Understanding the Self-identification of Autism in Adults Within the UK Population: Development of a Screening Questionnaire

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Abstract

Despite the recognition that autism may not be diagnosed until adulthood, many adults report difficulties throughout the referral and diagnostic processes of an adult autism assessment. Simultaneously, adults who self-identify as autistic is becoming a growing trend. Yet, little is known about the self-identification process of autism in adults, and minimal practical effort has been made to improve the autism diagnostic pathway for adults. To address these gaps, this thesis began by conducting a scoping review to ascertain (1) what research has been conducted on the self-identification process of autism in adults, who do and do not have a formal diagnosis of autism and (2) to ascertain which aspects of the self-identification process could be used to improve the referral and diagnostic processes of an adult autism assessment. These findings informed the two aims of this thesis: (1) to understand the self-identification process of autism in UK adults, who do and do not have a formal diagnosis of autism; (2) to use this understanding to develop a screening questionnaire to improve the referral and diagnostic processes for this population of adults, who may likely be autistic. Two online focus groups were conducted to understand the self-identification process of autism in UK adults, and to generate items for the screening questionnaire, named the Autistic Identity Questionnaire (AIQ). Through a two-round Delphi method, the AIQ was further developed with experts by experience and healthcare professionals who conduct autism assessments in adults, confirming face and content validity. Initial validation was with 850 adults who identified as autistic, and analyses of validity and reliability were very satisfactory. The AIQ could be a valuable addition within the adult autism diagnostic pathway, and should be trialled in clinical settings to ascertain whether it is a valid and reliable measure for its intended purpose.

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Author’s Declaration

I declare that the following work has been done in collaboration with my PhD supervisors:

The scoping review presented in Chapter 2 has been published in the peer-reviewed Journal ‘*Review Journal of Autism and Developmental Disorders’*, proof of which can be found in Appendix A (page 192 of this thesis). My independent contribution and the contribution of my PhD supervisors to this publication is outlined in Chapter 2, which corresponds to the published article.

The study “Who I am”: Understanding the self-identity process of autism in adults in the UK, presented in Chapter 4, has been submitted to a journal for publication. My independent contribution and the contribution of my PhD supervisors to this article is outlined in Chapter 4, which corresponds to the submitted article.

The studies presented in Chapters 5 and 6 have been submitted as one article to a journal for publication. My independent contribution, and the contribution of my PhD supervisors to this article is outlined in Chapters 5 and 6, which corresponds to the submitted article.

Chapter 1

Introduction

Our identity, ‘who we are’, is pivotal to how we conceptualise ourselves and relate to others (Marsà-Sambola, 2018). From a psychological perspective, our identity also has important implications for our wellbeing (Alexander Haslam, 2014), with a more positive identity being associated with better psychological wellbeing (Cooper et al., 2017). However, understanding who we are and developing a positive identity is not always an easy task (Marsà-Sambola, 2018), and is a task that can be further complicated if an aspect of our identity is perceived to be stigmatised within society, such as being autistic (Cooper et al., 2021; McDonald, 2017). As an aspect of identity that is often obtained from a clinical diagnosis, research has highlighted the importance of an early diagnosis to support identity formation (Battles, 2016) with the positive acceptance of an autistic identity (Moore, 2016). However, despite the perceived stigma attached to being autistic and the importance of an early diagnosis, an increasing number of adults are self-identifying as autistic (Lewis, 2016b; Lewis, 2017; McDonald, 2020). Defined as classifying the self as autistic, often after the recognition that autistic traits may explain some life experiences (Moore, 2016), little is known about why this population of adults lack a diagnosis or about their psychological wellbeing in the absence of a diagnosis.

Beginning with an explanation of what autism is, and then from the historical origins of autism through to the present day adult autism diagnostic pathway, this Chapter discusses the factors that could lead adults to self-identify as autistic. From this discussion, the most constructive method to systematically develop a research study on the self-identification of autism in adults is identified. The identified method is discussed at the end of this Chapter.

1.1 Autism

Derived from the Greek word ‘autos’ meaning self (Zahavi, 2010), autism is a neurodevelopmental disorder (Dogaru, 2018) and is classified as a disability in the United Kingdom (UK) (National Autistic Society, 2023). Specifically, autism is a hidden disability meaning that the symptomatology associated with the disorder is not always obvious and/or visible to other people (Fitzgerald & Wylie, 2016; Thompson-Hodgetts et al., 2020). As a consequence of having a hidden disability, autistic individuals are often subjected to a heightened level of stigmatisation within society (MacLeod et al., 2013; Portway & Johnson, 2005). From a diagnostic perspective, autism is currently referred to as autism spectrum disorder (ASD), a term that was applied in 2013 amalgamating three previously distinct disorders; autistic disorder, pervasive developmental disorder and Asperger’s disorder

(Diagnostic and Statistical Manual of Mental disorders, 5th edition (DSM-5), American Psychiatric Association (APA), 2013). As a spectrum disorder, the symptomatology of autism can present very differently and can vary in severity (Kroncke et al., 2016). Diagnostically, autism is characterised by two main deficits: social communication and social interaction and restricted, repetitive patterns of behaviour (APA, 2013). Characterisations not too dissimilar from Kanner's (1943) initial portrayal of autism (Anderson-Chavarria, 2022).

1.1.1 Aetiology of autism

Kanner (1943) is often credited with the first conceptualisation of autism in the influential paper 'Autistic Disturbance of Affective Contact' (Harris, 2018). In this paper, Kanner (1943) described the behavioural symptomology of 11 children (eight boys and three girls), which he summarised as a wish for "aloneness and sameness" (Kanner, 1943, p.249). From these case studies of 11 children, Kanner (1943) concluded that autism was genetic because all of the children displayed this behaviour from birth. Despite this conclusion, Kanner (1943) did allude to the role of environmental factors. Specifically, Kanner (1943) noted a commonality between the parents of all 11 children, whom he described as lacking emotional warmth. This commonality led Kanner (1943) to question whether or not parenting style was a contributory factor to the development of autism, though Kanner (1943) did maintain that autism was primarily genetic.

Consistent with psychodynamic perspectives at the time (O'Reilly et al., 2020), Bettelheim (1967) expanded on the commonality between the parents of the 11 children that Kanner (1943) had noted. Bettelheim (1967) firmly believed that autism was solely the result of maternal rejection, and it was from this belief that the Refrigerator Mother theory (Bettelheim, 1967) of autism was born. Bettelheim (1967) theorised that children were autistic because their mothers lacked the emotional warmth to provide the nurturing environment that they required in order to follow a typical pattern of development. Thus, mothers were ultimately the reason why some children were autistic (O'Reilly et al., 2020). Based on the Refrigerator Mother theory (Bettelheim, 1967), one recommendation was that autistic children should be taken from their homes and rehoused (Fishbein et al., 2017) in order to be cured (Sarrett, 2011). While it is known that severe deprivation can detrimentally affect child development (Harris, 2018), subsequent research evidence has since disproved the Refrigerator Mother theory (Bettelheim, 1967) of autism (Dogaru, 2018; O'Reilly et al., 2020). However, Anderson-Chavarria (2022) claims that the legacy of the Refrigerator Mother theory (Bettelheim, 1967) of autism remains evident in society today.

In a follow up study of the 11 children twenty-eight years after the original study, Kanner (1971) was able to determine the outcomes of nine of the children. From the findings of this follow up study, Kanner (1971) still maintained that autism was genetic. Yet, Kanner (1971) did still allude to the role of environmental factors. Kanner (1971) emphasised the very different outcomes that these nine now adults had, despite having a disorder that was so similar in terms of symptomology as children. Kanner (1971) detailed how three of the children had positive outcomes, which Kanner (1971) defined in terms of usefulness in society. Two of these children epitomised in Kanner's (1971) words "real success stories" (p.143) by gaining and maintaining regular employment and participating in activities within society. The outcomes of these two children led Kanner (1971) to question the extent to which the physical environment influenced the outcomes of these children, and whether there were other unknown influential factors.

Ten years after the publication of Kanner's (1971) follow-up study, the work of Asperger (1944) was published in English (Wing, 1981). In his paper 'Autistic Psychopathy', Asperger (1944) described the behavioural symptomology of four children (Harris, 2018). Asperger (1944) summarised these four children as having good grammar and vocabulary, and in striking similarity to Kanner (1943), impairments in social interaction with narrow interests and repetitive routines (Boucher, 2017). Asperger (1944) too deemed this syndrome to be genetic (Wing, 1981).

In terms of the current understanding of the aetiology of autism, Constantino and Charman (2016) state that Kanner (1943; 1971) and Asperger (1944; 1981) were very accurate. There is now strong research evidence for genetic factors in the aetiology of autism (Campisi et al., 2018; Dogaru, 2018), but this research evidence has not concluded a concordance rate (the degree in which a trait is evident in each individual) of 100% inferring the role of environmental factors (Campisi et al., 2018).

It is from reflecting on the historical origins of autism that the beginnings of the stigma associated with autism can be understood. The stigma associated with autism provides an explanation as to why accepting an autistic identity can be hard, and developing a positive autistic identity even more so (Cooper et al., 2017). From a parental perspective, knowing that genetics and parenting style may have contributed to what was considered a rare condition at the time may have discouraged parents from having their children labelled with autism. To explain, parents may have felt responsible and stigmatised for their children being autistic (Fitzgerald & Wylie, 2016). Today, perceptions of autism are still often associated with the disorder that Kanner (1943) initially described (Constantino & Charman, 2016; Rosen et al., 2021). As a result of these stereotypical perceptions, many parents nowadays may be hesitant about pursuing a formal autism diagnostic assessment for their children and/or unwilling to accept a diagnosis (Fitzgerald & Wylie, 2016).

1.1.2 Autism as a diagnostic entity

It was thirty-seven years after Kanner's (1943) first conceptualisation of autism that autism became a diagnosable disorder by the inclusion of 'infantile autism' in the DSM III (APA, 1980). Arguably, the creation of diagnostic manuals has partly shaped what is considered 'normal' and 'abnormal' within society (O'Reilly et al., 2020). By the very nature of distinguishing 'normal' from 'abnormal' diagnostic manuals focus on the 'deficits' and 'impairments' that an individual has in order to assess whether an individual has a diagnosable disorder, such as autism (Moore, 2016). The endorsement of autism as a diagnostic entity further implies that autism is a disorder whereby an individual is abnormal, impaired by the criteria stipulated in the diagnostic manuals (Brown et al., 2021). As such, a diagnosis can be stigmatising (Boucher, 2017; O'Reilly et al., 2020). With all of this in mind, it is not hard to understand why positively accepting an autistic identity can be a difficult task, for both autistic individuals and family members alike (Crane et al., 2018).

In spite of numerous changes to both the name of the disorder and diagnostic criteria since autism was first classified as a diagnostic entity in 1980 (Kenny et al., 2015), autism has remained classified as a neurodevelopmental disorder throughout the years (Harris, 2018). Consequently, autism is commonly depicted as a childhood disorder within society (Huws & Jones, 2011) and childhood is where research on autism has mainly been focused (Benevides & Cassidy, 2020; Howlin, 2021). Undeniably, knowledge of autism has been furthered by research on autism in childhood, so too, have the positive outcomes for autistic children (Thompson, 2013). For example, in terms of education, DeMyer et al. (1973) found that the likelihood of autistic children having a 'normal' outcome was between 1% and 2% and the prediction of having a 'poor' outcome was between 60% and 75%. Nowadays, over 50% of autistic children are educated in mainstream schools, with several autistic individuals going onto further education (Thompson, 2013). However, there is now growing recognition that many adults today may have been exempt from a diagnosis of autism in childhood, adults who Lai and Baron-Cohen (2015) have termed the 'lost generation'.

1.1.3 Autism in adults

Lai and Baron-Cohen (2015) state that because autism is relatively new as a diagnostic entity, it may not have been a diagnosable disorder when many of todays' adults were children. Additionally, the diagnostic criteria for autism has changed and widened over the years. For example, the initial diagnostic criteria stipulated in the DSM III (APA, 1980) were considered too narrow in clinical practice. Healthcare professionals said that the DSM III (APA, 1980) criteria were only really applicable to younger children with acute impairments (Harris, 2018).

So, even if autism was a diagnostic entity when todays' adults were children, several adults may have not met the narrow criteria for a diagnosis of autism (Lai & Baron-Cohen, 2015).

It has also now been recognised that autism may not be identifiable until adulthood, in some cases (Lai & Baron-Cohen, 2015). This recognition is reflected in the latest and current diagnostic criteria (Fusar-Poli et al., 2020), which are stated below;

The DSM-5 specifies "symptoms must be present in the early developmental period (but may not become fully manifest until social demands exceed limited capacities, or may be masked by learned strategies in later life)" (APA, 2013, p.50). Similarly, the International Classification of Diseases, 11th edition (ICD-11) specifies that "the onset of the disorder occurs during the developmental period, typically in early childhood, but symptoms may not become fully manifest until later, when social demands exceed limited capacities" (World Health Organisation (WHO), 2019).

Taken together, the aforementioned factors (the 'lost generation' of adults, the widening of the diagnostic criteria, and the recognition that autism may not be identifiable until adulthood) infer that many more adults may present for a formal autism diagnostic assessment in the future (Regan, 2016). Yet, despite these factors highlighting a clear clinical need for more research on autism in adults (Lai & Baron-Cohen, 2015; Regan, 2016), research in this area has been minimal (Howlin, 2021). As a consequence, still little is known about autism in adults (Pellicano et al., 2022).

1.1.4 Autistic identity in adults

Recent attempts to address the paucity of research on autism in adults (e.g. Lewis, 2016a; Stagg & Belcher, 2019) have mostly explored the experiences of obtaining a diagnosis of autism as an adult. Crucially, both of these studies concluded that obtaining a diagnosis of autism as an adult was beneficial, principally because it provided adults with an understanding of the self that was previously nebulous (Lewis, 2016a; Stagg & Belcher, 2019). For this reason, most of the adults in Lewis's (2016a) study had the belief that being diagnosed as autistic earlier in life would have positively improved their lives, in terms of having the self-understanding to accept their authentic self (an autistic identity). Theoretically, this can be explained by Social Identity Theory (SIT) (Tajfel & Turner, 1979). SIT (Tajfel & Turner, 1979) suggests that as we develop, we seek to attain a positive self-concept in order to preserve or enhance our self-worth, and our wellbeing. Indeed, in the context of explaining autistic identity, SIT (Tajfel & Turner, 1979) has predominantly been the theoretical framework used (e.g. Cooper et al., 2017; Cooper et al., 2021; Corden et al., 2021).

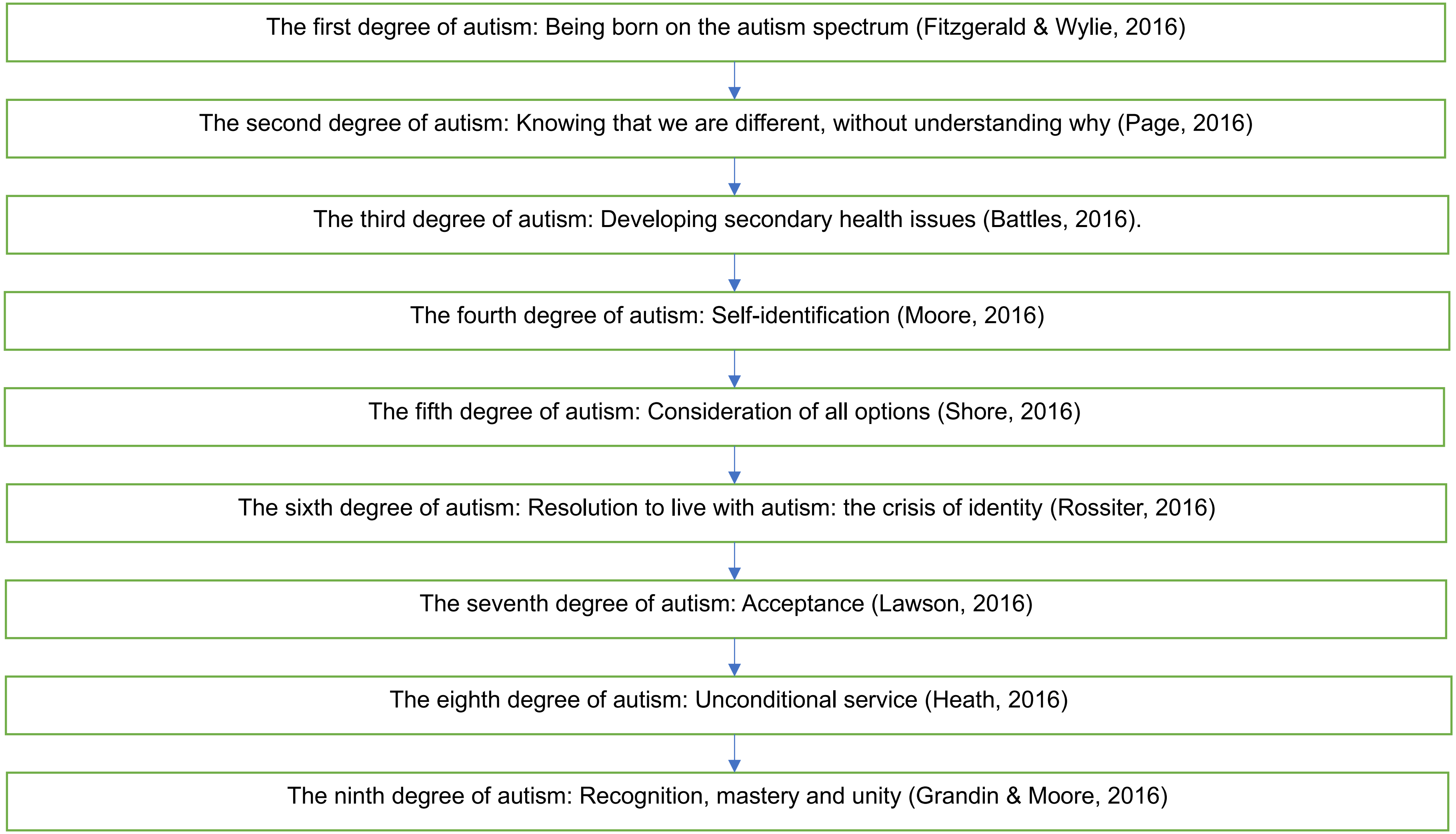
SIT (Tajfel & Turner, 1979) proposes that human identity is comprised of a personal identity; an individual identity that differentiates people from each other, and a social identity; a group identity that differentiates people from people in other groups (Branscombe & Baron, 2017; Maitland et al., 2021). People can have many social identities (e.g. autistic, mother, psychologist), which are mostly acquired through socially interacting with other people (Wantzen et al., 2021). These many social identities supplement, rather than substitute, each other (Marsà-Sambola, 2018) and are activated by the social context in which people find themselves (Branscombe & Baron, 2017). Therefore, it is the environment that determines which social identity is salient at any given point in time. Often people place greater emphasis on social identities rather than personal identities due to the strength of a collective shared identity, and the subsequent increase in psychological wellbeing that these identities provide (Alexander Haslam, 2014). Certainly, in several research studies an autistic identity has been defined as a social identity (e.g. Cooper et al., 2017; Cooper et al., 2021). In this instance an autistic identity is the group identity that differentiates autistic individuals (the in-group) from people in other groups (the out-group), such as neurotypical individuals (Corden et al., 2021). However, diagnostically autism is a condition with social interaction and communication deficits (APA, 2013), so the acquisition of social identities would seemingly be problematic for autistic individuals (Cooper et al., 2017; Wantzen et al., 2021). Even so, Cooper et al. (2017) argue that autistic individuals find a means of overcoming these difficulties to acquire a shared positive social identity. As such, autistic individuals are equally able to enjoy the gains that a shared positive social identity provides. Cooper et al. (2017) state online interactions as an example of a means that autistic individuals may use to overcome the diagnostically specified deficits in social interaction and communication. It is through online interactions that Cooper et al. (2017) say that aspects related to being autistic are discussed (e.g. the diagnostic pathway and the positive attributes of autism), which may well form the foundations of an autistic social identity. So, SIT (Tajfel & Turner, 1979) has provided an explanation as to how autistic adults can improve their psychological wellbeing by reframing autism in a positive way, despite invariably being categorised within a stigmatised group by society (Cooper et al., 2017).

On the contrary, given that autism is classified as a disability and the perceived stigma that is attached to being autistic, many adults may choose to distance themselves from an autistic identity. Indeed, as pointed out by four adults who wanted to participate in Lewis's (2016a) study, the current research on autism in adults overlooks an important issue; adults who have self-identified as autistic and who do not have a formal diagnosis of autism (Lewis, 2016b). In a recent study, McDonald (2020) investigated the similarities and differences between adults who self-identified as autistic and adults with a formal diagnosis of autism in terms of demographic factors, autistic identity, quality of life (QoL) and stigma. Demographically, McDonald (2020) found that adults who self-identified as autistic tended to be employed, female, and older. McDonald (2020) also found that adults who self-identified as autistic were comparable to adults who were formally diagnosed as autistic with regards to their experiences of developing an autistic identity, stigma and QoL. However, a notable difference was that adults who self-identified as autistic were, in general, more unlikely to choose a label of autism. So, if adults who self-identify as autistic are less likely to choose a label of autism (McDonald, 2020), it is equally unlikely that this population of adults would be categorised within an in-group that may be subject to stigmatisation.

1.1.5 Self-identifying as autistic in adulthood

The Nine Degrees of Autism (Wylie et al., 2016) provides a more useful theoretical framework in which to contextualise an autistic identity in adults who do not have a formal diagnosis of autism (self-identify as autistic). The Nine Degrees of Autism (Wylie et al., 2016) is a developmental theory and delineates nine stages (degrees) that autistic individuals journey through from the first degree: being born on the autism spectrum (Fitzgerald & Wylie, 2016) to the ninth: recognition, mastery and unity (Grandin & Moore, 2016). The Nine Degrees of Autism (Wylie et al., 2016) theory is illustrated below (Figure 1.) and is described after the illustration.

Figure. 1. An illustration of The Nine Degrees of Autism (Wylie et al., 2016) theory



The first degree of autism: Being born on the autism spectrum (Fitzgerald & Wylie, 2016)

The second degree of autism: Knowing that we are different, without understanding why (Page, 2016)

The third degree of autism: Developing secondary health issues (Battles, 2016).

The fourth degree of autism: Self-identification (Moore, 2016)

The fifth degree of autism: Consideration of all options (Shore, 2016)

The sixth degree of autism: Resolution to live with autism: the crisis of identity (Rossiter, 2016)

The seventh degree of autism: Acceptance (Lawson, 2016)

The eighth degree of autism: Unconditional service (Heath, 2016)

The ninth degree of autism: Recognition, mastery and unity (Grandin & Moore, 2016)

The Nine Degrees of Autism (Wylie et al., 2016) theory acknowledges that some autistic individuals will not have a linear journey from the first degree: being born on the autism spectrum (Fitzgerald & Wylie, 2016) to the ninth degree: recognition, mastery and unity (Grandin & Moore, 2016) and this will be discussed within the description of the theory.

The first degree of autism is being born on the autism spectrum (Fitzgerald & Wylie, 2016). The first degree of autism is based upon the fact that autistic individuals are autistic at birth, meaning that every autistic individual attains the first degree of autism. However, because autism is assessed and diagnosed based on behavioural observation there is normally a delay before individuals realise that they are autistic and/or they are diagnosed as autistic. The theory acknowledges that other people (e.g. parents and healthcare professionals) may recognise that autistic individuals are not 'typical' at the first degree of autism, but states that it is usually autistic individuals that recognise that they are 'different' (in comparison to neurotypical individuals) between the ages of six and twelve years. It is at this point that autistic individuals attain the second degree of autism.

The second degree of autism: knowing that we are different without understanding why (Page, 2016). Autistic individuals attain the second degree of autism when they realise that they are 'different' (in comparison to neurotypical individuals), but remain uncertain of the origin of this difference. In other words, at the second degree of autism autistic individuals do not realise that they are autistic. At this stage the influence of environmental factors is highlighted, as these factors largely determine whether autistic individuals remain at the second degree or move onto the third or a later degree of autism. For example, to compensate for the increasing awareness of being different autistic individuals may choose to conform to fit in, but this choice can become emotionally draining as the behaviour is unnatural. So, autistic individuals may choose to be their authentic self, but this choice can lead to emotional distress from being bullied and teased by other people. However, a supportive environment would buffer this negative outcome. The theory acknowledges that the outcome for autistic individuals may also be determined by other factors (e.g. personality) in combination with environmental factors, but maintains that a favourable environment is essential for autistic individuals to remain at the second degree of autism or skip the third degree and attain a later degree of autism.

The third degree of autism: developing secondary health issues (Battles, 2016). Autistic individuals attain the third degree of autism if they develop secondary health conditions (e.g. depression), which stem from difficulties in living due to being 'different' to others (neurotypicals). At the third degree of autism autistic individuals are still unaware that they are autistic, and some autistic individuals may remain at this degree due to not self-identifying as autistic or being formally diagnosed as autistic. Remaining at the third degree of autism means that autistic individuals never have an explanation for their difficulties and never fully understand who they are, which is detrimental to their wellbeing.

The fourth degree of autism: self-identification (Moore, 2016). The fourth degree of autism is attained when autistic individuals become aware that they could be autistic. For autistic individuals, it is theorised that there are three main routes to becoming aware that they could be autistic, of which the most common is seeing a description of autism in the media (e.g. television programmes and magazines/newspapers). The second is having a child diagnosed as autistic, and the third is a healthcare professional questioning whether mental health conditions (e.g. anxiety and depression) could be partly explained by being autistic. At the point that autistic individuals become aware that they could be autistic, the theory acknowledges the advantages to researching autism, but also emphasises the disadvantages. For example, self-understanding may be aided by completing autism online screening measures, but online screening measures do not have the ability to differentiate between autism and other conditions. It is primarily for this reason that the theory advises individuals to have a formal autism diagnostic assessment explaining that if a self-identity as autistic is correct, a formal diagnosis of autism can validate this identity and give adults an accurate knowledge of autism as a condition. Together, these can aid the development of a positive autistic identity as autistic individuals begin to fully understand who they are and access the support that they are entitled to. Therefore, self-identifying as autistic is recognised as a key sequential step in the journey to positively accepting an autistic identity, and the theory does state that it is possible for autistic individuals to progress to the ninth degree of autism without being formally diagnosed as autistic.

The fifth degree of autism: consideration of all options (Shore, 2016). At the fifth degree of autism, autistic individuals are post-diagnosis and beginning the transition to their new but authentic identity. Change epitomises this degree, as it is theorised that at this point autistic individuals consider their future options with this new understanding of who they are. For example, choosing to retreat or move on. The value of an understanding of personality and support from others is emphasised at this degree, as according to the theory personality determines how future choices are made and support from others can help with these choices. Autistic individuals reach the end of the fifth degree of autism once they have come to terms with being formally diagnosed as autistic and are ready to embrace their new identity.

The sixth degree of autism: resolution to live with autism: the crisis of identity (Rossiter, 2016). Autistic individuals attain the sixth degree of autism when they have come to terms with their new authentic identity and are ready to be their new authentic self. The sixth degree of autism is a time of crisis for autistic individuals as they begin their journey to accepting their new and authentic self. To help autistic individuals along this journey to acceptance, the sixth degree states seven principles of acceptance (willingness, start where you're at, nothing is personal, your existence is a miracle, there is nothing wrong with you, flexibility and expertise) which begin with having a willingness to change and ends with becoming an expert on yourself. The theory acknowledges that being their true self is something that autistic individuals have to do on their own, but it does recommend that autistic individuals seek a form of help that works for them at this time of crisis.

The seventh degree of autism: acceptance (Lawson, 2016). To attain the seventh degree of autism, autistic individuals need to accept who they are and be committed to becoming happy with their new identity. To help autistic individuals along this journey to acceptance, the seventh degree states nine action points (accept our label, believing in ourselves, seeking IT support, self-acceptance, environmental support, exercise, sensory dysphoria, coping with change and interests) which begin with accepting being autistic and ends with using interests to journey onwards. The theory recognises that the seventh degree of autism is an ongoing process and that the eighth degree of autism is the next part of this process.

The eighth degree of autism: unconditional service (Heath, 2016). At the eighth degree of autism, it is theorised that the combination of understanding and accepting their authentic self empowers autistic individuals to move forward with creating a place for themselves in society. To illustrate how autistic individuals can create a place for themselves in society, help others and be rewarded for their work, the eighth degree of autism uses other autistic individuals who have achieved this degree of autism as examples (i.e. Dr Danny Beath). The importance of ongoing support is again emphasised as autistic individuals continue their journey towards the ninth degree of autism.

The ninth degree of autism: recognition, mastery, and unity (Grandin & Moore, 2016). The ninth degree of autism resembles Maslow's hierarchy of needs in that when autistic individuals reach the ninth degree of autism they have achieved self-mastery, (e.g. proficiency in an area of interest), positively contributed to the environment (e.g., their local area, within family and friendship groups) and gained a sense of unity with the wider world (e.g. an interconnection with others). According to the ninth degree of autism, an important characteristic of all autistic individuals (self-identified or formally diagnosed as autistic) who reach this degree is "fit". "Fit" refers to an alignment between the unique attributes of an autistic individual and their environment, which fosters the aforesaid achievements (self-mastery, positive contribution to the environment and sense of unity with the wider world). At the ninth and final degree of autism, autistic individuals have grown to become at peace with themselves.

The Nine Degrees of Autism (Wylie et al., 2016) theory highlights the role of self-identifying as autistic in pursuing a formal diagnosis of autism and the value of being formally diagnosed as autistic. However, for some adults self-identifying as autistic is satisfactory and a formal diagnosis of autism is not deemed necessary (Lewis, 2016b; Sarrett, 2016). In the studies by Lewis (2016b) and Sarrett (2016) these adults cite reasons such as the potential stigma and discrimination that may result from a diagnosis, and no overall perceived value to being formally diagnosed as autistic. Nonetheless, self-identifying as autistic can result in a mixture of feelings for adults as it is realised that the condition may account for previous challenges in life (Lewis, 2016b; Moore, 2016) and although adults often describe identifying as autistic as enlightening, this new found aspect of their identity requires a renegotiation of their existing identity (Atherton et al., 2021; Shore, 2016). It is as adults renegotiate their identity that the risk of secondary psychological disorders (e.g. anxiety and depression) has been found to increase without appropriate support (Lewis, 2016b). A popular source of support for adults are autism online forums (Stagg & Belcher, 2019). Stagg and Belcher (2019) found that autism online forums are frequently chosen because they provide adults with a means in which to share their experiences of the autism diagnostic pathway, and their feelings, with other adults who have the same lived experiences. It has been reported that other sources of support, such as autism online forums, are sought by adults who choose not to access (or who are not eligible for) formal support. However, these other chosen sources of support may not always provide the supportive environment that was anticipated. For example, self-identifying as autistic can be a controversial topic in some autism online forums in which some users have been openly sceptical about the validity of it (Sarrett, 2016).

It is also noteworthy that the absence of a formal diagnosis of autism is not always through personal choice (Lewis, 2016b). The Nine Degrees of Autism (Wylie et al., 2016) seemingly implies that all individuals who choose to pursue an autism diagnostic assessment will receive one, only principally stating the fourth degree (self-identification) as a potential end point due to a deficiency of language and self-awareness. However, in a study to explore the experience of the self-diagnosis of autism in adults, Lewis (2016b) quotes one participant who explained that there were no healthcare professionals who conduct autism assessments in adults within their locality. So, opting for an autism diagnostic assessment does not always equate to receiving one (Lewis, 2017).

1.1.6 Adult autism diagnostic pathway

In terms of adult autism assessments in the UK, a National Health Service (NHS) autism diagnostic assessment is usually obtained by a referral from a General Practitioner (GP). The National Institute for Health and Care Excellence (NICE) guidelines state that children should be assessed within three months of being referred for an autism assessment (NICE, 2017), but no such guidelines exist for adults. In reality, adults face a much longer wait than three months to be assessed (Atherton et al., 2021). From their experiences, adults have also described how GPs have been unaware of how autism may present in adults (Crane et al., 2018), and/or how reluctant GPs have been to refer them for an assessment (Lewis, 2017).

To assist GPs, the AQ-10 (Allison et al., 2012) is a screening tool recommended by NICE (2016) for the purpose of determining whether an adult should be referred on for a full autism diagnostic assessment (NICE, 2016). The 10-question screening tool is self-report and has a 4-option response ('definitely agree', 'slightly agree', 'slightly disagree' and 'definitely disagree') to assess the extent to which autistic traits are evident. Adults are asked to read the 10 questions and to respond based on individual perception of how strongly the question applies to the self. After completion the tool is scored, with a total score being in the range of 1 to 10. Allison et al. (2012) advises that an AQ-10 score of 6 and above is indicative of autistic traits that are significant and would warrant a referral for a full autism diagnostic assessment.

For GPs, NICE (2016) provides clinical guidance on the interpretation of the AQ-10 (Allison et al., 2012) score that can be referred to in everyday practice. However, an inaccuracy in the NICE (2016) guidelines regarding the interpretation of the AQ-10 (Allison et al., 2012) score has recently been noticed. Waldren et al. (2021) recognised that the NICE (2016) guidelines stated an AQ-10 (Allison et al., 2012) score of more than 6 would warrant a referral for a full autism diagnostic assessment. This inaccuracy has potential repercussions for individuals who scored 6 or more on the AQ-10 (Allison et al., 2012). Worryingly, that individuals who may likely be autistic have failed to be referred on for a full autism diagnostic assessment (Waldren et al., 2021).

As a screening tool, the AQ-10 (Allison et al., 2012) has been criticised for being of little use in determining autistic traits in adults (Ashwood et al., 2016). Ashwood et al. (2016) investigated the utility of the AQ-10 (Allison et al., 2012) in identifying adults who would receive a clinical diagnosis of autism. AQ-10 (Allison et al., 2012) scores were computed from the completion of the AQ-50 (Baron-Cohen et al., 2001) and from the 456 adults who completed the AQ-50 (Baron-Cohen et al., 2001), 428 AQ-10 (Allison et al., 2012) scores were computed. Almost two-thirds of adults who scored under 6 on the AQ-10 (Allison et al., 2012) proceeded to receive a diagnosis of autism. Ashwood et al. (2016) concluded that the utility of the AQ-10 (Allison et al., 2012) is disputable. More recently, Taylor et al. (2020) concluded that the AQ-10 (Allison et al., 2012) is not a unitary measure of autistic traits. Using Gollwitzer et al.'s (2019) data, Taylor et al. (2020) examined the psychometric properties of the AQ-10 (Allison et al., 2012) with regards to the use of the tool as a measure of autistic traits in non-clinical samples. The AQ-10 (Allison et al., 2012) was found to be a multiple factor tool which does not reflect the DSM-5 diagnostic criteria for autism.

Based on the findings of a systematic review of the psychometric properties of questionnaires and diagnostic measures for autism spectrum disorders in adults, Wigham et al. (2019) advised that the AQ-10 (Allison et al., 2012) and RAADS-R (Ritvo et al., 2011) should not be used on their own in clinical settings for the purpose of screening and identification of autism due to the low specificity of the tools. Adapted from the Ritvo Autism Asperger's Diagnostic Scale (Ritvo et al., 2008), the RAADS-R (Ritvo et al. 2011) was developed as a supplementary diagnostic tool to assist healthcare professionals in the diagnosis of autism in adults with an average IQ and above. The 80-question diagnostic tool is self-report and has a 4-option response ('true now and when I was young', 'true only now', 'true only when I was younger than 16' and 'never true') to assist in the identification of autism in adults who may be underdiagnosed due to a milder presentation of autism, and is recommended by NICE (2021) for this purpose. Ritvo et al. (2011) stipulate that the RAADS-R should be administered by a healthcare professional in a clinical setting and scored by the healthcare professional after completion. A score of 65 or greater is congruent with a clinical diagnosis of autism, although Ritvo et al. (2011) advises that clinical judgment should always take precedence with scores of 64 or lower given the limitations of self-report tools.

In an international validation study of the RAADS-R, Ritvo et al. (2011) reported the RAADS-R to be highly accurate in differentiating between clinically diagnosed autistic adults and non-autistic adults. However, comparable to Wigham et al. (2019), Jones et al. (2021) concluded that the RAADS-R (Ritvo et al., 2011) has no clinical value in terms of differentiating between adults who would and would not be diagnosed as autistic after an autism diagnostic assessment. With the aim of providing a more effective service for adults awaiting an autism diagnostic assessment, Jones et al. (2021) evaluated the predictive validity of the RAADS-R (Ritvo et al., 2011) as a self-report screening tool for adults referred to the South West Yorkshire Partnership NHS Foundation Trust Adult ADHD and Autism Service. Fifty service users were sent the RAADS-R (Ritvo et al., 2011) and AQ-10 (Allison et al. 2012) to complete at home and return, then the RAADS-R (Ritvo et al., 2011) score was compared to the outcome of the autism diagnostic assessment for each service-user. The study found that

RAADS-R (Ritvo et al., 2011) scores had a 3.03% chance of detecting the absence of autism and concluded that the tool is ineffective for the purpose of screening for autism.

In addition to the shortcomings of the adult autism referral process, the adult autism diagnostic assessment can be a challenging assessment for healthcare professionals (Fusar-Poli et al., 2017; Roestorf et al., 2019) which may mean that many adults who are autistic do not receive a diagnosis. Diagnosing autism in adults can be difficult, as Lai and Baron-Cohen (2015) report, for a trio (clinical, developmental and practical) of reasons. These reasons can include problems gaining a developmental history and behaviour that has been learnt through life (Lai & Baron-Cohen, 2015). Learnt behaviour in combination with the spectrum nature of autism further complicates the adult autism diagnostic processes (Crane et al., 2018; Fusar-Poli et al., 2020), diagnostic processes which research implies serve to disadvantage some genders, particularly females (Muggleton et al., 2019). Compounding this already challenging assessment is the ambiguous referral information (Trammell et al., 2013) and the fact that most of the clinical tools used throughout the adult autism diagnostic pathway were originally developed for children (Fuentes et al., 2021). To date, there exist very few clinical tools that have been validated for adults (Wigham et al., 2020), and little research has focused on improving the adult autism diagnostic processes (Benevides & Cassidy, 2020).

For adults who are diagnosed as autistic, NICE (2021) recommends a follow-up appointment to give adults the opportunity to discuss the diagnosis and any further support that may be needed. However, in a study conducted by Wigham et al. (2023) to investigate optimal post diagnostic support for autistic adults from the perspective of autistic adults, relatives and healthcare professionals, only just over 50% of the autistic adults and relatives who participated reported having a follow-up appointment. Healthcare professionals who participated in Wigham et al.'s (2023) study reported not always being able to offer a follow-up appointment. Post-diagnostic support is essential for autistic adults given the negative outcomes that they may experience, yet it is limited (Crane et al., 2021) and difficult to access (Wigham et al., 2023).

In England, the Autism Act (2009) aimed to improve diagnostic and post-diagnostic services for autistic adults by making the provision of relevant services a statutory duty of local authorities, NHS bodies and NHS foundation trusts. Ten years since the Autism Act (2009) was passed, improvements to diagnostic and post-diagnostic services for autistic adults have been made. For example, the majority of areas in England did not have an adult autism diagnostic service in 2009. In 2019, 93% of areas in England had an adult autism diagnostic service (National Autistic Society, 2019). However, it is clear that there is still work to be done to ensure that all autistic adults have timely access to good quality diagnostic and post-diagnostic services.

As a consequence of the flaws of the adult autism diagnostic pathway it would seem that the only available option for adults who believe that they are autistic, is to self-identify as autistic (Lewis, 2016b; McDonald, 2020). Yet, it appears that only a handful of studies have researched the self-identification process of autism in adults in predominantly American populations (Lewis, 2016b; Sarrett, 2016; Lewis, 2017). As a consequence, the factors related to the self-identification process of autism in adults remain relatively unexplored (McDonald, 2020), despite the inclusion of adults who self-identify as autistic in several studies (e.g. Cooper et al., 2017).

Without doubt, for some adults the decision not to have an autism diagnostic assessment is personal choice (Lewis, 2016b). On the contrary, for adults who opt for a formal autism diagnostic assessment it has become clear that a referral for one may not be given (Lewis, 2016b; Lewis, 2017), so future research should investigate factors that facilitate or inhibit accessibility to an autism diagnostic assessment for adults who self-identify as autistic (Lewis, 2016b; Lewis, 2017; McDonald, 2020).

1.2 Outline and aims of thesis

In light of the recognised value of a formal diagnosis of autism, it is certainly of concern if self-identifying as autistic is becoming a replacement for being formally diagnosed as autistic. So, in terms of the psychological wellbeing of adults who may be autistic, it is important that the factors underpinning self-identifying as autistic are understood from a psychosocial perspective. Yet, it is known that research on the self-identification of autism in adults is scarce (Lewis, 2016b), Together, these factors provide a plausible basis for a research study. However, prior to developing the research study, it is important to gain a comprehensive knowledge of the self-identification of autism in adults (Kazdin, 2022). Kazdin (2022) suggests reading studies and reviews on the topic, and advises of the potential benefits of actually writing a review. From a search of the literature, it was revealed that no reviews exist that synthesises research on the self-identification of autism in adults. To address this gap in the research, and to systematically develop the research of this thesis, it was decided to conduct and write a review.

This thesis begins by presenting a scoping review (Chapter 2) that was conducted to ascertain (1) what research has been conducted on the self-identification process of autism in adults who do and do not have a formal diagnosis of autism and (2) to ascertain which aspects of the self-identification process could be used to improve the referral and diagnostic processes of an adult autism assessment. Findings of the scoping review informed the aims of this thesis, which were to (1) understand the self-identification process of autism in adults who do and do not have a formal diagnosis of autism within the UK population and (2) to use this understanding to develop a screening questionnaire to improve the referral and diagnostic processes for this population of adults who may likely be autistic.

Chapter 3 critically discusses the methodological approaches employed to address the aims of this thesis, which took into account the recommendations for future research specified in the scoping review. Whilst taking into account the specified recommendations, the participating population (a population who are deemed vulnerable) and the sensitivity of the topic was respected. So, considerable emphasis was placed on the ethics of the research to ensure that the wellbeing of participants was protected as far as possible.

Chapter 4 describes the first study in the development of the new screening questionnaire: two online focus groups with adults who self-identified as autistic. Adults who self-identified as autistic and did not have a formal diagnosis of autism participated in the first online focus group. In the second online focus group, adults who self-identified as autistic and had a formal diagnosis of autism participated. From a clinical perspective, online focus groups represented the first step to improving the referral and diagnostic processes of an adult autism assessment from a person-centred perspective and in a neurodiversity-affirming manner. Findings from each one of the two online focus groups, in conjunction with written feedback from participants, informed the initial adaptions to the Autism Spectrum Identity Scale (ASIS) (McDonald, 2016) for the new screening questionnaire.

Chapter 5 explains the development of the new screening questionnaire through a Delphi method. Principles of co-production were employed to aid the development of a credible questionnaire. Therefore, two sets of experts were recruited: healthcare professionals who conduct autism assessments in adults, and experts by experience (adults who self-identified as autistic and had since been formally diagnosed as autistic by a healthcare professional).

Chapter 6 details the findings from the initial validation of the new screening questionnaire: the Autistic Identity Questionnaire (AIQ). These findings are predominantly discussed with regards to the potential use of the AIQ, as a complementary screening tool within the UK adult autism diagnostic pathway, though, the potential use of the AIQ for research purposes is also discussed.

This thesis concludes with Chapter 7, which reflects upon the contributions of this thesis and considers the implications of these contributions for both clinical and research purposes.

Chapter 2

Understanding the Self-identification of Autism in Adults: a Scoping Review

“This is one of the major reasons I fully support self-diagnosis when it comes to autism. The barriers to official diagnosis are significant.” (Gibbs, 2021, p.321).

2.1 Introduction

As advocated by Sara Gibbs, a comedy writer diagnosed as autistic at the age of thirty, self-identifying as autistic may be attributable to the barriers to a formal diagnosis of autism. To ascertain if there was a relationship between self-identifying as autistic and the barriers to a formal diagnosis of autism, and whether there were other factors underpinning the phenomenon of self-identifying as autistic, a scoping review was conducted.

A scoping review is a method that maps the existing research in a given area of interest, providing an overview of the research conducted to date (Arksey & O’Malley, 2005). Therefore, scoping reviews are particularly beneficial in an emerging area of research, and when a given area of research has not previously been systematically reviewed (Peters et al., 2015). The findings of a scoping review allow for gaps in the research to be identified, which inform the direction of future research (Arksey & O’Malley, 2005; Munn et al., 2018). Furthermore, unlike a traditional literature review which can be deemed subjective, a scoping review has a rigorous methodology to help ensure that the findings are objective and trustworthy (Munn et al., 2018). It was for these reasons that a scoping review was considered an appropriate method to develop the research for this thesis.

Taking into account the barriers to an autism diagnostic assessment that have been reported by adults, the scoping review had two aims: (1) to ascertain what research has been conducted on the self-identification of autism in adults, who do and do not have a formal diagnosis of autism and (2) to ascertain which aspects of the self-identification process could be used to improve the referral and diagnostic processes of an adult autism assessment.

2.2 Method

The scoping review was conducted based on the five-stage framework by Arksey and O’Malley (2005): (1) identify the research question, (2) identify relevant studies, (3) select studies based on the inclusion and exclusion criteria set, (4) chart the data and (5) synthesise and report the findings. Guidance by Peters et al. (2015) was used in conjunction with the framework by Arksey and O'Malley (2005). For a scoping review, a minimum of two reviewers is a prerequisite (Peters et al., 2015), a prerequisite which aims to increase the reliability of the findings (Munn et al., 2018). Therefore, the scoping review was conducted iteratively with my PhD supervisors.

The research question that directed this scoping review was 'From the current literature, what is known about the self-identification of autism in adults with or without a formal diagnosis of autism?'

2.2.1 Inclusion criteria

In order to answer the aims of the scoping review, the following inclusion criteria were set:

(1) Research that involved adults, where the age of the participants was equal to or more than 16 years. For the purposes of this scoping review, an adult was defined as an individual of 16 years of age and older. This definition of an adult is in line with the age of transition of individuals from children to adult services in some areas.

(2) Research that included adults who self-identified as autistic with no formal diagnosis of autism, and/or adults who initially self-identified as autistic and who subsequently had a formal diagnosis of autism.

(3) Research that was written in the English language. This decision was taken on the basis of the time and financial costs of translating articles written in non-English (Arksey & O'Malley, 2005).

(4) Published academic literature. Although scoping reviews can include grey literature (Arksey & O'Malley, 2005; Peters et al., 2015), the decision was made not to. This decision was taken based on the difficulty and time costs of locating grey literature.

(5) Research that was published from 2000-2021. The year 2000 was chosen to ensure that, as far as possible, all research was identified.

2.2.2 Exclusion criteria

(1) Research that excluded adults who self-identified as autistic because the criteria for autism were not met on a screening tool.

2.2.3 Search procedure

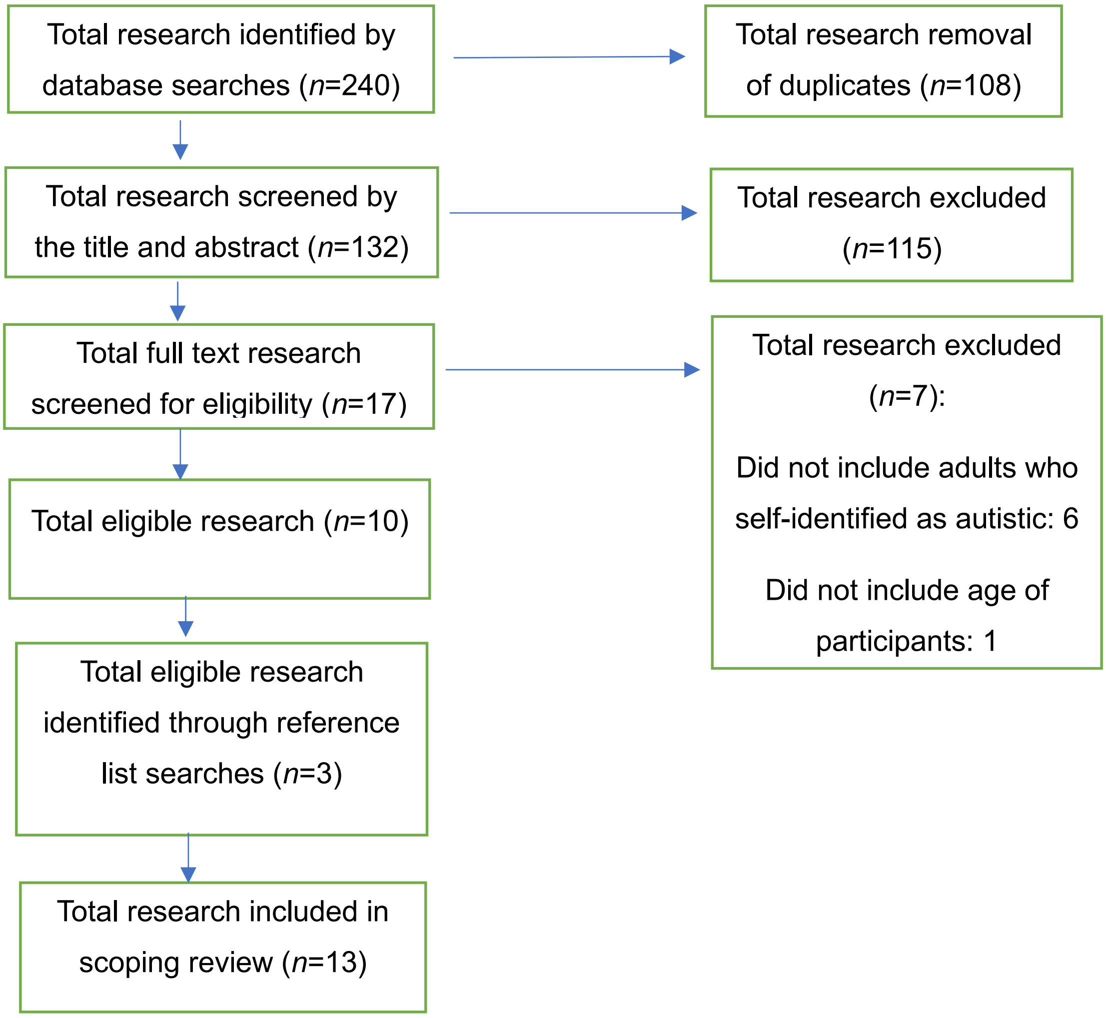
I searched four online databases (PsycINFO, CINAHL Complete, MEDLINE Complete and APA PsycArticles) to identify relevant studies. I searched these databases using eight searches in the following order: 'self-identification + autism spectrum disorder + adults', 'self-identification*+ autism spectrum disorder*+ adults*', 'self-identification + autism + adults', 'self-identification + Asperger’s + adults’, ‘self-diagnosis + autism spectrum disorder + adults’, ‘self-diagnosis* + autism spectrum disorder* + adults*’, ‘self-diagnosis + autism + adults’, ‘self-diagnosis + Asperger’s + adults’.

I conducted the last search on 24th July 2021.

2.2.4 Selection of the studies

Following the removal of duplicates, I screened the title and abstract sections of the remaining articles to remove any articles that did not meet the inclusion criteria of the scoping review. Next, I conducted a full text screening of the remaining articles, beginning with the participant section, to check the eligibility of these articles for the scoping review. A discussion with one of my PhD supervisors revealed no discrepancies regarding the articles deemed eligible. I then checked the reference lists of all eligible articles for any additional articles that may meet the inclusion criteria of the scoping review. This process was independently undertaken by one of my PhD supervisors, after which a discussion was held to ensure that there was agreement on the final articles that were included in the scoping review. A flow chart illustrating the study selection process can be found in Figure 2. (below).

Figure. 2. Scoping review study selection flow chart



2.2.5 Data extraction

Data extraction (or charting the results) was conducted using the guidance by Peters et al. (2015). Based on the guidance provided by Peters et al. (2015), I extracted six characteristics of the data from the included studies: (1) author(s) and title of the study, (2) characteristics of the study, (3) aims of the study, (4) methodology of the study, (5) outcome of the study, (6) relevant key findings of the study. The extracted data were put into the Table below (Table 1.), and this was used as a starting point for data analysis.

Table. 1. Table of the characteristics of the included studies in the scoping review

Study	**Characteristics of Study**	**Aims of Study**	**Methodology of Study**	**Outcome of Study**	**Relevant Key Findings of Study**
Angulo-Jiménez and DeThorne (2019) *Narratives about autism: An analysis of YouTube videos by individuals who self-identify as autistic.*	Study origin=USA. Participants, *N*=39 (perceived male=26, perceived female=13. Age range=13-45, mean=24, 21 did not state. Perceived as white=33, perceived Latino/Hispanic=2, perceived Asian American=2, perceived African American=1, not specified=1. Perceived country of origin: United States=13, United Kingdom/Great Britain=5, Canada=2, Australia=1, Denmark=1, Ireland=1, not specified=16 24 reported a formal diagnosis of ASD and 15	To answer the research questions: 1) who are the vloggers? and 2) do the videos represent autism as a disorder (medical model), a difference (neurodiversity paradigm), or both?	Qualitative. Narrative inquiry approach. Publicly accessible Vlog entries where the title was indicative of life with autism and/or an account of autism were found by the research team. Vlog entries were found by online searches conducted by the research team. 39 YouTube videos (published between 2007 and 2015) were analysed.	The majority of vloggers were adults who were white, male, likely from the USA and reported Asperger's syndrome. There were 3 main findings in relation to the representation of autism in the videos; 1) the representation of autism was complex and hybrid. 2) most content areas contained more medical model features, although it	ASD was viewed as both a disability and difference. Adults tended to prefer language associated with difference (e.g. Aspie) rather than disorder.

	reported self-identifying as autistic. 7 reported co-occurring forms of neurodivergence (obsessive compulsive disorder and synesthesia=1, anxiety and depression=2, schizotypal behaviour disorder=1, sensory-processing disorder=1, attention-deficit disorder=1, dermatillomania=1). No data regarding socio-economic status or levels of education were reported.			was most apparent in relation to the source of challenges that autistic individuals encounter (34 out of 39 assigned the challenges encountered to autism). 3) In relation to the content areas of language and description of autistic traits, neurodiversity characteristics were relatively high in prevalence.	
Au-Yeung et al. (2019)	Study origin=UK**.** Participants, *N*=420 (male=103, female=317.	To answer the research questions: 1) are autistic	Mixed methods. Participants were recruited through	Compared to non-autistic adults, autistic and possibly	Results from autistic and possibly autistic

Experience of mental health diagnosis and perceived misdiagnosis in autistic, possibly autistic and non-autistic adults.	Age range=18-67.) 208 identified as autistic (reported a formal diagnosis of ASD from a qualified healthcare professional, male=72, female=136. Age range=18-67, mean=38.6. Age range of diagnosis=4-59, mean=34.5), 71 identified as possibly autistic (reported thinking that they may have ASD and were either awaiting an assessment from a qualified healthcare professional or were yet to pursue an assessment, male=11, female=60. Age range=20-57, mean=40.1). 141 identified as non-autistic (reported no formal diagnosis of ASD and no thoughts of possibly being	individuals more likely to report receiving mental health diagnosis(es) and if so, what kind of diagnoses were they more likely to receive? 2) are autistic individuals more likely to disagree with these diagnoses? and 3) what were the reasons behind any disagreement?	charities, Cambridge Autism Research Database, Cambridge Psychology, MHAutism newsletter, online advertisements and MHAutism webpage. Participants were asked a series of closed and open-ended questions regarding mental health diagnoses. Participants also completed the Autism Spectrum Quotient (AQ-50) (Baron-Cohen et al., 2001).	autistic adults reported receiving more mental health diagnoses. Significant differences were found for; depressive disorders, anxiety disorders, obsessive compulsive and related disorders, trauma and stress related disorders, feeding and eating disorders and personality disorders. Autistic and possibly autistic adults were also significantly less likely to agree	adults were very similar. Autistic and possibly autistic adults reported barriers to an accurate diagnosis. Barriers related to experiences and interactions with healthcare professionals.

	autistic, male=20, female=121. Age range=20-60, mean=42.1). No other data on demographic characteristics was recorded.			with their mental health diagnoses than non-autistic adults. Two major reasons for their disagreement were 1) ASD characteristics were confused with symptoms of a mental health condition and 2) mental health difficulties perceived to be resultant of ASD. Autistic and possibly autistic individuals spoke about the clinical barriers that hinder accurate diagnosis and support, which include healthcare	

				professionals' lack of awareness and understanding of autism, poor communication between autistic adults and healthcare professionals and treatment not being suited to their needs.	
Brosnan (2020) *An exploratory study of a dimensional assessment of the diagnostic criteria for autism.*	Study origin=UK. Participants, *N*=1076 (male=203, female=798, non-binary=72, did not state=3. Age range=16-89, mean=41.0, did not state=14). 440 reported having a diagnosis of autism, 210 reported self-identifying	To explore the self-reporting of items that directly reflect the diagnostic criteria for autism on a dimensional assessment and compare them to existing dimensional	Quantitative. Two surveys were included in two different online courses; one that targeted autistic adults and one that targeted the general population.	There were no significant differences between adults who had a formal diagnosis of ASD and adults who self-identified as autistic on the social item.	Results from autistic and self-identified autistic adults were similar.

	autism, 425 reported no identification with autism, 1 did not state. No other data on demographic characteristics was recorded.	assessments of autistic-like traits.	Participants completed an online survey, which was comprised of the two diagnostic criteria (RRB and social items). The survey for the general population also included the Autism Spectrum Quotient 10 (AQ-10) (Allison et al., 2012) at the end of the survey.	There was a significant difference between adults who had a formal diagnosis of ASD and adults who self-identified as autistic on the RRB item. In comparison to the non-autistic group, adults with a formal diagnosis of ASD and adults who self-identified as autistic both scored significantly higher on both (social and RRB) items.	
Cooper et al. (2017) *Social identity, self-esteem, and*	Study origin=UK. Participants, *N*=539 272 were autistic participants, 81% of which	To investigate the relationship between autism identification,	Quantitative. Participants were recruited from online forums (e.g. forums	Compared to non-autistic individuals, autistic individuals had lower personal	The relationship between autism identification and

mental health in autism.	reported having a formal diagnosis (female=47%, average age=32.7 years, graduates=52%, heterosexual=50%, 63% reported having a mental health diagnosis). 267 were not autistic (female=53%, average age=34.2 years, graduates=79%, heterosexual=82%, 26% reported having a mental health diagnosis). No other data on demographic characteristics was recorded.	collective self-esteem and psychological wellbeing in autistic people.	for autistic individuals and forums at the university where the research was undertaken). Participants were asked to complete an online survey. All participants were asked to complete a personal self-esteem measure (Rosenberg, 1965), an anxiety measure (Spielberger et al., 1983) and a depression measure (Spielberger et al., 2003). Autistic participants were asked to complete an additional two	self-esteem, and higher depression and anxiety. Autism identification was positively related to personal self-esteem to the extent of providing a sense of collective self-esteem.	psychological wellbeing. In line with Social Identity Theory (SIT) (Tajfel & Turner, 1979), a positive autistic identity was related to better psychological wellbeing.

			measures: an autism identification measure (Leach et al., 2008) and an autism collective self-esteem measure (Luhtanen & Crocker, 1992).		
Egan et al. (2019) *The measurement of adult pathological demand avoidance traits.*	Study origin=UK. Study one. Participants, *N*=347 (male=94, female=230, other (non-binary/gender fluid) =19, did not state=4. Age range=18-84, mean=36.9). Mean years of education=14.7. Reported a prior formal mental health diagnosis=54.4%. Reported a belief that they had an undiagnosed mental health disorder=26.6%.	Study one. To validate the Extreme Demand Avoidance Questionnaire (EDA-QA) (O'Nions et al., 2014a) for use as a self-report measure of traits and behaviours related to PDA in adults without intellectual impairment.	Study one. Quantitative. Participants were recruited from online platforms that 1) focused on concerns/needs of autistic individuals and 2) incorporated the general population. Participants were asked to complete an online survey, which consisted of:	The EDA-QA (O'Nions et al., 2014a) was found to be a reliable and valid measure. Self-reported PDA traits were found to partially relate to self-reported ASD traits.	N/A

	Reported a formal diagnosis of ASD=59. Reported self-identifying as autistic with PDA=29. Reported solely self-identified PDA=44. Reported self-identified PDA with anxiety or depression=19. Study two. Participants, *N*=191 (male=47, female=14, other (non-binary/gender fluid) =3, did not state=127. Age range=18-76, mean=29.15). Reported more than 13 years of education=83.2%, in full or part time study=39.3%, in full or part time employment=51.8%, unemployed/retired=8.9%. 26.2% reported a confirmed psychological diagnosis	To use the EDA-Q to examine the relationship between PDA traits, ASD traits and other psychopathology dimensions in a community sample of adults reporting self-identified psychopathology. Study two. To validate the EDA-Q (O'Nions et al., 2014b) in relation to fuller measures of ASQ, EQ, personality and offending. To explore the predictive relationship between the	the EDA-QA (O'Nions et al., 2014a), the ASQ-SF (Kuenssberg et al., 2014), the ICU (Kimonis et al., 2008) and the PID-5-BF (Krueger et al., 2013). Study two. Quantitative. Participants were recruited from online platforms that 1) included individuals that self-identified ASD or PDA and 2) incorporated the general population. Participants were asked to complete an online survey, which consisted of:		

	(joint anxiety and depression were most prevalent). 11.5% reported a suspected psychological diagnosis (anxiety and Asperger's syndrome mostly).	dimensions and offending behaviour.	the EDA-QA (O'Nions et al., 2014a), the ASQ (Baron-Cohen et al., 2001), the EQ (Baron-Cohen & Wheelwright, 2004), the IPIP-50 (Goldberg, 1999) and the SRED (Moffitt & Silva 1988; Charles & Egan, 2005).		
Kapp et al. (2013) *Deficit, difference, or both? Autism and neurodiversity.*	Study origin=USA. Participants, *N*=657 (male=26.2%, female=68.6%, transgender and intersex=3.5%, did not state=1.7%. Age range=8-84, mean=32.5). Education range= no education – postdoctoral	To answer research aims: 1) to characterize awareness of and evaluations of the neurodiversity movement online (where the neurodiversity movement arose	Mixed methods. Online survey. Participants were recruited from the USA and UK via various online platforms, emails and social networks. Participants were asked to complete	Compared to non-autistic individuals, autistic individuals (individuals with a formal diagnosis and individuals who self-identify as autistic) were more likely to be aware of neurodiversity and	Results from autistic individuals and individuals who self-identify as autistic were very similar.

	training, mean years of education=15.5 years. Ethnicity, Caucasian=78.7%, Hispanic=4.6%, Asian=2.7%, African decent=1.8%, Pacific Islander=3%, mixed ethnicity=6.1%. *Gender or ethnicity were not reported by all participants* 223 reported a formal diagnosis of ASD, 78 reported self-identifying as autistic, 342 reported as non-autistic, 14 reported not knowing if a formal diagnosis had been given (excluded from analysis). No other data on demographic characteristics was recorded.	and often takes place; e.g. Jordan, 2010), 2) to confirm core distinctions between the medical model and the neurodiversity movement, and 3) to critically examine the perceived opposition between the medical model and the neurodiversity movement.	the AQ-50 (Baron-Cohen et al., 2001). Participants were asked a series of questions about neurodiversity and questions about autism; autism as identity, emotions about autism and attitudes towards parenting.	to have learned about it online. Compared to non-autistic individuals, autistic individuals assigned a lower priority to research on the cause of autism. Autistic individuals were more likely to assign a biological cause to autism. Being an autistic individual and having an awareness of neurodiversity was associated with a greater likelihood of preferring identity first (e.g. autistic person) language.	

Lewis (2016) *Exploring the experience of self-diagnosis of autism spectrum disorder in adults.*	Study origin=USA. Participants, *N*=37 (male=20, female=16, did not state=1. Age range=18-52, mean=29.9). Highest level of education, high school=5, Vocational/technical/trade=3, some college education=13, college graduate=9, some postgraduate work=2, postgraduate degree=4, did not state=1. Employment, employed=25, unemployed/disabled=3, student=8, did not state=1. Race/ethnicity, Asian=1, Black=2, Hispanic=1, white=31, did not state=2. Country, Argentina=1, Belgium=1, Germany=1, Canada=4, India=1, Russia=1, Norway=1,	To answer the research question 'What is the experience of being self-diagnosed with ASD?'	Qualitative. Participants were recruited through online support groups and public forums for autistic individuals. Participants asked to respond to the statement: 'Please describe your experience of coming to a self-diagnosis of autism spectrum disorder. Please share any thoughts, feelings, and specific experiences.'	Five themes ("feeling othered", "managing self-doubt", "sense of belonging", "understanding myself" and "questioning the need for formal diagnosis") were found to be descriptors of the self-diagnosis of ASD journey.	Participants felt that a self-diagnosis of ASD was beneficial in terms of understanding themselves. Some participants felt that a self-diagnosis of ASD was satisfactory and did not feel the need to pursue a formal diagnosis of ASD. Several participants stated barriers to pursing a formal diagnosis of ASD (some relating to physical barriers, e.g. not being able to afford

	Slovenia=1, Turkey=1, United Kingdom=5, United States=19, did not state=1. All participants reported self-identifying as autistic.				a formal diagnosis of ASD and no availability of adult ASD specialists. Others relating to personal barriers, e.g. the fear of not being believed and extreme anxiety in appointments).
Lewis (2017) *A mixed methods study of barriers to formal diagnosis of autism spectrum disorder in adults.*	Study origin=USA. <u>Study one.</u> Participants, *N*=114 (male=57, female=45, agender=2, gender fluid/gender queer/non-binary gender=2, did not state=8. Age range=18-65, mean=36.2, did not state=2). Highest level of education, some high school=3, high school graduate=8, vocational/technical/trade	To answer the research questions: 1) (qualitative) 'what barriers do adults with ASD face in reaching a formal diagnosis?' and 2) (quantitative) 'what is the incidence and severity of each of these barriers?'	Mixed methods. <u>Study one.</u> Qualitative. Secondary data analysis of two phenomenological studies: 1) being formally diagnosed with ASD as an adult (Lewis, 2016a) and 2) being self-diagnosed with ASD	Nine themes ("Anxiety", "Cost", "Access to ASD adult specialists", "Fear of not being believed", "Inability to describe symptoms", "Mistrust of healthcare professionals", "Stigma", "Complexity of	Participants reported personal barriers to obtaining a formal diagnosis, most frequently and as most severe. The personal barriers related to the interactions with healthcare professionals.

	training=7, some college=35, college graduate=32, some postgraduate work=4, postgraduate degree=15, did not state=10. Employment, employed=58, unemployed=18, homemaker=3, student=17, retired=2, disabled/unable to work=7, did not state=9. Ethnicity, white non-Hispanic=95, Hispanic/Latino=2, black/African American=5, native American/American Indian=2, Pacific Islander/Asian=4, did not state=6. 77 reported a formal diagnosis or evaluation of ASD and 37 self-identified as autistic). <u>Study two.</u>		as an adult (Lewis, 2016b). <u>Study two.</u> Quantitative. From the secondary data analysis in study one, a list of potential barriers to a formal diagnosis of ASD was devised. Participants were recruited through online forums and message boards for autistic individuals. Participants were asked to read each of the listed barriers and rate the severity of the barrier on a 4-point Likert-type scale (1=Not a	healthcare system" and "Lack of perceived value of formal diagnosis") were found to potential barriers to a formal diagnosis of ASD. The most frequently reported barriers were: concerns about not being believed (94.4%), followed by not being listened to (92.3%) and being told that they were 'making up' symptoms (92%). These barriers were also reported to be the most severe, with each barrier	

	Participants, *N*=665 (male=90, female=363, agender=90, gender fluid/gender queer/non-binary gender=69, transgender=15, unsure/questioning=7 and did not state=31. Age range=18-68, mean=30.9, did not state=29). Sexual orientation, heterosexual=190, gay/lesbian=57, bisexual=167, unsure=41, other=170, did not state=40. Marital status, single, never married=378, married/domestic partnership=198, widowed=4, divorced=47, did not state=38.		barrier/no influence, 2=Somewhat of a barrier, 3=Moderate barrier and 4=Extreme barrier) to obtaining a formal diagnosis of ASD. Participants were also asked to complete the AQ (Baron-Cohen et al., 2001).	reported as extreme barriers for at least 50% of participants. The mean score for not being believed was 3.28, for not being listened to was 3.21 and for bring told that they were ‘making up’ symptoms was 3.19.	

	Highest level of education, some high school=25, high school graduate=51, vocational/technical/trade training=29, some college=258, college graduate=135, some postgraduate work=43, postgraduate degree=85, did not state=39. Employment, employed=261, unemployed=77, homemaker=27, student=143, retired=6, disabled/unable to work=113, did not state=38. Health insurance, primary source from government=179, primary source from employer=87, primary source through member of family=211,				

	primary source self-funded=41, no insurance=105, did not state=42. 216 reported a formal diagnosis or evaluation of ASD, 135 reported an informal evaluation of ASD, 280 reported self-identifying as autistic and 34 did not state.				
Lewis et al. (2021) *“Straight Sex is Complicated Enough!”: The Lived Experiences of Autistics Who are Gay, Lesbian, Bisexual, Asexual, or Other Sexual Orientations.*	Study origin=USA. Participants, *N*=67 (male=22, female=28, agender=4, gender fluid/gender queer/non-binary=9, transgender=1 did not state=3. Age range=18-57, mean=27.6). Sexual orientation, gay/lesbian=15, bisexual=10, asexual, 19, pansexual=11,	To answer the research question ‘What is the lived experience of being an autistic who identifies as gay, lesbian, bisexual, asexual, or other sexual minority orientation?’	Qualitative. Participants were recruited through online platforms for autistic individuals. Participants asked to initially provide a written response to four open-ended questions; 1) What has been your experience as an	Six themes (“self-acceptance is a multi-layered journey”, “autism complicates understanding of sexual identity”, “anxiety, sensory overload, and social stressors affect sexual expression”, “feeling	ASD affected sexual identity and sexual relationships.

	demisexual=3, omnisexual=1, queer=3, no label=2, did not state=3. Relationship status, single=38, in a relationship=15, married=8, divorced=2, did not state=4. Highest level of education, some high school=2, high school graduate=8, vocational/technical/trade training=2, some college=19, college graduate=21, some postgraduate work=7, postgraduate degree=4, did not state=4. Employment, full time employment=19, part time employment=8, unemployed=13, student=18, disabled/unable to work=6, did not state=3.		individual with ASD and identifying with a sexual minority identity? Please share any thoughts, feelings, and specific experiences in as much detail as possible. 2) Please describe any challenges and/or aspects of pride. 3) How would you describe your sexual orientation? 4) Please describe your comfort level with your self-identity. How has this changed over time? Based on participant response to the four	misunderstood and misunderstanding others", "concerns about the ability to find mutually satisfying relationships and "inability to effectively identify and communicate intimate desires".) were found to be indicative of the lived experience of sexual minority autistic individuals.	

	Ethnicity, white, non-Hispanic=55, Hispanic/Latino=1, black/African American=2, Native American/American Indian=1, Asian/Pacific Islander=1, multi-racial=4, did not state=3. 42 reported a formal diagnosis of ASD, 17 reported having been informally identified as autistic by a healthcare professional, 5 reported self-identifying as autistic and 3 did not state.		open-ended questions, individualised follow-up questions were asked. Examples given were; ‘1) In your previous response, you said that you are “less willing to seek companionship out of fear of hurting other people by neither satisfying their emotional nor physical needs.” Can you tell us more about this? 2) In your previous response, you said that you “don’t have any sexual drive to form a romantic		

			relationship.” To clarify, do you desire a romantic relationship that does not involve a sexual relationship? For example, would you be interested in having an asexual romantic relationship with a partner?'		
Moore (2016) *The fourth degree of autism: Self-identification.*	Theoretical framework. Not a research study.	Theoretical framework. Not a research study.	Theoretical framework. Not a research study.	Theoretical framework. Not a research study.	Self-identifying as autistic is recognised as a key sequential step in positively accepting an autistic identity. The value of a formal diagnosis of ASD is highlighted. A formal diagnosis

					helps adults to understand themselves.
Parsloe (2015) *Discourses of disability, narratives of community: Reclaiming an autistic identity online.*	Study origin=USA. Participants, *N*=10 (male=4, female=6. Age range=18-56, average age=35). Ethnicity, Caucasian=10. 6 reported a formal diagnosis of autism, 2 reported an informal diagnosis of autism and 2 reported a self-diagnosis of autism. No other data on demographic characteristics was recorded.	To answer the research question: how do those with high functioning autism and Asperger's syndrome communicatively construct an Aspie identity on the Internet?	Qualitative. Netnographic approach. Public sections of the online community Aspies Central (AC) was used for data collection. 10 interviews (telephone=1, Skype with video feature=1, Skype without video or sound=4, Facebook chat=1, email=3) were also conducted. Participants were recruited through	Four themes ("naming versus labelling", "narrative identity construction", "coalition building" and "othering/ selfing") were found to be conclusions about the process of identity construction online.	A more positive view of Aspieness tended to be expressed by self-diagnosed participants and participants that self-diagnosed ASD before pursuing a formal diagnosis.

			online platforms for autistic individuals. Participants were asked to describe differences and similarities between Neurotypical and Aspie communities, to discuss the difficulties faced by Aspies and to describe disclosure and passing strategies.		
Penwell-Barnett and Maticka-Tyndale (2015) *Qualitative exploration of sexual experiences among adults on the autism spectrum:*	Study origin=USA. Participants, *N*=24 (6 reported a masculine identity, 13 reported a feminine identity and five reported a genderqueer or androgynous identity. Age range=18-61, mean=37).	The aim of the research was 1) to begin to develop an understanding of how autistic individuals describe their own sexuality and sexual experiences, and 2)	Qualitative. Participants were recruited through website announcements and Listservs for the autistic community. Participants participated in	Compared to the general population, individuals who self-identified as autistic were less likely to be gender conforming or heterosexual.	ASD affected sexual identity and sexual relationships.

Implications for sex education.	Identifying as Caucasian or white=22. Reported the completion of some post-secondary or professional education=21. Relationship status, married=9, single=8, domestic partnership=2, cohabiting=3, in a serious, not cohabiting, relationship=2. Many (number not reported) participants lived independently. Other (number not reported) participants received supplemental income, health insurance or had a personal assistant. All participants reported a self-identification as a person on the autism spectrum.	to examine the implications of those descriptions for the delivery of sex education.	online semi-structured interviews of their choice (email=18, chat=2, and in streaming (e.g. Skype) =4).	The most common reported concerns were courtship difficulties and sensory dysregulation in the context of partnered sexuality.	

Pohl et al. (2020) *A comparative study of autistic and non-autistic women's experience of motherhood.*	Study origin=UK. Participants, *N*=487 355 reported being an autistic mother: 235 reported a formal diagnosis of ASD and 120 reported self-identifying as autistic (male=2, female=339, other=2. Age, mean=42.7). Education, high school/some secondary=20, completion of high school/secondary=55, completion of some of an undergraduate degree=71, completion of an undergraduate degree=102, completion of a postgraduate/graduate degree=107. Marital status, single=36, married=202, civil partnership=9, divorced=44, widowed=4, separated=28,	The aim of the research was to explore autistic mothers' experience of the perinatal period and parenthood.	Quantitative. Community-based participatory research model. Participants were recruited through online platforms (social media and specific support groups for autistic individuals). An online survey was created and was completed by autistic and non-autistic mothers. Participants were also asked to complete the Autism Spectrum Quotient 10 (AQ-10) (Allison et al., 2012).	Compared to non-autistic mothers, autistic mothers find aspects of parenthood more difficult. Aspects included communication difficulties with professionals, negative perceptions of their mothering and high rates of postpartum depression.	40% of mothers with a diagnosis of ASD reported that they rarely or never disclosed their diagnosis. For adults who self-identified as autistic, 75% reported rarely or never disclosing. Compared to 41% of non-autistic mothers, over 70% of autistic mothers reported an additional psychiatric condition. Self-identified adults scored significantly higher than non-autistic

	long-term partner=29, other=3. Living with current partner, yes=240, no=3. Single parenthood, currently a single parent=98, been a single parent in the past=79, never been a single parent=178. Country (top 5), UK=173, USA=80, Australia=45, France=11, Canada=12. 132 reported being a non-autistic mother (male=3, female=129. Age, mean=44.6). Education, high school/some secondary=9, completion of high school/secondary=25, completion of some of an undergraduate degree=10, completion of an undergraduate degree=35,		Chi-squared analysis was used to compare responses.		mothers on the AQ-10 (Allison et al., 2012).

	completion of a postgraduate/graduate degree=53. Marital status, single=12, married=88, civil partnership=1, divorced=3, widowed=2, separated=9, long-term partner=16, other=1. Living with current partner, yes=103, no=2. Single parenthood, currently a single parent=23, been a single parent in the past=20, never been a single parent=89. Country (top 5), UK=75, USA=23, Australia=23, France=4, Canada=2.				

2.2.6 Data analysis

In line with the guidance by Arksey and O'Malley (2005) and Peters et al. (2015), I reviewed the data extracted from the studies (Table 1.) to identify key themes that illustrated the research that had been conducted on the self-identification of autism in adults who did and did not have a formal diagnosis of autism (the aim of the scoping review). From reviewing the characteristics of the included studies, it was identified that the studies predominantly focused on five themes. The research articles included in this scoping review were then categorised thematically into one of the five main areas according to the focus (aims) of their research. A review of the five key themes that I identified was independently undertaken by one of my PhD supervisors. There was no disagreement on the themes identified, but the names of the themes were refined following a discussion with my PhD supervisor. A numerical analysis of the characteristics of the studies (e.g. date of study and methodology used) was then conducted. At this stage the data analysis was reviewed by my other two PhD supervisors, and a subsequent discussion was held at a supervisory meeting to ensure consensus.

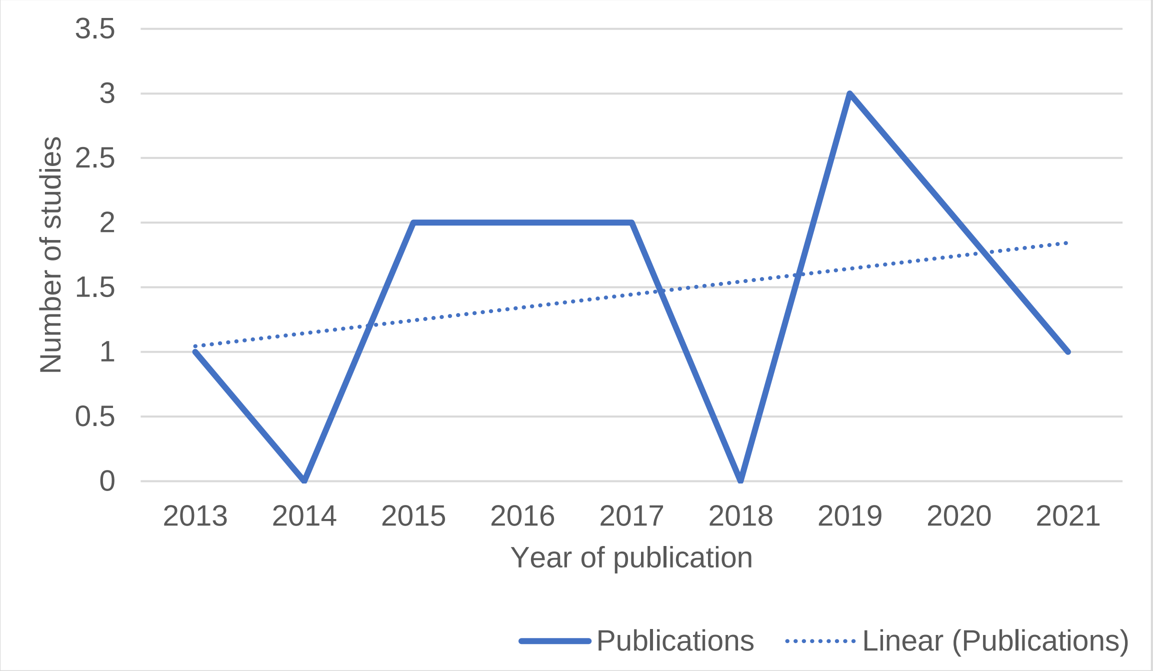
The five key themes that were identified from this scoping review were: (1) the diagnostic process from a client´s perspective, (2) the process of self-identifying as autistic from a lifespan perspective, (3) an autistic identity, (4) sexual identity and experiences, (5) the perception of autism as a difference or a disability.

2.3 Results

2.3.1 Study characteristics

The final 13 studies that were included in this scoping review consisted of five qualitative studies (Angulo-Jiménez & DeThorne, 2019; Lewis, 2016b; Lewis et al., 2021; Parsloe, 2015; Penwell-Barnett & Maticka-Tyndale, 2015), four quantitative studies (Brosnan, 2020; Cooper et al., 2017; Egan et al., 2019; Pohl et al., 2020), three mixed methods studies (Au-Yeung et al., 2019; Kapp et al., 2013; Lewis, 2017), and one theoretical framework (Wylie et al., 2016). Most of the studies were conducted in the USA (*n*=7) and the UK (*n*=6). Studies ranged in date from 2013 to 2021 with the most studies (*n*=3) published in 2019 (Angulo-Jiménez & DeThorne, 2019; Au-Yeung et al., 2019 & Egan et al., 2019) and the overall trend showing an annual increase in studies within the date range (see Figure 3. below). All of the included studies collected data online and most of the studies (*n*=9) used a survey as a method for data collection (Au-Yeung et al., 2019; Brosnan, 2020; Cooper et al., 2017; Egan et al., 2019; Kapp et al., 2013; Lewis, 2016b; Lewis, 2017; Lewis et al., 2021; Pohl et al., 2020). Two of the studies (Angulo-Jiménez & DeThorne, 2019; Parsloe, 2015) analysed publicly accessible online data (videos and forum posts) with the latter study also conducting interviews. The final study (Penwell-Barnett & Maticka-Tyndale, 2015) conducted interviews.

Figure. 3. A line graph to show the number of studies on the self-identification of autism in adults per year of publication in the scoping review.



Ten of the included studies collected data on the diagnostic status of participants (e.g. formally diagnosed as autistic, informally diagnosed as autistic or self-identified as autistic) and in nine of those studies the smallest proportion of participants were those who self-identified as autistic (Angulo-Jiménez & DeThorne, 2019; AuYeung et al., 2019; Brosnan, 2020; Cooper et al., 2017; Egan et al., 2019; Kapp et al., 2013; Lewis, 2017; Lewis et al., 2021; Pohl et al., 2020). In four of the studies, results from adults who self-identified as autistic were very similar to the results of adults with a formal diagnosis of autism (Au-Yeung et al., 2019; Brosnan, 2020; Kapp et al., 2013; Pohl et al., 2020).

Eight of the included studies (Au-Yeung et al., 2021; Brosnan, 2020; Kapp et al., 2013; Lewis, 2017; Lewis et al., 2021; Parsloe, 2015; Penwell-Barnett & Maticka-Tyndale, 2015; Pohl et al., 2020) had a higher proportion of participants who identified as female.

In line with the scoping review guidance developed by Arksey and O'Malley (2005) no studies were excluded based on their scientific quality.

From the 13 studies analysed, five themes were identified: (1) the diagnostic process from a client´s perspective, (2) the process of self-identifying as autistic from a lifespan perspective, (3) an autistic identity, (4) sexual identity and experiences, (5) the perception of autism as a difference or a disability.

2.3.2 First theme: the diagnostic process from a client's perspective

Four (Au-Yeung et al., 2019; Brosnan, 2020; Egan et al., 2019; Lewis, 2017) of the 13 included studies related to the diagnostic process for autism. Most of the studies (*n*=3) were conducted in the UK (Au-Yeung et al., 2019; Brosnan, 2020; Egan et al., 2019) and one was conducted in the USA (Lewis, 2017). In the study by Lewis (2017) data was collected from thirty countries, but the data was re-categorised into five countries (Australia, Canada, the UK, the USA and Other countries) for statistical purposes. The studies were split equally (*n*=2) between the use of mixed methods and quantitative approaches. The two studies (Au-Yeung et al., 2019; Lewis, 2017) that utilised a mixed methods approach investigated the experience of, and barriers to, a formal diagnosis of autism in adulthood. The two studies (Brosnan, 2020; Egan et al., 2019) that utilised a quantitative approach investigated measures of autistic traits in adulthood.

In two studies (Au-Yeung et al., 2019; Lewis, 2017) the predominant barrier to being referred for an autism diagnostic assessment in the UK and the USA was found to be the difficulties that adults, likely to be autistic, had in explaining to healthcare professionals (e.g. doctors) why they believed that they could be autistic. In both studies, all participants also reported not being taken seriously in their initial clinical appointment with a healthcare professional. This doubt from healthcare professionals in those initial clinical appointments (with perhaps little knowledge on how the different forms of autism may present in adults and young people) prevented an important proportion of participants being referred for an autism diagnostic assessment (Au-Yeung et al., 2019; Lewis, 2017). Lewis (2017) also found that a significant number of adults experienced a fear of being disbelieved by healthcare professionals in their initial clinical appointments. This fear was found to be another factor that acted as a barrier to being referred for an autism diagnostic assessment. Additionally, most of the adults in the study by Lewis (2017) reported feeling that healthcare professionals seemed to hold strong stereotypical views of the presentation of autism (more common in non-verbal children who are autistic), and lacked awareness and understanding of how autism may present through the lifespan. This lack of awareness and understanding of autism by healthcare professionals was also found in the study by Au-Yeung et al. (2019).

In both studies (Au-Yeung et al., 2019; Lewis, 2017) misdiagnoses were found to be another barrier to a formal autism diagnosis for adults. Adults reported that throughout their life (from childhood to adulthood), they had been labelled with a range of mental health conditions (e.g. anxiety, low mood, challenging behaviour and/or personality disorders, to name a few) which they totally disagreed with because they did not feel that these conditions fully explained who they were, or their personal strengths and difficulties (Au-Yeung et al., 2019; Lewis, 2017).

Adults also reported other barriers to an autism diagnostic assessment, which were country specific (Lewis, 2017). For example, the most significant barrier to being assessed for autism in Canada and the UK was found to be the waiting times. In the USA, it was found to be the expensive cost of the assessments (Lewis, 2017).

One study (Brosnan, 2020) aimed to improve the autism diagnostic pathway for adults. In order to achieve this aim, Brosnan (2020) tried developing a measure that mirrored the autism diagnostic criteria (criterion A: Social and criterion B: Restricted Repetitive Behaviours). Brosnan (2020) recruited adults with a formal diagnosis of autism and adults who self-identified as autistic to participant in the study. Findings of the study revealed no significant differences between adults with a formal diagnosis of autism and adults who self-identified as autistic in criterion A (social difficulties). However, a small but significant difference ($p=0.024$) was found between adults with a formal diagnosis of autism and adults who self-identified as autistic in criterion B (restrictive and repetitive behaviours) of the new measure that Brosnan (2020) developed. As a result of these findings, Brosnan (2020) suggested that criterion B of his new measure could be useful to distinguish between adults who would and would not meet diagnostic criteria for autism. Therefore, Brosnan (2020) recommended expanding the use of criterion B within the autism diagnostic pathway.

Considering that Pathological Demand Avoidance (PDA) has been linked with autism, Egan et al. (2019) aimed to examine this relationship by validating a measure that assessed PDA, the Extreme Demand Avoidance Questionnaire – Adult version (EDA-QA). The main purpose of the EDA-QA (Egan et al., 2019) was to use it as a screening tool for PDA in clinical settings. The EDA-QA (Egan et al., 2019) was adapted from the observer-rated EDA Questionnaire (EDA-Q) developed by O'Nions et al. (2014b) and used in children. The EDA-QA (Egan et al., 2019) was found to have good validity and reliability in a sample of 538 adults who identified as autistic with and without a formal diagnosis of autism, adults with PDA or who self-identified with PDA (Egan et al., 2019). Egan et al. (2019) concluded that the EDA-QA could be used as a complementary tool in clinical and research settings to determine PDA in adults.

Au-Yeung et al. (2019) and Lewis (2017) indicated that when adults were assessed for autism, they experienced a lot of difficulties in understanding the real meaning of the questions that healthcare professionals were asking during the assessment. Most of these adults also reported difficulties in providing specific examples regarding their personal strengths and difficulties interacting and communicating with others, and how these were part of their own identity (Au-Yeung et al., 2019; Lewis, 2017).

2.3.3 Second theme: the process of self-identifying as autistic from a lifespan perspective

All studies in this scoping review included adults who self-identified as autistic. However, it is important to remark from a neurodiversity-affirming perspective what the study conducted by Lewis (2016b) in the USA found. Lewis (2016b) used a qualitative approach (online survey) to investigate the process of self-identifying as autistic in terms of the experiences and feelings that adults had during that process. The Nine Degrees of Autism developed by Wylie et al. (2016) also described the process of self-identifying as autistic in the fourth degree of autism; self-identification. From a clinical perspective, the importance of this process as an identity facilitator in neurodivergent adults who are likely to be autistic was highlighted by both authors (Lewis, 2016b; Wylie et al., 2016). Self-identifying as autistic can really help these adults (and their relatives, friends, acquaintances, and mental health professionals) to understand how they think, feel and behave.

In the study by Lewis (2016b), the process of self-identifying as autistic was found to be facilitated by family members, friends, and acquaintances. Participants (adults who self-identified as autistic) in Lewis' (2016b) study reported how different the way they understood certain thoughts, feelings and behaviours was, in comparison to others. Adults who self-identified as autistic in Lewis' (2016b) study also mentioned that from a young age (e.g. late childhood/early adolescence), they had already realised that they had a different way in comparison to their peers and relatives of understanding their personal, social, and physical environment without being aware why. This is in line with the second degree of autism which explains that individuals on the autism spectrum realise that they perceive the world, themselves, and others in a different way, but cannot explain why their approaches are different to other´s ways of understanding the world (Wylie et al., 2016).

Considerations from others and personal realisations seemed to be the key factors that were associated with adults starting to think that being autistic could be a possibility (Lewis, 2016b; Moore, 2016). To validate or rule out this possibility of being autistic, adults and often their loved ones (e.g. parents, partners or friends) tended to do extensive searches on the internet, which sometimes included the completion of a wide range of online autism questionnaires (both reliable and unreliable). They also tended to read books/articles and/or watch documentaries about autism in adults (Lewis, 2016b; Moore, 2016).

The majority of adults in the studies that were included in this scoping review considered self-identifying as autistic to be beneficial, from a personal perspective, because it had a positive influence on understanding who they really were after several years wondering why they had different views from the world that they were part of (Lewis, 2016b). The majority of these adults seemed to find a space of safety and personal reassurance in online autism forums or face to face groups with other autistic individuals. The Nine Degrees of Autism´s theory (Wylie et al., 2016) deem self-identifying as autistic to be an essential stage in the process towards the positive acknowledgment of an autistic identity. According to Moore (2016) the self-identification process (the fourth degree of autism) commences with the recognition that being autistic could be a possibility and ends with obtaining a formal diagnosis of autism. This pattern appeared in the narrative of the majority of studies that were included in this scoping review.

For some adults, self-identifying as autistic was deemed satisfactory and the need to pursue a formal diagnosis of autism was not felt necessary. These adults explained how self-identifying as autistic provided the explanation and self-understanding that had been missing throughout their lives and did not see any value to being formally diagnosed as autistic (Lewis, 2016b). Still, for other adults there was a value to being formally diagnosed as autistic. For these adults, a formal diagnosis of autism was pursued for their own validation purposes or for getting reasonable adjustments in a broad range of settings (e.g. educational and/or at work) (Lewis, 2016b; Wylie et al., 2016).

In the absence of a formal diagnosis of autism, autistic individuals and their significant others are less likely to receive the support and social recognition they deserve. This has been identified as a factor that can influence in a negative way the positive acceptance of their autistic identity (Moore, 2016).

2.3.4 Third theme: an autistic identity

Two studies, one conducted by Cooper et al. (2017) in the UK using a quantitative approach (online survey) and one conducted by Parsloe (2015) in the USA using a qualitative approach (ethnography), studied the role of autistic identity in adults with a formal diagnosis of autism and in adults who self-identified as autistic without a formal diagnosis of autism.

Parsloe (2015) found that adults who self-identified as autistic prior to pursuing a formal diagnosis of autism had a more favourable opinion of autism. This is in comparison to adults who did not self-identify as autistic and were given a formal diagnosis of autism by a healthcare professional. Parsloe (2015) suggested that this positive attitude towards autism could be explained in terms of adults having chosen or identified with an identity in which they felt they fitted, rather than being labelled as autistic after having completed an autism assessment with a healthcare professional. In the study by Parsloe (2015) it was also mentioned that the active search of an autism identity by adults who self-identified as autistic, mainly through online platforms, could be linked with the need for these individuals to find an answer that explained who they really were. This seemed to be related with the development of a positive autistic identity, and to the understanding of autism as a condition rather than a disorder like the DSM-5 (APA, 2013) or the ICD-11 (WHO, 2019) suggests.

Cooper et al. (2017) found that participants who reported a higher positive autistic identity had higher levels of self-esteem and better psychological wellbeing. The study by Cooper et al. (2017) recruited 272 adults who identified as autistic, with 81% of these adults reporting having a formal diagnosis of autism.

2.3.5 Fourth theme: sexual identity and experiences

Two studies conducted in the USA by Lewis et al. (2021) and Penwell-Barnett and Maticka-Tyndale (2015) studied the sexual identity and sexual experiences of adults who identified as autistic (with or without a formal diagnosis of autism) using a qualitative approach (online survey and online interviews respectively).

The study by Penwell-Barnett and Maticka-Tyndale (2015) found that adults who identified as autistic were less likely to be gender-conforming or heterosexual. In this study, Penwell-Barnett and Maticka-Tyndale (2015) highlighted the need to develop sex education programmes (mainly focused on courtship, sensory dysregulation and adequate sex education) that took into consideration a neurodivergent perspective (identities and experiences of sexuality). The results of the study conducted by Penwell-Barnett and Maticka-Tyndale (2015) are in line with the study that Lewis et al. (2021) conducted with 67 participants who identified as autistic in the USA. Through an online survey, Lewis et al. (2021) identified participants as a “double minority” through the identification of six main themes (1 understanding self-acceptance as a journey, (2) taking into account that autistic traits may complicate self-identification of sexual orientation, (3) how social and sensory stressors may affect sexual expression, (4) how often sexual minority autistic people feel misunderstood and isolated, (5) the challenges that often sexual minority autistic people have in finding mutually satisfying relationships, and (6) the difficulties that sexual minority autistic people have in recognising and communicating sexual needs). Lewis et al. (2021) also concluded that as a consequence of all the challenges reported, numerous adults felt that autism had hindered the recognition of their true sexual identity.

In the study by Lewis et al. (2021), several participants also reported that throughout their lives they had often felt that other people were attributing their sexual orientation to being autistic instead of recognizing the legitimacy of their distinct sexual identity. This was particularly pertinent amongst those participants who identified as asexual.

2.3.6 Fifth theme: the perception of autism as a difference or a disability

Two studies conducted in the USA by Angulo-Jiménez and DeThorne (2019) and Kapp et al. (2013) studied the representation of autism in adults from a qualitative and mixed method approach respectively. One study conducted in the UK by Pohl et al. (2020) studied the representation of autism within the context of motherhood using a quantitative approach (online survey).

In the study by Kapp et al. (2013), it was found in an online survey completed by 657 participants (that included autistic people, relatives and friends of autistic people, and people with no specified relation to autism) that self-identification as autistic and neurodivergent awareness were correlated with viewing autism as a positive part of their identity that does not need any treatment or medical intervention. This suggests a key difference between how the medical model conceptualises autism (e.g. autism is a mental health disorder that must be treated medically) and the neurodivergent approach (autism is a condition that is characterised by a broad range of strengths and weaknesses). These main outcomes are in line with the study that Angulo-Jiménez and DeThorne (2019) conducted in the USA, in which the representation of autism was analysed through 39 YouTube videos (published from 2007 to 2015) authored by individuals who self-identified as autistic. In Angulo-Jiménez and DeThorne´s (2019) study, it was found that in most YouTube videos views of the medical model and the neurodivergent approach were acknowledged. It was also found that the neurodivergent approach appeared mainly in the use of the language in the videos and the description of autistic traits, whereas the medical model appeared mainly in the content areas that appeared in these videos. In both studies, the use of online environments was found to be a common means in which knowledge and awareness of the neurodivergent approach was gained (Angulo-Jiménez & DeThorne, 2019; Kapp et al., 2013). Autism was represented as a mixture of both disability and difference (Angulo-Jiménez & DeThorne, 2019; Kapp et al., 2013). Adults with a formal diagnosis of autism or who self-identified as autistic were more likely to assign a biological cause to autism (Kapp et al., 2013). Angulo-Jiménez and DeThorne (2019) found that a biological cause provided an explanation for the difficulties faced by autism, with 34 out of 39 bloggers assigning the difficulties encountered to autism. The contribution of societal factors, in the difficulties faced by autism, was also acknowledged in both studies (Angulo-Jiménez & DeThorne, 2019; Kapp et al., 2013).

In the context of motherhood, a study conducted by Pohl et al. (2020) with autistic mothers (n = 355) and non-autistic mothers (n = 132) from Western countries evaluated the experience of motherhood (including pregnancy, childbirth, the postpartum period, self-perception of parenting strengths and weakness, communication with professionals and the social experience of motherhood). Pohl et al.'s (2020) study found that the perceived societal representation of autism sometimes prevented mothers revealing an autism diagnosis in parenting contexts or to healthcare professionals. Pohl et al.'s (2020) study also found that the majority of mothers (75%) who self-identified as autistic never or rarely disclosed this information to other parents or healthcare professionals. As a result, autistic mothers or mothers who self-identified as autistic seemed not to have the needed support and were likeliest to find motherhood a lonely experience (Pohl et al., 2020).

2.4 Discussion

The first aim of this scoping review was to determine what research had been conducted on the self-identification of autism in adults, who do and do not have a formal diagnosis of autism. It was found that research was recent and limited, although steadily increasing. Although this scoping review identified five main themes: (1) the diagnostic process from a client's perspective, (2) the process of self-identifying as autistic from a lifespan perspective, (3) an autistic identity, (4) sexual identity and experiences, and (5) the perception of autism as a difference or a disability, there were some factors that overlapped themes (e.g. identity).

Kapp et al. (2013) was the first study in the USA that studied adults who self-identified as autistic. As a recommendation, Kapp et al. (2013) suggested that future research should investigate differences between individuals who do and do not have a formal diagnosis of autism, and the reasonings for not pursuing a formal diagnosis. Since 2013, much research conducted on adults who self-identified as autistic, with or without a formal diagnosis of autism, has focused on the diagnostic process. Research on the diagnostic process mainly found that adults faced difficulties in being referred for an adult autism diagnostic assessment, which in several cases had the consequence that many adults that would have liked to have had an assessment were never assessed (Lewis, 2017). Misdiagnosis was another common factor that appeared in this scoping review (Au-Yeung et al., 2019; Lewis, 2017).

Identity was a factor that was apparent in most of the themes that were identified in this scoping review. Similar to research conducted regarding the impact of an autism diagnosis in adulthood (Lewis, 2016a; Stagg & Belcher, 2019), the process of self-identifying as autistic allowed adults to understand who they really were (Lewis, 2016b). Even so, Moore (2016) advocates that a formal diagnosis of autism can aid the positive acceptance of an autistic identity, which has been associated with better psychological wellbeing (Cooper et al., 2017). Parsloe (2015) suggests that a positive autistic identity could be attained through the process of self-identifying as autistic, but the fact that Pohl et al. (2020) found in their study that three quarters of adults who self-identified as autistic never or rarely revealed this to healthcare professionals, might suggest otherwise or that this process is context specific. A formal diagnosis of autism is often deemed to be the authenticator of an autistic identity, which may enable self-acceptance (Lewis, 2016a). Self-acceptance can be particularly difficult for adults who identify as autistic and as a sexual minority (Lewis et al., 2021). Therefore, it is concerning that adults face barriers and misdiagnosis in the pursuit of an autism diagnostic assessment and diagnosis (Au-Yeung et al., 2019; Lewis, 2017).

Further studies should investigate what socio-demographic (e.g. ethnicity, education and employment) and psychosocial (e.g. quality of life, subjective wellbeing and self-esteem) factors are associated with the development of a positive autistic identity in adults who self-identity as autistic (with or without a formal diagnosis of autism).

Secondly, this scoping review aimed to identify which aspects of the self-identification process could be used to improve the referral and diagnostic processes of an adult autism assessment for adults who choose this route. Other research suggests that individuals who self-identify with having a mental health condition are more likely to seek help (Evans-Lacko et al., 2019). In several of the studies that were reviewed in this scoping review (Au-Yeung et al., 2021; Brosnan, 2020; Kapp et al., 2013; Pohl et al., 2020), it was found that the results from adults who self-identified as autistic were very similar to the results of adults with a formal diagnosis of autism. This may imply that adults who may likely be autistic do have a reasonably accurate understanding of autism as a condition. Interestingly, there were a higher proportion of participants who identified as female (who may likely be autistic) in all of these studies. However, this understanding of autism was often distrusted or ignored by healthcare professionals (Lewis, 2017).

Certainly, the presentation of autism can differ in adults as autistic traits may be masked by the use of learnt masking strategies (Fusar-Poli et al., 2020; Lai & Baron-Cohen, 2015). As a consequence, autistic traits may be less obvious to other people, including healthcare professionals (Fusar-Poli et al., 2020). It has been pointed out that learnt masking strategies may be used more by females (Lai & Baron-Cohen, 2015), which is a contributory factor to the additional challenges that females experience in the diagnostic process (Lockwood Estrin et al., 2021). Lockwood Estrin et al. (2021) note that research to address the barriers that females encounter is increasing, but it is still a largely under-researched topic. This is reflected in the findings of this scoping review, in which many of the included studies had a higher number of participants who identified as female.

To ensure the effective screening and diagnosis of autism in adults, Pivens and Rabins (2011) previously highlighted the need to develop tools that could take into consideration how autism presents in adults (instead of adapting clinical tools that are mainly used for children and young people). More recently, Lewis (2017) emphasised the need to ensure that these tools also consider the gender-based variations in the presentation of autism amongst adults. Yet, little effort has been made to improve the diagnostic pathway of an autism assessment for adults in recent years.

Just one study (Brosnan, 2020) in this scoping review had the aim of improving the autism diagnostic process. Although this is encouraging, the concept of autistic identity (including self-identifying as autistic) remains overlooked. Indeed, this scoping review found that little is known regarding how an autistic identity or the fact that an adult has self-identified as autistic has been considered in the referral process of an adult autism diagnostic assessment, or actually during an adult autism diagnostic assessment. In line with Gallo (2010), it is deemed important in clinical settings (e.g. in a GP appointment to get a referral for an autism diagnostic assessment or during an autism diagnostic assessment) to give adults who self-identify as autistic the opportunity to express in their own words the main strengths and difficulties that they experience in real life (e.g. at home or at work). It is also believed that this approach should be considered as a complementary procedure in the current recommendations suggested by NICE for adult autism assessments (NICE, 2016).

Only one scale that assesses autistic identity in adults could be found. This scale, ‘The Autism Spectrum Identity Scale’ (ASIS), was developed and validated by McDonald (2016) in the USA with a sample of 1139 adults who self-identified as autistic or had a formal diagnosis of autism. The ASIS (McDonald, 2016) comprises four factors (changeability, spectrum abilities, context dependent, and positive difference) that explain autism identity and is used in research settings. It is believed that this questionnaire (or similar ones) could be used as a facilitator tool in diagnostic and therapeutic processes with adults who self-identify as autistic or who are autistic.

To date, the ASIS (McDonald, 2016) has not been validated in the UK and has not been used therapeutically or as a complementary measure in the referral or diagnostic processes with adults who self-identify as autistic. In line with Leadbitter et al. (2021), it is believed that including the ASIS (McDonald, 2016), or similar neurodivergent-friendly clinical tools, in the referral and diagnostic process of an adult autism diagnostic assessment would allow healthcare professionals to understand the views of their clients from a client-centred approach and not only from a medical perspective.

2.4.1 Limitations

The results of this scoping review were limited to the studies on the four databases (PsycINFO, CINAHL Complete, MEDLINE Complete and APA PsycArticles) searched. Although searching four databases is in accordance with the search strategy of other scoping reviews (e.g. Huang et al., 2020), the search of more and other databases may have found more studies that met the inclusion criteria of this review. More studies may have also been found by including grey literature.

The results of this scoping review were further limited by the number of reviewers. More reviewers may have resulted in a different interpretation of the key themes of the final 13 included studies. Similarly, the data analysis process could have been enhanced by the inclusion of experts by experience. An expert by experience is defined as an autistic individual who is classed as an expert through lived experience of the condition (Gillespie-Lynch et al., 2017). Fletcher-Watson et al. (2019) highlight the value of that lived experience in ensuring that research has practical implications for autistic individuals.

2.4.2 Future research

Future research should focus on addressing the difficulties that adults encounter in the process to, and of, an autism diagnostic assessment. Difficulties that have been accentuated by the findings of this scoping review.

In doing so, future research should include the views of adults who identify as autistic (with and without a formal diagnosis of autism). The findings of this scoping review imply that adults who self-identify as autistic have a comprehensive understanding of autism as a condition and are able to plausibly recognise the condition in themselves. Yet, no measures exist that incorporate the insights of adults who identify as autistic. Given the potential benefit of incorporating the insights of adults who identify as autistic within the referral and diagnostic processes of an adult autism assessment, the development and validation of these measures should be a priority for future research.

Future research should also consider using other methods of data collection, such as focus groups. In the studies that were included in this scoping review, online surveys were mainly used to collect data. Focus groups would be an advantageous alternative in that they allow for participants to elaborate more on their answers, and for researchers to clarify the answers of participants and initiate further discussion. Focus group discussions can also be beneficial in providing new understandings and perspectives on emerging area of research (Coolican, 2014; Flick, 2014), such as autistic identity in adults.

2.5 Conclusion

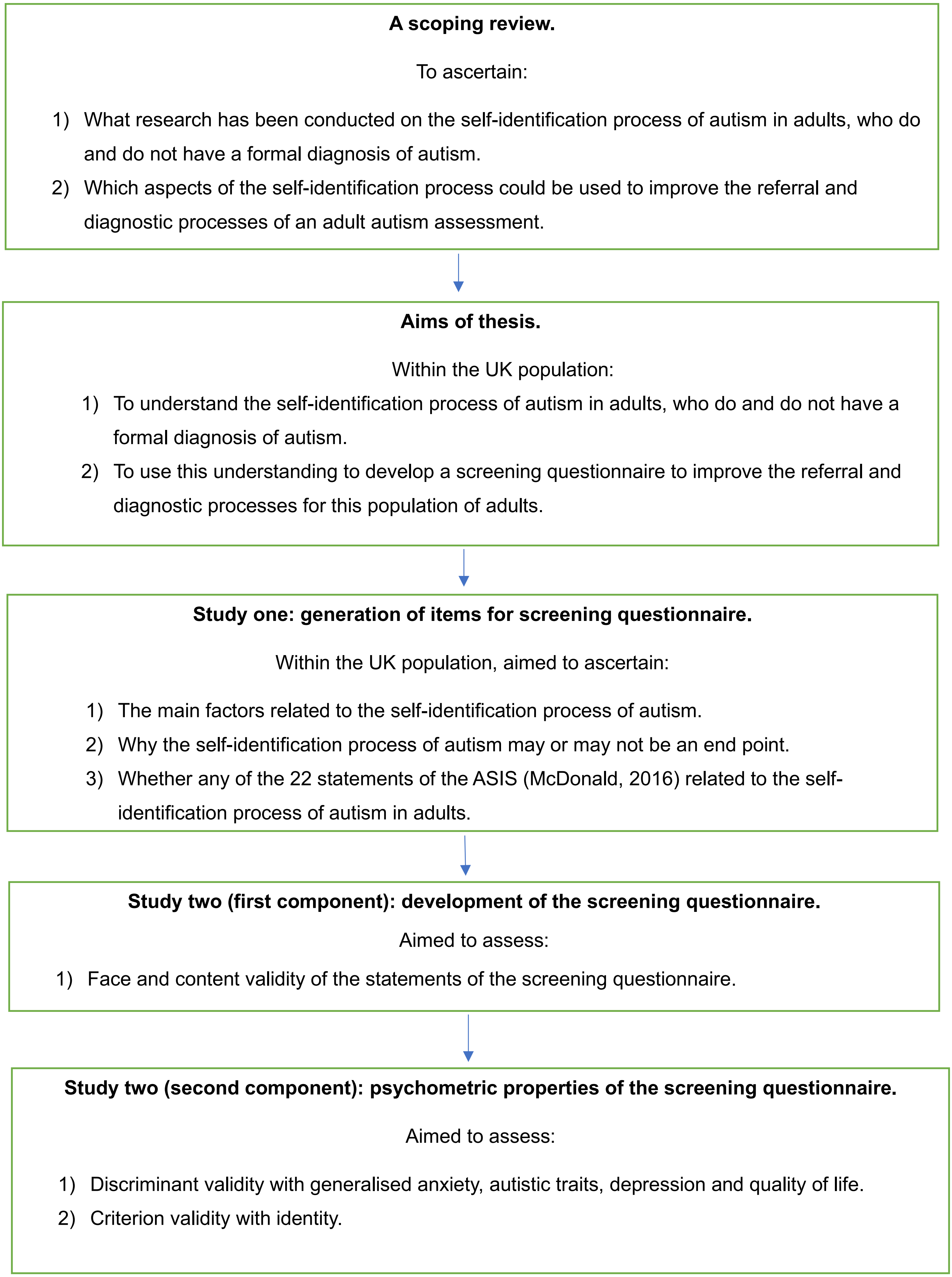
Firstly, this scoping review determined what research had been conducted on the self-identification of autism in adults, who do and do not have a formal diagnosis of autism. Secondly, the aspects of the self-identification process which could be used to improve the referral and diagnostic processes of an adult autism assessment were identified. Results indicate that adults who self-identify as autistic currently face difficulties in being referred and assessed for a formal autism diagnosis. The themes identified in this scoping review acknowledge the importance, from a client-centred perspective, of how vital it is to develop complementary clinical tools in the referral and diagnostic process of an adult autism assessment that are neurodivergent-friendly. The development and validation of these tools should be conducted considering the views of experts by experience, autism activists and healthcare professionals who conduct autism diagnostic assessments in adults (co-production).

Chapter 3

Methodology

The findings of the scoping review, presented in the previous Chapter (Chapter 2), highlighted the need to develop neurodiversity-affirming complementary clinical tools which can supplement the existing tools used within the adult autism diagnostic pathway. To begin to address this highlighted need within the UK, this thesis aimed to (1) understand the self-identification process of autism in adults who do and do not have a formal diagnosis of autism in the UK and (2) to use this understanding to develop a screening questionnaire to improve the referral and diagnostic processes for this population of adults who may likely be autistic. The two aims of this thesis were accomplished with two studies. The structure of this thesis is illustrated in the flow chart below (Figure 4.).

Figure. 4. A flowchart illustrating the structure of the PhD



A scoping review.

To ascertain:

1) What research has been conducted on the self-identification process of autism in adults, who do and do not have a formal diagnosis of autism.
2) Which aspects of the self-identification process could be used to improve the referral and diagnostic processes of an adult autism assessment.

Aims of thesis.

Within the UK population:

1) To understand the self-identification process of autism in adults, who do and do not have a formal diagnosis of autism.
2) To use this understanding to develop a screening questionnaire to improve the referral and diagnostic processes for this population of adults.

Study one: generation of items for screening questionnaire.

Within the UK population, aimed to ascertain:

1) The main factors related to the self-identification process of autism.
2) Why the self-identification process of autism may or may not be an end point.
3) Whether any of the 22 statements of the ASIS (McDonald, 2016) related to the self-identification process of autism in adults.

Study two (first component): development of the screening questionnaire.

Aimed to assess:

1) Face and content validity of the statements of the screening questionnaire.

Study two (second component): psychometric properties of the screening questionnaire.

Aimed to assess:

1) Discriminant validity with generalised anxiety, autistic traits, depression and quality of life.
2) Criterion validity with identity.

This Chapter (Chapter 3) will outline the two studies of this thesis and critically discuss the methodological approaches employed. The Chapter is arranged in six parts: The first part will state the overall methodological approach of the research and the second part will describe the Autism Spectrum Identity Scale (ASIS) (McDonald, 2016). The third part will detail study one (the generation of items for the screening questionnaire), the fourth part will detail the first component of study two (development of the screening questionnaire) and the fifth part will detail the second component of study two (validation of the screening questionnaire). Finally, the sixth part will outline the expert by experience involvement in the proposed research.

3.1 Methodological approach of the research

The research employed a mixed methods approach, which is the use of both qualitative and quantitative methods within a research study (Coolican, 2019). From a clinical perspective, employing a mixed methods approach to developing a questionnaire can ensure a more effective outcome in practice (Kazdin, 2022). To explain, including the insights of individuals with lived experience of the concept which is to be assessed is likeliest to result in an informative questionnaire (DeVellis & Thorpe, 2022; Kazdin, 2022). Certainly, a qualitative method has been employed in other research that has previously sought to develop a questionnaire (e.g. McConachie et al., 2018; Power & Green, 2010) Still, DeVellis and Thorpe (2022) point out the importance of incorporating this knowledge with the processes and standards of questionnaire development (e.g. assessments of validity and reliability). In line with these viewpoints, this research used a qualitative method to inform the generation of items for the screening questionnaire (study one), a quantitative and qualitative method to develop the screening questionnaire (first component of study two), and a quantitative method to validate the screening questionnaire (second component of study two).

3.2 The Autism Spectrum Identity Scale (ASIS) (McDonald, 2016)

Justification for the development of a complementary screening questionnaire to improve the autism diagnostic pathway for adults in the UK, who may likely be autistic, was provided by an absence of an equivalent existing questionnaire (DeVellis & Thorpe, 2022) and a need for the screening questionnaire (Overton et al., 2023). Overton et al. (2023) suggested the potential of adapting the ASIS (McDonald, 2016) for this purpose. The ASIS (McDonald, 2016) is shown in the Table below (Table 2.).

Table 2. The Autism Spectrum Identity Scale (ASIS) (McDonald, 2016)

Items	1 (strongly disagree)	2 (disagree)	3 (neither agree or disagree)	4 (agree)	5 (strongly agree)
1 I feel like I only have autism in certain activities, like completing work, organizing, getting ready to go somewhere, or new activities.					
2 There is little I can do about my autism.					
3 I am good at some things because I have autism.					
4 There are some people with whom I don’t feel I have autism.					
5 Autism only makes things harder for me.					

6 I like having autism or being autistic.					
7 My good qualities have little to do with autism.					
8 I feel like I only have autism around certain people, like classmates, teachers, parents, or co-workers.					
9 I feel autism has more benefits in abilities than challenges.					
10 If I work hard enough, I can minimize my autism.					
11 I would be better off if I didn't have autism.					

12 I like the way I am different from everyone else.					
13 I feel like I only have autism in certain places, like school, home, work or somewhere new.					
14 When I'm alone, I don't feel like I have autism.					
15 Autism means having unique abilities.					
16 If I work hard enough, I can minimize the challenges associated with autism.					
17 There are some places where I don't					

have Asperger’s/autism.					
18 If I were cured of autism, I wouldn’t be me anymore.					
19 I don’t feel I have additional abilities from my autism.					
20 I only “have autism” when people treat me like I do.					
21 I am better off because I have autism.					
22 My strengths have little to do with autism.					

Ensuring that there is no other existing measure (e.g. scale, questionnaire) that could be adapted to fulfil a highlighted need is an important step to undertake before starting to develop a questionnaire (DeVellis & Thorpe, 2022). Adapting an existing measure has many advantages, such as an established factor structure and psychometric characteristics (Kazdin, 2022), though, the limitations of adapting an existing measure to fulfil a highlighted need were taken into account. For example, it is vital that the chosen measure is measuring the same construct and is appropriate for the new intended purpose (Kazdin, 2022). Originally, the ASIS (McDonald, 2016) was developed to assesses how adults differ in identifying with autism and how this may be associated with the postsecondary outcomes of wellbeing and independence. In terms of a clinical use of the measure, McDonald (2017) had stated that it could aid healthcare professionals in understanding how their clients see themselves in relation to autism. So, the ASIS (McDonald, 2016) was considered an appropriate measure as it is a measure of autistic identity and it is strengths-based, which aligns with the need for a neurodiversity-affirming approach in developing a complementary screening clinical tool.

Once it has been satisfied that the measure being adapted is measuring the same construct and it is appropriate for the new intended purpose, it is of equal importance to ensure that the chosen measure is trustworthy (Kazdin, 2022). The trustworthiness of a measure refers to the reliability (that it consistently produces the same results) and validity (that it is measuring the construct it is supposed to be measuring) of it (Fenn et al., 2020). These are collectively termed the psychometric characteristics (Kazdin, 2022). The stages of the development of the ASIS (McDonald, 2016) have been published in high impact factor peer-reviewed academic journals (*Journal of Autism and Developmental Disorders* and *Autism in Adulthood*), which is a very good indicator of trustworthiness (DeVellis & Thorpe, 2022). Furthermore, good/moderate Cronbach's alpha values have reported in these published academic journal articles (e.g. McDonald, 2020). Cronbach's alpha is just one measure of the internal reliability of a scale, but it is the measure that is most frequently used to assess this form of reliability (Coolican, 2019). Internal reliability is how well each item of the scale correlate with each other. A higher Cronbach's alpha value signifies that the items of a scale are highly correlated and are therefore measuring the same construct (Pallant, 2020). No other forms of reliability of the ASIS (McDonald, 2016), such as inter-rater reliability and parallel (or alternate) forms reliability, have been published. More specific information regarding the published psychometric characteristics of the ASIS (McDonald, 2016) can be found in the method (*materials*) section of Chapter 4, page 90 of this thesis. Prior to adapting the ASIS (McDonald, 2016), written permission was obtained from the author of the scale; Dr T

McDonald and this was included in the application for initial ethical approval of the study (please see Appendix B, page 193 of this thesis, for the granted ethical approval).

Adapting a measure for a new purpose in a new population usually entails rephrasing and removing some items and incorporating new items (Kazdin, 2022). Principles of co-production were employed to ensure that the new screening questionnaire would be relevant for, and reflective of, the self-identification process of autism in adults within the UK population (Fletcher-Watson et al., 2019). The specific methods that were used for adapting the ASIS (McDonald, 2016) for use as a complementary screening questionnaire within the adult autism diagnostic pathway in the UK will now be discussed.

3.3 Study one: screening questionnaire item generation

Focus groups were chosen as the qualitative method in which to inform the adaption of the ASIS (McDonald, 2016) for the new screening questionnaire. Often defined as a 'group interview' focus groups allow for the discussion between participants that can be beneficial in providing new perceptions on a given topic (Coolican, 2019), which may not transpire from individual interviews (Babbie, 2021). For that reason, Coolican (2019) states that focus groups can be an effective approach for the exploratory study of specific under researched topics, perhaps providing an explanation as to why focus groups are routinely used as the preliminary data collection method to inform the development of a questionnaire (Krueger & Casey, 2015; Morgan, 1993, as cited in, Babbie, 2021, p. 318).

The use of focus groups also built upon the limitations of previous research on the self-identification process of autism in adults. As highlighted and discussed in the scoping review (Chapter 2), online surveys have been used as the predominant method of data collection to date. It was hoped that by offering adults a platform in which to discuss self-identifying as autistic, further insights into this process would be gained.

When deciding upon the most appropriate method of data collection, the participating population was considered. Participating in the focus groups would be adults who identified as autistic (both with and without a formal diagnosis of autism), a population who are notably 'hard-to-reach' with regards to partaking in research (Beadle-Brown et al., 2012; Lewis, 2016a). To encourage a population who are 'hard-to-reach' to partake in research, focus groups are deemed to be a good option (Barbour, 2007, as cited in, Flick, 2014, p.251; Brown, 2018; Dilshad & Latif, 2013). It is thought that participation is encouraged by the group context of focus groups, as expressing viewpoints is made easier through seeing and listening to others doing the same (Kazdin, 2022; Wilkerson et al., 2014). However, autism is typified diagnostically by deficits in social interactions and communication (APA, 2013). So, individual interviews were contemplated as an alternative as it was acknowledged that some adults may feel more comfortable sharing their thoughts and experiences in an interview setting (Krueger & Casey, 2015). Yet, autistic adults have expressed a preference for focus groups (Haas et al., 2016). In a mixed methods study by Haas et al. (2016) to ascertain the factors that would encourage autistic adults to partake in longitudinal research, focus groups were found to be a motivator. Specifically, it was the value of interacting and sharing views with other autistic adults in a mutually supportive environment that was favoured. Indeed, this preference is evidenced by later research (e.g. Ashworth et al., 2021; Kapp et al., 2019) that illustrates the successful engagement of autistic adults in focus groups. The fact that focus groups often replicate the discussions that autistic individuals are already having, for example in online forums (e.g. Brownlow & O'Dell, 2006; Kourti & MacLeod, 2019), may provide an additional reason as to why autistic adults both prefer and successfully engage in focus groups.

3.3.1 Design

It was acknowledged that self-identifying as autistic can be a divisive topic amongst autistic individuals (Sarrett, 2016). In a study to investigate the self-diagnosis/identification debate within the autistic community, Sarrett (2016) predominantly used one thread ("Why is there a lot of hatred towards people who self-diagnosis themselves with Aspergers or autism?") from the online forum Wrong Planet and found strong views for and against the acceptance of individuals who self-diagnosed autism/self-identified as autistic. A distrust of healthcare professionals was the most commonly stated reason by the users of Wrong Planet who accepted individuals who self-identified as autistic. In contrast, users of Wrong Planet who did not accept individuals who self-identified as autistic mostly stated that only trained healthcare professionals could diagnose autism, given the complexity of autism as a spectrum condition. It was also acknowledged that focus groups should be comprised of individuals who are of an equivalent status (Krueger & Casey, 2015; Brown, 2018). For the two aforesaid reasons, two focus groups were organised to ensure that participants were equal in terms of diagnostic status (focus group one consisted of adults who self-identified as autistic and had no formal diagnosis of autism, and focus group two consisted of adults who self-identified as autistic and had a formal diagnosis of autism) and would feel comfortable engaging and sharing their personal experiences with other participants who had been in, or experienced, similar situations (Green, 2019). Organising the focus groups in this way aimed to eliminate preventable distress to participants (Sim & Waterfield, 2019) and create the mutually supportive environment that autistic adults in the study by Haas et al. (2016) valued. This in turn aimed to maximise the amount and quality of the data collected from each focus group, which could have been restricted by dispute amongst participants (Pellicano et al., 2014). The design of the focus groups also allowed for comparisons between the groups to be made (Zalmstra et al., 2021). Given that this thesis aimed to improve the adult autism diagnostic pathway, being able to determine any similarities and/or differences between adults who did and did not have a formal diagnosis of autism was important. Additionally, as very little is known about the self-identification process of autism in adults within the UK the findings of this thesis could be used to guide future research.

In helping to maximise the amount and quality of the data collected, the size of focus groups is another important factor to consider. The general recommendations range from six to ten participants per focus group (Brown, 2018; Green, 2019). In certain circumstances, however, it is recommended that focus groups are limited to five or six participants (Krueger & Casey, 2015). Krueger and Casey (2015) suggest circumstances where participants are particularly knowledgeable and/or passionate about the topic of the focus group discussion, as this enables an equal contribution from all participants. Certainly, five/six participants per focus group is consistent with previous research (e.g. Gowen et al., 2019; Kapp et al., 2019) in which autistic adults have participated in focus groups. So, in line with the suggestion by Krueger and Casey (2015) and previous research (Gowen et al., 2019; Kapp et al., 2019) it was aimed for six participants to take part in each one of the two focus groups in study one of this thesis.

The decision was made to conduct the focus groups online. Primarily, this was due to the changeability of the situation with COVID-19 at the time. The decision was consistent with the transition to online meetings in a number of autism services, including research and clinical services (Gibbs et al., 2021). A favourable advantage of online focus groups is the elimination of geographical constraints which makes taking part in the research easier and cheaper for participants (Coolican, 2019). In the context of a participating population who may have found in person face-to-face discussions challenging (Moseley et al., 2020) and who are considered ‘hard-to-reach’ (Beadle-Brown et al., 2012; Brown, 2018), online focus groups were deemed a constructive choice. Still, it was recognised that the choice of online focus groups excluded adults who may have wanted to participate, but did not have access to, or feel comfortable participating in, an online platform (Lewis, 2016a). However, on balance of the points just discussed, it was felt that online focus groups would maximise the number of potential participants for the study. In line with previous research (Haas et al., 2016; Mason et al., 2021), both online focus groups were not scheduled to exceed two hours in duration.

For an online focus group two facilitators are deemed invaluable, namely because of the technical issues that could arise (Krueger & Casey, 2015). Therefore, both focus groups were facilitated with Dr Ferran Marsà-Sambola. Dr Marsà-Sambola was one of my PhD supervisors and is an HCPC registered clinical psychologist who specialises in autism in adults. Given Dr Marsà-Sambola's area of expertise, his presence also served an ethical purpose in helping to ensure that the wellbeing of participants was protected.

3.3.2 Ethics

Ethically, the primary concern with the focus groups was the sensitive nature of the topic (identifying as autistic with or without a formal diagnosis of autism) that was to be discussed with a group of adults who are deemed vulnerable. As discussed in the Introduction of this thesis (Chapter 1), autism is classified as a disability in the UK (National Autistic Society, 2022) and co-morbid psychological conditions (e.g. anxiety and depression) are also common in autistic adults (Benevides et al., 2020). Most research (e.g. Lewis, 2016a; Lewis, 2016b; MacDonald, 2017) does imply that adults, who are or may likely be autistic, welcome the opportunity to participate in research. Nonetheless, it was acknowledged that self-identifying as autistic can be life-changing (Moore, 2016) and discussing this life-changing event could evoke unanticipated emotions in the participating adults. Therefore, measures to minimise distress and/or harm to participants were put in place (e.g. with the design of the focus groups) and provisions were made for support (e.g. adults could take a break from participating at any time and contact details for two further sources of support would be issued to all participating adults).

A second ethical concern was the use of focus groups as a method of data collection. Ethically, focus groups can present challenges in terms of anonymity and confidentiality (Sim & Waterfield, 2019), as unlike individual interviews the facilitators are unable to fully guarantee anonymity and confidentiality (Green, 2019; Wilkerson et al., 2014). However, steps were taken to ensure that anonymity and confidentiality were protected. In line with Green's (2019) recommendation that the focus group facilitators should set clear expectations regarding these aspects, within each one of the two online focus groups guidance by Sim and Waterfield (2019) was followed: 1) participants were not required to give names and no other identifiable data of participants was taken and 2) at the beginning and end, participants were reminded that the discussion that would take/took place was confidential and must not be repeated outside of the discussion. Conducting online focus groups addressed some of the ethical concerns relating to anonymity (Moseley et al., 2020). For example, in contrast to an in person focus group, participants could choose not to be visible by keeping their camera turned off.

The specifics of each one of the two online focus groups (participants, materials, procedure and data analysis) are detailed in Chapter 4, pages 89 to 92, of this thesis. Chapter 4 also details the adaptations made to the ASIS (McDonald, 2016) following both online focus groups, and these can be found on pages 108 to 134 of this thesis.

3.4 Study two: development and validation of the screening questionnaire

3.5 First component of study two: development of the screening questionnaire

In accordance to guidance by DeVellis and Thorpe (2022), the next step in the questionnaire development process is to have the generated questionnaire items evaluated by experts. Given that the screening questionnaire was aiming to serve a clinical purpose, a Delphi method was chosen to accomplish this next step in the development process. A Delphi method amalgamates individual expert opinion in order to ascertain the extent of consensus on statements of a survey tool (Iqbal & Pipon-Young, 2009). Experts are sent a list of the developed questionnaire items and are asked to rate the extent to which they agree that each item of the questionnaire is relevant for a given clinical purpose (Spain & Happé, 2020). Therefore, a Delphi method is considered a useful method for applied psychologists (Brown, 2018), as it may aid the implementation of research into practice (Jorm, 2015). Certainly, in terms of autism research that has aimed to inform practice, a Delphi method has been the method of choice (e.g. Cumin et al., 2022; Spain & Happé, 2020; Wigham et al., 2022).

It was recognised that there are other methods that could have been used in order to gather expert evaluation on the generated questionnaire items, which too have been used to inform clinical practice. For example, consensus development conference and nominal group technique (Cook et al., 2023; Srivastava et al., 2019). However, these methods incorporate the use of in-person or online face-to-face groups (Black et al., 1999). As is further discussed in the method (*procedure*) section of Chapter 5, page 133 of this thesis, a Delphi method is conducted online via individual emails. Thus, responses are not influenced in any way by group dynamics (Brown, 2018; Dragostinov et al., 2022). Therefore, a Delphi method addressed some of the limitations of the use of focus groups in study one. To explain, the responses of participants in study one could have been influenced by the other participants within the respective focus groups as well as by the presence of me and Dr Ferran Marsà-Sambola (Coolican, 2019). A further concern with focus groups is whether the participants are representative of the population more generally (Babbie, 2021). With regards to this thesis, it would not be possible to generalise the findings of the focus groups to the self-identification process of autism in adults within the UK entirely (Brown, 2018). So, it was for all of the aforesaid reasons that a Delphi method was deemed appropriate to further develop the new screening questionnaire.

3.5.1 Design

With the Delphi method, the development of a questionnaire is achieved over a number of sequential stages referred to as ‘rounds’ (Iqbal & Pipon-Young, 2009). Although rounds can continue indefinitely until consensus is reached (Hsu & Sandford, 2007), this approach can lead to the loss of participating experts over time due to the high level of commitment required from them (Iqbal & Pipon-Young, 2009). Therefore, Delphi studies are normally conducted over two or three rounds (Niederberger & Spranger, 2020). Three rounds are deemed enough to reach a sufficient level of consensus without placing too much burden on the participating experts, two rounds are deemed justifiable if the survey tool is being developed from an established academic source(s) (Iqbal & Pipon-Young, 2009; Petry et al., 2007). Within a given research study that utilises a Delphi method a decision is needed to be made on the number of rounds that will be conducted (Brown, 2018). For the purposes of this thesis, it was decided to conduct two rounds. This decision took into account the fact that the new screening questionnaire would be based on the ASIS (McDonald, 2016) and the initial adaptions would be informed by adults who self-identified as autistic, with and without a formal diagnosis of autism (study one). For these reasons, and in accordance with the guidance provided by Iqbal and Pipon-Young (2009), two rounds were considered acceptable.

For the development of a credible questionnaire, different sets of experts are deemed a better option as the varied expertise increases the validity and reliability of the developed questionnaire (Iqbal & Pipon-Young, 2009; Zervogianni et al., 2020). In line with this viewpoint, and the principles of co-production, two sets of experts were recruited: experts by experience and healthcare professionals who conduct autism assessments in adults. However, the term ‘experts’ is vague (Cumin et al., 2022) and has many meanings in the literature (Iqbal & Pipon-Young, 2009). As the credibility of the developed questionnaire is dependent upon the expertise of the recruited experts (Heijnen-Kohl et al., 2022), it was vital to define who was classified as an expert for purposes of this thesis at the beginning of the research study (Iqbal & Pipon-Young, 2009). So, clear inclusion criteria were stipulated for participation, prior to recruitment of the experts. The inclusion criteria, and further information regarding the participating experts, can be found in the method (*participants*) section of Chapter 5, pages 142 and 143, of this thesis.

It was acknowledged that the Delphi method is not without limitations. For example, a different panel of experts may result in different consensuses reached and different feedback provided on the items of the questionnaire (Brown, 2018), though, the most notable limitation of the Delphi method is that it lacks definitive methodological guidance (Niederberger & Spranger, 2020). As a consequence, there is ambiguity regarding aspects such as how many participating experts are required and how consensus is ascertained (Dragostinov et al., 2022; Jorm, 2015). These aspects will be further discussed in the methods section of Chapter 5, pages 142 to 144, of this thesis. Nonetheless, in terms of the processes and standards of questionnaire development, the Delphi method provides a systematic and useful approach in which to adhere to these guidelines (Dragostinov et al., 2022). Through the use of a Delphi method, evidence for face and content validity for the newly developed screening questionnaire would be obtained (Kazdin, 2022; Olaya et al., 2012).

Face validity is simply whether a measure appears to measure the construct it is supposed to be measuring (Coolican, 2019). As such, face validity can be deemed subjective and there is some controversy regarding the usefulness of it (DeVellis & Thorpe, 2022). DeVellis and Thorpe (2022) highlight how using ‘appearance’ to assess the validity of a measure is problematic because the assessment will often be based on the personal opinions of the individuals being asked. Therefore, the results are likeliest to be contradictory and unempirical. It is also questioned whether it is always advantageous for a measure to have high face validity (that the construct being measured is clearly evident) as this means that test-takers may well be acutely aware of what a measure is measuring (Linden & Hewitt, 2018). With this in mind, Linden and Hewitt (2018) point out the potential for test-takers to answer a given measure in accordance to the outcome they desire. Conversely, from the perspective of individuals completing a measure/questionnaire, Allen et al. (2023) argue that a questionnaire with high face validity will result in better responses. Of relevance to the screening questionnaire being developed in this thesis, Allen et al. (2023) explain that this is because individuals are motivated to respond to questions that are straightforward to answer, pertinent to them, and are not judgemental. Indeed, the opposite of these factors, such as irrelevant and ambiguous questions, has been found to negatively impact adults throughout the autism diagnostic pathway (Crane et al., 2018; Wigham et al., 2020). So, in spite of the criticisms and the fact that face validity is not considered an official type of validity (Kazdin, 2022), there is some benefit to establishing the face validity of a newly developed questionnaire (Fenn et al., 2020). Benefit that was considered applicable to the development of the new screening questionnaire in this thesis. The previously discussed limitations of assessing face validity can addressed, as per the approach taken in this thesis, by incorporating an assessment of face validity within a formal assessment of content validity (DeVellis & Thorpe, 2022).

Defined as whether the items of a measure (the content) are reflective of the construct that the measure is supposed to be measuring, content validity is typically established by asking experts to evaluate the items of a measure (Kazdin, 2022). As DeVellis and Thorpe (2022) explain, the specialist knowledge that these individuals possess helps ensure that relevant items are kept and/or amended accordingly, whilst irrelevant items are abandoned. Clinically, experts are usually healthcare professionals; the individuals who will administer a given measure. However, as this thesis acknowledged, content validity can be further supported by the inclusion of service-users; the individuals who would potentially complete a given measure, as experts (Jorm, 2015). Content validity is an essential initial form of validity to establish as it also provides some indication of the usefulness of a measure for a given purpose (Fenn et al., 2020). Therefore, establishing content validity lays the foundations for further assessments of the psychometric characteristics of a given measure, such as the screening questionnaire being developed in this thesis (Dragostinov et al., 2022).

The specifics of the Delphi method (participants, materials, procedure and data analysis) are detailed in Chapter 5, pages 142 to 144, of this thesis. Chapter 5 also details the further and finalised adaptations made to the ASIS (McDonald, 2016) following the two-round Delphi. The newly developed screening questionnaire the ‘Autistic Identity Questionnaire (AIQ)’ can be found on pages 150 to 154 of this thesis.

3.6 Second component of study two: validation of the screening questionnaire

As Dragostinov et al. (2022) point out, in terms of the processes and standards of questionnaire development, the Delphi method constitutes the first step of a lengthy process to ensuring that the questionnaire is trustworthy. Indeed, there are other forms of validity that are equally important to establish, but which would not be assessed during the development of the screening questionnaire (DeVellis & Thorpe, 2022). These include convergent validity and divergent validity, two subdivisions of construct validity (Fenn et al., 2020).

Essentially, construct validity relates to the theoretical correlation of a given measure to other measures (DeVellis & Thorpe, 2022). More specifically, convergent validity refers to the extent to which a measure correlates with another measure which assess a similar construct. In contrast, divergent validity is the extent to which a measure does not correlate with another measure which assess a different construct (Kazdin, 2022). Clearly, these are key forms of validity to establish, as it would be problematic if the new screening questionnaire correlated with a measure that assesses a different construct (e.g. quality of life) (Coolican, 2019).

In addition to establishing the validity of the questionnaire, it is also imperative to establish the reliability of it (DeVellis & Thorpe, 2022). Although the screening questionnaire would be adapted from the ASIS (McDonald, 2016), which is reported to have good/moderate reliability (McDonald, 2020), it is paramount to assess reliability following the adaptations and use with the new intended population (Kazdin, 2022).

To assess reliability and the aforesaid forms of validity of a newly developed measure, the measure should be administered to a large sample of participants (DeVellis & Thorpe, 2022). So, for further initial validation the screening questionnaire was administered to a representative sample: adults in the UK who identify as autistic, with and without a formal diagnosis of autism.

The specifics (participants, materials, procedure and data analysis) of the validation of the screening questionnaire are detailed in Chapter 6, pages 161 to 166, of this thesis. Chapter 6 also details the findings of the validation of the AIQ.

3.7 Expert by Experience involvement

When conducting research with, and for, the autistic community, it is considered good practice to gain feedback from an expert by experience (Fletcher-Watson et al., 2019; Gowen et al., 2019). So, before the above research was finalised, the proposed research was reviewed by an expert by experience. Involving an expert by experience at the research proposal stage ensured that the entire research would be conducted in a manner that was considerate to the needs of autistic adults. Therefore, protecting the wellbeing of participants and facilitating maximum participation (Haas et al., 2016). It was only after expert by experience feedback was received and incorporated into the research proposal that an application was made for ethical approval to conduct the research.

The expert by experience who reviewed the proposed research was recruited from SUMMIT services. SUMMIT (https://www.summitservices.org.uk) is a mental health charity which provides numerous services for vulnerable adults, one of which is an advocacy service for adults pursuing a diagnosis of autism. Potential experts by experience who would be willing to voluntarily review the proposed research were contacted by Gaynor Jarrett (CEO of SUMMIT). One expert by experience reviewed the proposed research and consented to Gaynor emailing both the review and their email address to me. The expert by experience was formally diagnosed as autistic and had no further input in the studies of this thesis.

Overall, the expert by experience considered the research to be valuable for two reasons. Firstly, the expert by experience alluded to the fact that previous research regarding self-identifying as autistic had few participants from the UK. Therefore, the expert by experience thought that it was important to ascertain if there were any differences in the self-identification process of autism in the UK, in comparison to American populations. Secondly, the expert by experience thought that it was important to better understand the lived experience of autistic people, irrespective of whether they self-identified as autistic or were formally diagnosed as autistic. No concerns were raised regarding the proposed methodology of the research. Although, the expert by experience did state some minor considerations relating to the convenience sampling, materials and terminology used. These will now be discussed, together with how they addressed within the proposed research.

With regards to the convenience sampling that was initially proposed to recruit participants for study one (screening questionnaire item generation) and the second component of study two (validation of the screening questionnaire), the expert by experience emphasised that adults who self-identify as autistic and have no formal diagnosis of autism are a particularly hard to reach group. The expert by experience explained that a number of individuals who identity as autistic do not engage in any groups/forums and do not access any charities or other services. Stating the examples of the forums (Autism UK or Talk about Autism) that were suggested in the research proposal to use to recruit participants, the expert by experience said that they had never heard of the forums. So, in order to reach as many potential participants as possible, the expert by experience recommended that participants of the study are asked to pass on the details of the study to other adults who meet the inclusion criteria and would be willing to participate (snowball sampling (Coolican, 2019)). Following this feedback, the research proposal was amended to state that convenience and snowball sampling would be used to recruit participants for study one and the second component of study two. A question was also removed. This question was 'if online forums are used' with the response options 'yes' or 'no', and was originally input as a question at the beginning of the questionnaire for the second component of study two. In light of the feedback received, it was felt that nothing would be gained from asking this question.

With regards to the materials used, the expert by experience pointed out that some participants might have difficulty answering one particular statement. This statement was 'If a self-diagnosis was actively sought, or if a self-diagnosis was realised unexpectedly' with the response options 'actively sought' and 'realised unexpectedly'. The expert by experience felt that the response options would minimise participant responses. Speaking from personal experience, the expert by experience explained that the realisation that they may be autistic was a gradual process. For that reason, the expert by experience said that they would not be able to answer that question, and that this may be the same for participants of the study. Following this feedback, the question was removed.

With regards to the terminology that was used, the expert by experience highlighted a couple of phases that may offend some adults. Firstly, the expert by experience pointed out that the phrase 'charities that deal with ASD'. The expert by experience felt that 'deal with' implied that the research took a medical model perspective, rather than a social model perspective where adults make their own informed choices about the support and/or services they receive. Following this feedback, the phrase was amended to read 'institutions that work with autistic individuals'. Secondly, although it was realised that ASD was used because it is the diagnostic term, the expert by experience mentioned that some participants may view autism as a condition or neurological difference and so may not like it referred to as a disorder. Whilst this feedback was taken into account, it was decided to continue using ASD for the research proposal. This decision was based upon the fact that ASD was used because it is the diagnostic term and this research aimed to develop a screening questionnaire to improve the diagnostic pathway.

3.8 Ethical approval

Ethical approval to conduct the research was granted by the University of Suffolk Research Ethics Committee on 18th June 2021, with the condition that the final developed questions of the adapted ASIS (McDonald, 2016) were submitted for approval via Chair's Action before the new questionnaire was validated (please see Appendix B, page 193 of this thesis).

Chapter 4

"Who I am": Understanding the Self-identity Process of Autism in Adults in the UK

4.1 Introduction

In a first step to improve the autism diagnostic pathway for adults in the UK in a neurodiversity-affirming manner and from a person-centred approach, this study aimed to understand: (1) the main factors related to the self-identification process of autism and (2) why the self-identification process of autism may or may not be an end point for adults within the UK population. Additionally, this study aimed to ascertain whether any of the 22 statements of the Autism Spectrum Identity Scale (ASIS) (McDonald, 2016) related to the self-identification process of autism in adults within the UK population.

4.2 Method

4.2.1 Participants

Through convenience and snowball sampling twelve participants in the UK (9 identified as female, 2 identified as male, 1 identified as agender) were recruited from charities and organisations that work with adults who identify as autistic to partake in one of the two online focus groups (group one: adults who self-identify as autistic with no formal diagnosis of autism and group two: adults who self-identified as autistic and have a formal diagnosis of autism). The age range of participants in the study ranged from 41 to 58 years.

The six participants (5 identified as female, 1 identified as male) who partook in online focus group one were: (1) 18 years of age or older, (2) fluent in English, and (3) self-identified as autistic with no formal diagnosis of autism. Participants were not excluded if they were on a waiting list for an autism diagnostic assessment. The six participants in the first online focus group stated an age range from 41 to 51 years.

The five participants (3 identified as female, 1 identified as male, 1 identified as agender) who participated in online focus group two were: (1) 18 years of age or older, (2) fluent in English, and (3) self-identified as autistic with a formal diagnosis of autism. The five participants in the second online focus group stated an age range from 42 to 58 years.

4.2.2 Materials

I developed a script for the two online focus groups based on previous research (Lewis, 2016b; Lewis, 2017) on the self-identification of autism and The Nine Degrees of Autism (Wylie et al., 2016) theoretical framework. The script was reviewed by Dr Ferran Marsà-Sambola.

The script for both of the two online focus groups contained the following six discussion points: (1) what preceded the self-identification process of autism?, (2) what were the main route(s) that was/were linked with the self-identification process of autism throughout the lifespan?, (3) what were the main confirming factors that were identified within the process of self-identifying as autistic?, (4) what were the main feelings that were associated with the self-identification of autism throughout the self-identification process?, (5) how long did it take to self-identify as autistic?, and (6) what triggered adults to go (or not) for a formal assessment of autism?. The aforementioned discussion points were used as prompts to guide discussion in both of the two online focus groups.

The ASIS (McDonald, 2016) was included at the end of the script. In the validation paper of the ASIS (McDonald, 2016) with adults who self-identify as autistic, McDonald (2020) reported good/moderate Cronbach's alpha values in the main four factors of the scale: (1) Positive Difference (α= 0.84), (2) Spectrum Ability (α= 0.77), (3) Context Dependent (α= 0.84), and (4) Changeability (α=0.55). McDonald (2020) found similar values in the same study with adults who had a formal diagnosis of autism (Positive Difference (α=0.87), Spectrum Ability, (α=0.83), Context Dependent, (α=0.86), and Changeability, (α=0.67)).

The script used by me and Dr Ferran Marsà-Sambola for the two online focus groups was adapted into a 'guide of what to expect' for participants. This 'guide of what to expect' was sent to all participants prior to the online focus groups and this is discussed further in the *procedure* section below.

4.2.3 Procedure

Once the recruitment of participants was complete, participants were sent a poll which contained a selection of four dates and times. Participants were asked to indicate which date(s) and time(s) they would be able to attend the online focus group discussion, and then to submit the poll. This ensured that the chosen date and time was convenient for all participants of the respective focus groups (Krueger & Casey, 2015).

To help improve both the quality and the ethics of this research, guidance by Gowen et al. (2019) for conducting research studies with the autistic community was followed. In their study with 22 autistic adults and eight parents of autistic children, Gowen et al. (2019) identified four areas (pre-study considerations, recruitment of participants, study visit considerations and post-study considerations) of recommendations that should be incorporated into research to help ensure that the research meets the needs of autistic individuals. So, in line with Gowen et al.'s (2019) guidance the following materials and links were shared with all the participants of the two online focus groups a month before the day of each of the two online focus groups: (1) a link to the online focus group with written and visual guidance on how to use Google Meet, e.g. joining instructions and the main features of Google Meet (please see Appendix C, page 194 of this thesis) and (2) a guide of what to expect during the online focus group, which included a brief explanation of the discussion points that were aimed to be discussed during each online focus group (please see Appendix D, page 195 of this thesis). Sending a 'guide of what to expect' ensured that participants knew the structure and topics of the online focus groups in advance and had the opportunity to prepare for the session and, if needed, to ask questions beforehand. Although some authors like Reisner et al. (2018) have argued that prior awareness of the main topics of the focus group discussion can be detrimental in terms of the lack of spontaneous answers from the participants of the focus group, it was believed that in the context of research with autistic individuals it can maximise the quality of discussions by reducing the anxiety of uncertainty (Gowen et al., 2019). This approach is also consistent with other research undertaken with autistic adults (e.g. Ashworth et al., 2021). A written informed consent form was obtained from all participants prior to research participation.

The focus group script was followed for each one of the two online focus groups. At the end of both online focus groups participants in the study were asked to review, based on their personal experiences, the content of the 22 statements of the ASIS (McDonald, 2016). In line with the approach taken in the study conducted by Gowen et al. (2019), participants were invited to take part in the online focus group discussion verbally or through the chat option. If preferred, participants were also advised that written perspectives of any of the online focus group discussion topics could be emailed to me. In accordance to the recommendations that Gowen et al. (2019) identified in their study, participants of each online focus group were fully debriefed at the end of the focus group discussion.

4.2.4 Data analysis

To address the main aims of the study, the content of each one of the two online focus group discussions was analysed using a thematic analysis (Braun & Clarke, 2006). The six phases outlined by Braun and Clarke (2006) as guidance to conducting thematic analysis (step 1: become familiar with the data, step 2: generate initial codes, step 3: search for themes, step 4: review themes, step 5: define themes, and step 6: write-up) were followed by me and Dr Ferran Marsà-Sambola through an iterative process. Me and Dr Ferran Marsà-Sambola conducted thematic analysis within a critical realist framework which assumes that while one reality exists, we cannot be certain of that reality because there are many interpretations of it (Botha, 2021; Lyons & Coyle, 2016). In terms of autism research, a critical realist framework is considered a beneficial framework in which to understand the complexity of autism as a condition and create impactful change (Botha, 2021; Kourti, 2021). Given the aims of this study, it was for the aforesaid reasons that a critical realist approach was taken. To give an example, Botha (2021) explains that because autism is not reduced to a biological or social level within a critical realist framework it may help to understand why some autistic individuals consider themselves disabled, whilst other autistic individuals do not. Having this understanding can be instrumental in addressing issues related to autism, such as discrimination. The Nine Degrees of Autism (Wylie et al., 2016) was the theoretical framework that informed the approach to the thematic analysis taken in this study, which was a deductive approach with coding to identify semantic meanings. To explain, themes were directed by the research aims and the identified themes mirrored the content of the data. Thematic analysis was applied as a 'Big Q' method which places emphasis on contextualised understandings (Braun & Clarke, 2023; Lyons & Coyle, 2016).

The thematic analyses were then independently reviewed by my other two PhD supervisors (Dr Rachael Martin and Professor Penny Cavenagh). Once this review was completed, a supervisory meeting was held to discuss the analyses.

Participant feedback on the ASIS (McDonald, 2016) from both of the two online focus groups was summarised by me. Based on this feedback, and analyses of both online focus group discussions, revisions to the ASIS (McDonald, 2016) were made. Each statement of the ASIS (McDonald, 2016) was checked by me and Dr Ferran Marsà-Sambola (the two facilitators of the two online focus group discussions) and a decision was made to either (1) keep the statement, (2) rephrase the statement, or (3) remove the statement based on the views of the participants in the two online focus groups. New statements were also added to incorporate the findings from the two online focus group discussions. This procedure was undertaken independently by me and Dr Ferran Marsà-Sambola, after which a discussion was held between us to ensure consensus on the revisions made to the ASIS (McDonald, 2016).

4.3 Results

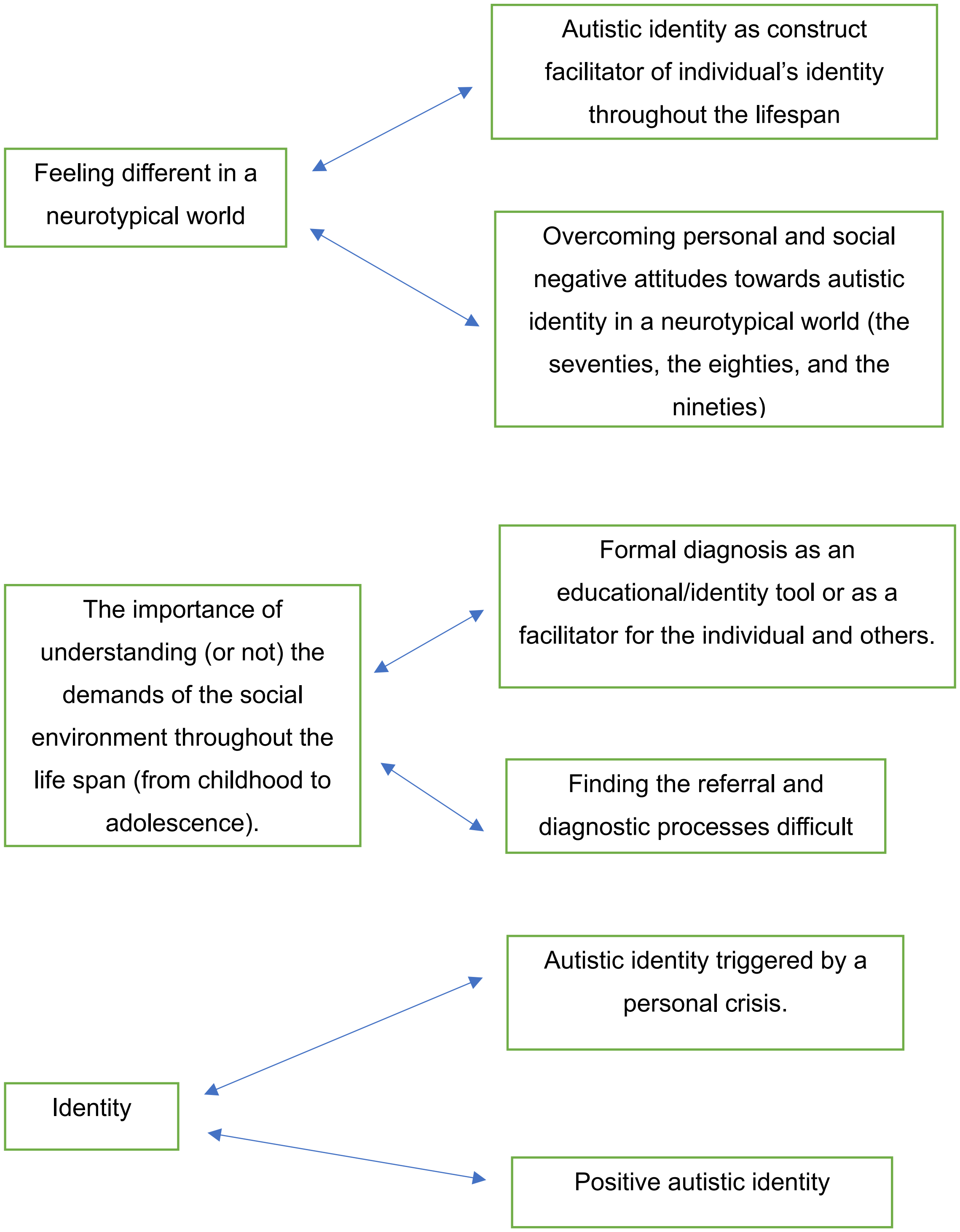
This section begins with a summary of the three themes, and subthemes of these themes, of each one of the two online focus groups. This summary can be found in Table 3. below.

Table. 3. A summary of the themes and subthemes from thematic analysis of both online focus groups.

Focus Group One (without a formal diagnosis of autism). N=6	**Focus Group Two (with a formal diagnosis of autism). N=5**
First theme	***First theme***
Feeling different in a neurotypical world.	A life of challenges.
First theme subthemes	***First theme subthemes***
Autistic identity as construct facilitator of individual's identity throughout the lifespan.	Partial explanation.
Overcoming personal and social negative attitudes towards autistic identity in a neurotypical world (the seventies, the eighties, and the nineties).	Negative reflection.
Second theme	***Second theme***
The importance of understanding (or not) the demands of the social environment throughout the life span (from childhood to adolescence).	Environmental impact (on the life stages and identity of participants).
Second theme subthemes	***Second theme subthemes***
Formal diagnosis as an educational/identity tool or as a facilitator for the individual and others.	Formal diagnosis as an educational tool.
Finding the referral and diagnostic processes difficult.	Finding the referral and diagnostic processes difficult.
Third theme	***Third theme***
Identity.	Identity
Third theme subthemes	***Third theme subthemes***
Autistic identity triggered by a personal crisis.	Resenting misdiagnoses
Positive autistic identity.	Positive autistic identity.

4.3.1 Online focus group one: adults who self-identify as autistic with no formal diagnosis of autism.

Figure. 5. Themes and subthemes from thematic analysis of online focus group one



4.3.1.1 First theme: feeling different in a neurotypical world

All participants in focus group one (n=6) reported that throughout their lives (from late childhood/early adolescence to adulthood) they had actively researched, through a broad range of sources, who they were in an attempt to understand why they were experiencing certain challenges when they had to interact with others. These sources came mainly from: (1) autism-related topics in some modules during school/college years, (2) reading books (e.g. Diary of a Young Naturalist, Fingers in the Sparkle Jar, Odd Girl Out, Neurotribes, Drama Queen: One Autistic Woman and a Life of Unhelpful Labels, and The reason I Jump, to name a few) or watching films or TV series (e.g. Love on the Spectrum, Atypical, Paddy and Christine McGuiness: Our Family and Autism) that were autism related, and (3) reading the content that several autistic influencers posted on Instagram, Facebook or Twitter. All participants in this focus group (n=6) agreed that trying to find out who they were through the experiences of others who were autistic was one of the main facilitators. It was also mentioned that suggestions made by relatives, acquaintances, work colleagues or friends was another facilitator together with self-identifying as autistic themselves. Most participants also reported that their gender identity, the different stages of human development (e.g. infancy, toddlerhood, childhood, adolescence and adulthood) and the historical social context (e.g. seventies, eighties and nineties) in which they grew up strongly influenced "*consciously and unconsciously*" the process of self-identifying as autistic throughout their lifespan.

4.3.1.2 Autistic identity as construct facilitator of individual's identity throughout the lifespan

All participants in this focus group reported that self-identifying as autistic provided an explanation to a lifetime of feeling different: *"feeling like an alien on earth" (P4),* and to several other diagnoses of psychological and/or physical conditions (given formally or informally by a broad range of healthcare professionals in the NHS or privately) that participants perceived to be incorrect: *"I thought that the thoughts and emotions were completely normal compared to the trauma I had experienced" (P5).* This "potential explanation" was questioned by some participants due to the medical and dichotomic nature of autism according to the diagnostic (DSM and ICD) criteria: *"am I on the spectrum or am I not? I don't know as I don't fit all of the traits, I'm very confused" (P6).*

So, four participants said that to confirm who they really were with their own strengths and limitations (autistic identity) they decided to pursue a formal autism assessment throughout their adulthood (early, middle and late adulthood): *"I need to know that who I am it's real and genuine, and that there's a reason for it" (P3); "I want a piece of paper that confirms who I am. I don´t think I'm sick or crazy but I just need to know why I am the way I am" (P6).*

As focus group facilitators, we perceived that the importance of a formal diagnosis in adulthood was a very important topic for the majority of participants in the focus group. However, it was not perceived by two participants as a life-changing experience: *“I know who I am and I don’t need that answer from someone that doesn´t really know me” (P2); “I don´t really understand why someone can tell if I’m on the spectrum with a two- hour interview with questions that I don´t understand (P1).*

4.3.1.3 Overcoming personal and social negative attitudes towards autistic identity in a neurotypical world (the seventies, the eighties, and the nineties).

All participants in this focus group discussed that throughout their lives (e.g. childhood, adolescence and adulthood) the perception they had of being different in comparison to others (e.g. parents, siblings, friends, peers, schoolteachers) was always negative. This was despite the strengths (e.g. a really good memory for historical dates, phone numbers or medical appointments and a really good ability to organise anything, such as books, CDs and DVDs following a specific pattern) that they really had not shown to others in different contexts (e.g. at home, school or work): *“I just felt like the weirdo with no conversation” (P1).*

Participants also explained that as they grew older (mainly from secondary education to college/university or in their first professional experiences), they learnt that masking and conforming to “neurotypical social norms” made their life easier: *“Masking made my life with others more manageable, but I often felt that when I was with others during college, or in my first job, I was somebody else. I wasn´t happy but I had to survive” (P6); “During secondary school, I tried hard to be that social butterfly and did things that I noticed my peers expected me to do. I have to confess that I didn’t always enjoy being the class clown” (P5)*.

There was also a general agreement between all focus group participants that throughout different decades (e.g. seventies, eighties and nineties) people around them had a negative perception of them because they were not like others (neurotypical). So, all participants felt the need to mask who they were to survive in a society that had very limited knowledge of neurodiversity. There were a couple of participants who, on reflection, questioned why nowadays they still have to mask who they are and how they communicate with others when actually both ways (neurodivergent and neurotypical) are equally valid: *“I’m direct in speech, which others have difficulties with, but I have difficulties with the indirectness of others” (P1); “I don’t feel I should mask anymore, so I try not to when I’m at work” (P2).*

4.3.1.4 Second theme: the importance of understanding (or not) the demands of the social environment throughout the life span (from childhood to adolescence).

All participants in this focus group reported that the social environment shaped the life stages and negative experiences that they underwent, and their subsequent autistic identity: *“I don’t quite know who I am yet without the mask” (P3).* Two participants who identified as female discussed how mimicking others was done more in particular periods of time or in certain environments (e.g. teenage years during break times or as an adult during social gatherings with family or with work colleagues): *“Mimicking was done a lot, especially in female friendship groups” (P5); “It´s so important to fit in with your girl group of friends, you can’t survive without it, so you learn to mask” (P3).*

4.3.1.5 Formal diagnosis as an educational/identity tool or as a facilitator for the individual and others.

All participants in this group felt that self-identifying as autistic was not fully understood within their social network (e.g. friends, family, work colleagues or acquaintances): *“When I self-identify as autistic, I feel that others think that I´m trying to get their attention, when actually I’m not. I’m just trying to explain who I am and why I do certain things in a certain way. Is that difficult to understand?” (P5).* Another participant (*P6*) stated that: *“I still hide it from my family”.* Participant 6 stated in the group discussion that she doesn´t share with her family that she self-identifies as autistic because *“they wouldn´t probably know what I´m talking about, they are from another generation”*. She (*P6*) also shared in the group discussion that once she gets a formal diagnosis of autism, she will reconsider whether she shares this condition with her family.

All participants in this focus group stated the importance of finding an *“online space”* to discuss the significance that a formal assessment of autism had for them all, as an identity or educational tool: *“Years ago, I used to question whether or not seeking a formal assessment was the right decision. Throughout the years, I´ve become more convinced that seeking a formal diagnosis of autism will help me to better understand who I really am” (P6).* The rest of the participants (*P1*, *P2*, *P3*, *P4* and *P5*) agreed with the statement that *P6* said. In line with the statement that *P6* made, *P3* emphasised that *“The more adults like us pursue these types of assessments, the more others will realize that we exist on this planet. Being assessed in my fifties is not only about me, it´s about others seeing that we live on the same planet as them and we do exist”.*

4.3.1.6 Finding the referral and diagnostic processes difficult.

All participants in this focus group agreed that across the UK there is a significant lack of knowledge, particularly in GP surgeries, regarding the presentation of autism in adults and their needs: *“They don´t have a clue. I asked months ago on several occasions for a referral for an adult autism assessment, but my GP didn´t know what I was talking about. I recall on* *one occasion being told that I was too old for this type of assessment" (P6)*. The rest of the participants agreed with this statement. Participant 3 added that, based on her experience (asking for the same referral and getting the same answer from her GP), she realised from the conversation she was having with her GP that her GP had in his mind a very *"cliché picture of what autism was. I'm not like Rain man and I think that they should be aware of the diverse way autism can present in people, particularly adults" (P3).*

Another aspect that was raised by Participant 3 was the type of questions that she was asked to complete, once her GP had finally agreed to start the referral process for an adult autism assessment: *"Answering all these random questionnaires, I felt like a seven-year-old girl that had no clue how the world was working. I don´t remember the name of the questionnaires I completed, but what I can remember is that none of the questions on those tests had any emphasis on how I identified myself as a person who was potentially autistic and why"* (*P3*). Participant 1 agreed with the reflection that *P3* made and added the following: *"From my experience with the referral process, I felt the questions I was asked were too ambiguous. I found it very difficult to give a straight answer, especially on the questions where you have multiple options for an answer. I don´t really know what exactly they were asking me. While answering the questions, I felt that I needed some more time to process the questions in order to give an answer that reflected who I was with my own strengths and weaknesses*" (*P1*).

All participants in this focus group highlighted the enormous waiting list that the UK currently has for an adult autism assessment through the NHS. Two participants (*P4* and *P5*) reported that they were considering having an assessment privately because they didn´t want to wait more than three years: *"I was told that the waiting times for an assessment was four years, I am looking at going private" (P5).* At the same time, they shared with the rest of the group their concerns in spending over one thousand to two thousand pounds for a private assessment without having the certainty of whether all this money would be worth it.

Another topic that was raised in this part of the focus group discussion was the different presentations of autism, particularly in girls and women. Participant 4 shared with the group that she was aware of private clinics in the UK that mainly specialise in autism assessments in women; *"I've done my own research and found a private clinic that specialises in female ASD diagnoses – in Warrington" (P4).*

A final comment that was made by all participants in this focus group was related to the constant questioning from healthcare professionals (e.g. GP's) about their insistence on pursuing a formal autism assessment through the NHS. All participants reported they had had the same experiences from their GPs and highlighted the lack of support they received from healthcare professionals that they had had an appointment with (e.g. GPs and nurses). Despite the questioning and challenges that all participants in this focus group received during the referral and diagnostic process of an adult autism assessment, one of them (*P6*) highlighted the importance of keeping in mind through the whole process the main reason for pursuing this diagnosis; their identity.

4.3.1.7 Third theme: identity

In the last part of this first focus group, all participants agreed that self-identifying as autistic was a vital part of their own identity. Participant 6 highlighted the following: *“This is my identity; this is who I am. Autism is not a disorder, or something that can be cured or fixed, this is who I am”* (*P6*). However, the group acknowledged that, for them, developing an autistic identity throughout the years (from childhood to adulthood) was triggered by a personal crisis and/or positive personal reassurance. In the next following lines, both themes will be developed in depth.

4.3.1.8 Autistic identity triggered by a personal crisis.

Half of participants (participants 4, 5 and 6) explained that challenges in one or more areas of their life throughout the lifespan (e.g. their relationships with their families, partners or work colleagues) preceded self-identifying as autistic. Participant 5 used the word *“crash”* to describe the impact that had on her *“to realise that there was something that explained the social and personal environment in a slightly different manner in comparison to how others perceived it”.*

After that statement, the rest of the participants in the group added that in their worst moments of their life they realised the way they used to perceive and understand their personal and social environment, and the strategies that they used to use to overcome their own personal difficulties were no longer working. All participants agreed that it was in different moments of their life (e.g. late adolescence or early or middle adulthood) when they started researching autism and when they started making connections with this condition and their perception of themselves and their environment. At the end of this group discussion, Participant 6 stated that becoming aware that she could potentially be autistic was not a solution. It was for her *“the beginning of a long process. I’m sometimes still struggling with self-identifying as autistic” (P6).*

Participant 3 added to Participant 6’s reflection that, based on her personal experience (like the one that *P6* experienced), she didn´t feel supported at all by the NHS. During her medical appointments, participant 3 found it quite overwhelming that at the time she was mentally struggling she was asked “*to answer questions that were not understandable”* and *"to provide specific evidence of current difficulties in a short amount of time"*. Participant 3 also mentioned that she has always needed extra time to process messages and emotions from others. She felt that during her medical appointments nobody noticed that she needed more time to process what others were asking.

Participants 3 and 6 commented that the lack of clarity of the whole referral process (including all the conversations with the admin team, the forms they had to complete and the questions they had to answer) delayed their assessment for a month to approximately a year: *"I expect to get back to the doctor in about a year when I believe I will finish it" (P3); "I am now at the end of my tether and thinking about going privately" (P6).*

4.3.1.9 Positive autistic identity

In the last part of this first focus group, two participants (*P4* and *P5*) shared their views with the rest of the group about how the initial negative attitudes and feelings they experienced after self-identifying as autistic became positive. Both participants described two different types of reactions that resonated with the rest of the participants within the group. Participant 4 described a change to a positive autistic identity in a sudden way: *"It came out as an aha moment, which brought me joy and peace of mind"* (*P4*). Participant 5 also shared with the group that all the fears and insecurities she had had all her life, one day became strengths. She explained that this process could be partially explained by the acceptance that we all develop as we get older in combination with the *"normalisation"* of autistic traits in a neurotypical world. All participants agreed with this statement and highlighted how autism has become a "normal thing" in our society mainly through the influence of grey literature (e.g. magazines, radio programmes or TV documentaries).

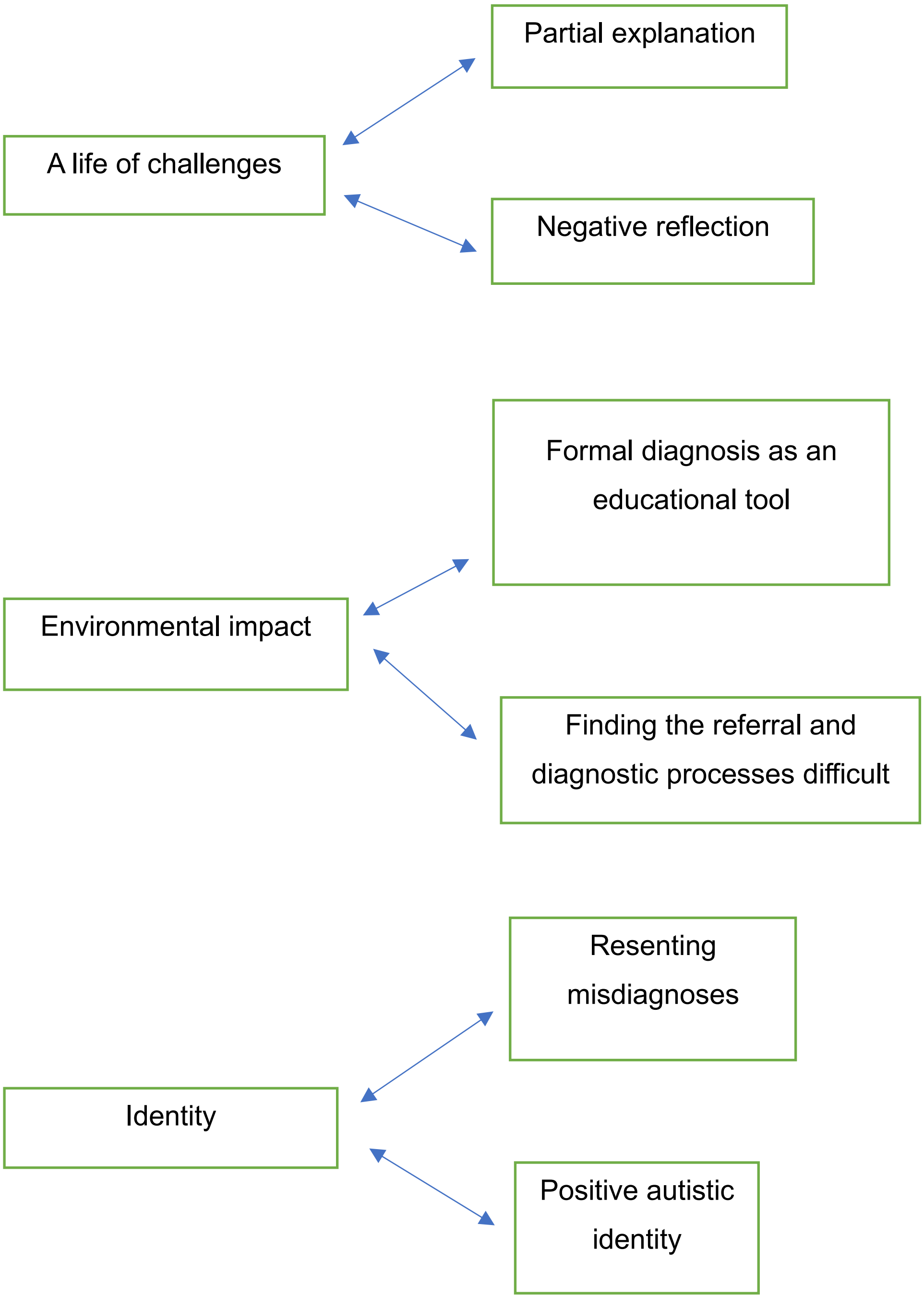
The remaining two participants in the group acknowledged the development of a positive autistic identity, but from their childhood or early adolescence. They recognised that *"differences may not always be easy to manage or cope with, but they make us who we are"* (*P2*); *"I've always had an awareness of being different, but most of the time I'm just me*" (*P1*).

Both participants stated that they felt the development of a positive autistic identity at early stages in their life (e.g. adolescence or early adulthood), could be linked with the normalisation of neurodivergent features by their loved ones (e.g. parents, teachers, peers/acquaintances, or friends): *"I was also told by my parents and teachers that I was special"* (*P2*).

All participants of this focus group agreed to describe autism as a condition and not as a mental health disorder. They all justified their answers by giving examples of the different strengths that autistic individuals have: "*We are all very organised" (P4);* "*We can see patterns* *in things that others can´t see and we should be proud of that*" (*P5*). They also acknowledged the difficulties that individuals who self-identify as autistic have when they interact and socialise with others, but they state that perfection doesn´t exist in any human being: *"I totally accept that I really struggle with eye contact or knowing when it's my turn to speak but that doesn´t make me a disabled person!!"* (*P6*).

4.3.2 Online focus group two: adults who self-identified as autistic with a formal diagnosis of autism.

Figure. 6. Themes and subthemes from thematic analysis of online focus group two



4.3.2.1 First theme: a life of challenges

Four of the five participants in the second focus group reported that as adults they thoroughly researched the main features of autism through a broad range of sources, including reading articles on the internet or completing autism online tests. Two of the five participants reported that doing their own research on autism was the starting point of the process of self-identifying as autistic. Two out of five participants also stated that another important aspect that was linked with the initiation of the process of self-identifying as autistic was the suggestion made by others (from late adolescence to middle adulthood) that they could be autistic. Two out of five participants reported that family members (e.g. siblings and partners), teachers, peers and work colleagues were the main ones that suggested the way they behaved, thought and felt could be explained by autism.

All participants reported that comments made from others were not always made in a very respectful and sensitive way. During that part of the group discussion, all participants, particularly those who were older, acknowledged that what was known about autism in the sixties, seventies, eighties and nineties (generational gap) was completely different to how autism is conceptualised now from a non-medical and gender-inclusive perspective: *"I have been on an extreme learning journey myself with understanding that autistic women and girls exist and so it was never something that crossed my mind" (P5),* or age*: "it's an age thing, not gender" (P1); "I can´t stop thinking about how many times during my school years my teachers told me that I was a naughty child (P4*); *"I feel really sad that nobody picked up on all the difficulties I had with the coursework, homework and making friends" (P2).*

4.3.2.2 Partial explanation

All participants in the second focus group reported that from their twenties until their forties, self-identifying as autistic provided a partial explanation to a lifetime of confusion associated with feeling different: *"I remember trying to fit in, but not understanding why I didn't fit in" (P6)*. Three participants in this focus group reported that from early childhood until their adult life they were labelled with a broad range of mental health conditions, such as social anxiety, OCD, bipolar disorder, borderline or unstable personality disorder. All three participants reported that they faced stages in their life in which they had tried to "forcibly" assimilate these conditions into who they were. To assimilate these conditions into who they were, these three participants stated that they took psychiatric medications (such as antidepressants, tranquilizers, or psychotic medication) and/or attended therapy sessions that they didn´t find useful. The three participants also emphasised that in all the past mental health appointments (before their autism diagnosis) they attended, they never really felt understood and often had difficulties in understanding what the therapists were saying: *"I was diagnosed* *with various forms of depression, severe anxiety, social phobias and lots of vestibular problems, but I remember having a constant feeling of having no answers" (P2).*

Despite all the efforts that the participants in the second focus group did throughout their lives to accept who they were from a medical perspective, they started to question all the medical labels and explanations that they had been given by a broad range of healthcare professionals as they became more aware that there was something else: *"As I became older, I started to question what my GP was telling me about my "supposed" OCD and started to read more about autism" (P4).*

After an important amount of time discussing between them the moment each of them decided to start thinking about their own identity in a self-personal and critical manner, they discussed their reasons for pursuing a formal diagnosis of autism. The main reasons were to find a real answer about their own identity and to get reasonable adjustments at work or at college.

4.3.2.3 Negative reflection

All participants in this focus group discussed how their perception of being different to others influenced in a negative way their social interactions with others. One participant said that they had lost count of the times, they had been told: *"you just don't get it, do you?"* (*P4*). To fit in, a majority of participants (three out of the five) discussed how they masked when they had to interact with neurotypical people. All participants in this group acknowledged that masking strategies were not always the most appropriate social communication strategies in unfamiliar contexts or new social situations. One participant described how they still found it difficult to maintain friendships: *"My friends drifted off when I was in my twenties"* (*P2*). Whilst another participant explained that, although masking helped them to be seen as more neurotypical, they still felt that others noticed their difference: *"I masked so much that I probably came across to most people as neurotypical, but a bit different"* (*P6*). Another participant stated that they had never felt the need to conform to neurotypical norms: *"I never masked, never copied peers, why would you do that?"* (*P1*). Participant 1 was aware that they had these stereotypical special interests, but they proudly spoke about them as they strongly believed they should not be seen as a negative difference.

4.3.2.4 Second theme: environmental impact

All participants reported the social environment influenced the life stages and negative experiences that they endured throughout the lifespan. For most participants in this focus group, their work environment was vital in the personal acknowledgement of their own identity. Two participants (*P2* and *P6*) stated that their work environment prompted them to self-identify as autistic: *“At the age of 46/47, I had a gut feeling, whilst working with special needs individuals”* (*P*2). After completing an online autism test at work and reading about autism, participant 6 recalled remembering: *“little lightbulbs were pinging off …. Ah, this is why I am the way that I am”*.

The importance, in terms of self-understanding, that participants attached to the process of self-identifying as autistic was critically discussed. However, it was equally reported that participants realised the limitations of this process. For example, *P5* stated: *“I went through the diagnostic process privately because I wanted more self-awareness, and dare I say it, more protection at work”* (*P5*). All participants agreed with *P5* and acknowledged the importance in practical terms (e.g. reasonable adjustments at work, at college or at university) of a formal diagnosis of autism.

4.3.2.5 Formal diagnosis as an educational tool

All participants in this focus group agreed that the knowledge of autism gained from having a formal diagnosis was particularly beneficial. Most participants explained how they had used this knowledge to educate others (e.g. work colleagues, friends, acquaintances, and members of their family) about autism. All participants in the group acknowledged the importance of that pedagogical action, given the limited knowledge their close ones had about autism in adults. However, at this point of the conversation participant 2 described the reaction that she often gets from others when as a woman she tells others that she is autistic: *“I get looked at in shock horror and I feel that I have to explain what people don’t understand. I often get comments from others like you don´t seem autistic or you can make perfect eye contact with me”* (*P*2).

Two participants described the positive feedback they had received from others (e.g. family members and work colleagues), once they had explained autism to them. One participant (*P6)* was pleased that colleagues from work went away and learnt about autism and discussed it with her. Another participant who shared with the group that she had recently started to write a blog about autism, was equally pleased that people she didn´t know had made the effort to contact her and thank her for the content of her blog: *“People have got in contact with me to say how much it enlightened them as they just didn’t know”* (*P*2).

4.3.2.6 Finding the referral and diagnostic processes difficult

All participants in this focus group agreed that getting a formal diagnosis of autism was difficult. From their experiences, many participants (three out of the five) stated that their GPs considered an autism assessment in adulthood to be irrelevant from a health perspective. Participants shared the comments that they had received from their GP or other healthcare professionals, which included: *"There is no benefit to be gained from it"* (*P6*) or: "*It wasn't something that I was particularly encouraged to do by my GP"* (*P4*). Participant 6 explained how she had viewed her GP as the *'expert'* and took their advice, which meant that self-identifying as autistic initially became an end point for her: *"I did not know what my options were really, so I just trusted the advice that my GP gave me"* (*P6*). In contrast, participant 4 told the group that the complex referral process that he had to go through in the NHS acted as a facilitator for the formal assessment. Participant 4 shared with the group that during the referral process he prepared a document in which he clearly stated with specific examples the main reasons that could suggest he was autistic. Participant 4 also mentioned that this document helped him to understand why a formal assessment of autism would be beneficial for him. The document that participant 4 created helped him through the referral and diagnostic process. He also stated that it was a really good exercise for him to put in a few pages who he really was.

On the other hand, two participants (*P5* and *P6*) shared with the group that they had an autism diagnostic assessment privately: *"I went down the private route and got an autism diagnosis last November (2021) because I couldn´t wait three years to be assessed through the NHS"* (*P6*). *"Yes, same here, the NHS it´s completely broken, there is no point in waiting almost four years for an autism assessment"* (*P5)*.

For participants in this focus group, another important issue that was discussed was the clinical tools used in different parts of the diagnostic process.

All participants in the focus group agreed that the questionnaires and clinical interviews that they completed during the referral and diagnostic processes were not really addressed to the adult population. All participants in the focus group also discussed the lack of time that they were given when they had to give specific answers, or to select which option of several answers (e.g. Likert Scale), was the most appropriate to them. In many situations during the referral and diagnostic processes, participants felt that they did not have enough time to process and fully understand the questions that clinicians were asking: *"You mask for so long, you don't really know how to answer the questions during the assessment"* (*P6*).

The final subtheme that came up in this part of the discussion was the limited support and understanding that participants received from healthcare professionals who oversaw the referral and diagnostic processes. All participants in the group stated that, despite their efforts explaining to healthcare professionals the challenges they face when they had to interact with others, they felt completely ignored during the referral and diagnostic processes.

4.3.2.7 Third theme: identity

All participants considered being autistic to be an important part of their identity, of which participants felt proud: "*I am very proud to be who I am"* (*P1*). Even so, the path to a formal diagnosis of autism meant that their validated autistic identity was coupled with mixed emotions for most participants.

4.3.2.8 Resenting misdiagnoses

Resoundingly, participants spoke about how the delay in being given a formal diagnosis of autism resulted in a range of several negative emotions, which included disappointment: *"I do feel let down by the system, If I had been diagnosed as a child, I think my life would have been completely different"* (*P2*) and anger: *"I felt angry and let down, I don´t really get why other mental health professionals when I was younger never once considered autism"* (*P4*). Ultimately, all participants reflected on the life they could have had, should they all had been diagnosed during their childhood. All participants in the group clearly reported that not having a diagnosis of autism in their childhood negatively influenced the support they did not receive from the school, their family and friends: *"it's almost like a grief, a grief for my life" (P2).*

4.3.2.9 Positive autistic identity

At the end of this focus group, all participants emphasised the importance of a formal diagnosis of autism from a self-perspective. All participants agreed with participant 2´s statement: *"A life of going undiagnosed has been traumatic for me. Now that I better understand who I am, I feel at peace with my own self".* Participant 4 stated that a formal diagnosis of autism helped him to validate who he has been for his entire life and to receive the support that he thinks he deserves. At the end of this focus group, all participants agreed that a formal diagnosis provided a greater level of self-understanding, social acceptance, and self-acceptance. Participants also reflected on how autistic traits can be context dependent in a positive and/or in a negative way. For example, Participant 4 described that when he is at work his autistic features are "completely invisible" because he feels in control with the environment that surrounds him: *"I know exactly what I have to do when and how. I´m the best where I work and I think that´s because I´m on the spectrum. The ways I have to complete every single task at work is extremely efficient. That´s what I´ve been told by my manager in several appraisals"*

However, participant 4 also stated that when he is in unfamiliar situations or faces unexpected changes in contexts that are less familiar for him (e.g. shopping in a supermarket), his autistic features may seem more apparent to others: *"I don´t see the point of talking to a* *person at the check-outs in a supermarket, I´m terrified when the self-checkout machines don´t work and I have to talk to a stranger for five minutes*". The rest of the participants in the group agreed with participant 4's views about his autistic features. All of them acknowledged that throughout the years, they all have faced similar situations in which their social and communication difficulties were less clear to others. Participants 2 and 6 also stated that in unfamiliar situations they have often mimicked what others were doing, in an attempt to follow social norms from a neurotypical perspective.

Participants 1 and 5 ended the focus group discussion by highlighting the importance of the abilities that both of them had developed (and still have) throughout the years, such as memorising and learning factual information quickly, having a logical thinking ability, being precise and orientated, being dependable in regards to schedules and routines, having a strong adherence to rules and having a drive to perfection and order. The rest of participants agreed with the final reflections of participants 1 and 5 and added that spectrum abilities have often made a positive difference in other people´s lives (e.g. in professional environments).

4.3.3 Feedback on the ASIS (McDonald, 2016)

As it is shown in Table 4, participants in both online focus groups gave very similar feedback on the ASIS (McDonald, 2016). Overall, results of the feedback provided by both groups primarily suggested that all the statements of the ASIS (McDonald, 2016) had to be reworded considering the following aspects: (1) to use a neurodivergent-affirmative approach in all the items of the scale, (2) to be clearer and more precise in each statement of the scale, and (3) to avoid the use of ableist language that may devaluate autistic people. Additionally, participants from both groups reported that there was a lot of repetition of topics within several items of the scale. Participants from both groups also reported that the scale did not have enough statements about the process of self-identification.

Me and Dr Ferran Marsà-Sambola systematically discussed the revisions we made on each statement of the ASIS (McDonald, 2016) based on the summarised participant feedback received on each of the statements. Due to the very similar participant feedback received on each of the statements from both focus groups (shown in Table 4, page 110 of this thesis) the revisions were straightforward and me and Dr Ferran Marsà-Sambola mostly agreed on the revisions to be made. Using statement 18 (If I were cured of autism, I wouldn't be me anymore) of the ASIS (McDonald, 2016) as an example, overall participants agreed that it was true because being autistic is who they are. However, participants strongly disagreed with the wording of the statement because they felt it denoted autism as a disease which could be cured. Three suggestions were made by participants regarding the statement: remove it; rephrase it to "Is autism an important aspect of my identity?" and rephrase it to "If I wasn't autistic, I wouldn’t be me.” In consideration of these comments and suggestions in addition to the general feedback received from participants on the ASIS (McDonald, 2016), me and Dr Ferran Marsà-Sambola agreed that statement 18 needed to be rephrased to ‘Being autistic is an important aspect of my identity’. The differences of opinion between me and Dr Ferran Marsà-Sambola on the revisions made to the statements stemmed from our different professional standpoints. To explain, as an HCPC registered clinical psychologist who conducts autism assessments in adults Dr Ferran Marsà-Sambola considered how each of the statements could be most effectively used during an assessment. Using statement 18 as an example again, Ferran suggested adding a qualitative response to the statement with the question “why?”. After a lengthy discussion, me and Dr Ferran Marsà-Sambola decided that we would not add the question why and a qualitative response to statement 18. Our decision was based on the fact that it was not suggested by participants of this study and that the adapted ASIS (McDonald, 2016) would be reviewed by healthcare professionals who conduct autism assessments in adults in the subsequent study (Development of the Autistic Identity Questionnaire (AIQ) presented in Chapter 5).

The reviewed version of the ASIS (McDonald, 2016) had the following structure: one statement (item 12*)* was kept, 17 statements (items 1, 3, 4, 5, 6, 7, 8, 9, 10, 11, 13, 14, 15, 16, 17, 18 and 19) were rephrased, and 4 statements (items 2, 20, 21 and 22) were removed. Additionally, 8 statements were added to the scale. These additional 8 statements were informed by the analyses of both online focus groups and are referred to as ‘extra item suggested by participants’ in Table 4. Table 4 (below) contains full details of the co-produced adapted version of the ASIS (McDonald, 2016).

Table. 4. Participant feedback on the Autism Spectrum Identity Scale (ASIS) (McDonald, 2016) from both online focus groups

Initial items	Participants without a formal diagnosis of autism		Participants with a formal diagnosis of autism		Final items
	Comments	Suggestions	Comments	Suggestions	
1 I feel like I only have autism in certain activities, like completing work, organizing, getting ready to go somewhere, or new activities.	From my awareness autism relates to every aspect of my life, highlighting areas I am really strong, proficient and excel in consistently. It is a very vague question to ask that confuses me. Yes, this is true for me, there are activities (such as	Prefer to remove the word 'feel'. Prefer to see the statement read, for example, what particular areas of your life do you struggle with? E.g. making new friends, keeping friends, socialising, having a boyfriend, girlfriend,		No suggestions given by participants.	Being autistic is only noticeable in certain activities, like completing work, organising, getting ready to go somewhere, or new activities.

	programming) where I am not aware of it.	partner, cooking and eating healthy and nutritious food, washing, bathing and keeping myself clean etc.			
2 There is little I can do about my autism.	This to me seems a very patronising and defeated statement, as if I am defective in some way, very derogatory where there seems to be a connation of shame attached to it. Unfortunately, I think my brain fog is impending my ability to	No suggestions given by participants.		No suggestions given by participants.	

	compensate for some of my communication deficits, so there are things that could be done, but I am not able to put them into practice (as it mostly involves reasoning about things).				
3 I am good at some things because I have autism.	The statement needs to remove the word ‘because’. I would not use autism as an excuse or justification with the word ‘because’.	Prefer to see the statement reworded as a question to invite more of a dialogue of specific gifts. For example, “what hobbies, interests, skills and talents are	The statement is a repetition of statement 15. The statement resonates with me.	No suggestions given by participants.	Being autistic means that I am good at some things.

	I think it makes me better in some respects in helping others as I tend to be thoughtful and logical rather than responding emotionally (which seems to be a good way of initiating action, but not of selecting a productive action).	you great at and you find easy and fun?”			
4 There are some people with whom I don’t feel I have autism.	Yes, I would say so. No, but some much less than others.	No suggestions given by participants.		No suggestions given by participants.	With some people, I don’t notice being autistic.

5 Autism only makes things harder for me.	No, I would say that I am exceptionally gifted at many things including being clear, direct and blunt in communication. This is what I find hard, trying to bend and contort myself to please and appease others. No, I find absolute statements like this rather difficult as it probably isn’t meant to mean that absolutely nothing is better in anyway, even	No suggestions given by participants.		No suggestions given by participants.	Being autistic makes life harder for me, like being lonely, or struggling in society.

	to a minimal degree, so I need to gauge what the intended meaning actually was.				
6 I like having autism or being autistic.	The statement resonates with me. No.	No suggestions given by participants.	The statement resonates with me. The statement is a repetition of statement 12.	No suggestions given by participants.	I like being autistic.
7 My good qualities have little to do with autism.	The statement is vague. What is meant by "qualities?" Some "qualities" could be due to autism and others from nature/nurture.	No suggestions given by participants.	The statement is a repetition of statements 19 and 22. The statements mean the same thing.	No suggestions given by participants.	Being autistic means that I am not good at some things.

8 I feel like I only have autism around certain people, like classmates, teachers, parents, or co-workers.	My communication difficulties stem around people who show little or no respect. I am more aware of it (being autistic) with some people (mostly my wife), but it is apparent to some extent with most people.	No suggestions given by participants.	Some of the statements feel like “autism” is a blanket ailment and a negative thing to have.	Prefer to see the statement read “I only feel I have difficulties around certain people, e.g. classmates/parents/teachers/co-workers.”	Being autistic is only noticeable around certain people, like classmates, teachers, parents, or co-workers.
9 I feel autism has more benefits in abilities than challenges.	I perceive the challenges come from trying to fit into a medical model system, rather than society adapting to an	No suggestions given by participants.		No suggestions given by participants.	Being autistic does not make life challenging.

	individualised social model system. More benefits will arise when education is embedded more in all sectors of life, and stigma, judgement, separations, expectations and prejudices are irradicated from society. No.				
10 If I work hard enough, I can minimize my autism.	The statement almost encourages masking. Masking has detrimental repercussions for	No suggestions given by participants.	The statement is about masking. I don't think there is such a thing as "minimising" autism – only how it's	Prefer to see the statement read "If I mask enough, others don't see me as autistic."	I have tried to minimise being autistic.

	health (e.g. breakdown and burnout). I find the concept of "minimizing" my autism highly insulting, like it is something to be ashamed and embarrassed about. The statement is a difficult one, as it seems a tautology.		perceived in response to making ability, whilst hiding the detrimental health effects underneath.		
11 I would be better off if I didn't have autism.	Better off financially? emotionally? mentally? physically? spiritually? all or some connected?	No suggestions given by participants.		No suggestions given by participants.	I would prefer not to be autistic.

	I find this a shamefully embarrassing statement, that perceives a sense of guilt for not being perfect. I am choosing to make no apology for me being me anymore and I love my traits of difference. Yes				
12 I like the way I am different from everyone else.	1,000,000% true for me! No.	No suggestions given by participants.	The statement is a repetition of statement 6. I would say that the statements mean the same thing.	No suggestions given by participants.	I like the way that I am different from everyone else.

13 I feel like I only have autism in certain places, like school, home, work or somewhere new.	I am selectively around certain people and places of interaction (I am aware of hidden agendas).	Some places are worse than others, especially 'somewhere new'.	The statement feels like 'autism' is a blanket ailment. The statement feels like autism is a negative thing.	Prefer to see the statement read "I only feel I have difficulties in certain environments."	Being autistic is only noticeable in certain places, like school, home, work or somewhere new.
14 When I'm alone, I don't feel like I have autism.	The statement is really odd and does not make sense. I am not sure how autism is supposed to feel! I'm just reminded of it (being autistic) less when I'm alone.	No suggestions given by participants.	The statement feels like 'autism' is a blanket ailment. The statement feels like autism is a negative thing. The statement resonates with me.	Prefer to see the statement read "When I'm alone, I feel better because there are no sensory or social demands."	When I'm alone, I don't notice being autistic.

15 Autism means having unique abilities.	1,000, 1,000% true for me – superpower gifts of magnitude that we are rarely acknowledged in this reality and society, other than perceived as ‘odd’, ‘crazy’, ‘weird’ to those who judge. I don’t think that this is the case (apart from an ability to have focused interests will inevitably make you better at those interests than you would otherwise be, possibly to the	No suggestions given by participants.	The statement is a repetition of statement 3. The statement resonates with me.	No suggestions given by participants.	Being autistic means having unique abilities.

	detriment of other things).				
16 If I work hard enough, I can minimize the challenges associated with autism.	The statement is a repetition of statement 10. The statement is very much like statement 10, see response to that.	No suggestions given by participants.	The statement resonates with me.	No suggestions given by participants.	Trying to minimise being autistic leads to a breakdown.
17 There are some places where I don't have Asperger's/autism.	It sounds like an ambiguous statement.	I would remove the word 'feel'.	The statement feels like "autism" is a blanket ailment, which could cover a multitude of characteristics and portrayed as a negative thing to have (and there are so many variations	Prefer to see the statement read 'find it easier'.	Being autistic is easier in some places, like working with other autistic individuals or being with family.

			of how people experience it).		
18 If I were cured of autism, I wouldn’t be me anymore.	The statement sounds like autism is a disease, which it is not. The statement comes across as highly discriminatory. The statement is always logically true, so the intended meaning is not clear.	The statement requires removing completely because it is discriminatory. Prefer to see the statement read “Is autism an important aspect of my identity?”	The statement feels like it’s promoting a damaging stereotype giving the notion that autism could be cured.	Prefer to see the statement read “If I wasn’t autistic, I wouldn’t be me.”	Being autistic is an important aspect of my identity.
19 I don’t feel I have additional abilities from my autism.	I have no idea what this statement means.	Perhaps use the word ‘think’ or ‘consider’ instead of ‘feel’.	The statement is a repetition of statements 7 and 19. The	No suggestions given by participants.	Being autistic does not mean having unique abilities.

	The statement resonated with one participant.	Prefer to see statement read “What other additional abilities would you say you have?”	statements mean the same thing.		
20 I only “have autism” when people treat me like I do.	The statement is really odd. I have no answer for the statement. No.	No suggestions given by participants.	The statement feels like ‘autism’ is a blanket ailment. The statement feels like autism is a negative thing.	Prefer to see statement read “I only feel autistic when people make light of my difficulties/differences”.	
21 I am better off because I have autism.	The statement is a repetition of statement 11. What is meant by better off? better off financially?	No suggestions given by participants.		No suggestions given by participants.	

	emotionally? mentally? physically? spiritually? all? or some connected?				
22 My strengths have little to do with autism.	The statement is ambiguous. The statement is a repetition of statement 7.	No suggestions given by participants.	The statement is a repetition of statements 7 and 19. The statements mean the same thing.	No suggestions given by participants.	
Extra item suggested by participants: I have not tried to minimise being autistic.					
Extra item suggested by participants: Being autistic is not noticeable by the					

healthcare system, like healthcare professionals or the tests used in assessments.					
Extra item suggested by participants: I noticed being different from everyone else.					
Extra item suggested by participants: I have had several other psychological diagnoses, like anxiety and depression.					
Extra item suggested by participants: I					

have other physical conditions, like epilepsy.					
Extra item suggested by participants: I tell people that I may be autistic.					
Extra item suggested by participants: Being autistic as an adult is not noticeable by society, like there is no awareness or understanding.					
Extra item suggested by participants: Being autistic is not noticeable due to					

demographic factors, like gender or age.					
General comments	Autism is perceived differently to different people also and I cannot always articulate in words what I want to say. More specific and direct questions would help to be clearer.		I'm not sure the scale covers any of the reasons or thoughts that led me to believe I might be autistic, other than that I knew something was incredibly wrong. My reasons were more so because of a lifelong accumulation of moderate mental health difficulties, physical tics, behaviours and social phobias. Also achieving so		

			much, yet gaining so little, overwhelmed by environments and sensory stimulation, which translated as failing to hold jobs down or becoming incredibly stressed very quickly along with burnout when involved in something social. It was ultimately my way of thinking – I knew it was more than something physical.		

			My first impression is that considering this was only 2016, the language and terminology feels incredibly out-dated, where I sense we have since moved forward somewhat in our understanding of the diversity of the spectrum. Whilst I can understand how the statements need to be kept simple and direct, I immediately noticed how autism is		

			described as something you ‘have’ rather than a way of being - you ‘have’ a cold, gingivitis or a bad foot, etc! (Though I notice no.6 is double phrased by using both contexts, which is not keeping in line with other statements.) According to the majority of forums and social media posts I follow, the general feel is that autistics prefer ‘identity first’ language.		

			That we are ‘autistic’ rather than autism is something we ‘have’. Our brain chemistry isn’t going to be cured or altered. ‘Having’ autism in my view, makes it sound like a separate entity - something that is a disease or can be removed. Of course, self-identity is a personal thing and some favour the ‘having’... though to me seems out-dated and less		

			encompassing, whilst promoting the schools of thought that it can be treated or removed. There’s an amount of repetition in the statements such as 3 &15, 6 & 12, and then 7 & 19, 22 (for example), which I would say mean the same thing. On a final note, not only does the whole series feel a little confusing because many mean the same		

			(just worded differently), they do jump from positive to negative affirming statements, where if the order was arranged in a less conflicting way with a better flow to it?		

4.4 Discussion

Through online focus group discussions, this study aimed to understand the main factors related to the self-identification process of autism in adults and why the self-identification process of autism may or may not be an end point for adults within the UK population.

Thematic analysis of both online focus group discussions revealed similar perspectives in both groups. The need and the meaning to have a formal diagnosis of autism in adulthood predominantly seemed to be the main reason for the different perspectives between the two groups. The three main themes that were identified from both focus group discussions were in line with The Nine Degrees of Autism theory (Wylie et al., 2016) and McDonald´s (2020) autism identity article.

4.4.1 First theme: feeling different in a neurotypical world/a life of challenges

Participants in both groups critically discussed the importance throughout their lives of seeking an answer about who they really were in a neurotypical world full of challenges. Both groups stated that this active search was made through a broad range of sources, such as books, media, or completing autism online questionnaires. Participants in both groups also highlighted as a key factor in the development of their neurodivergent identity the views others had of them.

According to the second degree of autism (knowing that we are different, without understanding why) (Page, 2016), participants in both focus groups vividly spoke about living life whilst always feeling different to most other people. In line with one of the first studies that described a lost generation of adults that missed a formal diagnosis of autism, due to recent changes in the diagnostic criteria and an increased awareness of autism in our society (Lai & Baron-Cohen, 2015), participants in both focus groups explained how the reason for this ‘difference’ was not recognised. However, the changing perception of autism over time (de Broize et al., 2022) meant that being autistic could finally provide them with an answer. It was then that their difficulties to cope in a world that they did not feel that they fitted, in combination with comments from others and their own research, that led participants to the realisation that they may be autistic.

4.4.2 Autistic identity as construct facilitator of individual's identity throughout the lifespan/partial explanation

In accordance to the fourth degree of autism, '*Self-identification'* (Moore, 2016) was found in both online focus groups to be a key factor with some shades in the development of participants' identity throughout the lifespan. It also provided an explanation for the numerous diagnoses that participants had received and disagreed with throughout the years. However, it was the participants of the first focus group (without a formal diagnosis of autism) who challenged these diagnoses. In contrast, participants of the second focus group (with a formal diagnosis of autism) discussed how they had tried to conform to the advice and treatments (medication and/or therapies) that they had been given. Therefore, a formal diagnosis of autism was sought to confirm these perceived misdiagnoses. It should be noted that this pursuit of a formal diagnosis was not as imperative for all participants, particularly participants who felt they knew who they were and did not need any support.

4.4.3 Overcoming personal and social negative attitudes towards autistic identity in a neurotypical world/negative reflection

Similar to what has been reported in previous studies, all participants described how 'being different' had negative repercussions throughout their lives (e.g. in social situations and in certain places, such as school and work) (Lilley et al., 2022). So, most participants discussed how they had masked their autistic traits as they felt it was the only way to survive in a challenging neurotypical world. Consistent with previous research, it was predominantly the participants who identified as female in both focus groups that masked (Leedham et al., 2020) and masked from an earlier age (childhood). However, within and between both focus groups there were differing views on masking as an adaptive coping strategy. These differing views related to the usefulness of masking and why there should be a need to mask in a society that theoretically seems more open to accept neurodivergent ways to communicate and socially interact with others.

4.4.4 Second theme: demands of social environment/environmental impact

Participants spoke about how specific environments (for the first group it was female friendship groups, and for the second group it was the work environment) were pertinent in recognising their autistic identity. Again, "social survival" seemed to be the key factor in both groups of participants, which explained the importance of belonging to a group of people and how participants chose to respond (e.g. masking to "fit in" and choosing to pursue a formal diagnosis for "protection" at work).

4.4.5 Formal diagnosis as an educational tool

All participants in both online focus groups felt that self-identifying as autistic was not really understood within wider society. So, most participants in the first focus group chose to pursue a formal diagnosis to better understand themselves, as well as increase public awareness of autism in adults. Certainly, the increased knowledge of autism that a formal diagnosis provides (Pukki et al., 2022) was substantiated, and valued, by participants in the second focus group. Like the participants of the first focus group intended, most participants in the second focus group used this increased knowledge to inform others. Interestingly, despite autism generally still being stigmatised within society (Cooper et al., 2021), two participants in the second focus group stated how others had positively engaged with the information on autism that they had shared.

4.4.6 Finding the referral and diagnostic processes difficult.

Despite the value that most participants in both online focus groups attached to a formal diagnosis of autism, it is evident that adults face difficulties in pursuing one. Participants in both focus groups of this study deemed that their demographic factors partly accounted for these difficulties, specifically their age and gender. The demographic profile of the study sample (the age of participants ranged from 41 to 58 years, and 8 out of 11 participants identified as female) is consistent with the demographic profile of individuals in previous research (Lewis, 2017; McDonald, 2020) who identified as autistic and reported difficulties with obtaining an assessment for autism. Participants in both focus groups felt healthcare professionals did not seem to appreciate the value of a formal diagnosis of autism in adulthood. Indeed, previous research has reported that some healthcare professionals are of the opinion that if an adult has managed to go through life without being diagnosed as autistic, then there is really no need for a diagnosis in adulthood (Rogers et al., 2016). This opinion is still clearly present, as participants described the constant questioning that they had received from healthcare professionals regarding their persistence on being assessed for autism.

In line with previous research (Lewis, 2017), participants in both online focus groups of this study also reported that healthcare professionals seemed to disregard the point that they had self-identified as autistic. The importance of exploring the reason(s) as to why adults have identified as autistic, throughout the diagnostic pathway, have been emphasised by some mental health professionals (Lewis, 2016b), including those who conduct autism assessments in adults (Hartman et al., 2023). In line with Cumin et al.'s (2022) study, this study found that self-identifying as autistic seemed to predict receiving a formal diagnosis of autism, so it certainly seems a factor that deserves consideration from a clinical perspective. Conversely, due to the medicalisation of society, concerns regarding self-identifying as autistic have been expressed by healthcare professionals who conduct autism assessments in adults (Crane et al., 2018; Cumin et al., 2022). Following self-identification, healthcare professionals have identified that some adults are unwilling to accept that they are not autistic after a formal assessment of autism. However, self-identifying as autistic and researching autism has been seen as one step to being formally assessed by a qualified healthcare professional (Jones et al., 2014; Lewis, 2017). This appeared in both focus groups in this study.

The challenges that participants encountered in being referred for an autism assessment were found to lead to a dichotomous outcome for them. Some participants stated that there was the requirement from the referrer for evidence to support their belief of being autistic and other participants mentioned that self-identifying as autistic became an end point for them.

In practice, the referrer's lack of knowledge meant that self-identifying as autistic became a temporary end point for most participants of both online focus groups in this study, as they began to produce evidence of why they believed that they were autistic. For this reason, together with the lengthy NHS waiting list for an autism assessment, half of the participants in the first focus group began to evaluate the possibility of having a private autism assessment. These participants identified as female and were acutely aware of the additional difficulties that females generally have with the autism diagnostic process (Fuentes et al., 2021; Lockwood Estrin et al., 2021). Therefore, these participants also emphasised that if they did choose to go private, they would choose a clinic that specialised in female autism assessments. Interestingly, although not explicitly stating their gender as the reason, two participants in the second focus group who identified as female got their diagnosis by going to a private clinic.

Two key limitations of the referral and diagnostic processes also emerged from both of the online focus group discussions: (1) that the tools used assessed for stereotypical autism and (2) that the questions were difficult to answer in an honest manner. Consistent with Jones (2022), participants felt that the tools used were totally inappropriate for the adult population explaining that the questions did not relate at all to how they identified being autistic. Participants also recalled being unsure if the answers they gave evidenced their true behaviour, or behaviour that they had learned through life. These difficulties were compounded by the lack of time that participants reported having to complete them. Clinically, autism assessments for adults is a relatively new service and so lacks evidence-based practice (Hartman et al., 2023). Therefore, there is a need to improve the autism diagnostic pathway for adults and the findings of this study further highlights that need.

The importance of improving the autism diagnostic pathway for adults is emphasised by the third theme from both online focus group discussions: identity. Ultimately, for participants being autistic was considered an important aspect of their identity, but self-identifying as autistic was generally viewed as a starting point for participants of both groups. For this reason, and consistent with the fourth degree of autism “Self-identification” (Moore, 2016), most participants of the first focus group (without a formal diagnosis of autism) and all participants of the second focus group (with a formal diagnosis of autism) decided to seek a formal diagnosis of autism to validate this autistic identity to themselves and also to other people (e.g. family and work colleagues). However, the complex diagnostic pathway meant that validating/their validated autistic identity resulted in negative emotions initially, before many participants were able to positively accept their autistic identity.

4.4.7 Online focus group one: autistic identity triggered by a personal crisis

Self-doubt has been reported as the dominant emotion in the absence of a formal diagnosis of autism (Lewis, 2016b). Most participants in this study described similar emotions as they realised that being autistic could explain why they found life so challenging, but remained uncertain as to whether they were autistic or not. These feelings were compounded by a personal crisis that most participants said preceded self-identifying as autistic and exacerbated by the difficulties that participants experienced with the NHS autism diagnostic pathway (e.g. the need to prove the belief of being autistic and the lengthy NHS waiting times) (Rutherford et al., 2018). Together, these factors were detrimental to the psychological wellbeing of most of the participants of the first focus group.

4.4.8 Online focus group two: resenting misdiagnoses

For participants of the second focus group (with a formal diagnosis of autism), it was the years of misdiagnosis and the delay in being diagnosed as autistic that led to negative emotions (disappointment and anger). Participants described how these negative emotions stemmed from thinking about how different their lives could have been if they had been diagnosed as autistic at an earlier age, a reaction that has been reported in previous research (Huang et al., 2022; Leedham et al., 2020).

4.4.9 Positive autistic identity

It has been suggested that positively accepting an autistic identity is primarily achieved by being formally diagnosed (Hartman et al., 2023). Nonetheless, two participants described how they had developed a positive autistic identity, whilst awaiting a formal autism assessment. Both participants described appreciating their traits, which they had always perceived so negatively, as strengths. Overall, the development of a positive autistic identity appeared to be partially associated with the “normalisation” of autistic traits that participants had been exposed to. Indeed, two participants who developed a positive autistic identity from an earlier age spoke about how they were able to ‘be themselves’ with the emphasis that no one is perfect.

The value of a formal diagnosis in enabling participants to ‘be themselves’ was highlighted by those who had received one, which they explained by the greater level of self-understanding and self-acceptance that they had gained from their diagnosis (Lewis, 2016a; Stagg & Belcher, 2019). Overall, it certainly seems that a formal diagnosis strongly aids the path to a positive autistic identity as The Nine Degrees of Autism theory (Wylie et al., 2016) suggests.

In both online focus groups, there was unanimous agreement that the referral and diagnostic processes of an adult autism assessment in the UK need to change in order to ensure that the assessments are more accessible to people who identity as neurodivergent. In accordance to Atherton et al. (2021), it is believed that the adult autism diagnostic pathway needs to be more effective and person-centred. To improve this pathway for adults, the findings of this study support the suggestion that neurodivergent identity (or the way adults’ identity as neurodivergent) might be a useful complementary concept to incorporate in the referral and assessment process. Throughout both focus group discussions, the phrase “who I am” was frequently used by participants when describing autism and what being autistic meant to them. Indeed, recent research has stated how autism is becoming recognised as an aspect of identity in addition to a clinical diagnosis (Cooper et al., 2023). The concept of neurodivergent identity has also been recommended for use in autism post-diagnostic support (e.g. Atherton et al., 2021).

Feedback on the ASIS (McDonald, 2016) was similar from participants of both online focus groups and was reflective of how they understood autism; as a condition that was part of their identity and not as a disorder that needs fixing or curing. For example, identity-first language was suggested along with suggestions to rephrase/remove statements that they felt portrayed autism negatively (see Table 4, page 110 of this thesis). The inclusion of the co-produced adapted version of the ASIS (McDonald, 2016), as a complementary tool within the referral and diagnostic pathway for adults, could positively improve both processes for both adults and healthcare professionals alike.

4.4.8 Limitations

The 11 participating adults self-selected to take part in the study, resulting in a predominantly female sample (8 of the 11 participating adults identified as female). Females typically have more difficulties with the autism diagnostic assessment process (Fuentes et al., 2021; Lockwood Estrin et al., 2021), so this may mean that participation was influenced by previous experiences. Although there are no gender differences in the core symptomatology of autism (Muggleton et al., 2019), females tend to develop coping strategies that mask the core symptomatology of autism more (Lai & Baron-Cohen, 2015). Furthermore, a number of participating adults did not provide full demographic data.

4.4.9 Future research

Future research should use the adapted ASIS (McDonald, 2016) or similar questionnaires of neurodivergent identity to complement the referral and diagnostic processes of an autism assessment for adults. Considering the limitations of this study, the adapted ASIS (McDonald, 2016) should be further developed in collaboration with experts by experience and healthcare professionals who conduct autism assessments in adults.

4.5 Conclusion

Self-identifying as autistic was considered a vital process in terms of self-understanding and as a starting point to pursuing a formal diagnosis of autism. This research found that self-identifying as autistic appeared to predict receiving a formal diagnosis of autism, but concerningly this was not considered at any point throughout the adult autism diagnostic pathway. Taken together, this study provides evidence in support of the use of identity to improve the adult autism diagnostic pathway in a neurodiversity-affirming manner, which should be explored further in future research given the urgent need.

Chapter 5

Development of the Autistic Identity Questionnaire (AIQ)

5.1 Introduction

The study presented in the previous Chapter (Chapter 4) provided further evidence in support of the use of identity to improve the adult autism diagnostic pathway. This previous study adapted the Autism Spectrum Identity Scale (ASIS) (McDonald, 2016) from the findings of two online focus groups (focus group one was with UK adults who self-identified as autistic and did not have a formal diagnosis of autism. Focus group two was with UK adults who self-identified as autistic and had a formal diagnosis of autism) and written feedback on the scale provided by participants to form a new screening questionnaire. In accordance to the findings of the previous study, the new screening questionnaire was named the Autistic Identity Questionnaire (AIQ).

The study presented in this Chapter explains the development of the AIQ through a two-round Delphi method, which aimed to assess face and content validity of the statements of the AIQ.

5.2 Method

5.2.1 Participants

Given that participants in a Delphi method study are experts in a specific topic, purposive sampling is usually the method of recruitment used (Brown, 2018). So, it was purposive sampling that was used to recruit participants for this study. Purposive sampling is the purposeful selection of participants who are likely to make a meaningful contribution to a research study, based on their expertise and/or experience of a specific topic (Coolican, 2019). For this reason, it is important that participating experts meet clear inclusion criteria, which is set to fulfil the aims of the research (Brown, 2018; Iqbal & Pipon-Young, 2009). As discussed in the Methodology Chapter of this thesis (Chapter 3), two sets of experts were recruited (experts by experience and healthcare professionals who conduct autism assessments in adults) with clear inclusion criteria stipulated for participation. The inclusion criteria stipulated are detailed below:

Experts in experience were required to: (1) be 18 years of age or older, (2) be fluent in English, (3) have a formal diagnosis of autism and (4) participate in activities that enabled a wider knowledge of autism (e.g. support groups, work as an expert by experience).

Healthcare professionals who conduct autism assessments in adults were required to: (1) be fluent in English and (2) have at least two years' experience conducting autism assessments in adults.

Consistent with other published research that has used a Delphi method study (e.g. Cumin et al., 2022), the stipulated inclusion criteria were based on previous research (Bond et al., 2019).

The AIQ was developed to be used as a screening questionnaire within the UK adult autism diagnostic service, so the sampling frame was limited to experts in the UK. This decision was made to mitigate against any potential differences in adult autism diagnostic services across different countries, and is consistent with other research (e.g. Spain and Happé, 2020). Experts by experience and healthcare professionals who conduct autism assessments in adults were recruited through the professional networks of me and Dr Ferran Marsà-Sambola, and through approaching expert by experience groups within the UK.

In total, fourteen experts (8 experts by experience and 6 healthcare professionals who conduct autism assessments in adults) were recruited to evaluate the items of the AIQ. Despite no existing definitive guidance on the number of experts required in a Delphi study (Hsu & Sandford, 2007; Jorm, 2015), fourteen experts seemed adequate. This adequacy was based on the recommendations by Turoff (2002) who suggests between 10 and 50 experts, and Brown (2018) who suggests between 10 and 20 experts. Furthermore, other published research (e.g. Cuesta-Gómez et al., 2019) has recruited fewer than 10 experts, with some research recruiting just seven experts (Iqbal & Pipon-Young, 2009).

5.2.2 Materials

A Google form was used to gather expert opinion on the statements of the AIQ and began by asking experts to create a response code number and then to tick their area of expertise (expert by experience or healthcare professional). The first part of form asked the experts to rate the clearness of each statement, and the second part of the form asked the experts to rate the representativeness (in terms of being representative of the self-identification of autism in adults within the UK population) of each statement of the AIQ. Experts were asked to rate the clearness and representativeness of each statement on a 5-point (1: strongly disagree, 2: disagree,3: neutral, 4: agree, 5: strongly agree) Likert scale and were given the option to provide written feedback.

5.2.3 Procedure

In both of the two rounds, experts were emailed the link to the Google form and invited to review the AIQ at their earliest convenience. Experts created a response code number to ensure anonymity and provided informed consent before reviewing the questionnaire. In the first round, experts were asked to review the initial version of the AIQ. In the second round, experts were asked to review the revised version of the AIQ which incorporated the proposed changes of the first round. Experts were fully debriefed before submitting their responses.

5.2.4 Data analysis

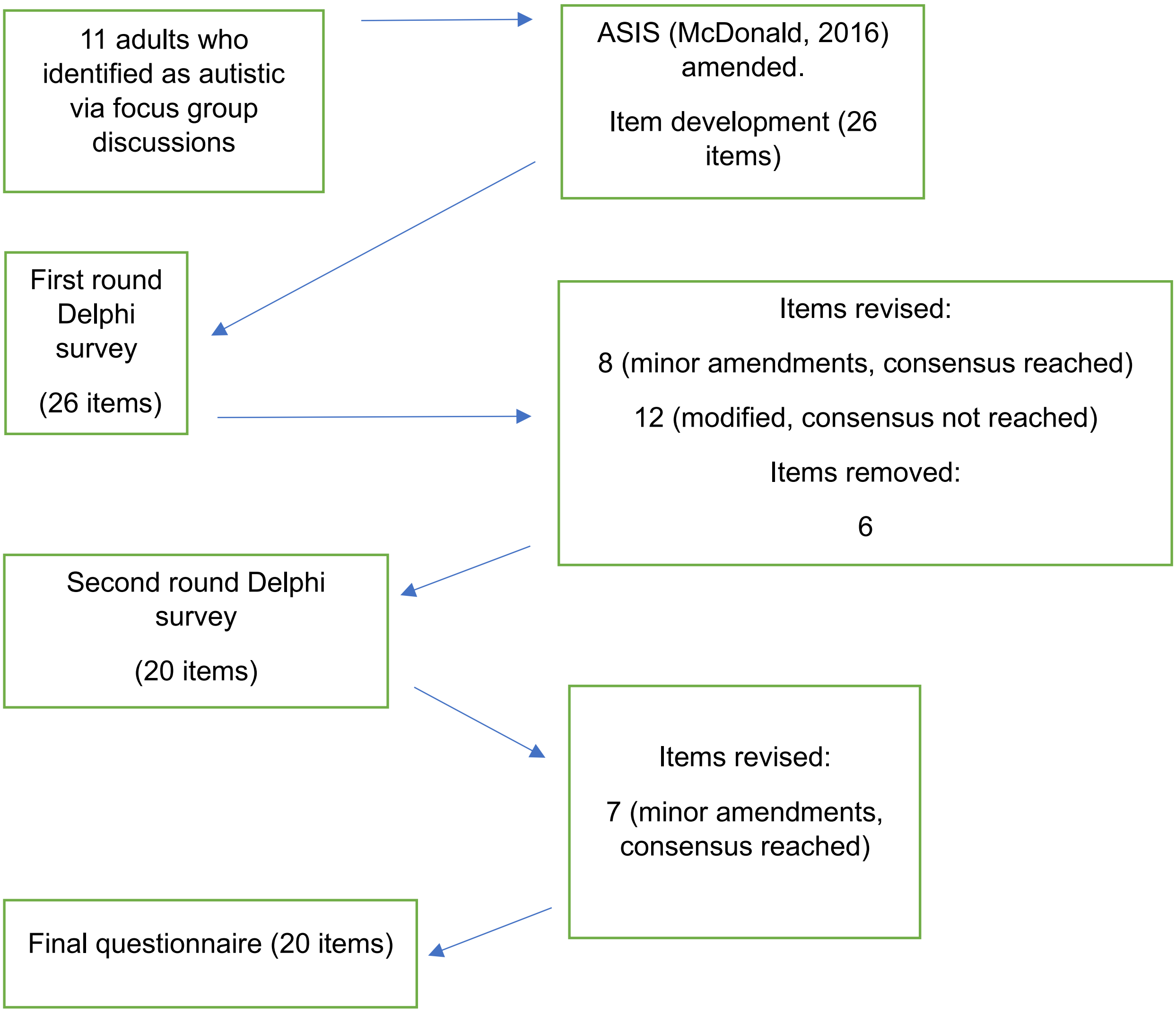
Data from each round of the two round Delphi was analysed using guidance provided by Hagen et al. (2008). In line with this guidance, experts were deemed to reach consensus on a statement if a mean score of 4 (agree) or 5 (strongly agree) was achieved for both clearness and representativeness. If a mean score of ≤ 3 was achieved, the statement was deemed to require amendment. With Delphi method studies, there is no universal definition on what constitutes ‘consensus’ (Niederberger & Spranger, 2020). Therefore, when a Delphi method study is used, it is for the researcher to define what constitutes consensus for the purposes of the given research and to justify that definition (Barrett & Heale, 2020; Jorm, 2015). Guidance by Hagen et al. (2008) was chosen because of the use of the guidance in other research that has sought to develop a tool for a clinical purpose (e.g. Bauer et al., 2019; Olaya et al., 2012).

Amendments to statements were informed by the qualitative feedback received from the experts. For each statement the qualitative feedback was combined and summarised. In accordance with the summarised feedback, I made the decision to either (1) remove the statement or (2) amend the statement. The qualitative feedback was also checked for statements that experts reached consensus on, to identify any improvements that could be made. The decisions that I made were independently reviewed by Dr Ferran Marsà-Sambola and then a discussion was held between us to discuss the decisions made.

5.3 Results

A flowchart illustrating the AIQ item development process is shown in Figure 7. below.

Figure. 7. Autistic Identity Questionnaire (AIQ) development flow chart



5.3.1 First round Delphi

In the first round, consensus was reached on eight statements (items 2, 4, 5, 6, 14, 16, 17, 21). These eight statements were kept, but minor amendments were made based on the qualitative feedback received. Generally, the qualitative feedback suggested the slight rewording of some statements to improve clearness (items 4, 6, 14, 16, 21) and indicated that responses to some statements could be dependent upon the person or context (items 2, 4, 5, 6, 17).

The other 18 statements (items 1, 3, 7, 8, 9, 10, 11, 12, 13, 15, 18, 19, 20, 22, 23, 24, 25, 26) did not reach consensus. Based on the qualitative feedback received, six statements were removed (items 3, 8, 9, 10, 18, 25). Mainly, the qualitative feedback on these six statements questioned the value of the statements (items 3, 8, 25), suggested that the statements overlapped with other statements (items 3, 18) and that the statement (item 9) had the potential to cause offence.

The remaining 12 statements (items 1, 7, 9, 11, 12, 13, 15, 20, 22, 23, 24, 26) were modified based on the qualitative feedback received. These modifications included removing the specified examples (items 1, 7), changing the terminology used (items 9, 11, 12, 13, 15) and rewording the statements (items 20, 22, 23, 24, 26).

Full details of the expert feedback, and further details regarding the revisions made in the first round, can be found in Appendix E (page 199 of this thesis). Following the first round Delphi, a revised AIQ containing 20 statements was developed. This revised version of the AIQ can be found in Table 5. below.

Table. 5. Revised version of the Autistic Identity Questionnaire (AIQ) following the first round Delphi

Initial items (following participant feedback on ASIS (McDonald, 2016))	**Revised items** (following first round Delphi)
1 Being autistic is only noticeable in certain activities, like completing work, organising, getting ready to go somewhere, or new activities.	For me, being autistic is more noticeable in certain activities.
2 Being autistic means that I am good at some things.	For me, being autistic means that I am good at some things.
3 With some people, I don't notice being autistic.	
4 Being autistic makes life harder for me, like being lonely, or struggling in society.	For me, being autistic generally makes life harder in society.
5 I like being autistic.	I am contented with being autistic.
6 Being autistic means that I am not good at some things.	For me, being autistic means that I find some things harder in life.
7 Being autistic is only noticeable around certain people, like classmates, teachers, parents, or co-workers.	For me, being autistic is more noticeable around certain people.
8 Being autistic does not make life challenging.	
9 I have tried to minimise being autistic.	I have always masked to hide being autistic.
10 I would prefer not to be autistic.	
11 I like the way that I am different from everyone else.	I like the way that I am different from neurotypical people.
12 Being autistic is only noticeable in certain places, like school, home, work or somewhere new.	For me, being autistic is more noticeable in certain environments.
13 When I'm alone, I don't notice being autistic.	For me, being autistic is less noticeable when I'm alone.
14 Being autistic means having unique abilities.	For me, being autistic means having useful abilities.

15 Trying to minimise being autistic leads to a breakdown.	For me, masking my autistic traits can lead to meltdowns and/or shutdowns.
16 Being autistic is easier in some places, like working with other autistic individuals or being with family.	For me, being autistic is easier in some contexts (e.g. working with other autistic people, being with family etc).
17 Being autistic is an important aspect of my identity.	For me, being autistic is an important aspect of my identity.
18 Being autistic does not mean having unique abilities.	
19 I have not tried to minimise being autistic.	
20 Being autistic is not noticeable by the healthcare system, like healthcare professionals or the tests used in assessments.	For me, being autistic has not been considered in healthcare appointments.
21 I noticed being different from everyone else.	I noticed always feeling different from everyone else.
22 I have had several other psychological diagnoses, like anxiety and depression.	I have been diagnosed with one or more psychological conditions (e.g. anxiety, depression, personality disorder etc).
23 I have other physical conditions, like epilepsy.	I have other conditions that are linked to being autistic (e.g. epilepsy, gastrointestinal disorders etc).
24 I tell people that I may be autistic.	I would be happy to share that I am autistic with other people.
25 Being autistic as an adult is not noticeable by society, like there is no awareness or understanding.	
26 Being autistic is not noticeable due to demographic factors, like gender or age.	For me, being autistic has not been considered because of my demographic factors (e.g. my gender, my age etc).

5.3.2 Second round Delphi

In the second round, 14 experts (8 experts by experience, 6 healthcare professionals who conduct autism assessments in adults) rated the clearness and representativeness of each of the 20 statements on the revised version of the AIQ. Consensus was reached on all 20 statements. On the basis of the qualitative feedback received, minor amendments were made to five statements (items 5, 6, 7, 11, 19) and the response options were amended (to yes/no) for two statements (items 17, 18). Minor amendments involved the refining of statements to improve clarity.

Full details of the expert feedback, and further details regarding the revisions made in the second round, can be found in Appendix F (page 227 of this thesis). Following the second round Delphi, a revised and finalised AIQ containing 20 statements was developed. This final version of the AIQ can be found in Table 6. below.

Table. 6. Final version of the Autistic Identity Questionnaire (AIQ) following the second round Delphi

Items	**1 (strongly disagree)**	**2 (disagree)**	**3 (neither agree or disagree)**	**4 (agree)**	**5 (strongly agree)**
AIQ. 1. For me, being autistic is more noticeable in certain activities.					
AIQ.2. For me, being autistic means that I am good at some things.					
AIQ.3. For me, being autistic generally makes life harder in society.					
AIQ.4. I am contented with being autistic.					
AIQ.5. For me, being autistic means that I find some things harder in my					

personal life (e.g. getting ready to go out, eating certain foods etc).					
AIQ.6. For me, being autistic is more noticeable around certain people (e.g. working with neurotypical people, people unknown to me etc).					
AIQ.7. I have mostly masked to hide being autistic.					
AIQ.8. I like the way that I am different from neurotypical people.					
AIQ.9. For me, being autistic is more noticeable in certain environments.					

AIQ.10. For me, being autistic is less noticeable when I'm alone.					
AIQ.11. For me, being autistic means having some useful abilities.					
AIQ.12. For me, masking my autistic traits can lead to meltdowns and/or shutdowns.					
AIQ.13. For me, being autistic is easier in some contexts (e.g. working with other autistic people, being with family etc).					
AIQ.14. For me, being autistic is an					

important aspect of my identity.					
AIQ.15. For me, being autistic has not been considered in healthcare appointments.					
AIQ.16. I noticed always feeling different from everyone else.					

	Yes	**No**
AIQ.17. I have been diagnosed with one or more psychological conditions (e.g. anxiety, depression, personality disorder etc).		
AIQ.18. I have other conditions that are linked to being		

autistic (e.g. epilepsy, gastrointestinal disorders etc).					
	1 (strongly disagree)	**2 (disagree)**	**3 (neither agree or disagree)**	**4 (agree)**	**5 (strongly agree)**
AIQ.19. I would be happy to share that I am autistic with most other people.					
AIQ.20. For me, being autistic has not been considered in healthcare appointments because of my demographic factors (e.g. my gender, my age etc).					

5.4 Discussion

Through a two round Delphi method, this study further developed a screening questionnaire (the AIQ) to complement the clinical tools currently used in the referral and diagnostic processes of an adult autism assessment in the UK.

The use of a Delphi method addressed the next step in the questionnaire development process; to have the generated questionnaire items evaluated by experts (DeVellis & Thorpe, 2022). The inclusion of healthcare professionals who conduct autism assessments in adults as experts also addressed the limitations of the previous study, presented in Chapter 4. Through this Delphi method, the AIQ has been co-developed by two sets of experts: experts by experience and healthcare professionals who conduct autism assessments in adults. Integrating the expertise of both of the aforesaid sets of experts allowed for the AIQ to be rated from the perspective of individuals who would potentially administer the questionnaire and individuals who would have completed the questionnaire. With the exclusion of experts by experience/service-users having being noted as a limitation in previous Delphi method studies (e.g. Heijnen-Kohl et al., 2022; Spain & Happé, 2020), including these experts in the development of the AIQ is a key strength of this study.

In the first round, expert consensus was reached on eight statements. Qualitative feedback was used to amend these statements and make a decision on the other 18 statements that did not reach expert consensus. In the second and final round, expert consensus was reached on all 20 statements of the AIQ, which indicates high face and content validity. Despite expert consensus being reached on all 20 statements of the AIQ, qualitative feedback was still considered and as a result minor amendments were made to seven statements to improve clarity. For this reason, and in line with Dragostinov et al. (2022), inviting experts to give qualitative feedback on each statement of the AIQ was considered invaluable. Had the decision been made to solely rely on quantitative data, the constructive feedback that informed the amendments to the statements of the AIQ would not have been gained (Dragostinov et al., 2022).

The final AIQ is a 20 statement self-report measure of the strength of an autistic identity. As discussed, the AIQ was further developed with the intention of it being used as a complementary screening questionnaire alongside the existing clinical tools used within the UK adult autism diagnostic pathway, such as the AQ-10 (Allison et al., 2012) and the RAADS-R (Ritvo et al., 2011). Although self-report measures of autism do exist, these are not considered fundamentally important within the referral and diagnostic processes of an autism assessment (Ratto et al., 2023). Perhaps this is due to the stereotypical, but largely misinformed assumption that autistic individuals lack self-awareness (Hartman et al., 2023). Furthermore, despite research stating the need to improve the adult autism diagnostic pathway (Rutherford et al., 2018), the little practical effort in doing so has been ineffective (O'Nions et al., 2023). This may be because most efforts have tried to be consistent with the diagnostic criteria and/or stereotypical autistic traits, which do not adequately reflect how adults perceive being autistic (Ratto et al., 2023). So, consistent with Ratto et al. (2023), the goal of this study and of the thesis overall was to develop a strengths-based screening questionnaire that would give adults the opportunity to tell of their lived experiences throughout the referral and diagnostic processes of an autism assessment. With the findings of the previous study (presented in Chapter 4) providing support for a more effective and person-centred autism diagnostic pathway (Atherton et al., 2021), the AIQ could be a valuable addition within this pathway. To explain, the statements on the final AIQ are reflective of recognising being autistic as an adult and of adults' lived experiences of being autistic; factors that are currently lacking within the diagnostic processes (Jones et al., 2022).

In the development of the AIQ there are many strengths to the use of a Delphi method, which is predominantly conducted online. One is that it enabled the recruitment of experts from a wider geographical area, which increased the sampling frame (Spain & Happé, 2020). Furthermore, it enabled the participating experts to review the AIQ at a time that was convenient for them (Spain & Happé, 2020), and the assurance of the anonymity of responses meant that the participating experts would likeliest have been more honest in their responses (Coolican, 2019). On the other hand, it is recognised that the participating experts may have had other distractions that may have impacted responses.

5.4.1 Limitations

Participating in a Delphi method study can be time consuming for experts, which can lead to experts dropping out after rounds (Barrett & Heale, 2020). Although no experts dropped out between rounds in this study, there were some variations in responses in and between rounds. One explanation for the variations in responses could be that the instructions on the expert form in the first round were not as clear as they could have been. For example, there was some confusion over what was meant by the representativeness of the self-identification of autism in adults within the UK. So, on the expert form in the second round the instructions were reviewed and amended to be clearer where necessary.

The variations in responses could also potentially be explained by the fact that all participating experts voluntarily reviewed the AIQ. It was recognised that it is rightly common in studies, such as this one, to financially imburse participants for their time and contribution (Gowen et al., 2019; McConachie et al., 2018). However, as this study formed part of a self-funded PhD no financial imbursement for participation could be offered to the participating experts. Offering financial imbursement for participation may well have resulted in more in-depth responses from experts, and in the recruitment of more experts. Though, comparable to the study conducted by Dragostinov et al. (2022), experts in this study seemed willing and eager to participate in the development of the AIQ irrespective of being financially imbursed.

In terms of the AIQ, a further limitation is that the questionnaire has no reverse scored items. From a research perspective, reverse scored items help to mitigate against response bias in the completion of a questionnaire (Coolican, 2019). However, as the AIQ was primarily developed to serve a clinical purpose it is the themes/items of the questionnaire, rather than the overall score, that are arguably more important (Bureau et al., 2023; Hartman et al., 2023). From a clinical perspective, both Bureau et al. (2023) and Hartman et al. (2023) have highlighted the importance of going beyond the test scores of a questionnaire in order to conduct a comprehensive assessment. Still, one overall score of the AIQ could be used for clinical and research purposes to gauge the strength of an autistic identity in adults. Furthermore, having no reversed items is not uncommon in identity questionnaires (e.g. Leach et al., 2008).

Lastly, given that the AIQ aims to serve a clinical purpose, the development of the questionnaire could have been enhanced by asking the experts an additional question regarding the feasibility of the AIQ as a complementary screening questionnaire within the adult autism diagnostic pathway (Brown, 2018). Brown (2018) states that including this type of question may be useful in aiding implementation, explaining that implementation of a given end product of a Delphi method study is not a guarantee even if the Delphi method study is published. Indeed, other research has included this question. However, in this study, the beginning of the expert form used clearly stated that the AIQ aimed to be used as a screening questionnaire within the adult autism diagnostic pathway. The participating experts were also invited to provide any written comments that they considered relevant on all the statements that they rated. So, it could be argued that the feasibility of the AIQ for use in clinical practice was addressed throughout the expert form. Supporting this point is the fact that one expert (a healthcare professional who conducts autism assessments in adults) did relate written feedback to the intended purpose of the AIQ. This comment was made in relation to statement 25 (being autistic as an adult is not noticeable by society, like there is no awareness or understanding) of the initial version of the AIQ (first round Delphi) and was “this isn’t answerable and I'm not sure what you would be able to get from this anyway.”

5.4.2 Future research

Despite the promising findings of this study in terms of the face and content validity of the AIQ, future research should continue to assess the validity of this questionnaire. For example, to ensure that the AIQ is a valid measure of identity it is crucial that the questionnaire discriminates from other different constructs (discriminant validity), such as quality of life. Equally crucial is that the AIQ positively correlates with another measure of autistic identity (criterion validity). Therefore, an assessment of the discriminant and criterion validity of the AIQ should be the first priority for future research.

5.5 Conclusion

The AIQ is a short and much-needed neurodiversity-affirming tool which has been developed in conjunction with two sets of experts, thus increasing the credibility of the questionnaire. High face and content validity was also confirmed after the second round Delphi. The AIQ has the potential to positively complement the existing tools used throughout the autism diagnostic pathway for adults in the UK, so the psychometric properties of the questionnaire should continue to be assessed by future research.

5.6 Ethical Reapproval

Following the development of the AIQ, the questionnaire was submitted to the University of Suffolk Research Ethics Committee for ethical approval via Chair's Action. This was as per the condition stipulated on the initial ethical approval granted on the 18th June 2021. This study was re-approved by the University of Suffolk Research Ethics Committee via Chair's action on 23rd September 2022. (please see Appendix G, page 233 of this thesis).

In the next Chapter (Chapter 6), the psychometric properties of the AIQ are assessed and detailed.

Chapter 6

Psychometric Properties of the Autistic Identity Questionnaire (AIQ)

6.1 Introduction

The previous Chapter (Chapter 5) explained the development of the AIQ through a two round Delphi method. This study explains the discriminant and criterion validation of the questionnaire, which aimed to assess these forms of validity with the relationships to generalised anxiety, autistic traits, depression, subjective quality of life (QoL) and identity.

6.1.1 Rationale for discriminant validity of AIQ with generalised anxiety, autistic traits, depression and QoL

How an adult conceptualises an autistic identity may well incorporate aspects of autistic traits. Indeed, as stated in the Introduction (Chapter 1), self-identifying as autistic has been defined as classifying the self as autistic often after the recognition that autistic traits may explain some life experiences (Moore, 2016). Recently, Ratto et al. (2023) used these autistic life experiences as a basis to develop a self-report measure of autistic traits; the Self-Assessment of Autistic Traits (SAAT). However, the AIQ was developed to measure the strength of an autistic identity as opposed to autism as defined by the diagnostic criteria and/or common autistic traits, so it is crucial that the AIQ discriminates between these constructs. Likewise, it is crucial that the AIQ discriminates from the symptomology of other psychological conditions that are co-morbid with autism, such as generalised anxiety and depression. To be a valid measure of identity, it would also be problematic if the AIQ correlated with a measure that assesses a different construct, such as QoL (Coolican, 2019). However, if factor analysis of the AIQ yields the same factor structure as the Autism Spectrum Identity Scale (ASIS) (McDonald, 2016), some correlations between these constructs and factors of the ASIS would be likely.

The ASIS (McDonald, 2016) has a four-factor structure: Positive Difference; Context Dependent; Spectrum Abilities and Changeability. Higher scores on the Positive Difference factor are indicative of the extent to which an individual perceives being autistic as a different but equally valid way of being, as opposed to perceiving it as a challenging disability (lower scores). Higher scores on the Context Dependent factor are indicative of the extent to which an individual perceives being autistic changes across contexts, as opposed to remaining stable across contexts (lower scores). Higher scores on the Spectrum Abilities factor are indicative of the extent to which an individual perceives being autistic as being related to specific positive traits, as opposed to perceiving specific positive traits as unrelated to being autistic (lower scores). Lastly, higher scores on the Changeability factor are indicative of the extent to which an individual perceives they could change the negative aspects of being autistic, as opposed to not being able to change (lower scores).

Clinically, a positive autistic identity may mediate co-occurring mental health conditions (especially anxiety and depression), to which autistic adults are susceptible (Cooper et al., 2017). So, it would be anticipated that the Positive Difference factor would negatively correlate with generalised anxiety and depression. Given that a positive autistic identity may mediate conditions, such as anxiety and depression, QoL is also enhanced (McConachie et al., 2018). Therefore, a positive correlation between the Positive Difference factor and QoL would also be anticipated. For the same reasons, a positive correlation would also be anticipated between the Spectrum Abilities factor and QoL.

Similarly, if an individual perceives that they are able to change aspects of being autistic it would be reasonable to anticipate a positive correlation between Changeability and QoL. However, arguably Changeability resembles elements of masking/camouflaging autistic traits, which has been found to negatively affect mental health (Hull et al., 2017). Therefore, whether the Changeability factor would discriminate from measures of generalised anxiety and depression is uncertain.

No correlations are anticipated with the factor of Context Dependent. In line with McDonald (2017), it is difficult to hypothesise how perceiving being autistic as contextually dependent or not would correlate with the constructs of autistic traits, generalised anxiety, depression and QoL.

6.1.2 Rationale for criterion validity

Following the development of the AIQ from the ASIS (McDonald, 2016), it is equally crucial to assess that the questionnaire is still measuring the construct of identity. Therefore, a positive correlation between the AIQ and another measure of autistic identity would be strongly anticipated. However, validated measures of autistic identity are extremely limited (Overton et al., 2023). For this reason, the Social Identity (SI) scale (Leach et al., 2008) was chosen to assess criterion validity of the AIQ, due to the adaptability of the scale and the use of the scale in other research with autistic adults (e.g. Bury et al., 2022; Cooper et al., 2017).

If the AIQ yields the same factor structure as the ASIS (McDonald, 2016) as described earlier, it may be that correlations are not found between the SI and any of the four factors of the AIQ. Identity is a multi-dimensional construct (McDonald, 2017) with limited consensus on how it should be measured (Leach et al., 2008), as such, different measures of identity may tap into the dimensions of the construct differently.

The SI (Leach et al., 2008) measures the strength of the construct of self-identification with a specified group, which for the purposes of this study is being autistic. Consistent with Social Identity Theory (SIT) (Tajfel & Turner, 1979), which theorises that individuals strive to develop a positive view about the groups to which they belong, a stronger autistic social identity is considered a positive difference. Therefore, a positive correlation between the SI (Leach et al., 2008) and the Positive Difference factor would be anticipated. Indeed, statements of the SI (Leach et al., 2008) include ‘It is pleasant to be autistic’ and ‘The fact that I am autistic is an important part of my identity’, which align with some statements of the AIQ, e.g. statement 4 (‘I am contented with being autistic’) and statement 14 (‘For me, being autistic is an important aspect of my identity’). However, an autistic identity may not always be viewed positively (Cooper et al., 2017), so whether and how the factor of Changeability would correlate with the SI (Leach et al., 2008) is uncertain. No correlations are anticipated between the SI (Leach et al., 2008) and the factors of Context Dependent and Spectrum Abilities, given that these factors are not seemingly incorporated by the construct of social identity.

6.2 Method

6.2.1 Participants

Through convenience sampling, this study recruited adults who were: (1) aged 18 years or older, (2) fluent in English, and (3) who identified as autistic, whether clinically diagnosed or self-identified. Participants were recruited through adverts placed around the University, local organisations and local charities. A network of individuals from the autistic community and other autism organisations distributed an advert for the study through their services and communication platforms.

850 adults completed the AIQ. Table 7. below shows the socio-demographic and clinical characteristics of these adults. In summary, the majority of adults identified as female (59%) and white (70.58%), were single (52.99%), had University level of education (29%) and were employed (58.82%). Clinically, most adults had a comorbid mental health condition (82.35%) and were taking medication for anxiety (70.59%).

Table. 7. Number and percentage of participant socio-demographic and clinical characteristics for the validation of the Autistic Identity Questionnaire (AIQ) (N=850)

Variable	**Number**	**%**	**Mean age (SD)**
Gender			
Male	300	35.30	35 (10.12)
Female	500	59	45 (11.20)
Non-binary	50	5.7	23 (12.20)
Autism			
Self-identified	400	47	44 (10.29)
Formal diagnosis of autism	450	53	34 (15.32)
Education			
Primary	100	12.30	
Secondary	250	29.40	
College	249	29.30	
University	251	29	
Employment Status			
Employed	500	58.82	
Unemployed	350	41.18	
Relationship Status			
Single	450	52.99	
Long-term relationship	250	29.41	
Married	150	17.60	

Ethnicity			
White	600	70.58	
Black	100	11.76	
Asian	0	0	
Other	0	0	
Mixed	150	17.66	
Comorbid mental health conditions			
Yes	700	82.35	
No	150	17.65	
Psychiatric medication use			
Anxiety	600	70.59	
Depression	200	23.52	
Psychosis	0	0	
Personality Disorder	50	5.89	

6.2.2 Materials

A Google form was used to validate the AIQ. The form included socio-demographic questions (gender, age relationship status, highest level of education, employment status, and ethnicity), two health questions (1: do you have a diagnosis of any other psychological disorder? (yes/no). If yes, please state the psychological disorder that you have received a diagnosis of. 2: are you taking any medication? (yes/no). If yes, please state the medication that you are taking.), and one clinical question (have you got a formal diagnosis of autism? (yes/no). If yes, please state your age when formally diagnosed as autistic.)

The form included the following measures to gather information about the clinical, identity and QoL characteristics of the adult sample:

1) Autism Spectrum Quotient 10 (AQ-10) (Allison et al., 2012). This is a ten item Likert scale self-report measure of autistic traits, which is recommended by the National Institute for Health and Care Excellence (NICE) as a screening tool for autism (NICE, 2021). Participants answer on a 4-point response scale ('definitely agree' to 'definitely disagree') the extent to which they agree with the items. A score of six or higher is indicative of autism.

2) Social Identity (SI) scale (Leach et al., 2008). This is a 14 item Likert scale self-report measure of identity, which was customised to autistic people for this study. The SI (Leach et al., 2008) has been used in other studies with the autistic adult population (e.g. Bury et al., 2022). Participants answer on a 7-point response scale ('strongly disagree' to 'strongly agree') the extent to which they favour an autistic identity. A higher score is indicative of more favourable autistic identity.

3) World Health Organisation Quality of Life – BREF (WHOQoL-BREF) (WHO, 1996). This is a 26 item (including two global items) Likert scale self-report measure of QoL across four domains (physical health, psychological, social relationships, and environment) and has been used in previous studies with autistic adults (e.g. Braden et al., 2022). Participants answer on a 5-point response scale the extent to which the items reflect their life over the last two weeks. A higher score is indicative of a better QoL.

4) Patient Health Questionnaire (PHQ-9) (Kroenke et al., 2001). This is a nine item Likert scale self-report measure of depression, which has been validated with autistic adults (Arnold et al., 2020). Participants answer on a 4-point response scale ('not at all' to

‘nearly every day’) the extent to which they have experienced the symptomology over the previous two weeks. A higher score is indicative of more severe depression.

5) General Anxiety Disorder (GAD-7) (Spitzer et al., 2006). This is a seven item Likert scale self-report measure of generalised anxiety, which has been used in studies with the autistic adult population (Griffiths et al., 2019). Participants answer on a 4-point response scale (‘not at all’ to ‘nearly every day’) the extent to which they have experienced the symptomology over the previous two weeks. A higher score is indicative of more severe anxiety.

6.2.3 Procedure

Participants accessed the Google form by a link that was advertised or was shared by word-of-mouth (e.g. previous participants of the study). Participants created a response code number to ensure anonymity and provided informed consent before completing the questionnaire. Following completion of the questionnaire, participants were debriefed before submitting their response.

6.2.4 Data analysis

The total AIQ score was calculated by adding the responses to the 18 items. Answers were coded as 1 (strongly disagree), 2 (disagree), 3 (neither agree or disagree), 4 (agree), 5 (strongly agree) and no statements were reverse coded. Total scores ranged from 18 to 90, with a higher score indicative of a stronger autistic identity.

Descriptive analyses were conducted to describe the socio-demographic and clinical characteristics of the sample. See Table 7. (pages 162 and 163 of this thesis) for further details.

The psychometric testing of the AIQ involved the assessment of internal reliability, discriminant and concurrent validity. Internal validity was tested through Cronbach’s alpha coefficient and item-total correlations. The confidence levels for the correlations were 95%.

Without an established gold standard measure, the validation process was based on construct validity. An exploratory factor analysis was conducted.

The internal consistency of the instrument was tested with the Cronbach’s alpha coefficients for general items (1-16, 19 and 20). Concurrent validity was assessed with correlations calculated between the scores on items of the AIQ with items of the SI (Leach et al., 2008).

Discriminant validity was determined with the calculation of correlation coefficients between the AIQ factors and the AQ-10 (Allison et al., 2012), WHOQoL-BREF (WHO, 1996), PHQ-9 (Kroenke et al., 2001) and GAD-7 (Spitzer et al., 2006).

6.3 Results

6.3.1 Pre-analysis checks

Statistical analyses were conducted using SPSS version 25 (IBM Corp., 2017). Prior to parametric tests, total score variables were examined for outliers, multicollinearity and normality. Non-normality was identified in a number of the variables. Square root transformations to correct for positive skew were conducted on the AQ-10 (Allison et al., 2012) and the WHOQoL-BREF (WHO, 1996) totals. To correct for negative skew in PHQ-9 (Kroenke et al., 2001) and GAD-7 (Spitzer et al., 2006) scores, square root transformations were conducted. Hereafter, reference to these scores is to the transformed totals.

6.3.2 Reliability

The Cronbach's alpha coefficient was 0.910 for the total scale, indicating good internal consistency (Coolican, 2019). Analyses showed that the Cronbach's alpha would not substantially increase by deleting any of the scale items. The greatest increase in alpha would come from deleting item 2, but removal of this item would increase alpha only by 0.007. Regarding the item analysis, item-total correlations ranged from 0.362 to 0.874. All items correlated with the total scale to a good degree, see Table 8. below for further details.

Table. 8. Psychometric properties of the Autistic Identity Questionnaire (AIQ) (N=850)

Items of the questionnaire	**Mean scores (SD)**	**Cronbach's Alpha if item is deleted**	**Correlation item-total**
AIQ.1. For me, being autistic is more noticeable in certain activities.	4.45 (1.07)	0.908	0.367
AIQ.2. For me, being autistic means that I am good at some things.	4.01 (1.17)	0.881	0.663
AIQ.3. For me, being autistic generally makes life harder in society.	4.55 (1.12)	0.885	0.643
AIQ.4. I am contented with being autistic.	4.7 (1.20)	0.883	0.672
AIQ.5. For me, being autistic means that I find some things harder in my personal life (e.g. getting ready to go out, eating certain foods etc).	4.65 (1.18)	0.876	0.712
AIQ.6. For me, being autistic is more noticeable around certain people (e.g. working with	4.23 (1.30)	0.874	0.783

neurotypical people, people unknown to me etc).			
AIQ.7. I have mostly masked to hide being autistic.	4.12 (1.15)	0.870	0.785
AIQ.8. I like the way that I am different from neurotypical people.	4.20 (1.23)	0.879	0.783
AIQ.9. For me, being autistic is more noticeable in certain environments.	4.19 (1.32)	0.877	0.700
AIQ.10. For me, being autistic is less noticeable when I'm alone.	4.20 (1.18)	0.880	0.722
AIQ.11. For me, being autistic means having some useful abilities.	4.07 (1.12)	0.884	0.663
AIQ.12. For me, masking my autistic traits can lead to meltdowns and/or shutdowns.	4.76 (1.34)	0.882	0.643
AIQ.13. For me, being autistic is easier in some contexts (e.g. working with other autistic people, being with family etc).	4.01 (1.76)	0.875	0.672

AIQ.14. For me, being autistic is an important aspect of my identity.	3.87 (1.84)	0.873	0.712
AIQ.15. For me, being autistic has not been considered in healthcare appointments.	3.95 (1.20)	0.869	0.783
AIQ.16. I noticed always feeling different from everyone else.	4.20 (1.16)	0.870	0.700
AIQ.19. I would be happy to share that I am autistic with most other people.	3.76 (1.20)	0.878	0.722
AIQ.20. For me, being autistic has not been considered in healthcare appointments because of my demographic factors (e.g. my gender, my age etc).	4.02 (1.22)	0.876	0.654

6.3.3 Factor analysis

To determine the construct validity of the AIQ, a factor analysis was conducted. The sample size was appropriate for factor analyses, as indicated by the Kaiser-Meyer-Olkin (KMO) measure of 0.945. A significant Bartlett's test ($X^2 = 33976.732$; $p \leq 0.001$) indicated that the correlation matrix was also appropriate for factor analysis.

To determine the factor structure of the AIQ, a Principal Component Analysis (PCA) with varimax rotation was conducted with the result of a four factor (Positive Difference, Context Dependent, Autistic Abilities and Changeability) accounting for 60.77% of the variance.

The four-factor model with promax rotation explained 50% of the variance in the correlation matrix with positive difference, context dependent, autistic abilities, and changeability accounting for 17%, 16%, 11%, and 6% of the variability, respectively.

Table 9. (below) contains the AIQ factor Pearson's correlations with the WHOQOL-BREF (WHO, 1996), AQ-10 (Allison et al., 2012), PHQ-9 (Kroenke et al., 2001), GAD-7 (Spitzer et al., 2006) and the SI (Leach et al., 2008).

Table. 9. Relations between the Autistic Identity Questionnaire (AIQ) and the WHOQoL-BREF (WHO, 1996), AQ-10 (Allison et al., 2012), PHQ-9 (Kroenke et al., 2001), GAD-7 (Spitzer et al., 2006) and the SI scale (Leach et al., 2008) (N=850)

	AIQ Factors			
	Positive Difference	**Context Dependent**	**Autistic Abilities**	**Changeability**
WHOQoL-BREF				
Physical health	0.123	0.045	0.023	0.108
Psychological health	0.183*	0.023	0.007	0.256*
Social relationships	0.201*	0.134	0.024	0.204*
Environmental health	0.163*	0.013	0.006	0.104
Overall quality of life	0.345*	0.062	0.120*	0.319*
AQ-10				
Total score	0.123	0.154	0.230	0.144
PHQ-9				
Total score	-0.234	0.028	-0.058	-0.065
GAD-7				
Total score	-0.256*	0.136	0.120	0.134
SI				
Total score	0.218*	0.123	0.210	0.143
*Correlation is significant at the 0.01 level (two-tailed)				

6.3.4 Changeability

Anticipated correlations were found between the Changeability factor and factors of the WHOQoL-BREF, with significantly small positive correlations with the psychological health and social relationships factors. A significant medium positive correlation was found with the overall QoL factor of the WHOQoL-BREF. No significant correlations were found between the Changeability factor and the physical health and environmental health factors of the WHOQoL-BREF, AQ-10, PHQ-9 and GAD-7 which confirms discriminant validity. Criterion validity was not confirmed for this factor with no significant correlation found with the SI.

6.3.5 Positive Difference

As anticipated, a number of significant positive correlations were found between Positive Difference and the other measures. Small positive correlations were found between the psychological health, social relationships and environmental health factors of the WHOQoL-BREF and a medium positive correlation was found with the overall QoL factor of the WHOQoL-BREF. A significantly small negative correlation was found with the GAD-7. Discriminant validity was confirmed with no significant correlations with the physical health factor of the WHOQoL-BREF, AQ-10 and PHQ-9. Criterion validity was confirmed with a significant small positive correlation between Positive Difference and the SI.

6.3.6 Autistic Abilities

Discriminant validity was confirmed for Autistic Abilities, with no significant correlations found between the factor and the four factors of the WHOQoL-BREF, AQ-10, PHQ-9 and GAD-7. As anticipated, there was a significantly small positive correlation between Autistic Abilities and overall QoL factor of the WHOQoL-BREF. No significant correlation was found between Autistic Abilities and the SI meaning criterion validity was not confirmed.

6.3.7 Context Dependent

No significant correlations were found between the Context Dependent factor and the WHOQoL-BREF, AQ-10, PHQ-9 and GAD-7, which confirms discriminant validity. Criterion validity was not confirmed for this factor as no significant correlation was found with the SI.

6.4 Discussion

This study assessed the discriminant and criterion validity of the AIQ with the relationships to generalised anxiety, autistic traits, depression, subjective QoL and identity.

With regards to the psychometric properties of the AIQ, the initial outcomes were very satisfactory. Internal consistency was established through two different statistics: (1) Cronbach's alpha was 0.910 and above the arbitrary threshold of 0.20 (Kline 1993; Nunnally 1978) and (2) all item-total correlations coefficients were above the suggested level of 0.2 (Streiner & Norman, 2003).

The inclusion of multiple measures in this study allowed for the examination of construct validity. The sample size was appropriate for factor analysis and also for ensuring enough power to detect factors across the questionnaire items, so construct validity of the scale was evaluated through factor analysis and principal component analysis. When performing factor analysis in the sample, all items met in four factors (1. Positive Difference, 2. Context Dependent, 3. Autistic Abilities and 4. Changeability). This outcome is in line with the original version of the scale developed by McDonald (2017) in the USA.

All four factors demonstrated discriminant validity with measurements of autistic traits (AQ-10; Allison et al., 2012) and depression (PHQ-9; Kroenke et al., 2001). With the exception of Positive Difference, all factors also discriminated with the measurement of generalised anxiety (GAD-7; Spitzer et al., 2006). The small negative correlation between Positive Difference and generalised anxiety was not unanticipated due to the mediating effect of a positive autistic identity on mental health (Cooper et al., 2017). Therefore, it was unsurprising that the Positive Difference factor positively correlated with all factors of the WHOQoL factors except for physical health, and the Autistic Abilities factor positively correlated with QoL. Equally unsurprisingly, albeit a little concerning, was the anticipated positive correlations between the Changeability factor and psychological health, social relationships and overall QoL factors of the WHOQoL-BREF (WHO, 1996). Although, considering the resemblance of the Changeability factor to masking/camouflaging autistic traits, it was reassuring that the factor discriminated from measures of generalised anxiety and depression.

If like the ASIS (McDonald, 2016) the AIQ factors are measuring different aspects of autistic identity, scores on one factor are likely to be affected by the scores on the other factors. McDonald (2017) gives the example of how a low score on Positive Difference might be buffered by a high score on Spectrum Abilities explaining that a person might view being autistic as a disability with very real challenges, but also believe that these challenges are compensated with positive abilities specific to being autistic. The results of this study should be interpreted within this context, as this may also provide an explanation as to why criterion validity was not confirmed for the changeability factor.

Criterion validity was only confirmed for the Positive Difference factor of the AIQ, which may be explained by the fact that, based on the accounts of the adults (adults who identify as autistic, experts by experience and healthcare professionals who conduct adult autism assessments) who were involved in the development of the AIQ, statements were amended and/or added to portray autism more positively and to reflect the self-identification process of autism more. Similarly, the SI (Leach et al., 2008) places more emphasis on the constructs of self-identity and the positive dimensions of a specified in-group identity. The SI (Leach et al., 2008) does not include statements relating to the context or abilities factors of identity.

Furthermore, following an examination of all four factors of the ASIS McDonald (2017) suggested that the factors may play different roles with other variables, such as self-concept and aspects of well-being. McDonald (2017) explained that Positive Difference and Spectrum Abilities may play a stronger role with self-concept valence and wellbeing, while the factors of Changeability and Context Dependent may play a stronger role with performance.

6.4.1 Limitations

There are limitations to this study, which should be noted. First, is the validity of the online responses, which concerns whether the questionnaire was filled out by adults who met the inclusion criteria of the study. Although this concern cannot be discounted in any online study, the pattern of responses and the comments provided by participants is consistent with other research with autistic adults (e.g. McDonald, 2017). Additionally, several adults reported other co-morbid conditions, and medication use for these conditions (e.g. anxiety and depression) (McDonald, 2017; McDonald, 2020), which provides further confidence.

A second limitation of this study is the potential for sample bias due to participant self-selection, which is common with voluntary research participation. Indeed, the higher percentage of participants who identified as female in the study may be indicative of self-selection bias. Nonetheless, this higher percentage of participants who identified as female is consistent with what has been reported in other autism research (Lewis, 2017; McDonald, 2017; McDonald, 2020). The higher percentage of participants who identified as female also arguably served as a strength, as this population of adults remain under-researched in the literature (Lockwood Estrin et al., 2021; McDonald, 2017) despite a growing body of literature highlighting the difficulties that they encounter throughout the autism diagnostic pathway (Fuentes et al., 2021; Lewis, 2017). All the same, the main aim of this study was to determine the discriminant and criterion validity of the AIQ. Irrespective of whether there was sampling bias, there were variations in participant responses.

A final limitation is that this study does not establish causal directions among any of the reported correlations. From a psychometric perspective though, the main focus of this study was on the construct validity of the AIQ.

6.4.2 Implications

The development of a reliable and valid measure of autistic identity in adults has the potential to significantly improve the referral and diagnostic processes of an adult autism assessment. For example, the AIQ could aid the previously reported difficulties that some adults have in explaining to healthcare professionals why they believe that they could be autistic (Lewis, 2017). Similarly, the AIQ could enable healthcare professionals to understand how service-users see themselves in relation to being autistic (McDonald, 2017).

A measure of autistic identity could also be beneficial in post-diagnostic support, as unlike other factors, such as socioeconomic status and access to services, autistic identity may be more amenable to change (McDonald, 2017) and clinical intervention (Cooper et al.,2017). Therefore, the AIQ could be a useful tool for assessing how adults identify with being autistic prior to, during, and after a formal autism assessment.

From a research perspective, the AIQ can be used to examine associations between how adults identify with being autistic and other factors, such as sociodemographic, clinical, health and QoL.

6.4.3 Future research

As DeVellis and Thorpe (2022) point out, validity is not an attribute of a questionnaire itself, but of how a questionnaire is used. The AIQ was developed to be used as a complementary screening tool alongside the existing clinical tools used within the UK adult autism diagnostic pathway, such as the AQ-10 (Allison et al., 2012) and the RAADS-R (Ritvo et al., 2011). Therefore, the AIQ would need to be administered in clinical settings to ascertain the validity of the AIQ for the purpose for which it was developed.

With a worldwide body of research stating the need to improve the adult autism diagnostic pathway (de Broize et al., 2022; Rutherford et al., 2018), the AIQ could be validated in other countries to determine whether the AIQ could be used more widely and whether there are cultural differences in the self-identification process of autism in adults. Likewise, the AIQ could also be validated with other age groups (e.g. adolescents) to determine whether there are age differences in the self-identification process of autism.

In line with McDonald (2017), it is also believed that future research should specifically investigate whether gender differences exist in autistic identity. Increasingly, autism research participation is signified by a greater number of adults who identify as female or as a gender other than male (Lewis, 2017), suggesting that this population of adults are wanting their views to be heard and are willing to participate in research to do this.

6.5 Conclusion

This study initially validated a questionnaire (AIQ) to positively complement the existing tools used in the referral and diagnostic processes of an adult autism assessment in the UK. The AIQ is a 20-item neurodiversity-affirming tool and preliminary analyses of its' validity and reliability were very satisfactory. It is believed that the AIQ should be trialled in clinical settings to ascertain whether it is a valid and reliable measure for its intended purpose.

Chapter 7

General Discussion

Interest often serves as the impetus for research (Kazdin, 2022). Indeed, this thesis began with an interest in whether the increase of adults who were self-identifying as autistic (Lewis, 2017) was related to the difficulties that adults reported in obtaining an autism diagnostic assessment (Lewis, 2016b; Lewis, 2017). Support for turning this interest into a potential research study was provided by the fact that little research had focused on the self-identification process of autism in adults (McDonald, 2020), so it was unclear whether self-identifying as autistic was solely related to the reported difficulties of obtaining an autism diagnostic assessment or whether there were other factors underpinning this phenomenon. More importantly, despite little efforts to improve the autism diagnostic processes for adults (Benevides & Cassidy, 2020) a growing body of literature was providing evidence for the value of a formal diagnosis of autism as an adult (e.g. Lewis, 2016a).

Studies had begun to explore the self-identification of autism in adults (Lewis, 2016b; Lewis, 2017; Sarrett, 2016; McDonald, 2020) and highlighted the limited research on this phenomenon (Lewis, 2017; McDonald, 2020), but no study had systematically synthesized the research that had been undertaken to date. Therefore, exactly what was known about the self-identification of autism in adults was uncertain. So, the first contribution of this thesis was a published scoping review that sought to ascertain firstly what research had been conducted on the self-identification process of autism in adults who do and do not have a formal diagnosis of autism, and secondly which aspects of the self-identification process could be used to improve the referral and diagnostic processes of an adult autism assessment. During the peer review process of the scoping review article, me and my PhD supervisors were commended for addressing this gap in the research by a reviewer who commented *"Thank you for the opportunity to review the manuscript "Understanding self-identification of autism spectrum disorder (ASD) in adults: a scoping review". This is an important topic area, and to my knowledge, a review of this research does not yet exist. As such, I commend the authors' efforts to address this gap in knowledge."*. Since publication in the *Review Journal of Autism and Developmental Disorders* the scoping review has been cited seven times.

In line with recommendations to investigate the barriers to diagnostic services for adults who self-identify as autistic and adults generally (Lewis, 2017; McDonald, 2020), the findings of the scoping review provided an informed platform in which to build upon what was already known about the self-identification of autism in adults in a way that would meaningfully improve the referral and diagnostic processes of an autism assessment for adults. A key finding of the scoping review was that adults were able to identify autistic traits/signs of autism in themselves with reasonable accuracy, yet this self-identification as autistic did not seem to be incorporated at any point throughout the adult autism diagnostic pathway. Indeed, as discussed in the scoping review, only one scale that assessed autistic identity could be found: the Autism Spectrum Identity Scale (ASIS) (McDonald, 2016). Lewis (2016b) had previously stated the importance of healthcare professionals acknowledging the perspectives of adults who self-identified as autistic, and since the scoping review was conducted other research (Hartman et al., 2023) has echoed that standpoint. Omitting the acknowledgement of an autistic identity seems to detrimentally impact the whole adult autism diagnostic pathway in a number of ways.

It has to be remembered that widespread access to adult autism assessments is relatively new (Hartman et al., 2023; Murphy et al., 2016). As a consequence, clinical tools that have been validated for use with adults are scarce (Conner et al., 2019; Wigham et al., 2020) and most of the clinical tools used throughout the adult autism diagnostic pathway were initially developed and validated for use with children (Fuentes et al., 2021). These clinical tools can be problematic for adults presenting for an autism assessment to respond to (Jones, 2022). Jones (2022) highlighted how adults have more understanding of, and freedom to control their behaviours and environment and how the questions can be ambiguous for adults in comparison to children. Jones (2022) uses the example of how an adult may query the definition of the words within the questions when answering them. For example, with regards to the first question (I often notice small sounds when others do not) of the screening tool the AQ-10 (Allison et al., 2012), adults may say it depends on how you define small sounds. It is for these aforesaid reasons that the responses of adults may be different (from those of children) and may result in a non-referral or underdiagnosis due to a more subtle presentation of autism. This is unless the quantitative responses of adults, on clinical tools, are further explored (Hartman et al., 2023). So, firstly, omitting the acknowledgement of an autistic identity seems to neglect valuable information. Hartman et al. (2023) emphasised how exploring the self-identification process of autism in adults gives an insight into the autistic experience which is not provided by the current clinical tools used. From experience of clinical practice, Hartman et al. (2023) say that incorporating this insight into the diagnostic assessment allows for a more inclusive assessment and aids the therapeutic relationship. Consistent with other research (Lewis, 2016b), Hartman et al. (2023) explain that dismissing autistic experiences leads to an unpleasant assessment for adults who may be autistic, and a subsequent distrust of healthcare professionals. Therefore, failing to acknowledge an autistic identity negatively impacts the therapeutic relationship. Given that a good therapeutic relationship is implicated with positive clinical outcomes, further support for exploring the concept of autistic identity in clinical practice is provided.

The findings of the scoping review informed the two aims of this thesis, which were: (1) to understand the self-identification process of autism in adults within the UK population, and (2) to use this understanding to develop a screening questionnaire to improve the referral and diagnostic processes for this population of adults who may likely be autistic. In accordance to the findings of the scoping review, I decided to adapt the ASIS (McDonald, 2016) to fulfil the purpose of a screening questionnaire. The findings of the scoping review also provided further support for using The Nine Degrees of Autism (Wylie et al., 2016) as the theoretical framework for the thesis. As discussed in the Introduction (Chapter 1), most research conducted in the UK has used SIT (Tajfel & Turner, 1979) to explain autistic identity (e.g. Cooper et al., 2017; Cooper et al., 2021; Corden et al., 2021). As such, the use of The Nine Degrees of Autism (Wylie et al., 2016) as the theoretical framework was a novel approach. In fact, after a search of the literature only one other study (Lewis, 2016b) that has used or tested The Nine Degrees of Autism (Wylie et al., 2016) could be found. Comparable to the research of this thesis, Lewis (2016b) explored the experience of self-diagnosed autism as an adult.

To further understand the self-identification process of autism in adults within the UK, and to develop a screening questionnaire based on this understanding and feedback on the ASIS (McDonald, 2016), two online focus groups with adults who identified as autistic were utilised. This initiative was extremely relevant from a clinical perspective because it takes into account, in the development of the screening questionnaire, the experiences of adults who self-identify as autistic and adults who self-identified as autistic and have since been formally diagnosed as autistic by a healthcare professional (e.g. clinical psychologist). Although the importance of involving autistic adults in all aspects of the research process has been highlighted (Fletcher-Watson et al., 2019), participatory research as it is referred to, is still uncommon in autism research (den Houting et al., 2020). As a consequence, autistic adults have historically had very little input in research that aims to improve services that impact upon them (Benevides et al., 2020). Perhaps this provides an explanation as to why the development and validation of screening and/or diagnostic tools specifically for the adult autism diagnostic processes are still in their infancy, and why adults may feel that the referral and diagnostic processes of an adult autism assessment do not reflect their lived experiences (Jones, 2022). Therefore, study one of this thesis represented the first step to improving the referral and diagnostic processes of an adult autism assessment from a person-centred approach.

Study one of this thesis also contributed to the psychological wellbeing of the adults who participated. To explain, there is some controversy regarding the phenomenon of self-identifying as autistic (Sarrett, 2016). Although some authors have reported that it is generally more accepted within the autistic population due to the recognised difficulties of accessing an autism diagnostic assessment and being formally diagnosed as autistic (Hartman et al., 2023; Pellicano et al., 2022), controversy still does exist within this population (Sarrett, 2016). For this reason, adults who self-identify as autistic often find themselves excluded from autistic communities (e.g. online forums) that were established to provide support as they do not possess the credentials (i.e. a formal diagnosis of autism) for access (Fletcher-Watson, 2023). Certainly, the controversy surrounding self-identifying as autistic mainly explained why participating in the online focus group was the first time that a number of adults in the first online focus group (adults who self-identified as autistic without a formal diagnosis of autism) had spoken publicly about why they believed that they were autistic. For these adults, participating in the online focus group was a valuable opportunity which was highlighted by comments such as *"the day has been huge for me"* and *"(I'm) grateful for the opportunity. I'm glad I have made a connection with the other participants, which has helped me and will hopefully help each other".* As a result of the first study of this thesis, the adults who participated in online focus group one formed a social media group that enabled them to keep in touch with each other *"(we) are all definitely going to get in touch with each other."*

An aspect that is potentially pivotal in changing opinions on a given disorder/condition, as proposed by Heimberg and Butler (2018) is how well that disorder/condition can be related to by others. Although Heimberg and Butler (2018) made this proposal with reference to social anxiety disorder, it is arguably generalisable. In terms of autism, this is a condition that was historically conceptualised as a disorder of childhood (O'Nions et al., 2023). Although this conceptualisation has evolved over time and autism is now viewed as a lifespan condition (Lord et al., 2018), views of autism held by the lay person seem to predominantly reflect that historical conceptualisation (Huws & Jones, 2011). Consistent with this view, there was consensus amongst the adults in both of the two online focus groups that being an autistic adult just was not understood within wider society. So, as discussed in Chapter 4, participants of the second online focus group (adults who were formally diagnosed as autistic) used the knowledge that they had gained from their diagnosis to educate others (e.g. through discussion with others and by the writing of blogs) in an attempt to change opinions surrounding autism in adults. In line with this viewpoint, the research of this thesis has been communicated to a non-specialist/lay audience throughout the period of my PhD study via my work as a PhD tutor on the Scholars Programme with The Brilliant Club. The Brilliant Club (https://thebrilliantclub.org) is a UK charity that supports less advantaged students access university and succeed at university. To achieve this aim, the Scholars Programme is one of four programmes that The Brilliant Club runs. Students who participate in the Scholars Programme receive university style tutorials and write two assignments (a baseline and final assignment) that incorporate the requirements of university assignments, such as referencing and critical evaluation. To give students a sample of life as an academic, The Scholars Programme has an academic journal ‘The Scholar’ in which a collection of excellent final assignments written by students is published yearly. The Scholar is not an academic journal in the ordinary sense, for example it has no peer review process and it is not a subject specialist journal. However, the selection process of final assignments for The Scholar is designed to replicate the process for academic journal publications in that only the highest quality final assignments are selected for publication. The final assignment of one of my students was selected for publication in the upcoming edition of ‘The Scholar’. As a result of this publication, the research topic of this thesis will reach a different and wider non-specialist/lay audience and academic audience. Encouragingly, findings from the second online focus group and feedback on my PhD course that I do with The Brilliant Club, suggest that overall, this ‘education’ on autism is well received by the general public. Therefore, the concept of autistic identity has the potential to change the views on autism (in general and in adults) held by society and could go some way in reducing the stigma attached to the condition.

Reducing the stigma attached to autism through a wider accurate awareness of the condition in society has been suggested as a better alternative, than expecting autistic individuals to develop a positive autistic identity amidst discrimination from society (Cooper et al., 2023) In line with Social Identity Theory (SIT) (Tajfel & Turner, 1979), participants in both online focus groups spoke of the importance of “social survival” in terms of belonging to a group of people and how masking was often used in an attempt to fit in. However, the perception that participants had of being different to other people coupled with being unaware that they were autistic meant developing a positive social identity was difficult. Consequently, the majority of participants had mental health challenges and were diagnosed with a number of physical and psychological conditions (Tajfel & Turner, 1979). Consistent with McDonald (2020), once participants had the realisation that they may be autistic they choose not to disclose this to others. The majority of participants wanted their autistic identity validated with a formal diagnosis before they considered disclosing it to others, which perhaps is unsurprising given that a formal diagnosis is often the gateway for inclusion to autistic communities (e.g. online forums) (Fletcher-Watson, 2023) that some autistic individuals use to develop a positive autistic social identity (Cooper et al., 2017).

In line with the fourth degree of The Nine Degrees of Autism theory: self-identification (Moore, 2016), once participants self-identified as autistic they all began to evaluate the option of pursuing a formal autism diagnostic assessment and potentially being formally diagnosed as autistic. In accordance to previous research (e.g. Lewis, 2016b), for some participants self-identifying as autistic was satisfactory and for these participants there was no urgency to pursuing a formal diagnosis. Indeed, the findings of this thesis aligned with The Nine Degrees of Autism (Wylie et al., 2016) theory up to and including the fourth degree. At this point, some participants in the first online focus group (adults without a formal diagnosis of autism) spoke about aspects that reflected later stages of the theory. Comparable to the findings of the study by Lewis (2016b), four participants in this first online focus group explained how, and when, they had positively accepted their autistic identity. The Nine Degrees of Autism (Wylie et al., 2016) theory does allude to the potential of attaining later stages of the theory without a diagnosis, but considers this unadvisable. However, Lewis (2016b) implied that self-awareness may be more instrumental than a formal diagnosis in attaining the later stages of The Nine Degrees of Autism (Wylie et al., 2016) and the findings from this thesis would suggest the same. Even so, the majority of adults in the first online focus group discussion wanted to pursue a formal autism diagnostic assessment, but found this to be a challenging task. The challenges of obtaining a formal autism diagnostic assessment were echoed by the adults who participated in the second online focus group discussion. Therefore, the findings suggested a clear need to improve the autism diagnostic pathway for adults.

Following study one of this thesis, the ASIS (McDonald, 2016) was adapted to form the initial screening questionnaire. In accordance to the findings of study one and feedback provided on the ASIS (McDonald, 2016) (e.g. a preference for identity-first language), this co-produced screening questionnaire was named the Autistic Identity Questionnaire (AIQ). This first study of the thesis joins a limited, but increasing body of research that aims to improve the adult autism diagnostic pathway from the ‘bottom up’ (e.g. Cage et al., 2022; Cumin et al., 2022; Ratto et al., 2022). Cumin et al. (2022) aimed to improve the autism diagnostic assessment for women by interviewing healthcare professionals who conduct autism assessments in adults. The other research (Cage et al., 2022; Ratto et al., 2022) aimed to improve the adult autism diagnostic pathway by taking into account the views of adults who were seeking an autism diagnostic assessment in the UK (Cage et al., 2022) and autistic adults (Ratto et al., 2023). Cage et al. (2022) recruited six adults who identified as women to share their experiences of navigating the autism diagnostic pathway in the UK. From this study, Cage et al. (2022) aimed to identify actions needed to improve the autism diagnostic pathway. Under the lead of a team of autistic researchers, Ratto et al. (2023) developed a self-report measure of autistic experiences and traits (The Self Assessment of Autistic Traits

(SAAT)). Ratto et al. (2023) developed the initial measure by leveraging publicly accessible descriptors of autism, and further developed the measure in consultation with autistic experts through two online surveys (Delphi method). Ratto et al. (2023) then invited five autistic adolescents to do cognitive interviewing with the items of the SAAT. The finalised SAAT (Ratto et al., 2023) is a 58- item self report measure of autistic traits that is intended to be completed by individuals who are 16 years of age and older.

The research of this thesis differs from that undertaken by Cage et al. (2022) and Ratto et al. (2023) in a number of aspects. First, the research of this thesis took into consideration the views of adults who self-identified as autistic, but who were not necessarily seeking a formal autism diagnostic assessment, in addition to the views of adults who had been through the autism diagnostic pathway in the UK. Although the adults in these studies predominantly identified as female, adults who identified as male and agender were also included which is an aspect that the study by Cage et al., (2022) is limited by. Second, the product of this thesis (the AIQ) is shorter than the SAAT developed by Ratto et al., (2023). In line with the ASIS (McDonald, 2016), the AIQ can be completed in approximately five to ten minutes, which is advantageous for clinical settings (McDonald, 2017). Finally, the AIQ is solely a measure of the strength of an autistic identity. Although the importance of involving autistic adults in research that aims to improve services for them (Fletcher-Watson et al., 2019; Howlin, 2021) was taken into account in study one of this thesis, it was recognised that the study was not without limitations. So, the AIQ was further developed in conjunction with experts by experience and healthcare professionals who conduct autism assessments in adults. The finalised AIQ is a 20-statement much needed neurodiversity-affirming tool.

The neurodiversity-affirming approach fits with the explanation for the “real success stories” of the two adults that Kanner (1971) detailed in the follow-up study of his case studies of 11 children (Kanner, 1943). Kanner (1971) believed that these two adults were successful because they were able to recognise their strengths and difficulties and had the ability to use them appropriately (Howlin, 2021). Indeed, Howlin (2021) cites Temple Grandin and Greta Thunberg as two examples of autistic individuals who have used their interests and passions to lead to great achievements, interests and passions that are arguably defined as impairments and deficits by the diagnostic criteria (criterion B of the DSM-5) (APA, 2013). Criterion B is restricted, repetitive patterns of behaviour, interests or activities (APA, 2013). Certainly, a criticism of the current diagnostic pathway, and the clinical tools used within this pathway, is that it is deficit-based (Brown et al., 2021; Hartman et al., 2023). As discussed throughout this thesis, there is a growing weight of evidence that provides support for being formally diagnosed as autistic by a healthcare professional (Pukki et al., 2022). One reason for the value of a formal diagnosis is that it is the start of seeing yourself more realistically and positively (Moore, 2016). However, it is difficult to begin to positively accept being autistic when descriptors of autism are referred to as ‘deficits’ and ‘impairments’ (Brown et al., 2021). Compounding this is the potential stigma attached to a diagnosis (Boucher, 2017; O’Reilly et al., 2020), and being autistic (Cooper et al., 2021; McDonald, 2017). However, it is known that the stipulated deficits/impairments can be advantageous strengths (Grandin, 1992; Grandin & Panek, 2013), and that a positive autistic identity can be associated with better psychological wellbeing (Cooper et al., 2017). So, understandably there have been calls for a strengths-based approach to autism assessments (Brown et al., 2021). With this in mind, the use of autistic identity in clinical practice does have potential.

With the lengthy waiting lists for a NHS adult autism assessment, screening tools are often the tools used to manage these lists (Hartman et al., 2023). It is for this reason that Thabtah (2019) said that more efficient screening tools are needed to mitigate these waiting times. So, taken together the AIQ does appear to contribute to the areas of improvement needed in the adult autism diagnostic pathway. Indeed, there have been attempts to develop complementary questionnaires to better understand the presentation of autism. One example is the Camouflaging Autistic Traits Questionnaire (CAT-Q) (Hull et al., 2019). The fact that the CAT-Q (Hull et al., 2019) is now used for research and clinical purposes (Bureau et al., 2023) highlights the benefits of these complementary questionnaires for both purposes. From a clinical perspective, Hartman et al., (2023) state how they have found the CAT-Q (Hull et al., 2019) to be a convenient measure for ascertaining the extent to which an individual is engaging in masking behaviour. So, in terms of the AIQ an important next step was to assess the forms of reliability and validity that were not assessed during the development of the questionnaire, namely discriminant and criterion validity. As discussed in Chapter 6, the findings of these were very satisfactory.

Improving the referral and diagnostic processes with a measure of a different concept is congruous with a recent call for the development of measures that align with the views of autistic people (Jones, 2022). As alluded to earlier in the discussion, Jones (2022) argues that the traditional measures that are deemed to have scientific rigour lack utility because they do not consider the lived experiences of autistic individuals. This may provide an explanation as to why the little practical effort in improving the adult autism diagnostic pathway has so far been ineffective (O’Nions et al., 2023). So, the development of a reliable and valid measure of autistic identity in adults does have the potential to significantly improve the referral and diagnostic processes of an adult autism assessment.

7.1.1 Potential dissemination of findings

With a potentially positive impact on the UK adult autism diagnostic pathway, the findings of this thesis need to be communicated to a wider audience. The usual first step in the dissemination process of research findings is journal article publications. As discussed, the scoping review of the literature on the self-identification of autism in adults (Chapter 2) has been published in the peer-reviewed journal *Review Journal of Autism and Developmental Disorders.* Two further articles from this thesis have been submitted to an autism specific peer reviewed journal for potential publication. The first of these two articles details the generation of items for the AIQ (Chapter 4), and the second details the development and validation of the AIQ (Chapters 5 and 6). To maximise the dissemination of the findings of this thesis to clinical academics and healthcare professionals, the findings should also be presented at a clinical psychology conference (e.g., International Congress of Clinical Psychology). In order to target a different academic audience and a non-academic audience the findings of this thesis should be published in magazines, such as *The Psychologist* (the magazine of the British Psychological Society) and *The Spectrum* (the magazine of the National Autistic Society).

Considering how the findings of this thesis should be disseminated has highlighted how the findings may also have an impact in other contexts, such as parenting and other psychological conditions. The potential implications of the findings for the UK adult autism diagnostic pathway and other contexts will now be discussed.

7.1.2 Implications of findings

With regards to the adult autism diagnostic assessment referral process, the AIQ could be used to obtain valuable information that may not be obtained from the overall AQ-10 (Allison et al., 2012) score, or the questions on the tool. The AIQ could offer the same advantages within an adult autism diagnostic assessment. For instance, the items of the AIQ can be used to initiate a discussion on certain aspects of autistic identity and aid the previously reported difficulties that some adults have in explaining to healthcare professionals why they believe that they could be autistic (Lewis, 2017). Similarly, the AIQ could enable healthcare professionals to understand how their clients see themselves in relation to being autistic (McDonald, 2017). From a clinical perspective, it is sometimes this discussion that comes from the completion of measures that is more valuable than the quantitative results of the measure (Hartman et al., 2023). For example, in a study to validate the CAT-Q (Hull et al., 2019) in French, Bureau et al. (2023) stated how the questionnaire had been instrumental in initiating a discussion between a clinical psychologist and service user about camouflaging. The service user did not realise that camouflaging was a concept. Likewise, in a study to assess the discriminant and criterion validity of the ASIS (McDonald, 2016), McDonald (2017) quoted a participant who said that taking part in the research had helped them talk about being autistic and understand the condition better. The AIQ could, therefore, be beneficial in feedback sessions and post-diagnostic support.

In terms of identity development, adolescence is a key stage (Mesa & Hamilton, 2022). Adolescents are also more influenced by others, such as parents and peers, which may impact upon how they react to a belief that they make be autistic and/or to being formally diagnosed as autistic (Riccio et al., 2021). Riccio et al. (2021) conducted a study to examine how autistic identity in adolescence is influenced by parental disclosure decisions and perceptions of autism, and concluded that parental disclosure of an autism diagnosis should be done intentionally, mindfully and holistically to help adolescents develop a positive autistic identity. However, not all parents may understand autism as a condition or view it positively (Crane et al., 2018; Lewis, 2016b). Therefore, incorporating the AIQ into autism diagnostic and post-diagnostic services for adolescents could be helpful in terms of adolescents (and parents) understanding autism and viewing being autistic more positively.

There have been worldwide calls for improvements to the referral and diagnostic processes of autism assessments (e.g. de Broize et al., 2022; Lupindo et al., 2022) so the findings of this thesis could be of relevance to autism diagnostic pathways in other countries.

The findings of this thesis could also be of relevance to other psychological conditions. Sarrett (2016) stated that the phenomenon of self-diagnosis/self-identification is comparatively unique to autism explaining that a brief look at an online community for schizophrenic individuals did not find anything related to self-diagnosis/self-identification. Still, recent research has highlighted how the concept of identity has implications for schizophrenia. Granello and Gorby (2021) conducted a study to investigate if there would be any attitude differences in how qualified mental health counsellors and trainee mental health counsellors worked with service-users based on the terminology used with regards to schizophrenia. Qualified mental health counsellors and trainee mental health counsellors were randomly sent one of two versions of the Community Attitudes Toward the Mentally Ill (CAMI) (Dear & Taylor, 1979) that either used the terminology “person with schizophrenia” or “schizophrenic”. Granello and Gorby (2021) found that the term “schizophrenic” elicited attitudes that were less benevolent and more authoritarian and socially restrictive in both qualified and trainee mental health counsellors, and concluded that the study provides the first empirical evidence for removing the term “schizophrenic” from use in clinical practice. However, in a mixed methods study to understand how young adults (college undergraduates) perceive different diagnostic labels in regards to autism (autism, autistic, autism spectrum disorder, or Asperger’s), schizophrenia (schizophrenia or schizophrenic) and to another unspecified clinical condition (clinical diagnosis or clinical disorder), Jones and Sasson (2023) found no significant differences in perceptions for person-first and identity-first language within diagnostic labels. The findings of the studies by Granello and Gorby (2021) and Jones and Sasson (2023) may be explained by the difference in preferences for person-first language and identity-first language between healthcare professionals and others, such as individuals with the condition (Kenny et al. 2016). Nonetheless, it is important to understand how the concept of identity relates to different psychological conditions to ensure that individuals who seek help are treated with the respect that they deserve.

The findings of this thesis have clear implications for the adult autism diagnostic pathway, clinical contexts and other contexts in the UK and beyond. However, the research does have limitations and these will be stated before discussing how the implications of the findings of this thesis could be addressed by future research.

7.1.3 Strengths and limitations

The use of online data collection methods throughout this thesis has many advantages. Firstly, taking into account that adults who identify as autistic are a' hard-to reach' population (Beadle-Brown et al., 2012; Lewis, 2016a), utilising online data collection methods meant that participants could be recruited from a larger sampling frame (Spain & Happé, 2020). Furthermore, adults who are, or who may likely be autistic, tend to prefer online communication. Thus, online data collection methods were deemed to maximise participation for all three studies of this thesis. However, online data collection methods also have limitations. For example, the fact that the AIQ has only been administered online to date may have impacted how adults have completed it (Coolican, 2019).

Consistent with the need to incorporate the views of autistic individuals in order to develop an informative questionnaire (Kazdin, 2022; Pukki et al., 2022), a further strength of this thesis is the inclusion of adults who identify as autistic throughout the development of the AIQ. Though, it is acknowledged that the thesis is limited by not including adults who identify as autistic in all aspects of the AIQ development (Pukki et al., 2022). For example, by including adults who identify as autistic in the decision-making processes would have undoubtedly enhanced these processes.

Despite failing to include adults who identify as autistic in the decision-making process, procedures were put in place to mitigate against any bias in the decision-making process, and to ensure that these processes were as objective as possible. As discussed in Chapters 4 and 5, decisions regarding the initial adaptations to the ASIS (McDonald, 2016) to form the AIQ, and subsequent decisions in the development of the AIQ were independently undertaken by me and Dr Ferran Marsà-Sambola. It is acknowledged that this combined knowledge could be viewed as both a strength and limitation. To explain, we both have experience of working with autistic individuals and are aware of the difficulties that adults may encounter with the autism diagnostic pathway. Though, the fact that I lack clinical experience meant that my decisions were not influenced in anyway by clinical procedures. However, it also meant that I would not be potentially aware of the practical real-world application of the AIQ. This was counter balanced by Dr Ferran Marsà-Sambola who, as a clinical psychologist, was aware of these practicalities.

Despite the findings of the development and initial validation of the AIQ being very promising, it is recognised that questionnaire development is an ongoing process that goes beyond the scope of this thesis.

7.1.4 Future research

To re-iterate what DeVellis and Thorpe (2022) point out, validity is not an attribute of a questionnaire itself but of how a questionnaire is used. The AIQ was developed for the intention of being used as a complementary screening tool alongside the existing clinical tools used within the UK adult autism diagnostic pathway, such as the AQ-10 (Allison et al., 2012) and the RAADS-R (Ritvo et al., 2011). Therefore, the AIQ would need to be administered in clinical settings (e.g. in GP surgeries; in an adult autism assessment) to ascertain the validity of the AIQ for the purpose for which it was developed.

In terms of post-diagnostic support in the UK, future research could incorporate the AIQ into adult autism feedback sessions with the purpose of aiding adults to positively accept their autistic identity. Expanding the use of the AIQ to the UK autism diagnostic pathway for young people should be another consideration for future research, given the benefits of a positive adolescent autistic identity for adulthood.

Future research should ensure that the AIQ is administered in face-to-face scenarios to check for consistency in online and offline responses (Coolican, 2019). Although Coolican (2019) states that participants tend to be more honest when completing online questionnaires, this is certainly an aspect that warrants exploration and clarity.

The AIQ could also be validated in other populations (e.g. in other countries) to determine whether there are cultural differences in the self-identification process of autism, and whether the AIQ could be used more widely. The fact that the CAT-Q (Hull et al., 2019) has been validated in three other populations (Dutch, Italian and Japanese) (Bureau et al., 2023) suggests that there is a need for complementary screening questionnaires within the autism diagnostic pathway beyond the UK. Indeed, despite any differences in the diagnostic pathway across countries, the limitations of the pathway appear to be strikingly similar. Furthermore, given that cultural differences were found with regards to autistic camouflaging, when the CAT-Q (Hull et al., 2019) was validated in Japan (Bureau et al., 2023), it may be that cultural difference exist in the self-identification process of autism also.

To date, research on the self-identification process of autism in adults has predominantly been conducted with Western populations (Lewis, 2016b; Lewis, 2017), particularly America (Lewis, 2017; McDonald, 2020). As such, there are a number of populations in which this process has received minimal research attention, or has not been researched at all. Some autistic adults have argued that self-identifying as autistic, and the motivation for a formal diagnosis of autism, has been fuelled by a number of high-profile people sharing their own journeys to realising that they were autistic (e.g. celebrities) (Sarrett, 2016). So, it would be interesting to ascertain if the process of self-identifying as autistic is universal, or if it is indeed population specific.

The concept of identity should be researched with other psychological conditions given the implications of the concept of identity on how individuals are potentially treated by healthcare professionals, as discussed earlier in this Chapter. To ensure that individuals who access clinical services are treated with the respect that they are entitled to and deserve, research in this area is vital.

Self-identifying as autistic remains a contentious topic within the realms of professional services, such as clinical and research settings (Pellicano et al., 2022). However, the predominant amount of research surrounding the views of healthcare professionals on self-identifying as autistic has come from the perspectives of adults who self-identified as autistic (e.g. Lewis, 2017), although recent literature has begun to refer to, and explore, the perspectives of healthcare professionals on self-identifying as autistic (e.g. Cumin et al., 2022; Hartman et al., 2023). Consistent with other literature (e.g. Hartman et al., 2023), Cumin et al. (2022) found that many adults who were presenting for an autism diagnostic assessment were already identifying as autistic. In several assessments, this self-identity as autistic was correct and a formal diagnosis of autism was given (Cumin et al., 2022; Hartman et al., 2023). Nevertheless, healthcare professionals raised concerns surrounding the extent of research that adults had undertaken to come to self-identify as autistic, which they felt hampered the assessment process (Cumin et al., 2022). Additionally, healthcare professionals reported that self-identifying as autistic became problematic if adults were not formally diagnosed as autistic (Cumin et al., 2022). Obviously, if the adult autism diagnostic pathway is to be improved, healthcare professionals play a key role in implementing this improvement and it is important that their views are taken into consideration. From the perspective of a healthcare professional, it is known that autism shares a number of similarities with other conditions, such as personality disorder (Lai & Baron-Cohen, 2015). So, a key task within an autism assessment is to distinguish between autism and another condition. In Cumin's et al. (2022) study, healthcare professionals reported that adults tend to view a diagnosis of autism as more socially acceptable compared to a mental health condition. So, despite the very clear advantages of incorporating the concept of autistic identity within clinical practice, it is evident that this may need to be balanced with an element of caution. For this reason, future research should specifically investigate the views on self-identifying as autistic held by healthcare professionals who conduct adult autism assessments, and the reasons for their views.

Similar to the approach taken in this thesis, research investigating the views on self-identifying as autistic held by healthcare professionals could begin by conducting a scoping review on the subject. By doing so, a clearer picture of what is known on this area would be ascertained, as well as where future research would be best directed.

Conclusion

In sum, this thesis began with a scoping review of the literature on the self-identification of autism in adults, which addressed a gap in the research and contributed to knowledge through publication in a peer-reviewed journal. The findings of the scoping review informed the aims of the thesis and how the aims of the thesis would be accomplished, which ensured that the thesis continued to contribute to knowledge by building upon current research conducted on the self-identification of autism in adults.

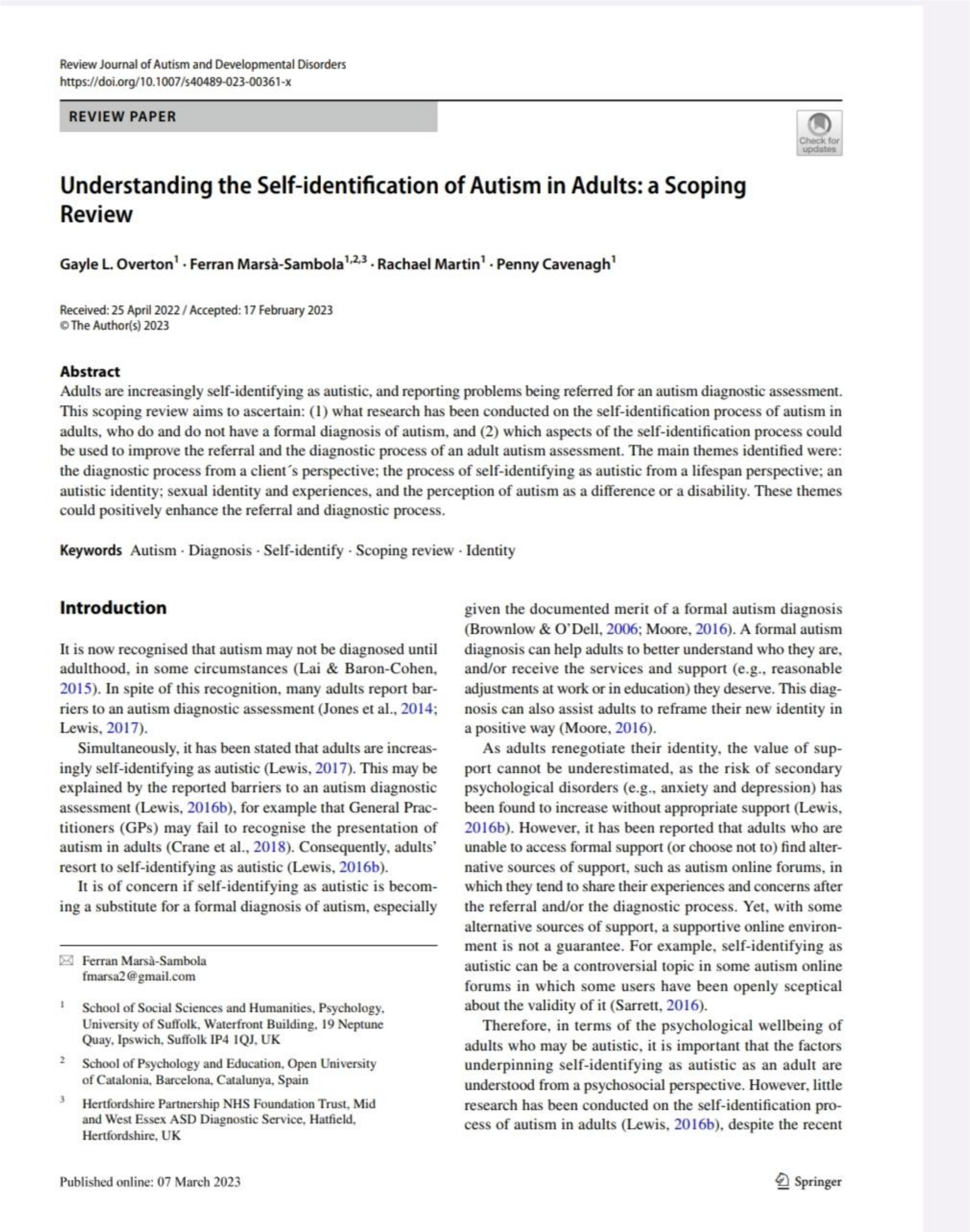
Building upon the current research on the self-identification of autism in adults, this thesis used the findings from two studies to address the need to improve the UK adult autism diagnostic pathway from a person-centred approach and in a neurodiversity-affirming manner. The product of this thesis was a short questionnaire to assess autistic identity in adults; the Autistic Identity Questionnaire (AIQ), which has the potential to be used as a complementary screening tool alongside the existing clinical tools used within the UK adult autism diagnostic pathway, such as the AQ-10 (Allison et al., 2012) and the RAADS-R (Ritvo et al., 2011).

By making a practical effort to improve the UK adult autism diagnostic pathway this thesis makes a rare contribution. The initial analyses of the reliability and validity of the AIQ were very satisfactory, so the validity of the AIQ for its intended purpose should now be assessed by the trialling of the questionnaire in clinical settings. The trialling of the AIQ in clinical settings should be accompanied by research investigating the views of healthcare professionals on self-identifying as autistic, which together could pave the way for a meaningful practical improvement to the autism diagnostic pathway for adults within the UK.

The findings of this thesis have clear implications for clinical and other contexts within the UK and beyond. These implications should be a priority for future research, given the favourable outcomes that can result from understanding and positively accepting all aspects of our identity that makes us who we are.

Appendices

Appendix A. Publication of scoping review (Chapter 2).



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REVIEW PAPER

Understanding the Self-identification of Autism in Adults: a Scoping Review

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Abstract
Adults are increasingly self-identifying as autistic, and reporting problems being referred for an autism diagnostic assessment. This scoping review aims to ascertain: (1) what research has been conducted on the self-identification process of autism in adults, who do and do not have a formal diagnosis of autism, and (2) which aspects of the self-identification process could be used to improve the referral and the diagnostic process of an adult autism assessment. The main themes identified were: the diagnostic process from a client´s perspective; the process of self-identifying as autistic from a lifespan perspective; an autistic identity; sexual identity and experiences, and the perception of autism as a difference or a disability. These themes could positively enhance the referral and diagnostic process.

Keywords Autism · Diagnosis · Self-identify · Scoping review · Identity

Introduction

It is now recognised that autism may not be diagnosed until adulthood, in some circumstances (Lai & Baron-Cohen, 2015). In spite of this recognition, many adults report barriers to an autism diagnostic assessment (Jones et al., 2014; Lewis, 2017).

Simultaneously, it has been stated that adults are increasingly self-identifying as autistic (Lewis, 2017). This may be explained by the reported barriers to an autism diagnostic assessment (Lewis, 2016b), for example that General Practitioners (GPs) may fail to recognise the presentation of autism in adults (Crane et al., 2018). Consequently, adults' resort to self-identifying as autistic (Lewis, 2016b).

It is of concern if self-identifying as autistic is becoming a substitute for a formal diagnosis of autism, especially given the documented merit of a formal autism diagnosis (Brownlow & O'Dell, 2006; Moore, 2016). A formal autism diagnosis can help adults to better understand who they are, and/or receive the services and support (e.g., reasonable adjustments at work or in education) they deserve. This diagnosis can also assist adults to reframe their new identity in a positive way (Moore, 2016).

As adults renegotiate their identity, the value of support cannot be underestimated, as the risk of secondary psychological disorders (e.g., anxiety and depression) has been found to increase without appropriate support (Lewis, 2016b). However, it has been reported that adults who are unable to access formal support (or choose not to) find alternative sources of support, such as autism online forums, in which they tend to share their experiences and concerns after the referral and/or the diagnostic process. Yet, with some alternative sources of support, a supportive online environment is not a guarantee. For example, self-identifying as autistic can be a controversial topic in some autism online forums in which some users have been openly sceptical about the validity of it (Sarrett, 2016).

Therefore, in terms of the psychological wellbeing of adults who may be autistic, it is important that the factors underpinning self-identifying as autistic as an adult are understood from a psychosocial perspective. However, little research has been conducted on the self-identification process of autism in adults (Lewis, 2016b), despite the recent

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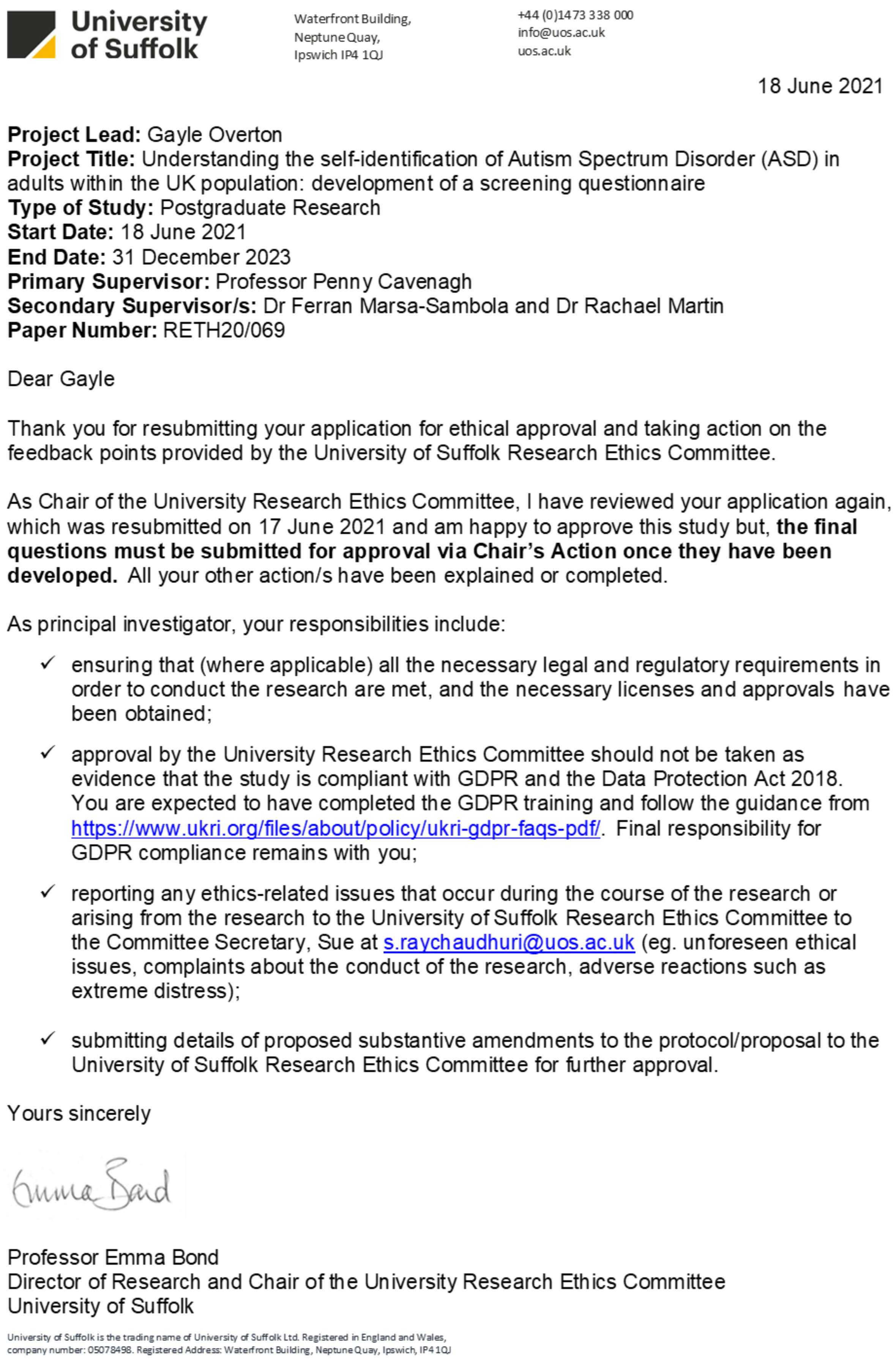
Appendix B. Initial ethical approval



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18 June 2021

Project Lead: Gayle Overton
Project Title: Understanding the self-identification of Autism Spectrum Disorder (ASD) in adults within the UK population: development of a screening questionnaire
Type of Study: Postgraduate Research
Start Date: 18 June 2021
End Date: 31 December 2023
Primary Supervisor: Professor Penny Cavenagh
Secondary Supervisor/s: Dr Ferran Marsa-Sambola and Dr Rachael Martin
Paper Number: RETH20/069

Dear Gayle

Thank you for resubmitting your application for ethical approval and taking action on the feedback points provided by the University of Suffolk Research Ethics Committee.

As Chair of the University Research Ethics Committee, I have reviewed your application again, which was resubmitted on 17 June 2021 and am happy to approve this study but, **the final questions must be submitted for approval via Chair's Action once they have been developed.** All your other action/s have been explained or completed.

As principal investigator, your responsibilities include:

- ✓ ensuring that (where applicable) all the necessary legal and regulatory requirements in order to conduct the research are met, and the necessary licenses and approvals have been obtained;
- ✓ approval by the University Research Ethics Committee should not be taken as evidence that the study is compliant with GDPR and the Data Protection Act 2018. You are expected to have completed the GDPR training and follow the guidance from https://www.ukri.org/files/about/policy/ukri-gdpr-faqs-pdf/. Final responsibility for GDPR compliance remains with you;
- ✓ reporting any ethics-related issues that occur during the course of the research or arising from the research to the University of Suffolk Research Ethics Committee to the Committee Secretary, Sue at s.raychaudhuri@uos.ac.uk (eg. unforeseen ethical issues, complaints about the conduct of the research, adverse reactions such as extreme distress);
- ✓ submitting details of proposed substantive amendments to the protocol/proposal to the University of Suffolk Research Ethics Committee for further approval.

Yours sincerely

Emma Bond

Professor Emma Bond
Director of Research and Chair of the University Research Ethics Committee
University of Suffolk

Appendix C. The email sent to participants with the link to the online focus group and guidance on using Google Meet

Dear (*populated with name of participant*),
I hope this email finds you well.
I am sending you this email to invite you to the focus group that will be held on Tuesday 11th January 2022 at 14:00/Tuesday 8th February 2022 at 14:00 (*amended to state the date and time of the focus group that the participant was attending*).
You will be able to join the meeting by accepting this invite and clicking "Join with Google Meet".
Alternatively, you can join the meeting by coping and pasting the link (below) on your web browser.

Video call link: (*populated with the call link to the focus group that the participant was attending*).
If you are not familiar with the use of Google Meet, please watch this video (https://www.youtube.com/watch?v=X4jAvaX73-U) before the meeting.

Please find attached to this email 'a guide of what to expect' during the focus group, which briefly outlines the structure and topics of the focus group.

Me and Ferran look forward to seeing you at the focus group, but please do not hesitant to contact me if you have any questions in the meantime.

Best wishes,
Gayle

Appendix D. The ‘guide of what to expect during the online focus group’ sent to participants before the online focus group.

A guide of what to expect in the group discussion

The group discussion will begin with an introduction to me (Gayle) and my research supervisor (Dr Ferran Marsà-Sambola). The introductions will be followed by a reminder of what your participation in the research will involve (for example, that the discussion will be recorded and what to do if you decide that you do not wish to continue participating) and there will be an opportunity to ask questions before we begin.

The group discussion will then move onto the aims of the discussion, which are to understand: 1) the reason(s) why some adults, who may likely be autistic, self-identify as autistic and 2) the reason(s) why self-identifying as autistic may or may not be an end point for adults.

Previous research (for example, Lewis, 2016b; Lewis, 2017) and a theoretical framework called The Nine Degrees of Autism (Wylie et al., 2016) have suggested that some factors may be associated with self-identifying as autistic at different times.

I am interested in how you would define the self-identification of autism in adults.

I am also interested to find out if there are any other factors/aspects that should be included.

The group discussion will follow the schedule below:

Prior to the self-identification of autism.

For example;

Awareness of being ‘different’ from others.

Use of coping strategies

Copied others.

Secondary psychological/health conditions

Anxiety

How would you define the time prior to the self-identification of autism in adults?

Are there any other factors/aspects that should be included?

Route to the self-identification of autism.

For example;

Having a chance encounter with a description of autism (for example, in the media).

How would you define the route to the self-identification of autism in adults?

Are there any other factors/aspects that should be included?

Confirming the self-identification of autism.

For example;

Used online forums.

How would you define confirming the self-identification of autism in adults?

Are there any other factors/aspects that should be included?

Now I identify as autistic, I feel ……

For example;

I understand myself.

How would you define the feeling of self-identifying as autistic in adults?

Are there any other factors/aspects that should be included?

Now I identify/identified as autistic, I would be/was ……

For example;

Concerned about how others in my life will/would react.

Hesitant about going for a formal diagnosis

Distrust healthcare professionals.

Willing to go for a formal diagnosis

To validate the self-identification of autism.

How would you define the time after the self-identification of autism in adults?

Are there any other factors/aspects that should be included?

Deciding to go for a formal diagnosis of autism.

For example;

I saw my General Practitioner (GP).

How would you define the decision to go for a formal diagnosis of autism, after the self-identification of autism in adults?

Are there any other factors/aspects that should be included?

The Autism Spectrum Identity Scale (ASIS) (McDonald, 2016)

The Autism Spectrum Identity scale (ASIS) (McDonald, 2016) was devised to assess how adults identify with autism and how this may be associated with wellbeing and independence.

Do any of the statements relate to the self-identification of autism in adults in the UK?

1) I feel like I only have autism in certain activities, like completing work, organizing, getting ready to go somewhere, or new activities.
2) There is little I can do about my autism.
3) I am good at some things because I have autism.
4) There are some people with whom I don't feel I have autism.
5) Autism only makes things harder for me.
6) I like having autism or being autistic.
7) My good qualities have little to do with autism.
8) I feel like I only have autism around certain people, like classmates, teachers, parents, or co-workers.
9) I feel autism has more benefits in abilities than challenges.
10) If I work hard enough, I can minimize my autism.
11) I would be better off if I didn't have autism.
12) I like the way I am different from everyone else.
13) I feel like I only have autism in certain places, like school, home, work or somewhere new.
14) When I'm alone, I don't feel like I have autism.
15) Autism means having unique abilities.

16) If I work hard enough, I can minimize the challenges associated with autism.
17) There are some places where I don’t have Aspergers/autism.
18) If I were cured of autism, I wouldn’t be me anymore.
19) I don’t feel I have additional abilities from my autism.
20) I only “have autism” when people treat me like I do.
21) I am better off because I have autism.
22) My strengths have little to do with autism.

The discussion will end with a reminder of the aims of the group discussion (to understand: 1) the reason(s) why some adults, who may likely be autistic, self-identify as autistic and 2) the reason(s) why self-identifying as autistic may or may not be an end point for adults). You will also be given the opportunity to ask any questions that you may have about your participation in the group discussion.

Finally, the debrief sheet that will be emailed to you after the group discussion will be explained and the discussion will finish.

Appendix E. Qualitative responses on the Autistic Identity Questionnaire (AIQ) from the first round Delphi

Initial Statements	Clearness of statement	Representativeness of statement	Summary of reviews	Revised statement
Being autistic is only noticeable in certain activities, like completing work, organising, getting ready to go somewhere, or new activities.	Sometimes being autistic is very evident - particularly with people with severe / profound intellectual disabilities. I think that being autistic can be chatersized by liking certain activties or becoming ingrained in such acitivty, however in my expierence new activities cause alot of uncertainy and stress so this would be noticeable in a different way. It's always there and It's there to all to see despite attempts to hide it. It all depends on the observer, if they are bothered or if the expression is more noticeable. I think I am always aware I'm autistic. I would probably say 'more noticeable'.	I agree that for me, these activities are particular problem areas, I would say that the list of issues is much wider - I agree but the list is too narrow to have true meaning. To me it's not something I 'feel' or I don't. But yes, certain activities exacerbate my stress levels, coordination, sensory processing etc I'm sorry, I have no idea what you mean by it's representativeness of self-identification. I will submit this as I don't want to waste my answers to part 1, having spent this much time on it, but can't answer this question. Represents SI in ASD adults well. haven't you asked me this already? if you are wanting me to generalise	There was a consensus that being autistic is noticeable in the listed activities. However, the listed activities were considered too limited and seemed to make the statement less clear. There was also confusion as to who was noticing being autistic.	**For me, being autistic is more noticeable in certain activities.**

	I think you lose clarity from adding the list at the end. Do you mean 'My autism is only noticeable in certain activities...'? Or are you after their thoughts about autism in general? Very clear I recommend removing the comma after "activities". unclear - sorry I don't know what this means, noticeable to who exactly? Are you assuming the person is already sure they are autistic? please note I'm a clinician but am also autistic myself - it was not possible to tick both options in your questionnaire.	to ALL autistic people, that's impossible surely. I do follow up appointments with clients post-diagnosis, they vary a great deal from each other in their feelings about the diagnosis.		
Being autistic means that I am good at some things.	Not all autistic people recognise their own strengths. Particularly those who are more passive. I think it is nice to remember that not everyone that is autistic is bad at things and this	I use my gift to help me do my work. It's taken years but I have found something where my ASD can be put to good use. It should be seen as a positive thing.	There was a consensus that the statement was clear and representative of self-identifying as autistic as an adult. However, it was noted that this could depend upon the person.	**For me, being autistic means that I am good at some things.**

	questions makes me feel good to be autistic. I use my ASD as my super power - In the role I find myself, my intense interest can be put to good use. Outside work and hobbies, the intensity is also my kryptonite. fairly clear. Clear, though it could depend on the person. is this the 'autistic superpower' notion - could be a bit misleading I think	I tend to use the word strengths as 'good' I assume is subjective? Represents SI in ASD adults well.		
With some people I don't notice being autistic.	Sometimes people say I am rude and that as I can talk and walk they assume i cannot be autistic because i function so although people might not notice it i think it more down to ignroance. I think I am more sensitive to other people with ASD - they have more in common with me than neurotypical folk.	I think some people treat me right and so my stress reduces, I can relax and can be more myself without being so self conscious. They understand me so I can less vigilant. Others just don't care. I'm not sure the question is helpful. I can't really answer because the minute I need to speak or listen to someone I struggle	The statement was considered reasonably clear and representative. However, the value of the statement was questioned, and responses to later statements suggested some overlap with this statement.	**Remove the statement.**

	I feel this sentence comes across as a little confusing. Are the people autistic or me? Maybe 'I'm not aware of being autistic when I'm around certain people'. usually only when I'm around other neurodivergent people. If I am around neurotypical people I definitely notice that I'm autistic. fairly clear Very clear	sensory wise and a wave of panic flows over me - it's even exhausting speaking to my partner! I guess for me it's more so feeling less pressured or less stressed around some people! Represents SI in ASD adults well.		
Being autistic makes life harder for me, like being lonely, or struggling in society.	I feel people do not understand me, they see me needing to mould into society but i cannot. Yes - it's difficult to relate - I have acquaintances and few friends. lonely is a term that is likely to confuse people Very clear. not sure what you are getting at with this statement really	rejection and standing out from society makes one feel isolated and misunderstood. It's obvious! Represents SI in ASD adults well. depends on the context and environment	There was a consensus that the statement was clear and representative. However, it was noted that it could be context dependent and the term lonely had the potential to cause confusion.	**For me, being autistic generally makes life harder in society.**

I like being autistic.	The people I've assessed have mixed feelings about being autistic. Some like it and feel proud of it and others don't it gives me a sense of belonging and understanding why i find some things different There is nothing to like - it's my reality. I ponder wishing to be normal but then that would change me as a person - I am me - warts and all Clear Very clear. also seems rather an odd statement - are you asking whether or not I see autism as a positive identity label? or whether I'm just contented being me?	not really - give me a magic pill to make me normal - if you did, I wouldn't be me though. So on balance, I may not like it but it's my reality. I thing I find is with this statement is that someone would more than likely identify because of their struggles and difficulties - so how this would come high up in a rated scale? Represents SI in ASD adults well. varies a great deal, some love the identity some dislike it	There was a consensus that the statement was clear. However, it was noted that it could very much depend upon the person. Furthermore, regardless of whether an individual liked or disliked being autistic, it was the reality.	**I am contented with being autistic.**
Being autistic means that I am not good at some things.	I nearly scored this "Neutral" but changed my mind - this depends on the person.	On balance, one has to have challenges to offset the gifts.... The trick is to manage the challenges to minimise impact and emphasize the gifts. This	There was a consensus that the statement was clear and representative. However, based on the comments, the statement	**For me, being autistic means that I find some things harder in life.**

	I am aware I struggle with daily task such as washing, socialsing eating certain foods emotions of others can be a mystery. Communication face to face can be difficult and stressful. not being good at some things tends to be judged by neurotypical standards. I used to think I was not good at a lot of things but have spent time, through my work as a professional working in a diagnostic service and an autistic person, reflecting on what expectations there are and if they are a fair judge of what I am, and am not good at. not so clear. Very clear. This almost seems redundant with the statement "Being autistic means that I am good at some things.".	question is apt but emphasizes the stigma of ASD Represents SI in ASD adults well. most autistic people I think would readily admit to being rubbish at some things	could be improved by being reworded slightly. For example, taking note that the statement could vary between people.	

Being autistic is only noticeable around certain people, like classmates, teachers, parents, or co-workers.	I think this applies to some but not all people - though in an environment where an autistic person feels secure and relaxed and people know them better, their autism may not be so noticeable I think strangers can notice autism if the adult is stimming or wearing headphones. It depends - It's more visible the longer one is exposed to them. Most people don't care and others will vote with their feet and ignore you and regard you as "difficult" I would change to '...when I am around certain people...' As before, if my co workers are also neurodivergent (which they are) then it is not noticeable because we have a shared experience of the world. like qu 1, are you after their thoughts about themselves	Those that have higher exposure have the opportunity to notice more. The question answers itself by being too specific. Represents SI in ASD adults well. too vague a statement, noticeable to who?	The statement was considered reasonably clear and representative. However, the listed examples were considered too specific and seemed to make the statement less clear. There was also confusion as to who was noticing being autistic.	**For me, being autistic is more noticeable around certain people.**

	and their autism or about tehri thoughts about autism in general? Not very clear, losing the list would make it much clearer. Very clear. This seems to overlap with "With some people I don't notice being autistic.". would help to clarify who is noticing what here, you could be oblivious yourself!			
Being autistic does not make life challenging.	Well it's not being autistic itself; it's society being unequal. I feel like this could be confusing and become a double negative. Much clearer to comment on 'being autistic makes my life challenging Alot of things that most neuro diverse adults can do I cannot things like going on a train by self is something I cannot complete. Every day is a challenge - the trick is to not let the challenge overwhelm	It's challenging... my aim is to make it less challenging to improve my quality of life. A daft question for someone who has ASD. Anyone with mental health or physical health issues finds life challenging. The question confirms the obvious, it does not add anything. I'd like to see this the other way round that it 'does make life challenging', again it's having to think in reverse!	Overall, there was the consensus that the statement was confusing. It was also noted that the statement was not considered particularly valuable.	**Remove the statement.**

	otherwise the only way to cope is to switch off and disengage. I had to think about this for a bit to work out where the assertion was (realised it means there are no struggles being autistic). Could it be changed to 'makes life challenging', then the relevant score taken from that? The world is designed by and for neurotypical people, so yes it can be very challenging. And often doesn't make sense. fairly clear Very clear this is context dependent surely - how can we generalise? in the right environment being autistic is fine.	Represents SI in ASD adults well. if you are wanting me to generalise to ALL autistic people, that's impossible		
I have tried to minimise being autistic.	I don't feel that it is clear if the question is referring to masking autistic traits, or developing coping mechanisms for them	I have to survive - perhaps the question discriminates between those who can function at a higher level and those	There was a consensus that the statement was reasonably clear and representative.	**I have always masked to hide being autistic.**

	Quite a lot of the people I have assessed use camouflaging to minimise some of their autistic traits When in public places or a work setting I try to reduce my stimming although sometimes this causes physical pain but I know that people will look at me like im wierd if im stimming. I work on it to minimize the impact of my condition - it's something I can manage if those around me make a few adjustments. Then life is much easier and autism isn't an issue. It's only an issue when things go wrong. Very much so in the past, which led to challenges with mental health and burnout. not clear. What does minimise mean? try hide, cover up, mask or make adjustments, or ideally use more than one.	that can't and need more help. Represents SI in ASD adults well. i've a problem with the word 'minimise', unclear what you mean	However, it was noted that the majority of responses did not consider the term minimise appropriate. The suggested alternative was masking.	

	Very clear I don't know how it would be possible to "minimize" autism. Maybe you can rephrase this? not sure what is meant by minimise being autistic, do you mean masking traits?			
I would prefer not to be autistic.	Can't say one way or another I would prefer the public to be more udnerstanding of what it means to be autistic. Who really wants to be the odd one out? But I have previously said that it is who I am so it's only a bit of an agree... I love my way of perceiving the world and I wouldn't change it. Clear Very clear I fear this could offend people, it sounds to me like	My ASD is part of me so yes, I prefer to be normal but I also prefer to me myself. Perhaps this question probes the person's understanding of self. Represents SI in ASD adults well. unable generalise to ALL autistic people, that's impossible, but I think many would find the statement offensive	The statement was considered reasonably clear. However, it was noted that several comments included the fact that being autistic was who they were. As such, it was considered a difficult question to answer. There was also a concern that the statement had the potential to cause offence to several people.	**Remove the statement.**

	'I would prefer not to be me', maybe you could put a more specific question here singling out some aspect of autism?			
I like the way I am different from everyone else.	"If you know one autistic person, you know one autistic person" I do believe some traits of my autism are like my superpower knowing that I notice the small details. I don't wish to stand out but sometimes I do. I do not feel comfortable being in the limelight. I am not difference from everyone else, I have many friends and colleagues who are also neurodivergent who I don't feel different from. clearish - maybe 'I like being different from everybody else'. 'the way I'm different' isn't the same as 'being different' - which one are you interested in here? Very clear	I prefer not to stand out. I am not an extrovert so perhaps the question is there to weed out the extroverts. Represents SI in ASD adults well. everyone?	There was a consensus that the statement was reasonably clear and that difference was reasonably representative. However, it was noted that "from everyone else" was not appropriate. A couple of responses included the reason that, with other neurodivergent individuals, there was no feeling of being different.	**I like the way that I am different from neurotypical people.**

	'everyone else' - there are a lot of neurodivergent people around, it may be clearer to put 'different from neurotypical people'			
Being autistic is only noticeable in certain places, like school, home, work or somewhere new.	I think I have commented on this before This feels similar to the first question and I had to scroll up to check, might be best to move it to follow on from first question to save scrolling I think its noticeable at home too, but more so notiable when I have heightned anxiety. ADS is not just for school - it's for life. Silly question. I find it more noticeable in a stressful environment. Minimize the stress and the ADS visibility shrinks in sympathy. as with previous questions like this one, see above Very clear	as a HF, it's always there - it's more noticeable in these specific areas. Perhaps the question should be phrased "more noticeable". Represents SI in ASD adults well. who's noticing what exactly?	There was a consensus that the statement needed to be rephrased to be clearer and more representative. Suggestions included amending the statement to ‘more noticeable’ and being more specific as to who is noticing being autistic.	**For me, being autistic is more noticeable in certain environments.**

	would help to clarify who is noticing what here, or maybe specify 'feeling autistic is very noticeable to me when I am in an unfamiliar environment'			
When I'm alone, I don't notice being autistic.	I couldn't say for all the people I've assessed. I notice the autism when I am doing things like watching tv I like to have the tv on even numbers. I am aware of myself despite being alone. If I let go of my control then my behaviour would become unacceptable. So in case I slip, it's a 24/7 effort. There is no remission for ASD. Sometimes if I'm struggling to work something out and I realise it is not a good fit for my autistic way of thinking, then I do notice that I'm autistic. Clear Very clear	I feel "less" when I am alone. I don't feel autistic at all - I just feel "me". I am not defined by a label. I can feel less aware of my issues. My ASD makes life different and all being alone does is remove the need to explain and be extra vigilant. I'm less stressed when alone which would be more relevant in my case. There is no sensory stimuli etc. Represents SI in ASD adults well.	There was a consensus that the statement was clear and representative. However, it was noted that being autistic was always noticeable, so less noticeable may be more appropriate.	**For me, being autistic is less noticeable when I'm alone.**

Being autistic means having unique abilities.	I am able to notice small details others are not, i am able to persure strong passions Everyone has talents. Some are obvious, some are useful, some are a burden. Play the hand we have and make it work. fairly clear Very clear again, I'm a quite uneasy about the 'unique/special/superpower' idea, most autistic people i meet are really very ordinary [myself included]. or are you just trying to figure out if people entertain these notions?	It can mean this but not in every case. The question seems to propagate a stereotype that perhaps is too rigid for ASD. Spectrum is the operative word. Again, I rather 'strengths' as not sure whether this terminology feeds stereotypes. Represents SI in ASD adults well.	The statement was considered clear and representative. However, it was noted that the statement could be improved by being reworded slightly. For example, there were concerns that the statement could reinforce the ASD stereotype.	**For me, being autistic means having useful abilities.**
Trying to minimise being autistic leads to a breakdown.	May not always lead to a breakdown, but can do so I find if i cannot stim i end up being angry or crying this then leads to me taking it out o other people and getting into arguments	it can break some - depends if they have support, understanding and space. The question amplifies a stereotype that we all break down.it "can" lead to breakdown. I don't think I can minimise as it's still there.	There was a consensus that the statement was representative. However, the majority of responses did not consider the term minimise appropriate. Masking was the suggested alternative.	**For me, masking my autistic traits can lead to meltdowns and/or shutdowns.**

	It's hard to keep things toned down. I do it because it's less stressful for me and others. It's an effort though and I have to balance control with my own capacity to do it. If I break down then I have no control at all. It needs a balance and I've made lots of mistakes in finding my happy place. again - hide, cover up or mask is clearer than minimise; or perhaps you want to ask 'trying to be like everyone else' or 'trying to fit in'? Maybe differentiate between breakdown, shut down and meltdown. Again, I don't know how it would be possible to "minimize" autism. this is so strongly worded - a breakdown?! do you mean 'masking autistic traits causes me to feel stressed and can lead to meltdowns' ?	Camouflage or mask I feel might be more relevant? I get what the statement is saying though! Represents SI in ASD adults well. see previous comment re wording	Furthermore, it was suggested to add ‘can’ and differentiate between breakdown, meltdown and shutdown.	

Being autistic is easier in some places, like working with other autistic individuals or being with family.	I find sometimes if you are with other autstic peiple too often you end up bouncing of them as such, and you still need to be able to fit in so you need someone who can tell you your being rude Not having to explain is easier - other engineers tend to have similar issues. The managers though tend not to have the "gift" so find us hard to understand. Managers need to be engineers too! not clear. neither of the examples are places. Maybe clarify I'd these people are understanding and supportive.	I suppose it does. I don't see it that way. It's never easy though not having to explain to others who "know" lowers stress. The question is meaningless really to someone with ASD but could help weed out those who aren't. Due to less masking! Represents SI in ASD adults well.	Overall, the statement was deemed clear and representative. Importantly, it was suggested that the statement could differentiate between an individual who is and who is not autistic. However, the statement could be improved by being reworded slightly.	**For me, being autistic is easier in some contexts (e.g. working with other autistic people, being with family etc).**
Being autistic is an important aspect of my identity.	When someone identifies as Autistic this can be as important as other aspects of themselves - like race & gender etc. I am not ASD. i am not defined by it but it is part of who I am. It's my reality so I agree.	It's part of me and part of who I am. I don't have an identity other than me. I'm not defined by a label and refuse to be bound. so I am neutral. all parts of me are important. There is no heirachy of aspects in who I am. The question has no meaning for me as	There was a consensus that the statement was clear and representative. However, it was noted that this could depend upon the person and may not be applicable to every individual that identifies as autistic.	**For me, being autistic is an important aspect of my identity.**

	Clear Very clear	I'm not hung up on labels or standing out - perhaps a diagnostic question to filter out ASD from those with an imagination. Represents SI in ASD adults well. this varies hugely, many people just see the diagnosis as useful info not an identity		
Being autistic does not mean having unique abilities.	Again this could end up in a double negative situation that could be confusing. Easier to respond to being autistic means having unique abilities I have uneven gifts. it makes me gifted in some areas and challenged in others. The trick is to use the ASD as a gift and try to avoid the situations where the challenges collide. The way I think and find answers defies description - even by my fellow engineers. Again, I struggle with opposing assertion type	ASD means neurodiverse so of course we have unique abilities - abilities to irritate too. Some cal that a challenge. The question answers itself and is more apt to questioning public awareness. Again, I rather the word 'strengths' due to possible stereotype associations. Represents SI in ASD adults well.	There was a consensus that the statement was not clear or representative.	**Remove the statement.**

	statements and have to think about them for a while! I do get it but have to study it first! I struggled with the wording of this question Clear Depends on the person So maybe add examples or mention special interests/talents. This is redundant with "Being autistic means having unique abilities.".			
I have not tried to minimise being autistic.	I don't feel that it is clear if the question is referring to masking autistic traits, or developing coping mechanisms for them I think lots of Autistic people try to minimise their Autistic traits - but not all. potential double negative confusion again I need to exist in society and put food on my plate - I need to tone down and	I'm an HF adult - of course I try to minimise being awkward. Perhaps the question helps discriminate HF from those who are unable to change, mask or modify to get along. As mentioned before I rather 'mask' or even 'hide'. Represents SI in ASD adults well.	There was a consensus that the statement was not clear or representative. Additionally, one comment suggested that the statement was too similar to an earlier statement (the reverse).	**Remove the statement.**

	take the edge off my abrupt (black and white) personality again not sure people will know what you mean by 'minimise'; I'm assuming you don't mean 'play down'? Very clear This is redundant with "I have tried to minimise being autistic.". Additionally, see my comments on the word "minimise" regarding previous questions. 'minimise' - unsure what is meant by this, could you use other wording?			
Being autistic is not noticeable by the healthcare system, like healthcare professionals or the tests used in assessments.	I'm not sure what this question means. Depends on the healthcare system - but a lot of people feel that those caring for them don't understand about their Autism. I don't understand this at all	I don't understand the question so can't comment No time, not interest. More a statement on the unsympathetic way the NHS regards mental health issues and sees only physical illnesses. The question conforms	There was a consensus that the statement was reasonably clear and representative. However, it was suggested that the statement is reworded to make it clearer.	**For me, being autistic has not been considered in healthcare appointments.**

	i think it depends how much training the health care professional has It's seldom looked for - there is no time available in the NHS to 1) be bothered, 2) talk and find out. My ASD is visible to those who choose to be bothered. If tests are done by professionals who do not have a good understanding of autism, they are useless. not clear. lose the word 'like', so '...system, by healthcare...' perhaps? Clear but clarify if this is assessments on general or autism specific assessment. you need to reword this it's really unclear what you mean	my own experience of accessing the NHS In my case, not suspected once in 30 years of mental health appointments which I feel is shocking! PIP assessment is also shocking and irrelevent! Represents SI in ASD adults well.		
I noticed being different from everyone else.	Most of the people I see for assessments are driven by a wish to understand why they feel different from others.	Of course I do. I am different as much as I would wish otherwise. The question only proves that I am sufficiently self	There was a consensus that the statement was clear and representative. However, it was noted that the statement could	**I noticed always feeling different from everyone else.**

	Maybe needs clarification about what is meant by different. My hair colour/eye colour/height is different but that's not what you're getting at It's hard not to notice being different living in a world where there is little common sense and few who seem to even notice. not clear - when is this referring to?; why past tense suddenly? Very clear noticed when exactly? you need to give a time or place eg I noticed at secondary school	aware and interested to care. Represents SI in ASD adults well.	be improved by being reworded slightly. Specifically, clarifying ‘different’.	
I have had several other psychological diagnoses, like anxiety and depression.	Many of the people I've seen have these diagnoses. Several indicates that if you've only had one, that's no enough. Maybe say one or more I have suffered with aniexty and depression for a long	There may be a degree of co-morbidity with ASD but why ask the question this way. If it's followed up by "if you answered yes then tick all the conditions that may apply" Represents SI in ASD adults well.	There was a consensus that the statement was clear and reasonably representative. However, the responses suggested that the statement could be improved by being reworded slightly. It was noted that the	**I have been diagnosed with one or more psychological conditions (e.g. anxiety, depression, personality disorder etc).**

	time including trying to end my own life and self harm when I was younger as I always felt different yes - stress, depression, adjustment disorder, PTSD, suicidal ideation, gender dysphoria. Anxiety I think this would be clearer without the word 'psychological' Very clear I'd give a few more examples of diagnoses here		suggestions included the removal of the word ‘several’ and adding a few more examples of diagnoses.	
I have other physical conditions, like epilepsy.	Delayed sleep phase disorder, and possibly a connective tissue condition Some people do and some don't Stress, undressed PTSD and depression have had an impact on my physical health. Poor sleep has caused issues as well with	as it happens yes - I am suffering complications from covid and have trigger finger but that's not related to a mental health issue Represents SI in ASD adults well.	There was a consensus that the statement was reasonably clear and representative. However, the statement could be improved by being reworded slightly. Suggestions included specifying that the conditions have to be comorbid with ASD and	**I have other conditions that are linked to being autistic (e.g. epilepsy, gastrointestinal disorders etc).**

	reduced immunity and muscle problems. ADHD clear, but better to say physical and neurological as people may think you're only looking for neurological conditions if you say 'like epilepsy' Clear but confirm.these have to be comorbid with autism. I have a spinal cord injury but this nothing to do with my autism. Thinking some people may read this literally. Epilepsy is neurological and therefore might seem to some people to be similar to a psychological condition even if it isn't. It might be appropriate to either use a different example of a physical condition or ask directly if participants have epilepsy. definitely need specific examples or you'll get too many people ticking yes - I		adding more specific examples.	

	don't think my bad back is relevant!			
I tell people that I may be autistic.	I tell them I *am* autistic, not may be. I prefer to tell people so they do not think I am rude or they understand why I may not do things that they deem as normal I share my suspicion (now diagnosed) on a need to know basis. I do not wave it on a flag or tell all who I meet. I treat disclosure proportionately as a means to an end - smoother engagement and conduct in work. Very much depends on context clear; depends what you're after here, but might it be better to ask 'I'm happy to tell people I'm autistic' or even @I will always tell people I'm autistic'; 'i tell people' really just means I can do it if I have to Very clear.	I don't make a thing of it - this question seems to discriminate between those who are self aware from those who want to feel special or are so disinhibited that they let it blurt out. Represents SI in ASD adults well.	There was a consensus that the statement was clear and reasonably representative. However, the statement could be improved by being reworded slightly. For example, it was noted that disclosing being autistic could be context dependent.	**I would be happy to share that I am autistic with other people.**

Being autistic as an adult is not noticeable by society, like there is no awareness or understanding.	This is phrased badly. It is noticed by society. But also awareness/understanding is lacking. There's a limited understanding by society I don't understand this question I think adults are deemed to be less autistic if they have not yet been diagnosed Awareness needs improving at all levels - then the world would be a happier place for both the ignorant, and the sufferer as both could better navigate interactions better for a better outcome - both are happy and friction is reduced. Fewer people would lose their jobs over bad communication. not at all clear. by 'like' do you mean 'because'? this isn;t answerable and I'm not sure what you would be able to get from this anyway.	I don't understand the question so can't comment It's seldom noticed because it's a child thing that is supposed to be spotted early. If you make it to adulthood then you've been left to get on with it unaided. Well, if it's not looked for then it won't be seen will it. Question confirms current society prejudice. Represents SI in ASD adults well.	There was a consensus that the statement was not clear or representative. The value of the statement was also questioned.	**Remove the statement.**

	Very clear a sweeping statement, I'd find it hard to generalise - do you want to know if the person feels autism is ignored in the media, or in education, or workplaces...			
Being autistic is not noticeable due to demographic factors, like gender or age.	Again I don't really know what you mean by this. Just checking - I'm a professional who carries out assessments;; I'm guessing I've completed the right form as this one seemed to be addressed to people with a lived experience. I don't understand this question The world doesn't care in general... Mental health was the same but it's slowly getting an airing so my hope is that things will improve. Struggling with this one as to what it's saying.. I think it's saying for example, older women are not	I don't understand the question so can't comment It's there for those who wish to see. A woman (or girl) can usually compensate for the issues better than a similarly aged male. As we grow older, we devise better ways to cope, mask and divert away from the bad aspects and make better use of the good ones. More misunderstood in adults without learning disability.. women but also men who present inwardly. Represents SI in ASD adults well.	There was a consensus that the statement was not that clear. It was noted that the statement needed to be reworded to make the intended meaning clearer.	**For me, being autistic has not been considered because of my demographic factors (e.g. my gender, my age etc).**

	noticed? I wonder if 'more misunderstood' might be perceived better? not clear. and what would this attitude tell you about someone's identification with autism? Very clear Based on the instructions in the book "The Elements of Style", I recommend replacing "due to" with "because of". Also, the sentence would be better grammatically if you remove the comma after "factors". sorry unsure what you mean exactly. maybe separate into different questions eg 'people do not recognise autism in' eg older adults / in young girls			

Appendix F. Qualitative responses on the Autistic Identity Questionnaire (AIQ) from the second round Delphi

Statements	Clearness of statement	Representativeness of statement	Summary of reviews	Finalised statement
For me, being autistic is more noticeable in certain activities.	A clear statement.	Very representative of a person with Autism.	There was a consensus that the statement was clear and representative.	**For me, being autistic is more noticeable in certain activities.**
For me, being autistic means that I am good at some things.	A clear statement.	Very representative of a person with Autism.	There was a consensus that the statement was clear and representative.	**For me, being autistic means that I am good at some things.**
For me, being autistic generally makes life harder in society.	A clear statement. I´d ask them why? This question could we use as a prompt during an ASD assessment.	For me I would maybe change harder to “makes me feel unaccepted/misunderstood” in society? Very representative of a person with Autism.	There was a consensus that the statement was clear and representative. The additional comments were noted. However, on the basis of the quantitative scores also, no further changes were made to the statement.	**For me, being autistic generally makes life harder in society.**
I am contented with being autistic.	A clear statement. I´d ask them why? This question could we use as a prompt during an ASD assessment.	Very representative of a person with Autism	There was a consensus that the statement was clear and representative.	**I am contented with being autistic.**
For me, being autistic means that I find some things harder in life.	It need to be clear whether you are asking if being autistic itself causes difficulties, or the fact that society discriminates against autistic people that is the issue.	Again I possibly feel the onus is on the autistic person when it rarely is.. it’s due to being misunderstood or unaccepted.. maybe wording such as: I find it harder to be understood or accepted. (But yes as it	Reviews suggest that the statement is clear and representative. However, it was noted that the statement was deemed too similar to the previous statement (For me, being autistic	**For me, being autistic means that I find some things harder in my personal life (e.g. getting ready to go out, eating certain foods etc).**

	I would say is too similar to distinguish from the question above the one before - I’d probably interpret as having the same meaning. A clear statement. I´d ask them why? This question could we use as a prompt during an ASD assessment.	stands I see it encompasses everything!). Very representative of a person with Autism.	generally makes life harder in society.). The statement could be improved with further clarification that distinguishes it from that previous statement.	
For me, being autistic is more noticeable around certain people.	Does this refer to masking in some situations, or that you feel more awkward (more "autistic") in some cases, or being yourself more? Not sure who it is noticeable by - the individual or people? Maybe “I am less able to hide being autistic” or “less able to mask”? I guess ‘noticeable’ feeds into stereotypes of it ‘looking’ like something. A clear statement. I´d ask them why? This question could we use as a	Very representative of a person with Autism.	Reviews suggest that the statement is clear and representative. However, it was noted that the statement could be improved with further clarification.	**For me, being autistic is more noticeable around certain people (e.g. working with neurotypical people, people unknown to me etc).**

	prompt during an ASD assessment.			
I have always masked to hide being autistic.	This may differ depending on gender. Also, perhaps even those who do mask won't "always" mask. It could depend on who they are with. Eg, close friends/family compared to a work setting. In a clinical context I´d ask why.	Very representative of a person with Autism.	There was a consensus that the statement was representative. However, it was noted that this could depend upon gender, and that the statement could be improved by amending the word ‘always’.	**I have mostly masked to hide being autistic.**
I like the way that I am different from neurotypical people.	A clear statement.	Very representative of a person with Autism	There was a consensus that the statement was clear and representative.	**I like the way that I am different from neurotypical people.**
For me, being autistic is more noticeable in certain environments.	Again, not sure is clear who it’s noticeable by? Possibly claims that autism is based on perceptive stereotypes? Maybe better as “Due to being autistic, I experience more difficulties in certain environments”? A clear statement.	Very representative of a person with Autism.	There was a consensus that the statement was clear and representative. The additional comment was noted. However, on the basis of the quantitative scores also, no further changes were made to the statement.	**For me, being autistic is more noticeable in certain environments.**
For me, being autistic is less noticeable when I’m alone.	“I experience less difficulties when alone”?	Very representative of a person with Autism.	There was a consensus that the statement was representative.	**For me, being autistic is less noticeable when I’m alone.**
For me, being autistic means having useful abilities.	For some, yes. Though, it depends what sort of outlook an autistic person has on their autism. For example, I used to be very	I don’t know if ‘useful abilities’ feeds into stereotypes and makes appear as a great thing to have.. “natural	There was a consensus that the statement was representative.	**For me, being autistic means having some useful abilities.**

	negative, but over time, I am much more positive about it.	advantages/strengths at some things"? Representative of a person with Autism.	It was noted that the statement could be improved by adding the word 'some' (some useful abilities).	
For me, masking my autistic traits can lead to meltdowns and/or shutdowns**.**	A clear statement.	Very representative of a person with Autism.	There was a consensus that the statement was clear and representative.	**For me, masking my autistic traits can lead to meltdowns and/or shutdowns.**
For me, being autistic is easier in some contexts (e.g. working with other autistic people, being with family etc).	Perfect! :). The examples given in this question seem to suggest that this question is about autistic people feeling comfortable in specific social situations. However, it is not absolutely clear that the question is not about more general situations. I recommend either rephrasing the question to indicate that it is about "social situations" or to add other examples after the "e.g." that describe non-social contexts. A clear statement.	This question is not clear to me, so I cannot comment on its representativeness. Very representative of a person with Autism.	Reviews suggest that the statement is clear and representative. The additional comments were noted. However, on the basis of the quantitative scores also, no further changes were made to the statement.	**For me, being autistic is easier in some contexts (e.g. working with other autistic people, being with family etc).**
For me, being autistic is an important aspect of my identity.	A clear statement.	Very representative of a person with Autism.	There was a consensus that the statement was clear and representative.	**For me, being autistic is an important aspect of my identity.**

For me, being autistic has not been considered in healthcare appointments.	A clear statement.	Very representative of a person with Autism.	There was a consensus that the statement was clear and representative.	**For me, being autistic has not been considered in healthcare appointments.**
I noticed always feeling different from everyone else.	A clear statement.	Very representative of a person with Autism	There was a consensus that the statement was clear and representative.	**I noticed always feeling different from everyone else.**
I have been diagnosed with one or more psychological conditions (e.g. anxiety, depression, personality disorder etc).	This seems like it should be a yes or no question. I don't see how "slightly agree", "neutral", or "slightly disagree" would apply. A clear statement.	Very representative of a person with Autism.	There was a consensus that the statement was clear and representative. However, it was noted that the statement could be improved by being amended to a ‘yes’ or ‘no’ response answer.	**I have been diagnosed with one or more psychological conditions (e.g. anxiety, depression, personality disorder etc).** **Response= Yes/No**
I have other conditions that are linked to being autistic (e.g. epilepsy, gastrointestinal disorders etc).	I did not quite understand how gastrointestinal disorders were linked to autism, and I have very rarely read about epilepsy being linked to autism (and it is sometimes mentioned in discussions from anti-vaxxers). This question may not belong in the questionnaire. A clear statement. I agree with having separate statements for mental health and other conditions.	Very representative of a person with Autism.	There was a consensus that the statement was clear and representative. However, it is noted that the feedback on the previous statement would be applicable to this statement also, given the similarity of the statements. The additional comment was noted. However, on the basis of the quantitative scores also, no further changes were made to the statement.	**I have other conditions that are linked to being autistic (e.g. epilepsy, gastrointestinal disorders etc).** **Response = Yes/No**

I would be happy to share that I am autistic with other people.	Which other people? I think this could be dependent on the person, not so much their autism. Or could depend on who the person was. It may differ if it was a friend or a manager at work.	Very representative of a person with Autism.	There was a consensus that the statement was representative. However, it was noted that this could depend upon the person. The statement could be improved by clarifying which other people clients would be happy to disclose being autistic to.	**I would be happy to share that I am autistic with most other people.**
For me, being autistic has not been considered because of my demographic factors (e.g. my gender, my age etc).	Considered by whom? A clear statement.	Very representative of a person with Autism.	There was a consensus that the statement was clear and representative. However, it was noted that the statement could be improved by clarifying whom being autistic has not been considered by.	**For me, being autistic has not been considered in healthcare appointments because of my demographic factors (e.g. my gender, my age etc).**

Appendix G. Ethical reapproval

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23 September 2022

Project Lead: Gayle Overton
Project Title: Understanding the self-identification of Autism Spectrum Disorder (ASD) in adults within the UK population: development of a screening questionnaire
Type of Study: Postgraduate Research
Start Date: 18 June 2021
End Date: 31 December 2023
Primary Supervisor: Professor Penny Cavenagh
Secondary Supervisor/s: Dr Ferran Marsa-Sambola and Dr Rachael Martin
Paper Number: RETH20/069

Dear Gayle
Thank you for submitting the revised questionnaire to the Ethical approval reference RETH20_069 dated 16 September 2022.

As Chair of the University PGR Research Ethics Committee, I have reviewed the questions for the screening questionnaire, and am pleased to advise that I give **approval** under Chair's Actions.

As principal investigator, your responsibilities include:

- ✓ ensuring that (where applicable) all the necessary legal and regulatory requirements are met in order to conduct the research, and the necessary licenses and approvals have been obtained;
- ✓ noting that approval by the University of Suffolk PGR Research Ethics Committee should not be taken as evidence that the study is compliant with GDPR and the Data Protection Act 2018. You are expected to have completed the GDPR training and follow the guidance from https://www.ukri.org/files/about/policy/ukri-gdpr-faqs-pdf/. Final responsibility for GDPR compliance remains with you;
- ✓ reporting any ethics-related issues that occur during the course of the research or arising from the research to the University of Suffolk PGR Research Ethics Committee to the Committee Secretary, Joanna Walpole at J.walpole2@uos.ac.uk (e.g. unforeseen ethical issues, complaints about the conduct of the research, adverse reactions such as extreme distress);
- ✓ submitting details of proposed substantive amendments to the protocol/proposal to the University of Suffolk PGR Research Ethics Committee for further approval.

Yours sincerely

S. Richards

Dr Sarah Richards
Head of Suffolk Doctoral College and Chair of the PGR Research Ethics Committee
University of Suffolk

cc

Professor Penny Cavenagh	Lead Supervisor:
Dr Ferran Marsa-Sambola	Co-Supervisor:
Dr Rachael Martin	Co-Supervisor:
Dr Amanda Hodgkinson	Associate Dean Research and Knowledge Exchange

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