did it cost?
Psychiatrist	☐	☐	☐	☐
Psychologist	☐	☐	☐	☐
Individual counselling/therapy	☐	☐	☐	☐
Group counselling/therapy	☐	☐	☐	☐
GP	☐	☐	☐	☐
Community learning disability nurse	☐	☐	☐	☐
Community nurse (other services)	☐	☐	☐	☐
Other community learning disability team member	☐	☐	☐	☐

	Visits in the last 6 months	Average length of visit (if known)	Paid for direct by carer or individual (Yes/No)	If yes, how much did it cost?
Community challenging behaviour team member				
Child development centre/community paediatrics				
Occupational therapist				
Speech therapist				
Physiotherapist				
Social worker				
Home help/home care worker				
Outreach worker/family support				
Private tuition				
Befriender				

	Visits in the last 6 months	Average length of visit (if known)	Paid for direct by carer or individual (Yes/No)	If yes, how much did it cost?
Day care centre	☐	☐	☐	☐
Social club	☐	☐	☐	☐
After-school club	☐	☐	☐	☐
Play-schemes	☐	☐	☐	☐
Sheltered workshop	☐	☐	☐	☐
Individual placement and support	☐	☐	☐	☐
Holiday schemes	☐	☐	☐	☐
Baby-sitter	☐	☐	☐	☐
Other (please specify type) ☐	☐	☐	☐	☐

If none of the above has been used in the last 6 months, please tick here and continue to the next question

None - continue to next question ○

PARENT/FAMILY/CARER IMPACT

Please complete only if you are a parent, family member or person caring for the individual with ASD

How would you rate the impact on your own life and that of your family of caring for the individual with ASD?

	No impact	Little impact	Moderate impact	Major impact
My ability to be in employment, training or education	○	○	○	○
The quality of my relationship with a partner or spouse	○	○	○	○
My ability to pursue social and leisure activities	○	○	○	○
The impact on my mental health	○	○	○	○
The impact on my physical health	○	○	○	○
The impact on other family members	○	○	○	○

If the answer to the previous question was ‘moderate impact’ or ‘major impact’, please tell us more about how these aspects of your life have been influenced by caring for someone with ASD.

Please complete only if you are a parent, family member or person caring for the individual with ASD

What is your own employment status? (please tick all that apply)

Employment (paid, including apprenticeship/internship or other training)	○
Employment (unpaid, including apprenticeship/internship, other training or voluntary work)	○
Supported employment	○
Unemployed - but available to work	○
Unemployed - and not available to work	○
Retired/pensioned – and not in employment	○
Housewife/husband - and not in employment	○
Full time student - and not in employment	○
Other (please specify)	○

Please complete only if you are a parent, family member or person caring for the individual with ASD.

If employed (paid), how many hours per week do you work in paid employment?

Please complete only if you are a parent, family member or person caring for the individual with ASD.

If employed (unpaid), how many hours per week do you work in unpaid employment?

Please complete only if you are a parent, family member or person caring for the individual with ASD.

If employed/full-time student, did you have any absences from work/place of study over the last 6 months as a result of your caring for the individual with ASD?

No ○

Yes ○ (If yes, please specify how many times in the last 6 months)

Please complete only if you are a parent, family member or person caring for the individual with ASD.

Have you (the carer) used any health or social care services over the last 6 months as a result of your caring for the individual with ASD? (For example, additional visits to the GP, family planning, social services, psychiatric services, marriage guidance, counselling, self-help groups, advice lines)

No ○

Yes ○

If yes, specify the type of health or social care service, how many times you used it over the last 6 months, and how long was the average appointment/contact

Contact for further information

We will contact some participants for further information. If you are willing to be one of them, please select the method by which you would like to be contacted below and provide us with the relevant details:

By phone at this telephone number:

By email at this address:

By post at this address:

Additional comments

If you wish to make any further comments please do so here.

B2 Combination of High Functioning Autism and Asperger's Syndrome Diagnostic Groups

High-Functioning Autism (HFA) is an unofficial diagnostic term used to describe individuals who presented autistic symptoms without cognitive impairment. Despite not appearing in DSM-IV or ICD-10, HFA is commonly used by researchers and clinicians to describe the nature of an individual's specific presentation of autistic symptoms and behaviours. It has also often been used interchangeably with Asperger's Syndrome, though some have also argued that it represents a distinct syndrome (Gillberg, 1998; Mattila et al., 2007).

A large number of studies have investigated to what extent those given HFA diagnoses differ from those with Asperger's Syndrome (AS). One meta-analysis provided evidence to suggest that those with AS typically report higher levels of IQ on average, with a higher proportion of individuals with AS reporting IQ scores of greater than 100, and a higher proportion of individuals with HFA reporting IQ scores below 100 (Chiang et al., 2014). However, in terms of the specific symptoms, behaviours and outcomes associated with AS and HFA, a large number of studies have found no evidence to suggest that these diagnoses can be considered to represent distinct conditions (Gillberg, 1998; Manjiviona & Prior, 1999; Noterdaeme et al., 2010; Ozonoff et al., 2000).

Overall, a decision was to group together those with HFA and AS for the purposes of analysis in this study, given that there is insufficient evidence to suggest that they are distinct diagnoses or sub-groups of ASC.

B3 Re-categorisation of Employment and Residential Responses Provided by Participants

Table A.4

Original Employment Categories Which Informed the Employment Status Variable used in Statistical Analyses

Original Employment Category	Assigned Category
Employment (paid, including apprenticeship/internship or other training) Employment (unpaid, including apprenticeship/internship or other training) Supported Employment Full-Time Student Part-Time Student Carer	Employed
Unemployed but available to work Unemployed but unavailable to work Housewife/Househusband Retired/Pensioned	Unemployed

Table A.5

Original Residential Categories Which Informed the Residential Status Variable used in Statistical Analyses

Original Employment Category	Assigned Category
In a Private Household with Friends/Flatmates In a Private Household with a Partner In a Private Household Alone In Supported Living Accommodation	Independent
In a Private Household with Parents or Relatives In Residential Care	Non-Independent

B4 Comparisons of Age Differences in Service Use

Mann Whitney U analyses were used to determine the impact of age on patterns of service use. No differences were found in the age of those who had and had not used at least one service in the previous six months, U = 19302.50, *p* = .46 or those who had and had not used psychiatric or psychological services, U = 19603, *p* = .031. Similarly, no differences were found between those who had and had not used cognitive and physical support services, U = 42223, *p* = .024, employment services, U = 961.50, *p* = .890 or general support services (including visits from social workers or community/district nurses), U = 11961, *p* = .026.

B5 Comparison of Gender Differences in Service Use

Chi-square analyses were used to assess whether there was a relationship between gender and the type of services used. No significant differences were found between those who had used at least one service in the six months prior to data collection and those who had used no services at all, χ^2 [1, n = 404] = .30, *p* = .58. Similarly, chi-square analyses indicated that there was no significant relationship between gender and the use of psychiatric or psychological services, χ^2 [1, n = 404] = .87, *p* = .35, physical and cognitive support services, χ^2 [1, n = 404] = .32, *p* = .567, employment services, χ^2 [1, n = 404] = .19, *p* = .66, or general support services (including visits from social workers or community/district nurses), χ^2 [1, n = 404] = 1.68, *p* = .20.

Appendix C: Study 3 Appendices

C1 Considerations relating to Sample Size

Guidelines for IPA recommend that it is best suited to studies involving smaller samples, given that it is a labour-intensive and time-consuming approach to analysis, aimed at providing an in-depth understanding of rich data (Pietkiewicz & Smith, 2014; Smith & Osborn, 2009). Several authors have proposed that the sample size for IPA studies can range between one and fifteen participants, with samples including between five and eight participants considered most ideal for this kind of analysis (Larkin et al., 2011; Pietkiewicz & Smith, 2014; Smith & Osborn, 2009; Smith & Shinebourne, 2012b; Turpin et al., 1997). However, the same recommendations advocate that the sample size required for this kind of study may also vary according the richness of data collected and the extent to which this data is helpful in answering research questions (Pietkiewicz & Smith, 2014; Smith & Osborn, 2009). For this reason, the sample size required in an IPA study is something that may continuously be reassessed throughout data collection, and it may be the case that the final sample size targeted may decrease or increase during data collection based upon on a researcher's assessment of the data they have so far collected (Pietkiewicz & Smith, 2014; Smith & Osborn, 2009). There may also be instances in which researchers prefer to focus on very small samples of one or two individuals, as a means of focusing-in on highly specific experiences (Smith et al., 1999; Smith & Osborn, 2009). In line with this, a number of studies have published an IPA of data collected from a single individual (e.g. Eatough & Smith, 2006; Steffen & Coyle, 2017).

Sample homogeneity is an additional factor that must be considered as part of the recruitment process for an IPA study (Pietkiewicz & Smith, 2014). Generally speaking, guidelines indicate that IPA studies should target homogenous samples, in which participants share at least some common traits, characteristics and experiences (Larkin et al., 2011; Smith et al., 1999). However, there is also an acknowledgement within the IPA literature that no sample will be truly homogenous, and that researchers should aim to highlight differences between participants and indicate the significance of these differences to the interpretations of results and the broader implications of findings (Pietkiewicz & Smith, 2014; Smith & Osborn, 2009).

In line with these recommendations, this study set out to recruit between six and eight participants with Autism Plus (i.e. those with an ASC diagnosis and at least one co-occurring mental health or neurodevelopmental diagnosis). Further details of the participant criteria for this study are described in Section 7.2.1.

C2 Social Media Advertisement

The following form of words was used to advertise Study Three on the websites and social media pages of organisations and communities which provided support for individuals with ASC and their families.

Life with Autism Spectrum Disorders and additional Neurodevelopmental or Mental Health Diagnoses

I am a PhD researcher at the University of Strathclyde, and I am currently looking to interview individuals, aged 25 years and older from West Central Scotland, who have previously received a Autism Spectrum Disorder diagnosis (including autism, atypical autism, Asperger’s and PDDNOS), and who have at least one other neurodevelopmental or mental health diagnosis (e.g. ADHD, depression or anxiety).

The aim of the interview is to learn more about the impact of these symptoms, particularly in relation to independent living, relationships, employment, service use and support. The interview will be carried out at the University of Strathclyde, and will last no longer than 1 hour and 20 minutes. If you are interested in taking part in this research, please click the link below to find out more about the study, and to agree to take part.

https://strathbusiness.qualtrics.com/jfe/form/SV_cYgVda6DsOwOiIR

If you have any other questions about this research, please contact:

michael.connolly@strath.ac.uk

C3 Participant Information Sheet

Participant Information Sheet

Name of department: Department of Psychological Sciences & Health
Title of the study: Life with Autism Spectrum Disorders and additional Neurodevelopmental or Mental Health Diagnoses

Introduction

My name is Michael Connolly and I am a PhD researcher at the School of Psychological Sciences and Health at the University of Strathclyde, and my research focuses on the everyday experiences of individuals with Autism Spectrum Disorders (including those with Autism, Atypical Autism, High Functioning Autism, Asperger's Syndrome and PDDNOS diagnoses). My research is being supervised by Professor James Boyle, also at the University of Strathclyde, and our contact details can be found at the end of this information sheet.

What is the purpose of this research?

The aim of this research is to learn more about the experiences of those with Autistic diagnoses, who also have at least one other diagnoses (e.g. ADHD, Depression or Anxiety). In particular, we are interested in how your symptoms impact your everyday life, with a particular focus on your ability to live independently, form relationships, travel and gain employment, and your experiences with service use and support.

Researcher Christopher Gillberg has proposed that individuals who have an autistic diagnosis, and at least one other clinical diagnosis, may be less likely to experience positive outcomes across different aspects of life. The data you provide as part of this study will be used to investigate whether there is evidence to support this theory.

Further, it is hoped that the information collected as part of this study may be used to inform the planning and provision of services and support for individuals with autistic diagnoses who also have other conditions.

Do you have to take part?

Participation in this study is voluntary, and it is completely your decision whether you chose to take part. You are free to withdraw from the research at any stage without consequence, and any information you have provided prior to withdrawing will be destroyed.

If after taking part in the study you decide you would like to withdraw the information you have submitted, this can be done any time until the reports relating to this data have been published. With this in mind, please make any requests to withdraw data within one month of completing the interview.

What will you do in the project?

To take part in the study you will be asked to attend the University of Strathclyde, and to complete a short questionnaire which will ask about your age, gender identification, the diagnoses which you have and the symptoms that you experience. Following this, you will be asked to take part in an interview that will last no longer than 1 hour and 20 minutes, and will focus on the impact of your symptoms on different aspects of your life (examples of the kind of questions you will be asked have been included at the end of this information sheet).

Who can take part?

Individuals aged 25 years old and above, living in West Central Scotland (that is, anyone living in the Greater Glasgow, Argyll & Clyde, Lanarkshire or Ayrshire & Arran NHS Health Board areas), who have a co-occurring neurodevelopmental or mental health diagnosis in addition to having an Autism Spectrum Disorder Diagnosis (including diagnoses of Autism, Atypical Autism, High Functioning Autism, Asperger’s Syndrome and PDDNOS diagnoses). As the study is interested in interviewing individuals who meet these criteria, it is important that anyone interested in taking part can communicate information about their everyday life in an interview setting.

For those unable to travel independently to the study, reasonable transport costs can be covered.

What are the potential risks to you taking part?

The interview will discuss aspects of life that may be difficult and it is possible that some individuals will feel uncomfortable. With this in mind, those taking part will be able to take breaks any time they feel they need to, and will be reminded that they are not required to provide an answer each and every question. In cases where a question makes a participant uncomfortable, they can ask the researcher to move on without any consequence.

In the event that a participant experiences distress, the researcher will ensure that support is available from a first aider. Participants will also be encouraged to bring details of an emergency contact with them to the study, and in the event of an anxiety attack or any other health issues, the researcher will be able to call this emergency contact on behalf of a participant, should this be requested, or it is judged by a first aider to be necessary.

In terms of more general health and safety risks, the researcher will be familiar with the fire action plan for rooms where the research will be taking place, and will be able to contact first-aiders in the case of any other accidents or emergencies. However, such incidents are considered to be very unlikely.

What information is being collected in the project?

Data collected using the questionnaire mentioned above, will be analysed with the use of computer software. Personal information (which could be used to identify an individual) will not be uploaded onto the computer. Instead, participants’ names will be replaced with pseudonyms (made-up names). Interviews will be audio recorded, transcribed and written up once the interview has been completed. As part of the writing up process, personal or identifiable information will be blanked out (redacted).

Who will have access to the information?

Data collected will only be accessible to the researcher, and the Supervisor for this project, Professor James Boyle. The researcher will use the data to complete analyses which will be presented as part of a PhD research thesis, and in the future may be published or presented at academic conferences.

An anonymised version of the data (where names have been changed to protect the potential identification of participants), will also be held on the University of Strathclyde's secure online database 'Pure'. Data will be stored on this database in order to respond to follow-up enquiries about the research. This data will continue to only be accessible to the researcher and Professor Boyle.

For more information on how your personal information will be used and stored, please read the Privacy Notice for Research for Participants, which has been included at the end of this information sheet.

Where will the information be stored and how long will it be kept for?

All data will be stored on the University of Strathclyde's secure, encrypted online storage facilities. In order to ensure the authenticity of research, the University of Strathclyde policy is that data collected for research purposes is stored until it is no longer required.

Thank you for reading this information – please ask any questions if you are unsure about what is written here.

What happens next?

If you would like to participate in the study, please review and sign the consent form on the following page, and if at any stage you would like to find out more information about the study, then please use the contact details provided below.

If you are no longer interested in taking part in this study, thank you for taking the time to read this information.

If you would like to learn more about the findings of this research, please let Michael know, and he will record this, and be in touch once the research is complete.

Researcher Contact Details:

Michael Connolly (PhD Researcher)

Email: michael.connolly@strath.ac.uk

Chief Investigator Details:

Professor James Boyle
Graham Hills Building
University of Strathclyde
School of Psychological Sciences & Health
50 George Street
Glasgow
G1 1QE
Email: j.boyle@strath.ac.uk

This research was granted ethical approval by the University of Strathclyde Ethics Committee.

If you have any questions/concerns, during or after the research, or wish to contact an independent person to whom any questions may be directed or further information may be sought from, please contact:

Secretary to the University Ethics Committee
Research & Knowledge Exchange Services
University of Strathclyde
Graham Hills Building
50 George Street
Glasgow
G1 1QE

Telephone: 0141 548 3707
Email: ethics@strath.ac.uk

Sample Interview Format (Interview Schedule)

General Starter Questions

1. How do you feel your autistic symptoms affect your day-to-day life?
2. How do you feel the symptoms associated with your other diagnosis affect your day to day life?

Independent Living and Travel

3. In what way do you feel that your autistic symptoms have an impact on your ability to live an independent life?
4. In what way do you feel that the symptoms associated with your other diagnosis affect your ability to live an independent life?
5. In what way do you feel there have been times in your life where you need to rely on the support of others?
6. Tell me about your current living situation, do you live on your own or with someone else?

Follow up questions (if required):

Do any aspects of your autistic or the symptoms associated with your other diagnosis make it difficult to live independently?

How do you feel about the fact that you are/are not able to live independently?

7. What difference would it make to your life if you were able to live more independently?
8. Do you feel comfortable travelling independently/are you able to use public transport?

Follow up questions (if required):

What freedom does independent travel afford you?/ To what extent do you feel limited by not being able to travel independently?

What are the specific problems that your autistic symptoms cause when travelling independently?

What are the specific problems that your other symptoms cause when travelling independently?

Employment

1. Are you currently in employment or a student?

Follow up questions:

If not, how do you spend your day?

To what extent do you feel your autistic symptoms affect your ability to work or be employed? And how do these symptoms affect your relationships in the work place?

To what extent do you feel the symptoms associated with your other diagnosis affect your ability to work or be employed? And how do these symptoms affect your relationships in the work place?

Relationships

9. Do you have friends who you spend time with?

   Follow up questions:

   If yes, how regularly do you see your friends, and how do you spend your time together?

   If no, what have been your experiences with friendships in the past?

10. Do you have any relationships which are closer than friendships, such as a girlfriend, boyfriend, partner or spouse?

    Follow up questions:

    In what way do you feel your autistic symptoms make it difficult to interact with people and make friends or form closer relationships?

    In what way do you feel the symptoms associated with your other diagnosis have an impact on the relationships that you have?

11. Do you get on well with your family members?

    Follow up questions:

    Do you feel your autistic symptoms or the symptoms associated with your other diagnoses affect your relationship with your other family members?

Support, Service Use and Social Media

12. Have you ever attended any services or received any support for your autistic symptoms?

    Follow up questions:

    If yes, which services and support have you received, and what has your experience with these services been?

    If no, are there any factors which you feel have prevented you from accessing or using this kind of support?

13. Other than those already discussed, have you ever attended any services or received any support for your other symptoms?

    Follow up questions:
    If yes, which services and support have you received, and what has your experience with these services been?

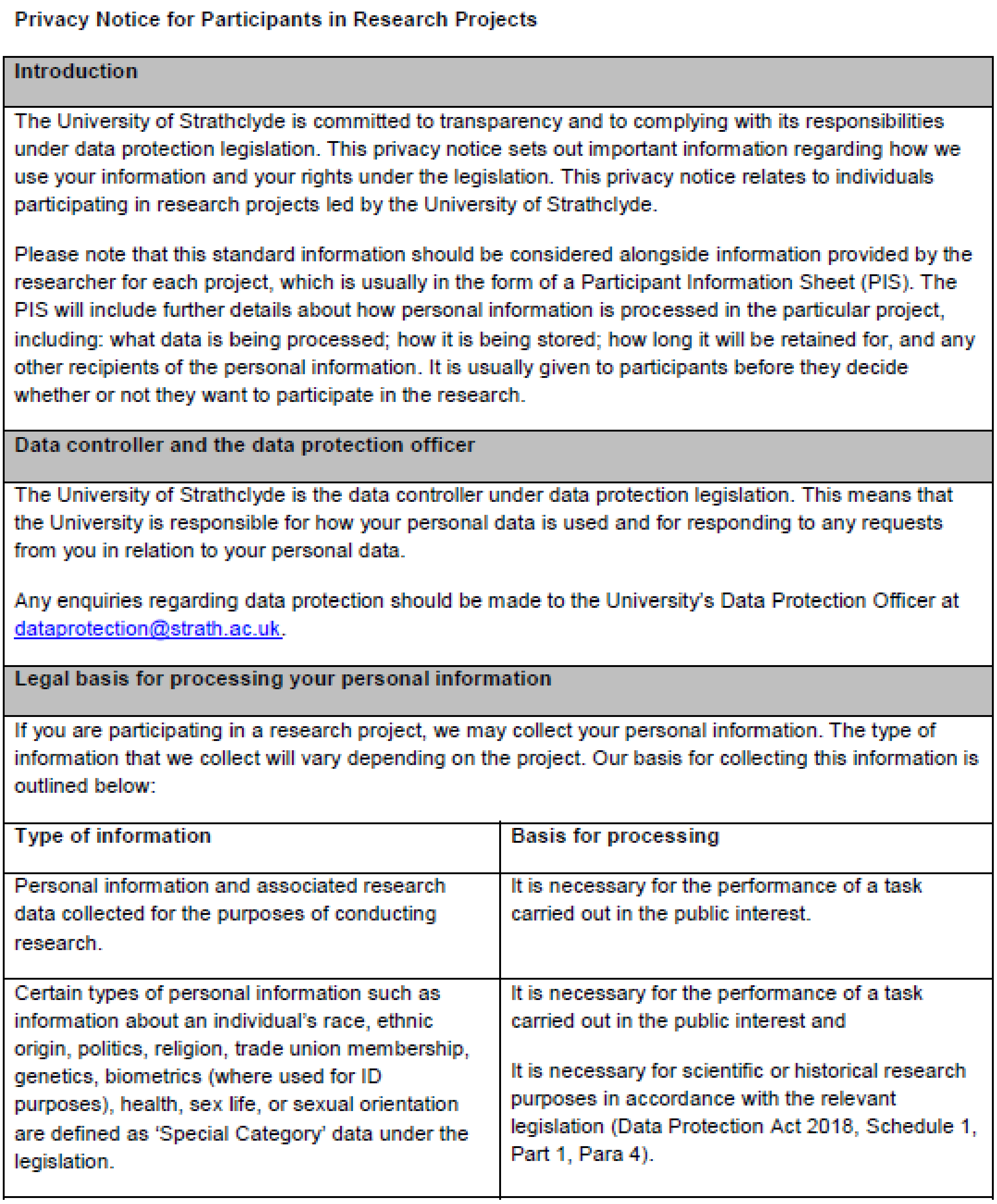
    If no, are there any factors which you feel have prevented you from accessing or using this kind of support?

14. Have you found any kind of support for your autistic symptoms online? This can include support sites, forums, online communities (e.g. Facebook).

    Follow up question:
    In what way have these resources been useful?

15. Have you found any kind of support for the symptoms associated with your other diagnosis online? This can include support sites, forums, online communities (e.g. Facebook, WhatsApp).

    Follow up question:
    In what way have these resources been useful?



Privacy Notice for Participants in Research Projects

Introduction

The University of Strathclyde is committed to transparency and to complying with its responsibilities under data protection legislation. This privacy notice sets out important information regarding how we use your information and your rights under the legislation. This privacy notice relates to individuals participating in research projects led by the University of Strathclyde.

Please note that this standard information should be considered alongside information provided by the researcher for each project, which is usually in the form of a Participant Information Sheet (PIS). The PIS will include further details about how personal information is processed in the particular project, including: what data is being processed; how it is being stored; how long it will be retained for, and any other recipients of the personal information. It is usually given to participants before they decide whether or not they want to participate in the research.

Data controller and the data protection officer

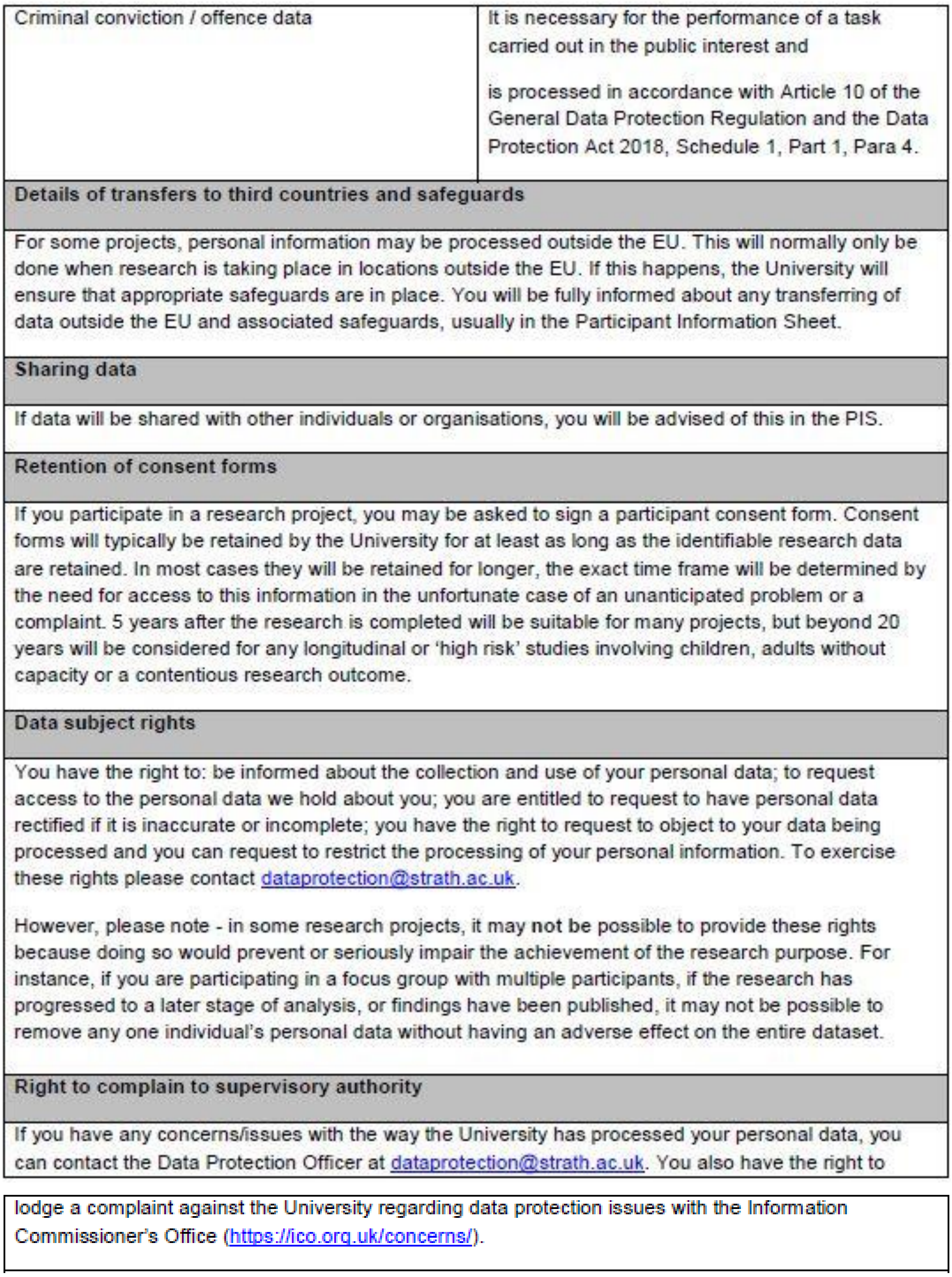
The University of Strathclyde is the data controller under data protection legislation. This means that the University is responsible for how your personal data is used and for responding to any requests from you in relation to your personal data.

Any enquiries regarding data protection should be made to the University's Data Protection Officer at dataprotection@strath.ac.uk.

Legal basis for processing your personal information

If you are participating in a research project, we may collect your personal information. The type of information that we collect will vary depending on the project. Our basis for collecting this information is outlined below:

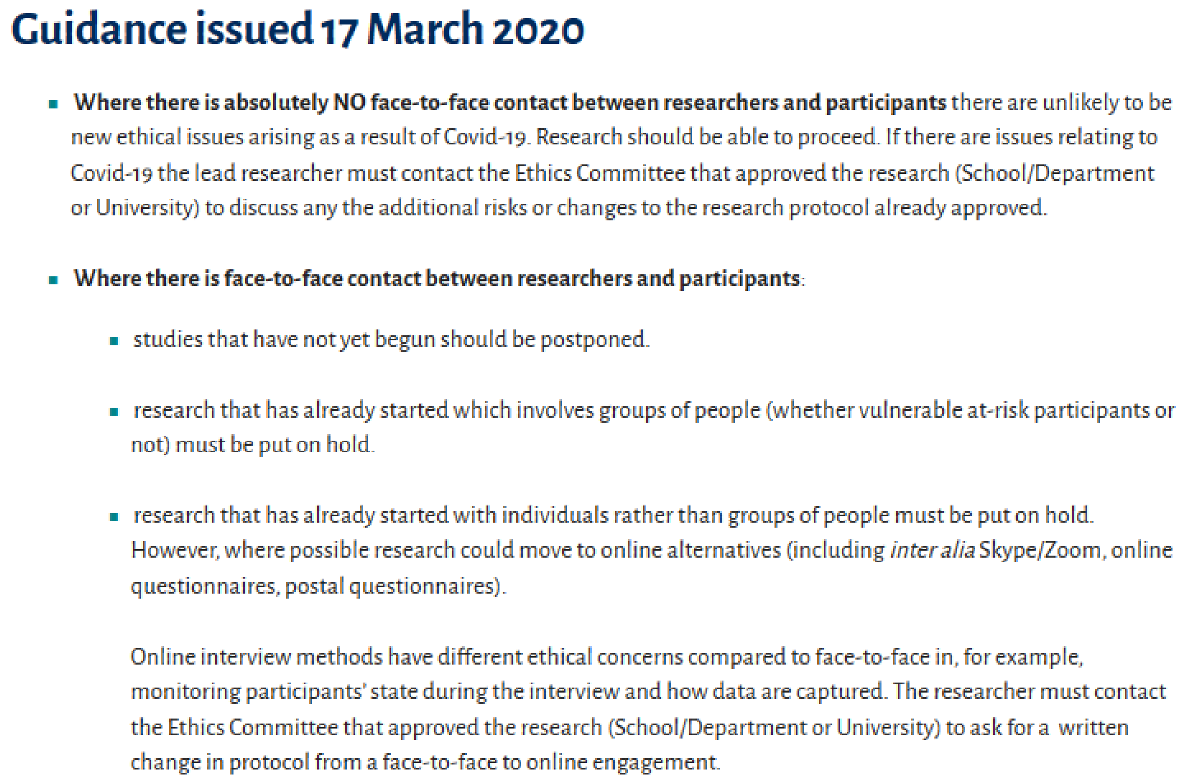
Type of information	**Basis for processing**
Personal information and associated research data collected for the purposes of conducting research.	It is necessary for the performance of a task carried out in the public interest.
Certain types of personal information such as information about an individual's race, ethnic origin, politics, religion, trade union membership, genetics, biometrics (where used for ID purposes), health, sex life, or sexual orientation are defined as 'Special Category' data under the legislation.	It is necessary for the performance of a task carried out in the public interest and It is necessary for scientific or historical research purposes in accordance with the relevant legislation (Data Protection Act 2018, Schedule 1, Part 1, Para 4).



Criminal conviction / offence data	It is necessary for the performance of a task carried out in the public interest and is processed in accordance with Article 10 of the General Data Protection Regulation and the Data Protection Act 2018, Schedule 1, Part 1, Para 4.
Details of transfers to third countries and safeguards	
For some projects, personal information may be processed outside the EU. This will normally only be done when research is taking place in locations outside the EU. If this happens, the University will ensure that appropriate safeguards are in place. You will be fully informed about any transferring of data outside the EU and associated safeguards, usually in the Participant Information Sheet.	
Sharing data	
If data will be shared with other individuals or organisations, you will be advised of this in the PIS.	
Retention of consent forms	
If you participate in a research project, you may be asked to sign a participant consent form. Consent forms will typically be retained by the University for at least as long as the identifiable research data are retained. In most cases they will be retained for longer, the exact time frame will be determined by the need for access to this information in the unfortunate case of an unanticipated problem or a complaint. 5 years after the research is completed will be suitable for many projects, but beyond 20 years will be considered for any longitudinal or 'high risk' studies involving children, adults without capacity or a contentious research outcome.	
Data subject rights	
You have the right to: be informed about the collection and use of your personal data; to request access to the personal data we hold about you; you are entitled to request to have personal data rectified if it is inaccurate or incomplete; you have the right to request to object to your data being processed and you can request to restrict the processing of your personal information. To exercise these rights please contact dataprotection@strath.ac.uk. However, please note - in some research projects, it may **not be** possible to provide these rights because doing so would prevent or seriously impair the achievement of the research purpose. For instance, if you are participating in a focus group with multiple participants, if the research has progressed to a later stage of analysis, or findings have been published, it may not be possible to remove any one individual's personal data without having an adverse effect on the entire dataset.	
Right to complain to supervisory authority	
If you have any concerns/issues with the way the University has processed your personal data, you can contact the Data Protection Officer at dataprotection@strath.ac.uk. You also have the right to lodge a complaint against the University regarding data protection issues with the Information Commissioner's Office (https://ico.org.uk/concerns/).	

C4 University of Strathclyde Ethics Committee Covid-19 Guidance

The University of Strathclyde Ethics Committee made the following recommendations on the 17th March 2020.



Guidance issued 17 March 2020

- **Where there is absolutely NO face-to-face contact between researchers and participants** there are unlikely to be new ethical issues arising as a result of Covid-19. Research should be able to proceed. If there are issues relating to Covid-19 the lead researcher must contact the Ethics Committee that approved the research (School/Department or University) to discuss any the additional risks or changes to the research protocol already approved.

- **Where there is face-to-face contact between researchers and participants**:

  - studies that have not yet begun should be postponed.

  - research that has already started which involves groups of people (whether vulnerable at-risk participants or not) must be put on hold.

  - research that has already started with individuals rather than groups of people must be put on hold. However, where possible research could move to online alternatives (including *inter alia* Skype/Zoom, online questionnaires, postal questionnaires).

    Online interview methods have different ethical concerns compared to face-to-face in, for example, monitoring participants' state during the interview and how data are captured. The researcher must contact the Ethics Committee that approved the research (School/Department or University) to ask for a written change in protocol from a face-to-face to online engagement.

This information was retrieved from:
https://www.strath.ac.uk/coronavirus/staff/universityethicscommittee/

Date retried: 9 November 2020

C5 Considerations Relating to Video Calls as an Alternative to Face-to-Face Interviews

Given the Government restrictions put in place in response to the COVID-19 pandemic, it was not possible to continue data collection for Study Three through the use of face-to-face interviews. As a result, data collection through video call was considered as a means of proceeding with data collection in line with University and Scottish Government Guidelines.

Online communication platforms such as Skype and Zoom offer researchers an alternative method of collecting qualitative data, which may be considered to have several advantages over in-person interviews (Archibald, Ambagtsheer, Casey & Lawless, 2019; Deakin & Wakefield, 2014). Researchers may not always have the time or budget to travel to interview individuals who are further away, and similarly potential participants may be put-off taking part in an interview if they know they will be required to travel for a significant length of time or pay travel costs. As online interviews can often take place in a location which suits both the research and participant’s needs, it may be the case that research which allows for interviews to be conducted online, could allow researchers to collect data from a larger number of people (Edje, Miller, Kiefer & Oram, 2013; Krouwel, Jolly & Greenfield, 2019). Research focusing on the participation of autistic individuals in research has also argued that given that there are a diverse range of needs and impairments across the autistic spectrum, it is important to offer individuals with ASC multiple ways in which they can take part in research, so that samples do not exclude those who may have difficulties travelling or visiting a particular type of environment as part of their symptoms (Nicolaidis et al., 2019).

Video calls were therefore considered as a way in which data collection for Study 3 could proceed in line with the Government COVID-19 restrictions. However, in exploring this possibility, a number of limitations to this approach also emerged, some of which had particular relevance to the type of individuals who would potentially take part in Study 3.

Firstly, the interviews conducted as part of Study Three were intended to cover potentially sensitive topics and given that the target population for this study included individuals who experienced mental health conditions such as depression and anxiety, it was possible that some individuals could become upset as part of the discussions. With this in mind, a major concern regarding the use of video calls was that the researcher would have very little control over what happened next in a situation where participants became upset, particularly if they ended the call as a result. This was in contrast to the face-to-face interviews that took place within the University of Strathclyde campus in which a protocol was put in place for addressing this kind of situation (see Section Appendix C8).

In addition to calls being deliberately cut-off there were also concerns about calls unintentionally ending as a result of software and connectivity issues. Video calls are prone to technical faults (e.g. loss of connection and delays in the transfer of audio/video information), with a recent methodological paper focusing on research involving video calls indicating that 14 of the 16 participants they interviewed using video call experienced difficulties connecting to the call in the first instance and 4 continued to experience quality issues throughout the call (Archibald et al., 2019). More generally, ‘Dropped calls’ (i.e. calls cutting out) and issues associated with the quality of video calls have regularly been cited as a feature of this methodology in reviews of research involving video calls (Deakin & Wakefield, 2014; Seitz, 2016). This kind of disruption have the potential to be particularly stressful and frustrating for participants when discussing topics of a sensitive nature, and there is some evidence of this in previous research of this nature. Seitz (2016) conducted interviews with student researchers who had used video calls as part of their research projects and reported that a when discussing sensitive topics, a dropped call could change the atmosphere of the interview in a way that was difficult to move on from.

On a related note, there was also some concern that video calls prevent participant and interviewer from being able to see one another entirely which can create difficulties in perceiving body language. This has particular significance to interviews involving sensitive questions (as was the case in Study Three of this Thesis), as such body language is key to knowing whether it is suitable to continue asking questions on a topic or whether there is a need to take a pause and check that the participant is well (Seitz, 2016; Weller, 2015).

A further concern was the location in which video calls would potentially be conducted, which given the constraints of the pandemic would have been within participants homes. This was considered to be disadvantageous to the research conducted as part of Study Three for two reasons. Firstly, the researcher would have no control over potential interruptions or noise cause by other members of the participants household, an issue raised by previously cited by researchers using this methodology (Deakin & Wakefield, 2014). These disruptions could not only affect the flow of the conversation within the interview, but also make parts of the interview inaudible which could mean questions and responses had to be repeated and could create difficulties transcribing the interview (Seitz, 2016). This would be in contrast to the face-to-face interviews conducted for this study were carried out in a room in a quiet corridor within the University of Strathclyde campus, meaning that disruptions to the interview and the potential impact of these on the interview recoding was minimal. Secondly, the intention of the interviews was to allow participants to speak freely about their lives and experiences, and this is something which may have been restricted by others in the household being in close proximity as the interview conducted. The location of the interview could therefore have also led participants to be less open in their responses to interview questions.

Finally, previous research has indicated that participants involved in video interviews will provide less detailed responses than those who take part in face to face interviews (Krouwel et al., 2019). This was also of some concern, given that the aim of these interviews was to develop a deeper, more detailed understanding of the impact of co-occurring symptoms through discussion, which allowed participants to discuss any issues which they believed to be relevant. It may have therefore been the case that video calls would have resulted in participants telling only part of their story, and as such providing a less complete account of their experiences.

While offering a useful and convenient alternative to face-to-face interviews, it was ultimately decided that it would not be appropriate to proceed with data collection for Study Three using video calls given (1) concerns about the safety and well-being of participants and (2) the potential for this method of data collection to affect the quality and depth of information collected as part of the interviews.

C6 Participant Questionnaire

Demographic and Diagnostic Questionnaire

The following questions will ask you to provide some basic details about yourself and your diagnoses. If you have any difficulties understanding any of the questions, please ask the researcher for some assistance.

Demographic Information

1. Please state your age: ________

2. Indicate your preferred gender identity: ____________________________

   Or, if you would prefer not to specify, please tick here ☐

Diagnostic Information

3. Please state the formal **autistic diagnoses** you have been given (e.g. Autism Spectrum Disorder, Autistic Disorder, Asperger’s, PDD-NOS etc). This diagnosis should have been given to you by a professional.

4. Please specify which **other diagnoses** you have been given (e.g. ADHD, Epilepsy, Depression, Anxiety etc.). These diagnoses should have been given to you by a professional.

5. Please state whether there are any terms you prefer to use when describing your autistic symptoms (e.g. Asperger’s, High Functioning Autism, ASD etc.):

Adult Social Behaviour Questionnaire (ASBQ: Horwitz et al., 2016)

The following pages will ask you to provide further information on your symptoms and behaviours. These pages will provide you with a list of behaviours – please indicate the extent to which these behaviours applied to you **within the last two months**.

QUESTIONNAIRE GUIDANCE

- If the **behaviour applies to you**, and it something you have done **regularly** in the **previous two months** please mark '**clearly applies**' with a tick ✓
- If the **behaviour applies to** you, and it something you have done **sometimes** in the **previous two months** please mark '**somewhat applies**' with a tick ✓
- If the behaviour **does not apply to you**, and is not something you have done in the **previous two months**, please mark '**does not apply**' with a tick ✓
- **If you make a mistake,** please draw over the incorrect answer with a cross × and mark the correct answer with a tick ✓

The questionnaire consists of 44 questions, and should take no longer than 10 minutes to complete. Please take a break if you feel you need to, and if you have questions about any aspects of the questionnaire, please let the researcher known.

Remember that you are free to withdraw from the research at any stage

Adult Social Behaviour Questionnaire (ASBQ)

		Does Not Apply	Somewhat Applies	Clearly Applies
1.	You find it difficult to put yourself in someone else's shoes, for example, you can't see why someone is angry.	☐	☐	☐
2.	You don't get jokes.	☐	☐	☐
3.	You panic when things turn out differently than you are used to.	☐	☐	☐
4.	You feel the urge to flap your hands or arms about when you are excited.	☐	☐	☐
5.	You take everything literally, for example, you don't understand certain expressions.	☐	☐	☐
6.	You don't differentiate between friends and strangers, for example, you don't care who you are with.	☐	☐	☐
7.	The reason why you would contact others is to get things done rather than because you are interested in them.	☐	☐	☐

		Does Not Apply	Somewhat Applies	Clearly Applies
8.	You are very naïve: you believe everything you are told.	☐	☐	☐
9.	It takes you ages to get used to somewhere new.	☐	☐	☐
10.	You resist change; if it were left up to you everything would stay the same.	☐	☐	☐
11.	You feel the urge to rock back and forth.	☐	☐	☐
12.	You feel the urge to make strange, quick movements with your hands and fingers.	☐	☐	☐
13.	You don’t notice when others make fun of you.	☐	☐	☐
14.	You want to do certain things in exactly the same way every time.	☐	☐	☐
15.	You find it hard to follow the gist of a conversation – you miss the point	☐	☐	☐
16.	You seek contact with anyone and everyone; you show no reserve.	☐	☐	☐

		Does Not Apply	Somewh at Applies	Clearly Applies
17.	You do not like surprises, for example, unexpected visitors.	☐	☐	☐
18.	You really enjoy making certain movements and you want to repeat them	☐	☐	☐
19.	You do not take the initiative in contacts with other people.	☐	☐	☐
20.	You are unaware of other people's emotional needs, for example, you do not need encourage other people or reassure them.	☐	☐	☐
21.	You touch people when it is not suitable, for example, you hug virtual strangers.	☐	☐	☐
22.	You don't like a lot of things happening at once.	☐	☐	☐
23.	You often want to smell objects	☐	☐	☐
24.	You have little or no interest in socialising with others.	☐	☐	☐

		Does Not Apply	Somewhat Applies	Clearly Applies
25.	The questions you ask are too personal, or you tell others things that are too personal.	☐	☐	☐
26.	You find it hard to sense what someone else will like or think is nice.	☐	☐	☐
27.	You need an explanation before you understand the meaning behind someone’s words	☐	☐	☐
28.	You behave the same wherever you are; it makes no difference to whether you are at home or somewhere else (visiting others, at work, in the street)	☐	☐	☐
29.	You give answers that are not relevant – because you haven’t really understood the question.	☐	☐	☐
30.	You ignore invitations from others to do something with them.	☐	☐	☐
31.	You are not really bothered by someone else in pain.	☐	☐	☐

		Does Not Apply	Somewhat Applies	Clearly Applies
32.	The only contact you have with others is when you have to buy something or arrange something, for example with people in a shop or in a government office	☐	☐	☐
33.	You are fascinated by certain sounds, for example, the squeaking of a door, the humming of a fridge, the rustling or paper.	☐	☐	☐
34.	You don’t notice when someone is upset or has problems.	☐	☐	☐
35.	You really need fixed routines and things to be predictable.	☐	☐	☐
36.	You avoid people who try to make contact with you.	☐	☐	☐
37.	It’s easy to take advantage of you or get you to do other people’s dirty work.	☐	☐	☐
38.	You don’t enjoy doing things with other people, for example, doing a chore together, or goings somewhere together.	☐	☐	☐

		Does Not Apply	Somewhat Applies	Clearly Applies
39.	You feel the urge to often touch things to see what they feel like.	☐	☐	☐
40.	You ask strangers for things you need, for example, for food or drink if you are hungry or thirsty.	☐	☐	☐
41.	You hate it when plans are changed at the last minute.	☐	☐	☐
42.	You really revel in certain colours, shapes or moving objects.	☐	☐	☐
43.	You are a loner, even in a group you hold yourself apart.	☐	☐	☐
44.	You don’t show sympathy when others hurt themselves or are unhappy.	☐	☐	☐

You have reached the end of the questionnaire. **Please return your responses to the researcher.**

C7 Further Details on the Construction of the ASBQ Measure

The construction of the ASBQ was partly based upon a pre-existing measure, the Childhood Social and Behaviour Questionnaire (CSBQ), which had been used successfully as an indicator of autistic symptoms and behaviours amongst children (Luteijn et al., 2000).. The ASBQ was intended to capture many of the same traits and characteristics as the CSBQ, and in doing so converted many of the items from the CSBQ to be relevant to adult life. Horwitz et al. (2016) combined these converted items with additional items they considered relevant to the lives of ASC adults, resulting in 90 candidate items aimed at capturing autistic symptoms and behaviours. A two-step model was used to refine these items and construct the final measure. Firstly, principle components analysis (PCA) was used to assess to what extent these items could load onto three factors representing the three core domains of autistic symptoms and behaviours; social difficulties, problems with communication and stereotyped behaviours. Items which clearly loaded onto one of these factors, and did not cross-load with additional factors, were retained. Following this, the second stage of this process used a second PCA to establish the extent to which these remaining items could be found to load onto six hypothesised sub-domains of autistic symptoms and behaviours (namely, reduced empathy, social contact, violation of social conventions, reduced social insight, insistence on sameness and sensory stimulation/ stereotyped behaviours). From this analysis, Horwitz et al. (2016) included the items which best loaded onto each of these hypothesised sub-domains in their final measure, though limited the maximum number of items selected to a maximum of 8 per sub-domain. Factor loadings ranged from .44 - .93, though the average factor loadings across the scales was .68. As such, the final measure included six subscales, relating to the six sub-domains mentioned above, each of which included between 6 and 8 items. These sub-scales are described further in section 5.1.2.

C8: Protocol for Responding to Concerns about Participant and Researcher Well-being

Given the potentially sensitive nature of the interviews, a protocol was developed for responding to situations where participants became uncomfortable or upset. In the first instance, at any signs of discomfort the researcher would pause the interview and check that the participant was completely comfortable with proceeding. In any instances where are participant became visibly distressed or where the researcher was concerns about the well-being of the participant after the interview the interview would be terminated, and a pre-determined Health and Care Professions Council (HCPC) registered practitioner psychologist located within the University campus would be contacted. This psychologist was qualified to debrief any participants who became distressed during the interview and to provide guidance on any additional actions required within a situation of this nature. Any time an interview was conducted, it was ensured that this individual was free to respond to potential requests for assistance and was within the building in which the interviews were being conducted to allow them to quickly access the interview room if necessary. This individual was also the first point of contact in instances where the researcher was for any reason concerned about their own well-being.

C9 Debrief Sheet

Debrief

Name of department: Department of Psychological Sciences & Health

Title of the study: Life with Autism Spectrum Disorders and additional Neurodevelopmental or Mental Health Diagnoses

The aim of this study is to learn more about the impact which co-occurring conditions may have for individuals with Autistic diagnoses. Researcher Christopher Gillberg has proposed that individuals who have an autistic diagnosis, and at least one other clinical diagnosis, may be less likely to experience positive outcomes across different aspects of life.

Your data from the questionnaire and the interview will help us to further investigate this theory, and the impact of your diagnoses on your everyday experiences.

It is hoped that the information collected as part of this study can be used to inform the planning and provision of services and support for individuals with autistic diagnoses who also have other conditions.

Finally, I would like to express my thanks to you for your time and for taking part in this research.

Michael Connolly

PhD Researcher

If this interview has made you think more about your symptoms, the impact that they have, and the support that is available to individuals with autistic symptoms, then you may find the following online resources useful.

Scottish Autism: https://www.scottishautism.org/

National Autistic Society: https://www.autism.org.uk/

Autism Network Scotland: https://www.autismnetworkscotland.org.uk/

Autism Initiatives: https://www.autismnetworkscotland.org.uk/

C10 Smith (2011) Quality Evaluation Criteria for Interpretative Phenomenological Analysis (IPA) Studies

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Acceptable

The paper meets the following four criteria:

- Clearly subscribes to the theoretical principles of IPA: it is phenomenological, hermeneutic and idiographic.
- Sufficiently transparent so reader can see what was done.
- Coherent, plausible and interesting analysis.
- Sufficient sampling from corpus to show density of evidence for each theme:
  N1_3: extracts from every participant for each theme;
  N4_8: extracts from at least three participants for each theme; and
  N_8: extracts from at least three participants for each theme + measure of prevalence of themes, or extracts from half the sample for each theme.

Overall the paper is judged sufficiently trustworthy to accept for publication and include in a systematic review.

Caveats
Compensation. Evidence base and interest factors considered together so that, e.g., a paper with particularly interesting data may gain compensation for a less than ideal evidence base.
Partial acceptability. A paper may be deemed acceptable if it has partial but discrete pockets of acceptable, e.g.,
1. Paper may present four themes, two of which are interesting and well evidenced while two of them are not. In this case, the paper can be considered acceptable as the two good themes make a sufficient contribution in their own right.
2. Paper may have number of themes but evidence each with data from the same single participant. This paper may be considered acceptable if the account of the individual is sufficiently coherent that it can be read as an interesting idiographic case-study.
3. Paper may present data from two participant groups, e.g., males and females and be deemed acceptable for one participant group but not the other.
Safe or borderline? A paper showing sufficient sampling as described above is deemed safe. A paper with a sample over eight with extracts from enough participants to illustrate variation but without detail of prevalence or enough evidence of density of themes is deemed borderline. See text for more details.

Unacceptable

The paper fails on one of the four criteria for acceptable. It may be:

- not consistent with theoretical principles of IPA;
- insufficiently transparent for reader to see what was done;
- not of sufficient interest; and
- poorly evidenced.

Predominantly what lets a paper down is the poor evidence base. Typical ways this can occur:

- large number of descriptive/superficial themes from a large number of participants;
- each theme has short summary and one or two extracts without interpretation;
- insufficient extracts from participants to support the themes being illustrated;
- no explanation for how prevalence of the themes was determined; and
- analysis is crude, lacks nuance.

Overall the paper is not trustworthy and would not be judged acceptable for publication.

Good

Paper must clearly meet all the criteria for acceptable. It then offers these three extra things:

- well focused; offering an in-depth analysis of a specific topic;
- data and interpretation are strong; and
- reader is engaged and finds it particularly enlightening.

Overall the paper could be recommended to a novice as a good exemplar of IPA.

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