Advancing the understanding of autistic women and girls: Development of a screening tool to improve recognition and access to diagnostic pathways and support

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Abstract

Delayed, missed or misdiagnosis of autism in women and girls is an ongoing concern worldwide, which has potentially life altering consequences on a person’s mental health and quality of life. Autism is often thought of as a predominantly male condition and as such, has shaped the way in which we have come to understand autism over the years. Despite increasing evidence into the potentially more subtle differences between males and females, there is still a lack of transference of this knowledge to the general population and wider clinical settings. The purpose of this thesis was to design a screening tool that may be better at identifying autism in women and girls, that will in future aim to improve access to diagnostic pathways and reduce missed or misdiagnosis. Four related studies were conducted which led to the development and refinement of the Female Autism Spectrum Screening Tool (FASST).

Stage 1 of the research was to systematically examine and synthesise the existing research literature to determine what was known about the experiences and behavioural presentations of autistic women and girls. More specifically, the review aimed to identify areas of difference between males and females that could be used to develop specific items in a new screening tool that may be helpful in screening for autism in women and girls. Conflicting evidence was found for social and communication difficulties, with some studies finding equal levels of difficulty for autistic males and females, while others reported fewer difficulties for autistic females. More lifetime sensory issues were found for females compared to men, while RRBI were seen more frequently in males than females. In relation to camouflaging, again the research was conflicting, with some studies suggesting females engaged in more camouflaging than males, with some reporting no differences. Experiences related to diagnosis, mental health, social relationships and a lack of general support were reported. A total of 17 new items were added to the FASST post systematic review.

Stage 2 of the research involved two development studies. The overall aim was to assess the item content of the FASST using Focus Group and Delphi methodologies in order to prepare the FASST for testing in the pilot stage of study 3. Four focus groups were conducted which led to the amendment of 16 original FASST items and the addition of 18 new items. A total of 83 items were then sent to the Delphi consultation, where a panel of autistic people and key stakeholders were asked to rate the importance of each item. Both the focus group and the Delphi methodology resulted in a final version of the FASST which incorporated 58 items.

Stage 3 involved the piloting of the refined FASST. The overall aim of this study was to conduct preliminary evaluations of the FASST's psychometric properties. The FASST demonstrated excellent internal consistency and Test re-test reliability. The FASST demonstrated a robust capacity to discriminate between autistic and non-autistic women, with significant differences found between groups.

The following conclusions were drawn from the combined studies included within this thesis. First, it can be concluded that the FASST is able to successfully identify autism in females. Preliminary evidence suggests that the FASST is psychometrically robust and is likely a useful resource for future use clinically in front line services such as GP's and mental health teams, as well as for use in future research. While there is evidence to suggest that autism presents differently in women and girls, most of the research remains contradictory. Despite this, the research conducted within this thesis has ensured that the evidence base is synthesised which is important for future dissemination to improve awareness of the differences that autistic women and girls might present with. Second, to the best of our knowledge, this is the first screening tool that has been developed with detailed input from autistic people and key stakeholders. The use of various research methodologies throughout this thesis ensured that the lived experiences of autistic people were explored to develop a screening tool that will potentially reduce the number of incorrect referrals as well as reducing misdiagnosis in the future.

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Introduction

Autistic women and girls are often missed or misdiagnosed and as a result, quite often find themselves struggling to cope with understanding where they fit in to society. Experiencing a late diagnosis not only impacts on the development of their social identity but has significant impacts on their quality of life and mental health. As a professional who has supported autistic people in the community for over the last twenty years, I frequently met women who were diagnosed with a mental health condition prior to receiving their autism diagnosis. Part of my role in the community is to support women to understand their autism diagnoses and this quite often-involved retrospective discussions on their lived experiences. I noticed that most women had reached the point of crisis and thus triggered a referral to the community mental health team where they then received their mental health diagnoses. Almost all of the women I have supported were never considered by professionals that they might actually be autistic and as such, these women were discharged from mental health services and left without the support they very much needed. The lack of clear pathways for women led me to question what more could be done to prevent future women and girls from being missed or misdiagnosed.

This thesis sought to consider the most appropriate way to develop a new screening tool that specifically aimed to identify autism in women and girls. An overview, thesis outline and systematic review are laid out in the first two chapters and then four empirical studies are outlined which were conducted in order to refine and develop a new screening tool for autistic females: The Female Autism Spectrum Screening Tool (FASST).

Chapter 1 begins with a comprehensive introduction to autism, focusing on background, terminology, diagnosis, prevalence and the screening and assessment of autism. Chapter 2 then provides a full overview of the methodologies that guided this thesis, including epistemological and ontological frameworks and a full thesis outline. Chapter 3 is the first empirical study and details the systematic review of the literature pertaining to the experiences and behavioural presentations of autistic women and girl. Chapter 4 is the start of the two assessment studies of the screening tool, study 2a details the use of focus groups in the refinement of the tool, with Chapter 5 focusing on study 2b, the Delphi consultation. Chapter 6 provides a more detailed introduction to the Female Autism Spectrum Screening Tool (FASST) which is followed by Chapter 7, the pilot of the FASST. The pilot chapter focus on the preliminary evaluations of the psychometric properties of the FASST and provides detailed findings. Chapter 8 concludes with a full discussion of the overall thesis, highlighting the specific implications for the FASST as a result of all four empirical studies conducted throughout this research. Implications for clinical practice are discussed, with future research recommendations detailed.

Chapter 1. Autism – Description, Language, and Identity

1.1. Autism

1.1.1. Autism – History and Background

Autism is a lifelong developmental condition characterised by difficulties in social communication and interaction, restrictive and repetitive behaviours, and sensory sensitivities (APA, 2013). Over the last 80 years or so, many terms have been used to define autism including childhood schizophrenia, Kanner's autism, autism spectrum disorder, Asperger Syndrome, autistic disorder, pervasive developmental disorder not otherwise specified, and autism spectrum conditions. More recently, most autistic people, professionals and researchers use the singular term, autism. Autism was most notably discussed by the work of Leo Kanner and Hans Asperger in the 1940s (Lai et al., 2014; Silberman, 2015). Their observations of small groups of male children, led to the development of the diagnostic criteria that is still used today. Initial descriptions provided by Kanner (1943) focused on children with marked difficulties in social and communicative abilities, whereas Asperger (1944), although reportedly describing similar characteristics, detailed a group of children with 'milder' difficulties. However, the work of Asperger was not formally translated until the 1980s, where the term Asperger syndrome became more widely recognised. Kanner (1943) provided detailed descriptions, a set of common characteristics, shared by the group of eleven children that were clinically observed throughout his research (Volkmar et al., 2012). These characteristics included ***social and emotional difficulties*** i.e., difficulties forming and maintaining relationships, difficulties responding to the emotions of others, lack of interest in others and limited eye contact; ***communication difficulties*** i.e., difficulties understanding nonverbal communication, limited functional speech and atypical language development; ***repetitive and restricted interests*** i.e., displaying intense interests in objects and engaging in repetitive movements such as hand flapping; ***resistance to change*** i.e., becoming increasingly distressed with change to their surroundings and finally ***differences in intellectual abilities*** i.e., displaying varying levels of cognitive functioning ranging from severe intellectual disability to sometimes average or above-average intelligence. In contrast, the work of Asperger (1944) particularly focused on individuals with average or above average intelligence and as such became known as subtype of autism in later years. Although prior historical accounts describe autistic-like characteristics, suggesting that autism was indeed present for many years prior, it was not until the work of Kanner and Asperger, did autism become known as a distinct condition through clinical observation, and as such, laid the foundations for future research and the advancement of understanding autism (Silberman, 2015).

Despite the changes we have seen in diagnostic labels used to describe autism over the years, there has been a shift in the autistic community, researchers, and professionals alike, that aims to views autism in light of strengths and abilities, rather than being particularly deficit focused. Many people across the world who advocate for the rights of autistic people now suggest that autism is a form of neurodivergence (Axbey et al., 2023), where autistic people experience the world in a way that is different from the majority of people who are not autistic. Autism is one of several neurodivergent conditions recognised within the neurodiversity movement which proposes that neurodivergent people are a natural part of human variation rather than a defective version of neurotypical people (Pellicano & den Houting, 2021). The concept of neurodiversity was first discussed in the work of Judy Singer in the late 1990s (Lorenz et al., 2017), proposing the idea of neurological diversity, with a particular focus on autism. The aim of Singer’s work was to shift the narrative that viewed autism as a disorder, in turn promoting the recognition of natural neurological variations. Over the last 30 years, the neurodiversity movement gained significant traction and now encompasses an array of neurological differences including not only autism, but also other conditions such as ADHD, OCD, and dyslexia. The movement aims to promote acceptance, inclusion and understanding, rather than focusing on what can be ‘cured’ or ‘fixed’ in a person. Furthermore, the movement actively calls for the creation of more inclusive environments for neurodivergent people, advocating for the accommodation of individual specific needs so that all people can be included and make meaningful contributions to society (Anderson-Chavvaria, 2022). However, the neurodiversity movement is not without its challenges. Although the movement is acknowledged and accepted as a positive step forward in decreasing the stigma attached to autism, some suggest that the movement diminishes autistic people who have higher support needs. There are still a number of autistic people who believe that they are disabled by their autism, and as such do not feel that it is something to be celebrated. Anecdotally, autistic people have expressed concerns that by continually implementing strategies that actively promote autism as a strength, this might in turn affect access to support services if professionals/clinicians no longer view autism through the lens of the many challenges and difficulties that autistic people face as a result of their specific needs. Even though there appears to be some polarity in how neurodiversity is viewed across the autistic community, what does remain crucial is the importance of supporting individual preferences (Anderson-Chavvaria, 2022). For example, this might mean respecting if an individual views their autism as a disability rather than a strength or the way in which they refer to their autism, for example ‘I am autistic’ or ‘I have autism’. The importance of challenging stereotypes and creating a more positive and inclusive attitude towards autistic people will be reflected in this thesis. Recognising and valuing the unique perspectives of autistic people will be a key focus and as such respectful language will be used throughout.

1.1.2. Person first language vs. Identity first language

Over the years a myriad of research studies has been conducted investigating language preferences and terminology in relation to autism (Keating et al., 2022). Most notably, Kenny et al. (2016) conducted a wide scale study in the UK investigating the use of person first language i.e., ‘person with autism’ compared to identity first language i.e., ‘autistic person’. Evidence from this study demonstrated that most autistic people preferred identity first language (autistic person), whereas professionals endorsed the use of person first language (person with autism). A further study asked participants to rank order terminology related to autism in order of preference and most offensive. In line with other studies, participants ranked ‘autistic’ and ‘autistic person’ in their top three preferences, with ‘person with ASD’ and ‘person with autism’ in the top three of being most offensive (Bury et al., 2020). In contrast, Buijsman et al. (2023) conducted a large online study with Dutch autistic adults, utilising a questionnaire that examined terminology, and reported that most self-reporting adults (68.3%) and parents (82.5%) preferred person first language. Notwithstanding the differences emerging in recent literature, what does seem important is the consideration of the impacts of language more broadly. It is critical for autism researchers to be aware of ableism and how this might manifest in language choices. In social sciences research, ableism is broadly defined as the negative attitudes, biases, and discriminatory practices that autistic people and those with disabilities face. This includes stereotypes, prejudice, discrimination, and social oppression based on their autism and/or specific disabilities (Bogart & Dunn, 2019). The language used when referring to autistic people in research has the power to have a profound impact on how society views autistic people as well potentially shaping the way autistic people view themselves (Bottema-Beutel et al., 2021). When person first language was first adopted in the 1970s it was a way to put the person first as opposed to the disability first (Vivanti, 2019). However, many self-advocates and scholars have challenged this over the years suggesting that autism is an identity-defining feature that cannot be separated from the person, that autism is key to making an individual who they are. Furthermore, the continued use of person first language may perpetuate the stigmatising views that society holds, implying that autism is an undesirable attribute that deviates from the norm (Gernsbacher, 2017; Sinclair, 1999; Vivanti, 2019).

Whether we use person first language or identity first language is not just an issue of semantics but has real world implications including societal perceptions, public policy, clinical practice and research direction. As such current recommendations suggest the importance of using a mix of person first and identity first language in autism research to ensure academic papers cover the full range of autistic preferences (Buijsman et al., 2023). Although there is no unanimous approval of one term to describe autism, the language used throughout this thesis will reflect the preferences of most of the autistic community in the United Kingdom and as such will refer to ‘autistic person’.

1.1.3. Profound autism and functioning labels

Whilst the debate over language preferences have centred around the use of person first language and identity first language, there are also other terms such as high and low functioning labels that warrant further discussion (Keating et al., 2022). Even though these functioning labels are often used within scientific research, other scholars suggest that levels of support needs should be described when referring to the specific strengths and needs of autistic people, rather than using descriptors that have the potential to perpetuate stigma (Bottema-Beutel et al., 2021). In fact, many autistic people directly oppose the use of functioning labels (Kenny et al. 2016; Pukki et al., 2022). A recent international study demonstrated a wide agreement that functioning labels were unhelpful, divisive, and may unnecessarily segregate autistic people. Further suggesting that autistic individuals who were labelled as high functioning may potentially miss out on much needed support due to their external presence appearing to fit in with the 'norm', and similarly when an autistic individual is labelled as low functioning, this may in turn infantilise their abilities and/or leave them ignored (Keating et al., 2022). More recently, The Lancet Commission proposed the term 'profound autism' as a label specifically for individuals with high support needs who may need 24-hour access to a carer, who cannot be left alone and who may not be able to take care of their own needs independently (Lord et al., 2022), describing their reason for doing so was due to the fact the term 'low functioning' was disliked by many. The Global Autistic Task Force on Autism Research published a response detailing the classification of 'profound autism' to be misleading and counterproductive (Pukki et al., 2022). Intellectual disability and impaired language development are not core characteristics of autism, and as such using the term 'profound autism' may give the false impression that they are explicitly linked. It is important to remember that often the needs of an autistic person fluctuate and having one label that is intended to encompass all needs would not be sufficient to ensure the correct service provision is provided. The taskforce recommends that brief descriptions would be both more helpful and purposeful, for example 'autistic person with high mobility needs’ or ‘autistic person with intellectual disability’ or ‘autistic person with co-occurring mental health needs’. (Pukki et al., 2022). Despite the commission detailing that this term would likely be used in most cases to classify extremely vulnerable autistic people with a substantial intellectual disability and/or limited language, these are still needs that are not necessarily autism specific or linked to any extreme autistic characteristics or needs (Pukki et al., 2022). As described earlier, incorrect use of labels can significantly affect a person’s options for support. Descriptions and measurements of a person’s needs and abilities need to be thoughtful and accurate, as an incorrect assessment and subsequent label may have serious future consequences (Kapp, 2023). Throughout this thesis, when discussing the needs of autistic people, the language used will adopt the principles suggested by The Global Autistic Task Force, unless reference is being made to research that specifically mentions these terms in order to interpret their findings.

1.1.4. Sex and Gender Identity

As seen within the language used to describe autistic people, there is also a discrepancy between the way gender is described within the scientific literature and the way in which gender is defined and understood within the autistic community. The concept of gender identity and the autistic person’s lived experience of such is multi-faceted and as such cannot be understood through binary concepts of sex and gender. When discussing ‘sex’ and ‘gender’ as independent concepts, it is first important to understand their specific differences. Sex is often perceived as a binary concept, by definition, sex refers to biological and physiological characteristics, including specific sex related chromosomes (World Health Organisation). Researchers will often refer to sex systematically i.e., classifications such as male, female and intersex (Rioux et al., 2022). In contrast, gender is a complex multifaceted construct encompassing a range of social, experiential, and cultural elements. As a social construct, these elements include ***gender norms,*** which are the rules and expectations that dictate socially acceptable behaviours for people based on their gender. Similarly, ***gender roles,*** are the societal expectations of how people should act and think based on their gender. ***Gender-related expressions*** are the various ways in which a person might choose to express their gender, for example their clothing, and ***gender related interests*** refer to the activities a person might pursue or be interested in based upon their gender (Strang et al., 2020). Finally, and most referred to, is the concept of ***gender identity,*** which is the internal way in which a person experiences their gender (American Psychiatric Association, 2015). To understand gender as a construct and the autistic person's lived experience of such, it is vital to understand these elements and how they interact with each other. Further, improving understanding of sex and gender related terminology will be an important step forward in providing more gender-inclusive research (Rioux et al., 2022). The intersectionality of these elements is also crucial in understanding autism and gender as a social identity. Although some autistic people describe greater freedom and less pressure in being able to express their gender identity (Strang et al., 2018), some autistic people report the devastating effects on their mental health of having to 'mask' to fit in. Given the complexities surrounding the lived experience of being autistic and navigating gender identity, as well as the fact that many autistic people experience an incongruence between assigned sex at birth and gender identity (van der Miesen et al. 2016), it is critical for autism researchers to be respectful and provide acknowledgement to the complexities experienced by autistic people. The majority of the existing literature reviewed and discussed as part of this thesis refer to sex and gender interchangeably, with sex discussed in terms of binary concepts for example 'male, men and boys' and 'female, women and girls'. When reporting data from these studies, the terminology will not be changed in order to reflect accurate findings and discuss thereafter. It is hoped that future research will begin to include the experiences and quantitative exploration of people who identify as other genders.

1.2. Diagnostic criteria, pathways, and access to support

1.2.1. Autism through the lens of the medical and social models – a brief overview

Traditionally, autism is viewed through the lens of the medical model (Kapp, 2019) and is described as a developmental disorder characterised by challenges in social communication, repetitive behaviours, and sensory processing (American Psychiatric Association, 2013). Recent conceptualisations of autism suggest that it is a lifelong developmental condition that includes a spectrum of varying presentations and a condition that is associated with high rates of co-occurring mental health difficulties (Happe & Frith, 2020). Despite the commonly known term 'autism spectrum disorder (ASD)' being a classification in the Diagnostic and Statistical Manual (DSM; American Psychiatric Association, 2013), many clinicians and autistic people, respect the preferences of the autism community by not referring to autism as a disorder or condition, and instead use the singular term 'autism'. When considering autism through the lens of the social model, it is suggested that autism has a societal cause, that autistic people experience barriers in society due to the sometimes-adverse attitudes they experience from non-autistic people (Chown, 2019).

As discussed earlier, the way we have come to understand autism and the constructions of the autistic person are intertwined with dominant understandings of 'normal development' which has arisen from historical normative models based on descriptions from Kanner and Asperger in the late 1940s (Brownlow, et al., 2023). Although most diagnostic assessments and screening tools used to date will focus on areas of difficulties in order for a diagnosis of autism to be made, it is equally important to recognise the many unique strengths and positive attributes that can also be associated with autism (Happe & Frith, 2020). Advocates for the neurodiversity movement view autism as a cognitive and sensory difference rather than an impairment (Kapp et al., 2013; Milton, 2015) and one in which autistic strengths and unique perspectives should be celebrated, rather than being a deficit in functioning that needs to be fixed. Furthermore, recently autistic, and non-autistic scholars have called for autism to be removed from diagnostic manuals suggesting that an autistic persons' needs should be met through a proposed new manual of needs experienced by neurodivergent people (Chown & Leatherland, 2018). While we aspire to such changes, it is important to recognise that the current system, albeit grounded in epistemological injustice, necessitates a medical model perspective in order for people to access services and diagnostic pathways. In contrast to both the medical and social models of autism, Anderson-Chavarria (2022) proposes the 'predicament model' of autism. This model positions autism as neither a deficit or as a social difference, rather, autism should be viewed as a highly individualised and variable experience and should be considered both a disability and a positive difference. The predicament model of autism suggests the importance of building practices that prioritise a multidimensional and nuanced understanding of autism. Further, Anderson-Chavarria (2022) suggest that the neurodiversity movement has evolved our understanding of autism to such an extent that autism can no longer be situated within either the social or medical model. As such, by adopting the predicament model, it allows for the extensive variability of autism, both the autistic experience in a social context, as well as in the context of surroundings and environments, to be better understood and in turn appropriate supported can be provided (Anderson-Chavvaria, 2022).

1.2.2. Current diagnostic criteria

There are two manuals used internationally that set out the essential criteria for autism to be diagnosed. These are the ICD-11, used internationally, and the DSM-5, mainly used in the United States. The ICD-11 details essential features that are required in order for a diagnosis of autism to be given. These include persistent difficulties in ***"initiating and sustaining social communication and reciprocal social interactions"*** and ***"persistent restricted, repetitive, and inflexible patterns of behaviours, interests or activities"***. In addition, the ICD-11 states that the onset of autism typically occurs in early childhood but acknowledges that autistic characteristics may not fully manifest until later on in life. Lastly, the ICD-11 states that autistic characteristics as detailed in the criteria must result in significant difficulties for the person in their personal, family, social, educational and occupational lives. In addition, autistic people may present with co-occurring intellectual disabilities and as such, additional assessments may be required to assess levels of adaptive functioning in order to provide a separate diagnosis of 'Disorder of Intellectual Development'. Similarly, the DSM-5 criteria for autism are based on identifying difficulties in several key areas of observable behaviour. The first section in the DSM-5 requires the person to display difficulties in three areas, there must be observable difficulties in all three areas in order for a diagnosis to be considered. These three areas include difficulties in ***socio-emotional reciprocity, nonverbal communication*** and ***developing and maintaining relationships***. In addition, there must be observed difficulties in two out of the four following areas, ***stereotyped or repetitive speech, excessive adherence to routines, restricted interests*** and ***hyper or hypo-reactivity to sensory input.***

The ICD-11 and DSM-V criteria form the foundation of most formal diagnostic tools, such as the DISCO (Diagnostic Interview for Social and Communication Disorders), the Autism Diagnostic Observation Schedule (ADOS-2; Lord et al., 2012), the Autism Diagnostic Interview-Revised (ADI-R; Lord et al., 1994) and the Developmental, Dimensional and Diagnostic Interview (3Di; Mandy et al., 2018). The information collected with these tools will help to decide whether a diagnosis of autism will be given, and relies heavily on clinician experience, interpretation and professional judgement. The main purpose of each diagnostic tool is to gather information on a person's current life, how their difficulties are affecting them, direct observations of behaviour as well as information on their developmental history. Currently, there are no obligations on diagnosticians to use a specific tool and will largely depend on clinical background and the clinic/team providing the assessment. Most diagnostic assessments will include semi-structured interviews and direct periods of observation of the person who is being assessed for autism (NICE, 2012).

1.2.3. Diagnostic Pathways

Assessment processes in the UK vary and as a result, access to diagnostic pathways will differ dependent on several variables, for example geographical, local and/or socio-economic status. The process of initiating contact to access diagnosis may begin in different ways, for children, the first person to raise concerns about areas of difficulties with everyday life may be parents or carers and/or teachers. For adults, they might start to notice difficulties in everyday life when social demands become greater. Concerns are usually then raised to either a GP, an educational psychologist of a member of the local mental health team and/or social services (Huang et al., 2020). Following this an initial referral will be made to the local autism/neurodevelopmental service to request an assessment of autism (NICE, 2012). Dependant on the service and current level of need, some diagnostic teams will have a pre-assessment phase which may include gathering information about the persons current circumstances, areas of life that they may be experiencing difficulties with and contextual information from parents, carers or somebody that knows the person well. The information gathered during the initial referral and pre-assessment will then be used to inform the diagnostic assessment (Pilling et al., 2012). As described earlier, there is not one standardised tool that will be used for every person. However, the assessment will be comprehensive overall and will be conducted by a multi-disciplinary team which may include clinical psychologists, speech and language therapists, occupational therapists, and other specialists in the field of autism. The diagnostic assessment will include observations, interviews, and dependant on the person, may include assessments for associated cognitive and developmental needs as well additional assessments for co-occurring conditions such as physical or mental health needs (Pilling et al., 2012). Although assessments for autism will vary depending on the neurodevelopmental service referred to, all services have the overall aim of providing accurate diagnosis and appropriate intervention planning and access to post-diagnostic support (NICE, 2012).

1.2.4. Autism strategies and the provision of support

When discussing diagnostic pathways and assessment, it is reasonable to assume that access to and progress through diagnostic pathways should be seamless, given that the ‘gold-standard’ process is seemingly easy to describe. However, this is not always the case in practice. Many people, children and adults alike, can wait several years before they are able to access a diagnosis, which in turn means they are missing out on accessing crucial support. In the UK alone, 1 in 57 people are thought to be autistic (Roman-Urrestarazu & van Kessel, 2022), making it one of the most common developmental conditions. Yet despite this, autistic people still face long waits for a diagnosis which is key in being able to access much needed services and support. Over the last 20 years there has been a demonstrable shift in autism being included in various policies, strategies, and Governmental Acts. 2009 saw the implementation of the Autism Act, which established a legal framework in the UK that aimed to improve the lives of autistic people and to ensure the appropriate provision of support and services were accessible. Prior to the Autism Act (2009), many people and professionals alike often misunderstood what autism was, which perpetuated misconceptions and stigma, making it difficult for autistic people to engage in their local communities in a meaningful way, that both benefitted and improved their quality of life. The Autism Act (2009) set out to recognise autism as a priority and highlighted the need for targeted policies and strategies that would address the inequalities faced by autistic people. These priorities included promoting awareness and understanding of autism and ensuring local authorities developed their own autism strategies. Furthermore, the Act promoted collaboration between local authorities, NHS bodies, autistic people, and other key stakeholders to ensure decision-making processes were inclusive for all. Notwithstanding the importance of the Act and the impact this had at a national level for improving awareness of autism, more than a decade on there is still a significant amount of unmet need for autistic people across the UK. The All-Party Parliamentary Group on Autism (APPGA; 2019) published a report demonstrating their findings from a national inquiry into how services have responded to the requirement of developing an adult autism strategy.

The inquiry involved over 11,000 autistic people, their families, and professionals. A significant number of autistic people (71%) reported unmet mental health and social care needs, equating to as many as 327,000 autistic people living across the UK without support. Due to cuts in funding nationally, this has led to profoundly negative impacts on autistic people and their families being able to access the services they need. APPGA (2019) published a number of recommendations for the Government to consider when developing their new autism strategy which included the establishment of specialist autism teams in every local authority, the commission of mental health services for autistic people and to improve access to diagnosis, in particular reducing waiting times for assessment.

Since the UK introduced the Autism Act (2009), we have seen several policies and strategies implemented by the UK Government and the NHS. Following the Autism Act (2009), in 2010 The Autism Strategy *"Fulfilling and Rewarding lives"* (Department of Health, 2010) was introduced which set out guidance for local authorities in key areas such as diagnosis, intervention and support, with the overall aim of improving the lives of autistic people and their families. This initial strategy laid the foundations for change and demonstrated an increase in accessible services and awareness of autism. Despite progress made, there were still many autistic people and their families reporting a lack of improvement, with their lives remaining largely unchanged due to service provision at a local level. Due to the often stereotyping of autism coupled with autistic people facing continual discrimination, it was further acknowledged at a national level that autistic people had an equal right to a meaningful, rewarding and fulfilling life. As a result, the Government updated the strategy in 2014 '*Think Autism',* (Department of Health, 2014) which encompassed 15 identified priorities set by autistic people and other key stakeholders.

These included, increased acceptance and understanding of autism, safety in the community, timely access to diagnosis, increased support during key transitional phases of life and support to develop skills and independence. In the present context, there is still a long way to go before realising the vision for autistic people first set out in 2010 by the '*Fulfilling and rewarding lives'* strategy.

One primary criticism of the 2010 and 2014 strategies were that the identified priorities mainly focused on the lives of autistic adults, further, there appeared to be a lack of enforceable targets and accountability mechanisms that ensured local authorities adhered to their legal duties set out in the framework. The autism strategies developed in the 2010s recognised the importance of providing access to support that was specifically tailored to individual need. Despite this, significant disparities persist in both the availability of support and consistency of implementation across different regions of the country. Anecdotally, access to support is often described by autistic people as a 'postcode lottery', highlighting the shortage of specialist services and inequitable access to interventions and supportive therapies. In addition, the importance of engaging with autistic people, their families and local advocacy groups were identified as being crucial in the future development and planning of services. However, despite some progress being made in acknowledging the importance of such collaboration, the involvement of autistic people remains limited. Finally, whilst efforts have been made to secure funding to improve diagnostic pathways, persistent challenges remain across the UK. One of the main concerns in relation to diagnosis are the significant delays in accessing assessment. Across local authorities, waiting times vary considerably meaning that many people will experience prolonged periods of uncertainty as well as significant delays in being able to access much needed support.

To continue the prioritisation of autistic people and their families, the Government released a new national strategy in 2021 which now also included autistic children and young people, entitled '*The national strategy for autistic children, young people and adults: 2021-2026'* (Department of Health, 2021). The strategy aims to build upon the initial foundations laid by '*Fulfilling and rewarding lives'* (Department of Health, 2010) and replaces the '*Think Autism'* strategy (Department of Health, 2014). The new strategy outlines a framework of six key themes specifically related to: *"improving understanding and acceptance of autism within society; improving autistic children and young people's access to education, and supporting positive transitions into adulthood; supporting more autistic people into employment; tackling health and care inequalities for autistic people; building the right support in the community and supporting people in inpatient care and improving support within the criminal and youth justice systems"* (Department of Health, 2021). The strategy overall aims to address previous limitations in policy development and work towards creating a more equitable, inclusive, and supportive environment for autistic people and their families.

1.2.5. Challenges in accessing diagnosis

Accessing an autism diagnosis is not only crucial in the development of a person's identity but is often the key to accessing the right services, support and adjustments needed to ensure autistic people can live a healthy, meaningful, and fulfilling life. One challenge that has been prevalent throughout the development and implementation of all autism strategies over the last decade is the issue of waiting times for a diagnosis. The current recommendation from the National Institute for Health and Care Excellence (NICE, 2012) guidelines is 13 weeks from initial referral to assessment, however in 2021 it was reported that many autistic people across the UK still face significantly long waits, with some reporting several years before being able to access their first appointment with a clinician (Department of Health, 2021; Huang et al., 2020). According to the data release on autism waiting times in the UK, at least 79.2% of people have been waiting longer than 13 weeks and still have no current appointment scheduled (NHS Digital, 2023). In specific areas across the UK, significantly long waits have been reported. For example in Kent, the current waiting times for an assessment is between 36-42 months (Kent Community Health, 2023), and in Leicester, wating times are between 18 to 24 months (Leicestershire Partnership, 2023). Such long delays have been shown to impact on the health and well-being of autistic people in general, but for women and girls the delays in diagnosis are often significantly longer (Brugha et al., 2016). On average, autistic women were found to be diagnosed 10 years later compared to autistic men from age at first contact and age of diagnosis (Gesi et al., 2021). Many autistic people have documented their experiences of missed or misdiagnosis and the significant impacts this has on their mental health (Mandy et al., 2018; Talcer et al., 2023). Although delayed diagnosis is not specific to just women and girls, men and people who identify as other genders also experience such. Autistic women recall their difficulties as problematic due to the stereotyped assumption that women do not fit in with the male presentation of autism often understood by clinicians and professionals (Spain et al., 2022) Moreover, autism diagnosis in adulthood has proven to be problematic for several reasons. First, diagnostic assessment relies on knowledge of developmental history, which may not always be available. Second, there may be a lack of access to early medical records. Third, recall of developmental milestones sometimes prove to be inaccurate or a person might find it difficult to remember. Finally, by the time adults recognise that they might be autistic, they will have learnt several coping strategies which enable them to mask their difficulties, making it harder for professionals to recognise and then diagnose (Fusar-Poli et al., 2022; Huang et al., 2020; Lai & Baron-Cohen, 2015).

One of the priorities set out in the latest autism strategy is “tackling health and care inequalities for autistic people” and specifically acknowledges by the end of 2026 the government wants to have made significant progress in “improving early identification, reducing diagnosis waiting times and improving diagnostic pathways for children and adults”. However, several factors have compounded the mounting delays in demand for diagnostic assessments. Over the last two decades we have seen a steady increase in the understanding of autism, partly due to the implementation of national strategy, and as a result there have been increased referrals and more people placed on long waiting lists (Russell at al., 2021). In recent years this has been further compounded by the COVID-19 pandemic (Spain et al., 2022) and more recently professionals and clinicians are increasingly realising that perhaps current diagnostic tools are outdated and may not be sufficient for recognising autism in harder to diagnose populations, such as those with non-stereotypical presentations of autism. There is increasing awareness that women and girls may be missed and not diagnosed until adolescence or adulthood due to differences in autistic presentation (Lockwood-Estrin et al., 2021). Furthermore, it is not just the presentation of women and girls who are often misunderstood or missed by professionals/clinicians, this also extends to people of other genders, the LGBTQIA+ community and people from other ethnic minority groups. Given that many people find themselves waiting several years for a diagnosis, it is not surprising that many will begin to self-identify as autistic (Lewis, 2016; Overton et al., 2023). When considering the literature on autistic people who have received a diagnosis later in life, a common theme reported throughout was how important their autism diagnosis was crucial in the formation of their identity (Kelly et al., 2022). Autistic people have described that their autism diagnosis finally gave them the validation they were seeking, that they could finally understand why they had found so many things in life difficult. Some describing an almost ‘light bulb’ moment when they realised that there was ‘nothing wrong with them’, that instead they just process the world around them differently. Understanding one’s identity may be important for several reasons, it supports self-awareness and personal growth, builds resilience and the ability to cope with daily life challenges, promotes feelings of empowerment, supports the establishment of a sense of belonging enabling a person to find a community that they can connect and relate to, and finally, supports mental well-being and quality of life (Lewis,2016a; Lewis, 2016b). Anecdotally we know that waiting times for a diagnostic assessment is one of the main contributing factors as to why a person chooses to self-identify as autistic. Autistic people have described that turning to self-identification felt like the only way in which they could understand and explain their experiences to others, most importantly it allowed them to connect with the autistic community which provided a sense of validation. Furthermore, self-identification has been a means to accessing resources and support systems, as many services and support groups now accept autistic people who self-identify instead of having to rely on a formal diagnosis, as this too often gatekeeps access to more formal services from community mental health teams and NHS services (Lewis, 2016; Overton et al., 2023). Notwithstanding the myriad of benefits that self-identification may provide in terms of identity and mental well-being, it is also important to recognise that self-identification does not replace the essential need for formal diagnostic services. The process of formal diagnostic evaluation will provide in-depth assessment of a person’s strengths, weaknesses, abilities, and cognitive profiles, enabling tailored interventions and support strategies to be implemented from specialist professionals. Increases in self-diagnosis has sparked recent debate, with discussions on social media surrounding such, raising concerns over the validity of a diagnostic label of autism. Whilst some people suggest that autism diagnoses is on the rise, ‘an autism epidemic’, due to increases in self-identification, it is important to note that this does not necessarily indicate an actual rise in the overall prevalence of autism (Smiley et al., 2018).

1.3. Prevalence, sex ratios, and gender bias

1.3.1. Prevalence of autism

Over the last decade there has been an international improvement in both awareness and public response to autism, which has accounted for improvements in early identification of autism and in turn, accounts for the higher prevalence rates reported over the last decade (Zeidan et al., 2022). Prevalence rates refer to the number of people who have been diagnosed as autistic within a specific population. In the wider discourse, the increase in rates of diagnosis have given rise to the number of people discussing an ‘autism epidemic’. However, we know, that an increase in prevalence is due to increased awareness of autism in the community, as well as broader diagnostic categories since the updates to the DSM-5 (American Psychiatric Association, 2013) and the ICD-11 (World Health Organization, 2019) diagnostic manuals (Russell et al., 2021). Understanding autism prevalence and how this has changed over the years has key implications for both autistic people, their families, and health and social care services. First, increases in autism diagnoses necessitates the importance of being able to provide information, resources, services and support to autistic people and their families. The impact of the increasing number of autistic people being diagnosed each year means that public health professionals, government officials and policy makers need to ensure that adequate service provision is provided, hence the need for the updated autism strategy discussed previously (Department of Health, 2021). Second, many autistic people face everyday challenges with trying to fit into a world that was not designed for them and may often need specialist support services, early intervention, and access to therapeutic activities. In line with the national autism strategy in the UK, understanding prevalence from the perspective of the autistic person ensures that key stakeholders can continue to design services and support systems which meet the needs of all autistic people. Furthermore, understanding prevalence rates is particularly important for service provision, understanding rates of diagnosis enables the planning and delivery of appropriate services at key transitional phases of the autistic person's life. Finally, to promote a more inclusive society, the broader societal implications of increasing diagnoses of autism should be considered. Fostering positive conversations and reducing the stigma attached to the misconception that autism is an increasing 'epidemic', will promote awareness, understanding, and acceptance of autistic people in their local communities.

The historical context of autism prevalence demonstrates significant changes in society's awareness and understanding of autism, including evolving perspectives because of research, and additional changes to diagnostic criteria. As discussed earlier, it was not until the 1940s did we begin to understand autism as a distinct diagnosis through the work of Kanner (1943). Despite Kanner's work being a significant milestone in autism history, his diagnostic criteria were narrow, meaning that unless children presented with more severe characteristics, many people who would have probably been diagnosed as autistic were missed or misdiagnosed, which could have accounted for lower prevalence rates. Through the work of Lorna Wing in the 1980s and 1990s, the diagnostic criteria broadened, meaning that more autistic people were diagnosed with ‘autism spectrum disorder’, thus increasing the overall prevalence rates. The prevalence of autism has also increased due to advancements in research and technology, which has increased identification through both improved awareness of autism, as well as the development of increased understanding of more subtle presentations of autism and co-occurring conditions. Historical contexts of autism play an important role in how prevalence rates are calculated. Our understanding of autism continues to evolve through research and as such prevalence rates will continually be shaped by improvements in understanding and identification, especially through intersectional research that includes people who identify as other genders and people from ethnic minorities (Silberman, 2015).

Currently, the majority of research focuses on the prevalence of autism in children, and as such accurate estimates of the number of autistic adults is limited. Zeidan et al. (2022) provided an up-to-date global estimate of autism prevalence. Previously Elsabbagh et al. (2012) reported a median prevalence of 62/10,000, approximately 1% of the population being autistic, whereas Zeidan et al. (2022) report a median prevalence of 65/10,000, demonstrating that recent studies continue to report an increase in measured prevalence. Despite this study being the most up to date synthesis of prevalence estimates worldwide, Roman-Urrestarazu & van Kessel (2022) call for an update to the study findings and estimates of prevalence due to the omission of their 2021 paper which was the largest

European study on prevalence to date and provides novel findings. Roman-Urrestarazu et al. (2021) reports significantly higher rates of autism than what was previously thought, with around 1/57 (1.76%) autistic children living in the UK. The study findings revealed significant differences in autism prevalence across sex, age, ethnic groups, and geographical locations, further suggesting that autism aetiology may be affected by environmental and social factors. When considering prevalence of autism in adults, including those with an intellectual disability, Brugha et al. (2016) report a rate of 1.1%. The original study on prevalence conducted by Brugha (2011) did previously not account for people with moderate to profound intellectual disability and as such the authors combined and reweighted the sample in this 2016 study to find an overall prevalence rate. Autism prevalence was found to be similar between men and women who had at least a moderate intellectual disability. Additionally, the usual higher rates of autism in males during childhood was not evident amongst adults with intellectual disability.

Evidence suggests that prevalence rates of autism can be associated to several specific factors. These factors are often interconnected, contributing to the wide variability in reported prevalence rates. First, the use of different labels or definitions of autism worldwide during diagnosis, for example, autism spectrum disorder, autism, asperger’s syndrome or autism spectrum conditions, may contribute to differences in reported prevalence. Diagnostic criteria employed by clinicians during diagnosis may also play a crucial role in determining prevalence rates. For example, diagnosis may be based on criteria outlined in either the DSM-5 (American Psychiatric Association, 2013) or the ICD-11 (World Health Organization, 2019). diagnostic manuals. Additionally, due to long waiting times for diagnostic assessment, many people now choose to self-identify as autistic, without receiving a formal diagnosis (Lewis, 2016), and as a result may affect the way in which prevalence is measured. Second, the screening tools used during the assessment process may vary among clinicians and researchers, there is no tool or method that a clinician is required to use or follow (Hayes et al., 2018), which may lead to discrepancies in prevalence estimates. In addition, clinician understanding, including potential bias towards the male stereotype of autism may further contribute to variations in estimates (Brugha et al., 2016). Prevalence rates can also be influenced by several genetic and environmental factors. Moreover, socioeconomic factors such as disparities in access to healthcare and services and diagnostic pathways as well as cultural beliefs and differences about autism can influence reporting, diagnosis, and overall prevalence rates (Hayes et al., 2018). These interconnected factors highlight the complexity of understanding and reporting autism prevalence rates and as such, emphasises the need for standardised approaches in prevalence assessment, to develop a comprehensive view of the causes and variations seen in autistic cohorts.

Taking into consideration what we currently understand about prevalence in autism, it is important to further consider the patterns and potential variations in sex ratios in autism as this may provide further insights into the mechanisms and factors contributing to varying autistic presentations. By exploring sex differences in prevalence, we can ascertain further knowledge and understanding of the potential genetic, hormonal, and socio-cultural influences that may account for the higher rates of diagnosis seen in males.

1.3.2. Sex rations and gender bias in research

Sex ratios in autism refer to the ratio of males to females who are diagnosed as autistic. Historically, autism was reported to be a male condition and is more frequently diagnosed in males than females, with a ratio of 4.56:1 (Lai & Szatmari, 2020). In contrast a recent systematic review and meta-analysis suggested that the male-to-female ratio is closer to 3:1, this means that for every three males diagnosed as autistic, only one female is diagnosed (Loomes., et al., 2017). When accounting for individuals without intellectual disabilities (ID) the ratio has been reported to increase to 8-9:1, but this may be an overestimate, with others having reported ratios of 2-2.6:1 (Fombonne, 2003, 2005; Grove et al., 2017). The reasons behind skewed sex ratios are yet to be fully understood, however the topic of why more males are diagnosed as autistic compared to females has become an increasing area of interest.

Historically, the representation of women and girls in social, cultural and scientific knowledge has been hindered by the sex/gender data gap i.e., the lack of data on females, which in turn has given rise to the male-dominated perspective seen in so many areas of life and research agendas. This lack of available data has resulted in the underrepresentation of females in areas such as social studies, health, politics, medicine, technology and media (Cleghorn, 2021; Perez, 2019). For example, in medical research, research studies were primarily centred on males, assuming that the only differences between males and females were related to reproductive anatomy and physical body size. Consequently, females were often excluded from research for many years due to the supposed complexities surrounding the menstrual cycle, which led to harmful outcomes in many areas of women's health (Blair, 2007).

In the same way, much of what we have discovered about autism over the years relates to specifically male presentations of autism, purely because most of the research includes exclusively male participants and/or smaller samples of females (Lai et al., 2015; Rivet & Matson, 2011b). The potential gender bias seen across the wider literature also continues to be a major issue in autism research, perpetuating the stereotype that autism is a male condition (Huang et al., 2020). Collectively, this has led to a lack of understanding about how autism can affect males, females, and other genders differently. This lack of awareness has led to the potential exclusion of females and other genders in research on the experiences of autistic women and girls and as a result this may have meant that support services available including diagnostic pathways, may not be tailored to their specific needs and/or autistic characteristics. Until recently, there has been a lack of specific data accounting for intellectual disability when considering sex differences, which makes it difficult to assess the potential influences this may have on the outcomes of research studies. However, a recent systematic review suggested that the female phenotype of autism is moderated by intellectual disability, with autistic girls/women with intellectual disability appearing to be more severely affected than their boy/men counterparts. Autistic girls/women without intellectual disability displayed less problems with linguistic abilities, fewer RRBIs and more sensory symptoms than autistic boys/men. In contrast autistic girls/women with intellectual disabilities displayed poorer linguistic abilities, more motor problems, and displayed more social difficulties and RRBIs than autistic boys/men (Saure et al., 2023). Moreover, given that girls with subtler autistic presentations and what is considered IQ within the typical range (sometimes described as ‘normal’), tend to be diagnosed later than boys, it is likely these individuals are being excluded from the research, which further suggests that we are most likely not seeing an accurate picture in research in terms of specific sex differences (Jamison et al., 2017; Van Wijngaarden-Cremers et al., 2014). Furthermore, existing research differs in methodological rigour and quality (Kirkovski et al., 2013; Rivet & Matson, 2011; Rubenstein, Wiggins & Lee., 2015) and most of the research focuses on comparisons between autistic males and females (Halladay et al., 2015; Jamison et al., 2017). It is important to note that many aspects of social functioning in typically developing populations vary as a result of sex differences, with girls demonstrating greater social skills and competencies from an early age. When comparing this to autistic females, research has shown milder challenges in social skills and particular coping strategies, suggesting what we are seeing may be representative of a recapitulation of sex differences seen in the typically developing population. Therefore, this can make the identification of specific difficulties seen in autistic females particularly difficult if comparison groups only include male to female comparisons, rather than comparisons between autistic and non-autistic females (Jamison et al., 2017).

The lack of inclusion of autistic females in research as well as inconsistent comparison groups has perpetuated the under recognition of autism in women and girls. Since most of the policies and procedures in place to support autistic people are informed by research, it seems reasonable to suggest that at times, our limited understanding of how autism presents in females may have contributed to autistic women being largely overlooked in the community, particularly when trying to access diagnostic pathways.

1.4. Missed or misdiagnosis of autistic women and girls?

1.4.1. Under recognition or missed diagnosis of autistic women and girls?

In recent years an increasing amount of research has investigated the reasons why many autistic women and girls are often missed or misdiagnosed. More frequently discussed is the issue that the diagnostic criteria still used today was primarily developed based on a series of observations of males, which has led to a potential clinician gender bias in recognising and understanding autism (Huang et al., 2020; Rosen et al., 2021). When considering some of the core characteristics of an autism diagnosis, there are specific areas where women and girls might be missed. First, in relation to challenges with social communication and interaction, these difficulties may manifest differently in females, making their behaviours or interactions with others appear less noticeable or typical (Lai & Szatmari, 2020). Additionally autistic women and girls have been described as being able to imitate neurotypical interactions, mimic social cues and/or adopt specific coping strategies in order to navigate social situations that they might find difficult. These specific abilities have been described as the ability to 'camouflage' and because of being so adept at being able to blend in, may cause them to go unnoticed, making it difficult for others to identify autistic characteristics (Hull et al., 2017). Consequently, the challenges that autistic females face may be attributed to shyness, introversion, or other mental health needs/conditions (Fusar-Poli et al., 2022). It is important to note that the DSM-5 itself acknowledges that "girls without accompanying intellectual disability or language delays may go unrecognised, perhaps because of subtler manifestations of social and communication difficulties" (APA, 2013; Fusar-Poli et al., 2022). Moreover, unique presentations of autism in women and girls may overlap with other conditions such as anxiety, depression or eating disorders, resulting in support that focuses solely on the co-occurring conditions rather than supporting their autism. However, differences across research studies in terms of autistic presentation between the sexes remain ambiguous. Some studies found that males and females present with similar autistic symptom severity, however in childhood, it has been suggested that some autistic girls have been found to display less RRBI's than autistic boys. It is also unclear as to whether or not female repetitive behaviours are in fact lower compared to males, or whether it is a possibility that their particular set of behaviours do not register on current diagnostic tools. Moreover, it remains unclear as to whether females exhibit greater, fewer or equal social communication difficulties. In addition, age appears to be a confounding factor within research, suggesting that autism is detected earlier in infant girls if displaying classic symptoms as well as intellectual disability. Whereas females who show milder symptoms of autism are diagnosed later on in life (Kirkovski et al., 2013; Van Wijngaarden-Cremers et al., 2014). The potential ambiguity of research findings over the years, coupled with knowledge gaps and potential unconscious biases may continue to hinder the accurate identification of autistic females, leaving them overlooked or misdiagnosed. Autistic women have reported that GPs and psychiatrists dismissed their initial concerns, thus causing a significant delay in access to diagnostic pathways and subsequent diagnosis (Kelly et al., 2022). In contrast, recent research demonstrates encouraging developments in the increased awareness of autistic women and girls by professionals involved throughout various aspects of the diagnostic process. However, despite the improvement in knowledge, updated information on differing presentations of autism is not translating into formal changes. Instead, clinicians report adapting their own procedures to ensure they are able to respond appropriately to the person they are session (McLinden & Sedgewick, 2022).

1.4.2. Theories that may account for the missed or misdiagnosis of autistic women and girls

Understanding theories related to autism is crucial for several reasons. From a biological and behavioural perspective, understanding theories can support clinicians and professionals to better understand autism and in turn develop improved diagnostic processes and strategies for support. Furthermore, developing understanding based on theoretical perspectives, allows for greater awareness which may help reduce the social stigma and discrimination often experienced by autistic people (Chown, 2019). As demonstrated in the research thus far, there does appear to be a potential misconception that autism is a male condition which may impact the identification of autism in females. Taking this into consideration it therefore seems important to consider theories related to autism that may account for some of the missed or misdiagnosis of autistic women and girls.

1.4.3. The Extreme Male Brain Theory

The extreme male brain (EMB) theory was first proposed by Simon Baron-Cohen (2002). The theory suggests that autism is specifically related to male characteristics, both cognitively and behaviourally. Baron-Cohen suggests that autism is connected to hyper-masculinised brains, characterised by more logical reasoning, a strong ability for systemising and a particular attention to detail, whilst lacking empathy. Characteristics such as high levels of systemising, and difficulties with cognitive empathy are often associated with autism. Since these characteristics are often suggested to represent the masculine, it is not surprising that that autistic people are often referred to as having ‘extreme male’ behavioural and psychological presentations (Hull et al., 2017). The EMB theory assumes that males are better suited in manipulating and solving complex systems, while females are more suited for understanding and handling complex social relationships. The EMB theory is based on research demonstrating sex differences in brain structure and function between males and females (Baron-Cohen et al., 2011, 2015). Research has demonstrated anatomical differences between the sexes, for example the amygdala (the brain region involved in emotional processing), where studies show that this particular area in the brain has been found to be larger and asymmetrical in males compared to females. Additionally, research has shown that females tend to have larger corpus callosum, which is an area of the brain that connects the hemispheres, playing a role in facilitating the communication and interaction between both sides of the brain. Furthermore, research has demonstrated that males are more suited for spatial reasoning and mental rotation tasks, whereas for females, they are better suited for verbal fluency tasks, communication, and social cognition. At the centre of this theory is the disparity in sex ratios which has led researchers to assume that autism may be linked to hormonal and genetic traits specific to males because more men are diagnosed as autistic than women. Moreover, stereotypical interests of autistic people, such as excelling in areas of systemising including maths, engineering and computer science, has perpetuated the stereotypes further.

Despite the fact that this theory is often critiqued by autistic people and other academics and professionals, the EMB theory still lives on. Critics of the EMB theory argue that the complexity of the biological and behavioural relationships are being over-simplified, and that these specific areas need a much more in-depth approach in order to truly understand how autism presents between the sexes. Furthermore, it is now widely discussed in the literature that not all autistic people have strong systemising skills and poor emphasising abilities (Botha et al., 2022).

1.4.4. The Female Protective Effect

Our understanding of autism though the lens of specific areas such as genetics, hormones, environmental factors, and neurobiology is continually evolving. Many researchers continue to investigate the complex interactions and one theory that links in with the EMB theory of autism is the female protective effect (FPE). When considering sex prevalence in autism, it is suggested the reason more males are diagnosed as autistic compared to women is in part driven by FPE. FPE suggests that females possess certain factors that shield them from developing autism or experiencing more challenges/difficulties because of their autism (Lawrence et al., 2022). Current evidence suggests that females require a greater combination of genetic and environmental risk factors than males in order to develop autism (Lai et al., 2015; Lei et al., 2019; Werling, 2016). In addition, there is evidence to suggest that the involvement of X chromosomes may play a role in FPE. For example, females possess two X chromosomes in comparison to males who have one X and one Y chromosome, and as such it has been proposed that possessing the Y chromosome may be a risk factor for neurodevelopmental conditions whereas the additional X chromosome is protective in females. The presence of two X chromosomes may support females in being able to successfully mask the effects of certain genetic mutations (Ferri et al., 2018). Finally, research has also considered the effects of sex hormones. Oestrogen is found in higher levels in females and as such may impact brain development and function and as a result, may influence autism-related genes and mitigate their effects on autistic females. Moreover, foetal testosterone is critical for the development of many observed sex differences, suggesting that genes associated with autism may be modulated by specific sex hormones (Baron-Cohen et al., 2005; Ferri et al., 2018). Interestingly, a recent study investigating neuroimaging genetics and sex differences demonstrated that the neural circuitry related to the sensorimotor regions were protected in autistic girls (Lawrence et al., 2022) which links in with existing evidence that suggests that autistic females typically present with less restrictive and repetitive behaviours compared to autistic males. However, a key limitation when considering the evidence presented in relation to FPE is that most studies have been conducted on autistic females who meet current diagnostic criteria and given that we know females may be missed or mis-diagnosed (see earlier), this limits the overall generalisability of the FPE theory to all autistic females (Hull et al., 2017).

1.4.5. The Camouflaging theory

A possible explanation for why females are on average diagnosed later than males is the ‘camouflaging’ hypothesis. Camouflaging has been explained as the ability to ‘mask’ or ‘compensate’ autistic characteristics, using conscious or unconscious techniques which overall contribute to a less autistic behavioural presentation in social and interpersonal situations (Hull et al., 2018; Lai et al., 2017; Livingstone & Happe., 2017). The ‘camouflaging’ hypothesis has been presented in various studies, however further work is needed in order to understand the constructs behind the autistic females’ ability to camouflage in order for this specific area to be used further in quantitative research studies (Bargiela et al., 2016). Emerging research is beginning to specifically focus on this area with one study suggesting that although previously camouflaging has been described as a predominantly female expression of autism, research suggests that many males and individuals who identify with other genders have also reported the use of camouflaging abilities (Hull et al., 2017).

1.4.6. The Female Autism Phenotype

The conceptualisation of the female autism phenotype (FAP) theory has emerged gradually over the last decade and aims to encompass a distinct presentation of autism exclusive to females. The FAP is said to represent autistic characteristics that are similar to those described in current diagnostic criteria but may be either expressed differently, be subtler in presentation or involve additional characteristics not currently included in the criteria (Fusar-Poli et al., 2022). The FAP considers unique female presentations in areas such as social relationships, restricted and repetitive interests, internalising problems, and camouflaging (Hull et al., 2017). Difficulties with social interaction (friendships and relationships) are key characteristics of autism (APA, 2013) and many autistic people describe difficulties with developing and maintaining friendships. However, despite these difficulties being present in both autistic males and females, research has shown that autistic females may experience more challenges in making, developing and maintaining friendships (Bargiela et al., 2016; Milner et al., 2019; Tierney et al., 2016). The FAP theory of sex differences in restrictive and repetitive interests suggest the interests of females may appear more socially acceptable and/or appropriate and therefore may lead to them being missed during diagnostic assessments. Hull et al. (2017) suggests that unless these interests are specifically probed during assessments, the qualitative differences may be missed. Moreover, if autistic females' interests create fewer difficulties in their environments, this may not be deemed as clinically significant and as such would reduce the likelihood of a diagnosis of autism being made (Hull et al., 2017).

1.5. Screening and assessment of autism

1.5.1. Context, policy, and the purpose of assessment

Presentations of autism will vary from one person to another; indeed, every autistic person will have their own unique characteristics, however all autistic people will share some similarities in presentation that makes it possible to identify and subsequently diagnose. As discussed in previous chapters there are several potential reasons why autistic women may be missed or mis-diagnosed. The importance of understanding theories that relate to autism and how this may impact screening and identification were proposed previously. In addition, although research has shown that there might be several biological factors involved in reducing the likelihood of autism in women and girls, there is still substantial evidence to suggest that current diagnostic processes, including screening are less effective at identifying autism in females, especially those without ID (Hull et al., 2017).

Evidence suggests that current screening tools may not be sensitive enough to pick up on the potentially different characteristics that women and girls may present with. In the UK, according to NICE (2012) clinical guidelines, the current recommended assessment tool used to screen for autism spectrum conditions is The Autism Spectrum Quotient (AQ; Baron-Cohen et al., 2001). The AQ is also widely used across the world and has been translated into several different languages, it is a self-report tool that assesses the presence of autistic traits over a number of domains, the higher the score on the AQ the more autistic traits a person has (see more below 1.5.2.1). The AQ provides a set of standard questions which can be used in both short and long form and provides for the measurement of autistic traits to support a referral to diagnostic assessment services. Despite being widely used for many years since its initial development, recent investigations uncovered that cut off scores used by clinicians to warrant further assessment for possible autism were interpreted incorrectly which may have led to potentially incorrect assessments and missed opportunities for referrals to specialist services (NICE 2021; Waldren et al., 2021) Given that in recent years we have come to understand that women and girls may often be missed or misdiagnosed (Rosen et al., 2021), it poses specific questions as to how many individuals in the UK may have missed out on much needed referrals for a formal diagnostic assessment. Furthermore, accessing diagnostic pathways may be particularly difficult for autistic communities of different ethnic backgrounds (Roman-Urrestarazu et al., 2021) and warrants further investigation.

Whilst the AQ has been a valid and instrumental tool in the way autism is screened for in the UK, in recent years it has come under scrutiny for exhibiting biases that may disproportionately affect females (Belcher et al., 2022). The potential biases stem from multiple factors including gender differences in social skills, the male stereotype of autism, and because the diagnostic criteria that the AQ is based on was originally developed on male-centric research participants (Rosen et al., 2021). Furthermore, the current format of the AQ limits its ability to take into consideration the influence of contextual factors that may impact the expression of autistic characteristics in females. For example, the AQ is not able to account for situational variations or the autistic persons abilities in masking techniques. As such, this lack of sensitivity may lead to inaccuracies in screening results which could potentially exclude females from being referred on for further diagnostic assessment. In addition, diagnostic overshadowing may occur if the autistic female's specific autism presentation is misunderstood and attributed to other personality traits or mental health conditions. The AQ is suggested to be sufficient and reliable in identifying autistic women and girls, so long as the clinician is experienced and knows what they are looking for, demonstrating an understanding of the key differences in presentations that are often associated with autistic women and girls. However, clinician bias is thought to be potentially problematic due to the fact that professionals may not always be up to date in their understanding and are guided by what information is most readily available to them (Hayes et al., 2018).

The AQ has remained in use for over 20 years, back when autism was still thought of as a predominantly male condition, but until recently we have only had access to anecdotal evidence reporting on potential gender biases. Despite being sufficient in some key areas of assessment, it is frequently suggested that current tools such as the AQ are outdated in relation to their wording and specific stereotyping in relation to outdated autistic presentations. It was not until very recently that a study revealed that the AQ was heavily gender biased (Belcher et al., 2022). Belcher et al., (2022) reports that the AQ does not measure the same autistic characteristics in males and females, which therefore suggests that it may not be a valid tool for either pre-diagnostic screening, referral processes and/or in research studies. Failing to address the suggested biases will continue to perpetuate the potential of diagnostic overshadowing as well as the perpetuation of gender disparities in the understanding and subsequent diagnosis of autism in females. Moreover, one of the most commonly used diagnostic tools used in the UK is the ADOS-2 (Lord et al., 2012) and similarly to the AQ (Baron-Cohen et al., 2001), was developed on a predominantly male cohort (Rosen et al., 2021).

The use of screening tools are crucial in the early identification of autism and facilitates timely access to referrals for diagnostic assessment and additional support. However, the heterogenous nature of autism and the unique experiences of different populations, such as women and girls, present challenges in accurately capturing and assessing autistic characteristics. In clinical practice, screening tools refer to standardised instruments designed to identify people who have a high probability of being autistic. Screening tools enable professionals and clinicians to efficiently and effectively screen for autism, leading to the identification of people who may require further assessment or diagnostic evaluation (Pilling et al., 2012). Most commonly used are self-report screening tools, these are measures that rely on an person's own perceptions, experiences, and self-reflection on their thoughts, feelings, and autistic behaviours, strengths and challenges. In contrast, informant measures rely on information provided by people who have close relationships with, and who understand the person in depth, in order to understand the strengths, challenges and needs of the autistic person. An informant may be a parent, carer or a schoolteacher. Informant measures can be particularly important in the assessment of people who may have difficulties completing self-report measures, such as young children, people who experience communication difficulties, as well as people who may lack self-awareness of their autistic characteristics and the challenges associated.

Screening tools for autism are an initial step in the assessment process and helps to determine whether further evaluation and/or referrals to diagnostic pathways is needed. Whilst screening tools cannot provide a formal diagnosis of autism, they can support the collection of preliminary information to build a picture of a person's strengths and challenges. Screening tools are often used in a variety of settings where concerns about potential autism are first considered, such as schools, hospitals, mental health teams, and GPs (Huang et al., 2020). There are currently no overall regulations as to which screening tools must be used during assessment (Hayes et al., 2018), only recommendations, for example NICE (2012) guidelines in the UK. As a result, which type of assessment is chosen will depend on the service and/or professional responsible for the screening process. Depending on what assessment has been chosen, best practice would ensure that the autistic person is provided the opportunity to communicate their own perceptions of their needs and challenges, and if this was not possible and/or if the person is a child, then someone who knows the person well will be asked to complete the forms on their behalf. In general, research recommends the importance of utilising multiple tools in order to ascertain a broad picture of the person’s needs. Most screening tools will be in the format of a questionnaire, accompanied by a series of statements that relate to specific characteristics of autism, for example social interaction and communication. Moreover, each statement in the tool will be allocated a score, there will be a specific cut-off/threshold for autism where the total overall score will then be used to provide an indication of the likelihood of autism.

1.5.2. Types and purposes of autism assessments

1.5.2.1. The Autism Quotient (AQ)

The AQ (Baron-Cohen et al., 2001) was originally developed as a 50-item self-report questionnaire used to measure autistic traits in adults aged 16 years and above, with an IQ in the normal range (IQ>=80). The AQ asks the person to rate the 50 items based on a 4-point likert scale of definitely agree, slightly agree, slightly disagree and definitely disagree. The AQ has a scoring range of 0-50 and scores above 26 suggest that the person might be autistic, the higher the score, the more autistic characteristics a person is said to have. 79.3% of autistic people who complete the AQ score 32 or higher (Baron-Cohen et al., 2006). Most frequently used in clinical screening is the AQ-10, first because the smaller number of items makes it easier and more time efficient to administer in clinical settings, and second due to the fact that some studies suggest that the AQ contains a number of items that are potentially biased, recommending the use of the AQ-10 when comparing between groups (Agelink van Rentergem et al., 2019). Furthermore, some studies suggest that items of the AQ re unrepresentative of autistic traits and as such would benefit from revision (Lundqvist & Linder, 2017). Notwithstanding, the AQ demonstrates good test-retest reliability and inter-rater reliability (Baron-Cohen et al., 2001). The AQ-10 (Allison et al., 2012) is not as comprehensive as the AQ and comprises of 10 items based on a 4-point likert scale of definitely agree, slightly agree, slightly disagree and definitely disagree. The AQ-10 scoring system suggests that if a person scores 6 or higher, this is likely to be indicative that the person may be autistic. The AQ-10 has been found to be a useful screening tool for rapidly identifying autism in adults and has been reported to have retained the predictive validity of the full AQ-50 tool (Allison et al., 2012). However, in contrast a recent study by Conner et al., (2019) suggested that AQ was in fact only moderately effective in identifying who would be diagnosed with autism.

1.5.2.2. The Empathy Quotient (EQ)

The EQ (Baron-Cohen & Wheelwright, 2004) is a self-report measure used to measure empathy in adults, however there are also versions for children and adolescents also. The original EQ was designed to be administered to those 16 years and older with an IQ in the normal range (IQ>=80). Th EQ consists of 60 items based on a 4-point likert scale of definitely agree, slightly agree, slightly disagree and definitely disagree, and are broken down into two types of statements, 40 items on empathy and 20 filler items designed to distract the participant from the intense focus on empathic characteristics. In contrast to the AQ, scores below 30 are indicative of autism i.e. the lower the score the more likely you are to be autistic. The EQ demonstrates good reliability and validity, with a good test-retest reliability of 0.835 when re-taken 12 months later (Lawrence et al., 2004).

1.5.2.3. The original Systemising Quotient (SQ)

The SQ (Baron-Cohen et al., 2003) was developed primarily from traditionally male domains and was later revised to further incorporate items that might be more relevant to females (Wheelwright & Baron-Cohen, 2006). The Systemising Quotient-Revised (SQ-R; Wheelwright & Baron-Cohen, 2006) is a self-report measure used to assess systemising cognitive styles. The SQ-R was designed for those 16 years and older with average or higher IQs, there are also versions for both children and adolescents. The SQ-R includes 75 items based on a 4-point likert scale of strongly agree, slightly agree, slightly disagree and strongly disagree. The SQ-R is scored between 0-150, with a score of 75 or higher being indicative of autism. For both the SQ and the SQ-R limited reliability and validity data is reported (Ling et al., 2009), however shortened versions of both the EQ and SQ were found to demonstrate reasonable validity, however further research is needed to evaluate these further (Wakabayashi et al., 2006).

1.5.2.4. The Friendship Questionnaire (FQ)

The FQ (Baron-Cohen & Wheelwright, 2003) is a self-report measure designed to measure a specific model of friendship, suggesting that differences in friendships will be different for autistic people compared to non-autistic people. Moreover, Baron-Cohen and

Wheelwright (2003) utilised this study to further prove the EMB theory of autism (described earlier in chapter X). The FQ contains 34 multiple choice questions and has a scoring range of 0-135. It is suggested that the lower the FQ score, the more indicative of specific autistic characteristics related to friendships. Moreover, the research suggested correlations with the AQ and EQ in theoretically consistent ways, those scoring low on the FQ demonstrated higher AQ scores and lower EQ scores (Baron-Cohen & Wheelwright, 2003).

1.5.2.5. The Ritvo Autism Asperger Diagnostic Scale-Revised (RAADS-R)

The RAADS-R (Ritvo et al., 2011), also used in clinical settings in the UK, is a self-report measure designed to identify autism in adults who may not be identified by other readily used screening tools due to subclinical levels of autistic presentation. The RAADS-R is an 80-item measured intended to be used by adults who are 16 years or older and have an IQ in the normal range (IQ>=80). The RAADS-R is scored between 0-240 and a score of 65 or over is likely to indicate autism. Further, the RAADS-R is reported to be a reliable instrument, demonstrating high test-retest reliability (Ritvo et al., 2011). Like the AQ described earlier, Conner et al. (2019) also assessed the RAADS-R alongside the AQ and the ADOS-2 (Lord et al., 2012) and again reported that all measures, including the RAADS-R were only moderately effective in identifying people who would be diagnosed as autistic.

1.5.2.6. The Camouflaging Autistic Traits Questionnaire (CAT-Q)

The CAT-Q (Hull et al., 2018), is a self-report measure used to identify social camouflaging behaviours in adults aged 16 or above, with an average to higher IQ. The CAT-Q comprises of 25 items that measure three sub-categories: *compensation*, the strategies used by the person to compensate for autistic related difficulties that they experience in social situations; *masking*, the strategies used by the person in order to hide the autistic characteristics and/or to appear as a non-autistic person; and *assimilation*, the strategies used by the person in order to fit in with others. A total score of 100 or above indicates that the person camouflages their autistic traits, the higher the score, the more autistic traits the person is likely to supress. The CAT-Q is reported to have high internal consistency, with good test-retest reliability. For the three sub-categories good stability was demonstrated for the total scale and the compensation category, with moderate stability demonstrated for the masking and assimilation categories (Hull et al., 2018).

1.5.2.7. The Adult Repetitive Behaviours Quesionnaire-2 (RBQ-2A)

The RBQ-2A (Barrett et al., 2015) is a 20-item self-report measure intended to assess restricted and repetitive behaviours (RRB) in adults aged 18 or older with average or higher intelligence. The RBQ-2A focuses on two main categories, *insistence on sameness* and *repetitive motor behaviours.* The RBQ-2A has demonstrated that it is a reliable and valid measure of RRBs, with the ability to successfully differentiate between autistic and non-autistic people (Barrett et al., 2018).

1.5.2.8. The Comprehensive Autistic Trait Inventory (CATI)

The CATI (English et al., 2021) is a recent screening tool that aims to measure a broad range of autistic characteristics that are not always included in previous screening tools, for example sensory sensitivities. The CATI is a 42-item measure separated into six categories: social interactions, communication, sensory sensitivity, repetitive behaviour, social camouflage, and cognitive rigidity. Preliminary evidence suggests that the CATI is a reliable measure, with the internal consistency of the total scale and individual subscales exceeding the threshold for practical use and interpretation. Although initially developed to measure characteristics associated with autism in non-autistic people, initial testing demonstrated that the CATI appears to be better at distinguishing between autistic and non-autistic people compared to other measures of autistic traits (English et al., 2021).

1.5.2.9. The Girls Questionnaire for Autism Spectrum Condition (GQ-ASC)

The GQ-ASC (Brown et al., 2020) is an extension of the original Questionnaire for Autism Spectrum Condition (Q-ASC; Attwood et al., 2011) which aims to identify autistic characteristics in women. The GQ-ASC is a 22-item measure broken down into five categories: imagination and play during childhood, camouflaging, sensory sensitivities, socialising and interests. Preliminary evaluation of the GQ-ASC demonstrated moderately low to adequate internal consistency, a high degree of sensitivity and a robust capacity to discriminate between autistic and non-autistic women (Brown et al., 2020).

1.5.2.10. The Autism Screening Questionnaire (ASSQ) and the Autism Spectrum Screening Questionnaire-Revised (ASSQ-R)

The original ASSQ (Ehlers & Gillberg, 1993) was first tested in children with high-functioning autism and Asperger syndrome, it was a 27-item checklist designed to be completed by parents or teachers. The tool was shortly revised to become the ASSQ-REV which was developed with the purpose of supporting the early identification of autistic girls (Kopp & Gilberg, 2011). The original study of the ASSQ did not report any psychometric properties of the tool, however the revised version was reported to demonstrate considerable discriminative ability. However, overall, it appears that when combining evidence from both studies, both the ASSQ and the ASSQ-REV demonstrate insufficient reliability and validity (Cederberg et al., 2018).

1.5.3. Assessment Scale Development

1.5.3.1. Psychometrics

Psychometrics is the science of psychological assessment and focuses on the measurement of psychological attributes or traits (Cooper, 2023; Rust & Golombok, 2009). Psychometrics is widely used in the field of psychology and focuses on the development and evaluation of measurement tools that are designed to measure and predict psychological traits, aptitudes, and behaviour (Wijsen et al., 2021). These measurement tools may be used to assess a wide variety of abilities, personality traits, intelligence, or specific behaviours, also referred to as psychological constructs. A psychological construct refers to a concept or variable that cannot be directly observed, but instead is inferred from observable behaviours, thoughts, feelings, or other indicators, for example engagement in an activity. Such constructs are typically defined through established frameworks in the field of psychology and/or theories of human behaviour, as well as the empirical research evidence of a particular topic. Measurement tools may be presented in the form of tests or questionnaires, for example, interviews, examinations, or diagnostic assessment. Even though psychometric assessments can be used in a variety of applications, all assessments share fundamental characteristics in that they should be reliable, valid, standardised, and free from bias. Therefore, psychometrics is the science of maximising the quality of the assessment to ensure that they become reliable and valid measures to understand and quantify different aspects of human behaviour and/or experiences (Cooper, 2023; Rust & Golombok, 2009). Thus, the quantitative approach taken in psychometrics aims to make research more rigorous and reliable (Wijsen et al., 2021). Moreover, the principle of psychometrics acknowledges that all assessments and measurement tools are imprecise and subject to error, known as the theory of true scores (Cooper, 2023; Rust & Golombok, 2009). This specifically relates to classical test theory (CTT) which is a fundamental theory of psychometrics, CTT provides a framework for understanding the reliability and measurement of an instrument and states that an individual's score on an assessment are represented by two components, the true score and the measurement score (Cooper, 2023; Rust & Golomok, 2009). The 'true score' represents the person's true ability or characteristic and refers to the hypothetical score that a person would obtain on a measurement tool if there was no measurement error, however because no measurement tool is 100% precise, there will always be some degree of 'measurement error' present in the total score. In contrast, the 'measurement error' refers to the discrepancy between the true score and the observed score from the tool and represents the variability or inconsistency between scores that are unrelated to the person's ability or characteristic. These errors may arise due to various factors such as random fluctuations in a person's presentation, situational factors or the imprecision of the actual measurement tool. In the context of autism, researchers/clinicians will often rely on various assessments and screening tools to identify and measure autistic characteristics. Using a framework such as CTT provides methods of evaluating the quality of the measurement tool such as reliability and validity in order to gain confidence in the tools accuracy and consistency (Cooper, 2023).

Reliability refers to the consistency of a measurement tool over time, in the context of autism the reliability of a measure demonstrates whether or not the observed scores are accurately reflecting the autistic characteristic it is intended to measure. Procedures to assess reliability may include test-retest reliability and internal consistency reliability. Test-retest reliability can sometimes be referred to as test stability, the process involves administering the assessment tool twice to the same respondent with an interval of time between e.g., two weeks, this provides a total of two scores which can be used to determine a reliability coefficient (Cooper, 2023; Rust & Golombok, 2009). Assessing internal consistency ensures that the items in a measurement tool are related and that they are measuring the same underlying construct and is typically evaluated using Cronbach's alpha. For example, for a measurement tool assessing autistic characteristics you would expect to see items relating to social communication difficulties, which are consistent with the concepts of autism. In other words, a high value of internal consistency provides an indication that the items on the measurement tool are measuring the same construct. Notwithstanding, reliability is necessary when evaluating measurement tools, however further assessments of validity are needed to determine the overall effectiveness of the tool. Validity is best explained as the extent to which a measurement tool accurately reflects the construct it is intended to measure. However, as identified in frameworks such as CTT, although there are various methods that can provide evidence to the validity of a tool, there is no way of suggesting that a tool is completely valid with absolutely certainty. For example, validity is entirely contextual, meaning that a measure can be valid in one setting, but may not be valid in others (Cronbach, 1970). There are various assessments of validity that can be conducted to assess a measurement tool overall. In reference to autism, items on the measurement tool should capture the core characteristics associated with autism and can be gathered by assessing content, criterion, or construct validity. Content validity is an assessment to ascertain the extent to which the measurement tool covers all of the relevant aspects of the concept it is intended to measure. For example, content validity of a measure to assess autism would be ensuring that the full spectrum of autistic characteristics was captured i.e., social communication, relationships, sensory and repetitive or restricted behaviours. Criterion validity pertains to how scores on a new measure for example, correlates with existing measures that purport to measure the same construct (Rust & Golombok, 2009). Finally, construct validity is one of the primary forms of validation and focuses on the underlying theoretical construct and whether or not the measurement tool in question accurately measures the intended concept (Rust & Golombok, 2009). The methods used to assess reliability and validity in this study will be outlined further in chapter 7.

Chapter Summary

This introduction chapter has provided a comprehensive overview of autism with a particular focus on the experiences and challenges faced by autistic women and girls. Prevalence rates and current sex ratios have been explored, which links in with the growing recognition that traditional screening assessments and/or diagnostic criteria may not adequately capture the potentially different presentations of autistic women and girls. Furthermore, the introduction provided an overview of some of the current theories of autism which may account for the missed or misdiagnosis of autistic females, particularly highlighting that potential gender biases may have prevented their identification and access to much needed appropriate support services. Moreover, the potential limitations of widely used screening tools, such as the AQ are discussed. The reported gender biases embedded within not only policies and procedure related to diagnostic pathways, but within the screening tools themselves, may have contributed to the missed or misdiagnosis of autistic females, perpetuating disparities in their access to timely diagnosis and access to much needed support.

Chapter 2. Rationale, Methodology, and Thesis Outline

2.1. Rationale for this Thesis

Autism is a lifelong developmental condition characterised by difficulties in social communication and interaction, restrictive and repetitive behaviours, and sensory sensitivities (APA, 2013). The presentation of autism varies significantly across people as well as individual backgrounds. Over the last ten years or so, understanding and identifying autism in women and girls has been a subject of growing interest and concern within the field of autism research. Historically, much of the research has focused on understanding autistic males, and as such, the stereotype that autism is a predominantly male condition still exists today. Due to the fact that over the last several decades more males have been diagnosed as autistic compared to females, this has resulted in a potential gender bias that has contributed to a disparity in both the recognition and subsequent diagnosis of autistic females. Consequently, this potential bias has implications for the missed or misdiagnosis of autistic women, further impacting access to much needed support due to delays in recognition. In addition, various theories of autism such as the extreme male brain theory, the female protective effect and camouflaging, have all potentially contributed to the misunderstanding of the way in which autism presents in females. Moreover, current screening tools such as the AQ were widely developed based on predominately male participants, and as such have been criticised for its reliance on stereotypical male presentations (Belcher et al., 2022; Rosen et al., 2021).

As explored in Chapter 1, there may be a potentially unique presentation of autism in females in areas such as social relationships, restricted and repetitive interests, internalising problems, and camouflaging (Hull et al., 2017). Although there does appear to be a delay in diagnosis for autistic females compared to autistic males, this may not be exclusive to females. Additionally, research suggest that autistic females may be missed or misdiagnosed due to their camouflaging abilities. As seen in the wider literature, evidence suggests that current screening tools and/or diagnostic criteria may not adequately capture the diverse ways that autism may present in women and girls, and as such, lays the foundations for this research. Consequently, the overarching aims of this research is to develop a measure that primarily serves two purposes: first to be utilised as a comprehensive screening tool designed to identify and assess autistic characteristics in women, serving as an effective measure to support earlier identification and recognition. Second, the measure aims to go beyond the use of a generic screening tool to provide a nuanced and detailed description of the presentation of autism in women. This potential dual functionality serves the broader objectives of this thesis in understanding the diverse presentations of autism in non-male samples. By encompassing both screening and descriptive dimensions that may not necessarily be a specific autism criterion, the measure aims to provide a more inclusive and accurate portrayal of the needs and characteristics of autistic women, thus addressing the need for a more nuanced understanding that moves beyond traditional diagnostic criteria and frameworks. . The following chapters in this thesis will detail the studies conducted to achieve these aims and will include the examination of the literature pertaining to the experiences and behavioural presentations of autistic women and girls. This will be followed by a series of studies that incorporates autistic perspectives and feedback in the development and refinement of a new screening tool for autism, The Female Autism Spectrum Screening Tool (FASST; see chapter 6), and finally evaluating the psychometric properties of the FASST, as well the efficacy in being able to accurately discriminate between autistic and non-autistic people.

2.1.1. The Research Question

The main research question for this thesis is:

> How can the experiences and behavioural presentations of autistic females be better understood and assessed, and to what extent can the new screening tool for autism, the FASST, accurately discriminate between autistic and non-autistic people?

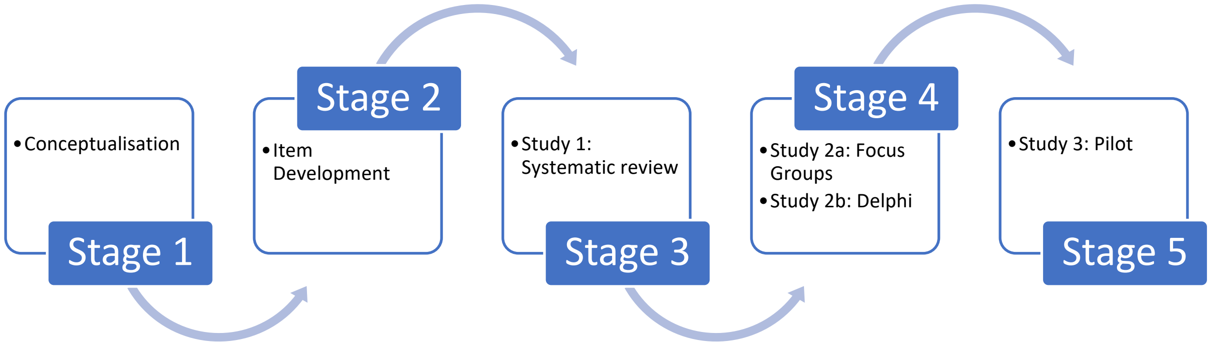
This broader research question will be broken down into more specific research questions for each stage of this research. These individual research questions will be provided when each subsequent study is described.

2.2. The Research Framework

2.2.1. Scale Development

To understand and measure complex phenomena within health, social and behavioural sciences, scale development and validation is critical (Morgado et al., 2018). Measurement scales are typically used to capture behaviour, attitudes, and hypothetical scenarios that cannot be assessed directly (Boateng et al., 2018). According to Boateng et al. (2018) there are three phases to creating a measurement scale, item development, scale development, and scale evaluation. The first phase, ***item development,*** includes the generation of the construct to be measured and the development of an initial set of questions that will be used in the measure. Following this, content validity will be considered. The second phase, ***scale development,*** focuses on turning the individual items into a harmonious construct to ensure the phenomena is being accurately capture. This included pre-testing questions, sampling and survey administration, item reduction and lastly, the extraction of latent factors. In the final phase, ***scale evaluation,*** three further steps are required which include tests of dimensionality, tests of reliability and tests of validity (Boateng et al., 2018). Scale development methodologies may include deductive methods, the use of existing literature, established theory or current measures, or inductive methods, the use of focus groups, interviews or observations in order to develop a new assessment measure (Boateng et al., 2018; Morgado et al., 2018). Moreover, Boateng et al. (2018) suggests that best practice in the development of assessment item content is to utilise a combination of both deductive and inductive approaches.

Throughout this research we have aimed to gather preliminary evidence for the usefulness of a screening tool (the FASST) that might improve identification of autistic women and girls. A series of research studies were conducted that supported this overall aim, and whilst not following the above framework in a strict and comprehensive manner, we aligned the current research methodologies with the key principles and overall steps of Boateng's (2018) framework. This thesis is divided into five stages (see diagram below): conceptualisation, item development, systematic review, focus groups and Delphi, and finally the pilot of the new screening tool. Each stage will be broadly discussed, with further detailed information provided in the following sections of this chapter.



The first stage was an introduction to the context of the research (Chapter 1), also referred to as ***conceptualisation.*** Each study in this thesis was grounded in the overarching construct of improving the identification of autism in women and girls. By recognising the potential limitations of existing screening tools, our aim was to develop a screening tool that included items that may be more relevant to the experiences and behavioural presentations of autistic women and girls, moving beyond stereotypical presentations of autism currently understood. This overarching conceptualisation guided the subsequent stages of this research. The second stage was ***item development,*** this research commenced based on an original item pool developed by Professor Peter Langdon and Dr Fiona Gullon-Scott, drawing from their expertise and previous literature at the time. The initial item pool was considered; however, it was recognised that further research was needed to enhance the initial content validity of the FASST. To address this, the first study (Stage 3) in this thesis was a ***systematic review*** of the literature pertaining to the experiences and behavioural presentations of autistic women and girls (primarily adolescents, young women and adults) which expanded the item pool of the FASST by incorporating additional items that were identified through a comprehensive analysis of the existing research. The fourth stage (Study 2a and 2b) was ***refinement through Focus Groups and Delphi consultations and*** included the collection of qualitative data through focus groups and second, utilised a

Delphi methodology to further refine the item pool. These methods allowed for the involvement of autistic women with lived experiences, professionals, and other key stakeholders in the process. Through iterative rounds of discussions, feedback, and consensus building, we were able to identify and address items in the FASST that needed modification, removal, or addition, ensuring that the final draft of the FASST captured a comprehensive range of potentially relevant autistic characteristics. The final stage (Study 4) was ***pilot testing,*** which involved administering the FASST to a sample of participants that included autistic people, people who self-identified as autistic and non-autistic people, to gather preliminary data on the FASST's reliability and validity. Although this stage was not a comprehensive assessment, the pilot allowed for the initial assessment of the FASST's psychometric properties such as internal consistency and test-retest reliability. Following Boateng's (2018) framework more broadly ensured that the research aims of this thesis were guided by recommended principles of scale development and validation. Therefore, the results from this pilot phase will lay the groundwork for future research into the potential of the FASST, allowing for further revisions and improvement of the FASST on wider scale.

2.3. Overall Methodology

The second half of this chapter presents the methodological approaches used throughout this thesis and provides an outline of the three studies conducted within this thesis. The research design, methods employed and the rationale behind each methods' selection will be presented, highlighting each methodologies congruence with epistemological and ontological perspectives. The studies in this thesis focused on exploring the experiences and behavioural presentations of autistic women and girls, with the overall aim of developing a screening tool specifically designed to capture the female presentation of autism. Throughout each study it was important to adopt research methodologies that not only ensured the perspectives and experiences of autistic people were captured, but to also account for potential gender biases in the current evidence base, that may lead to missed or misdiagnosis. To ensure the robustness and validity of the findings within this thesis, epistemological and ontological standpoints were carefully considered to ensure the methodologies were aligned with these perspectives.

In the following sections a brief introduction to epistemology and ontology will be provided, followed by a discussion of the specific methodologies employed throughout this research, beginning with the use of focus groups to gather diverse perspectives and further refine the FASST. The utilisation of the Delphi consultation to further validate and refine the items on the FASST will then be discussed, followed by a description of the pilot study where the revised FASST will be tested for its effectiveness in being able to accurately identify autistic women. Consideration of quality assessment in quantitative and qualitative research will be discussed and finally, ethical considerations will be presented. This thesis aims to adhere to rigorous methodological principles in order to contribute valuable insights that can further inform our understanding of the female presentation of autism, as well as potentially informing clinical practice, policy development and future research.

2.3.1. Epistemological and Ontological Frameworks

Philosophy provides the social sciences with the overarching principles of theoretical thinking, consequently, two main branches of philosophy are important (Moon & Blackburn, 2014). Epistemological and ontological frameworks are crucial in shaping our understanding of the world, and thus supports the decisions made when choosing methodologies for research. Epistemology is the study of knowledge and how it is acquired, acknowledging the subjective nature of the human experience. Ontology, in contrast, seeks to understand the nature of reality, in other words ‘the study of being’. It explores knowledge and reality, and in turn seeks to understand the relationships between the existence of objects and concepts, acknowledging that these are socially developed through human interaction and interpretation (Creswell, 2023; Moon & Blackburn, 2014).

When considering specific methodologies, an epistemological perspective shapes the way in which we understand meaning, how knowledge can be obtained and considers the reliability and validity of the evidence presented. In social sciences research, many different epistemological stances exist that emphasise the use of different methodologies to explore a particular research question. These include: interpretivism, a methodology frequently used in social science, it prioritises understanding the subjective meaning related to the experiences lived by people; constructivism, emphasises that knowledge is derived from personal experiences and individual interpretation, acknowledging that cultural contexts and social interactions play key roles in the creation of meaning; and finally pragmatism, this methodology suggests that knowledge is a means for solving practical problems, it values the practical consequences of ideas and actions, through experimentation and testing in real-world settings (Creswell, 2023). In contrast, an ontological perspective guides our understanding of the phenomena in question and the assumptions made about their existence and properties. Like epistemology, there are different ontological stances that can be adopted, these include: objectivism, which suggests that empirical observation and logical analyses are important in understanding and identifying facts. This perspective specifically highlights that objective facts relevant to the world are independent of human perception, and that beliefs and knowledge are generated based on facts; realism, emphasises that an objective reality is shaped by social, cultural and historical factors and focuses on identifying and understanding the causes and mechanisms that impact social aspects; and finally positivism, which emphasises that knowledge is revealed from measurement of quantifiable observation, in other words, if something is not measurable then it cannot be known for certain. The use of such epistemological and ontological frameworks supports the development of a theoretical perspective, in which researchers develop a specific framework which guide interpretation of the phenomena being investigated. A theoretical framework sets out guiding principles, concepts, and assumptions which are then used to interpret data, identify patterns and relationships, and further provide explanations or used to develop theories. Theoretical perspectives can be influenced by various factors, including the researcher's own background and research interests, and as such careful consideration is needed in the development of working philosophical frameworks (Creswell, 2023).

2.3.2. Research Philosophy

A philosophical worldview can be defined as "a basic set of beliefs that guide actions" (Creswell, 2023 p.7), also referred to as epistemologies and ontologies. As a researcher, my worldview is underpinned by the many roles I have experiences both professionally and as an academic, and as a result, I approach research from the standpoint 'nothing for us, without us'. Despite the fact this suggests a more qualitative approach to my research, this does not discount the importance of quantitative methods of data collection. Consequently, a mixed methods approach was adopted for this research project. The worldviews that have been paramount in the underpinning of the methodologies chosen for this research are again mixed in principle and overlap in some areas. Much of this research is rooted in constructivism, a belief that subjective meanings are negotiated both socially and historically. Further, these meanings focus on the specific contexts in which people live, to understand the historical and cultural settings of each individual participant. In addition to the constructivist worldview, this research is further underpinned by a transformative worldview. Transformative research provides a voice for autistic people (Rosqvist et al., 2023), it demonstrates an agenda for change; for research to become a united voice for reform and policy development. Both constructivist and transformative world views demonstrate the importance of understanding the viewpoints of the individuals included in their research, in this context autistic women and girls. However, the transformative worldview specifically focuses on collaborative processes to ignite change, in this context, redesigning the autism screening process to better identify autistic women and girls, to provide more timely access to support (Creswell, 2023).

2.3.3. Theoretical Perspectives

Given the information discussed in the chapters thus far and the research question posited, the theoretical perspective taken in this research appear to align with a combination of social constructionism, feminist theory and critical autism studies. These theoretical perspectives emphasise first, that dimensions of autism can be both social and cultural; second, recognises the importance of considering gender and societal factors in understanding the experiences of autistic women and girls, and finally, challenges essentialist views and understandings of autism. Social constructionism suggests that knowledge and meaning are socially constructed through interactions and shared understandings within contexts. Social constructionism acknowledges that autism is not an objective fixed entity, but rather defined by shared observable behavioural categories as well as being socially constructed, shaped by historical, cultural, and social factors (Cockerham & Scambler, 2021). This perspective aligns with our research question which focuses on understanding the social construction of autism and how suggested gender biases may influence the experiences and subsequent diagnosis of autistic women and girls. Feminist theory considers the gender inequalities, power dynamics, and social structures that may influence the experiences and identities of a person. In the context of this forthcoming research, feminist theory (Mallipeddi & VanDaalen, 2022) highlights the need to specifically address potential biases and challenges the assumption that autism is primarily a male condition. This perspective encourages the exploration of the unique experiences and needs of autistic women and girls by exploring how the presentation of autism in women and girls may go against societal norms and expectations. Critical autism studies are a cross-disciplinary field that critically examines dominant discourse and practices related to autism. Critical autism studies *"offer potential and possibilities to continue to seek the emancipation of autistic people, focus on intersectionality and injustices, and for academics who are autistic and non-autistic to work together in producing important scholarship that gas reach and impact"* (p.4, Milton & Ryan, 2023). Furthermore, this perspective challenges stereotypes and advocates for the inclusion of diverse perspectives and experiences in research. Critical autism studies therefore aligns with our overall aims of challenging essentialist views, exploring and developing alternative screening tools, and actively involving autistic people and other key stakeholders in this research process. Overall, by integrating these three theoretical perspectives, our research aims to contribute to a more inclusive and nuanced understanding of autism.

2.3.4. Research Design

The purpose of this research was a combination of descriptive and correlational, as the goal was to first describe the experiences and behavioural presentations of autistic females, second, to then use this information to develop the FASST, and third, to pilot the FASST to ascertain whether the new screening tool could accurately discriminate between autistic and non-autistic people, as well as assessing the tool's psychometric properties. The research overall can therefore be understood as an inductive mixed methods approach, using a non-experimental correlational research design.

Employing an inductive approach allowed for the collection of specific data to generate new insights, identify patterns, and develop a comprehensive understanding of experiences and behavioural presentations of autistic girls, to inform the development of the FASST. Notwithstanding, a deductive approach may have also provided valuable information if for example the FASST screening tool results were compared to formal diagnostic assessments, however an inductive approach was chosen for several reasons. First, as a pilot study, the focus was on exploring and refining the FASST, rather than testing a specific prediction. Second, using focus group methodologies allowed for the collection of rich qualitative data from the experiences and perspectives of autistic women and other key stakeholders, which aligned well with an inductive approach. Lastly, the use of an inductive approach allowed for flexibility and adaptability throughout each study, enabling the FASST to be iteratively refined based on the emerging findings and feedback from participants. However, it is important to note that reviewing the evidence base as part of scale development can be referred to as a deductive approach, so although this research was primarily inductive by nature, there were some elements of deductive reasoning as a result of the systematic review.

Epistemologically, this research approach emphasises the importance of capturing diverse autistic voices as well as a person’s lived experience of such, to gain a more nuanced understanding of differing autistic presentations. Qualitative methodologies are not only important in exploring subjective experiences, but also recognises various contextual factors as well the social dimensions of autism. The use of mixed methods allowed for the collection of both qualitative and quantitative data, acknowledging the value of different types of knowledge within autism research. The qualitative components of this research supports the epistemological emphasis on ensuring the voices and lived experiences of autistic people were captured. The use of focus group and Delphi methodologies allowed for the exploration of the potential nuances in autistic women and girls, and how individual perspectives and the interplay of different social, cultural and personal factors influenced the identification of autism in females. The quantitative component allowed for the collection of numerical data which was specifically used to identify any correlations between the FASST, other screening measures and whether or not the FASST was able to accurately discriminate between autistic and non-autistic people.

Moreover, ontologically, it is crucial to acknowledge the social construction of autism and the importance of challenging essentialist views (Kapp, 2019) by actively involving autistic women, parents/carers, professionals, and other key stakeholders in the research process. The mixed methods approach employed throughout this research allowed for the development of a comprehensive understanding of how autism may present in women and girls, beyond the standard stereotype of autism. Further, acknowledging that in order to move beyond simplistic categorisations of autism, autism research must begin to accurately capture the complexity and diversity inherent in the lives of autistic people.

2.3.5. Sampling

The sampling process is a crucial step in ensuring the validity and generalisability of the research findings. The sampling strategy used throughout the studies of this research was purposive sampling. Purposive sampling is a non-probability sampling technique that involves the intentional selection of participants who are most representative/relevant to the research objectives (Coolican, 2014).

2.3.6. Participant Selection

The research focused on autistic women and girls; therefore, participants were required to either identify as female or be assigned female at birth, and either have received a diagnosis of autism or self-identify as autistic. This also included autistic people who identify as other genders or describe themselves as non-binary. Participants were required to be over the age of 18, spoke English as their first language and had capacity to consent. The inclusion criteria were kept deliberately broad in order to maximise the potential of including as wide a range of experience as possible. We also specifically looked to identify autistic women who had experienced missed or mi-diagnosis, and/or delayed diagnosis.

2.3.7. Recruitment

The use of purposive sampling allowed for the targeted recruitment of participants with specific characteristics and experiences who were able to provide valuable insights into their lived experiences of diagnosis and access to diagnostic pathways. Although study 2 (focus groups and a Delphi consultation) and study 3 (pilot of the FASST) utilised the same purposive sampling strategy, there were slight differences in the recruitment methods and participant characteristics for each method. For both the study's, participants were recruited through the use of social media, professional networks and online support groups and organisations. For study 2, the aim was to gather a diverse group of autistic women, parents/carers, professionals, and academics who could participate and share their insights in specific relation to the refinement of the FASST prior to the pilot study. For study 3, the same strategy was used, however the pilot study also involved the inclusion of non-autistic people, and people who self-identified as autistic as comparison groups. All participants were required to have a paired informant who could complete the FASST. The inclusion of non-autistic participants allowed for the assessment of the FASST's discriminative abilities between autistic and non-autistic people. The use of the same sampling strategy across each of the different research studies ensured consistency of the findings. Additionally, the recruitment of specific participants for each method ensured that the participant characteristics were tailored to meet the objectives of the respective study. For each individual study participants were provided with information sheets and consent forms which outline the research objectives, confidentiality measures, and assure that participation was entirely voluntary in nature.

2.3.8. Sample Size

The overarching objectives of this research was to obtain a comprehensive understanding of the presentation of autism in women and girls including their lived experiences, and second, to use this information to refine the FASST ready for testing. To achieve this, a large and diverse sample of participants was sought. The intention of this research was to include as many people as possible within the available resources as well as the time constraints of a PhD. The rationale for a large sample size was considered for several reasons. First, the diversity of autistic people is recognised as being widely variable when considering age, cultural backgrounds, personal circumstance, socio-economic factors as well autistic presentation/characteristics. Second, aiming for a larger sample size had the potential to explore subgroups of autistic women and girls, such as those from marginalised communities. Moreover, a larger sample size is important for statistical power, thus potentially enhancing the reliability and validity of the findings.

2.3.9. Assessing Quality

In order to assess the quality of the proposed methodologies outlined in this chapter, it is important to consider the frameworks most commonly used in quantitative and qualitative research. In quantitative research, quality is assessed based on the principles of validity, reliability, and generalisability (Coolican, 2014; Creswell, 2023). Validity refers to the extent to which the research accurately measures what it is intended to measure. This principle encompasses specific aspects which include construct validity, whether or not the chosen measure captures the concept being studied; internal validity, which assesses the extent to which the observed variables can be attributed to the variables that are being studied; and external validity, which examines to the generalisability to other populations or settings. Reliability is another criterion that is considered crucial in the assessment of quality on quantitative research, this refers to the consistency or replicability of the results. Moreover, an important form of reliability is internal consistency, the degree to which a set of items on a measurement instrument behave in the same way. Internal consistency is measure by a Cronbach’s alpha value that ranges between 0 and 1, with suggested optimal values ranging between 0.7 and 0.9 (Creswell, 2023). In addition, test-retest reliability is another form of instrument measurement which assesses whether or not a scale is reasonably stable over time, i.e., repeated administrations of the same measurement. Lastly, generalisability is important in quality assessment as it looks at the degree to which the participant sample represents the target population overall.

In qualitative research, quality is assessed by the utilisation of specific criteria including, credibility, transferability, dependability, and confirmability. Credibility in this context refers to the trustworthiness of the research findings and is achieved by the employment of different strategies such as triangulation (the examination of multiple data and sources), member checking (the process of confirming the accuracy of the data collected by referring back to participants) and maintaining an audit trail (the process of documenting all decision made throughout the study). Transferability in quality assessment is the potential to which findings can be applicable to other contexts or populations and to achieve such, the use of rich and detailed descriptions are needed in order for the reader to assess the transferability of the findings to their own settings. Dependability focuses on the consistency of the research process over time and ensures findings are not influenced by external factors or biases and finally, confirmability ensures that the findings are based on the participants of the study, rather than potential researcher biases. This can be achieved through peer debriefing (the involvement of a person who reviews and asks questions about the qualitative study to ensure the processes and findings are able to resonate with people beyond the researcher), clarifying any bias the researcher brings to the research study (the reflexive practice of the researcher) and finally intercoder agreement (achieved through the cross-checking of any codes developed by different researchers to check comparability). The proposed methods in this research study were carefully selected with the overall aim of maximising the quality and trustworthiness of the findings (Coolican, 2014; Creswell, 2023). By utilising the quality criteria for both quantitative and qualitative research, this research project aims to produce reliable, valid, and credible findings that contribute to the development of a new screening tool for autism as well adding to the existing body of literature on autistic women and girls.

2.3.10. Ethical Considerations

Ethical considerations are crucial when designing and implementing research that involves human participants and as such several aspects were considered to ensure the overall ethical integrity of the research project. First, ethical approval was obtained from the Tizard Centres Ethical Committee for all research study's including the focus groups, Delphi consultation and the pilot study (see appendices 3.1, 4.1, 5.1). Second, informed consent was obtained from all participants for each study, ensuring that the participants understood all aspects of each individual study, for example the purpose, procedures, risk and benefits and the confidentiality measures of each study (see appendix for all information sheets 3.2, 4.2, 5.2 and consent forms 3.3, 4.3, 5.3, 5.4). Participants were assured that their participation was completely voluntary and that they had the right to withdraw their consent at any time without facing any negative consequences. Third, confidentiality and anonymity were ensured throughout. For the focus groups, participants shared their first names during each group in order to interact with each other, upon transcription of the focus groups, individual participant names were replaced with a unique code. Similarly, for the Delphi consultations, participants were provided with a unique identifier code in order to access to the Delphi survey. The pilot study also made use of unique identification codes which were paired between the participant completing the self-report form and their informant. All data collected was anonymised throughout and information was secured on a password protected computer. Additionally, GDPR guidelines were adhered to strictly throughout all of the research studies. Participants were informed how data would be stored and consent was obtained from each participant in relation to the future use of each study's findings. Fourth, risk management and participant well-being were considered carefully. The risks and benefits of taking part in the research were clearly outlined in the participant information sheet and participants were encouraged to contact the lead researcher if they had any questions or needed further clarification. Given the sensitive nature of the topic in exploration, coupled with the fact that many participants who were offering to provide their input were more than likely to have experienced a late diagnosis, participants were offered the chance to debrief post their involvement in any of the studies if they felt they needed to. Fifth, careful consideration was also given to the complexities of sex, gender identity and a participant's lived experience of such. Due to the short nature of each study and the time constraints of the overall research project, inclusion criteria for the FASST were people who were assigned female at birth. Transparency and openness were important, as this inclusion criteria were sensitive by nature, and may have been difficult for trans people and those who identify as other genders who would have liked to have taken part. This was explicitly acknowledged to participants caveated by the fact that future research must take into consideration the complexities of gender to ensure all people, no matter their gender identity could take part. Sixth, acknowledging and respecting autistic voices were a crucial part of this overall research project. The voices of autistic people were actively sought out to ensure that the FASST was co-created with autistic people, parents/carers and other professionals by experience. Finally, the importance of ethical considerations when reporting findings were taken into account. This practice continually ensured participant confidentiality and anonymity, and that findings were reported in an accurate and unbiased manner.

2.4. Thesis Outline

2.4.1. Study 1: Systematic Review

The systematic review, along with the contextual information provided in Chapter 1, made up the deductive aspect of the screening tool development. The primary research question for the systematic review was:

> What are the experiences and behavioural presentations of autistic females, and what additional items informed by the literature pertaining to the experiences of women and girls should be included in the FASST at this development stage?

The above research question guided the systematic review and was central to understanding the unique experiences and behavioural presentations of autistic women and girls. The importance of reviewing the literature is essential in the development of any assessment, first, to ensure that measures serving the intended purpose does not already exist (Boateng et al., 2018) and second, to identify any gaps in the evidence base that may be relevant and provide further justification for the research (Moher et al., 2009). Prior to the commencement of the systematic review, the PROSPERO databased was searched in order to ensure the proposed review was not replicating existing research. The systematic review protocol was subsequently registered with PROSPERO (REF: CRD42020164621). The formulation of this research question aimed to address the potential gaps in existing knowledge and shed light on the potential differences in presentation, as well as the lived experiences, of autistic women and girls. Furthermore, the systematic review guided the identification of relevant studies, the synthesis of findings, generation of meaningful conclusions, as well as serving to refine the FASST in the early stages of its development. The systematic review aimed to provide a comprehensive overview of what is known about autistic women and girls, specifically adults and adolescents, highlight specific areas of consensus and divergence, and generate recommendations for additional items for inclusion in the refinement of the FASST.

2.4.2. Study 2a: Focus Groups

Following the systematic review, version 2 of the FASST was created (appendix 2.2). The decision to use focus groups was driven by several reasons. The primary research question for the focus groups was:

> What are the perspectives and feedback of autistic women, carers, parents and professionals regarding the content of the FASST, a new screening tool designed to assess autism in females?

First the main goal of the focus groups was to ask autistic women, parents/carers and professionals to comment on the content of the FASST, specifically, did the items cover a wide range of experiences that might be relevant to autistic females, were any topics/experiences missing, and/or the amendment of items. Second, focus groups provided an accessible platform for capturing the perspectives of these key stakeholders. The focus groups provided the ability to offer different formats that might be better suited for individual need, for example either face to face groups or virtually online. The interactive nature of focus group discussions supported the dynamic sharing of ideas, allowing participants to interact with each other and generate new perspectives that might not have emerged through individual interviews. In contrast, focus groups are not without their limitations, for example, some participants may dominate the conversation and some participants may have difficulty speaking up in front of a group. Additionally, social desirability bias, feeling pressure to conform to the social norms of a group, were also factors to consider. However, since many autistic women have often faced great difficulty accessing diagnostic pathways, focus groups were chosen because they allowed for a sense of community and mutual support to be developed, ensuring that the participants felt safe to share their thoughts and/or lived experiences of being autistic. The qualitative data collected from the focus groups provided contextual information and personal accounts which provided the identification of challenges and needs specifically related to the diagnostic process. For each item, participants were able to provide their perspectives and insights on how specific amendments might improve the content of the FASST overall. Notwithstanding, alternative methodologies such as individual interviews or case-studies could have been utilised, however due to time constraints, focus groups were chosen as the optimum methodology that both met the epistemological and ontological frameworks adopted throughout this research, but also allowed for the collection of data in a short space of time.

2.4.3. Study 2b: Delphi Consultation

Following the focus groups, version 3 of the FASST was created (appendix 2.3). The primary research question for the Delphi was:

How can a Delphi consultation process be utilised to further refine and validate the items included in the revised version of the FASST, based on feedback from autistic women and other key stakeholders?

The decision to employ the use of a Delphi consultation was to further triangulate the FASSTs development post systematic review and focus groups. There a several reasons why the Delphi consultation was chosen. First, the Delphi consultation process allows for the development of expert consensus, in other words, it allows for the collection of feedback from a panel of experts who have specialised knowledge and experience in autism. Second, the consultation process facilitates an iterative approach to refining the item pool of the FASST. Through multiple rounds of consensus-building, panel members were able to provide input on the wording, relevance, and appropriateness of the FASST items. Third, the Delphi consultation allows for feedback and ratings to be provided anonymously, which counters potential limitations that might have been seen in focus groups where panel members can be more dominant and/or not feel comfortable providing their views in a group setting. Finally, the use of the Delphi methodology promotes rigor and validity, ensuring that feedback is collected in a systematic and structured way. Further, the use of multiple rounds of rating scales and feedback enhances the validity and reliability of the consultation process. In contrast, there are some potential limitations to the use of Delphi consultations which include potential expert selection bias if the panel is not as diverse as anticipated, to mitigate this, careful representation of experts is crucial. Additionally, the consultation process can be time-consuming due to the multiple rounds of data collection and analysis between rounds. Despite this, the importance of deriving a final set of items using an expert panel outweighed the potential limitations of a Delphi methodology.

Notwithstanding, alternative methodologies such a face-to-face meeting with an expert panel or individual interviews may have offered the opportunity for direct discussion and interaction and therefore the collection of more in-depth information. But again, due to time constraints, the Delphi consultation was chosen as the optimum methodology that both met the epistemological and ontological frameworks adopted throughout this research, but also allowed for the development and refinement of a final version of the FASST ready for piloting. Overall, the use of focus groups and the Delphi consultation played a central role in the development and refinement of the FASST. These methodological processes promoted collaboration and co-creation of knowledge, whilst also ensuring that the development of the FASST remained inclusive throughout.

2.4.4. Study 3: Piloting the Female Autism Spectrum Screening Tool (FASST)

Upon completion of the triangulation process used to refine the FASST (systematic review, focus groups and a Delphi consultation), a final version of the FASST was created ready for piloting (see Chapter 6; appendix 2.4). The structure of the screening tool will be detailed in Chapter 6. The primary research question for the pilot study was:

> To what extent does the piloted version of the FASST demonstrate reliability, validity, and discriminative ability in identifying autism among women, when compared to non-autistic women, following revisions based on a systematic review, feedback from focus groups, and refinement via a Delphi consultation?

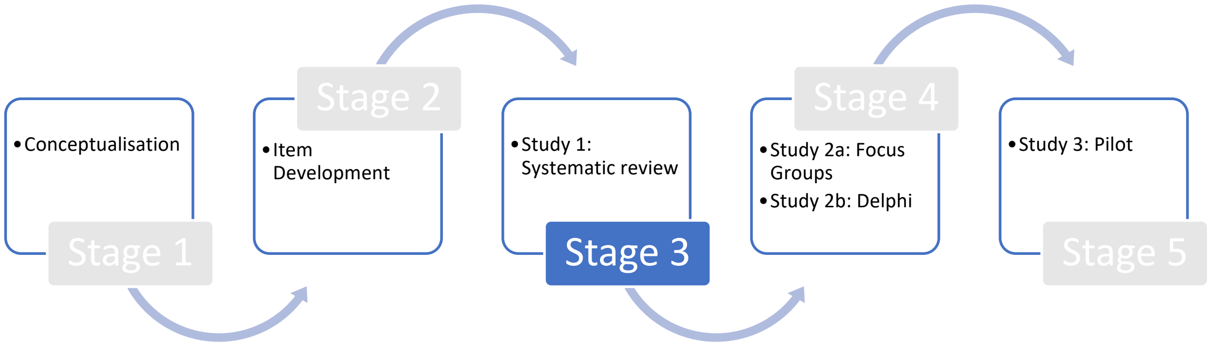
The design of the pilot involved the recruitment of three distinct participant groups, autistic people, people who self-identify as autistic and non-autistic people. All participants from each group were required to have a paired informant to take part with them throughout the study. A pilot study was used for several reasons. First, piloting the FASST allowed for the preliminary assessment of the screening tools psychometric properties. Depending on a screening tools purpose and the sample population, different aspects of reliability and validity may be utilised. Second, the administration of the FASST supported the initial assessment of the tool’s overall validity and reliability, thus determining whether or not the FASST could accurately discriminate between autistic and non-autistic people and whether or not the FASST was correlated to other widely used screening tools in theoretically consistent ways. Second, although not a feasibility study, conducting the pilot in this way supported the understanding of how well the FASST could potentially be used in real-life settings, for example time requirements and ease of use. Finally, piloting the FASST enabled the collection of data that can be used in future evidence-based decision making, for example the findings can be used to further refine the FASST to enhance the screening tool overall, ensuring that the FASST items remain aligned with the intended purpose of the tool. An alternative approach to the chosen study design could have been the use of field observations, for example collaborating with health professionals and frontline services who routinely screen for autism and observing the application of the FASST in clinical practice. However, the use of a small-scale pilot study suited the time constraints of the current project and serves as a study exploratory in nature before seeking future funding for further empirical testing of the FASST. Although it could be argued that a small-scale study limits generalisability of the findings due to the small number of participants, the pilot allowed for initial data exploration which can be used to guide the development of future hypotheses or research questions. Furthermore, the pilot allows for the evaluation of any ethical considerations that may have arisen during the process.

In summary the mixed-methods approach underpinned by epistemological and ontological methodologies, allowed for the FASST to be developed, refined, and piloted with the collaboration of autistic people and the key people in their lives. This robust research strategy combining a systematic review, focus groups and Delphi in a triangulation process, was used to optimise data collection and interpretation in order to ensure the production of a successful screening tool (FASST), in a co-ordinated approach.

Chapter Summary

This chapter has outlined the specific methodologies employed throughout this research, highlighting how each individual study aligns with epistemological and ontological viewpoints. The chosen methodologies which included a systematic review of the literature, focus groups, a Delphi consultation and the piloting of the FASST, were carefully selected in order to address the overarching research question and the individual goals of each study. In summary, the systematic review allowed for a comprehensive synthesis of existing knowledge of autistic women and adolescents, while the focus groups allowed for the collection of valuable insights and feedback from the lived experiences of autistic women and other key stakeholders. Both of which enabled further revisions of the FASST. The Delphi consultation further refined the FASST by incorporating consensus building from diverse perspectives and expertise, and finally, the pilot study enabled structured assessment of the effectiveness of the final version of the FASST. The mixed methods approach adopted throughout this research enabled the collection of both qualitative and quantitative data, thus enabling the exploration of subjective, narrative and empirical data, in order to strengthen the validity and reliability of the FASST. The subsequent chapters of this thesis will present the empirical research and analysis, further discussing the results and an overall discussion of the implications and future research of the FASST.

Chapter 3. The Experiences and Behavioural Presentations of Autistic Females: A Systematic Review



3.1. Introduction

Despite the emerging research interest in autistic women and girls, there is currently little consensus about how autism presents amongst females. In a recent review by Hull et al. (2020) the existence of a female autism phenotype (FAP) was suggested which captured differences within the social domain, inclusive of more social relational interests, as well as an increased co-occurrence of internalising conditions. However, it remains important to ascertain whether such is a unique female presentation of autism, or a variation of stereotypical autistic presentations identified many years ago (Hull et al., 2020). Previous meta-analyses (Hull et al., 2017; van Wijngaarden-Cremers et al., 2014) found no significant differences in social interaction and communication domains between autistic males and females when using data derived from diagnostic assessments such as the ADOS-2 (Lord et al., 2012). In contrast, a recent meta-analysis (Wood-Downie et al., 2020) that only focused on narrow construct measures of social and communication domains, found significant differences between autistic males and females, specifically, autistic females demonstrated significantly better skills in social and communication domains than autistic males, and this same pattern was present in non-autistic males and females. Additionally, evidence that there are no differences between autistic females and non-autistic males implied that autistic women present in a similar way to non-autistic men. Therefore, during the diagnostic process, clinicians should be making comparisons between non-autistic and autistic women (and not making comparisons between autistic women and non-autistic men; Wood-Downie et al., 2020).

Although findings are inconsistent across studies, there is evidence that autistic girls are at a greater risk of having their autism overlooked compared to autistic boys (Loomes et al., 2017), particularly as symptoms of autism in females become more apparent with age (Wood-Downie et al., 2020) and sex differences are thought to lead to delayed or even missed diagnosis for girls and women (Hull et al., 2017; Kirkovski et al., 2013; van Wijngaarden-Cremers et al., 2014). Authors have suggested current diagnostic assessments may not be sensitive to the subtle differences in presentations between the sexes (Halladay et al., 2015; Hull et al., 2020; Jamison et al., 2017; Kreiser & White., 2014; Lai & Szatmari., 2020) because autism is thought to be characterised upon a stereotypical male presentation and therefore an associated ascertainment bias may occur (Moseley et al., 2018; Van Wijngaarden-Cremers et al., 2014). Diagnostic criteria may be biased towards male presentations (Jamison et al., 2017), and gender stereotyping by professionals during diagnostic assessments may account for some of the delayed or misdiagnoses for women and girls (Gould & Ashton-Smith., 2011). The increased awareness of autistic presentations in non-males and the differences in opinions between researchers, have led to an expanding body of research taking place to evaluate sex differences in autism (Lai & Szatmari., 2020).

3.2. Aim

Most of the research into sex differences within autism has involved children (Rivet & Matson., 2011b), it has only been in recent years that attention has been focused on adolescent and adult women. Whilst extensive research has contributed to our understanding of the experiences and behavioural presentations of autistic people, it remains crucial to continue to explore the needs and experiences of specific populations who are not widely included in research agendas, for example autistic women and girls. In this context, study one of this thesis employed a systematic review methodology, for a dual purpose. First, the use of a systematic review sought to add to the existing body of literature on autistic people by specifically reviewing the research evidence on adolescent and adult autistic females. Second, the review aimed to identify specific information relevant to autistic women and girls that could inform the inclusion of additional items in the FASST during its developmental stage. A greater understanding of the experiences of autistic women and girls who have been through the assessment and diagnostic process will allow for the refinement of the FASST to ensure that the item pool is relevant, up to date and inclusive of the female autism presentation. By utilising the systematic review process for these dual aims, study one contributes to a more nuanced understand of the experiences and needs of autistic females. The research question guiding this study is:

> What are the experiences and behavioural presentations of autistic females, and what additional items informed by the literature pertaining to the experiences of women and girls should be included in the FASST at this development stage?

3.3. Methodology

A systematic review of studies focused upon autistic women and girls was conducted and included quantitative, qualitative and mixed methods literature. The systematic review protocol was registered with PROSPERO (REF: CRD42020164621).

3.3.1. Systematic Search

The systematic search was conducted using the following databases: Web of Science, Academic Search Completed, Medline and PsychInfo. The four databases were searched using the terms ‘autis*’, ‘female’, ‘girls’ and ‘women’. Boolean logic was used in the following order to combine the search terms: ((autis* AND female) OR (autis* AND girls) OR (autis* AND women)). Backward searching was also conducted on all eligible papers; a grey literature search was also performed on Google Scholar. The date of the final search was 2nd January 2020.

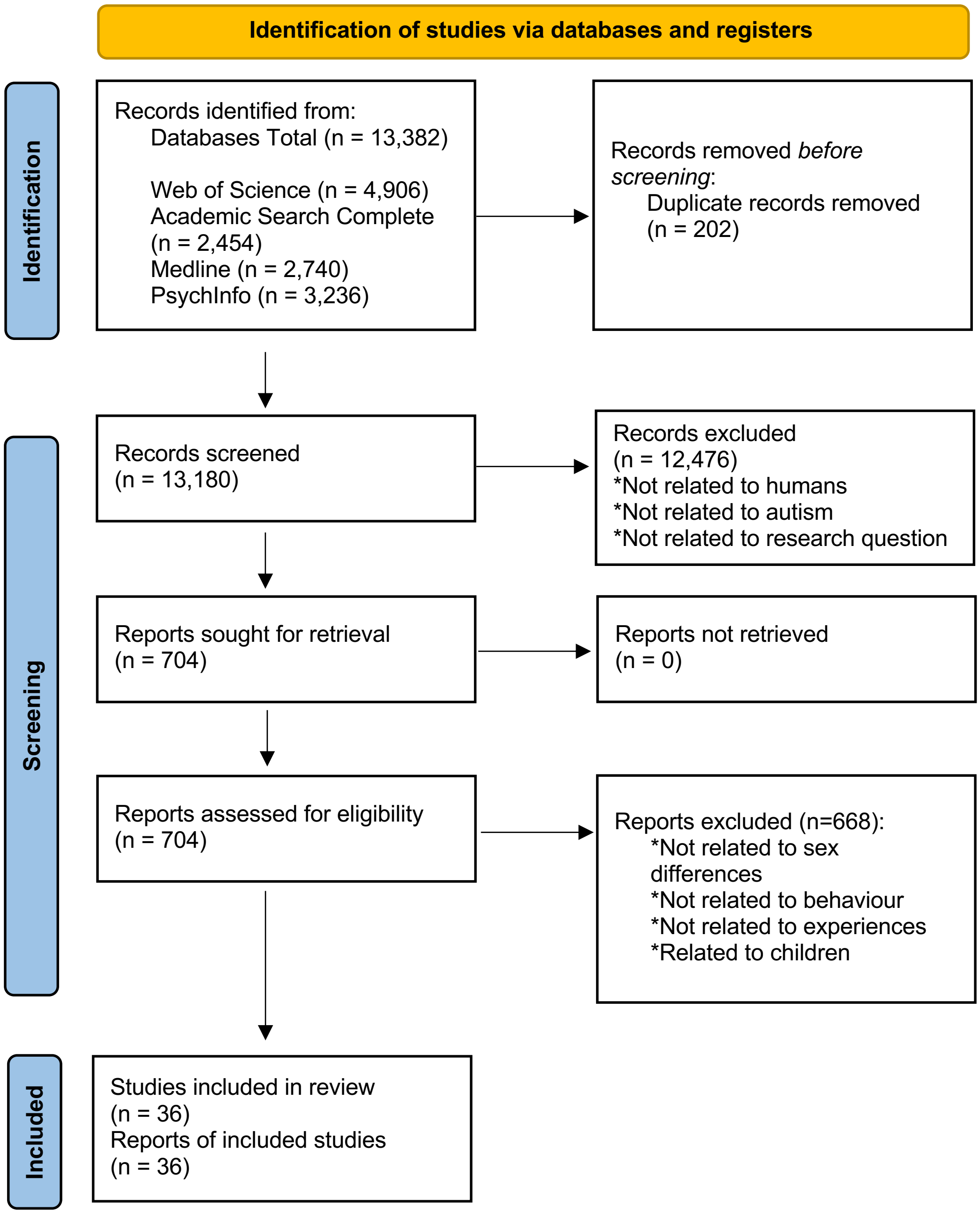
3.3.2. Eligibility Criteria

Studies were included that: (a) reported data about sex differences regarding the behavioural phenotype associated with autism, or the experiences of adolescent or adult autistic females, in participants older than ten years, and (b) published in English. Studies were excluded if they were: (a) review papers, (b) had not been subject to peer review, or (c) were focused upon genetics, neuroimaging, or cognition.

3.3.3. Screening

Initially, title and abstract screening was completed by the first author, applying the eligibility criteria. The full text of remaining articles were then retrieved and further screened against the eligibility criteria. The final sample of included papers were checked against the eligibility criteria by a second author (JB) revealing k = 1. Thirty-six studies were included in the review. A flowchart detailing the screening and selection process is outlined in Figure 1.

Figure 1: Flow diagram depicting study selection



3.3.4. Data Extraction

Key characteristics were extracted from each study using a data extraction template. Studies were initially categorised according to whether the study included adolescents or adults. Data about each study are presented within Table 1 including a summary of the main results.

3.3.5. Quality Assessment

The Quality Assessment Tool for Studies with Diverse Designs (QATSDD; Sirriyeh et al., 2012) was used to assess the methodological quality of the included studies and was chosen because it allowed for the assessment of a range of designs and methodologies. The QATSDD included 16 items applicable to quantitative and qualitative studies and were rated on a four-point scale: ‘not at all” (0), ‘very slightly’ (1), ‘moderately’ (2) and ‘complete’ (3). As per Wells (2016), studies that had a total percentage score of 75% or above were rated as ‘high’, those with a score between 50% and 75% were considered ‘good’, between 25% and 50% ‘moderate’ and scores below 25% were considered ‘poor’. To check reliability, 20% of the included papers were rated by a masked second rater (JB) who assessed the papers using the QATSDD. Differences in ratings were found within in two papers due to variation in interpretations, for two QATSDD criteria only. These were discussed and agreed upon. Whilst these differences only appeared in two papers, all papers in the final sample were re-checked across these two criteria revealing complete agreement, k=1.

3.3.6. Analysis

The findings from studies were synthesised using thematic analysis (TA; Braun & Clark., 2006) into broad themes across a large, varying and complex data set. The six phases of TA as outlined by Braun and Clark (2006) were followed: (1) familiarisation with the data,

(2) generating initial codes, (3) searching for themes, (4) reviewing themes, (5) defining and naming themes, and (6) producing the report; inductive analysis was used in order to code the data without trying to fit the findings within an existing coding framework or with the researchers own preconceptions. Themes were identified at a semantic level in order to theorise the significance of the data and their broader meanings and implications for both clinical practice and future research.

3.3.7. Trustworthiness

To ensure trustworthiness throughout the analytical process, the following criteria as outlined in Nowell et al. (2017) were adhered to: (a) prolonged engagement in the research papers, (b) well organised coding and record keeping, (c) researcher triangulation, (d) theme diagrams, (e) reflexive journaling, and (f) discussions with a second author where the themes were vetted, and consensus reached.

3.4. Results

The included studies focused on a variety of topic areas. Fifteen studies reported on the experiences and perceptions of autism; eight studies investigated sex differences using specific assessment tools; four studies explored camouflaging; three studies explored pathways to diagnosis and the remaining six reported on sex differences and psychopathology (n=2), restrictive and/or repetitive interests (n=3) and clinical need (n=1). Ten studies made use of qualitative research methods, nineteen studies used quantitative research methods, while seven studies made use of mixed methods. Most studies made use of cross-sectional observational designs, with a few using descriptive and ex post facto research designs.

Thirty-one studies required that participants had prior autism diagnosis before enrolment, but twenty studies did not detail information about the steps taken to verify this diagnosis, with the authors of four studies acknowledging that it was not possible. Including females with a diagnosis of autism may be inadvertently problematic if diagnostic tools and criteria are biased towards a 'stereotypical' male presentation of autism; females who are un-diagnosed or mis-diagnosed may have been excluded. However, participants who self-diagnosed as autistic were included in two studies, and the authors argued that allowing individuals who self-identify helped to address the issue of excluding un-diagnosed or mis-diagnosed autistic women from research studies. However, while there are potential benefits, it must be recognised that this may increase the probability of including females without autism within research studies.

Thirteen studies implemented their own verification procedures to assess the accuracy of reported diagnoses. One study using parental confirmation (Vine Foggo & Webster, 2017) and one study detailed that the majority of their participants were confirmed through a diagnostic clinic, but for those recruited online, diagnoses remained unconfirmed (Kock et al., 2019). Three studies were research questionnaires which were either completed in paper format or completed electronically online. As a result, these studies relied on the honesty of the disclosure of an autism diagnosis and could not verify the accuracy of such.

Table 1: Characteristics of Included Studies

Authors	Number of Participants	Study Aims	Method/Study Design	Key Findings	Quality Rating (QATSDD)
Adolescents					
Cridland et al. 2014	Three mother-daughter dyads and two additional mothers. 3 **Autistic adolescents** – age range 12-17 years old.	To investigate the experiences of females with ASC during adolescence, including mother perspectives.	IPA using semi-structured interviews. Cross-sectional observational design – single group.	- Results categorised into seven main themes: Diagnostic issues, being surrounded by boys, Experiences of high school, Complexity of adolescent female relationships, Puberty and its related issues, Sexual relationships and concerns and Impact of having an adolescent daughter with ASC. - Obtaining a diagnosis was difficult. - Lack of access to early intervention and support. - Difficulties with making friends and classwork. - Feelings of being bullied, picked on and ignored. - Teachers have a limited understanding of the female presentation of autism.	High
Mandy et al. 2012	325 **autistic participants** **Female** n = 52 **Male** n = 273	To investigate developmental effects upon sex differences and whether these were moderated by age.	3Di, ADOS, SDQ and IQ. Cross-sectional observational design between groups.	- Both males and females presented with equal levels of social and communication impairments. - Females experienced milder repetitive stereotyped behaviours across their lifespan. - Teachers report females to have fewer externalising and interpersonal problems and were less likely to report difficulties for females compared to males. - Females had superior fine motor skills, had a greater vulnerability to internalising problems and a reduced risk of externalising pathology.	High
McFayden et al., 2019	75 **autistic** participants **Female** n = 20 **Male** n = 55	To investigate RRB presentation in autistic females, namely restricted interests.	ADI-R, ADOS, RBS-R and SRS-2. Cross-sectional observational design between groups.	- Severity scores similar between the sexes, but only on composite scores; males scored higher when isolating the subscale for restricted behaviour. - Females demonstrated narrower range of interests and were more socially orientated. - Female interests focused more on living constructs, males focused more on object related interests.	High

				- Important to look at female interests qualitatively - With autistic females' interests being more socially appropriate, may hinder referral and diagnostic process	
Oswald et al. 2016	64 participants **ASC Group** n = 32 (**Female** n = 14 and **male** n = 18) **TD Group** n = 32 (**Female** n = 14 and **male** n = 18)	To examine the effects of sex and developmental stages of adolescence on internalising symptomology in autism.	RCADS-P, MASC and CES-D. Cross-sectional observational design between groups.	- Greater symptoms of anxiety and depression found in the ASC group compared to the TD group. - During early adolescence, females had greater depressive symptoms compared to TD females and autistic males. Late adolescence, showed similar levels of depression. - During early adolescence, females may have a unique combination of genetic, hormonal and psychosocial vulnerabilities which may place them at a higher risk of depression. - During early adolescence, autistic females and TD males had higher levels of separation anxiety and panic. Late adolescence showed that autistic males and females had higher levels of separation anxiety and panic compared to the TD group.	High
Pisula et al. 2017	118 participants **Autistic Group** n = 70 (**Female** n = 35 and **male** n = 35) **TD Group** n = 48 (**Female** n = 24 and **male** n = 24)	To investigate how males and females assess the emotional and behavioural difficulties they experience and how these difficulties are rated by their parents.	CBCL. Cross-sectional observational design between groups.	- Autistic group presented with more behavioural and emotional problems than the TD group, however no differences were found between the sexes. - Parents of the autistic group also reported higher levels of behavioural and emotional problems compared to the parents of the TD group.	Good
Sedgewick et al. 2016	46 participants **ASC Group** n = 23 (Females n =13 and males n = 10) **Non-autistic group** n = 23 (Females n =13 and males n = 10)	To investigate gender differences in the social motivation and friendship experiences of males and females with and without ASC.	FQS, SRS-2 and Semi-structured interviews. Cross-sectional observational design between groups.	- Autistic vs. Non-autistic girls – quality of friendships similar in terms of companionship, help, closeness and security. - Autistic girls vs. autistic boys – girls reported friendships to be closer, more helpful and more secure. - Autistic girls had greater social motivation compared to autistic boys. - Teachers report autistic girls to have less severe social difficulties and had greater levels of social motivation compared autistic boys.	High
Sedgewick et al., 2019	102 **adolescent** participants	To compare and examine gender differences in	Mixed methods: Friendship	- Significant gender differences between autistic girls and boys.	High

	27 **autistic girls**, 26 **autistic boys**, 26 **NT** girls, 23 **NT** boys; age 11-18 years	relation to friendship and conflict experiences between autistic and non-autistic adolescents.	Qualities Scale, Revised Peer Experiences Questionnaire and semi-structured interviews. Cross-sectional observational design between groups.	- Autistic girls report experiencing more relational conflict compared to autistic boys who report overt conflict difficulties. - Autistic girls had fewer close relationships - Autistic girls reported more social challenges compared to autistic boys and their NT peers.	
Tierney et al. 2016	10 participants **Autistic Adolescents** – age range 13-16 years old.	To investigate whether autistic adolescents use social management strategies 'masquerading' as a way to hide difficulties and fit in with peers.	IPA using semi-structured interviews. Cross-sectional observational design – single group.	- Results were categorised into four main themes: Experiences of social environment, Desire for Friendship, Overcoming challenges and Developmental Tasks. - Social environments difficult. - Gender expectations – Aligned more with male peers. - Difficulties managing friendships, social contact was exhausting. - Masking difficulties exhausting and often had severe mental health repercussions. - Transition from primary to secondary school was when difficulties started to emerge.	Good
Tint et al. 2017	284 parent participants reporting on their autistic children **Autistic Adolescents** n = 157 (**Female** n = 33 and **male** n = 124) **Autistic Adults** n = 127 (**Female** n = 28 and **male** n = 99)	To investigate the clinical needs and service use of female autistic adolescents and adults, comparing experiences between the sexes.	SCQ, ID status, Psychiatric and medical diagnoses, Caregiver strain (RCAS) and Service Use. Cross-sectional observational design between groups.	- 40% of adolescent girls had at least one co-morbid psychiatric diagnosis. 36.4% had at least one co-morbid medical diagnosis. - 60.7% of female adults had at least one co-morbid psychiatric diagnosis. 42.9% had at least one co-morbid medical diagnosis. - High levels of care giver strain reported (54.5% of parents of adolescent girls and 71.4% of parents of female autistic adults). - No significant sex/gender differences were found. - Adolescent girls accessed a wider range of services compared to adolescent boys whereas no sex differences emerged in service use for adults.	High

				- Females were more likely to access emergency services than men.	
Vine Foggo et al. 2017	7 participants **Autistic Adolescents** – age range 13-17 years old.	To investigate the perceptions of autistic adolescent females on their social experiences and friendships.	Semi-structured interviews analysed through inductive reasoning. Cross-sectional observational design – single group.	- Results categorised into two main themes: Social interactions are important and Social interactions are difficult. - Participants valued and enjoyed their friendships but needed time to de-stress afterwards. - Less able to manage conflict than TD peers.	Good
<u>Adults</u>					
Baldwin & Costley 2015	282 participants **Male** n = 200 **Female** n = 82	To analyse the data collected as part of a larger study 'We Belong', to investigate the everyday life experiences of female adults with high functioning autism.	Questionnaire methodology – Research questionnaire designed in conjunction with an advisory group. Cross-sectional observational design between groups.	- In terms of quantifiable outcome measures, females only differed slightly from males, supporting the evidence that qualitative, anecdotal and autobiographical data remains important in understanding the female presentation. - Autistic women disadvantaged by a lack of timely and/or accurate diagnosis. - Supports the notion that masking abilities prevents earlier identification of autism in women. - Results categorised into areas of difficulties that the women experienced: Diagnosis, Health and Mental Health, Education, Employment, Social Experiences and General Support Needs. - Stress and anxiety the most problematic across everyday life. - Peer relationships difficult, feelings of being lonely, isolated and bullied.	Good
Bargiela et al. 2016	14 participants **Female** n = 14 aged between 18 – 35.	To investigate the experiences of late diagnosed female adults.	Framework Analysis Semi-structured Interview, AQ,	- 13 participants met threshold for anxiety - 3 participants met threshold for depression - In GHQ, three participants fell in the 'distress' range and two in the 'severe' range.	Good

			GHQ-12, HADS and WTAR Cross-sectional observational design – single group.	- Results categorised under four main themes: ‘You’re not autistic’, Pretending to be ‘normal’, Passive to assertive and Forging an identity as a woman with ASC. - All participants experienced one or more mental health problems, namely, anxiety, depression and eating disorders. - Easier to form friendships with males. - Not recognised by their teachers. - Online platforms were helpful in maintaining and developing friendships.	
Begeer et al. 2013	2,084 participants **Children** n = 1,354 (**Female** n = 204 and **male** n = 1,150). **Adults** n = 730 (**Female** n = 183 and **male** n = 547).	To examine sex differences in the timing of autism diagnoses.	Survey – 53 questions across a wide range of topics. Cross-sectional observational design between groups.	- Overall average times between initial signs and identification were longer for females. - For children, the only group that showed a sex difference in timing of diagnosis was the AS group (no sex differences in delay of diagnosis for ASC group or PDD-NOS). - For adults, females experienced a 4.3-year delay compared to males in the ASC group (no sex differences found in AS group or PDD-NOS). - Lack of recognition by clinicians of female autism may be caused by their high verbal abilities.	Good
Cage & Burton, 2019	40 participants 20 **Autistic** 20 **Non-Autistic** Observers n=205	To examine the gender differences in the first impressions of autistic adults, rated by non-autistic observers	Video Modalities and Text Transcripts. Cross-sectional observational design between groups.	- Non-autistic people reported more negative first impressions of autistic people - Autistic women were viewed more favourably compared to autistic men - These findings have implications for clinical professionals and employers and how they view autistic people	High
Cage & Troxwell-Whitman, 2019	266 **autistic** participants **Female** n = 135 **Male** n = 111 **Other Genders** n = 12	To examine the reasons, contexts and costs of camouflaging	CAT-Q, Items for Camouflaging reasons and contexts, DASS-21, RAADS-14.	- Camouflaging results poorer mental health; stress and anxiety - Autistic women endorsed conventional reasons for using camouflaging more than autistic males; however, both autistic males and females report conventional reasons over relational reasons.	High

			Cross-sectional observational design between groups.	- Most frequently reported theme by participants for reasons of camouflaging was to fit into neurotypical society.	
Grove et al. 2017	550 participants. **Male** n = 265 **Female** n = 285	To study the sex differences in the autism phenotype within an adult sample, evaluating the factor structure of the AQ short form.	AQ-Short Form. Cross-sectional observational design between groups.	- AQ-Short Form was found to detect autism traits equivalently in both males and females. - Women scored significantly higher on social behaviour subscales and significantly lower on the numbers and patterns scale. - Two items on the AQ showed increased sensitivity towards autism in women.	Good
Grove et al., 2018	687 **autistic** participants **Female** n = 338 **Male** n = 349	To explore the range of interests as reported by autistic adults, including gender differences	Participant self-report; Satisfaction with Life Scale; The Cantril Ladder; Special Interests Motivation Scale. Cross-sectional observational design between groups.	- 65% of participants reported having a special interest. 35% did not - Significantly more males than females reported a special interest - No sex differences in the intensity, frequency and motivation of special interests - Special interests do not hinder quality of life	High
Guerts et al. 2011	125 adults. **Male** n = 89 **Female** n = 36	To explore the pathways to an autism diagnosis in adulthood.	Chart Review Ex Post facto study design.	- Men contacted the clinic slightly earlier than women. - Women were more commonly diagnosed with anxiety, mood disorders and psychosis prior to an autism diagnosis compared to men.	Moderate
Haney & Cullen 2017	1,636 online posts made by 212 autistic women.	To gather insights into the experiences of female autistic adults, including how autistic women use forums in	Content analysis of online forum posts.	- Results categorised into four main themes: Impact of diagnosis, Symptom discussion, Impact of autism on relationships and Impact of autism on employment. - Mis-diagnosed with depression, anxiety, personality disorders, post-traumatic stress and social anxiety.	Good

		online autism communities.	Descriptive study design.	- Many participants received diagnosis in late teens or adulthood. - Many women preferred platonic relationships with men, many finding romantic relationships stressful. - Experiences of being bullied both during childhood and adulthood.	
Hattier et al. 2011	140 participants with severe to profound intellectual disabilities. **Female** n = 63 **Male** n = 77	To investigate the frequency of restrictive and/or repetitive behaviours and interests in adults with ASC.	DASH-II. Cross-sectional observational design between groups.	- Females were found to exhibit fewer restrictive and/or repetitive behaviours and interests than males.	Good
Hull et al., 2017	92 **autistic** adults **Female** n = 55 **Male** n = 30 **Other gender** n = 7	To investigate the camouflaging experiences of autistic adults.	A newly designed questionnaire of camouflaging. Cross-sectional observational design between groups.	- No consistent sex differences were found in relation to camouflaging. - Key themes underlying the motivations, techniques and consequences in relation to social camouflaging were found. - Assimilation and connection were two main themes identified in relation to the motivation of camouflaging. - Masking and compensation were two main themes identified in relation to techniques used. - Exhaustion during and after camouflaging was an unpleasant and unwanted consequence. - ‘I’m not my true self’ was also reported as consequence.	High
Jarman et al. 2015	45 participants **Parents** n = 15 **Female autistic adults** n = 30	To investigate female autistic adults’ experiences and perspectives of school including parent views.	Online Survey Analysed using Inductive Reasoning Descriptive study design.	- Results categorised under three main themes: Teachers recognition of AS, Lack of understanding about the challenges associated with an AS diagnosis, Helpful attitudes of teachers. - Participants felt un-noticed as they were able to ‘blend in’ and did not show many behavioural problems. - Difficulties with sensory sensitivities, handwriting, executive functions and higher order thinking. - Call for teachers to be more aware of AS in females.	Moderate

Kanfiszer et al. 2017	7 participants - women with variation in age, demographics, intellectual ability, social support and mental health needs.	'What are the lived experiences of women with ASC?'	Narrative Inquiry Semi-structured interviews. Cross-sectional observational design – single group.	- Descriptions of lived experiences fell into two overarching categories 'gender identity' and 'social relationships' - Social relationships challenging and experiences of maltreatment from others. - Their differences appeared as 'odd' due to cultural and gender specific expectations. - Transition to secondary school problematic. - Interests aligned more with male peers. - Sexual victimisation reported; difficulty judging flirting, coercion and aggression - Some experienced being sexually assaulted multiple times	Good
Kock et al., 2019	8 Autistic Women	To explore the experiences of late diagnosed autistic women's intimate relationships	IPA using semi-structured interviews. Cross-sectional observational design – single group.	- Results categorised into four main themes: Response to diagnosis and receiving more information about autism, Factors influencing dating behaviour, Sex and sexual experiences and Experience of intimate relationships as a person with autism - Emotional responses to diagnosis ranged from relief to grief; hopelessness and self-doubt - Several factors reported that affected the development of intimate relationships or dating	Good
Lai et al. 2011	62 participants. **Male** n = 33 Mean age: 27.0 **Female** n = 29 Mean age: 26.9	To investigate the behavioural sex differences in high functioning autistic adults	Large battery of assessments including: ADI-R, ADOS Module 4, WASI, AQ, EQ, SQ, the Reading the Mind in the Eyes Test, BAI, BDI and OCI-R. Cross-sectional observational design between groups.	- Comparable level of autistic traits during childhood. - Females fewer current socio-communication difficulties and self-report more autistic traits in adulthood. - Females more lifetime sensory issues. - No differences in co-occurring psychiatric symptoms.	Good

Lai et al. 2017	60 participants **Female** n = 30 **Males** n = 30	To investigate camouflaging in male and female autistic adults.	WASI, ADOS Module 4, AQ, the Reading the Mind in the Eyes Test, BAI and BDI. Neuroimaging measures using MRI. Cross-sectional observational design between groups.	- On average women showed more camouflaging than men. - Camouflaging may be more specifically associated with aspects of cognitive abilities, personality, motivational and/or contextual factors. - Although camouflaging is largely associated with the female presentation of autism, men were also found to present with marked camouflaging skills.	Good
Leedham et al., 2020	11 autistic females over the age of 40	To explore the lived experiences of adult autistic females who received a diagnosis over the age of 40	IPA – Semi-structure interviews. Cross-sectional observational design – single group.	- Four superordinate themes; 'A hidden condition'; 'The process of acceptance'; 'Post diagnostic impact of others' and 'A new identity on the spectrum' - Autistic women felt misunderstood by professionals; previous diagnosed mental health conditions never explained their experiences - Finally receiving a diagnosis gave feelings of relief and provided validation - Many women describe a grieving process post-diagnosis; that life would have been much easier if their needs had been recognised earlier - Many women described ongoing mental health difficulties but these were less distressing after receiving a diagnosis.	High
Lum et al. 2014	58 participants **Female autistic adults** n = 32 **Non-autistic** (female carers and family members of autistic children or adults) n = 26	To investigate the healthcare experiences of women with and without HF ASC.	Online survey Cross-sectional observational design between groups.	- Autistic women more likely to perceive difficulties/dissatisfaction with their health care provider; including: overall healthcare anxiety, difficulties communicating when under emotional distress, anxiety specifically related to waiting room areas, support during pregnancy and difficulties communicating their pain and needs during childbirth compared to non-autistic women. - 75% of participants did not disclose their ASC diagnosis to their healthcare provider.	Good

McGillivray & Evert., 2018	109 autistic participants Female n = 30 Male n = 79	To examine gender and age differences in the frequency and severity of symptoms of depression, stress and anxiety.	Self-report Mood and Stress questionnaire comprising of demographic info, DASS and SSS. Cross-sectional observational design between groups.	- Both sexes reported greater emotional distress in relation to the depression, anxiety and stress subscales of the DASS - No significant sex differences found, however when separating for age, adult autistic females reported higher levels of distress associated with depressive symptoms - Autistic adult females scored above normal ranges on the depression subscales compared to males - Autistic females reported everyday life events, sensory and personal contact, socialising with others and environmental events more stressful compared to autistic males. - Both sexes aged 25 and over reported perceiving social and environmental events increasing stressful compared to their younger counterparts	High
Milner et al., 2019	18 autistic females 4 mothers of autistic females	To capture the experiences of autistic females to reduce the current male-bias in the understanding and recognition of autism.	Topic guide to facilitate a group discussion. Two groups, one for autistic women and one for parents. Cross-sectional observational design – single group.	- Five overarching themes were revealed from the group discussions; fitting in with the norm; potential obstacles for women and girls; negative aspects of autism; the perspective of others and positive aspects of autism. - There were also 17 sub-themes reported. - Provided a thorough insight into the first-hand experiences of autistic women.	High
Pecora et al., 2019	459 adults 227 TD (62 males, 152 female and 12 other-gender) 232 autistic (95 males, 111 females and 26 who identified as 'other')	To examine the sexuality and the sexual experiences of autistic females	AQ, SBS-111. Cross-sectional observational design between groups.	- Autistic females at a greater risk of negative sexual experiences (victimisation and abuse) compared to autistic males. - Autistic females report less sexual interest, but more sexual experiences than autistic males. - Autistic females report engaging in sexual behaviours that they regretted later or were unwanted, as well as receiving unwanted sexual advances.	High

Rutherford et al. 2016	150 participants **Children** n = 46 (Female n = 7 and male n = 39). **Adolescents** n = 40 (Female n = 12 and male n = 28). **Adults** n = 47 (Female n = 15 and male n = 32). **Adults 40 +** n = 16 (Female n = 7 and male n = 9).	Exploring whether gender differences existed in the ratio of young children, adolescents and adults diagnosed with autism, including age of referral and diagnosis and the duration of the diagnostic process.	Retrospective case note analysis of 150 case notes submitted from 16 diagnostic services in Scotland. Ex Post facto study design.	- Male to female gender ratio for adults: 1.8:1 (1.2:1 for those with ID and 2.5:1 without ID). - Male to female gender ratio for children and adolescents 3.5:1. - No significant gender effects were found on age of referral, diagnosis or duration of diagnostic processes. - Gender ratio across the sample reduced with increasing age. - Girls referred and diagnosed significantly later than boys. Delays occur prior to referral due to under-recognition.	Good
Steward et al., 2018	237 participants **Autistic** n = 123 **Non-autistic** = 114	To investigate the experiences of menstruation in autistic people	Online Survey. Cross-sectional observational design between groups.	- Amplified autistic related difficulties and challenges - Before, during and after the menstruation period autistic people experience heightened anxiety and difficulties regulating emotions and behaviour - Intensified sensory sensitivities during menstruation - Menstruation has a significant negative impact on lives	Good
Taylor et al., 2019	443 autistic adults **Female** n = 267 **Male** n = 176	To investigate sex differences in employment and support needs	Independent adult with autism Questionnaire (Self-Report). Cross-sectional observational design between groups.	- Rates of employment and engagement in higher education were similar for both sexes (67.6% males, 66.2% females) - Both sexes reported finding the workplace too challenging - 50% of participants reported unemployment. - Sex differences found in attitudes and access to support - 30.6% of males reported wanting to find work but could not compared to 19.1% of females - 34.4% of females reported not wanting to work at present compared to 13.9% of males. - Both sexes were similarly to be receiving financial support from families and state benefits, however of those receiving such, females received significantly less family support and fewer state benefits compared to males.	High
Tsakanikos et al. 2011	150 participants **Female** n = 50	To investigate whether autistic males and	PASS-AD Checklist	- No difference in mean age for referral to services between the sexes.	Good

	Male n = 100	females present with different rates of co-morbid psychopathology when referred to specialist services; and whether they access different pathways of care.	Statistical analyses used SPSS software. Cross-sectional observational design between groups.	- Females more likely to be living at home, males more likely to be living independently or in a health service setting. - Larger proportion of males were either married or in a stable relationship compared to females. - Males had a higher proportion of personality disorder and schizophrenia diagnoses, females had a higher proportion of dementia. - Females more likely to receive sedatives and anti-convulsant, however males more likely to receive combinations of the two medications.	
Wilson et al. 2016	1244 participants **Male** n = 935 **Female** n = 309 Age range: 18-75	To investigate whether sex influences the diagnostic evaluation of ASC.	Clinical assessment using ADI-R and ADOS-G. Cross-sectional observational design between groups.	- Significantly more males diagnosed with autism than females. - Females displayed less restrictive interests and repetitive behaviours. - Both sexes displayed similar levels of socio-communicative symptoms. - Women had slightly higher levels of mental health co-morbidities (61% females and 58% males experiencing at least one co-morbid mental health diagnosis).	Good

3.4.1. Thematic Analysis

3.4.1.1. Theme 1: Social and Communication Skills

Eight studies reported on the theme of social and communication skills. Of these, three quantitative studies and one mixed methods study compared groups of males and females. One of the remaining four studies made use of a mixed methods approach while the final three were qualitative studies that included only female participants.

Mandy et al. (2012) and Wilson et al. (2016) reported that both sexes displayed similar levels of difficulty in social and communication skills; however, although both studies had a large sample size, there were significantly fewer females in comparison to males. Other studies did report differences (Lai et al., 2011; Sedgewick et al., 2016). Teachers rated autistic girls as having less severe difficulties and greater levels of social motivation compared to autistic boys (Sedgewick et al., 2016). Lai et al. (2011) reported that females display fewer socio-communication difficulties compared to males, with females reporting more autistic traits during adulthood. Although this study had a small sample size, the sex ratio was equal.

Considering studies that focused upon describing the experiences of autistic teenagers and women, miscommunication and feeling misunderstood often resulted in feelings of confusion, anxiety and feeling different to their peers. Difficulties with communication were said to have obstructed the development of friendships, and intricacies such as understanding humour made social interaction difficult (Milner et al., 2019; Tierney et al., 2016). In one study, most women (62%) were reported to want support to improve their skills in this area (Baldwin & Costley., 2015).

3.4.1.2. Theme 2: Sensory processing and Repetitive and/or restricted behaviours and interests

Only three studies considered whether there are sensory processing differences amongst autistic people; one used a quantitative methodology and the remaining two used qualitative methods. Lai et al. (2011) found that females had more lifetime sensory issues relative to males. This was also reflected in the qualitative study by Milner et al. (2019) where 11 out of 18 female participants reported sensory sensitivities as playing a large role in their everyday lives. Sensory overload was described as causing severe distress, was overwhelming and debilitating and, often resulted in shut down (Milner et al., 2019; Tierney et al., 2016). In contrast, some participants described some positives in relation to sensory hypersensitivity (Milner et al., 2019). Overall, these findings are based on relatively small numbers of autistic people, thus limiting the generalisability to others.

Six studies reported information about repetitive and/or restricted behaviours and interests (RRBIs). Four of these used quantitative methods and two use mixed methods. Two of the studies had a balanced male to female ratio in their sample while three of the studies had a smaller number of female participants compared to males. Four studies found males had more RRBIs compared to females (Mandy et al., 2012, Grove et al., 2018; Hattier et al., 2011; Wilson et al., 2016). However, one of these studies included participants with an autism diagnosis and a severe or profound intellectual disabilities (Hattier et al., 2011). McFayden et al. (2019) found similar scores across sexes, but they suggested that females had interests that were more socially orientated, including interests in living constructs, with a narrower range of overall interests (animals, people science) whereas interests for males focused more on object related interests (vehicles, history, symbols). One study examined the intensity, frequency and motivation of RRBs and found no differences between males and females. However, autistic males had higher restricted behaviours than autistic females. Further, the authors reported that more males had a special interest (Grove et al., 2018). The final mixed methods study examined the views of autistic people about RRBIs; the participants described that their interests were an important aspect of their identity which provided them structure and a sense of achievement (Bargiela et al., 2016).

3.4.1.3. Theme 3: Camouflaging and coping strategies

Seven studies reported on camouflaging and coping strategies. One study used a quantitative methodology, two used mixed methods and four used qualitative methodologies. Of these seven, only three studies used comparison samples to investigate sex differences (Lai et al., 2017; Hull et al., 2017; Cage & Troxell-Whitman., 2019). Autistic women reported using coping strategies to develop friendships, to understand 'social codes' and build reference points, and to fit in and cope with social situations (Bargiela et al., 2016; Hull et al., 2017; Leedham et al., 2020; Milner et al., 2019; Tierney et al., 2016). Furthermore, in one study, autistic women self-reported that they believe masking contributes to the missed or mis-diagnosis of autism in women and girls (Milner et al., 2019).

Lai et al. (2017) found that on average, autistic females showed more camouflaging compared to autistic males. However, the study reports that even though sex differences were found, some females showed less camouflaging and some men showed marked camouflaging, suggesting that these abilities cannot be exclusively linked to autistic females.

Although the sample size was small in this study, an equal participant sex ratio was present. In contrast, Hull et al. (2017), found no consistent sex differences related to camouflaging. Although both studies had small sample sizes, sex ratios were more evenly balanced in Lai et al. (2017), whereas Hull et al. (2017) had more female participants than males.

Cage and Troxell-Whitman (2019) reported sex differences in relation to the reasons for camouflaging and found that autistic women endorsed using conventional (to fit in/get by in formal settings such as education or employment) as opposed to relational (to fit in/get by in relationships with others) reasons compared to autistic men. However, both groups reported more conventional reasons over relational reasons, and increasing use of camouflaging was associated with poorer mental health.

The mental and physical impact of camouflaging and other coping strategies (mimicry; imitation; learnt phrases and facial expressions) were also reported. Regardless of how often an autistic person used camouflaging strategies, it was suggested that camouflaging as a concept appears related to poorer mental health in autistic people (Cage & Troxell-Whitman, 2019). When asked about the impact on their mental health, autistic women described the consequences of camouflaging as exhausting, not being able to be true to themselves, feeling misunderstood/mis-interpreted, feeling anxious and depressed, and in some cases, this led to self-harm (Bargiela et al., 2016; Hull et al., 2017; Tierney et al., 2016).

3.4.1.4. Theme 4: Diagnosis

Six studies reported on diagnosis and access to diagnostic services. Four used quantitative methodologies and two used qualitative methodologies. Four of the six studies compared males and females and included a higher number of male participants; only one study had an equal sex ratio.

Autistic women and their parents were asked to describe their experiences with referral and diagnostic processes. In a single study, experiences were negative and limited support or after care post-diagnosis was provided (Milner et al., 2019). In another study, parents described that obtaining a diagnosis for their child was difficult because of the differences in the female presentation of autism. They perceived these barriers being caused by their daughters' abilities to imitate social behaviour, the higher incidences of autism in boys and reluctance from professionals to provide a formal diagnosis coupled with their daughters being diagnosed with other conditions before receiving an autism diagnosis (Cridland et al., 2015).

Wilson et al. (2016) considered whether sex influenced diagnostic evaluation of autistic adults and found that significantly more males were diagnosed with autism compared to females. Although the study had a large sample size, a large proportion of male participants compared to females were included in the analysis. In contrast, Grove et al. (2017) evaluated the Autism Spectrum Quotient Short Form (AQ) with a large sample of autistic adults, including a balanced male to female ratio, reporting no sex difference in the sensitivity of the AQ according to sex.

When investigating age of identification and subsequent referral, Begeer et al. (2013) found that the average time between initial signs and identification of autism was longer for females. They reported a 1.8-year delay in diagnosis for girls with Asperger syndrome but not autism, atypical autism, or PDD-NOS, relative to boys. For adults, women experienced a 4.3-year delay compared to men diagnosed with autism spectrum disorder, but not for Asperger syndrome or PDD-NOS. Rutherford et al. (2016) also investigated age of referral and reported that for children and adolescents, males were referred and diagnosed at a younger age compared to females. However, for adults, no relationship between gender and age of referral, diagnosis or duration of the diagnostic process was found. It is important to note that in both studies the authors included a smaller number of females compared to males.

Six studies reported on aspects of late and mis-diagnosis. Two used mixed methods and four used qualitative methodologies, with no studies investigating sex differences by making comparisons to samples of males. Participants in all six studies reported receiving a late diagnosis (Baldwin & Costley., 2015; Bargiela et al., 2016; Haney & Cullen., 2017; Kanfiszer et al., 2017; Kock et al., 2019; Leedham et al., 2020). Autistic women described that life would have been easier if they had received their diagnosis earlier (Baldwin & Costley, 2015; Leedham et al., 2020) and some stated that their late diagnosis negatively affected their well-being and education (Bargiela et al., 2016). Haney and Cullen (2017) described that autistic women believed that their delays in diagnosis were a result of their abilities in social mimicry and being able to ‘pretend to be normal’. In the same study, autistic women felt they had been mis-diagnosed with anxiety, depression, personality disorder, post-traumatic stress disorder and/or social anxiety disorders prior to receiving their autism diagnosis (Haney & Cullen., 2017).

Three of the six studies reported that autistic women saw receiving a late diagnosis as positive. This included being able to make sense of their previous experiences through a new autistic lens, as well as feeling a sense of relief, validation, calmness and vindication post-diagnosis, along with increased self-acceptance and confidence (Kanfiszer et al., 2017; Kock et al., 2019; Leedham et al., 2020). In contrast, a range of negative emotional responses were described by autistic women, such as feelings of grief, hopelessness, self-doubt as well as concerns around disclosure of their new diagnosis (Kock et al., 2019; Leedham et al., 2020).

3.4.1.5. Theme 5: Co-existing mental health conditions, emotional and behavioural difficulties

Eleven studies reported data relating to co-existing mental health conditions. Seven of these were quantitative studies, two used mixed methods and two were qualitative. Eight studies investigated sex differences using comparison groups; however, five of the eight studies which compared males and females had a smaller number of female than male participants.

Lai et al. (2011), Tint et al. (2017), and McGillivray and Evert (2018) reported no sex differences overall, with similar levels of co-existing mental health present for both autistic males and females. In contrast, one study, Wilson et al. (2016) reported that autistic females had slightly higher levels (61%) of co-existing mental health conditions, compared to autistic males (58%). However, when making comparisons between groups separated into age bands (young people 13-24; adults 25-44 and older adults 45-71 years), McGillivray and Evert (2018) found that adult autistic females scored above normal ranges on a measure of depression compared to males, and this was associated with higher levels of distress. Oswald et al. (2016) investigated symptoms of depression and anxiety amongst younger and older adolescents (autistic and non-autistic) and concluded that autistic adolescent girls were not at increased risk of developing mood disorders but noted that younger autistic adolescent girls included within their study did have more parental-reported symptoms of depression, relative to younger autistic adolescent boys, bearing in mind that these differences were not present amongst older adolescents.

Guert and Jansen (2011) and Tsakanikos et al. (2011) reported data about referrals to mental health services. Tsakanikos et al. (2011) found no sex differences in mean age of referral to services; however, Guert and Jansen (2011) found that males contacted the clinic slightly earlier than females, while females were more commonly diagnosed with anxiety, mood disorders and psychosis prior to an autism diagnosis relative to males.

Tsakanikos et al. (2011) recruited a sample with both intellectual disabilities and autism and reported that males had a higher proportion of diagnoses of personality disorder and schizophrenia diagnoses, whereas females had a higher proportion of dementia diagnoses. They also found that females were more likely than males to receive sedatives or anti-convulsant; however, males were more likely to receive a combination of both medications. This is the only study that included participants with intellectual disabilities while the majority of the other studies included within this review recruited autistic participants without intellectual disabilities.

In studies investigating experiences of mental health (Bargiela et al., 2016; Leedham et al., 2020; Milner et al., 2019), autistic women frequently described co-existing mental health conditions. Anxiety, depression, eating disorders and obsessive-compulsive disorder were most commonly reported (Bargiela et al., 2016; Milner et al., 2019). Autistic women described coping with their mental health impacted upon their everyday lives, with these difficulties acting as a barrier in understanding themselves (Leedham et al., 2020; Milner et al., 2019). Furthermore, Baldwin and Costley (2015) reported a higher proportion of autistic females who self-reported that they had a mental health condition relative to autistic males. In another study, autistic women described that their mental health difficulties were associated with trauma, complex family history, difficulties with school and bullying (Leedham et al., 2020).

Three studies reported further data about emotional and behavioural difficulties. Two studies used quantitative and one used qualitative methods. In one study (Mandy et al., 2012), data were collected by proxy measures; teachers reported that autistic males had greater externalising and interpersonal problems compared to autistic females, with parents reporting that autistic females have worse emotional difficulties compared to autistic males. The authors also reported that teacher-reported psychopathology (emotional and conduct problems, hyperactivity and inattention) was greater amongst autistic males relative to autistic females. In contrast parents reported similar levels of psychopathology between the sexes. Again, although this study had a large sample size, the number of female participants were small. However, Pisula et al. (2017) reported no sex differences in relation to emotional and behavioural problems amongst autistic males and females, but those who were non-autistic had fewer emotional and behavioural difficulties.

3.4.1.6. Theme 6: Friendships, romantic relationships, sex and abuse

Eleven studies reported on different aspects of friendships and relationships. Of these, four studies used mixed methodologies and seven used qualitative methodologies. Of the eleven, only two studies used a comparison sample which limits our ability to understand further whether sex differences are present. Nevertheless, both included comparable sex ratios and also made comparisons with a non-autistic sample.

In relation to friendships, autistic females reported experiencing more relational conflict compared to autistic males and experienced more social challenges compared to autistic males and their non-autistic peers (Sedgewick et al., 2019). The quality of friendships between autistic and non-autistic females were found to be similar (Sedgewick et al., 2016), but autistic females were found to have fewer close relationships compared to their non-autistic female peers (Sedgewick et al., 2019). Autistic females were also found to have a greater social motivation compared to autistic males (Sedgewick et al., 2016). Challenges around making, developing, maintaining and managing friendships were described by autistic women in five of the eleven studies (Bargiela et al., 2016; Cridland et al., 2014; Milner et al., 2019; Tierney et al., 2016; Vine Foggo & Webster., 2017). Social relationships were described as having emotional consequences (Kanfiszer et al., 2017), with social contact described as exhausting and time was required to de-stress after (Tierney et al., 2016; Vine Foggo & Webster., 2017). Meeting new people was also described as anxiety provoking, with social and school environments described as particularly challenging (Cridland et al., 2014; Kanfiszer et al., 2017; Tierney et al., 2016).

Autistic women also described finding it easier to have friendships with males (Bargiela et al., 2016; Cridland et al., 2014), and some women also highlighted the importance of having relationships with other autistic people (Vine Foggo & Webster., 2017). Difficulties with managing conflict within friendships was also briefly mentioned in one study as autistic women described themselves lacking conflict negotiation skills, which made relationships difficult to cope with and understand (Vine Foggo & Webster., 2017). Some participants described being bullied, picked on, ignored, and also described feeling lonely because they were unable to fit in (Baldwin & Costley, 2015; Cridland et al., 2014; Milner et al., 2019).

Romantic relationships were discussed in three of the studies. Some autistic women described needing more support with romantic relationships (Baldwin & Costley., 2015), while others described a preference for platonic relationships with men as they considered romantic relationships too stressful (Haney & Cullen., 2017). Autistic women described difficulties around dating such as understanding whether someone was interested, the rules and expectations of relationships, and the social expectations to date. In contrast, some also described the positive aspects of being in a relationship (Kock et al., 2019). Overall, the majority of studies that reported findings on friendships and relationships had small sample sizes which limits their generalisability to other autistic women.

Seven studies reported data about sexual experiences, including negative sexual experiences, and abuse. One study used a quantitative methodology, one used mixed methodology, and five used qualitative methodologies. Only one study used a comparison sample and although the sample size was large, there was a higher female ratio. Percora et al. (2019) compared the sexual experiences of men and women and reported that autistic and non-autistic females indicated that they would like to have sex, had a sexual experience, or had a sexual experience they regretted at similar rates. However, autistic females were more likely to endorse having agreed to sex when they did not want to, or that they had been subject to unwanted sexual advances more frequently than either non-autistic females or autistic males. In a different study using interpretative phenomenological analysis with eight autistic women, difficulties within sexual relationships, with some describing having been taken advantage of sexually or exploited, were also reported (Kock et al., 2019).

Similar issues were reported in other studies, with evidence to suggest that autistic women had been subject to various forms of victimisation and bullying related to their autistic difficulties (Bargiela et al., 2016; Haney & Cullen., 2017; Kanfiszer et al., 2017). There was evidence that autistic women had been sexually abused in the past (Bargiela et al., 2016; Haney & Cullen., 2017; Kanfiszer et al., 2017; Milner et al., 2019) and authors reported that difficulties understanding other people's intentions and understanding social cues, naivety, 'giving out the wrong body signals' and difficulties understanding social rules were all aspects that increased the risk of sexual vulnerability for autistic women.

In the small study by Cridland et al. (2014) involving five participants, parents reported that their autistic daughters faced unique challenges related to sexuality and relationships which included: becoming fixated on issues, misunderstandings with personal boundaries and confusion around social communication such as flirting. Furthermore, parents were also concerned that their daughters' vulnerability may be exploited due to their overly trusting nature of others.

3.4.1.7. Theme 7: Everyday life, employment and education, and access to services

Four studies reported on aspects of daily life. One study used a quantitative methodology, two used mixed methods and one used qualitative research methods. Only one study compared autistic females and males and the authors reported that everyday life events such as sensory issues, personal contact, socialising with others, and environmental events were more stressful for autistic females. Furthermore, they found that both sexes aged 25 and over perceived social and environmental events as more stressful relative to their younger counterparts (McGillivray & Evert, 2018). The further three studies reported similar findings, with everyday life seen as an ongoing struggle characterised by feelings of being ignored or misunderstood, with the lack of recognition and available support, making it increasingly difficult to live in a neurotypical world (Baldwin & Costley, 2015; Bargiela et al., 2016; Milner et al., 2019).

Three studies reported data about employment, with one having used quantitative, one having used mixed and one having used qualitative methods. Only one of the three studies compared males and females. When autistic women were asked to describe their experiences with employment, many challenges were described including feeling unrecognised or devalued in the workplace along with encountering difficulties with the social aspects of employment, although women described more social interaction difficulties compared to men (Baldwin & Costley, 2015). Autistic women also talked about difficulties with executive functioning, feeling unsupported by co-workers and supervisors, having sensory issues and difficulties understanding and recognising social cues, as well as describing they had increased employment-related stress related to their autistic traits (Baldwin & Costley, 2015; Haney & Cullen, 2017).

Taylor et al. (2019) recruited a sample of 443 autistic participants and reported similar rates of employment and engagement in higher education for both sexes, with both males and females reporting the workplace as a challenging environment. However, more males than females reported wanting to work but could not, while more females reported that they did not want to work. A similar number of autistic males and females reported receiving financial support from families and state benefits, but amongst females receiving this support, they received significantly less family support and fewer state benefits compared to males (Taylor et al., 2019).

Four studies reported data about education, and three of these studies made use of qualitative research methodologies, while one used mixed research methods. Only one study used a comparison sample of males and females. Autistic women described that the transition to secondary school was problematic and during this period specific difficulties emerged (Kanfiszer et al., 2017; Tierney et al., 2016). At school, autistic women described social environments as uncomfortable, distressing, and that they mostly felt rejected and unsafe (Tierney et al., 2016). Furthermore, some autistic female students said they felt unnoticed because they were able to blend in and did not present with behaviour difficulties that were problematic for teachers (Jarman & Rayner, 2015)

Autistic females described specific difficulties with sensory sensitivities, executive functioning, higher order thinking, handwriting (Jarman & Rayner, 2015) and the demands of formal learning (Baldwin & Costley, 2015), with just under half of the female participants reporting that the lack of support available to them was the worst thing about school. Compared to males, a higher number of autistic females (77%) reported receiving inadequate social support throughout their education compared to autistic males (65%; Baldwin & Costley, 2015).

Two studies reported on access to generic services; both were quantitative and only one of these studies used a comparison sample with a smaller number of females compared to males. Tint et al. (2017) reported that during adolescence, females accessed a wider range of services compared to males. The same study found no sex differences in service use during adulthood, but females were more likely to access emergency services compared to males. When investigating healthcare experiences, autistic women were also found to experience higher levels of anxiety and difficulties communicating their needs. This was a smaller study without a male comparison group, but autistic women were more likely to perceive difficulties/dissatisfaction with health care services compared to non-autistic women (Lum et al., 2014).

3.4.1.8. Theme 8: How others understand autism and caregivers’ experiences

Nine studies reported data about the perceptions and awareness of autism amongst others. One study used a quantitative methodology, two used mixed methods and the remaining six used qualitative methodologies. Only one study compared males and females. Cage and Burton (2019) investigated sex differences in relation to first impressions of autistic adults. Overall non-autistic people reported more negative first impressions of autistic people. Autistic women were viewed more favourably compared to autistic men but they were still viewed less favourably by non-autistic men and women. Lack of awareness and understanding of potential autistic female presentations by teachers were reported in five studies; one mixed method and four qualitative (Baldwin & Costley, 2015; Bargiela et al., 2016; Cridland et al., 2014; Jarman & Rayner, 2015; Tierney et al., 2016). Being academically able, quiet, as well as being perceived as high functioning, meant that teachers often overlooked the support needs of autistic females (Baldwin & Costley, 2015; Tierney et al., 2016; Jarman & Rayner, 2015).

Three studies also reported similar issues regarding a lack of understanding about female autistic presentations by professionals and GPs (Bargiela et al., 2016; Haney & Cullen, 2017; Leedham et al., 2020). Autistic women described that health professionals lacked the ability to recognise how autism presents in females, further suggesting that the male “stereotype” of autism added to the reluctance of professionals to provide a diagnosis (Bargiela et al., 2016). Haney and Cullen (2017) reported that autistic females stated that they thought that professionals perceived them as not significantly impaired by their autism due to being able to cope with social challenges and masking abilities. Finally, Milner et al. (2019) reported that autistic women described that a lack of understanding about autism in the general population, particularly in women and girls was frustrating, with more awareness needed.

Two studies reported on caregivers' experiences and one of these used interpretative phenomenological analysis, while the other involved parents of autistic adolescents and adults to complete questionnaires. Tint et al. (2017) recruited fewer parents of autistic females relative to males, but parents of females reported higher rates of caregiver strain relative to males. Cridland et al. (2014) reported that parents of adolescent autistic females described being heavily involved in their daughter's life compared to parents they knew of non-autistic females of the same age.

3.4.1.9. Theme 9: Gender expectations and gender identity

Four studies reported on gender expectations and gender identity. Three used qualitative methodologies and one used mixed methods. However, none of these studies involved comparisons between males and females. All four studies reported that autistic women felt pressured to conform to gender stereotypes and felt unable to fit in with these expectations (Bargiela et al., 2016; Kanfiszer et al., 2017; Milner et al., 2019; Tierney et al., 2016). Autistic women in two of the studies described aligning themselves more with male peers (Kanfiszer et al., 2017; Tierney et al., 2016). Additionally, some autistic women described not being able to relate to their own gender which led to confusion and discomfort of their female physiology (Kanfiszer et al., 2017; Milner et al., 2019; Tierney et al., 2016). Finally, some participants described difficulties with the communication style between the sexes, for example, preferring to communicate with male peers because they did not have to engage in emotion-based conversations (Milner et al., 2019; Tierney et al., 2016).

3.4.1.10. Theme 10: Menstruation

There were only two studies reporting data about menstruation, and one was an online survey of the experiences of autistic women (Steward et al., 2018), while the other was a study which used interpretative phenomenological analysis, where the focus was not solely upon menstruation, and included parents (Cridland et al., 2014). Steward et al. (2018) reported that while autistic and non-autistic women had similar issues around menstruation, amplified autistic related difficulties and challenges were reported for autistic women. Autistic women tended to experience heightened anxiety before, during and after their period; difficulties regulating emotions and behaviour and intensified sensory sensitivities during this time (Steward et al., 2018). Cridland et el. (2014) reported that parents of autistic females described that they though that their daughters demonstrated a factual and logical attitude towards their periods and coped well, which is inconsistent with the findings reported by Steward et al. (2018), bearing in mind this was a small-scale study with an early adolescent sample.

3.5. Discussion

The aim of this systematic review was to synthesise the findings from studies which had examined the experiences and behavioural presentations of autistic adolescent and adult females. Although research remains contradictory, there does appear to be converging evidence to support particular areas of differences between the sexes.

In summary, conflicting evidence was found for social and communication difficulties, with some studies finding equal levels of difficulty for autistic males and females, while others reported fewer difficulties for autistic females. Regardless, a common theme in the experiences of women and girls was the impact these difficulties had upon their everyday lives. More lifetime sensory issues were found for females compared to men, while RRBI were seen more frequently in males than females. In relation to camouflaging, again the research was conflicting, with some studies suggesting females engaged in more camouflaging than males, with some reporting no differences. However, for both sexes, camouflaging was associated with poorer mental health. Diagnostic challenges were described, with one study finding delays in diagnosis for autistic females. Differences in specific co-existing mental health diagnoses were reported, but both autistic males and females presented with similar levels of co-existing mental health, regardless of the specific diagnostic label. Finally, everyday experiences of life as an autistic female and the associated challenges were documented. These findings included more social challenges and conflict, and difficulties with friendships and relationships overall. Autistic women felt pressured to conform to gender stereotypes, and everyday life events were suggested to be more stressful for autistic women than autistic males, with a lack of general support described as a frequent issue.

3.5.1. Methodological quality of the evidence base

Due to the variety of research papers using multiple designs, it was necessary to identify a quality assessment tool that would allow for assessment of multiple studies regardless of the research methodology. As this systematic review included ascertaining information on the experiences of autistic women, it was important to ensure that the experiences and voices of autistic women were heard, therefore a tool was needed that was going to equally assess quality across a broad range of items. The QATTSD was chosen as the quality criteria allowed for multiple methods to be appraised, but more specifically because a key quality criterion was that of stakeholder input, which is important as autistic people are frequently excluded from participating in research studies (Milton, 2014).

Overall, most studies scored low on items appraising sample sizes and this was due to a lack of explanation provided about how unbalanced sex ratios were accounted for and whether studies were representative of the target group. The findings of this systematic review have been largely produced from small samples, and where comparison samples were used, more often than not, sex ratios were unequal with more males than females included in the samples. The lack of comparison groups and small sample sizes may therefore limit our abilities in being able to draw a conclusive picture of sex differences in female autistic adolescents and adults. Biological sex is frequently treated as a confounding variable and as such can potentially affect and contribute differently to the research topic in question. Although some of the studies included in this review accounted for unequal sex ratios in their statistical analysis, it can be argued that important aspects such as theoretical richness and intuitive interpretation can be lost (Ruiz-Cantero et al., 2007).

Most studies required participants to have a formal diagnosis of autism in order to meet inclusion criteria, this in itself may be inherently problematic as it is possible that there might be a potential male bias in the use of current diagnostic tools. Research samples are predominantly male (Haney & Cullen, 2017; Tsakanikos et al., 2011), so it is likely that female autistic participants in research are those who meet the criteria when assessed by the current diagnostic tools (Lai et al., 2011). This means that only people (whether they are female, non-binary or are transgender) whose presentation is similar to the stereotypical male presentation of autism are likely to be identified and therefore meet criteria for inclusion as a research participant. This potentially limits the identification of broader sex differences (Kanfiszer et al., 2017).

3.5.2. Limitations and areas for further study

As with any systematic review, there are always several aspects of the conduct of the review process that may result in limitations of the overall findings (Harrison et al., 2021). First, systematic reviews and the associated search terms are dependent on the availability of the research literature and as such it is possible that some relevant studies may have been missed or were not accessible due to a variety of reasons i.e., not published in English (Gough, 2017). Second, as discussed in chapter one, autism is a complex, multifaceted, and heterogenous condition and as such, studies investigating various aspects of autism, i.e., sex differences, will differ in terms of participant inclusion criteria, methodologies, and outcome measures employed throughout the research process. As expected, the studies included in this review all reported variations in their participant characteristics, study designs, methodologies, and analyses which, overall can impact on the comparability and generalisability of the findings, making it difficult to draw definitive conclusions.

Moreover, due to large amount of search results retrieved at the start of systematic search, inclusion criteria were refined to only include studies that specifically focused on behavioural presentations, discounting any research that focused on genetics and cognitive imaging. It should be acknowledged that omitting these studies may have in turn discounted potentially important information that may have furthered our understanding of autism. However, the rationale for such exclusion was based on two reasons, first screening tools and assessment rely on observable behaviours and lived experiences in order to be referred for diagnosis and/or receive an autism diagnosis, and second, an in-depth exploration of the wider literature would not have been possible due to the time constraints of this PhD and as such, future research should consider an update to this review to include all research studies focusing on autistic women and girls, irrespective of topic.

All studies identified were included within this review despite their quality in order to provide a thorough overview of the literature. This decision was made due to a paucity of literature relevant to autistic women, as the majority of previous studies have focused mainly on children. Consistent with other reviews, a further limitation is the possibility of missing papers throughout the database search process. However, to combat this, reference lists of all included papers were screened, as well as a grey search of the literature performed via Google Scholar. Furthermore, this review is not representative of participants across ethnic diversities as well as people who identify as LGBTQIA+ (which includes transgender and non-binary people), which is seen in much of the literature. Future research would benefit from an intersectional approach to highlight the different experiences of autistic women and those who identify as other genders (Cage & Troxwell-Whitman, 2019).

Despite limitations, this review revealed important findings and suggestions for expansion in particular research areas. Important to note, the findings emerging from the studies reviewed are not an exhaustive summary of difficulties and differences in presentation specific to females (as studies investigating children were not included) and equally, may not be exclusive to autistic females, with some characteristics also being observed in autistic males. To encapsulate a thorough understanding of sex differences across the lifespan, more high-quality research involving autistic people (including those who identify as other genders) remains important.

The majority of differences emerging between autistic males and females were mainly seen in single studies, so the generalisability to the wider autistic population is limited. Nevertheless, this an important starting point for future research studies and replications of such. To drive future research, having a qualitative focus would allow for further in-depth exploration and guide prospective interventions and support for autistic women and girls. Baldwin and Costley (2015) suggested that although there might not be a distinct ‘female profile’, the use of qualitative, anecdotal, and autobiographical accounts will continue to be meaningful to our understanding of the subtle differences in presentations. Increased qualitative and quantitative research studies are needed to examine potentially unique autism presentations in women that may not be currently captured by existing screening and assessment tools (Krieser & White, 2014). Furthermore, given that many research studies often use the terms sex and gender interchangeably, it would be important to see more structured definitions provided when exploring sex as a biological construct. Moreover, with gender identity remaining a complex issue, and given that many autistic people identify with other genders, this poses a particularly complex situation in unpicking who meets specific diagnostic criteria, for example the repetitive and restricted interest’s category is a particular area where misconceptions and contradiction are discussed.

Previous reviews (Hull et al., 2017; Moseley et al., 2018; Wood-Downie et al., 2020) have not focused on the lived experiences reported by autistic women. The current review enabled the qualitative experiences of autistic women and girls to be synthesised alongside previous quantitative investigations into sex differences, specifically focusing on adolescent and adult autistic females. Given that autistic women and girls experience similar patterns of late diagnosis, further research into specific age groups with a qualitative methodology would likely reveal further insight into the lived experiences of autism (Zener, 2019) and the diagnostic process across the lifespan. Pellicano et al. (2014) note there is a paucity of research that investigates the experiences of autistic adults, therefore the findings of this review adds to the growing body of literature which focuses on different time points of life such as adolescence and adulthood.

3.5.3. Broader considerations relating to screening and diagnosis

Although a defining characteristic of an autism diagnosis, evidence on how RRBIs are understood and documented by clinicians remains scarce. The results in this review suggested that autistic males had more RRBI compared to autistic females (Mandy et al., 2012; Grove et al., 2018; Hattier et al., 2011; Wilson et al., 2016). However, it is important to note that few studies have documented what these exact sex differences may be, as well as the fact that gender differences within autism may indeed reflect the wider gender differences in people overall. For example, it may not be that females display fewer, but rather they display different behaviours that are perhaps more in line with gender stereotypes. It is reasonable to suggest that if autistic females express their interests in a more socially appropriate way, including lower scores when subscales are isolated, this may make it more difficult to identify RRBIs for referral procedures or even recognised during the diagnostic process (McFayden et al., 2019).

It is a frequent misconception that autistic people will always have at least one special interest and this is often not the case. Furthermore, special interests or RRBIs are often described using the deficit model of autism, and as such it is important to consider the many positive aspects that autistic people report when describing their interests (Grove et al., 2018). This is particularly important to keep in mind when supporting people through the diagnostic process. Thorough understanding about the many differing and sometimes non-existent presentation of RRBIs will be needed to both recognise and refer to relevant services accordingly. Exploring the nature of how RRBIs present in autistic females in qualitative studies would perhaps be beneficial in broadening our knowledge and understanding of key sex differences in this area. Furthermore, research investigating clinical perspectives of sex differences found that clinicians reported RRB's to be subtler which could explain the underrepresentation found in previous studies (Jamison., 2017).

Understanding how camouflaging affects screening and diagnosis remains an area that warrants further investigation as research studies report inconclusive differences between the sexes. In terms of comparisons between the sexes, one study (Lai et al., 2017) found that females showed more camouflaging than autistic males, while Hull et al. (2017) found no sex differences. Throughout the literature the 'camouflaging' hypothesis has been presented to account for potential reasons why autistic females are often diagnosed later than males. However, there are minimal studies which have systematically investigated camouflaging, especially in adult autistic women specifically. Lai et al. (2017) defines camouflaging "…*as (consciously or unconsciously) compensating for and/or masking difficulties in social and interpersonal situations*." (p.693). However, it is important to note that camouflaging does not appear to be exclusive to the female phenotype of autism, with men also demonstrating camouflaging abilities, suggesting that camouflaging should be viewed as "*a phenomenon reflecting individual differences in social coping, rather than a diagnostic behavioural pattern*" (p.698).

With some evidence to indicate that autistic females more likely to experience more internalising problems (anxiety, depression and eating disorders) rather than externalising problems (hyperactivity, impulsivity and conduct problems), this poses particular difficulties for screening and diagnosis especially when camouflaging abilities are also utilised. Further research into events and prior diagnoses given before an autism diagnosis will be important in furthering our understanding as to why autistic women are often missed or mis-diagnosed. In general, there appears to be a lack of autistic female participants who take part in research studies, particularly quantitative studies (McGillivray & Evert, 2018), and with potential gender biases currently in play, it seems reasonable to suggest that what we understand about the mental health needs of autistic females more broadly may be based on what we know about autistic males (Tsakanikos et al., 2011).

There is a lack of information on gender differences in relation to psychiatric comorbidities and it is suggested that this may be due to diagnostic instruments that are potentially bias towards stereotypical male presentations of autism (McGillivray & Evert, 2018). Again, although the majority of the findings reported in this review are based on singular studies, they are important as a starting point for future investigation into the impacts of mental health conditions on the everyday life of autistic people. A further confounding factor which warrants future investigation are the similarities between autism and other psychiatric conditions. It has been suggested that characteristics of autism are often confused or may overlap with symptoms of mental health conditions (Stewart et al., 2006). Given that an autism diagnosis may overshadow the presence of mental health conditions which has been previously reported (Au-Yeung et al., 2018), it is also reasonable to suggest that prior diagnoses of mental health conditions may indeed overshadow the traits of autism and therefore may have led to the missed or mis-diagnosis of autism in females.

As this review has shown, delays in diagnosis were found for autistic women, but again findings were contradictory, with late diagnosis reported as remaining a significant challenge for both sexes during adulthood (Rutherford et al., 2016). Taking into consideration the notion of potentially missed or incorrect referrals, the higher levels of diagnoses in males may have either been due to GP's/psychiatrists being less sure of female differences/presentation, or that current diagnostic criteria may need adjusting (Wilson et al., 2016). The delays in diagnosis are of particular concern as this may continue to negatively impact on the health and well-being of autistic females, as self-reports highlight significant challenges experiences across a wide variety of quality-of-life domains (Baldwin & Costley, 2015; Bargiela et al., 2016). Furthermore, given that anxiety and depression are two of the most common co-morbid diagnoses in autism, and taking into consideration the significant challenges autistic females face (Baldwin & Costley, 2015), it seems reasonable to suggest if females are more able to mask their difficulties, then more specific strategies to identify concealed difficulties need to be put in place (Hull et al., 2020).

3.5.4. Rationale for the development of an autism female specific screening tool

Based upon the findings of this review, there are two clear reasons why a more comprehensive autism female specific tool is needed. Firstly, it seems particularly important to support the development of clinical awareness of autistic presentations. It is suggested that health care professionals including social workers, lack knowledge about autism and how this may present in both autistic males and females (Haney & Cullen, 2017). Further, autistic females report that they felt professionals did not understand the possibility of alternative presentations of autism, instead they felt the stereotype of 'Rain Man' and that all people with autism had to present with severe autistic behaviours seemed to be at play (Bargiela et al., 2016). Parents with autistic daughters reported the severe difficulties they encountered when trying to support teachers to recognise and understand their daughter's problems, describing *"Because her behaviour is perfect, teachers think she is fine and happy"* (p.132, Jarman & Rayner, 2015). Autistic female adults further describe the importance of not just dismissing the child just because she may have good eye contact, minimal behaviour problems and wants to interact with other children (Jarman & Rayner, 2015). With schoolteachers likely to be one of the first professionals young autistic girls come into contact with, it seems imperative that understanding on how autism may present in young school children, particularly females, is broadened.

Secondly, increased access to support services is paramount to the well-being of autistic people. Autistic females diagnosed later on in life appear to have been disadvantaged in terms of lack of support, describing feelings of being misunderstood and viewed in a negative light by their peers and adults (Bargiela et al., 2016). This suggests the importance of earlier diagnosis, especially for those without significant intellectual abilities as well as behavioural challenges, who may ‘fly underneath the radar’ of professional recognition (Baldwin & Costley, 2015; Lai et al., 2017). Autistic females report that their lives would have been much easier if they had received a diagnosis earlier and were able to access a variety of support services (Baldwin & Costley, 2015). Further having a diagnosis also enabled autistic women to feel more assertive with their rights, which is particularly important given the accounts described earlier of abusive situations and bullying that they had previously experiences (Bargiela et al., 2016).

3.6. Conclusion

Sex does in fact appear to influence diagnostic assessment, with further implications being apparent for access to services and service design. Specialist diagnostic assessments are expensive and time consuming to conduct with current increases in demands for specialist autism services, pressure on current healthcare resources will continue to increase. In order to both reduce incorrect referrals as well as prevent potentially missed opportunities for diagnoses, having a gendered developmental framework for use when assessing autism in females may become beneficial (Tierney et al., 2016; Wilson et al., 2016). It seems reasonable to suggest that a gender specific screening tool, or rather a tool that is used for better identification of specific subtleties and presentations that may well be seen in males as well as people who identify as LGBTQIA+, will be important for use in primary care and mental health services.

3.7. Systematic Review Update

The decision to not fully update the systematic review by rerunning the initial search terms was based on several important considerations. Whilst updating the review with the most recent studies could have a provided a more comprehensive analysis of the current literature on autistic women and girls, it would have disrupted the logical progression and coherence of the subsequent studies that were conducted for the development and refinement of the FASST. First, the systematic review served as the foundational study for initially refining the first draft of the FASST. Updating the systematic review with new studies and evidence could have introduced divergent findings and altered the item content of the FASST. Second, by conducting a scoping review of recent literature rather than a full update, it allowed for the identification of key papers that could provide relevant and recent insights into the experiences and behavioural presentations of autistic women and girls. This approach ensured that the systematic review chapter incorporated an update of the most recent research, without altering the conclusions and implications drawn from the original review. Finally, conducting a full update of the systematic review would have involved the analysis of a large volume of new research which would have been outside of the time constraints for the completion of this thesis. A scoping search was identified as a practical and time efficient approach in order to capture some of the most recent developments in autism research related to autistic women and girls. However, this strategy is not without its limitations, specifically in terms of comprehensiveness and potential selection bias. The aim of the following section of to provide an overview of recent research to demonstrate and awareness of current advancements in the field. Recent research will be summarised and reported in general themes noticed during selection and review.

3.7.1. Camouflaging

In line with the current assumption that autistic females may engage in more camouflaging behaviours, Hull et al., (2020) report that autistic females overall engage in camouflaging more than autistic males but demonstrated higher scores on the masking and assimilation subscales compared to males, however no differences were found on the compensation subscale (Hull et al., 2020). Further studies have also aligned with these findings. McQuaid et al., 2022 reported higher levels of camouflaging across all CAT-Q scores in autistic females compared to autistic males. Moreover, autistic adults who identify as gender diverse endorsed more CAT-Q compensation behaviours compared to cisgender autistic adults. This study was also the first to compare camouflaging between autistic adults diagnosed in childhood and autistic adults diagnosed in childhood/adolescence. Results found that adult-diagnosed participants reported significantly more camouflaging behaviours, suggesting that these skills have been learnt over time, specific categories with reportedly more differences were in the subscales of compensation and assimilation.

Two further studies reported on the impact of camouflaging. One study investigated the perceived consequences of camouflaging, autistic women reported that camouflaging was difficult and they were left feeling drained after engaging in various strategies. In contrast autistic males reported feeling positive after using camouflaging strategies and did not find this difficult to achieve. Bernadin et al., (2021). Halsall et al. (2020) investigated the experiences of autistic adolescent girls. Findings demonstrated that autistic girls used camouflaging to hide both their autism and learning needs. This in turn became a vicious cycle; concealing learning challenges resulted in missed learning, teacher unawareness and under-achievement. Most of the time their camouflaging was unsuccessful which resulted in their relationships and their sense of belonging being affected. Camouflaging was described as exhausting and distressing, as well as the fact that most strategies were used inconsistently which is matched with other literature that describes the breakdown of strategies when the social environment becomes too complex.

Finally, the impact of camouflaging on undiagnosed autistic women were also considered. Beck et al. (2020) recruited a sample that included women who were in a ‘grey zone’, potentially undiagnosed due to their camouflaging abilities. The majority of women with autistic traits reported significant psychological distress i.e. depression, anxiety and stress. The study suggests that many women with symptoms of a broader autism phenotype, are in significant distress and as such, concludes with recommendations for clinicians to carefully consider mental health concerns, especially for women who are verbally fluent, have IQs in the average range or above and who ‘seems to function well’. Although camouflaging efforts may promote social inclusion, evidence also suggests these strategies are significantly associated with psychological distress, even when severity of traits were accounted for. Moreover, the authors conclude that an outward appearance of ‘coping well’ does not indicate that she is functioning well emotionally and may be in a significant amount of distress (Beck et al., 2020).

3.7.2. Societal Expectations

Further experiences were described in qualitative research with regards to societal expectations and the pressure to have to conform to gender roles. Specifically, it was felt by the autistic women that because of the ‘invisibility’ of their autism, interpretations of their behaviour were often misunderstood (Mo et al., 2022). Seers and Hogg (2021) also investigated the impact of gender roles and social expectations on autistic identity and expression. An overarching theme found that autistic women found the stereotypical deficit model of autism impacted significantly on their overall wellbeing. Participants all reported experiencing difficulties with their formative years, but upon receiving their diagnosis they were able to recognise their unique strengths and embrace their identities as an autistic woman.

In a similar area and line with societal expectations, recent research on first impressions demonstrated that although autistic people were rated more poorly overall by non-autistic people, autistic males were rated less favourably than autistic females, perhaps suggesting that the subtler autistic presentations of autistic females make them more amenable to a society that places an emphasis on gender conformity (Belcher et al., 2022).

3.7.3. Diagnosis, social challenges, and mental health difficulties

Gesi et al. (2021) report findings that autistic women experienced on average a ten-year delay compared to autistic males in both age at first contact with a mental health service and age of diagnosis, thus supporting that the widespread notion that unfamiliarity of how autism presents in females does appear to affect access to a diagnosis. Autistic males were more likely than autistic females to be diagnosed with autism, in contrast, autistic. Females were more likely to be misdiagnosed when first evaluated by mental health services. Moreover, the way autistic present with their communication abilities, as well as the way their interests manifest, may not fit the classic professional understanding of autism, and as such may be linked to other mental health diagnoses such as OCD and/or eating disorders. Females also reported higher sensory sensitivities.

Additional research also suggests that autistic women are diagnosed later than autistic males, particularly if their autistic characteristics are considered mild, the study specifically found that the largest sex difference in age of diagnosis was related to lower RRBI severity, delayed parental concern and intact language abilities. Again, this aligned with recent research that suggests differences in interests and social communications difficulties may perpetuate the stigma that autism is a predominantly male condition (Kavanaugh et al., 2021.)

Similarly in Ireland, diagnostic delays were found for autistic girls, detailing that they also struggle with social challenges and mental health difficulties. Moreover, as described in the SR, parents reported feeling stress, despair and guilt post diagnosis, especially if the diagnosis was delayed. Fowler & O’Conner. 2021.

In line with accessing diagnosis, a qualitative study investigating the experiences of mothers who are parenting an autistic daughter, report that initially they did not consider an autism diagnosis as an explanation for their daughter’s experiences, thus again highlighting that the perpetuated stigma that autism is a predominantly male condition extends beyond professional awareness, but also impacts the understanding of parents too. The study concludes that increased awareness and dissemination of sex differences in autistic presentations is much needed and as such, the diagnostic process needs to be adapted, with clinicians ensuring they are aware of potential biases when using assessments of autism during the diagnostic process (Anderson et al., 2020).

Five studies also focused specifically on the mental health of autistic females. First, Arwet and Sizoo (2020) conducted a study investigating suicidality and whether or not rumination and self-esteem are risk factors for suicide. Findings demonstrated that although autistic females reported more suicidal ideation compared to autistic males, there were no significant difference between the degree of suicidality between the sexes. Notwithstanding, the high prevalence of suicidality, this study suggests suicidality is a potentially major concern in autistic adults irrespective of sex and highlights the importance of mental health professionals being alert to these signs especially if the autistic person is presenting with depressive symptoms. Depression, rumination and low self-esteem are all risk factors and significant effort must be made in order to decrease the risk of suicidality.

Recent research also examined autistic adolescents who access emergency services in the Netherlands. Findings demonstrated that autistic girls presented with a higher percentage of comorbid anxiety, risk of suicide and self-harm compared to autistic boys. However, in contrast, the persistence of their difficulties over time was rated as lower compared to autistic boys. The study recommends that for autistic girls presenting at emergency services a full screening/examination of their anxiety should be explored. Additionally, autistic adolescents presenting with need in crisis situations should be screened for internalising and externalising co-morbid conditions, relational problems, potential abuse, and specific types of harm such as cyber-bullying. Specific support is needed for autistic adolescents as they navigate puberty, especially for girls as they navigate much more complex social situations compared to the peer-to-peer relationships of autistic boys. In line with previous research, the continued exhaustion and stress associated with camouflaging may lead to more frequent emergency psychiatric referrals (So et al., 2021).

In line with previous research, autistic girls were found to experience more internalising problems compared to autistic boys. In addition, although there were minimal differences in social interactions between autistic girls and boys, increased differences were found between their same sex autistic peers, suggesting that further research would benefit from investigated differences peer to peer rather than comparisons to their autistic male counterparts (Dawalt et al., 2020). Finally, in an investigation into emotion dysregulation in an inpatient psychiatric sample, autistic women were found to experience significantly more difficulty with emotion regulation compared to autistic men (Weieckowski et al., 2020).

Lastly, Darling (2023) conducted a case series of six autistic women, all participants had received a previous diagnosis of borderline personality disorder before their autism was recognised. It was suggested that clinicians had misinterpreted their presentations and symptoms, such as anxiety, depression, self-harm and suicidal thoughts. Author recommendations suggest that clinicians should be cautious in diagnosing mental health conditions such as BPD until autism is ruled out. The impact of misdiagnosis has longer-term implications if current practices in identification of autistic women are not improved. Future research is crucial in understanding how to differentiate between developing comorbidities, as if autistic women continue to be missed or misdiagnosed, this will cause great personal pain and severely compromised functioning in their daily lives.

3.7.4. Health

Three studies reported on various aspects of the health care needs and experiences of autistic women. As far as I known, the first population-based study to provide comprehensive descriptions of reproductive age autistic women compared to non-autistic women was conducted by Tint et al. (2021). Results demonstrated that autistic women experience poorer health outcomes compared to non-autistic women in specific areas such as chronic medical conditions, increased rates of material deprivation, psychiatric conditions, increased use of teratogenic medications, whilst also experiencing a history of assault. In contrast, autistic women had better continuity of primary care when compared to non-autistic women. The study concludes with a call to action for more appropriate interventions and support for autistic women (Tint et al., 2021).

Emerging research also suggests that the needs of autistic women who are accessing health care services for an eating disorder are not being met, and overall increased understanding of autism, as well as how this may present in women is paramount. Furthermore, given that many autistic women experience a late diagnosis, this also has potential implications for supporting people who are currently accessing ED services but who may not be recognised as autistic, therefore the support they are offered would potentially not be meeting their needs. There are current pilot pathways underway to support eating disorders and autism, however, until such pathways are rolled out nationally, the importance of understanding differing presentations is far reaching in relation to tailored support (Babb et al., 2021). The final study related to health demonstrated that in comparison to autistic males, autistic women were found to be at greater risk for overall health problems, specifically nutrition conditions, psychiatric conditions and sleep disorders (DaWalt et al., 2021).

3.7.5. Menopause

The importance of understanding the menopausal experiences of autistic women were reported in a study by Moseley et al. (2021). Their findings suggest that the menopausal experiences of autistic women vary, with some experiencing a marked deterioration in their daily function and coping skills, mental health, and social engagement. Like other evidence in the literature, barriers, and access to appropriate health care support is limited, with women not feeling confident enough in the help they receive from health care professionals. Findings also demonstrated that autistic women have to navigate major midlife changes whilst also living within multiple circles of marginalisation: female, ageing and autistic. Findings also suggest that autistic people may lack knowledge needed to make empowered health decisions during menopause, and many may struggle alone. The study's findings highlight potential unmet support needs, in terms of accessing support and accessible information around menopause. Overall, the study suggests that inadequate support and lack of menopausal awareness from health care professionals may contribute to autistic women experiencing deterioration in everyday functioning, communicative abilities, extant relationships, emotional regulation and mental health.

3.7.6. Autistic Motherhood

In line with the health care needs of autistic women, qualitative research has also investigated the sensory experiences of autistic mothers and the need for more informed support and adaptations in certain environments. Autistic mothers described a range of sensory experience that had significant impacts on their overall well-being (Talcer et al., 2023). In a different study, the sensory needs of autistic mothers particularly during pregnancy, were deemed as an important life transition needing support, particularly that professionals need more training on how autism presents in adulthood, recognising that autistic women will often mask their true self. Autistic mothers describe the profoundly negative consequences they experience when their needs and experiences are not taken into account by professionals (Dugdale et al., 2021).

A study investigating experiences of motherhood, a comparison between autistic and non-autistic mothers, reported that autistic mothers were more likely to experience additional psychiatric conditions such as pre- or post-partum depression. Moreover, autistic mothers reported feeling misunderstood by professionals, providing further evidence that increased awareness of autism is needed for health services and professionals to provide more in-depth support (Pohl et al., 2020).

3.7.8. Employment

Two further studies investigated the experiences of employment. A recent qualitative study that conducted focus groups and 1-1 interviews report findings suggesting that autistic women experience specific expectations in the workplace to act and behave as a non-autistic person would, particularly in relation to emotions. Autistic women report encountering specific gender expectations related to communication styles, particularly lack of eye contact was looked at as a deviance from social norms by employers. Autistic women reported feeling pressured to adopt more gender appropriate behaviours in order to fit in. All participants felt they had to ‘mask’ in their roles, as well as having to supress stimming behaviours. Findings suggest women are supposed to fit in and not present as an inconvenience (Gemma, 2023). A further study reviewed content from an online community of autistic people in relation to career exploration and job-seeking. Autistic women described a ‘Double disadvantage’ in relation to gender roles, which meant that first they experienced an expectation to be employed in more feminine roles, but then they also to cope with the disabling barriers that autistic people often face with employment. Autistic women expressed more unfavourable experiences accessing and using employment support services, compared to autistic men who reported experiencing more difficulties with the job application process (Nagib & Wilton, 2019).

As discussed, only a scoping search of the literature was conducted, whilst every effort was made to be as thorough as possible, the search was not conducted systematically, the initial search terms will need to be run again, with any new studies quality assessed and thematically analysed before final up-to-date conclusions can be made on the current experiences and behavioural presentations of autistic women and girls.

Chapter Summary

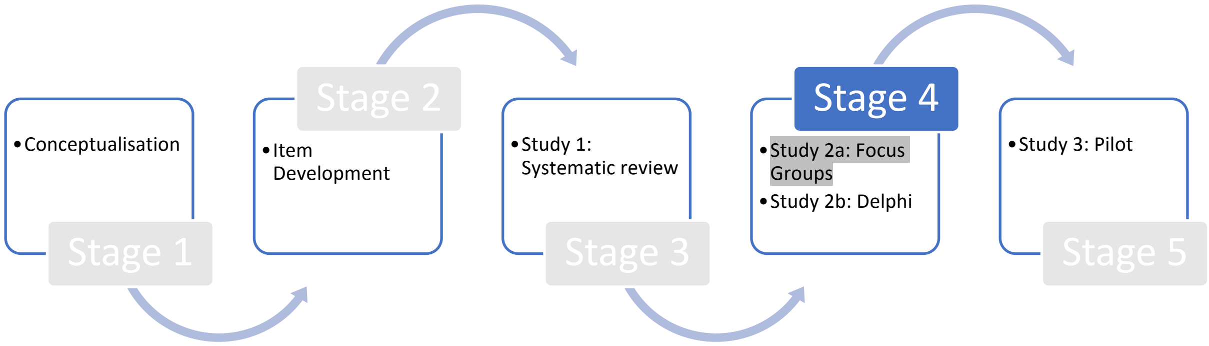
The systematic review undertaken in this chapter has provided valuable insights into the experiences and behavioural presentations of autistic women and girls. Through an extensive analysis of the existing literature and research findings, key areas that contribute to the development of improved understanding of the female presentation of autism has been found. Moreover, this systematic review allowed for the identification of important aspects that were missing from the initial version of the FASST v1, thereby informing its further development through the addition of new screening items. Study one was completed with two overall aims, first to add to the current literature of what is known about autistic women and girls, and second, to be used as a guide to inform the refinement of the FASST. Prior to commencement of the study, FASST v1 consisted of 48 items (see appendix 2.1). As a result of the information gleaned from the systematic review, a total of 17 items were added to the FASST (see table 2 below).

Whilst this process has revealed important information and allowed for version 2 of the FASST to be created, there are still gaps and limitations that necessitate further investigation. For instance, the existing research reviewed primarily focuses on the experiences and behavioural presentations of autistic females in specific age groups or research contexts, thereby potentially limiting the identification of important nuances that might be present in different cultural or socioeconomic backgrounds. To ensure a more diverse range of perspectives are considered whilst developing the FASST, the next stage of the research will involve the use of focus groups, and will specifically seek to recruit autistic women, parents/carers, professionals, and academics. By employing the use of focus group methodology, we aim to gather additional perspectives that will inform the refinement of the FASST, with the aim of improving the accuracy and sensitivity of the screening tool overall. Version 2 of the FASST (see appendix 2.2) will be used at the beginning of study 2 during the focus groups in order to continue with the triangulation process of refining the FASST.

Table 2: Additional FASST items added post systematic review

		Rarely/Never True	Sometimes True	True Most of the Time	Don't Know
49	*She feels exhausted after social situations*				
50	*She has difficulty managing conflict*				
51	*She experiences difficulties developing and maintaining friendships*				
52	*She is able to engage in 'small talk'*				
53	*She finds it easier to form friendships with males*				
54	*She has more shared interests with males and may be described as a 'tomboy'*				
55	*She experiences high levels of stress*				
56	*She is skilful at imitating the behaviours of others around her*				
57	*She uses online platforms to develop and maintain friendships*				
58	*She experiences difficulties with romantic relationships*				
59	*She experiences difficulties with school work*				
60	*She experiences difficulties with employment*				
61	*She expresses feelings of loneliness and isolation*				
62	*She experiences bullying*				
63	*She feels pressured to fit in with the social expectations of 'being female'*				
64	*She experiences mental health conditions*				
65	*Adolescence is/was a difficult period*				

Chapter 4. Study 2a: Focus Groups – Involving autistic voices: Gathering feedback on the FASST, a new screening tool to support the earlier identification of autistic women and girls



4.1. Introduction

The findings of the systematic review found conflicting evidence in relation to autistic differences between men and women. Areas of convergence were found in sensory issues, RRBI's, mental health conditions, delays in diagnosis and camouflaging traits. These findings underpin the importance of considering the potentially unique characteristics and presentations of autistic women and girls. Furthermore, evidence from both preceding chapters support the notion that current screening tools may not adequately capture the diverse ways that autism may present in women and girls, and as such, lay the foundation for the following studies in this thesis.

Notwithstanding the importance of reviewing the scientific literature, the inclusion of autistic individuals' experiences and perspectives in research is crucial for developing policy, support services, intervention and diagnostic evaluation that are truly meaningful and effective. When investigating a particular phenomenon, using combined research methods can provide collective insights into both the social and everyday knowledge of a particular topic (Caillud & Flick, 2017). In relation to this study, when designing a potential new screening tool for autism, the accounts of autistic females, parents/carers and professionals are paramount. Co-production in autism research refers to an approach where autistic people are actively involved in all stages of the research process, so that their thoughts and opinions are included (Stark et al., 2021). It recognises the importance of including the expertise and lived experiences of autistic people in order to shape research questions, methodologies, and outcomes. A framework for participatory research developed by Fletcher-Watson et al., (2019) identified key areas of importance to consider when conducting autism research. This included aspects such as respect and how to respectfully represent lived experiences in research, and authenticity, how autism communities can shape research (Fletcher-Watson et al., 2019). This collaborative approach aims to ensure that research is meaningful, relevant, and respectful of the needs and priorities of the autistic community. Additionally, co-production can promote a more inclusive and equitable research environment by challenging the traditional power dynamics between researchers and participants to ensure autistic people are heard and valued. Many women report that their lives would have been easier if they had of received their diagnosis earlier (Kelly et al., 2022). Thus, the importance of qualitative research into the lives and experiences of autistic females is vital for furthering our understanding into how autism may present differently between males and females.

Recognising this importance, study two of this thesis sought to actively involve autistic women, alongside parents, carers and professionals, in the evaluation of the FASST, a newly designed screening tool specifically developed to support the earlier identification of autism in women and girls. Focus groups were employed as a qualitative methodology to gather insights, experiences and feedback directly from this cohort. Focus groups are an important first step in the development of a measurement tool as it gives participants the opportunity to provide important information about topics that affect their everyday lives, it also provides the opportunity for participants to identify new areas of importance that may not have been recognised (Vogt et al., 2004).

The overall aim of the focus groups was to ensure that the content of the FASST accurately captures the unique characteristics and presentations of autistic females. The following chapter presents the findings of the focus group discussions conducted, providing valuable insights, perspectives, and recommendations from autistic people and other key stakeholders regarding the content of the FASST. By actively involving autistic people in the development of the FASST, study two aims to enhance the relevance and accuracy of the FASST, prior to the. The research question guiding study two is:

> What are the perspectives and feedback of autistic women, carers, parents and professionals regarding the content of the FASST, a new screening tool designed to assess autism in females?

4.2. Methodology

4.2.1. Participants

Participants were recruited via advertisements circulated through a range of charitable organisations and professional networks in the United Kingdom, as well as current known contacts through pre-existing networks of the research team. The study was also regularly circulated through various social media forums. Participants were a mixture of ages and genders, spoke English as their first language and had capacity to consent. There were no other inclusion/exclusion criteria. The inclusion criteria were kept deliberately broad in order to minimise difficulties with recruitment and maximise the potential of including as wide a range of experiences as possible. We specifically looked to identify autistic women who had experienced missed or mi-diagnosis and/or delayed diagnosis. This also included autistic people who identify as other genders or describe themselves as non-binary. In total, 14 autistic women and 4 parents of autistic girls took part.

4.2.2. Procedure

Once a participant had expressed interest, a participant information sheet and consent form was emailed. Once consent was received, details of how to attend the focus group were provided. Prior to the start of the focus groups, participants were emailed in advance and provided with concise information on what to expect during the focus group. If participants had any questions or were concerned about any aspect of the conduct of the group, they were supported to contact the researcher in advance and contact details were provided.

Prior to conducting the focus groups and based on reviewing both the initial version of the FASST (see appendix 2.1) and the wider literature (see chapter 1 and 2), 65 items were provided to the participants of the focus groups. The goal was to seek the feedback of key stakeholders on the item content of the FASST. Four focus groups in total were held. One face to face, the remaining three were held via Zoom conferencing. Two focus groups for each group were initially planned, a total of four focus groups, however due to recruitment issues and a lack of professional/academic participants, focus groups were only held for autistic people and family members/carers. In line with focus group methodology, the overall aim was to facilitate a discussion using a loose structure to guide the participants. One focus group was held face to face, but due to difficulties with recruitment and distance between the researcher and potential participants, focus groups were moved online and facilitated via the use of Zoom conferencing.

On the day of the focus groups the researcher provided an overall introduction and orientated the group to the structure of the session. The moderator followed the same interview guide (the FASST – appendix 3.5). Each focus group lasted between 90-120 minutes. The item content of the FASST was used and the researcher led with reading out each item. All participants were given adequate time to discuss each item and were free to discuss the FASST within the group, with the researcher passing no personal comments or judgements on what was being discussed within the group. All focus groups were audio recorded and transcripts of each were produced.

4.2.3. Ethical Consideration

Ethical approval was obtained from the Tizard Centre, University of Kent ethical review committee on X. (see appendix 3.1).

4.2.4. Data Analysis

As discussed in the overall methodology (chapter 2), a broad and liberal approach was taken to the analysis of the data (Vogt et al., 2004). For the purposes of item construction, the analysis of focus group data was not extensively coded, rather the purpose was to “get into” the mindset of autistic women and other key stakeholders to ensure the items in the FASST captured potentially unique autistic presentations (Nassar-McMillan et al., 2014). Broad principles of thematic analysis (Braun & Clarke, 2006) were followed, with the aim to identify responses specifically related to item generation or item amendments of the FASST. This included familiarisation of the data, coding of related items and searching for themes within participant discussion. The analytical strategy involved producing a second abridged document that included the most useful parts of the discussion (Krueger, 1998b; Vogt et al., 2004). The relevance of each discussion within each individual focus group was determined by whether it contained direct suggestions for item amendment or generation. After each focus group the researcher met with a member of the supervisory team (JB) to process the experience, this member served as an auditor in terms of recognising any inherent researcher bias, ensuring this was not imposed on the participants or the group process. The original transcripts and the abridged documents were provided to a second coder (JB) to ensure agreement on the themes identified as well as the suggestions for item content and/or amendments. There was complete agreement between the researcher and the second coder in relation to themes identified and items generated.

4.3. Results

Participants provided a wide range of experiences and commentary on the item content of the FASST. Five key themes were identified (see table 3), participants made suggestions for alternative wording of 16 of the original items on the FASST presented to them (see table 4) and 18 new items were added to the FASST as a result of participant suggestions (see table 5).

4.3.1. Focus Group Discussion Themes

The analysis of the focus group discussions revealed five key themes including: *structure of the FASST, masking, autistic experiences, item content and interpretation.* Examples from each theme is presented below in table 3.

Table 3: Themes emerging from participant comments

Theme	Examples
Structure of the FASST	• How the FASST would be scored is important i.e. would the item be a positive or negative indicator of autism • Ensuring that the person filling out the form had space to write additional comments or elaborate on an item • The importance of pairing this with a self-report version of the FASST
Masking	• Concerns around how well the informant could answer these items if the person was good at masking • Lots of autistic people develop coping strategies so difficulties may still go unnoticed • Autistic people are good at mimicking behaviour so you may not notice any differences on the surface
Autistic Experiences	Participants described a myriad of personal experiences: • Social Interaction and Communication • Friendships • Challenging the empathy myth • Trying so hard – but still getting it wrong • Social events/interactions are exhausting • Challenging the stereotypes of autistic routines and special interests • Understanding emotions and intentions
Item Content	• Suggestions for re-phrasing and/or additions • Depends on circumstances and the person • Autistic stereotypes • Links to other conditions • May not be observable • Delayed reactions to events • Negative wording • Gender stereotypes • Not exclusive to women • Not specific to autism
Interpretation	• Concerns around professional skill sets and knowledge base – this can affect the interpretation of how the informant has answered • The relationship with informant is important

4.3.1.1. Theme 1: Structure of the FASST

Participants discussed concerns on the tool being another deficit-based model, they expressed the importance of also looking at a person's strengths as this was considered important for overall mental health when progressing through the diagnostic pathways.

Participants also described the importance of having space on a screening tool to write additional comments, as sometimes an answer is not as simple as ticking a box. Although participants felt that an informant tool was needed, they also expressed the important of pairing this with a self-report version of the FASST in order for the autistic person to be able to share their views and experiences too.

In reference to language used "I think you want to word a lot of these in a more positive and supportive way…this questionnaire is a little bit negative and like the other tools out there if you don't change the wording now…there's actually some really good stuff to being autistic".

Participants also understood that a screening tool relies on difficulties to some extent "Like I know it's a screening tool and that we have to have these little tick boxes of all the things we can't do in order to get access to benefits and support…but also the actual aftermath of getting your summary report is f**ing awful, like that made me feel really bad for a while…so yea you know, if there was also a strengths assessment which could be written up at the same time, it wouldn't feel like such a blow to read about yourself in all the negative ways".

Finally, participants made reference to the need to be able to express themselves "so the person I'm getting to fill out my form for me is obviously someone who knows me, but they're never going to really know you like we know ourselves, I'd like to be able to answer the same questions, because you've got some good ones here…but from my own perspective".

4.3.1.2. Theme 2: Masking

Concerns were raised by participants in relation to masking, describing that autistic people develop a myriad of coping strategies as they grow up to cope with the world around them. Participants felt that unless the clinician, professional and/or parents and carers understood how a person might mask, then some of the questions may in fact not pick up the difficulties the person might be experiencing. Suggestions for a guide on 'what to look for' to accompany the FASST was made by several participants.

Participants suggested age matters when it comes to masking skills *"A child or young person may have some good masking skills, but compared to a 64-yeard old with years of experience, their masking skills would be a lot better…I can talk the hind legs of a donkey, but that doesn't mean that's what's going on inside of me"*

Some shared their own experiences in relation to masking *"My husband stated the other day he believed I loved meeting new people because I have got so good at the skills require. People who don't know me for very long would not know that I am experiencing any of the things on this questionnaire, because I have learnt all the skills…however if this questionnaire was around when I was 20 before I had the chance to learn all of these skills then it might have actually been useful."*

Finally, several participants all made suggestions for a guide for professionals *"you know that saying 'when you've met one autistic person, you've met one autistic person', well the same goes for Doctors and the people assessing you, because sometimes I think it's* *actually pot luck if you get someone who actually understands what its like to be an autistic woman".*

"Like a guide for them to how not to get it wrong and miss us…yea, that would be important".

"I agree…a how to not fob autistic women off and label us with mental health conditions guide".

4.3.1.3. Theme 3: Autistic Experiences

A plethora of experiences were provided by participants describing the importance of having items in the FASST that specifically looked at female presentations of difficulties within social relationships, understanding emotions and intentions, finding social events and interactions exhausting and 'trying so hard…to fit in' but still getting it wrong.

Referring to group chats *"We do it (engage in big groups) at a consequence afterwards, it gives me migraines…but I didn't realise the link until after I realised, I was on the spectrum…if there's more than two people in the room I am stressed out to the max trying to juggle it all".*

When discussing sensory needs *"None of the assessments or screening stuff that was done on me ever took into consideration my sensory needs, it is such a huge part of my life, but I just felt fobbed off, just because it's not on one of their tick boxes does not mean it's not happening to me".*

Participants also referred frequently to difficulties with friendships *"I have friends now, autistic ones, and I think that's because they get me, but I've never really had any friends before that because I always seemed to be getting it wrong, no matter how hard I tried".*

"A lot of the assessments will ask you about how you communicate and interact, but no-one every really asks you about your friendships, if you're happy, I would actually really like some support to make new friends, but it's really hard to get that help you know because I don't really know what help to ask for".

A lot of participants shared their experiences of a late diagnosis *"It just makes me feel so sad that I was labelled with all these things before this Dr actually thought I might be autistic, the impact of not fitting in for years took me so long to process, I mean, I don't think I have fully processed it all, but I definitely feel better knowing who I am now".*

"I didn't get my diagnosis until I was 62, people didn't understand why I wanted it (the diagnosis) now, but it was so important to me to be validated for the first time in my life".

"I just think back to all the times I could have done better at school and college if I had been recognised as being autistic and been given the help, I needed…I actually feel really resentful, but I guess I should be grateful now…I just wish I could have my label of BPD removed".

4.3.1.4. Them 4: Item Content

Participants provided many suggestions for re-phrasing of items and/or addition of items in order to counteract some of the autistic stereotypes found in traditional screening tools. Participants described that a lot of the items may not be exclusive to women and that caution should be given when considering gender stereotypes. Some participants expressed concerns that there may be an overlap with other conditions and may not be specific to autism. Participants requested that the word ‘she’ should be replaced with ‘they’ to make the item content more inclusive.

Participants across all groups were in agreement that it would be important to be mindful of negative stereotypical phrasings of items “Like, I really hate that everyone thinks we’re tomboys...I love pink and girlie things, oh yea and I have empathy”.

“It’s not just all about the men, and this stereotype is really annoying that we find it easier to get on with males…I just find it easier to not get on with neurotypicals at all!”.

In relation to the specific wording of the item ‘she can always pick up and respond appropriately to other people’s feelings’, one participant suggested *“some of these questions you need to split up into more than one question…because sometimes you may pick up on things, but you might not always be able to, or know how to respond appropriately”.*

For the item ‘she expresses feelings of loneliness and isolation’, participants had several different comments and suggestions. Some said that they liked feeling isolated so each item can be contextual *"I don't think I ever realised I was lonely or isolated…I actually go out of my way to stay isolated from people…ha ha ha".* In addition, *"loneliness implies a negative. If you enjoy being on your own then you wouldn't say you're lonely. But saying you're lonely implies you are lacking something".* Finally, a participant suggested "*You are assuming the person completing the form are able to recognise what loneliness is. Maybe you could ask 'does she seem to be isolating herself' instead?".*

Referring to interests *"its so sad that its always pulled down to the negatives, why can't it be asked has it lead to a new hobby, or a lucrative career, or making new friends…because my answer would be yes…the happy autistic woman is the one who has turned their obsession into a job…but I have learnt I cant keep changing my career every time I have a new obsession!!".*

4.3.1.5. Theme 5: Interpretation

Finally, participants described the importance of being aware that all informant screening tools are reliant upon the person who is completing it. In other words, all informant tools are subjective, and the answers provided will be based upon how well the informant knows the person that they are completing the form on. Concerns were raised around professional skill sets and knowledge base, and that if the professional does not have experience of assessing autistic women and girls, then this may affect the interpretation of how the informant has answered.

Concerns about what would happen if the person didn't have anyone else in their life were raised "So what happens when we don't have anyone…I think that's why my autism diagnosis took so long because everyone just kept saying I needed to have a family member, but all my relatives had passed on” and “it’s really important that the person knows you well because our whole lives are at stake”.

Finally, almost every participant, apart from the parents described feeling like there was a lack of professional understanding of how autism presents in females “I can’t even tell you how many Doctors I saw first who had absolutely no understanding that I could be autistic”.

“The amount of teachers, doctors and professionals that all told me I couldn’t be autistic because only men were autistic was ridiculous”.

“It does really seem to be pot luck, like all of the people I’ve met online and not just in the UK but in other countries too, they all say similar things, some people get good access to support, and others, well we don’t get anything and have to fight to be understood”.

4.3.2. Alternate wording and addition of FASST items

Participants provided suggestions on wording amendments for 16 items on the FASST. Suggestions included the removal of negative associations, ensuring personal experiences remained neutral as well as ensuring items were contextual, for example ‘She experiences bullying’ should be rephrased to include past experiences. All wording amendments are detailed below in table 4.

Table 4: Alternate wording of FASST items

Original FASST Item	Participants Comments	Re-phrased Item
She is able to chat about anything with you.	Add ‘almost”	She is able to chat about almost anything with you
She tends to have lots of fleeting relationships.	Change ‘fleeting’ to short-lived.	She tends to have lots of short-lived relationships
It is easy to feel a comfortable connection with her.	This should not be a personal observation, change to ‘Do other people’	Do other people feel a comfortable connection with her
She is highly organised and likes lists, special arrangement of objects, or ordering things.	There is no need to comment on whether or not she is highly organised – remove.	She likes lists, special arrangements of objects, or ordering things
She has specific routines that she HAS to stick to or she becomes upset.	It should not be ‘has’ or ‘needs’ – there could be a lot of reasons.	She gets upset if she cannot follow specific routines
She has really focussed interests or passions which she will spend hours pursuing.	There could be many interests at any one time – phrase with ‘particular’	She can spend long periods of time focused on a particular activity
She seems excessively bothered by noises that do not bother others.	Using ‘excessive’ demeans what the person is experiencing.	She is distressed by noises that do not bother others
She has excessively intense dislike of specific textures, tastes, or smells.	Using ‘excessive’ demeans what the person is experiencing.	She has unusually intense like/dislike of specific textures, tastes, smells or places/spaces
She is a really calm, content person.	There is no need for the word ‘content’ – split into two questions	She is a really calm person
Other people think she takes things too literally.	Clarifying the question by stating ‘she can’	Other people think she can take things too literally
She complains of feeling different to other people.	Does not need the negative associations with the word ‘complains’	She mentions or talks about feeling different to other people
She can easily pick up on and respond appropriately to other people’s feelings.	Separate into two questions.	She can easily respond appropriately to other people's feelings
She experiences difficulties with romantic relationships.	Add in ‘likely to’ as well.	She experiences difficulties or is likely to experience difficulties with romantic relationships
She experiences difficulties with school work.	Add in ‘previously experienced’	She experiences difficulties or previously experienced difficulties with school work
She experiences difficulties with employment.	Add in ‘likely to’ as well.	She experiences difficulties or is likely to experience difficulties with employment
She experiences bullying.	Add in ‘previously experienced’	She experiences or previously experienced bullying
She experiences mental health conditions.	Add in ‘previously experienced’	She experiences or previously experienced mental health conditions

As a result of the focus groups and additional 18 items were added to the FASST based on participant perspective and suggestions. These can be found below in Table 5.

Table 5 - Additional items added post focus groups

		Rarely/Never True	Sometimes True	True Most of the Time	Don't Know
66	She is always direct, blunt and to the point				
67	She is described as overbearing and/or intense				
68	She has a smaller number of friends that she trusts				
69	She is very conscious of her impact on her environment				
70	She has intense attachments to objects				
71	She has intense attachments to animals				
72	She has an intense reaction to things on the TV that others find acceptable				
73	She has difficulties with proprioception				
74	She is sensitive to temperature				
75	She has difficulties understanding her own emotions				
76	She is a content person				
77	She has a strong sense of justice, of right and wrong and seeking the truth				
78	Other people think she can take things too seriously				
79	She can easily pick up on other people's feelings				
80	She can spend a long time ruminating				
81	She has difficulties understanding boundaries in relationships				
82	Does she isolate herself from others				
83	Do people complain about how she treats others				

4.4. Discussion

The aim of this study was to gather the perspectives from autistic women and other key stakeholders on the item content of the FASST. The discussions and feedback from the participants facilitated the wording amendment of 16 original FASST items and generated 18 new items. During each focus group, participants actively engaged in discussions about their experiences, perspectives and challenges related to autism and their diagnosis. The use of employing a focus group methodology enabled the engagement with diverse stakeholders including autistic women, parents, and carers and enabled the research question "***What are the perspectives and feedback of autistic women, carers, parents and***

professionals regarding the content of the FASST, a new screening tool designed to assess autism in females?" to be answered. By actively involving these participants we were able to ensure a collaborative approach to refining the FASST which enabled the collection of nuanced perspectives on the content and the wording of the FASST. Through this collaborative and inclusive approach, the focus groups enabled participants to share their lived experiences, insights and recommendations regarding the refinement and enhancement of the FASST. The co-production element of this study sought to capture a comprehensive range of perspectives to ensure that the FASST is sensitive, inclusive, and meaningful to autistic people and the key people in their lives. All participants offered valuable suggestions for improving the FASST, including the addition of new items that they felt were potentially important in capturing the unique characteristics and experiences of autistic women.

The focus groups identified five overarching themes that emerged from the discussions with autistic women and parents regarding the development of the FASST: the importance of the structure of the FASST, masking and the potential this has to impact on identification, autistic experiences, item content of the FASST, and consideration of how FASST items may be interpreted by professionals. These themes reflect key aspects of autism screening assessments and provided valuable insights into the challenges faced by autistic women in the diagnostic process. One of the significant themes highlighted by the participants was the importance of the structure of the FASST, in particular, concerns over negatively phrased language and the associations to deficit based, medical model language often used in other assessment measures. The discussions revealed that autistic women often struggle with current assessment measures that do not adequately capture their unique experiences and characteristics of autism. This finding aligns with previous research that suggests the potential limitations of existing screening tools in capturing diverse presentations of autism. The participants' perspectives underscore the need for inclusive screening measures that account for the variability and complexity of autistic characteristics in women.

The theme of autistic masking emerged as a crucial aspect for consideration during the discussions. Participants expressed their experiences of masking or developing camouflaging strategies to hide their autistic characteristics and as such raised important questions as to how screening tools that are informant based can account for this. This finding aligns with existing literature which suggests that autistic women and girls may be missed during assessments due to their camouflaging abilities. The participants' insight into camouflaging highlighted the potential impact of masking on the accuracy of screening measures, as they may underestimate the presence and/or qualitative autistic characteristics on the accuracy of screening measures. This theme aligns with the overall aim of this thesis in that these concerns raise questions about the potential sensitivity of currently used screening tools in capturing differing presentations of autism and supports the notion that more inclusive screening tools are needed.

The theme of autistic experiences identified the lived realities of autistic women and parents and some of the unique challenges they may face. The focus group discussions revealed a range of experiences related to sensory sensitivities, difficulties with social interactions and friendships, and mental health issues. These findings align with the existing literature emphasising the heterogeneity and complexity of the autistic experience. The experiences described by the participants supported the incorporation of their concerns into the FASST items, therefore adding more depth and context to the screening process overall. It highlights the importance of capturing the lived experiences of autistic women to ensure comprehensive and holistic evaluations take place.

The item content of the FASST was a particular focal point of the conversation and therefore produced an overall theme highlighting their concerns. Participants provided valuable feedback on existing items and made suggestions for new items that they felt were essential for capturing specific autistic characteristics and experiences that may not be covered in currently used screening tools. This emphasis on item content, specifically the amendments and addition of items is in line with current evidence that suggests the importance for the inclusion of gender-sensitive and culturally relevant items in autism screening assessment measures.

Lastly, the focus groups discussions highlighted particular concerns about how items in the FASST would be interpreted by professionals as well as concerns around how well an informant could answer the items unless they are very closely related to the person being screened. For example, some autistic people may not have a close family network or a friend that knows them well, so if a GP or mental health professional was asked to complete the tool, this may impact the results, especially if the person is very good at masking their autistic characteristics. The challenge with professionals was discussed more broadly in terms of potential diagnostic disparities and challenges in identifying autism in women. Participants expressed concerns about the lack of awareness and understanding among professionals and/or teachers regarding the potentially unique presentations of autism in women. This finding resonates with existing literature highlighting the potential for missed or misdiagnosis of autistic women due to the potential gender bias in professionals understanding different presentations of autism. It therefore seems reasonable to suggest that more targeted training and education for professionals involved in the assessment and diagnostic pathways is sought.

4.5. Strengths and Limitations

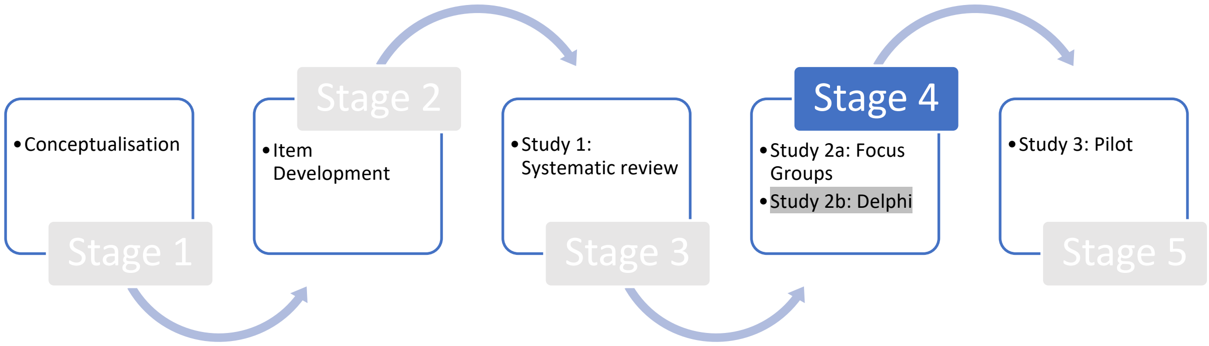
The collaborative nature of the focus group sessions allowed for an interactive process of item generation and refinement, that incorporated the voices of autistic people, enhancing the FASST's authenticity and relevance. The inclusion of participant-generated items in the FASST is a significant strength of this study. By consulting with autistic people, who are considered 'experts by experience', this increases the content validity of the FASST and thus supports the improvement in the relevance and the representativeness of each individual item (Vogt et al., 2004). Moreover, the focus groups gave the researcher the opportunity to learn from autistic people from their own perspectives, which is important as "researchers may unconsciously interpret the experiences of other 'cultures' through the lens of their own cultural beliefs and values" (p.233, Vogt et al., 2004). A further strength of the focus groups was providing autistic people the opportunity to connect and discuss sensitive topics, this potentially was validating for autistic people in that their experiences could be recognised and shared with one another.

This study was not without its limitations as is such with qualitative research. First, it is a well-known fact that sometimes focus groups can include a dominant participant that controls the group discussion at any one time (Vogt et al., 2004). Although this was not noticed by the moderator it might have been possible that not all participants felt comfortable in participating in all the topic discussions had within the groups. At times, participants did veer away from the item content when sharing their own personal perspectives which occasionally resulted in conversations that extended beyond the topic discussion. Although the moderator utilised skills to orientate back to the item content of the FASST, this may have altered the dynamics of the focus group by steering participants back to the item content. Lastly, it is important to recognise that this was a small-scale study and the findings are specific to the participants involved and as such, may not be representative of the entire population of autistic women. However, the insights gained from these focus groups provide valuable preliminary evidence for the usefulness and relevance of the generated and amended items in the FASST, as well as aligning with existing research that highlights some of the unique challenges experienced by autistic women during the diagnostic process.

4.6. Conclusion

As an initial stage in the iterative process of refining the FASST, the focus groups have successfully facilitated the generation and amendment of items in the FASST through active participation and valuable insights of autistic women and parents. However, recognising the importance of further validation and consensus building, the refined FASST will now undergo further rigorous evaluation through the use of a Delphi consultation. This iterative approach ensures that the FASST continues to evolve, incorporating diverse perspectives and expert consensus to enhance its overall validity and reliability prior to pilot testing. The following chapter will report the findings of study 2b – Delphi Consultation.

Chapter 5. Study 2b: Refining and Validating the FASST: Utilising a Delphi consultation to incorporate additional and alternative perspectives from key stakeholders



5.1. Introduction

The development of a valid and reliable screening tool for assessing autism in women and girls necessitates a comprehensive and iterative process that integrates diverse perspectives and expertise. In response to feedback gathered from autistic women and parents during the focus groups, a revised version of the FASST was created through the amendment and addition of items which captured their unique experiences and perspectives. While the focus groups provided valuable insights, qualitative methodologies inherently possess some limitations in terms of generalisability and consensus-building which is important in scale development. For this reason, the integration of the Delphi consultation was chosen, as this quantitative methodology offers a structured and iterative process, that aims to utilise a panel of experts to establish consensus and quantify agreement. The Delphi consultation is a research methodology that incorporates multiple rounds of consensus-building, to refine and validate the items included in the revised version of the FASST. The Delphi was therefore chosen as the last stage in the triangulation process to achieve social and content validity, as highlighted in chapter 2.

To ensure the robustness and validity of the FASST prior to piloting, further investigation is required. By engaging a panel of experts comprising of autistic women, parents, professionals and researchers/academics, this process enables the inclusion of alternative perspectives to ensure the FASST's relevance, accuracy, and comprehensiveness. The data collected during this study will be used to refine the FASST for a final time prior to the pilot study. Since this research study is exploratory in nature for the purpose of the development and refinement of the FASST, the views gained from these methodologies are important for two reasons. First, as previously discussed in chapters 2 and 4, understanding the experiences and seeking the views of autistic females, their parents and carers may help us to identify where previous screening tools are missing women and girls. Second, it is hoped that the FASST will be used in frontline services, therefore the views and opinions of professionals who have supported individuals throughout the diagnostic process will be able to provide valuable commentary on the items contained within the FASST and how these items may improve the identification of autism in women and girls.

This chapter presents the findings of the Delphi consultation, highlighting the iterative refinement of the FASST and the consensus achieved among the panel of experts. The research question guiding this study is:

How can a Delphi consultation process be utilised to further refine and validate the items included in the revised version of the FASST, based on feedback from autistic women and other key stakeholders?

5.2. Methodology

5.2.1 Participants

Due to difficulties with recruitment, a shortage of professionals and academics was experienced, therefore the Delphi Consultation was opened to all participants that had registered, including those who had previously taken part in the focus groups. Participants were recruited via advertisements circulated through a range of charitable organisations and professional networks in the United Kingdom, as well as current known contacts through pre-existing networks of the research team. The study was also regularly circulated through various social media forums. Participants were a mixture of ages and genders, spoke English as their first language and had capacity to consent. There were no other inclusion/exclusion criteria. The inclusion criteria were kept deliberately broad in order to minimise further difficulties with recruitment and maximise the potential of including as wide a range of experiences as possible. We specifically looked to identify autistic women who had experienced missed or mi-diagnosis and/or delayed diagnosis. This also included autistic people who identify as other genders or describe themselves as non-binary. Although there is no consensus as to how many participants should take part in a Delphi consultation, for example numbers can range from a few participants into the hundreds, research suggests the larger the number the greater the generation of data (Hasson et al., 2000). Therefore, no limit was set as to how many participants were recruited. The final panel consisted of 108 participants, 65 autistic people, 33 family members/carers, 22 people who self-identify as autistic, 20 professionals and 4 academic researchers. Participants took part from all over the world including the UK, Germany, USA, Portugal, Australia, Austria, Israel, Canada and New Zealand.

5.2.1.1. Participant Characteristics

Table 6: Participant Characteristics – Delphi

	Participants	**n=108**	**%**
Category 1 – Participant Information	Autistic	65	60.19%
	Family Member/Carer	33	30.56%
	Professionals	20	18.51%
	Academic Researchers	4	3.70%
Category 2 Gender	Identified as Female	84	77.78%
	Identified as other gender	24	22.22%
Category 3 Age	18-39 years	39	36.11%
	40-59 years	60	55.56%
	60 years	9	8.33%

5.2.2. Procedure

Once a participant had expressed interest, a participant information sheet and consent form was emailed. After receiving informed consent, participants were sent an electronic link to the Delphi exercise. Each form was generated via Google Forms. For each round, participants were permitted two weeks to complete the questionnaire, the researcher provided regular email updates to remind participants to complete their link.

Two modifications to the established Delphi method were utilised for the purposes of this study. First, it is common for the first round of the Delphi to have a qualitative component, however, the utilisation of focus groups in the previous study was used to inform the quantitative rounds in the Delphi (Hasson et al., 2000). Second, adjustments were made to response questions in rounds two, three and four. Overall, panel members were asked to rate FASST items in terms of their importance, with an additional space for comments and suggestions after each question, however the format for rating ‘importance’ changed in rounds two and three which will be further outlined below. Questions for each subsequent round were generated based on the data collected after each round. These were discussed with the supervisory team prior to any changes being made between rounds. Upon completion of each round, the researcher provided the panellists with a summary of findings before an invitation was sent to complete subsequent rounds. Questionnaires for all rounds were prepared and distributed to participants using Google Forms software. This software was chosen for its ease of use as well as the importance of being able to offer flexibility for the completion of the questionnaires, participants were able to complete the questionnaires at a time and location convenient to them.

5.2.2.1. Round 1: Procedure

During round one, each participant was asked to rate the FASST items using a five-point scale (‘Essential’, ‘Important’, ‘Don’t know/Depends’, ‘Unimportant’ and ‘Should not be included’.) Space was also be provided after each item for participants to comment on either the wording of the question and/or make other suggestions including the addition of new questions if they felt appropriate. On completion of the first round, the data was analysed to determine levels of consensus. The participants were provided with two weeks to provide their responses and were reminded mid-way to take part. All participants who had signed up, took part and completed round one n=108. 83 FASST items were presented to the participants.

5.2.2.2. Round 2: Procedure

During round two, the option for ‘Don’t know/Depends’ was removed. In the comments, participants frequently noted that items had the potential to be interpreted differently based on the context. Research suggests that if there is a midpoint within a scale, there is a chance that participants will choose this option if they are unsure how to answer and/or avoidance of what may appear to be the socially undesirable behaviour of choosing a potentially 'negative' item (Shang, 2023). After discussion with the supervisory team it was decided that in order to account more broadly for central tendency and social desirability bias, the option for 'Don't know/Depends' would be removed in order to achieve more concise responses. As a number of items had reached consensus in the first round, 56 items were re-presented to the participants. 94 responses were received for round two. Participants were offered the opportunity to provide comments and feedback after each FASST item and this data was collected and broadly analysed, specifically looking for suggestions and comments on item amendments and suggestions for re-wording.

5.2.2.3. Round 3: Procedure

During round three, the response options were again modified. Almost all remaining items (items that did not meet the 80% criteria for inclusion) in round 2 increased to a higher percentage range. For example, items previously in the 60% range moved up to the 70% range. Although most items moved up a percentage range, some still did not meet criteria. With this in mind it was decided by the supervisory team that it would be unhelpful to ask participants to re-rate the items again. Instead, in Round 3 we asked participants to rank order the remaining items in terms of how influential they believed the item to be for each category. The remaining items were further separated into 5 categories, ***Social Communication and Interaction, Responses to sensory input, Mental health, Patterns of behaviour and Awareness/Self-awareness.*** Items were re-presented to participants in order of their percentage score, for example, items nearly meeting criteria, or items reaching the 60% range. For each category participants were either asked to rank order the items in terms of importance, or if there was a small number of items in the specific category, participants were asked whether an item should be included or excluded. Taking into consideration the items that had already reached consensus in rounds one and two, 44 items were re-presented to the participants. 76 responses were received for round three. As before, participants were offered the chance to provide comments and feedback after each FASST item.

5.2.2.4. Round 4: Procedure

The iterative process of the Delphi across the three rounds, allowed for several items to reach consensus. One of the overall aims of this thesis was to ensure a collaborative approach was taken and we specifically aimed to have the input from autistic women and other key stakeholders during all stages of the FASST development. It is well documented in the literature that most Delphi's will run for three rounds, namely because the burden on the participant can cause higher rates of drop out due to the time commitments needed to stay involved for several weeks (Shang, 2023). However, it was decided by the supervisory team that it was crucial to offer participants an opportunity to comment on the final items of the FASST that had reached consensus. Thus, round four was provided to participants which provided details of the final number of FASST items that had reached consensus. 54 responses were received for this final round.

5.2.3. Ethical Considerations

Ethical approval was obtained from the Tizard Centre, University of Kent ethical review committee (see appendix 4.1).

5.2.4. Data Analysis

Depending on the data analysed across each round and level of consensus reached, the items of the FASST were either (a) accepted for inclusion in the FASST, (b) presented to the panels in a subsequent survey for re-rating or (c) excluded from the FASST. In round one, accepted questions were those items rated as either 'Essential' or 'Important' by 80% or more by participants. If these criteria were not met, and items were deemed to have achieved a moderate consensus, these items were presented again in a subsequent round for re-rating (B.Pharm et al., 2015). For round two, the same criteria were applied and items that reached 80% or above, were automatically retained. For round three, two additional options were presented to participants. If item groupings contained more than three items, participants were asked to rank order the items in terms of importance, for two or singular items, participants were asked to choose from either 'include' or 'don't include'. As a rule for round three, items that scored in the top two of the ranking order were automatically included. For the alternative option of 'include' or 'don't include', the 80% consensus criteria were applied as before in previous rounds. Once the final items that met inclusion were compiled into a final draft, the supervisory team met to discuss the remaining results from round three. Some exceptions were made for the retainment of FASST items that had not met inclusion criteria. These decisions were based on participants expressed comments on the importance of specific items, as well as recommendations from the supervisory team based on their extensive clinical experience.

5.3. Results

A summary of all Delphi rounds are presented in Figure 2.

5.3.1. Round 1: Results

In round one, 27 items met criteria for inclusion (80% or over), meaning that these items would be included in the final draft of the FASST (see table 7). 10 items were rated highly with over 90% consensus agreement. These items fell into specific categories. First, were items related to sensory sensitivities, including intense like/dislike of textures, tastes, smells and places/places. Second, were items related to difficulties with social interaction, these included the development and maintenance of friendships, difficulties with picking up on other people's intentions and feeling exhausted after social situations. Finally, items related to interests were also highly rated as important, for example, spending long periods of time focused on particular activities which may lead to neglecting other duties.

Figure 2: Flow diagram of Delphi results across round

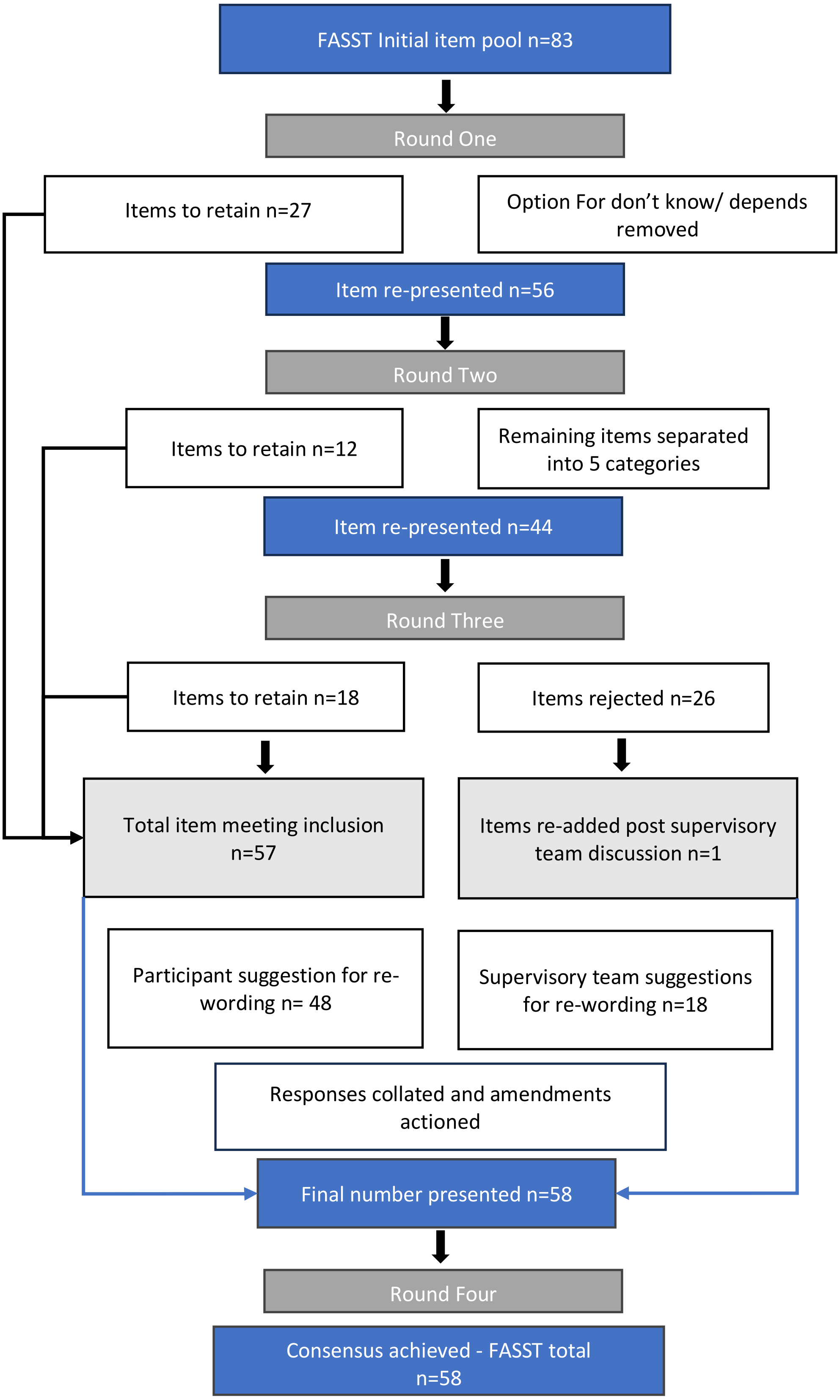


Table 7: Delphi Round One – Items that met 80% consensus

FASST Items	Essential / Important	Don't know / Depends	Unimportant / Should not be included
She has unusually intense like/dislike of specific textures, tastes, smells or places/spaces.	97.2%	2.8%	0.0%
She feels exhausted after social situations.	97.2%	1.9%	0.9%
She is distressed by noises that do not bother others.	96.3%	3.7%	0.0%
She becomes anxious and upset when something unexpected happens.	95.4%	4.6%	0.0%
She has a strong sense of justice, of right and wrong and seeking the truth.	93.5%	6.5%	0.0%
She doesn't seem to pick up easily on other people's intentions.	93.5%	4.6%	1.9%
She can spend long periods of time focused on a particular activity.	91.7%	7.4%	0.9%
Her interests can lead to her neglecting other activities or duties.	90.7%	6.5%	2.8%
She doesn't seem to understand subtle social cues.	90.7%	8.3%	0.9%
She experiences difficulties developing and maintaining friendships.	90.7%	6.5%	2.8%
She experiences high levels of stress.	89.8%	6.5%	3.7%
Other people think she can take things too literally.	87.9%	11.1%	0.9%
She can join in easily with group chats, when more than three people are talking together.	87.1%	11.1%	1.8%
She seems particularly socially naive for her age.	87.0%	9.3%	3.7%
She gets upset if she cannot follow specific routines.	87.0%	12.0%	0.9%
Other people think she can take things too seriously.	86.1%	12.0%	1.8%
Does she isolate herself from others.	86.1%	10.2%	3.7%
She has difficulty managing conflict.	86.1%	7.4%	6.5%
She is able to adjust her behaviour in different social situations.	86.1%	9.3%	4.7%
She likes lists, special arrangement of objects, or ordering things.	86.1%	8.3%	5.5%
She has difficulties understanding her own emotions.	85.2%	13.0%	1.9%
She can spend a long time ruminating.	85.1%	13.9%	0.9%
She experiences or previously experienced mental health conditions.	83.3%	13.0%	3.7%
Adolescence is/was a difficult period.	82.4%	11.1%	6.5%
She seems very anxious compared to others.	81.5%	16.7%	1.9%
She prefers solo activities and interests which she can do on her own.	80.6%	16.7%	2.8%
She has difficulties understanding boundaries in relationships.	80.5%	14.8%	4.7%

5.3.2. Round 2: Results

56 items were re-presented to participants. A further 12 items (see table below) met the 80% criteria for inclusion in the final version of the FASST, bringing the total to 39 items after two rounds. The items that met criteria were further separated into 5 categories, ***Social Communication and Interaction, Responses to sensory input, Mental health, Patterns of behaviour and Awareness/Self-awareness.*** Like round one, items related to interests and social interaction were rated more highly.

Table 8: Delphi Round Two - Items that met 80% consensus

FASST Item	Essential/Important	Unimportant/Should not be included
She has at least one really intense or obsessive interest	88.3%	11.7%
She is always direct, blunt, and to the point	88.3%	11.7%
She can easily respond appropriately to other people's feelings	87.4%	12.6%
She expresses feelings of loneliness and isolation	87.3%	12.8%
She will often do things that others think are rude or inappropriate	87.3%	12.7%
She mentions or talks about feeling different to other people	86.2%	13.8%
She experiences difficulties or is likely to experience difficulties with employment	85.1%	14.9%
She is skilful at imitating the behaviours of others around her	85.1%	14.9%
She has excessively intense attachments to others that are not reciprocated	83.0%	17.0%
She experiences or previously experienced bullying	83.0%	17.0%
She is described as overbearing and/or intense	82.9%	17.0%
She can easily pick up on other people's feelings	82.9%	17.0%

5.3.3. Round 3: Results

As a general rule, the top two items of the ranking results were included into the final version of the FASST, where there were only two in a group, only the first item was included. Unless otherwise explained below, all other items were not included.

Items that were included into the final version at Round 3 have been highlighted in grey. A further 18 items were retained for inclusion in the final draft of the FASST.

Round 3 – items that almost met criteria – 70% +

Social Communication and Interaction

Table 9: Delphi Round Three - Social Communication and Interaction 70%+

FASST Item	Score	Ranking
She is able to engage in 'small talk'	520	1
She has a smaller number of friends that she trusts	515	2
She tends to be quiet and does not initiate	514	3
She is really easy going and flexible	470	4
She experiences difficulties or is likely to experience difficulties with romantic relationships	442	5
She prefers social and shared activities and interests	406	6
She seems to stare too long at people and this makes her seem hostile or intense	380	7
She finds it easier to form friendships with males	371	8
She is good at listening to others	370	9
She does not hold your eye when she talks to you	362	10

Responses to Sensory Input

Table 10: Delphi Round Three – Sensory Input 70%+

FASST Item	Score	Ranking
She has difficulties with proprioception	126	1
She is sensitive to temperature	109	2

The items in this category were both incorporated into the final version as the general consensus throughout participant comments was the importance of sensory items.

Mental Health

Table 11: Delphi Round Three – Mental Health 70%+

FASST Item	Include	Exclude
She has really low self esteem	69.7%	30.3%

Although this item did not reach the 80% inclusion criteria, overall consensus in participant feedback was the importance of keeping items that related to self-esteem and anxiety as they are important in building a picture of the person.

Patterns of Behaviour

Table 12: Delphi Round Three – Patterns of Behaviour 70%+

FASST Item	Score	Ranking
She can rage, or cry, or laugh with little apparent trigger	208	1
She has intense attachments to objects	196	2
She has an explosive temper that appears to come out of nowhere	189	3
She has intense attachments to animals	186	4

Awareness and Self-Awareness

Table 13: Delphi Round Three – Self-Awareness 70%+

FASST Item	Score	Ranking
When she does things, she is considerate of the impact on other people's feelings	173	1
She is careful not to say things that could cause offence	154	2
She will always show consideration for other people	138	3

Stand-alone questions

Table 14: Delphi Round Three – Stand-alone 70%+

FASST Item	Include	Exclude
She feels pressured to fit in with social expectations of 'being female"	65.8%	34.2%
She experiences difficulties or previously experienced difficulties with school work	64.5%	35.5%

Although these items did not reach the 80% inclusion criteria, overall consensus in participant feedback was that these items were important and it was the phrasing of the item that needed amending.

Round 3 – items that reached the 60% range

Social Communication and Interaction

Table 15: Delphi Round Three – Social Communication and Interaction 60%

FASST Item	Score	Ranking
She enjoys meeting new people	549	1
She tends to have lots of short-lived relationships	534	2
It is always easy to tell how she is feeling just by her facial expressions	519	3
She can really express herself clearly through gesture and intonation	519	4
She uses online platforms to develop and maintain friendships	504	5
When other people meet her, they find her really easy to talk to	492	6
She has at least one friend that she has stayed in touch with and regularly communicates with, whom she has known for years	487	7

When other people meet her, they find it easy to get on with her	470	8
She tends to be outgoing and sociable	458	9
Do other people feel a comfortable connection with her	433	10
She is able to chat about almost anything with you	427	11

Patterns of behaviour

Table 16: Delphi Round Three – Patterns of Behaviour 60%

FASST Item	Score	Ranking
She has an intense reaction to things on the tv that others find acceptable	122	1
She has more shared interests with males and may be described as a 'tomboy'	111	2

Round 3 – items that reached the 50% range

Social Communication and Interaction

Table 17: Delphi Round Three – Social Communication and Interaction 50%

FASST Item	Score	Ranking
She has at least one close relationship that seems genuinely shared	169	1
She has several people who would call her a real friend	149	2
When people meet her they find her engaging and friendly	140	3

Patterns of behaviour

Table 18: Delphi Round Three – Patterns of behaviour 50%

FASST Item	Score	Ranking
Do people complain about how she treats others	201	1
She is a content person	195	2
She seems really calm and confident compared to others	191	3
She is a really calm person	178	4

Round 3 – items that reached the 40% range

Awareness/Self-awareness

Table 19: Delphi Round Three – Social Communication and Interaction 40%

FASST Item	Include	Exclude
She is very conscious of her impact on the environment	38.2%	61.8%

Although this item did not reach the 80% threshold for non-inclusion, overall consensus in participant feedback across all three rounds was that this item was irrelevant and did not support the development of a succinct picture of the person.

Round 3 – items that reached the 20% range

Patterns of Behaviour

Table 20: Delphi Round Three – Patterns of behaviour 20%

FASST Item	Include	Exclude
She has always had a great fashion sense	19.7%	80.3%

This final item was automatically excluded and was consistently rated as irrelevant by participants.

5.3.4. Round 4: Results

In Round 4 we provided participants with the opportunity to comment on whether the research team had the item correct or if any final amendments to the wording of each item needed to be made. 54 responses were received. No final changes were made to the FASST after this round. The feedback from round four mirrored previous rounds with suggestions about context, the importance of self-report measures and concerns around professional interpretation. It was deemed necessary at this stage to finalise the FASST as the participant suggestions could not be actioned further at this stage in the research.

5.4. Discussion

The Delphi consultation method was chosen as a robust and inclusive approach to gather further insights and perspectives from a diverse panel of experts in the field of autism, most importantly the inclusion of autistic women and those who identify as other genders. The iterative and anonymous feedback process enabled the research question "***How can a Delphi consultation process be utilised to further refine and validate the items included in the revised version of the FASST, based on feedback from autistic women and other key stakeholders?"*** to be answered, and allows for the further revision and refinement of FASST items. Throughout the process of the Delphi consultation, the aim was to further enhance the content, relevance, and potential accuracy of the FASST, building upon the data collected from the focus groups. The Delphi consultation provided an opportunity for in-depth evaluation and consensus-building, ensuring that the final version of the FASST aligns with best practices and expert opinions.

After the initial three rounds, the supervisory team met to discuss the items that did not meet criteria as well as appraisal of participant feedback. Out of all the items that did not meet consensus, one item was returned to the final item pool of the FASST. This item was *'It is always easy to tell how she is feeling just by her facial expressions",* based on the clinical expertise of one of the supervisors, it was deemed important to include this specific item in the FASST. Further, all comments from participants in relation to wording amendments were considered and utilised into re-phrased versions of the original items. Of the 58 final items that met consensus, 48 of these items had suggestions from participants for re-wording.

Like the feedback gleaned from the focus groups, item amendments mainly focused on alternative words to frame the item in a more positive light, for example original item *'she has at least one really intense or obsessive interest'*. Participants felt strongly about this item suggesting "Please do not use 'obsessive' it has negative connotations and associations with the deficit model, 'passion' would be better than obsessive". In addition, participants also made suggestions for separation of items for example, original item 51 *'she experiences difficulties developing and maintaining* friendships', this item was then split into two as it was felt by participants that this item was asking two very different aspects of friendships.

The items were amended by the lead researcher and presented to the supervisory team for discussion. Of the 48 re-worded items, the supervisory team was in complete agreement with participants on the wording changes for 40 items. For the remaining 18 items, 17 of these were shortened in order to be more succinct and precise, however, important to note these amendments did not change the overall meaning of the item. For example, *'They often appear and/or describe feeling exhausted after some social interactions'* was shortened to *'They often appear exhausted after some social interactions'.* The final remaining item was reverted back to its original format. Again, based on clinical expertise, the changes made to the item were deemed to have changed the overall meaning. The item was initially changed to *'They express extreme emotion to apparently small triggers which, can be hard to work out what they are responding to'* was reverted back to *'They can rage, cry or laugh with little apparent trigger'*. One final change was made and that was in relation to making the FASST as gender inclusive as possible. Throughout previous rounds as well as being communicated in the focus groups, participants requested that 'she' was removed and replaced with 'they' in order to be more respectful of other gender identities. All items in the FASST were therefore changed to 'They' throughout. Full details of all items, their addition through different stages of the research process, stages of inclusion/exclusion, participant comments and final item wording can be found in appendix 6.1 and 6.2.

The aim of this study was to ensure that the FASST was developed and remodelled based on input from key stakeholders, specifically women and girls with experience of a late diagnosis. Through both the focus groups and Delphi consultation, a myriad of experiences, feedback and knowledge sharing were achieved. Participants were able share the difficulties they had experienced throughout diagnostic processes and pathways and impart their knowledge on how items in the FASST could be improved. This allowed for the FASST to be refined, additional items were added and ensure the process remained iterative in nature. A final 58 items were assigned to the FASST ready for the piloting stages.

Overall, studies 2a and 2b have involved four focus groups and a Delphi consultation which lasted for four rounds. A total number of 126 participants; 101 autistic people (22 who self-identified as autistic), 37 family members/carers, 20 professionals and 4 academic researchers took part throughout this period. Participants came from multiple destinations in the UK as well as participants from all over the world including Australia, Austria, Canada, Germany, Israel, New Zealand, Portugal and the USA.

5.5. Implications and Future Directions of the FASST

The complexities surrounding autistic presentations and how these impacts on diagnosis are being increasingly explored and even more so in recent years in relation to the missed or misdiagnosis in women and girls. As discussed earlier it is often suggested that professionals and clinicians have a lack of understanding on how autism may present in females, and this is reasonable considering what we know about autism is largely based on the autistic presentations seen in males. One way in which we can counteract such and improve understanding and awareness is through the development of an updated framework for screening for autism. Throughout the focus groups and Delphi consultation participants had commented on the importance of trying to readdress some of the gender imbalance, bias and misunderstanding within the diagnostic process. Some participants felt strongly about society’s gendered approach, with some wanting the FASST to become an overall more gender-neutral tool; whilst some felt very strongly that a female specific tool is equally important.

At the start of this study the screening tool was named the FASST, The Female Autism Spectrum Screening Tool, because anecdotally it is known that there is a large proportion of women and girls who are either being missed or mis-diagnosed. There is limited research evidence as to why this is happening and even less research on gender identity and autism which, is why at this current stage the following study will begin by piloting the FASST with cisgender women and girls (people assigned female at birth who identify as women). Whilst it has become clear throughout the research process thus far that a lot of the subtleties in autistic presentation are not exclusive to just women and girls, for example, masking; the complexities of gender and the autistic person's lived experience of such, was outside of the current research agenda for this study, however it is a topic that would benefit from further qualitative exploration in order to produce first hand experiences that can be shared in order to aid understanding.

Many of the participants highlighted the importance of having a self-report version of the FASST. The complexities of missed or misdiagnosis, the differences between 'typical' and 'non-typical' autism presentations are a huge research area and one in which a lot of time needs to be spent to ensure we are understanding the complexities correctly. Listening and ensuring that autistic voices and experiences are heard and acknowledged is crucial; our research as well as the work of others, are all starting points in trying to bridge the gap for those individuals who have and/or are being missed or mis-diagnosed.

5.6. Strengths and Limitations

Like the strengths highlighted in the focus group chapter, a particular strength was ensuring that autistic people took part in the Delphi. Autistic women possess unique insights and first-hand experiences of autism specific to a wide range of topics including living through assessment and diagnostic processes and pathways, which is of valuable interest to our research topic. By actively involving autistic people in the final refinement of the FASST, this decision-making process empowers them to have a voice in shaping research. Furthermore, both the focus groups and Delphi methodologies promoted inclusivity, autonomy, and respect for their rights and perspectives.

During the Delphi consultations, a notable observation was the drop in participant numbers across subsequent rounds. In the initial round, a total of 108 participants provided their input and feedback. However, as the Delphi process progressed, the number of participants decreased in subsequent rounds. In round two, the participant count dropped to 94, further reducing to 76 participants in round three, and ultimately resulting in 54 participant responses in the final round. The decreases in participant numbers throughout the Delphi study aligns with existing evidence highlighting the potential for drop-out rates in extended consultation rounds (Gargon et al., 2019). Evidence suggests that participant fatigue and time burdens can contribute to reduced engagement. Although the drop in participant numbers is a limitation, it is important to note that the numbers only dropped considerably in round four where participants were asked to provide qualitative feedback on the final wording of the FASST items. Rounds 1-3 still held a good number of responses which were the crucial rounds in deciding if items were to be retained or excluded. Given that the FASST items had already been explored qualitatively in the focus groups, the lack of feedback in round four ultimately did not affect the findings overall. Additionally, it is important to consider the insights and contributions provided by the remaining participants. Their perspectives and expertise still hold value in shaping the development and refinement of the FASST. Furthermore, the reduced participant count in later rounds may reflect a natural attrition process, where participants who are most invested and engaged in the topic continue to contribute. If future work was to be carried out on the FASST it would be important to consider strategies that minimise participant fatigue, such as shorter more focused rounds or offering incentives to encourage continued engagement.

Although the Delphi consultation conducted within this thesis offered valuable insights and consensus-building among ‘experts’ (either by experience or professionally) and other key stakeholders, there are still limitations to acknowledge when applying this method to the development of the FASST. Firstly, the Delphi process relies on the participation and contributions of a panel of ‘experts’. In the case of the FASST development, the group consisted of autistic people, professionals, parents/carers and researchers. However, the composition of the group may introduce biases or limitations in terms of representation and diversity. Despite our best efforts to include a range of perspectives, we were unable to recruit a large number of professionals and clinicians. Given that the target group of professionals we wanted to recruit would more than likely have been working in services that assess and screen for autism, having a larger cohort take part in this study would have been beneficial. Furthermore, we did not collect demographic information on ethnicity which limits our understanding of how diverse our participant sample was. Additionally, the nature of the Delphi method may prioritise convergence towards consensus, potentially overlooking valuable dissenting perspectives or innovative ideas. This limitation could potentially impact the inclusivity and comprehensiveness of the FASST, as alternative viewpoints or considerations may have not been fully explored. Finally, the Delphi consultation represents a snapshot of knowledge and opinions at a particular timepoint. Over the last few years the research into autistic women and girls have increased dramatically, and as such new research and evolving understandings may have arisen after the completion of the Delphi process and the refinement of the FASST.

5.7. Conclusion

The information gathered as part of this study allowed for full remodelling and development of the FASST pre-piloting. This research contributes to the increasing body of research focusing on the experiences of autistic women and girls using qualitative methodologies. In developing and validating the FASST, we hope to fundamentally change how autism in women and girls is screened for in future years. This will not only provide potentially more direct pathways to diagnosis but will also ensure that the voices and expectations of autistic women and girls are respected and validated as important components of autism research.

Chapter Summary

The aim of both the Focus Groups and the Delphi Consultations was to find out whether our screening tool, The FASST, was asking the right questions to help identify if a woman or girl might be autistic, whether we had missed anything, and finally if we had got anything wrong. This process has helped us to refine the content of the FASST to make sure we were getting it right. Version 3 of the FASST contains 58 items and will be used in the following pilot study to assess the effectiveness and viability of the FASST.

Chapter 6. The Female Autism Spectrum Screening Tool (FASST) – Initial Development

6.1. Introduction

This chapter provides a brief overview of the development of The Female Autism Spectrum Screening Tool (FASST), which serves as the foundation for this research.

The FASST in its original form (version 1; appendix 2.1), was first put together by two of the researchers' supervisors, Dr Fiona Gullon-Scott and Professor Peter Langdon. As highlighted in the introduction of this thesis, evidence suggests that current screening tools may not be sensitive enough to capture the subtler differences in presentation between autistic males and females, hence why some women and girls may be missed or misdiagnosed during assessment processes. The overall purpose of the FASST was to develop a screening tool that may be more sensitive in identifying autism in women and girls. The FASST is an informant screening tool, which is designed to gather information about a person's potential autism characteristics, behaviours, and experiences from people who know the individual well, for example their daily life, routines, and interactions. An informant can be a family member, carer, teacher, friend, or any other person who has frequent and meaningful contact with the person for whom the FASST is intended to assess.

6.2. The addition and refinement of FASST items

The FASST has been refined over several empirical studies. The systematic review of the literature identified 17 additional items and the focus groups identified the addition of 18 more items for inclusion. A total of 83 items were then presented to the Delphi panel for further refinement. The final draft of the FASST v4 (see Table 21 below) is comprised of 58 items measured across a 3-point Likert scale, covering a range of areas that may be particularly relevant to the potential female presentation of autism. The below version will be used in the preliminary investigations into the psychometric properties of the FASST. The intended use of the FASST is to provide a broader, comprehensive, and holistic understanding of the person, including their strengths and challenges, particularly in areas that may not be observable or reported by the person themselves. Informant-based tools such as the FASST enables valuable insights to be gathered on the person's behaviour, social interactions, communication abilities, and other relevant aspects of their daily life such as friendships and sensory sensitivities. The future utility of the FASST is to help inform diagnostic decisions to further refer for an assessment of autism by relevant teams/professionals.

Table 21: The Female Autism Spectrum Screening Tool (FASST)

FASST (Female Autism Spectrum Screening Tool)

(Adolescent to adult, no LD)

Informant questionnaire: You are being asked to complete the Female Autism Spectrum Screening Tool (FASST). This is an informant-based questionnaire. This means that each item you are answering is about someone you know who is autistic, and not yourself. We ask that you have known the person well for at least 3-months, but preferably, over several years. You could be a parent, friend, partner, sibling, or carer.

Instructions: Choose one option for each statement. You should base your answers on how consistent the person has been over the time that you have known them. This means choose the response that best describes the person from your point of view.

Item	True most of the time	Sometimes True	Rarely/Never True
1. They can join in easily with face to face chats, when more than three people are talking together			
2. They can easily adjust their behaviour in different social situations without difficulty			
3. They mostly prefer solo activities and interests which they can do on their own			
4. They can take things literally			
5. They do not seem to understand subtle social cues			

6. They often appear exhausted after some social interactions			
7. They have difficulty managing conflict			
8. They have difficulties developing friendships			
9. They have difficulties maintaining friendships			
10. They can take things too seriously			
11. They sometimes have difficulties understanding boundaries in relationships			
12. They sometimes do things that others think are rude or inappropriate without understanding why this has caused offence			
13. They are skilful at imitating the behaviours of others around them			
14. They are usually direct, blunt and to the point			
15. They can be controlling and/or intense			
16. They have friendships with people that are not always reciprocated to the same extent			
17. They can easily respond appropriately to other people’s feelings			
18. They find it easy to maintain and engage in ‘small talk’			
19. They enjoy ‘small talk’			
20. They have a small number of people that they trust			
21. They feel comfortable meeting new people			
22. They tend to have short-lived relationships due to difficulties in maintaining relationships			
23. They have at least one close relationship outside of the household/family that seems genuinely shared			
24. They have a few close friends rather than a large and varied group of friends			
25. They can be distressed, distracted or overwhelmed by noises that do not bother others			
26. They can be under or over responsive to sensations e.g. specific textures, tastes, smells or temperatures			
27. They are usually able to sense the movement and position of their body			
28. They are often stressed			
29. They experience or previously experienced mental health conditions			
30. They are often anxious			
31. They often appear lonely and/or isolated			
32. They experience or previously experienced bullying			
33. They often spend a long time thinking/worrying about situations			
34. They sometimes seem to isolate themselves from others			
35. They talk about feeling like they are different to other people			
36. They often have low self-esteem			
37. They have a set way of doing things such as careful arrangement of objects and/or organise things systematically e.g. lists			
38. They may find it difficult if they cannot follow specific routines or unexpected changes occur			

39. They can spend long periods of time focused on a particular activity			
40. Their interests can lead to them forgetting other activities or duties			
41. They become anxious, upset and/or unsettled when something unexpected happens			
42. They have a strong sense of justice, of right and wrong and seeking the truth			
43. They have at least one intense interest at any one time			
44. They can rage, cry or laugh with little apparent trigger			
45. They have intense attachments which may include specific objects and/or animals			
46. They sometimes experience intense emotional reactions to things they hear or see (e.g. things on the tv, newspapers and social media), which others may not share			
47. Other people sometimes raise/have concerns about how they treat others			
48. They do not always pick up easily on other people’s intentions			
49. They sometimes seem socially naïve for their age			
50. They sometimes have difficulty understanding or describing their own emotions			
51. They often find it difficult to notice or understand other people’s emotions			
52. When they do things, they often do not think of the impact on other people’s feelings			
53. They often do not understand when or why they have caused offence			
54. Adolescence is/was a noticeably difficult period			
55. They experience difficulties or are likely to experience difficulties with employment			
56. It is always easy to tell how they are feeling just by their facial expressions			
57. They experience difficulties or previously experienced difficulties with school			
58. They find it difficult to predict how other people will feel or respond			

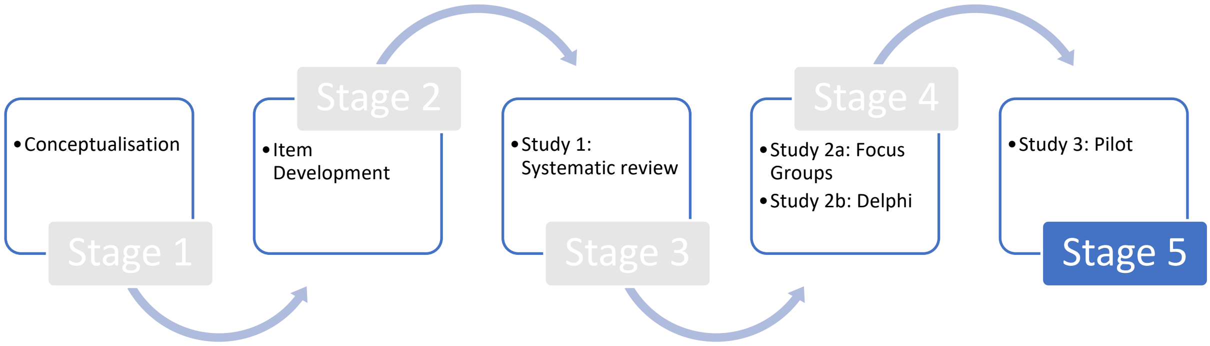
6.3. Scoring

For each item, informants select the option which best suits the person being assessed (*true most of the time – 2, sometimes true – 1, rarely/never true - 0*). The majority of items are potential characteristics of autism, however items: 1, 2, 17, 18, 19, 21, 23, 27, and 56 are contrast items and are therefore reverse scored (*true most of the time – 0, sometimes true – 1, rarely/never true - 2*). All items are summed to produce a total score. A higher score is indicative that autism should be considered as an explanation of strengths and challenges.

6.4. Conclusion

This chapter aimed to provide a brief overview of the final draft version of the FASST that informed the next stage of this research, the pilot. Recognising the current gap in screening tools and the potential lack of sensitivity needed to better understand autism in women and girls, this research sought to produce a final version of the FASST by incorporating insights from diverse perspectives and lived experiences. Through an iterative and participatory research approach, a series of studies of have been undertaken in order to enhance the FASST's validity and sensitivity in identifying autism in women and girls prior to psychometric testing.

Chapter 7. Study 3: Preliminary testing of the Female Autism Spectrum Screening Tool – (FASST)



7.1. Introduction

The accurate identification of autism in women and girls is a crucial step towards providing access to timely support and appropriate interventions. In order to both reduce incorrect referrals as well as prevent potentially missed opportunities for diagnoses, having a gendered developmental framework for use when assessing autism in women and girls may be beneficial (Tierney et al., 2016; Wilson et al., 2016). Although research into autistic women and girls have been increasing of late, there is still a paucity of literature that focuses directly on difficulties relating specifically to assessment and diagnostic procedures. Given that currently many of the measures used in practice were developed several years ago, the current study was driven by the need to develop an up to date and comprehensive screening measure that was designed in co-production with autistic people.

A new screening tool for autism, the FASST (Female Autism Spectrum Screening Tool), has been developed which aims to identify females earlier, and will support relevant signposting for further diagnostic assessment and support. Previous attempts have been made at developing a screening tool for females (see GQ-ASC; Brown et al., 2020 and the ASSQ-REV; Kopp & Gillberg, 2011), however these tools do not appear to be widely used in services and more notably, have been developed for children (and then later modified for adults). Furthermore, to the best of our knowledge, the FASST is the first screening tool for autism to have been produced with significant input from autistic people. Subsequent to its development, the FASST had not been trialled for use in the autistic population.

In response to the potential limitations of existing screening tools (see chapter 1), study three of this thesis focuses on piloting the final draft of the FASST that was developed through an extensive process of refinement. This comprehensive revision process conducted throughout this PhD involved several stages. Initially the item pool was developed by co-authors P.L and F.G.S (appendix 2.1), additional items were added following a systematic review of the literature pertaining to the behavioural presentations and experiences of autistic women and girls (chapter 3). Following this, a series of focus groups were conducted to investigate at a cognitive level the initial item pool (consisting of 64 items; see chapter 4). The final stage was the Delphi consultations which resulted in further revisions of the FASST (see chapter 5), and further to this, a final item pool of 58 items was decided upon (see chapter 6).

The current study therefore was a preliminary investigation into the component structure and psychometric properties of the FASST. By piloting the FASST in real-world settings, we aimed to assess its utility, validity, and reliability in capturing the potentially unique presentations of autistic females. This research sought to create a screening tool that would demonstrate: (i) good face and content validity through consultation with autistic people and key stakeholders, as well as good domain/component coverage; (ii) good test-retest reliability, as well as internal consistency; and (iii) good construct validity (confirming both discriminant and convergent validity through high correlations between the FASST and other measures used to screen for autism), including multiple factors that reflect distinct aspects of presentations seen in autistic women and girls. Finally, it was expected that the FASST would demonstrate a theoretically consistent relationship with other measures of autism.

This chapter presents the findings of the pilot study, providing insights into the performance of the FASST and its potential utility as a valuable instrument for identifying autistic women and girls. The research question guiding this study is:

> To what extent does the piloted version of the FASST demonstrate reliability, validity, and discriminative ability in identifying autism among women, when compared to non-autistic women, following revisions based on a systematic review, feedback from focus groups, and refinement via a Delphi consultation?

7.2. Methodology

7.2.1. Design

As described in chapter 2, revision of the initial FASST and the piloting phase broadly followed Boateng et al’s (2018) framework for screening tool development and validation. The first phase encompasses item generation and content assessment. Phase two focuses solely on the construction of the screening tool, including administration of the tool (pilot), reduction of items and generation of overall factors. The final phase includes evaluation of the screening tool as well as assessment of reliability and validity. Prior to the pilot of the FASST, a discovery-orientated approach was taken through the use of a systematic review, focus groups and a Delphi consultation in order to update the initial item pool of the FASST with pertinent information applicable to autistic women and girls.

The research design for the pilot study involved recruiting participants and administering both the newly developed informant-based screening measure (FASST) and widely used current self-report screening measures of autism (AQ, FQ, EQ and CAT-Q). The participants consisted of three groups: autistic people, people who self-identified as autistic and non-autistic people for comparison purposes. To ensure the accuracy and reliability of the FASST, each participant had a paired informant who provided information about their autistic characteristics. The participants completed the battery of self-report measures and the paired informants completed the FASST, which was designed to capture a comprehensive understanding of autistic traits in women.

The data collected from the participants and their paired informants were then subjected to statistical analyses. The primary aim of these analyses was to examine the discriminative ability of the FASST in distinguishing between autistic and non-autistic people. This was assessed by comparing the scores on the FASST between the two groups using appropriate statistical tests. Furthermore, the research design also involved evaluating the construct validity of the FASST by examining its associations with the scores obtained from the current self-report screening measures of autism. The expected associations were based on theoretically consistency, where higher scores on the FASST would be expected to align in theoretically consistent ways with scores on the current established measures, indicating convergent validity.

Overall, we sought to examine the psychometric properties of the FASST. The initial pool of items derived from the consultation process were subject to initial assessment of reliability and validity. Principal component analysis (PCA) was then conducted on the final pool of items derived from the consultation process. The component structure derived from the PCA further enabled appropriate items to be retained for inclusion in the final version of the FASST. Finally, both reliability and validity were then re-assessed on the final item pool.

7.2.2. Participants

A total of 140 participants took part across three groups (Table 22). Each participant was asked to provide details of a person that could act as their informant for the completion of the FASST. The informant was asked to be someone that knew the participant well in order to make judgements and associated ratings on items of the FASST. Group 1 included individuals who disclosed having a formal diagnosis of autism (***22 autistic people; 22 informants***), Group 2 included individuals who self-identified as autistic (***26 self-identify; 26 informant***) and Group 3 included individuals who were not autistic (***22 non-autistic; 22 informant***). The age range for each of the groups completing the self-report battery were ***autistic:*** 21 = 18-39 years, 1 = 40-59 years; ***self-identify:*** 12 = 18-39, 9 = 40-59, 5 = 60+ years and ***non-autistic:*** 14 = 18-39years, 6 = 40-59 years, 2 = 60+ years. Sixty-seven participants identified as a cis woman and three participants identified as non-binary. Participants came from all over the word including England, Ireland, Scotland, Wales, Canada, Australia, Spain, USA, and Bermuda. Demographic information for informants was not collected. No significant differences were found between groups when accounting for age and diagnosis ($\chi^2 = 1.921$, df = 4, p = 0.750).

Table 22 – Participant Information

			Age Group			Total
			18-39	40-59	60 years and over	
Group	Autistic	Count	11	8	3	22
		% within Group	50.0%	36.4%	13.6%	100.0%
		% within What is your age group?	29.7%	34.8%	30.0%	31.4%
		% of Total	15.7%	11.4%	4.3%	31.4%
	Self-Identify	Count	12	9	5	26
		% within Group	46.2%	34.6%	19.2%	100.0%
		% within What is your age group?	32.4%	39.1%	50.0%	37.1%
		% of Total	17.1%	12.9%	7.1%	37.1%
	Non-autistic	Count	14	6	2	22
		% within Group	63.6%	27.3%	9.1%	100.0%
		% within What is your age group?	37.8%	26.1%	20.0%	31.4%
		% of Total	20.0%	8.6%	2.9%	31.4%
Total		Count	37	23	10	70
		% within Group	52.9%	32.9%	14.3%	100.0%
		% within What is your age group?	100.0%	100.0%	100.0%	100.0%
		% of Total	52.9%	32.9%	14.3%	100.0%

7.2.3. Ethics

University of Kent’s Tizard Centre research ethics committee granted ethical approval for the study (appendix 5.1). Consent was required for all participants, information sheets were circulated with the opportunity provided to ask the researcher any questions prior to the commencement of the study.

7.2.4. Procedure

All participants (n =140) were provided with a unique confidential code in order to match the online responses (self-report paired with the informant). The self-report measures (AQ, EQ, FQ and CAT-Q) were sent to the three groups of participants. The 58-item FASST were sent to their paired informants. Test-retest data were captured by asking the informants to complete the FASST at two time points, at least 7 days from first completion, but no later than two weeks apart. Reminders were sent to participants and all measures were completed online.

7.2.5. Measures

The following measures were included in the battery of self-report measures provided to participants (see chapter 1 for descriptions and psychometric properties).

7.2.5.1. Self-report measures

The Adult Autism Spectrum Quotient (AQ; Baron-Cohen et al., 2001)

The Empathy Quotient (EQ; Baron-Cohen & Wheelwright, 2004)

The Friendship Questionnaire (FQ; Baron-Cohen & Wheelwright, 2003)

The Camouflaging Autistic Traits Questionnaire (CAT-Q; Hull et al., 2018)

7.2.5.2. Informant Measure

The FASST was provided to the participants paired informant. The refined item list of the FASST was presented in chapter 6, Table 21.

7.2.6. Data Analysis

Initially, the data was exported from Qualtrics into SPSS for data cleaning. Cases were sorted in ascending order and self-report responses were matched to informant responses using the unique ID code assigned to each pair of participants. Following this, we first looked at the descriptive statistics and found that the data was not normally distributed, so non-parametric bootstrapping, resampling with replacements were used to run and calculate statistics. Using this method generates robust estimates of standard error and confidence intervals as an alternative to parametric statistics (Jobson, 1992). Bootstrapping is a resampling technique that involves creating multiple subsamples from the original dataset, allowing for the estimation of the sampling distribution of the correlation coefficient. Following this, we conducted initial assessments of reliability and validity. Principal component analysis (PCA) was then run, followed by the re-assessment of reliability and validity (outlined in detail below). The rationale for conducting the assessments in this way lies in the iterative nature of the research process conducted throughout this thesis. Initially, the reliability and validity assessments were conducted to examine the psychometric properties of the FASST and determine its internal consistency and ability to measure the intended construct, autism. These assessments provide a baseline understanding of the FASST's performance and helps identify any initial issues or areas for improvement. By performing the PCA after the initial assessments, we gain insights into the underlying structure of the FASST. PCA allows for the exploration of the interrelationships among the items and identify key factors that contribute to the overall measurement. This analysis aids in refining the FASST and enhancing its psychometric properties by ensuring that it capture the multidimensional nature of the construct being assessed. After conducting the PCA, re-running the reliability and validity tests on the final version of the FASST serves as a validation step. This process ensures that the revisions made based on the PCA findings have improved the FASST's performance and aligns it more closely with the intended construct, in this case autism in women and girls. It allows for a comprehensive assessment of the reliability and validity of the final version, providing further evidence of its measurement properties. The following statistical tests conducted within this chapter will be explained in detail below.

7.2.6.1. Principal Component Analysis

Principal component analysis (PCA) is a statistical technique used to identify the underlying components or factors within a set of variables (Rust & Golombok, 2009). It is commonly employed in psychometric analysis to understand the structure of a measurement instrument and identify the key dimensions or constructs it measures. During the PCA, the interrelationships among the items in the FASST were examined to determine whether they can be grouped into distinct components. This analysis helps in reducing the dimensionality of the data and identifying the major sources of variation. By extracting the principal components, which are linear combinations of the original variables, PCA reveals the underlying structure and patterns within the dataset (Rust & Golombok, 2009). PCA is valuable in psychometric assessment as it helps identify the key factors that contribute to the overall measurement. By understanding the underlying structure of the FASST, we can ensure that the items are measuring the distinct aspects of each construct being assessed. This aids in evaluating the internal consistency of each identified component and enables a more comprehensive analysis of the reliability and validity of the FASST. PCA was conducted on the final item pool of the FASST, following guidance from Fabrigar et al. (1999), in order to examine the structure of the FASST. As this was a tool anticipated to screen for autism (autism being underpinned by various theoretical constructs), the components were expected to be related, so a direct oblimin (oblique) rotation was performed (Shrestha, 2021).

PCA as a method of statistical analysis is commonly used in the development of screening measures and as such will typically utilise larger sample sizes to assess the stability and generalisability of the results. However, the practical constraints of the current study led to a relatively small sample size of autistic women and their paired informants being recruited, and thus highlighted the importance of careful justification for the use of PCA in this context. In order to assess the relevance of each item on the FASST, it is recommended that statistical analyses are conducted on a higher participant-to-variable ratio in order to achieve reliable outcomes (Shrestha, 2021). Recognising the time constraints of this thesis, a comprehensive set of criterion rules were established from the available literature on PCA in order to maintain methodological rigor.

Criterion rules were decided upon prior to the start of the PCA and were as follows. After the first analysis, the correlation matrix was inspected, items needed to have met the criterion of 0.3 or above for retainment. Items were further excluded if they did not meet the criterion of 0.6 or above on the anti-image matrices. Item communalities needed to meet the criterion of 0.5 or higher. The Kaiser-Meyer-Olkin (KMO) measure of sampling adequacy needed to meet 0.6 or above, and finally Bartlett’s test of Sphericity needed to be below 0.05. A KMO value over 0.5 and a significance level for the Bartlett’s test below 0.05 suggest there is a substantial correlation in the data (Shrestha, 2021).

Whilst recognising the suboptimal participant-to-variable ratio, these criterions aimed to extract meaningful components from the data, which ensured that the use of PCA within this specific sample size was justified. Moreover, it is important to emphasise the exploratory nature of this research and thus cautious interpretation of the PCA results was undertaken. In summary, the use of PCA therefore focused on extracting meaningful patterns within the identified components rather than making definitive conclusions about whether each item on the FASST is representative of the entire population of autistic women.

7.2.6.2. Construct Validity

To evaluate the construct validity of the FASST, a Pearson's correlation analysis with bootstrapping was conducted. Bootstrapping with 5,000 samples with replacement was used. This analysis aimed to examine the relationship between the overall scores obtained from the FASST and the battery of self-report measures that assess similar constructs. Pearson's correlation coefficient measures the strength and direction of the linear relationship between two continuous variables (Cooper, 2023). In this analysis, it was used to assess the association between the scores obtained from the FASST and the scores from the established self-report screening measures of autism. To account for potential sampling variability and to enhance the robustness of the findings, bootstrapping was applied. This procedure helps to assess the statistical significance of the correlation coefficient. The results of the bootstrapped correlation analysis provided information about the strength and significance of the relationship between the FASST scores and the scores from the established self-report measures of autism.

7.2.6.3. Discriminant Validity

To assess the discriminant validity of the FASST, analysis of variance (ANOVA) with posthoc testing (Sidak method) was used to compare: autistic people, people who self-identified as autistic, and non-autistic people. These pairwise comparisons examined the mean differences between each group and determined the significance of these differences. The significance levels were reported to indicate the strength of the observed group distinctions. Bootstrapping with 5,000 samples with replacement was used, and 95% BCa confidence intervals are reported in Table 26. Additionally, the BCa (bias-corrected and accelerated) method was applied to estimate the 95% confidence intervals for the mean differences between the groups. The BCa method is a non-parametric approach that accounts for potential bias and skewness in the data. The presentation of BCa 95% confidence intervals provided a range of values which the true mean differences are likely to fall.

7.2.6.4. Test re-test Reliability

Test re-test reliability assesses the consistency and stability of measurement over time (Cooper, 2023). To examine the test-retest reliability of the FASST, participants were asked to complete the screening tool on two different occasions, with a time interval between administrations. The total scores obtained from each administration of the FASST were used to calculate the intraclass correlation coefficient (ICC). ICC is a statistical measure that quantifies the degree of agreement or consistency between the FASST total scores obtained from repeated measurements. The test-retest reliability analysis provides insights into the extent to which the FASST yields consistent results when administered to the same person on different occasions. A high ICC value suggests that the FASST demonstrates good stability and reproducibility, indicating that the FASST may be a reliable tool in capturing the intended construct related to autism in women and girls. Finally, the test-retest reliability assessment helps to establish the confidence in the FASST's ability to produce consistent results and reinforces the reliability of its measurements.

7.2.6.5. Internal Consistency

Internal consistency is a measure of how closely related the items within a measurement instrument are to each other (Cooper, 2023). In this study, the internal consistency of the FASST was as assessed at two levels: overall and for each identified component. To evaluate the overall internal consistency, the interrelatedness of all the items in the FASST were examined. This analysis helps determine the extent to which the items within the FASST are measuring the same underlying construct. Cronbach's alpha was the statistical measure chosen to assess the internal consistency reliability. A higher value of Cronbach's alpha indicates a greater consistency among the items, suggesting that they are measuring the same construct. A Cronbach's alpha value of more that 0.7 is considered acceptable (Shrestha, 2021). Additionally, as described above PCA was conducted to identify the underlying components within the FASST. Following the PCA, the internal consistency of each identified component was examined separately. This analysis allows for the evaluation of internal consistency of each of the specific dimensions captured by the FASST. These statistical tests help determine the reliability and consistency of the FASST and ensures that it is capturing the intended constructs accurately.

7.3. Results

7.3.1. Principal Component Analysis

The principal component analysis was conducted on the full item pool (n = 58), producing 13 components. Upon inspection of the correlation matrix and applying the criterion of 0.3 or above for retainment, two items were removed (items 20 & 56) and the analysis was re-run. Items were further excluded if they did not meet the criterion of 0.6 or above on the anti-image matrices (items removed: 13, 14, 23, 24 and 27). All remaining items satisfied the criterion of 0.5 or higher on communalities. Upon inspection of the pattern matrix, items 7 and 36 did not load clearly onto a single component, therefore they were removed and a final analysis was run (see Table 22 for items removed). All items met analysis criterion and were retained for component structure analysis. The retained items (n = 49), their components (n = 9) and their loadings are shown in Table 24. Table 23 provides the variance explained by the retained components.

Table 23 – FASST items excluded during Principal Component Analysis

FASST Items	Reason for exclusion*
7: They have difficulty managing conflict	3
13: They are skilful at imitating the behaviours of others around them	2
14: They are usually direct, blunt and to the point	2
20: They have a small number of people that they trust	1
23: They have at least one close relationship outside of the household/family that seems genuinely shared	2
24: They have a few close friends rather than a large and varied group of friends	2
27: They are usually able to sense the movement and position of their body	2
36: They often have low self-esteem	3
56: It is always easy to tell how they are feeling just by their facial expressions	1

*Reasons for exclusion: 1 = did not meet 0.3 or above on correlation matrix; 2 = did not meet 0.6 or above on anti-image matrices; 3 = did not load clearly onto a single component.

Table 24 – Principal component analysis - % of variance explained by final components

	Initial eigenvalues and extraction sums of squared loadings		
Component number	**Total**	**% of variance**	**Cumulative %**
1	24.711	50.430	50.430
2	2.712	5.534	55.964
3	2.124	4.335	60.299
4	1.606	3.277	63.576
5	1.466	2.991	66.567
6	1.333	2.719	69.287
7	1.255	2.561	71.848
8	1.184	2.416	74.264
9	1.014	2.069	76.333

7.3.1.1. Component Structure

Interpretation of the nine retained components are as follows. Component 1 contained items relating to *social cues,* for example “understanding other people’s intentions”. Component 2 contained items relating to *perspective taking,* for example “understanding boundaries in relationships”. Component 3 contained items relating to *friendship,* for example “difficulties developing and maintaining friendships”. Component 4 contained items relating to *rigidity,* for example “spending long periods of time focused on one particular activity. Component 5 contained items relating to *coping with transitions,* for example “becoming anxious, upset and/or unsettled when something unexpected happens”. Component 6 contained items relating to *regulation,* for example “being under or over responsive to specific textures, tastes, smells and temperatures”. Component 7 contained items relating to *mental health,* for example, “often stressed and/or anxious. Component 8 contained items relating to *emotion,* for example, “difficulties understanding or describing their own emotions”. Finally, Component 9 contained items relating to *social interactions,* for example, “feeling comfortable meeting new people”.

Table 25: Component loadings from the PCA, and the associated Cronbach's alpha (n = 49)*

***PM = Pattern Matrix; SM = Structure Matrix**

	1		2		3		4		5		6		7		8		9	
	PM	SM	PM	SM	PM	SM	PM	SM	PM	SM	PM	SM	PM	SM	PM	SM	PM	SM
1: Social Cues (α = 0.88)																		
49: They sometimes seem socially naïve for their age	0.603	0.747																
48: They do not always pick up easily on other people's intentions	0.423	0.668																
5: They do not seem to understand subtle social cues	0.322	0.604																
2: Perspective taking (α = 0.93)																		
52: When they do things, they often do not think of the impact on other people's feelings			0.823	0.893														
47: Other people sometimes raise/have concerns about how they treat others			0.810	0.775														
53: They often do not understand when or why they have caused offence			0.722	0.841														
11: They sometimes have difficulties understanding boundaries in relationships			0.593	0.775														
12: They sometimes do things that others think are rude or			0.559	0.753														

inappropriate without understanding why this has caused offence									
51: They often find it difficult to notice or understand other people’s emotions			0.514	0.738					
58: They find it difficult to predict how other people will feel or respond			0.499	0.746					
3: Friendship (α = 0.87)									
22: They tend to have short-lived relationships due to difficulties in maintaining relationships					0.585	0.716			
16: They have friendships with people that are not always reciprocated to the same extent					0.585	0.738			
8: They have difficulties developing friendships					0.575	0.756			
9: They have difficulties maintaining friendships					0.568	0.747			
31: They often appear lonely and/or isolated					0.368	0.609			
4: Rigidity (α = 0.90)									
42: They have a strong sense of justice, of right and							0.673	0.734	

wrong and seeking the truth						
4: They can take things literally		0.646	0.761			
10: They can take things too seriously		0.544	0.721			
43: They have at least one intense interest at any one time		0.500	0.732			
37: They have a set way of doing things such as careful arrangement of objects and/or organise things systematically e.g. lists		0.431	0.639			
33: They often spend a long time thinking/worrying about situations		0.395	0.652			
39: They can spend long periods of time focused on a particular activity		0.353	0.675			
5: Coping with transition (α = 0.87)						
55: They experience difficulties or are likely to experience difficulties with employment				0.743	0.841	
40: Their interests can lead to them forgetting other activities or duties				0.727	0.808	
41: They become anxious, upset and/or				0.414	0.672	

unsettled when something unexpected happens						
38: They may find it difficult if they cannot follow specific routines or unexpected changes occur		0.395	0.675			
6: Regulation (α = 0.90)						
25: They can be distressed, distracted or overwhelmed by noises that do not bother others				0.624	0.806	
26: They can be under or over responsive to sensations e.g. specific textures, tastes, smells or temperatures				0.536	0.741	
6: They often appear exhausted after some social interactions				0.526	0.756	
46: They sometimes experience intense emotional reactions to things they hear or see (e.g. things on the tv, newspapers and social media), which others may not share				0.438	0.611	
15: They can be controlling and/or intense				0.410	0.605	
45: They have intense attachments which may include specific				0.402	0.620	

objects and/or animals								
7: Mental Health (α = 0.89)								
29: They experience or previously experienced mental health conditions				0.862	0.857			
32: They experience or previously experienced bullying				0.836	0.855			
28: They are often stressed				0.475	0.659			
30: They are often anxious				0.427	0.669			
57: They experience difficulties or previously experienced difficulties with school				0.370	0.585			
54: Adolescence is/was a noticeably difficult period				0.323	0.655			
35: They talk about feeling like they are different to other people				0.301	0.643			
8: Emotion (α = 0.68)								
44: They can rage, cry or laugh with little apparent trigger						0.749	0.362	
50: They sometimes have difficulty understanding or describing their own emotions						0.437	0.573	

9: Social Interaction (α = 0.92)			
34: They sometimes seem to isolate themselves from others		0.353	0.646
18: They find it easy to maintain and engage in ‘small talk’		0.823	0.206
19: They enjoy ‘small talk’		0.652	0.275
1: They can join in easily with face-to-face chats, when more than three people are talking together		0.609	0.362
21: They feel comfortable meeting new people		0.579	0.750
3: They mostly prefer solo activities and interests which they can do on their own		0.523	0.718
17: They can easily respond appropriately to other people’s feelings		0.474	0.644
2: They can easily adjust their behaviour in different social situations without difficulty		0.320	0.555

7.3.2. Construct Validity

The correlations between the FASST and the self-report measures used in this study (AQ, EQ, FQ and CAT-Q) are reported in Table 25. The FASST was positively correlated with the AQ and the CAT-Q and inversely correlated with the EQ and the FQ, indicating that the FASST is associated with the variables in the comparison measures in theoretically predictable ways. All correlations were significant at the $p < .01$ level. The strength of the relationship demonstrated correlations within the moderate range (0.4 to 0.7; Taylor, 1990).

Table 26: Correlations between the FASST and AQ, EQ, FQ and CAT-Q

Measure	**Correlation Coefficient**
Autism Quotient	0.565*
Empathy Quotient	-0.456*
Friendships Quotient	-0.473*
Camouflaging Autistic Traits Questionnaire	0.621*

*$p < 0.01$

7.3.3. Discriminant Validity

There were significant differences between groups, F(2, 67) = 55.69, p <.001. Post-hoc tests identified that both the autistic and self-identify group scored significantly higher on the FASST than the non-autistic group, whilst there was no significant difference between the autistic group and the self-identify group (Table 26).

Table 27: Significance levels and confidence intervals between groups

Bootstrap for Pairwise Comparisons			BCa 95% Confidence Interval	
Group	Group	Sig. (2-tailed)	Lower	Upper
Autistic	Self-Identify	.683	-6.225	9.707
	Non-autistic	<.001	34.971	56.858
Self-Identify	Autistic	.683	-9.756	6.286
	Non-autistic	<.001	33.477	55.188
Non-autistic	Autistic	<.001	-56.534	-35.393
	Self-Identify	<.001	-54.484	-34.694

7.3.4. Test re-rest Reliability

Test re-test reliability was based on all informants completing the FASST twice at two separate time points. The intraclass correlation coefficient was, .98, 95% CI [.96, .99].

7.3.5. Internal Consistency

The FASST demonstrated excellent internal consistency, α = .99, N = 94. As demonstrated in Table 3, alpha values for eight out of the nine components were .80 or above.

Table 28: Alpha values for individual components

Component number and label	**Alpha values**
1: Social Cues	0.88
2: Perspective taking	0.93
3: Friendship	0.87
4: Rigidity	0.90
5: Coping with transition	0.87
6: Regulation	0.90
7: Mental Health	0.89
8: Emotion	0.68
9: Social Interaction	0.92

7.4. Discussion

The pilot study aimed to answer the specific research question ***"To what extent does the piloted version of the FASST demonstrate reliability, validity, and discriminative ability in identifying autism among women, when compared to non-autistic women, following revisions based on a systematic review, feedback from focus groups, and refinement via a Delphi consultation?".*** The pilot served as a critical step in evaluating the practical utility and effectiveness of the revised version of the FASST. By piloting the FASST with a sample of autistic women, we aimed to assess whether or not the FASST could accurately predict autism in females. The pilot phase allowed for the testing of feasibility, sensitivity, and specificity of the FASST in real-world settings, enabling the collection of valuable insights into the FASST’s strengths and limitations. Furthermore, the pilot aimed to understand how well the FASST aligned with other screening tools for autism and current diagnostic criteria.

The first aim of the study was to investigate the component structure and psychometric properties of the FASST. The results of this pilot study demonstrated that the FASST was significantly correlated with currently used screening tools AQ, EQ, FQ and CAT-Q, indicating that the FASST is associated with variables that the comparison tools measure in theoretically predictable ways. The FASST demonstrated excellent internal consistency overall, with alpha values of 0.8 or higher on eight of the nine extracted components. Test-retest reliability of the FASST was found to be high, with an intraclass correlation coefficient of 0.98, indicating a strong positive relationship between FASST scores at the two time points. The second aim was for the FASST to successfully discriminate between autistic and non-autistic women. The FASST demonstrated a robust capacity to discriminate between autistic and non-autistic women, with significant differences found between groups. Overall, the findings suggest that the FASST is a reliable screening measure for the identification of autism in women and girls.

7.4.1. FASST Extracted Components

Using the PCA allowed for the removal of certain items, reducing the FASST to a shorter version of the original instrument.

7.4.1.1. Social Cues

The three items in this component relate to specific elements of social cognition which includes understanding the intentions and social cues of others and social naivety during interactions with others. Social cognition refers to a person’s ability to perceive and interpret social information (Brothers, 1990) encompassing areas such as the detection of social information and identifying the emotional state of others (Morrison et al., 2020). The component overall demonstrated high internal consistency (α =0.88), which aligns with current research that suggests autistic people experience difficulties interpreting facial expressions, body language and tone of voice (Morrison et al., 2020).

7.4.1.2. Perspective Taking

The seven items in this component again relate to elements of social cognition including difficulties in being able to predict how other people will respond, difficulties understanding why they may have caused offence to someone and difficulties noticing or understanding other people's emotions. The component overall demonstrated high internal consistency (α =0.93) aligning with previous research that proposes autistic people may experience difficulties with Theory of Mind (ToM; Baron-Cohen, 1991). Although these difficulties in perspective taking exist for autistic people, recent studies have questioned the accuracy of ToM as a singular theory to explain such difficulties. Milton (2012) proposes the Double Empathy theory of autism, which suggests that both autistic and non-autistic people may have difficulties inferring the mental states and interpreting the social cues of each other and should not be viewed as a 'deficit in functioning' purely driven by autistic misunderstanding (Edey et al., 2016; Morrison et al., 2020).

7.4.1.3. Friendship

The five items in this component relate to relationships, including items such as difficulties developing and maintaining friendships. The component overall demonstrated high internal consistency (α =0.87) with these items appearing to explain the difficulties that autistic women experience, although that is not to say that autistic men and other genders do not experience the same. The component overall aligns with the qualitative research evidence where autistic women describe challenges related to making, developing, maintaining, and managing friendships (Bargiela et al., 2016; Cridland et al., 2014; Milner et al., 2019; Tierney et al., 2016; Vine Foggo & Webster., 2017).

7.4.1.4. Rigidity

This component comprised of seven items including intense interests, spending long periods of time focused on particular activities and the systematic arrangement of objects and/or things. The component overall demonstrated high internal consistency ($\alpha = 0.90$) which aligns well with specific diagnostic criteria of the DSM-5 in relation to restricted interests and repetitive behaviour. The construct of rigidity encompasses aspects such as inflexibility and difficulty adapting to change with much research focusing on the challenges an autistic person may experience as a result. Having said that, recent evidence suggests that rigidity as a concept may be too broad, with further research needed in order for the construct to become better understood and made more precise (Petrolini et al., 2023).

7.4.1.5. Coping with Transition

The four items in this component encompasses difficulties with transitions including becoming anxious or upset when something unexpected happens experiencing difficulties when they cannot follow their specific routines or when unexpected changes occur. The component overall demonstrated high internal consistency ($\alpha = 0.87$) and similarly to the rigidity component covers specific elements of the DSM-5 criteria. The component aligns well with current research evidence where autistic people describe the importance and necessity of having structured and predictable routines (Dreaver et al., 2020).

7.4.1.6. Regulation

The six items in this component relate to specific areas of regulation that autistic may experience difficulties with. These include areas of sensory sensitivities, feeling exhausted after social situations and experiencing intense emotional reactions to certain things they hear or see. The component overall demonstrated high internal consistency (α = 0.90) which aligns with current research evidence that autistic women are likely to experience more lifetime sensory issues relative to autistic men (Lai et al., 2011). Furthermore, intense emotional reactions may also be linked to sensory sensitivities as autistic women describe the often-debilitating effects of sensory overload which causes severe distress and overwhelm (Milner et al., 2019; Tierney et al., 2016).

7.4.1.7. Mental Health

The seven items in this component relate to aspects of mental health and experiencing difficulties with school and bullying. The component overall demonstrated high internal consistency (α = 0.90) and although not a definitive characteristic of autism itself, appears to be reflective of the mental health experiences described by autistic women. Autistic women frequently report living with co-existing mental health conditions such as anxiety, depression, eating disorders and obsessive-compulsive disorder (Bargiela et al., 2016; Milner et al., 2019), and that the root of these conditions were associated with trauma, complex histories and difficulties with school and bullying (Leedham et al., 2020). Although these items reflect the experiences of autistic women it is important to note that several studies report no sex difference in relation to mental health, and that similar levels of co-existing mental health conditions are present for both autistic women and autistic men (Lai et al., 2011; Tint et al., 2017; McGillivray & Evert, 2018).

7.4.1.8. Emotion

The two items in this component related to difficulties describing their own emotions and experiencing emotional responses with little apparent trigger. The component overall demonstrated the lowest internal consistency of all the nine components ($\alpha = 0.68$) which perhaps reflects the difficulty in being able to observe these internal states and report as an informant. Emotions as a construct can be multifaceted and complex and may not be able to be captured by only two FASST items. Future research should investigate the addition of items in this component which may be needed to enhance the internal consistency of this component.

7.4.1.9. Social Interaction

This component comprised of eight items related specifically to social interaction including experiences in reciprocal conversations, meeting new people, engaging in small talk and the ability to adjust their behaviour in different social situations without difficulty. The component overall demonstrated high internal consistency ($\alpha = 0.92$) and aligns well with specific diagnostic criteria in the DSM-5. It is well documented that difficulties in social interaction are core characteristics of autism, although not exclusive to autistic females, remains a defining characteristic in autism diagnosis (APA, 2013).

7.4.2. FASST Items mapped to DSM-5 Criteria

For a diagnosis of autism to be given observations of difficulties need to be seen in areas of socio-emotional reciprocity, nonverbal communicative behaviours, development and maintenance of relationships, repetitive and restrictive behaviours, and sensory sensitivities (APA). The FASST was designed to screen for key characteristics of autism that would specifically include areas linked to women and girls, and in line with the above DSM-5 criteria. The items included in the FASST were carefully selected, revised, and reworded with input from autistic women, family members and professionals to ensure the FASST was able to capture these characteristics. For instance, the FASST includes items that assesses for difficulties with understanding boundaries in relationships and friendships with people that are not always reciprocated to the same extent which are aspects of social interaction that are central to receiving a diagnosis of autism. The FASST also includes items that are used to assess the presence of repetitive and restrictive routines or behaviours which are also key areas central to DSM-5 criteria, such as having at least one intense interest and spending long periods of time thinking/worrying about situations. In addition, the FASST assesses for sensory sensitivities including under or over responses to sensations and distress caused by noises that do not appear to bother others, which as outlined in diagnostic criteria, can have a significant impact on the autistic person’s daily life. Table 28 below displays the FASST items mapped to the current DSM-5 criteria. Even though one criterion of the DSM 5 is not covered by the FASST, this should not deter from the fact that the FASST overall includes items that may specifically be relevant to autistic women and girls. The overall aim of the FASST was to create increased understanding and awareness for frontline professionals of key areas that might be more relevant to autistic women and girls. Frontline professionals such as GPs, school educators or mental health teams may be one of the first people to recognise that an individual may be autistic, so it is crucial that these professionals are able to use a tool that will provide them with the knowledge that has the potential to change this person’s life, by giving them access to diagnostic pathways. By demonstrating how each item maps onto the DSM-5 criteria, the FASST has the potential to provide a more accurate and comprehensive screening of autism in women and girls.

Table 29: FASST items mapped to DSM 5 criteria

	DSM V - A. 1. ***Deficits in socio-emotional reciprocity, ranging from abnormal social approach and failure of back and forth conversation through reduced sharing of interests, emotions, and affect and response to total lack of social interaction.***
1	They can join in easily with face to face chats, when more than three people are talking together
3	They mostly prefer solo activities and interests which they can do on their own
4	They can take things literally
10	They can take things too seriously
21	They feel comfortable meeting new people
31	They often appear lonely and/or isolated
34	They sometimes seem to isolate themselves from others
50	They sometimes have difficulty understanding or describing their own emotions
52	When they do things, they often do not think of the impact on other people’s feelings
53	They often do not understand when or why they have caused offence
	DSM V - A.2. ***Deficits in nonverbal communicative behaviours used for social interaction; ranging from poorly integrated verbal and nonverbal communication, through abnormalities in eye contact and body-language, or deficits in understanding or use of nonverbal communication, to total lack of facial expression or gestures.***
5	They do not seem to understand subtle social cues
17	They can easily respond appropriately to other people’s feelings
48	They do not always pick up easily on other people’s intentions
51	They often find it difficult to notice or understand other people’s emotions
56	It is always easy to tell how they are feeling just by their facial expressions
	DSM V - A.3. ***Deficits in developing and maintaining relationships, appropriate to developmental level (beyond those with caregivers); ranging from difficulties adjusting behaviour to suit different social contexts through difficulties in sharing imaginative play and in making friends to an apparent absence of interest in people.***
2	They can easily adjust their behaviour in different social situations without difficulty
7	They have difficulty managing conflict
8	They have difficulties developing friendships
9	They have difficulties maintaining friendships
11	They sometimes have difficulties understanding boundaries in relationships
12	They sometimes do things that others think are rude or inappropriate without understanding why this has caused offence
14	They are usually direct, blunt and to the point
15	They can be controlling and/or intense
16	They have friendships with people that are not always reciprocated to the same extent
18	They find it easy to maintain and engage in ‘small talk’
19	They enjoy ‘small talk’
20	They have a small number of people that they trust
22	They tend to have short-lived relationships due to difficulties in maintaining relationships
23	They have at least one close relationship outside of the household/family that seems genuinely shared
24	They have a few close friends rather than a large and varied group of friends
32	They experience or previously experienced bullying
35	They talk about feeling like they are different to other people
47	Other people sometimes raise/have concerns about how they treat others

49	They sometimes seem socially naïve for their age
58	They find it difficult to predict how other people will feel or respond
	DSM V - B.1. ***Stereotyped or repetitive speech, motor movements, or use of objects (such as simple motor stereotypies, echolalia, repetitive use of objects, idiosyncratic phrases)***
	No applicable FASST items
	DSM V - B.2. ***Excessive adherence to routines, ritualised patterns of verbal or nonverbal behaviour, or excessive resistance to change (such as motoric rituals, insistence on same route or food, repetitive questioning or extreme stress at small changes).***
37	They have a set way of doing things such as careful arrangement of objects and/or organise things systematically e.g. lists
38	They may find it difficult if they cannot follow specific routines or unexpected changes occur
41	They become anxious, upset and/or unsettled when something unexpected happens
42	They have a strong sense of justice, of right and wrong and seeking the truth
	B.3. ***Highly restricted, fixated interests that are abnormal in intensity or focus (such as strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interests).***
39	They can spend long periods of time focused on a particular activity
40	Their interests can lead to them forgetting other activities or duties
43	They have at least one intense interest at any one time
45	They have intense attachments which may include specific objects and/or animals
	B.4. ***Hyper- or hypo-reactivity to sensory input or unusual interest in sensory aspects of environment (such as apparent indifference to pain/heat/cold, adverse response to specific sounds or textures, excessive smelling or touching of objects, fascination with lights or spinning objects)***
25	They can be distressed, distracted or overwhelmed by noises that do not bother others
26	They can be under or over responsive to sensations e.g. specific textures, tastes, smells or temperatures
27	They are usually able to sense the movement and position of their body
	Other characteristics possibly associated:
6	They often appear exhausted after some social interactions
13	They are skilful at imitating the behaviours of others around them
28	They are often stressed
29	They experience or previously experienced mental health conditions
30	They are often anxious
33	They often spend a long time thinking/worrying about situations
36	They often have low self-esteem
44	They can rage, cry or laugh with little apparent trigger
46	They sometimes experience intense emotional reactions to things they hear or see (e.g. things on the tv, newspapers and social media), which others may not share
54	Adolescence is/was a noticeably difficult period
55	They experience difficulties or are likely to experience difficulties with employment
57	They experience difficulties or previously experienced difficulties with school

7.4.3. Strengths and Limitations

As far as is known, this is the first informant-based screening tool designed specifically with autistic females in mind. As highlighted in previous chapters, a significant strength of the overall research was the inclusion of autistic people throughout the refinement of the FASST, which without such input, would not have facilitated the piloting of the FASST. The pilot study allowed for an initial evaluation of the psychometric properties of the FASST and as such served as a starting point for assessing the FASST's performance as well as identifying areas for improvement in future refinements and/or larger-scale studies.

As with any pilot of a new instrument, there are limitations to this study which are important to consider. First, due to the design of the study in which lead participants needed to have an informant in order to complete the FASST, limited the number of participants overall. We received many completed self-reports that could not be used in the final analysis due to the informant participant dropping out or failing to respond within the two-week time frame. Second, the sample size was much smaller than anticipated and therefore results need to be interpreted with some caution, however using the statistical methods selected for analysis allowed us to interpret the data with adequate sampling replacements. The item communalities, KMO and Bartletts were all adequate for the type of analysis used on the FASST. In addition, it is important to consider sampling bias. The participants in the pilot study may not have been fully representative of the broader population of autistic women and as such may affect the generalisability of the findings. Moreover, the development and evaluation of any screening measure needs to ensure consideration of processes that optimise sensitivity and specificity. Specifically related to autism, sensitivity refers to the measure's ability to accurately identify people who truly have autism, minimising false negatives. On the other hand, specificity, pertains to the measure’s capability to correctly identify people without autism, therefore minimising the potential for false positives. Given that this research was exploratory in nature, coupled with the fact that the study overall had a small number of participants, it was not possible to fully explore the sensitivity and specificity of the FASST. In the context of any future research undertaken on the FASST it will be paramount to ensure that the right balance between sensitivity and specificity is captured. For example, if the FASST was overly sensitive, this may capture a broad range of autistic characteristics but risks including false positives that could potentially lead to unnecessary resource allocations. Conversely, if the FASST became a measure that prioritises specificity, this could potentially reduce the number of false positives but could miss less stereotypical presentations of autism. This in turn could then become potentially problematic, particularly as the research topic focuses on the underdiagnosis and missed diagnosis of autism in women and girls. As discussed later within the overall limitations of this research, further investigation into the utility of the FASST will need to ensure that the measure is refined through larger empirical data sets, which may include adjusting cut-off scores as well as considering the many diverse profiles of autism through the exploration of other gender identities. Moreover, the importance of continued collaborative efforts, particular with experts in the field on autism diagnosis, will provide valuable perspectives in achieving a balance that ensures the FASST is both sensitive to the unique characteristics of autism in females and specific in accurately identifying cases.

Third, in relation to the participants who completed the self-report measures it is also important to consider social desirability bias or memory recall issues, which may influence the accuracy of the reported information. Finally, it was not possible to either (a) confirm diagnoses for the group who reported receiving a diagnosis by a clinician or professional and (b) confirm whether those in the self-identified group would go on to receive a diagnosis of autism. It is therefore reasonable to suggest that some participants in this category may not meet the criteria of having a formal diagnosis of autism.

7.5. Conclusion

With access to diagnostic pathways remaining a significant challenge resulting in delays in diagnosis, the importance of a screening tool such as the FASST, that can accurately predict autism in females remains important. The pilot of the FASST represents an important first step in the broader effort to improve autism screening in women. By developing a tool that addresses the specific needs and experiences of autistic women, the FASST has the potential to contribute to more accurate and timely identification, leading to better access to appropriate support and services.

Chapter 8. Overall Discussion

8.1. Introduction

This thesis aimed to systematically review the existing literature on adult and adolescent autistic females, utilising the findings to inform the development of a new screening tool, and consequently assessing and amending the tool with input from autistic women and other key stakeholders. Through a series of studies conducted over the course of this research, the overall aim was to develop and refine the FASST which was specifically designed to screen for autism in women. This overall discussion chapter will critically synthesise findings from this thesis, drawing upon the original research question that guided this research project which was ***"How can the experiences and behavioural presentations of autistic females be better understood and assessed, and to what extent can the new screening tool for autism, the FASST, accurately discriminate between autistic and non-autistic people?***

First a summary of the research findings will be provided, revisiting the initial research questions that framed each study. A clear overview will be provided as to how the findings from each study offer a unique contribution to the field. Following this, key additional themes that emerged from the findings will be highlighted and discussed in relation to the overall thesis aim and the existing evidence base. Finally, the overall limitations will be considered alongside recommendations for future research arising from the findings of this thesis.

By synthesising the insights gained from the systematic review, focus groups, Delphi consultation and the pilot of the FASST, this discussion aims to demonstrate the multifaceted aspects of autistic women and girls, whilst critically evaluating the effectiveness and implications of the FASST that was developed and refined through this research. Through the undertaking of this research project, we hope to contribute to the ongoing research efforts in improving the recognition, understanding, and support provided to autistic women and girls and other harder to diagnose populations. Through the integration of diverse perspectives and the engagement of autistic women, parents/carers, professionals, and researchers/academics in studies 2-3, this research offers a valuable contribution to the field of autism research, with implications for diagnosis, intervention, and policy development.

8.2. Overview of the Main Findings

As outlined throughout this thesis, it is particularly important to continue the exploration of the potential biases at play in both the screening assessments and diagnostic tools used to currently assess for autism in women and girls (Seers & Hogg, 2023). Given the complexities surrounding the understanding of differing autistic presentations in autistic females, it seems reasonable to suggest that this may be applicable to other autistic people who may be harder to diagnose due to more subtler presentations. At the start of this thesis, it was assumed that this tool would develop into something specifically for autistic females, however it seems likely that a screening tool is also needed to identify males and other gender identities who may experience challenges like that of autistic women. This suggestion will be discussed later in this chapter in relation to future research and implications, however the following sections will discuss the findings specifically related to our original research question detailed above. The following chapter will summarise the findings related to each individual research question and will be discussed in relation to their contribution to the overall aim of this thesis.

8.2.1. Study 1: Systematic Review - Discussion

Research Question:

> What are the experiences and behavioural presentations of autistic females, and what additional items informed by the literature pertaining to the experiences of women and girls should be included in the FASST at this development stage?

The above research question guided the systematic review and was central to understanding the unique experiences and behavioural presentations of autistic women and girls. As highlighted in chapter 1, there was a growing recognition that autism in females may present differently to their male counterparts, and as such it was suggested that current or more traditional screening tools and/or diagnostic procedures may not adequately capture the seemingly diverse presentations of autistic women and girls. The formulation of this research question aimed to address the potential gaps in existing knowledge and shed light on the potential differences in presentation, as well as the lived experiences, of autistic women and girls. Furthermore, the systematic review guided the identification of relevant studies, the synthesis of findings, generation of meaningful conclusions, as well as serving to refine the FASST in the early stages of its development. The systematic review aimed to provide a comprehensive overview of what is known about autistic women and girls, specifically adolescents, highlight specific areas of consensus and divergence, and generate recommendations for additional items for inclusion in the refinement of the FASST.

Our findings demonstrated conflicting evidence for social and communication difficulties, with some studies reporting equal levels of difficulty for autistic males and females, while others reported fewer difficulties for autistic females. Regardless, a common theme in the experiences of women and girls was the impact these difficulties had upon their everyday lives. More lifetime sensory issues were found for females compared to men, while RRBI were seen more frequently in males than females. In relation to camouflaging, again the research was conflicting, with some studies suggesting females engaged in more camouflaging than males, with some reporting no differences. However, for both sexes, camouflaging was associated with poorer mental health. Diagnostic challenges were described, with one study finding delays in diagnosis for autistic females. Differences in specific co-existing mental health diagnoses were reported, but both autistic males and females presented with similar levels of co-existing mental health, regardless of the specific diagnostic label. Finally, everyday experiences of life as an autistic female and the associated challenges were documented. These findings included more social challenges and conflict, and difficulties with friendships and relationships overall. Autistic women felt pressured to conform to gender stereotypes, and everyday life events were suggested to be more stressful for autistic women than autistic males, with a lack of general support described as a frequent issue.

As seen in the quality assessment of the included studies, most research included higher numbers of male participants compared to females, this is not surprising given that autism has historically been thought of as a predominately male condition. Taking into consideration that most of what we understand about autism is a result of research conducted on large samples of males, it is not surprising that the male stereotype of autism persists. Even in recent years there is little to no mention of autistic females in national guidance and recommendations. For example, in 2015 a consultation in the United Kingdom was conducted for new NHS guidance on autism and no attempt was made to address the needs of autistic women and how these may differ to autistic males (DoH, 2015). Moreover, in the new strategy for adults with autism (DoH, 2016) only a brief mention was given that stated the need for awareness in differences in presentation for autistic women and girls. No attempt or reference to recent research on the significant delays autistic females faced in receiving a diagnosis and the subsequent impact this had on their physical and mental wellbeing.

Given that in the general population the physical and mental health needs of women are under-researched, under-funded and often overlooked, it is not surprising that we see the same patterns extended to the autistic community. Over several decades, we have seen a strong male bias in relation to investigating the health needs of the population, with research in general often conducted predominantly on males. This includes areas such as heart disease, diabetes, depression, anxiety and many more. Females who are not autistic are more likely than non-autistic males to experience inadequate access to health care as well as delays in subsequent diagnoses (Cleghorn, 2021; Perez, 2019), and although no direct comparisons have been made in single studies, research conducted on autistic females revealed similar findings in terms of inadequate support and access to healthcare services, delays in diagnosis, were more likely to have a mental health condition as well as reporting a failure by professionals to understand their needs as well as a lack of understanding of what autism looks like in females. The delays in diagnosis that non-autistic females experience in health care are also experienced by autistic women. Recent research has shown a 10 year delay in identification and subsequent access compared to their autistic male counterparts (Gesi et al., 2021), highlighting the importance of screening tools that are specifically tailored to better support the identification of autism in women and girls.

8.2.1.1. Implications for the FASST

The systematic review highlighted specific areas in relation to the experiences and behavioural presentations of autistic women and girls that may address some of the limitations in currently used screening tools. The review identified key areas where females may exhibit differences compared to males. As a result of the findings, an additional 17 items were added to the FASST based on the current evidence base of the experiences and behavioural presentations in autistic women and girls. These specifically clustered into areas of friendships and social communication abilities within these relationships, experiences of mental health, and challenges during specific transitions such as adolescence, or environments such as school or employment. Out of the 17 items added from the current literature, 5 items were excluded post Delphi consultation (items related to stereotypical assumptions such as being described as a tomboy) and a further 2 items were excluded upon employment of the PCA protocol (difficulty managing conflict and being skilful at imitating others). The systematic review had significant implications for the development of the FASST, as it led to the incorporation of ten new items that emerged from the current literature on autistic women and girls. These additional items, which withstood subsequent scrutiny during focus groups, the Delphi consultation, and psychometric testing, underscore the vital role of existing research in informing and shaping the FASST. The inclusion of these items highlights the recognition of their relevance and significance in capturing the potentially diverse experiences and behavioural presentation of autistic women and girls. By integrating findings from the literature, the FASST demonstrates a critical and evidence-based approach to scale/measurement development, enhancing its potential effectiveness in accurately identifying autism in women and girls.

8.2.2. Study 2a: Focus Groups - Discussion

Research question:

> What are the perspectives and feedback of autistic women, carers, parents and professionals regarding the content of the FASST, a new screening tool designed to assess autism in females?

The overall aim of the focus groups was to ascertain feedback from autistic people and other key stakeholders on v2 of the FASST (appendix 2.2). Participants were asked to engage in group discussions on the item pool of the FASST and by doing so, the focus groups sought to create a supportive and inclusive environment for the participants to speak freely about their experiences of being an autistic woman and/or being missed, mis-diagnosed or experiencing a late diagnosis. The focus group discussions were guided by the item pool of the FASST, allowing for flexibility to discuss personal experiences, whilst staying focused on the FASST. Participants provided in-depth feedback on the item pool of the FASST and through the analysis of the focus group data, five key themes were found: structure of the FASST, the importance of being able to provide contextual and more detailed information;

masking, concerns around how well an informant could answer this if the person was good at masking. A lot of people may develop coping strategies that hides the difficulties that they are experiencing; autistic experiences ‘trying so hard…but still getting it wrong’, particularly around friendships, challenging the stereotypes around autistic routines and special interests, and sensory sensitivities; item content of the FASST, suggestions for re-phrasing to avoid the use of negative language, autistic and gender stereotypes, may not be specific to autism; and lastly, interpretation, concerns around professional skills sets and knowledge base, the importance of the informant being someone that the person being assessed knows well.

8.2.2.1. Implications for the FASST

The implications for the FASST arising from the focus groups are substantial and contribute to its refinement and contextual relevance. The focus groups discussions revealed key themes related to the structure, content, and potential interpretations of the FASST. All participants provided valuable insights into their lived experiences, offering unique perspectives on the challenges they have faced in their lives as well as describing specific characteristics of autism. These insights directly influenced the item development and modification process, resulting in the inclusion of new items and the revision of existing items. As a result of the suggestions from the focus groups, an additional 18 items were added to the item pool of the FASST. These items included specific areas of intense attachments to objects and animals, intense reactions, difficulties in self-regulation and difficulties understanding boundaries and understanding other people’s feelings. Out of these additional items 2 were excluded at the point of the Delphi consultation (she is very conscious of her impact on her environment and she is a content person), 3 additional items were excluded at the point of the PCA (they are direct, blunt and to the point, they have a small number of people they trust, and they are usually able to sense the movement and position of their body). The inclusion of the additional 18 items proposed by autistic women and parents, reflects the authenticity and relevance of their contributions. These items underwent rigorous evaluation and refinement through the Delphi consultation and psychometric testing, which further validated their importance and alignment with the overall goals of the screening tool. With only five items excluded out of the 18 additions, this process highlights the critical role of involving autistic people in research, ensuring that their perspectives are integrated into the development of assessment measures. By incorporating the voices and experiences of autistic women, the FASST has become potentially more attuned to the diverse needs and characteristics of autistic women. The implications from the focus groups highlight the importance of involving autistic people in the development of assessment measures and emphasises the value of capturing the nuanced experiences of autistic people in both research and clinical practice.

8.2.3. Study 2b: A Delphi Consultation – Discussion

Research Question:

> How can a Delphi consultation process be utilised to further refine and validate the items included in the revised version of the FASST, based on feedback from autistic women and other key stakeholders?

The Delphi consultation was a crucial component in the final refinement of the FASST, the process provided a platform to gather expert insights and achieve consensus on the item pool of the FASST prior to the pilot stage. Throughout the Delphi consultation, participants engaged in a series of rounds involving the presentation of the FASST items. This approach allowed for the systematic exploration of any key issues with the FASST items and facilitated the refinement based on the ratings of each item from the individual rounds. Participants were asked to rate each individual item in terms of relevance and importance in the assessment of autism in women and girls and were also provided an option to comment on the final wording of each item. The use of the Delphi provided a structured and iterative process to the refinement of the FASST and most importantly ensured that an inclusive and comprehensive approach was always undertaken (see appendix 6.1).

In relation to the initial item pool of the FASST v1 (appendix 2.1), at the point of the Delphi consultation, 19 items were excluded. These included areas such as eye contact, self-expression, having a great fashion sense, contrast questions such 'she prefers social and shared activities and interests' and 'she tends to be outgoing and sociable', and specific areas of social communication such as 'being able to chat about almost anything with you'. As a result of the exclusions throughout the Delphi consultation, a final item pool of 58 was prepared for use within the pilot study.

8.2.3.1. Implications for the FASST

The high threshold for item retainment (inclusion) and the fact that many of the proposed items reached that threshold, provided support that the items contained in the FASST were appropriate and relevant to assess autism characteristics in females. As discussed, many of the items included in the final draft of the FASST were as a result of the systematic review and the focus groups, the results of the Delphi added a quantitative element to scale development (Boateng et al., 2018) and thus, supported the triangulation of data across all three empirical studies.

As discussed in chapter 5, the collaborative approach of the Delphi supported the inclusion of autistic people in the decision-making process in relation to item retainment, thus the FASST was able to be refined with their unique experiences and perspectives. The direct involvement of autistic people helped to identify key areas of focus to ensure the FASST better captured the specific strengths and challenges faced by autistic women. There were a number of FASST items that were amended after the first three rounds of the Delphi in response to participant comments. There were several comments from participants relating to the negative use of language in item content. This reflected findings from both the existing literature on language (chapter 1) and the comments from participants in chapter 4. By prioritising inclusivity and collaboration, the Delphi contributed to the overall strength and validity of the FASST, thus enhancing its potential future utility in clinical and research settings.

8.2.4. Piloting the FASST

Research question:

> “To what extent does the piloted version of the FASST demonstrate reliability, validity, and discriminative ability in identifying autism among women, when compared to non-autistic women, following revisions based on a systematic review, feedback from focus groups, and refinement via a Delphi consultation?”.

The overarching aim of the pilot study was to conduct the preliminary assessment of the psychometric properties of the FASST. By involving a diverse group of participants, including autistic people, those who self-identify as autistic, and non-autistic people, the study aimed to evaluate the FASST's performance across different populations. Throughout the pilot of the FASST, participants completed a battery of self-report items currently used in practice, alongside the administration of the FASST which was completed by the participants paired informant. This methodology allowed for the comparison of the FASST against currently used screening tools, supporting the exploration of potential correlations and the FASST's ability to accurately discriminate between autistic and non-autistic people.

The results of the pilot demonstrated that the FASST was significantly correlated with currently used screening tools AQ, EQ, FQ and CAT-Q, indicating that the FASST is associated with variables that the comparison tools measure in theoretically predictable ways. The FASST demonstrated excellent internal consistency overall, with alpha values of 0.8 or higher on eight of the nine extracted components. Test-retest reliability of the FASST was found to be high, with an intraclass correlation coefficient of 0.98, indicating a strong positive relationship between FASST scores at the two time points. The FASST demonstrated a robust capacity to discriminate between autistic and non-autistic women, with significant differences found between groups. Overall, our findings suggest that the FASST is a potentially reliable screening measure for the identification of autism in women and girls. Furthermore, the findings of this pilot study have significant implications for the future directions of research in to screening tools used for autism assessment.

8.5. Implications of the FASST

8.5.1. The future of screening for autism

To our knowledge, only one study specifically tested the sensitivity of an assessment tool to ascertain differences between the sexes in adulthood. Grove et al. (2017) investigated the use of the Autism Spectrum Quotient Short Form (AQ-Short; Hoekstra et al., 2011) and found that the AQ-Short was able to consistently identify autism in both sexes. However, important to note here is that inclusion criteria for this study was based on participants having a formal diagnosis of autism, so it is reasonable to suggest that the same biases as described earlier are in play, in that only the females with a similar stereotypical presentation to males were likely to have received a diagnosis through current diagnostic tools and were therefore able to meet the criteria for inclusion in the study. Lai et al. (2011) suggested that since a diagnosis of autism is given based on behaviour, and if males and females are presenting with differences in symptom presentation, albeit subtle differences, it is reasonable to suggest the importance of sex specific assessment tools in order to ensure individuals are identified and subsequently diagnosed.

A previous review by Kirkovski et al. (2013) found that one of the greatest reported difficulties of female autistic children was that of the development and maintenance of appropriate friendships and peer relationships. However, these difficulties did not meet statistical significance in the sub-scale of ‘group play with peers’ in the Autism Diagnostic Interview-Revised (ADI-R; Lord et al., 1994) or the ‘socialisation’ sub-scale in the ADOS-2 (Lord et al., 2012). In addition, studies using other assessment tools, such as the Diagnostic Interview for Social and Communication Disorders (DISCO; Billstedt et al., 2007 as cited in Kirkovski et al., 2013) that rely on less stringent diagnostic criteria, found greater social difficulties in females. This further supports the hypothesis that current diagnostic assessments may not be sensitive enough to capture subtler or perhaps autistic presentations that are more likely considered a ‘normal’ gender stereotyped behaviour. Moreover, it seems likely to suggest that a diagnosis of autism in females may also be dependent on what assessment tool is used as well as on the skills and experience of the clinician conducting the diagnostic assessment (Kirkovski et al., 2013).

8.5.1.1. Comparisons between the FASST and the ASSQ-REV

As far as is known there are no specific informant screening tools that cater to supporting the identification of autism in people that are perhaps harder to diagnose due to subtler, less stereotypical presentations of autism. Furthermore, to the best of the authors knowledge, this is the first screening tool to be produced with significant input from autistic people and other key stakeholders. Despite significant increases in the last decade related to the exploration of autistic women and girls, little attention has been paid to the development of informant screening tools. As discussed in chapter one, the first screening tool that adapted its item pool to consider the autistic presentation of girls was Kopp and Gillberg’s study in (2011). The ASSQ was revised to include an additional 18 items that may be relevant to the identification of autism in girls. The study findings suggested that the use of the adapted ASSQ may lead to a better understanding of gender differences among girls and boys, however reported that larger samples were needed to confirm these differences. In relation to our findings, FASST items do appear to relate to items on the ASSQ-REV, even though the tool was first developed over a decade ago. This suggests that early considerations of varying autistic presentations were on the correct lines of inquiry. When considering the revised items in the ASSQ-REV, some relate to outdated stereotypes such *‘extremely interested in pop bands’* and *‘too much sympathy’*. Further items of similarity are considered as follows, item 30 on the ASSQ-REV *‘no time perception’* can be related to our updated item ‘*their interests can lead them to forgetting other activities or duties’.* Additionally, item 39 on the ASSQ-REV *‘comes too close to other people’* can be related to our item *‘they sometimes have difficulties understanding boundaries in relationships’*. Further, item 43 on the ASSQ-REV ‘*talks without content’* can be related to our item *‘they do not seem to understand subtle social cues*’ and finally, item 38 on the ASSQ-REV *‘naïve’* still appears relevant to our item *‘they sometimes seem socially naïve for their age’*. In contrast, item 28 of the ASSQ-REV *‘copies you’* appears relevant to the wider literature on camouflaging and masking, however our item *‘she is skilful at imitating the behaviours of others around them*’ interestingly did not make it through our statistical analyses, considering proposed assumptions that autistic women engage in camouflaging behaviours more which as a result may make them harder to diagnose. However, *‘imitating others’* could have been excluded because camouflaging intent may be more difficult for parents/informants to rate. Specific questions that either related to camouflaging abilities or specific internalised processes were criticised during the focus groups as autistic women reported concerns that some questions may be difficult to answer as the autistic person may be extremely adept at masking their difficulties.

8.5.1.2. Comparisons between the FASST and the GQ-ASC

More recently, Attwood and colleagues attempted the revision of their earlier screening tool the Girls Questionnaire for Autism Spectrum Conditions (GQ-ASC; Attwood et al., 2011) in order to assess adults (Brown et al., 2020). The modified GQ-ASC is a self-report tool, however some interesting findings in terms of comparability to the informant based

FASST were considered. Stereotyped questions on the FASST such as *'she has a great fashion sense', 'finding it easier to form friendships with males'* and *'has more shared interests with males and may be described as a tomboy'* were excluded at the stage of the Delphi consultation. These findings demonstrate that both at the consultation stage which included professionals, academics, and parents' and at the focus group stage which included predominantly autistic women, both perspectives aligned to state that these gendered stereotypes were outdated. This contrasts with the revised GQ-ASC (Brown et al., 2020) which still included what can be suggested as gender stereotyped interests, such as enjoying fantasy worlds, interested in fiction, and talented in music. Despite the authors stating that items were added and/or modified for the use with older participants, the study does not detail as to how these additional items were derived for use. The importance of including autistic perspectives is continually highlighted throughout recent academic literature, and as such, a strength of our FASST items are due to the fact that they have been co-produced with autistic people, which challenges essentialist views specific sex stereotypes.

Areas of convergence between the FASST and the GQ-ASC included items aligning with sensory sensitivities, experiencing intense emotions, feeling exhausted after social situations and being able to adjust behaviour *'become a different persona'* in different situations. However, the GQ-ASC demonstrated moderately low to approaching adequate levels of internal consistency, suggesting that the overall groupings of the items within the extracted components may not be sufficient in measuring the intended areas (Brown et al., 2020). In contrast, the internal consistency of the FASST demonstrated excellent internal consistency across all extracted components, except for one 'Emotion' which comprised of two items pertaining to coping with or describing emotions. As far as is known, these are the only two screening tools that have specifically investigated the addition of items that may be more relevant to autistic women and girls. Given that the ASSQ-REV was developed in 2011, and the GQ-ASC was revised in 2020, both screening tools still appear to be outdated in terms of the broader considerations of how autism might present more subtly and perhaps less stereotypically to what was once thought of as being particularly relevant to autistic women and girls. It is worth noting that previous literature highlighted the need for the development of assessment measures specifically tailored for adults, rather than solely adapting tools originally designed for children (Piven & Rabins, 2011). However, it is notable that the GQ-ASC, in their efforts to address the needs of adults, chose to revise their existing measure originally developed for children. Although this decision may have been influenced by various factors and logical considerations, it raises questions as to whether the GQ-ASC's adaptions will be able to effectively capture the distinct experiences and characteristics of autistic adults. In contrast to the adaption of screening tools originally developed for children, the development of informant tools such as the FASST, holds potential advantages. By tailoring the tool to the unique characteristics of autistic adults, it may offer a more accurate assessment of autism in this population. Our screening tool therefore provides a framework for not only being inclusive in the way in which items on the FASST were developed in order to account for autistic perspectives but is also the first informant tool to attempt such a collaborative approach to development in comparison to the several available self-report screening tools currently in circulation.

8.5.1.3. Comparisons between the FASST and the AQ-10

Although not specific to screening for autism in females, it is also worth discussing comparisons between the AQ (Baron-Cohen et al., 2001) and the FASST considering that the

AQ-10 is still current the recommended screening tool according to NICE clinical guidance (NICE, 2012). Anecdotally, although the AQ is a tool that is completed by the person themselves, in clinical practice the AQ-10 can often be utilised as a checklist and/or read about aloud by the clinician, providing opportunities for the person to respond, which in turn may not always produce the most comprehensive results. One notable difference between the items on the FASST and the AQ is in the descriptions of interests. There is only one item in the AQ related to interests *'I like to collect information about categories of things',* in contrast the FASST asks specific questions such as *'they have at least one intense interest at any one time'*, and *'they can spend long periods of time focused on a particular activity'*. More broadly in relation to rigidity, the FASST asks questions such as *'They have a set way of doing things such as careful arrangement of objects and/or organise things systematically e.g., lists', 'They can spend long periods of time focused on a particular activity', 'Their interests can lead to them forgetting other activities or duties' and 'They have intense attachments which may include specific objects and/or animals'.* The FASST includes more nuanced items that align with current research highlighting the diversity of interests in women and girls as well the fact that girls' interests are more likely to be deemed socially acceptable and thus often not recognised as a restrictive or repetitive behaviour (Hull et al., 2017). The items in the FASST aim to be worded more positively and capture the potentially different presentation of female behaviours around interests, which may differ from the more stereotypical and restricted interests often described in the AQ and AQ-10.

The FASST also included items specifically related to sensory sensitivities which may be absent or not extensively covered in the AQ-10. For example, the AQ-10 includes a singular item ‘I often notice small sounds when others do not’. However, as revealed throughout this thesis sensory sensitivities are significant experiences for many autistic people. The FASST included items such as *‘They can be distressed, distracted, or overwhelmed by noises that do not bother others’, ‘They can be under or over responsive to sensations e.g., specific textures, tastes, smells, or temperatures’ and more broadly, ‘They sometimes experience intense emotional reactions to things they hear or see (e.g., things on the tv, newspapers and social media), which others may not share’*. Thus, the incorporation of these items in the FASST offers a more in-depth assessment of the sensory needs of the autistic person and acknowledges the potentially unique sensory profiles of autistic females. Overall, this aligns with the emerging evidence that autistic females report experiencing more sensory sensitivities compared to autistic males.

In addition, the inclusion of items related to friendships in the FASST was also a notable difference from the AQ-10. Through the systematic review and the insights shared by women in the focus groups, it become evident that friendships present unique challenges for autistic women and girls, however the AQ-10 does not specifically address this aspect of social interaction. Our FASST items included: *‘They tend to have short-lived relationships due to difficulties in maintaining relationships’, ‘They have difficulties developing friendships’, ‘They have friendships with people that are not always reciprocated to the same extent’ and ‘They have difficulties maintaining friendships’.* By incorporating items that capture the complexities of forming and sustaining friendships, the FASST acknowledges the social difficulties that autistic females may encounter, particularly in the context of developing and maintaining meaningful relationships.

Despite differences in item content, there are however important areas of convergence between the AQ and the FASST in relation to social communication. Items on the AQ-10 such *as ‘I find it difficult to work out people’s intentions*’, align with our FASST item *‘They do not always pick up easily on other people’s intentions’*. Similarly, the AQ-10 item ‘I find it easy to work out what someone is thinking of feeling just by looking at their face’ relates to our FASST item *‘They can easily respond appropriately to other people’s feelings’.* Finally, the AQ-10 item *‘I find it was to “read between the lines” when someone is talking to me’* can be related to our FASST item *‘They do not seem to understand subtle social cues’.* The presence of shared items and overlap in areas of social interaction between the measures, suggest a degree of consistency between the FASST and theoretical accounts of autism. This consistency lends support to the construct of the FASST, as it demonstrates alignment with recognised domains of autism, as was demonstrated in the psychometric testing in chapter 7.

Although attempts have been made in this discussion to establish a contrast between the FASST and existing self-report measures, it remains challenging to directly compare two distinct approaches to the initial screening of autism. Informant-based tools such as the FASST rely directly on observers who may have limited insight into the internal experiences and nuances of the person being assessed. In contrast, self-report measures provide perspectives directly from the person themselves. These two methods offer different sources of information, making it difficult to directly compare their outcomes. However, considering the item content of the FASST in relation to other trialled measures offers valuable insights into the potential alignment and complementarity between our research and existing approaches. By acknowledging the different perspectives and item content across screening tools, we can promote a more comprehensive understanding of autism assessment and contribute to the ongoing refinement and advancement of screening tools in the field.

8.5.2. The future of screening for autism in harder to diagnose populations

When considering the way forward in how we approach screening for autism, it is essential to understand that our understanding of autism is continuously evolving and that previous assumptions and/or theories of autism may not always hold true. In chapter 1 theories related to autism that may account for missed or misdiagnosis were discussed and whilst previous research has suggested that autism is a predominantly male condition, new studies and evidence has challenged this. What we understand about autism today, may indeed evolve and change again in future years, however what will be continually important to recognise is that autism is a complex and diverse condition that affects each autistic person differently. As seen throughout this thesis research methodologies and topics of investigation vary widely, which can impact not just the findings of the study, but also the generalisability to the wider community. Rather than relying on stereotypes and current generalisations, it is vital that autism research continues with approaches that includes autistic people's research priorities, as well as considering specific populations and methodologies of individual research studies.

Researching autism in women and girls has many inherent challenges as discussed throughout this thesis, primarily stemming from the potential inadequacies and gender biases of existing diagnostic systems in identifying this demographic. Current diagnostic criteria, which have historically been developed on male presentations of autism, pose specific challenges in recognising and understanding how autism presents in women and girls. Considering that we know females are historically underdiagnosed, coupled with the underrepresentation of females within research, this has created a skewed understanding of autism, and as such has potentially hindered the development of effective support and interventions for autistic women and girls.

Navigating these challenges requires researchers to consider the balance of acknowledging the potential limitations of existing diagnostic and screening frameworks, whilst exploring alternative methodologies which capture the diverse presentations and experiences of autistic women and girls. Both in relation to how we create research projects investigating differences in gender presentations and how in which autistic women are currently screened and diagnosed, lies the difficulties of adhering to established criteria, which may inadvertently exclude or misidentify autistic women and girls. One potential way to manage these challenges is to create research designs that both include the lived experiences of autistic women and girls (which may include people who do not currently meet diagnostic criteria and/or people who self-identify as autistic), coupled with both the existing literature and input from diverse stakeholders in the community such as clinicians and diagnosticians. Ensuring a wide net is cast when exploring the diversities in autism may contribute to the development of a more nuanced and gender-sensitive approach to understanding differing autism presentations.

It can be argued that current screening tools are adequate in identifying autistic and women and girls if, clinicians and practitioners know what they are looking for and, have suitable experience in understanding and supporting people who are perhaps harder to diagnose due to the presentation of subtler autistic characteristics. However, in practice this is not always the case. The long-standing stereotypical understanding that autism is a male condition is still prevalent today and without improved awareness, understanding and acceptance that autism presents for example in women, girls, trans people and people of colour, the cycle will continue to perpetuate. The intersection of autism and gender has revealed many aspects of stigma and marginalisation that effects autistic women's' psycho-emotional needs. Moreover, autistic women report feeling disabled by societal, attitudinal, and structural barriers, as well as experiencing social exclusion within the broader society (Kelly et al., 2022). Access to diagnosis is often gatekept by how the medical model views and understands autism (Kapp, 2019; Lewis, 2016), furthermore, actually obtaining a diagnosis is often the only way that autistic people are able to access support services. We currently do not live in a society that provides access to support based on individual need and fluctuating circumstances, instead a person's needs are met based on whether they have consistently met the correct criteria and ticked the right boxes. For autistic people who are perhaps adept at masking their difficulties, who internalise their problems and display less stereotypical characteristics of restricted and repetitive behaviours, they may face a long wait before they encounter a professional who recognises that they may well indeed be autistic. The consequences of such are far reaching, and as reported in chapter SR, the mental health impacts of such delays for a diagnosis can have a catastrophic impact on the person's mental health.

Despite calls for more inclusive language and the inclusion of strengths-based assessments, screening and diagnostic procedures continue to rely on the identification of ‘deficits’, ‘impairments’ and ‘deviation from normal behaviour’ in order to provide a diagnosis of autism (Singer et al., 2023). It is important to consider the views of autistic people when developing new ways of thinking about, assessing and screening for autism in order to improve access to diagnostic support. The process of developing the FASST was iterative by nature which allowed for autistic people to be involved in the refinement of each item contained within the FASST, and as a result provided the opportunity to re-phrase some of the language used in order to align more with neurodiversity affirming language (Hartman, 2023). For many years now, autistic self-advocates have called for autism researchers to consider autistic perspectives (Sinclair, 1993), with the demand for more emic approaches such as participatory research (Milton et al., 2014), to avoid contributing to stigmatisation in autism which is often a by-product of the etic perspectives frequently utilised in autism research (Bottema-Beutel et al., 2021). In the academic literature, quantitative assessment and research of autism in various contexts dominates the field, often being considered the gold-standard of academic research. In contrast, qualitative research is most published outside of major autism research journals (Crane et al., 2021). Over the years, most research into autism has focused on biological, cognitive, and genetic perspectives, with little attention to lived experiences and areas that impact the daily lives of autistic people (Pellicano et al., 2014). In a recent study, autistic people describe that there is often a mismatch between the research prioritised by funders and the research priorities of autistic people (Roche et al., 2021).

Given that most academics and professionals working in the field of autism ultimately have the goal of improving the quality of life of autistic people and the key people in their lives, it is crucial that the voices and research priorities of autistic people are put to the forefront of autism research. From the viewpoint of ethnographers, (researchers who study cultural phenomena from the viewpoint of the group member), research that does not aim to understand a group of individuals from their cultural surroundings and experiences, in this context autistic people, risk disregarding knowledge that is crucial to the development in our understanding of autism (Malinowski, 1922). Autistic culture refers to the community of autistic people who all share common experiences, values, and beliefs, including their own communication preferences (language), social norms and ideologies. Autistic culture advocates that the neurological differences observed in autism are a natural and valuable part of human diversity (Axbey et al., 2023). Further, autistic culture aims to promote the positivity of autism, in that each autistic person will have their own unique perspectives and strengths and aims to address the challenges faced in a society that may not always accommodate for needs specific to autism. It has been suggested that the use of more neutral terminology within autism research hinders the accurate scientific description of autistic experiences within clinical and medical contexts (Singer et al., 2023). However, many autistic and non-autistic researchers, including other professionals, caregivers and clinicians, challenge the deficit construal's supported by Singer et al. (2023) arguing that the use of inclusive language alternatives are more respectful, inclusive and practical when discussing autistic needs (Natri et al., 2023). Therefore, the importance of accurate screening assessments that makes use of inclusive language, and that is accessible for all genders and individuals who are perhaps more difficult to diagnose due to subtler presentations is far reaching. Not only is it important for the persons self-worth and the development and understanding of their own individual identity, receiving a diagnosis is often the gateway to accessing much needed help and support (Lewis, 2016).

The collective literature seems to suggest that autistic females may be overlooked due to their superior abilities in in communication skills, differences in intensity of interests and camouflaging abilities (McLinden & Sedgewick, 2022; Tsirgiotis et al., 2022). To evolve the way current screening assessments for autism are conducted, it is important that researchers and professionals within the field continue to expand their knowledge and understanding. One such way is through more comprehensive training for both teachers and clinicians (McLinden & Sedgewick, 2022). To advance our understanding of autism, it is crucial to both understand and recognise that knowledge in this field is increasingly evolving. This necessitates actively seeking input from autistic people who hold expertise in their own experiences, and by involving autistic people within research and clinical practice, researchers and professionals can gain valuable insights. Embracing a culture of continuous learning enables the refinement of current screening and diagnostic pathways to ensure they align with the diverse lived realities of autistic people. The potential of gatekeeping, wherein access to a diagnosis is hindered by outdated views of autism, poses a significant barrier for many people seeking an assessment and diagnosis. By promoting a more inclusive and accessible approach to screening, this will allow for a more accurate and equitable assessment process. The future of screening in autism should also include the adoption of more positive language and the inclusion of strengths-based assessments. These screening tools should be developed to accommodate diverse communication styles, sensory needs, and cognitive profiles, ensuring that people from all backgrounds can effectively engage in the assessment process.

8.6. Implications for clinical practice and research

It remains unclear as to whether there really is a bias in screening or diagnostic instruments or whether a lot of missed or misdiagnosis is a result of gender stereotyping or a lack of clinical awareness. This does not mean current diagnostic procedures do not contain bias, rather it is difficult to quantify what is happening through the research data. However, the emerging research highlights an over-arching theme that autistic females are still missed or mis-diagnosed. As a result, this may negatively impact access to appropriate mental health and support services for some. It is suggested that often difficulties are not picked up until women reached adult services and emphasises the call for more awareness of the subtle differences between autistic males and females. It is also likely that these women will not have received any contact with professional services prior to adult services and as a result may display more complex needs (Kanfiszer et al., 2017).

Although our understanding of the female presentation of autism is now beginning to increase, further work to ensure timely identification (Gould & Ashton-Smith, 2011) as well as further education for various professionals in recognising subtle differences in presentation seems vital (Bargiela et al., 2016; Haney., 2016). There needs to be consistent protocols in place to ensure this cohort of individuals do not ‘slip through the net’ and continue to be missed. Lai et al. (2011) suggested the importance of not solely relying on one form of diagnostic assessment such as direct observation and interview, and that further exploration of childhood behaviours as well as self-reports and other psychological reports, will benefit the professional in identifying potentially subtle differences that may otherwise go unnoticed. Further, Lai et al. (2011) recommend that due to hypotheses around camouflaging abilities, assuming judgements based upon initial interviews may not reveal the individuals' true difficulties.

Gould and Ashton-Smith (2011) suggested that within current diagnostic tools, examples are not given on specific difficulties and activities experienced and followed by autistic females and highlighted the importance of taking a much wider perspective during assessment in order to understand their presentations. Further, even when research is conducted into clinical perspectives on sex differences, the question of '*How are females different?'* is not clearly asked and therefore not described in detail within the current findings. Moreover, understanding exactly how females present differently is paramount in supporting the timely identification of autistic females, in particular using the qualitative responses from autistic females and translating these into new questions or measures, may more accurately identify groups of females, males or others who may be harder to diagnose (Jamison et al., 2017). Finally, recommendations for reviewing and reconfiguring diagnostic pathways in order to better recognise autistic women and girls remains important (Seers & Hogg, 2023).

8.6.1. The Utility of the FASST

The potential utility of the FASST is far-reaching in both clinical practice and autism research. The development of a reliable and valid screening tool for harder to diagnose people such as women and girls, holds the potential to improve earlier identification in a range of settings, for example GP services and frontline mental health teams. Providing such professionals with reliable screening tools can support appropriate referrals to diagnostic assessment teams, potentially providing the person with much need access to tailored support. Moreover, the FASST can potentially be used to complement existing diagnostic processes by providing professionals/clinicians with additional information to support decision-making processes associated with referral pathways. Utilising the FASST as an initial method to screen for autism, can assist with the development of a comprehensive background to the person being assessed, and provide detailed areas of autistic characteristics which can determine whether a referral for a full diagnostic assessment is warranted. Given that many professionals, especially within the NHS are often working in high pressured and time restricted environments, the use of a validated tool such as the FASST would not only be time but resource efficient too. Due to the sheer volume of requests for autism assessments coupled with long waiting lists, the use of a potentially efficient tool such as the FASST can support professionals to optimise their time and resources, allowing for more focused evaluations to take place and/or reducing unnecessary referrals to diagnostic services for people who are less likely to be autistic. The FASST was designed to be person-centred and inclusive in capturing more diverse presentations of autism, through the inclusion of autistic people throughout this research process, we have aimed to address potential biases and limitations associated with traditional screening tools.

Our rationale for choosing to develop an informant tool over a self-report tool was considered based on the following reasoning. First, in line with current diagnostic assessments, a diagnosis of autism is given based on observable behaviours and a discussion of a person’s developmental history with someone that knows them well. That is not to say that an autistic person cannot seek a diagnosis if they do not have an informant who knows them well, but current practices do consider the importance of understanding the descriptions of behaviour and detailed history of concerns from a parent/caregiver and/or someone that is able to provide the required information. As such, an informant tool such as the FASST provides an external perspective of a person’s behaviours and characteristic which may be crucial in them being able to access diagnostic pathways. The utilisation of a reliable informant provides potentially helpful accounts of a person’s strengths and challenges and can help minimise potential biases and/or subjective interpretations. Second, the use of an informant-based tool can help to provide a more comprehensive overview of the daily life of a person, considering a holistic view of their strengths and challenges in specific contexts. This might be particularly relevant if the person trying to access a diagnosis has difficulties in recognising and/or reporting their own behaviours and characteristics. Moreover, self-report measures may be limited by a person’s cognitive abilities, language, or communication difficulties and/or challenges in introspection. Notwithstanding, some autistic people may well indeed be able to complete such measures, so future development of the FASST will include a self-report version which can be utilised to compare the findings between the two measures. Finally, many studies in autism research often go to lengths to enhance the reliability and validity of the research by employing the use of diagnostic tools to confirm the presence of autism in their participant sample. However, these assessments are lengthy, and it is anticipated that with further exploration of the FASST’s utility in wider settings, the use of our measure can be used in the future to offer valuable contributions to autism research and established best practices, contributing to the assessment of autism overall within research protocols. However, in contrast, recent research (Taylor et al., 2022) has investigated whether informant report and self-report measures are comparable or provide different sets of information during the screening process. There are limited studies investigating this difference in autism, especially in the adult population. Some studies have found agreement between informant and self-report measures in terms of key autistic characteristics, whilst differences were found in reports of daily living skills and quality of life. The presence of discrepancies between the two types of report, highlight the need for the utilisation of both self and informant reports when building a picture of the autistic person. By not collecting self-report data important information about a person’s experiences and presentations may be missed (Taylor et al., 2022).

8.6.2. Toward a more holistic approach to screening in autism

The development of the FASST for identifying autistic women and girls holds potentially significant clinical implications for improving the screening and diagnostic process and reducing the possibility of diagnostic overshadowing (Tsirgiotis et al., 2022). The findings from the literature highlight significant challenges related to the mental health experiences and conditions in autistic women. Diagnostic overshadowing and the prevalence of mental health conditions preceding an autism diagnosis are important considerations in the development of future screening tools such as the FASST. These issues underscore the urgent need to address the potentially unique mental health profiles of autistic women to ensure that appropriate support and interventions are provided. In line with current research evidence, it seems particularly important that mental health professionals are provided with more specific information as to the potentially unique characteristics of autism in women, and how these characteristics might be interpreted as symptoms of a mental health conditions. More specifically, how can the overlap between autism and the presence of mental health symptoms be better understood. While the development of the FASST necessitates the inclusion of deficit-based questions that align with current diagnostic criteria, it is important to acknowledge that it is not feasible to encompass all items related to mental health with the FASST. Given the considerable overlap in characteristics and symptom presentation between autism and various mental health conditions, it would be challenging to disentangle and capture the nuances of each distinct condition with the FASST alone. However, to provide a more comprehensive understanding of potential mental health symptom presentations and their overlap with autism, the development of a complementary framework for use in clinical settings could be highly valuable. For example, this framework would potentially work alongside the FASST and provide a broader context for assessing and interpreting mental-health related aspects. Moreover, the framework could provide a more thorough overview of a person's presentation, considering both autistic characteristic and the potential impact of co-occurring mental health conditions. For example, recent research has suggested that the high prevalence of suicidality is a serious concern in autistic adults. It raises the importance of mental health and other professionals being alert to signs of suicidality, especially if an autistic person is presenting with depressive symptoms. Depression, rumination, and low-self-esteem are all risk factors and significant efforts need to be made in order to decrease the risk of suicidality (Arwet & Sizoo, 2020). Noteworthy, the concept of rumination and its applicability to autistic women and girls was also suggested as an item for inclusion on the FASST. The item originally was *'She can spend a long-time ruminating'*, however this was further adjusted for ease of explanation to ***'They often spend a long time thinking/worrying about situations'.*** The latter item made it through the subsequent Delphi and PCA evaluations of the FASST suggesting that this item is important in the future use of the FASST, not only because it aligns with the current research, but because this was also further validated through the qualitative explorations of the lived experiences of autistic women.

An area of increasing interest and significance in the field of autism research is the exploration of camouflaging, particularly among autistic women and girls, and its potential impact on accurate diagnosis. As discussed earlier in this thesis, camouflaging has garnered attention due to its potential role in missed or delayed diagnoses, as well as the impact masking strategies may have on mental health and well-being. Given the growing body of research into camouflaging and its implications, it seems vital to discuss this aspect when considering the future utility of the FASST. As the FASST is an informant tool, one potential challenge is the difficulty in detecting camouflaging behaviours. As the FASST would be completed by someone who knows the person being assessed well, they may not always recognise or fully appreciate the presence of camouflaging. Informant based tools such as the FASST rely on the subjective interpretations and awareness of the observer, who may not be aware of the extent to which the person they are reporting on is engaging in camouflaging strategies to mask their autistic traits. As such, this may lead to an underestimation or misinterpretations of the persons true autistic characteristics. To address this issue, it seems reasonable to therefore suggest the importance of pairing the FASST with a tool like the CAT-Q in order to gain a more comprehensive understanding of the interplay between core autistic characteristics and camouflaging behaviours, thereby minimising the risk of missed diagnoses and providing a more accurate assessment. The importance of using self-reported information during assessments also aligns with recent research. For example, Baghdadli et al. (2017) found limited evidence for the measurement properties of current screening tools such as the AQ and RAADS-R when used for adults with a mean normal range of intelligence and suggests the importance of further validation studies as well as the parallel use of self-report tools.

Considering the overall findings of this thesis, it does seem reasonable to suggest that the overall utility of the FASST may carry implications that extend beyond its initial primary function of solely being used as screener to identify autism in the specific population of women and girls. Thus, the overall utility of the FASST may be beneficial in identifying specific needs commonly experienced by women known to be autistic, even in cases where these needs may not strictly align with current diagnostic criteria. In considering the broader implications, the FASST could potentially serve as a valuable framework in delineating and understanding the diverse needs of autistic women, offering a nuanced profile that extends beyond traditional diagnostic criteria.

Whilst the initial focus of this research concerned the development of a specific screening tool, a myriad of additional learning experiences took place which highlighted important dimensions of autistic women's experiences. As discussed throughout, some of the items on the FASST were focused solely on the everyday experiences of what it might be like to be an autistic woman and as such might not necessarily be important for diagnostic purposes, for example, many items may also be relevant to other conditions, but nevertheless are all important questions to be asking when considering the needs of autistic women. It therefore seems reasonable to suggest that the FASST may also be utilised as a broader assessment framework that may highlight the specific strengths, challenges and support requirements that are characteristic of the female autism experience. This potential expanded role of the FASST aligns with our evolving understanding of autism across diverse presentations which acknowledges the importance of tailoring assessments and support strategies to individualised needs.

In summary, what seems to be important in screening for autism is the need for comprehensive and multidimensional approaches that considers both the strengths and limitations of individual assessment measures. Whilst our informant-based tool, the FASST, will provide valuable insights from someone who knows the autistic person well, it may have challenges in detecting camouflaging behaviours and exploration of mental health needs. Therefore, incorporating additional measures, such as self-report tools like the CAT-Q, and considering a gendered framework of mental health experiences, can enhance the accuracy and thoroughness of screening for autism in women and girls. By integrating multiple measures and frameworks, we can move towards a more inclusive and comprehensive approach to autism assessment, potentially reducing the risk of missed or misdiagnosis and better addressing the unique needs of autistic people.

8.6.3. Future Research

The research conducted throughout this thesis has aimed to contribute to the field of autism research, specifically in the contexts of understanding more comprehensively how autism presents in women and girls and by addressing the challenges associated with screening and identifying autism in females. The findings of this research represent an initial step in improving access to diagnostic pathways and the timelier identification of autistic women and girls. When considering future research plans more broadly, there is the need to address specific critical questions surrounding the nature of the FASST and its applicability in diverse contexts. It will be important to investigate further as to whether the FASST distinctly captures a female-specific presentation of autism or if the FASST inherently leans toward a non-gendered, subtle autistic presentation. In other words, is the FASST sensitive enough to be used as a screener to identify the potentially unique characteristic of autism in females and is it specific enough to accurately identify such cases? The answer to this lies in the further exploration of refining the FASST's items and criteria to ensure it is attuned to the nuanced ways in which autism may manifest in females and people who identify as other genders and whether or not there is a need for specific gender categories.

The following suggestions encompass a range of research avenues that include: the continued validation of the FASST across larger samples, the development of a self-report version, including potential versions for the assessment of children, further comparative studies, the incorporation of intersectional perspectives, as well as assessments of impact in real-world clinical settings. Each avenue offers distinct opportunities for the continued expansion of our knowledge of autism, addressing current gaps in knowledge, policy, and practice, as well as the advancement of autism research and clinical practice.

Further validation of the FASST is crucial for the ongoing development and potential use in both clinical and research settings. Although the FASST has shown promising results in the pilot study, further validation is needed in order to establish the FASST's reliability, validity, and utility across more diverse populations and settings. Utilising the FASST in larger scale validation studies involving a significantly larger and diverse sample group will further strengthen the psychometric properties of the FASST. As discussed earlier, our rationale for developing an informant tool first was led by the fact that current diagnostic assessments are also conducted in this way. We also chose to focus on adolescents and adult females as we know from the wider literature that challenges often appear for potentially autistic girls during key transitions such as puberty. Further, we also know that many autistic women are often missed or diagnosed later on in life (Lockwood-Estrin et al., 2021). Equally, the importance of providing autistic people with autonomy to communicate their own perceptions of their needs, challenges and strengths is equally important and warrants the further development of a self-report version of the FASST. Notwithstanding, the utilisation of a tool that can assess all age ranges seems important for consistency, as such the importance of developing the FASST for use in children is an important area for future research. Future comparison studies would also be beneficial in understanding the FASST's effectiveness in assessing autism in women and girls, for example, comparisons to the GQ-ASC in clinical settings. As discussed earlier, a limitation of this research was a lack of diversity within participant samples, nor did we collect data on socioeconomic status or cultural backgrounds. Given the intersectionality of autism with other identities and experiences, future utility of the FASST investigating the influence of factors such as race, ethnicity, gender identity, socioeconomic status, and cultural influence and backgrounds and how these intersect with autistic characteristics and access to diagnostic pathways will be important. Recent research has suggested that autism research has been propagated and overly saturated by the white male identity of autism and as such the experience of black autistic women and girls are completely missing from the medical and educational research (Lovelace et al., 2022). The importance of understanding the intersectional experiences of autistic people is crucial in autism research and can support the development of more inclusive and culturally sensitive approaches to diagnostic assessment and support (Pellicano et al., 2018). Finally, as briefly touched upon in suggestions for comparisons with the GQ-ASC, future research would also benefit from trialling the FASST in clinical settings, perhaps alongside other assessments processes to assess whether or not the FASST is accurately predicting autism prior to the conduct of formal assessment. Conducting research in clinical settings such as GP's, mental health teams or even school environments will support the further evaluation of the FASST's utility and ease of integration within current policy and practice. Additional areas for future research will be suggested within the following section specifically related to the overall limitations of the thesis.

8.7. Overall Limitations of the Thesis

While this thesis has made important contributions to our understanding of autistic women and girls and the development of a new screening tool, the FASST, it is important to acknowledge its inherent limitations more broadly. One notable limitation of this thesis was the small sample sizes across all studies. Aside from the focus groups, we had aimed to have more professionals take part in the Delphi, and in addition we had aimed for a larger sample group for the piloting of the FASST. However, difficulties with recruitment were experienced for both the Delphi and the pilot study. This limited sample size may impact the generalisability of the findings and the ability to detect more nuanced effects. Moreover, throughout this thesis there is a lack of data on participants' ethnicity. The potential lack of diversity in our data means that it is difficult to determine whether our sample was representative of the broader population. Additionally, it was not possible to identify whether there were experiences and characteristics of autism across different ethnic or cultural groups. It is important to acknowledge these sample limitations and recognise the importance for larger and more diverse participant groups in future research in order to enhance the generalisability of our findings. Subsequent validation studies would benefit from involving larger and more diverse samples of participants, including more rigorous psychometric analyses and as such will be able to more closely adhere to Boateng's (2018) complete framework.

As mentioned, the lack of professional involvement throughout the development stages of the FASST is a notable limitation that warrants reflection, particularly concerning the intersection of the phenomenology of autistic people and clinical perspectives. The difficulties with recruitment, particularly the lack of clinicians and diagnosticians working directly with autistic people, meant that the integration of diverse perspectives in the development of the individual items of the FASST was limited. The exploration of the lived experiences of autistic people surrounding missed or misdiagnosis was helpful in developing and refining a large majority of the items contained within the final version of the FASST. However, the limited availability of direct comment from professionals on individual items, potentially limits our understanding of how these first-person narratives align with the diagnostic considerations made by clinicians when assessing people who are potentially autistic.

Clinical perspectives are rooted in many years of practice and diagnostic expertise, and as such, bring a valuable dimension to the discourse on autism. How we define autism has been the centre of much debate and has evolved considerably in recent decades. With that in mind, it is important to consider that the items in the FASST may be an incomplete representation of screening and diagnostic intricacies, potentially overlooking critical aspects that influence the conceptualisation of autism within clinical settings. Moreover, the interplay between the lived experiences of autistic women and screening/diagnostic criteria employed by clinicians is complex and multifaceted and as such, increased involvement from professionals would likely enhance the refinement of the FASST. Future research which involves a more collaborative approach to the development of the FASST, involving professionals from various clinical settings and disciplines could mitigate this limitation.

Another limitation of the thesis was the lack of inclusion of diverse gender identities, including trans people, people who identify as non-binary or other genders, as well as males. The research predominantly focused on the experiences and perspectives of autistic women and girls, although some people who identified as non-binary took part, overall, the full breadth and complexity of gender and an autistic person's lived experience of such, could not be captured. By not including a more diverse range of gender identities, our findings may not adequately reflect the experiences and challenges faced by autistic people across all gender identities. This limitation highlights the need for future research to intentionally include and examine the experiences of autistic people with diverse gender identities. Moreover, it is important to acknowledge that many of the experiences and challenges discussed within this thesis may not be exclusive to females. It would be valuable to explore the experiences of men who have received a late diagnosis of autism and examine whether they have similar autistic characteristics, presentations, and challenges as their female counterparts. This exploration could help determine the potential relevance and applicability of the FASST beyond just female, expanding its utility and impact to a broader population of autistic people. As described previously, exploring intersectionality in future research across a diverse range of participants, will be important in not only validating the use of the FASST more broadly, but may also the development of a more comprehensive understanding of the similarities and differences in the experiences of autistic people across all gender identities.

A further notable limitation within these studies were the absence of confirmed diagnoses of autism. This was a deliberate decision based on the recognition that long waiting times both to access diagnostic pathways, as well as diagnostic assessments can result in people experiencing significant delays in receiving an official diagnosis. To be inclusive and capture the experiences of people who may have been overlooked by current diagnostic criteria and screening tools, the research studies therefore included people who self-identified as autistic, regardless of whether they had a formal diagnosis (Lewis, 2016). However, it is important to then acknowledge that relying solely on self-identification, introduces a level of uncertainty in terms of the accuracy and consistency of the participants autism status. Future research should strive to find a balance between confirming a diagnosis of autism, whilst also being sensitive to the challenge and limitations of current assessment practices.

Lastly, a critical limitation of the overall thesis lies in the distinction between a collaborative approach and true co-production. Whilst the focus groups, Delphi and pilot made deliberate efforts to involved autistic people and other key stakeholders throughout the development of the FASST, it is important to acknowledge that the research did not fully meet the criteria of co-production. As highlighted in chapter 4, co-production entails the active involvement and decision-making power of autistic people in shaping the research agenda, methodology, and outcomes. This level of involvement often requires dedicated resources and funding to employ an autistic advisory board or research team members who can actively contribute and guide the research process. Unfortunately, this was outside of the remit of this PhD, whilst efforts were made to incorporate the perspectives and insights of autistic people, the decision-making power was ultimately retained by the researchers. In future development and refinement of the FASST, it will be crucial to strive for true co-production which ensures autistic people, and their insights are integrated into all stages of the study design, data collection, analysis and dissemination.

8.8. Concluding Comments

Overall, this thesis has made an important contribution to the field of autism research by focusing on the development of a screening tool specifically designed for identifying autism in women and girls. Throughout the systematic review, focus groups, Delphi consultation, and pilot study, valuable insights were gained into the experiences and characteristics of autistic women and girls. The involvement and collaboration of autistic people throughout each study has been crucial in shaping the FASST and as such is an important first step towards true co-production and the development of a more comprehensive approach to screening processes for autistic people. One of the strengths of this research lies in its comprehensive exploration of the experiences and perspectives of autistic women. The systematic review synthesised what was currently understood about autistic adults and adolescents and identified specific areas of interest that informed the addition of new items to the FASST. The focus groups and Delphi consultation further refined the FASST, incorporating the unique insights and perspectives provided by autistic women and other key stakeholders. The pilot study served as a critical phase in assessing the initial reliability, validity, and psychometric properties of the FASST. The results demonstrated promising outcomes, indicating its future potential in accurately identifying autism in women and girls. Moreover, the FASST has clinical implications for frontline services involved in the identification and support of autistic people, such as schools, mental health teams and GPs. The FASST offers a potentially valuable resource for clinicians and professionals working within these settings as it provides a comprehensive approach to assessing autism in women and girls. However, it is important to acknowledge that the FASST is not yet ready for widespread use in clinical or educational settings and that further validation and testing on a larger and more diverse sample are necessary to establish its reliability, validity and generalisability. Nevertheless, this thesis represents an important advancement in our understanding of how screening and assessment of autism can be improved.

The collaborative and inclusive approach throughout the research process sets a standard for future studies aiming to develop assessment tools that capture the diverse experiences and presentations of autistic people. Incorporating the voices and perspectives of autistic people is essential for promoting equitable and person-centred research practices. Moving forward, further research is needed to expand the utility of the FASST to ensure the experiences of people who present less stereotypically including other gender identities, are included and to explore the cultural applicability of the FASST. Ongoing efforts in co-production and collaboration with autistic people will continue to advance our knowledge, refine screening and diagnostic practices and foster inclusivity in autism research. In conclusion, the FASST has the future potential to enhance the identification process of autistic people who are perhaps harder to diagnose due to less stereotypical presentations of autism, minimise diagnostic overshadowing, and facilitate more timely access to appropriate support and interventions. By acknowledging and actively addressing the distinct barriers and experiences encountered by autistic people, we can work towards a more inclusive society that values neurodiversity, promoting inclusivity and equality for all.

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Appendices

Appendix 1:
Prospero
Submission
for
Systematic
Review

UNIVERSITY of York
Centre for Reviews and Dissemination

PROSPERO

Systematic review

1. * Review title.

Give the working title of the review, for example the one used for obtaining funding. Ideally the title should state succinctly the interventions or exposures being reviewed and the associated health or social problems. Where appropriate, the title should use the PI(E)COS structure to contain information on the Participants, Intervention (or Exposure) and Comparison groups, the Outcomes to be measured and Study designs to be included.

The experiences and behavioural presentations of autistic females: a systematic review

2. Original language title.

For reviews in languages other than English, this field should be used to enter the title in the language of the review. This will be displayed together with the English language title.

3. * Anticipated or actual start date.

Give the date when the systematic review commenced, or is expected to commence.

30/07/2017

4. * Anticipated completion date.

Give the date by which the review is expected to be completed.

01/07/2020

5. * Stage of review at time of this submission.

Indicate the stage of progress of the review by ticking the relevant Started and Completed boxes. Additional information may be added in the free text box provided.

initial registration are not eligible for inclusion in PROSPERO. Should evidence of incorrect status and/or completion date being supplied at the time of submission come to light, the content of the PROSPERO record will be removed leaving only the title and named contact details and a statement that inaccuracies in the stage of the review date had been identified.

publication of the review. If this field was pre-populated from the initial screening questions then you are not able to edit it until the record is published.

The review has not yet started: No

Review stage	**Started**	**Completed**
Preliminary searches	Yes	No
Piloting of the study selection process	Yes	No
Formal screening of search results against eligibility criteria	Yes	No
Data extraction	No	No
Risk of bias (quality) assessment	No	No
Data analysis	No	No

Provide any other relevant information about the stage of the review here (e.g. Funded proposal, protocol not yet finalised).

6. * Named contact.

The named contact acts as the guarantor for the accuracy of the information presented in the register record.

Lizzie Gale

Email salutation (e.g. "Dr Smith" or "Joanne") for correspondence:

Miss Gale

7. * Named contact email.

Give the electronic mail address of the named contact.

eeg6@kent.ac.uk

8. Named contact address

Give the full postal address for the named contact.

Tizard Centre, University of Kent, Cornwallis Northeast, Canterbury, Kent, CT2 7NZ

9. Named contact phone number.

Give the telephone number for the named contact, including international dialling code.

07900806447

10. * Organisational affiliation of the review.

Full title of the organisational affiliations for this review and website address if available. This field may be completed as 'None' if the review is not affiliated to any organisation.

University of Kent

Organisation web address:

https://www.kent.ac.uk/social-policy-sociology-social-research/tizard

11. * Review team members and their organisational affiliations.

Give the personal details and the organisational affiliations of each member of the review team. Affiliation refers to groups or organisations to which review team members belong. **NOTE: email and country are**

Miss Lizzie Gale. University of Kent
Dr Jill Bradshaw. University of Kent

Dr Fiona Gullon-Scott. University of Kent

12. * Funding sources/sponsors.

Give details of the individuals, organizations, groups or other legal entities who take responsibility for initiating, managing, sponsoring and/or financing the review. Include any unique identification numbers assigned to the review by the individuals or bodies listed.

This review forms part of my PhD; I received the University of Kent, Tizard Centre's Scholarship

None.

Grant number(s)

13. * Conflicts of interest.

List any conditions that could lead to actual or perceived undue influence on judgements concerning the main topic investigated in the review.

None

14. Collaborators.

Give the name and affiliation of any individuals or organisations who are working on the review but who are not listed as review team members. **NOTE: email and country are now mandatory fields for each**

15. * Review question.

State the question(s) to be addressed by the review, clearly and precisely. Review questions may be specific or broad. It may be appropriate to break very broad questions down into a series of related more specific questions. Questions may be framed or refined using PI(E)COS where relevant.

There is currently little consensus regarding the female presentation of autism and findings are inconsistent within the research. It is suggested within the literature that females may present with an altered presentation of autism that does not fit within current male-based conceptualisations and established diagnostic criteria (Kirkovski et al., 2013). Given that the majority of research into sex differences in autism has involved children (Rivet & Matson, 2011b), this systematic review aims to review the recent research in order ascertain what autism looks like in adolescent and adult females with particular reference to experiences and behavioural presentations. This information will then be used to inform the development of a Female Autism Screening Tool.

16. * Searches.

State the sources that will be searched. Give the search dates, and any restrictions (e.g. language or publication period). Do NOT enter the full search strategy (it may be provided as a link or attachment.)

The review will be conducted using computerised searches of the following databases: Web of Science, Academic Search Completed, MEDLINE and PsycINFO.

All dates will be searched.

I will exclude papers that are not published in English, are not peer-reviewed and if Full Text is not available.

17. URL to search strategy.

Give a link to a published pdf/word document detailing either the search strategy or an example of a search strategy for a specific database if available (including the keywords that will be used in the search strategies), or upload your search strategy.Do NOT provide links to your search results.

https://www.crd.york.ac.uk/PROSPEROFILES/164621_STRATEGY_20200326.pdf

Alternatively, upload your search strategy to CRD in pdf format. Please note that by doing so you are consenting to the file being made publicly accessible.

Do not make this file publicly available until the review is complete

18. * Condition or domain being studied.

Give a short description of the disease, condition or healthcare domain being studied. This could include health and wellbeing outcomes.

Autism Spectrum Conditions / Autism Spectrum Disorder

19. * Participants/population.

Give summary criteria for the participants or populations being studied by the review. The preferred format includes details of both inclusion and exclusion criteria.

Adolescent and Adult Females with Autism Spectrum Conditions

20. * Intervention(s), exposure(s).

Give full and clear descriptions or definitions of the nature of the interventions or the exposures to be reviewed.

We will be looking at the experiences and behavioural presentations of autistic females; this will include their experiences particularly with the diagnostic process. Anecdotal evidence has shown thus far that a high number of autistic women have either been missed or mis-diagnosed. The use of specialised diagnostic instruments to detect autism will be focused upon, paying particular interest to any adaptions made to these instruments and how they might be used in clinical practice. Further, anecdotal evidence also shows that many currently used diagnostic tools are not tailored to a female presentation and therefore may be a reason why autistic women and girls are under-identified. Autistic women and girls are also underrepresented in current autistic literature, an overall aim of the review being that we want to find out exactly what is out there within the current evidence base for this particular cohort.

21. * Comparator(s)/control.

Where relevant, give details of the alternatives against which the main subject/topic of the review will be compared (e.g. another intervention or a non-exposed control group). The preferred format includes details

We are looking specifically at methods used to diagnose autistic women and girls and their personal

experiences of such. We are looking to understand what diagnostic tools have been used, if any, what these tools have shown in relation to autistic women and girls and whether or not this is an accurate representation of their real life experience of the diagnostic process.

22. * Types of study to be included.

Give details of the types of study (study designs) eligible for inclusion in the review. If there are no restrictions on the types of study design eligible for inclusion, or certain study types are excluded, this should be stated. The preferred format includes details of both inclusion and exclusion criteria.

We will include both quantitative and qualitative papers that are focusing on sex differences in autism; studies will be excluded if they are not peer reviewed, are not written in English, if the article is a review paper and if full text was not available. Studies that focus on genetics, brain imaging or cognition will also be excluded.

23. Context.

Give summary details of the setting and other relevant characteristics which help define the inclusion or exclusion criteria.

This is applicable to autistic women and girls, measures used across a variety of contexts including educational, health and social care settings.

24. * Main outcome(s).

Give the pre-specified main (most important) outcomes of the review, including details of how the outcome is defined and measured and when these measurement are made, if these are part of the review inclusion criteria.

The primary aim of this systematic review is to draw together the literature on both the experiences and behavioural presentations of autistic women and girls but furthermore to draw conclusions on why this particular cohort continues to be missed or mis-diagnosed. Studies that have researched the topic of sex differences within autism have remained ambiguous, with research methodologies differing in both their quality and rigour. Within both the scientific evidence base as well as anecdotal reports, it is suggested that there is subtle but important differences in autistic presentations between the sexes. In order to disseminate information on potentially important descriptors of autistic women and girls, a thorough review of the literature is needed. This will help inform clinical practice. Furthermore, it is reasonable to suggest based on the evidence so far that a female specific screening tool may be useful in the identification of autistic women and girls; therefore the information gleaned from the review will be used to develop such a tool.

* Measures of effect

Please specify the effect measure(s) for you main outcome(s) e.g. relative risks, odds ratios, risk difference, and/or 'number needed to treat.

This is not a meta-analytic study therefore we are not calculating measures of effect size.

25. * Additional outcome(s).

List the pre-specified additional outcomes of the review, with a similar level of detail to that required for main outcomes. Where there are no additional outcomes please state 'None' or 'Not applicable' as appropriate

None.

* Measures of effect

Please specify the effect measure(s) for you additional outcome(s) e.g. relative risks, odds ratios, risk difference, and/or 'number needed to treat.

Not applicable

26. * Data extraction (selection and coding).

Describe how studies will be selected for inclusion. State what data will be extracted or obtained. State how this will be done and recorded.

Study Selection: The lead researcher will fully screen all retrieved search results. A second reviewer will then check and report on decisions. For quality assessment of each paper included, the lead researcher will complete a full assessment, the second reviewer will then assess a percentage of the papers and will be blinded to the lead researchers decisions. Disagreements will be resolved through discussions and further review; decisions will also be discussed during the lead researchers supervisions. If a disagreement is still not resolved, a further discussion with joint supervisors will take place. All decisions and ratings will be recorded in Excel.

Data Extraction: The lead researcher will extract all of the relevant data. This data will include: the number of participants, study aims, methodology and study design, and key findings. Papers will be read and analysed using a thematical analysis approach. The lead researcher will identify key themes and these will be discussed within the research team. Co-supervisors will check the log of extracted data via Excel.

27. * Risk of bias (quality) assessment.

Describe the method of assessing risk of bias or quality assessment. State which characteristics of the studies will be assessed and any formal risk of bias tools that will be used.

Due to the range of methodological approaches within the literature on autistic women and girls, a quality assessment tool designed to review mixed method approaches has been identified. The Quality Assessment Tool for Studies with Diverse Designs (QATSDD; Sirriyeh, Lawton, Gardner & Armitage, 2012) will be used to assess the methodological quality of the included studies. The QATSDD includes 16 items applicable to quantitative and qualitative studies and will be rated on a four-point scale: 'not at all" (0), 'very slightly' (1), 'moderately' (2) and 'complete' (3). A summary of full scores and their derived percentages will be reported via a spreadsheet in Excel.

For quality assessment of each paper included, the lead researcher will complete a full assessment, the second reviewer will then assess a percentage of the papers and will be blinded to the lead researchers decisions. Disagreements will be resolved through discussions and further review; decisions will also be discussed during the lead researchers supervisions. If a disagreement is still not resolved, a further

discussion with joint supervisors will take place. All decisions and ratings will be recorded in Excel.

28. * Strategy for data synthesis.

Provide details of the planned synthesis including a rationale for the methods selected. This **must not be generic text** but should be **specific to your review** and describe how the proposed analysis will be applied to your data.

Due to the vast amount of differing opinions in the literature detailing the experiences of autistic women and girls, a thematic approach will be used in order to synthesis the information accurately. A thematic approach will allow us to identify broad themes across a large, varying and complex data set.

Information from the included papers will be extracted and then analysed using Thematic Analysis. We will be expecting to extract data from a wide range of experiences of autistic women and girls, including their pathways to diagnosis and the tools used to assess and diagnose. We are looking to build a picture across a broad range of topics in order to justify why a new female specific screening tool is needed.

The quantitative literature differs greatly to that of the lived experiences of autistic women and girls thus, the importance of this review is to therefore synthesise the data and derive links between the two. Both areas are of equal importance however a synthesis between the two will provide us with a firm evidence base to report key areas of importance.

Key themes will then be reported and discussed with specific reference to the importance of disseminating this information to research professionals, clinical teams etc; so that the amount of missed or mis-diagnosed women and girls can be reduced.

29. * Analysis of subgroups or subsets.

State any planned investigation of ‘subgroups’. Be clear and specific about which type of study or participant will be included in each group or covariate investigated. State the planned analytic approach.

In this review we will be investigating the experiences and behavioural presentations of both autistic adolescents and adults. Their autistic presentation may present differently and will therefore be presented and discussed accordingly.

30. * Type and method of review.

Select the type of review and the review method from the lists below. Select the health area(s) of interest for your review.

Type of review

Cost effectiveness
No

Diagnostic
No

Epidemiologic

No

Individual patient data (IPD) meta-analysis
No

Intervention
No

Meta-analysis
No

Methodology
No

Narrative synthesis
No

Network meta-analysis
No

Pre-clinical
No

Prevention
No

Prognostic
No

Prospective meta-analysis (PMA)
No

Review of reviews
No

Service delivery
No

Synthesis of qualitative studies
No

Systematic review
Yes

Other
No

Health area of the review

Alcohol/substance misuse/abuse
No

Blood and immune system
No

Cancer
No

Cardiovascular
No

Care of the elderly
No

Child health
No

Complementary therapies
No

COVID-19
No

Crime and justice

No

Dental
No

Digestive system
No

Ear, nose and throat
No

Education
No

Endocrine and metabolic disorders
No

Eye disorders
No

General interest
No

Genetics
No

Health inequalities/health equity
No

Infections and infestations
No

International development
No

Mental health and behavioural conditions
Yes

Musculoskeletal
No

Neurological
No

Nursing
No

Obstetrics and gynaecology
No

Oral health
No

Palliative care
No

Perioperative care
No

Physiotherapy
No

Pregnancy and childbirth
No

Public health (including social determinants of health)
No

Rehabilitation
No

Respiratory disorders
No

Service delivery
No

Skin disorders
No

Social care
No

Surgery
No

Tropical Medicine
No

Urological
No

Wounds, injuries and accidents
No

Violence and abuse
No

31. Language.

Select each language individually to add it to the list below, use the bin icon to remove any added in error.
English

There is not an English language summary

32. * Country.

Select the country in which the review is being carried out from the drop down list. For multi-national collaborations select all the countries involved.

England

33. Other registration details.

Give the name of any organisation where the systematic review title or protocol is registered (such as with The Campbell Collaboration, or The Joanna Briggs Institute) together with any unique identification number assigned. (N.B. Registration details for Cochrane protocols will be automatically entered). If extracted data will be stored and made available through a repository such as the Systematic Review Data Repository (SRDR), details and a link should be included here. If none, leave blank.

34. Reference and/or URL for published protocol.

Give the citation and link for the published protocol, if there is one

Give the link to the published protocol.

Alternatively, upload your published protocol to CRD in pdf format. Please note that by doing so you are consenting to the file being made publicly accessible.

No I do not make this file publicly available until the review is complete

Please note that the information required in the PROSPERO registration form must be completed in full even if access to a protocol is given.

35. Dissemination plans.

Give brief details of plans for communicating essential messages from the review to the appropriate audiences.

The Systematic Review will form part of the Lead Researchers thesis for the award of Doctor of Philosophy

(PhD). It will be presented at various conferences both in the UK and internationally. The findings will also be presented to local and national charities to raise awareness of the female presentation of autism.

Do you intend to publish the review on completion?

Yes

36. Keywords.

Give words or phrases that best describe the review. Separate keywords with a semicolon or new line. Keywords will help users find the review in the Register (the words do not appear in the public record but are included in searches). Be as specific and precise as possible. Avoid acronyms and abbreviations unless these are in wide use.

Autism; ASD; ASC; Females; Women; Girls; Behavioural; Experiences; Phenotype

37. Details of any existing review of the same topic by the same authors.

Give details of earlier versions of the systematic review if an update of an existing review is being registered, including full bibliographic reference if possible.

38. * Current review status.

Review status should be updated when the review is completed and when it is published. For newregistrations the review must be Ongoing.

Review_Ongoing

39. Any additional information.

Provide any other information the review team feel is relevant to the registration of the review.

Due to the Lead Researchers disability and ongoing health conditions, a formal intermission was taken during the period of initial design of this protocol. The intermission was taken before any data was fully extracted and now post-intermission the Lead Researcher is now in a position to complete the full systematic review.

**UPDATE - 26/03/202. Apologies for the delay in being able to edit and send changes back to you; I have been self-isolating and unwell due to coronavirus and have only just resumed my work.

Further to your queries in your email dated 14.02.2020 I have made the below amendments for your consideration:

- 16: amended correctly detailing sources, dates and restrictions and have also uploaded a PDF of an example search strategy.
- 20 and 21: additional information has been provided on intervention and comparators
- 24: more detailed outcomes of the review have been explained
- 28: data synthesis has been explained in more detail.

Thank you, Elisabeth Gale.

40. Details of final report/publication(s) or preprints if available.

This field should be left empty until details of the completed review are available OR you have a link to a preprint.

Give the link to the published review.

Appendix 2: Development of the FASST

2.1. Original Version of the FASST – Version 1

FASST (Female Autism Spectrum Screening Tool)

Draft 23 May 2013

(Adolescent to adult, no LD)

Informant questionnaire: Informant to have known person well for at least 3 months, preferably over several years (e.g., parent, friend, partner, sibling)

Choose one option for each statement, based on consistency over the time you have known the person. That is, the response that describes her best since you have known her.

		Rarely/Never True	**Sometimes True**	**True Most of the Time**	**Don't Know**
1	She is able to chat about anything with you.				
2	She is good at listening to others.				
3	She enjoys meeting new people.				
4	When other people meet her they find her really easy to talk to.				
5	She can join in easily with group chats, when more than three people are talking together.				
6	She will always show consideration for other people.				
7	She is careful not to say things that could cause offence.				
8	She will often do things that others think are rude or inappropriate.				
9	She has several people who would call her a real 'friend'.				
10	She has at least one friend that she has stayed in touch with and regularly communicates with, whom she has known for years.				
11	When she does things, she is considerate of the impact on other people's feelings.				
12	She has excessively intense attachments to others that are not reciprocated.				
13	She has at least one close relationship that seems genuinely shared.				

14	She tends to have lots of fleeting relationships.				
15	It is easy to feel a comfortable connection with her.				
16	She is able to adjust her behaviour in different social situations.				
17	She seems particularly socially naive for her age.				
18	When other people meet her, they find it easy to get on with her.				
19	She tends to be quiet and does not initiate.				
20	She tends to be outgoing and sociable.				
21	She is highly organised and likes lists, special arrangement of objects, or ordering things.				
22	She has specific routines that she HAS to stick to or she becomes upset.				
23	She has really focussed interests or passions which she will spend hours pursuing.				
24	Her interests can lead to her neglecting other activities or duties.				
25	She prefers social and shared activities and interests .				
26	She prefers solo activities and interests which she can do on her own.				
27	She seems excessively bothered by noises that do not bother others.				
28	She has excessively intense dislike of specific textures, tastes, or smells.				
29	She becomes anxious and upset when something unexpected happens.				
30	She has an explosive temper that comes out of nowhere.				
31	She is a really calm, content person.				
32	Other people think she takes things too literally.				
33	She doesn’t seem to understand subtle social cues.				
34	She can rage, or cry, or laugh with little apparent trigger.				

35	She complains of feeling different to other people.				
36	She seems very anxious compared to others.				
37	She seems really calm and confident compared to others.				
38	When people meet her they find her engaging and friendly.				
39	She has always had a great fashion sense.				
40	She has at least one really intense or obsessive interest.				
41	She is really easy-going and flexible.				
42	She has really low self-esteem.				
43	She doesn’t seem to pick up on other people’s feelings or intentions.				
44	She seems to stare too long at people and this makes her seem hostile or intense.				
45	She doesn’t hold your eye when she talks to you.				
46	She can really express herself clearly through gesture and intonation.				
47	It is always easy to tell how she is feeling just by her facial expressions.				
48	She can easily pick up on and respond appropriately to other people’s feelings.				

Appendix 2.2: FASST Version 2 – Post Systematic Review

		Rarely/Never True	**Sometimes True**	**True Most of the Time**	**Don't Know**
1	She is able to chat about anything with you.				
2	She is good at listening to others.				
3	She enjoys meeting new people.				
4	When other people meet her they find her really easy to talk to.				
5	She can join in easily with group chats, when more than three people are talking together.				
6	She will always show consideration for other people.				
7	She is careful not to say things that could cause offence.				
8	She will often do things that others think are rude or inappropriate.				
9	She has several people who would call her a real 'friend'.				
10	She has at least one friend that she has stayed in touch with and regularly communicates with, whom she has known for years.				
11	When she does things, she is considerate of the impact on other people's feelings.				
12	She has excessively intense attachments to others that are not reciprocated.				
13	She has at least one close relationship that seems genuinely shared.				
14	She tends to have lots of fleeting relationships.				
15	It is easy to feel a comfortable connection with her.				
16	She is able to adjust her behaviour in different social situations.				
17	She seems particularly socially naive for her age.				
18	When other people meet her, they find it easy to get on with her.				

19	She tends to be quiet and does not initiate.				
20	She tends to be outgoing and sociable.				
21	She is highly organised and likes lists, special arrangement of objects, or ordering things.				
22	She has specific routines that she HAS to stick to or she becomes upset.				
23	She has really focussed interests or passions which she will spend hours pursuing.				
24	Her interests can lead to her neglecting other activities or duties.				
25	She prefers social and shared activities and interests .				
26	She prefers solo activities and interests which she can do on her own.				
27	She seems excessively bothered by noises that do not bother others.				
28	She has excessively intense dislike of specific textures, tastes, or smells.				
29	She becomes anxious and upset when something unexpected happens.				
30	She has an explosive temper that comes out of nowhere.				
31	She is a really calm, content person.				
32	Other people think she takes things too literally.				
33	She doesn’t seem to understand subtle social cues.				
34	She can rage, or cry, or laugh with little apparent trigger.				
35	She complains of feeling different to other people.				
36	She seems very anxious compared to others.				
37	She seems really calm and confident compared to others.				
38	When people meet her they find her engaging and friendly.				
39	She has always had a great fashion sense.				

40	She has at least one really intense or obsessive interest.				
41	She is really easy-going and flexible.				
42	She has really low self-esteem.				
43	She doesn’t seem to pick up on other people’s feelings or intentions.				
44	She seems to stare too long at people and this makes her seem hostile or intense.				
45	She doesn’t hold your eye when she talks to you.				
46	She can really express herself clearly through gesture and intonation.				
47	It is always easy to tell how she is feeling just by her facial expressions.				
48	She can easily pick up on and respond appropriately to other people’s feelings.				
49	***She feels exhausted after social situations***				
50	***She has difficulty managing conflict***				
51	***She experiences difficulties developing and maintaining friendships***				
52	***She is able to engage in ‘small talk’***				
53	***She finds it easier to form friendships with males***				
54	***She has more shared interests with males and may be described as a ‘tomboy’***				
55	***She experiences high levels of stress***				
56	***She is skilful at imitating the behaviours of others around her***				
57	***She uses online platforms to develop and maintain friendships***				
58	***She experiences difficulties with romantic relationships***				
59	***She experiences difficulties with school work***				
60	***She experiences difficulties with employment***				
61	***She expresses feelings of loneliness and isolation***				
62	***She experiences bullying***				
63	***She feels pressured to fit in with the social expectations of ‘being female’***				

64	***She experiences mental health conditions***				
65	***Adolescence is/was a difficult period***				

Appendix 2.3: FASST Version 3 – Post Focus Groups

		Rarely/Never True	**Sometimes True**	**True Most of the Time**	**Don't Know**
1	She is able to chat about anything with you.				
2	She is good at listening to others.				
3	She enjoys meeting new people.				
4	When other people meet her they find her really easy to talk to.				
5	She can join in easily with group chats, when more than three people are talking together.				
6	She will always show consideration for other people.				
7	She is careful not to say things that could cause offence.				
8	She will often do things that others think are rude or inappropriate.				
9	She has several people who would call her a real 'friend'.				
10	She has at least one friend that she has stayed in touch with and regularly communicates with, whom she has known for years.				
11	When she does things, she is considerate of the impact on other people's feelings.				
12	She has excessively intense attachments to others that are not reciprocated.				
13	She has at least one close relationship that seems genuinely shared.				
14	She tends to have lots of fleeting relationships.				
15	It is easy to feel a comfortable connection with her.				
16	She is able to adjust her behaviour in different social situations.				
17	She seems particularly socially naive for her age.				
18	When other people meet her, they find it easy to get on with her.				

19	She tends to be quiet and does not initiate.				
20	She tends to be outgoing and sociable.				
21	She is highly organised and likes lists, special arrangement of objects, or ordering things.				
22	She has specific routines that she HAS to stick to or she becomes upset.				
23	She has really focussed interests or passions which she will spend hours pursuing.				
24	Her interests can lead to her neglecting other activities or duties.				
25	She prefers social and shared activities and interests .				
26	She prefers solo activities and interests which she can do on her own.				
27	She seems excessively bothered by noises that do not bother others.				
28	She has excessively intense dislike of specific textures, tastes, or smells.				
29	She becomes anxious and upset when something unexpected happens.				
30	She has an explosive temper that comes out of nowhere.				
31	She is a really calm, content person.				
32	Other people think she takes things too literally.				
33	She doesn’t seem to understand subtle social cues.				
34	She can rage, or cry, or laugh with little apparent trigger.				
35	She complains of feeling different to other people.				
36	She seems very anxious compared to others.				
37	She seems really calm and confident compared to others.				
38	When people meet her they find her engaging and friendly.				
39	She has always had a great fashion sense.				

40	She has at least one really intense or obsessive interest.				
41	She is really easy-going and flexible.				
42	She has really low self-esteem.				
43	She doesn’t seem to pick up on other people’s feelings or intentions.				
44	She seems to stare too long at people and this makes her seem hostile or intense.				
45	She doesn’t hold your eye when she talks to you.				
46	She can really express herself clearly through gesture and intonation.				
47	It is always easy to tell how she is feeling just by her facial expressions.				
48	She can easily pick up on and respond appropriately to other people’s feelings.				
49	She feels exhausted after social situations				
50	She has difficulty managing conflict				
51	She experiences difficulties developing and maintaining friendships				
52	She is able to engage in ‘small talk’				
53	She finds it easier to form friendships with males				
54	She has more shared interests with males and may be described as a ‘tomboy’				
55	She experiences high levels of stress				
56	She is skilful at imitating the behaviours of others around her				
57	She uses online platforms to develop and maintain friendships				
58	She experiences difficulties with romantic relationships				
59	She experiences difficulties with school work				
60	She experiences difficulties with employment				
61	She expresses feelings of loneliness and isolation				
62	She experiences bullying				
63	She feels pressured to fit in with the social expectations of ‘being female’				

64	She experiences mental health conditions				
65	Adolescence is/was a difficult period				
66	***She is always direct, blunt and to the point***				
67	***She is described as overbearing and/or intense***				
68	***She has a smaller number of friends that she trusts***				
69	***She is very conscious of her impact on her environment***				
70	***She has intense attachments to objects***				
71	***She has intense attachments to animals***				
72	***She has an intense reaction to things on the TV that others find acceptable***				
73	***She has difficulties with proprioception***				
74	***She is sensitive to temperature***				
75	***She has difficulties understanding her own emotions***				
76	***She is a content person***				
77	***She has a strong sense of justice, of right and wrong and seeking the truth***				
78	***Other people think she can take things too seriously***				
79	***She can easily pick up on other people's feelings***				
80	***She can spend a long time ruminating***				
81	***She has difficulties understanding boundaries in relationships***				
82	***Does she isolate herself from others***				
83	***Do people complain about how she treats others***				

Appendix 2.4: FASST Version 4 – Post Delphi (Version used in Pilot)

	FASST Item
1	They can join in easily with face to face chats, when more than three people are talking together
2	They can easily adjust their behaviour in different social situations without difficulty
3	They mostly prefer solo activities and interests which they can do on their own
4	They can take things literally
5	They do not seem to understand subtle social cues
6	They often appear exhausted after some social interactions
7	They have difficulty managing conflict
8	They have difficulties developing friendships
9	They have difficulties maintaining friendships
10	They can take things too seriously
11	They sometimes have difficulties understanding boundaries in relationships
12	They sometimes do things that others think are rude or inappropriate without understanding why this has caused offence
13	They are skilful at imitating the behaviours of others around them
14	They are usually direct, blunt and to the point
15	They can be controlling and/or intense
16	They have friendships with people that are not always reciprocated to the same extent
17	They can easily respond appropriately to other people's feelings
18	They find it easy to maintain and engage in 'small talk'
19	They enjoy 'small talk'
20	They have a small number of people that they trust
21	They feel comfortable meeting new people
22	They tend to have short-lived relationships due to difficulties in maintaining relationships
23	They have at least one close relationship outside of the household/family that seems genuinely shared
24	They have a few close friends rather than a large and varied group of friends
25	They can be distressed, distracted or overwhelmed by noises that do not bother others
26	They can be under or over responsive to sensations e.g. specific textures, tastes, smells or temperatures
27	They are usually able to sense the movement and position of their body
28	They are often stressed
29	They experience or previously experienced mental health conditions
30	They are often anxious
31	They often appear lonely and/or isolated
32	They experience or previously experienced bullying
33	They often spend a long time thinking/worrying about situations
34	They sometimes seem to isolate themselves from others
35	They talk about feeling like they are different to other people
36	They often have low self-esteem
37	They have a set way of doing things such as careful arrangement of objects and/or organise things systematically e.g. lists
38	They may find it difficult if they cannot follow specific routines or unexpected changes occur
39	They can spend long periods of time focused on a particular activity
40	Their interests can lead to them forgetting other activities or duties
41	They become anxious, upset and/or unsettled when something unexpected happens
42	They have a strong sense of justice, of right and wrong and seeking the truth
43	They have at least one intense interest at any one time
44	They can rage, cry or laugh with little apparent trigger
45	They have intense attachments which may include specific objects and/or animals
46	They sometimes experience intense emotional reactions to things they hear or see (e.g. things on the tv, newspapers and social media), which others may not share

47	Other people sometimes raise/have concerns about how they treat others
48	They do not always pick up easily on other people’s intentions
49	They sometimes seem socially naïve for their age
50	They sometimes have difficulty understanding or describing their own emotions
51	They often find it difficult to notice or understand other people’s emotions
52	When they do things, they often do not think of the impact on other people’s feelings
53	They often do not understand when or why they have caused offence
54	Adolescence is/was a noticeably difficult period
55	They experience difficulties or are likely to experience difficulties with employment
56	It is always easy to tell how they are feeling just by their facial expressions
57	They experience difficulties or previously experienced difficulties with school
58	They find it difficult to predict how other people will feel or respond

Appendix 3: Focus Groups

Appendix 3.1: Ethical Approval – for both Focus Groups and Delphi

TIZARD
University of Kent

Tizard Ethics Feedback Form

Student Name:	Lizzie Gale
Supervisor:	Dr Jill Bradshaw, Dr Fiona Gullon-Scott & Prof Peter Langdon
Title:	*"Developing a screening tool for autism spectrum conditions (ASC); a Delphi consultation and focus groups"*

The Tizard Ethics Committee have considered the above proposal and understand that the amendments have been approved by the Supervisors. This proposal now has ethical approval.

Signed: J.Ruffels **Date: 15.05.18**

On behalf of Tizard Ethics Committee

Alterations approved by Supervisor	**Signature**	**Date**
Final approval On behalf of Tizard Ethics		

Committee	**Michelle McCarthy** **Signature** **Date 15.05.18**

Appendix 3.2 Focus Group Participant Information Sheet

Participant Information Sheet

Developing a screening tool for autism spectrum conditions (ASC): A Focus Group.

My name is Lizzie Gale and I am PhD student in Intellectual and Developmental Disabilities at the Tizard Centre, University of Kent. My PhD is supervised by Dr Jill Bradshaw, Dr Fiona Gullon-Scott and Prof Peter Langdon (contact details below). We are designing a screening tool for autism, which focuses on earlier identification of autism in women and girls. Please read the following information provided below, so you can decide if you would like to take part. Please do contact me on the details below if you have any questions.

What is the project about?

This study relates to the use of a female specific screening tool, and whether this will help to identify autistic women and girls. Currently we know:

- Males are more likely to be diagnosed with autism than females
- Females are often diagnosed later, either during adolescence or adulthood.
- Later diagnosis causes problems for women and girls and autistic women say that their lives would have been improved if they had been diagnosed sooner.

We have developed a screening tool called the FASST (Female Autism Spectrum Screening Tool) and we want to find out from autistic people, family members/carers and professionals whether the questions included in the tool may be more relevant in identifying females, thus supporting earlier identification of autism within this group. This will mainly include females but may also include autistic people who identify as other genders or who describe themselves as non-binary, whose presentation may be harder to diagnose due to subtler autistic presentations.

What will the project involve?

The first part of this study utilises the method of a focus group. A focus group is a method of research where participants will be asked to meet in small groups to express their views on a specific topic, in this case, your opinions on our screening tool, the FASST, developed to identify autism in women and girls. We will also be asking you to provide some information about yourself, including your location area and background.

The researcher will be looking to recruit 6-8 autistic people and family members/carers for the first focus group, specifically parent/carers of autistic girls and females (including autistic people who identify as other genders or who describe themselves as non-binary) who may have experienced a late diagnosis; and 6-8 professionals and researchers from various backgrounds within the field of autism and Intellectual Disabilities, for the second focus group.

If you decide to take part, you will be asked to attend a focus group which will be held in a mutually agreeable location. On the day of the focus group, you will meet with the researcher and the other participants. The session will focus on a facilitated discussion around the content of the FASST, the researcher is there to ensure the discussion stays on topic, but you will be asked to discuss freely within the group your opinions on the FASST.

The session will be audio recorded and later transcribed by the researcher. This is to ensure all the opinions discussed will be recorded so that nothing will be missed when the researcher comes to analyse your opinions. After the researcher has transcribed the recording, the audio file will be deleted. At the end of the session, if you have any concerns, the researcher will offer time for debriefing before you leave.

What are the potential benefits of taking part?

This study will provide us with information on how to improve the FASST screening tool before it is piloted. The FASST aims to support the much-needed earlier identification of autism in females.

What are the potential risks if I take part?

This study requires the use of your time in relation to attending the focus group, however the research team will do their best to ensure the venue for the focus group is held at a mutually agreeable location to minimise the impact on your day.

Your option to take part in the study.

Your participation is completely voluntary. If you choose to take part and then later change your mind then that is ok and you can withdraw your information at any time. Your participation in the study will remain completely anonymised. Any information you provide will be confidential, you will be assigned a unique reference number in order for us to store your information.

You will be asked to provide your contact details (name, telephone number and email address) to enable me to contact you throughout the study, however these details will be stored securely in a locked filing cabinet. Your personal information will then be destroyed at the end of the study. Information such as your location area and background will be used to summarise participant information in our study write ups, but we will not discuss or present your individual information, all your private information will remain anonymous.

The next steps

If you would like to take part in the focus group for this study, please complete and sign the attached consent form to me by email. If you have any questions, please contact me on the details below.

Main Researcher:	Lizzie Gale	eeg6@kent.ac.uk
Academic supervisors:	Dr Jill Bradshaw	J.Bradshaw@kent.ac.uk
	Dr Fiona Gullon-Scott	F.Scott-256@kent.ac.uk
	Prof Peter Langdon	P.E.Langdon@kent.ac.uk

Address: Tizard Centre, University of Kent, Cornwallis North East, Canterbury, Kent, CT2 7NF

Thank you for taking the time to read this information.

Complaints and Comments Procedure

Developing a screening tool for autism spectrum conditions (ASC): A Focus Group.

You will be given a form at the end of your involvement so that you can provide feedback or make a complaint. In addition, at any time you are welcome to contact us.

If you have any questions, concerns or complaints regarding this study, please do not hesitate to get in contact.

In the first instance please speak to the main researcher:

Lizzie Gale (eeg6@kent.ac.uk, Address: Tizard Centre, University of Kent, Cornwallis North East, Canterbury, Kent, CT2 7NF)

If this is not appropriate, you can contact my supervisor:
Dr Jill Bradshaw (J.Bradshaw@kent.ac.uk, Address: Tizard Centre, University of Kent, Cornwallis North East, Canterbury, Kent, CT2 7NF)

Alternatively, you can contact the Secretary of the Tizard Centre's Ethic Committee:
Jo Ruffles (J.Ruffles@kent.ac.uk, Tel: 01227 827373, Address: Tizard Centre, University of Kent, Cornwallis North East, Canterbury, Kent, CT2 7NF)

Thank you.

Appendix 3.3 Focus Group Consent Form

TIZARD
University of Kent

Consent Form

Developing a screening tool for autism spectrum conditions (ASC): A Focus Group.

	Please initial
• I have read the information sheet relating to the Focus Group. I understand what participation in this study will involve and have had my questions answered.	☐
• I understand that the Focus Group will be audio recorded. I understand that after the Focus Group has been transcribed, the recording will be deleted.	☐
• I understand that my views expressed during the Focus Group will remain confidential and that I will not be identifiable in any reports or publications about the Focus Groups.	☐
• I **would** like to take part in this study.	☐

Name:
Date:
Signed:

Please provide the following details to allow the researcher to contact you during the study.

Email address:
Telephone number:

Thank you for taking the time to complete this form.

Appendix 3.4 Focus Groups: Comments and Feedback Form

TIZARD
University of Kent

Feedback/Comments Form

Developing a screening tool for autism spectrum conditions (ASC): A Focus Group.

Thank you for agreeing to take part in the Focus Groups run by Lizzie Gale as part of her research into the design of a screening tool for autism, which focuses on earlier identification of autism in women and girls.

We hope that everything was alright during your participation in the study with Lizzie. We would be interested in any comments you would like to make, positive or negative.

When things go well, we like to encourage researchers by giving them good feedback. But if things don't go well, it will help us to know this.

Please send any comments you have to:

> **Jo Ruffles** (J.Ruffles@kent.ac.uk, Tel: 01227 827373, Address: Tizard Centre, University of Kent, Cornwallis North East, Canterbury, Kent, CT2 7NF)

Contact Information:

Main Researcher:	Lizzie Gale	eeg6@kent.ac.uk
Academic supervisors:	Dr Jill Bradshaw	J.Bradshaw@kent.ac.uk
	Dr Fiona Gullon-Scott	F.Scott-256@kent.ac.uk
	Prof Peter Langdon	P.E.Langdon@kent.ac.uk

Address: Tizard Centre, University of Kent, Cornwallis North East, Canterbury, Kent, CT2 7NF

Thank you once again for helping the Tizard Centre with our research.

Appendix 3.5 Focus Groups: Structure and Guidance

Guidance for structuring the Focus Group

Introduction

1. Welcome participants to the focus group
2. Give a brief overview of topic
3. Ground rules i.e.:
    - There are no right or wrong answers, just different points of views
    - Only one person to speak at a time – please allow each other the time to get their views across
    - We don't need to agree with each other, but please listen respectfully as others share their views
    - Please do have mobile phones on silent, if you do need to respond to a call, please do so quietly and re-join us as quickly as you can
    - My role as the moderator will be to guide your discussions today
4. Provide information about refreshments and bathroom facilities

Questions

1. To begin with drawing attention to the FASST screening tool which will be the focus of the group. Questions will include asking participants to comment on each question in the FASST and provide their thoughts, comments and experiences. For example: Read out item one – tell me what you think about this item?

Pauses and Probes

1. Use five second pause after each comment
2. Probes:
   'Would you explain further?'
   'Would you give an example?'
   'I don't understand'
3. Avoid using verbal responses such as 'that's good' and 'excellent'
4. Do not use closed questions

Conclusion

1. Summarise information discussed in the focus group
2. Review the purpose of the focus group and ask the participants if anything has been missed
3. Offer opportunities for debriefing
4. Thanks

Appendix 4: Delphi Consultation

Appendix 4.1: Ethical Approval – for both Delphi and Focus Groups

Tizard Ethics Feedback Form

Student Name:	Lizzie Gale
Supervisor:	Dr Jill Bradshaw, Dr Fiona Gullon-Scott & Prof Peter Langdon
Title:	*"Developing a screening tool for autism spectrum conditions (ASC); a Delphi consultation and focus groups"*

The Tizard Ethics Committee have considered the above proposal and understand that the amendments have been approved by the Supervisors. This proposal now has ethical approval.

Signed: J.Ruffels **Date: 15.05.18**

On behalf of Tizard Ethics Committee

Alterations approved by Supervisor	**Signature**	**Date**
Final approval On behalf of Tizard Ethics		

Committee	**Michelle McCarthy** **Signature** **Date 15.05.18**

Appendix 4.2: Delphi – Participant Information Sheet

TIZARD
University of Kent

Participant Information Sheet

Developing a screening tool for autism spectrum conditions (ASC): A Delphi Consultation.

My name is Lizzie Gale and I am PhD student in Intellectual and Developmental Disabilities at the Tizard Centre, University of Kent. My PhD is supervised by Dr Jill Bradshaw, Dr Fiona Gullon-Scott and Prof Peter Langdon (contact details below). We are designing a screening tool for autism, which focuses on earlier identification of autism in women and girls. Please read the following information provided below, so you can decide if you would like to take part. Please do contact me on the details below if you have any questions.

What is the project about?

This study relates to the use of a female specific screening tool, and whether this will help to identify autistic women and girls. Currently we know:

- Males are more likely to be diagnosed with autism than females
- Females are often diagnosed later, either during adolescence or adulthood.
- Later diagnosis causes problems for women and girls and autistic women say that their lives would have been improved if they had been diagnosed sooner.

We have developed a screening tool called the FASST (Female Autism Spectrum Screening Tool) and we want to find out from autistic people, family members/carers and professionals whether the questions included in the tool may be more relevant in identifying females, thus supporting earlier identification of autism within this group.

What will the project involve?

The first part of this study utilises the Delphi method of consultation. A Delphi consultation is a method of research where participants will be asked to express their views on a specific topic, in this case, your opinions on our screening tool, the FASST, developed to identify autism in women and girls. We will also be asking you to provide some information about yourself, including your location area and background.

The researcher will be looking to recruit one panel of 15-20 autistic people and family members/carers, and a second panel of 15-20 professionals and researchers from various backgrounds within the field of autism and Intellectual Disabilities.

If you decide to take part, you will be sent a copy of the FASST and a link to complete questionnaires electronically in up to three rounds. The questionnaires will ask you to rate individual items on the FASST using a 5-point scale in terms of their importance. You will also have the opportunity to comment and/or make suggestions underneath each question. It is expected that each round will take between 30-45 minutes for you to complete.

After each round, I will collate and summarise all of the responses and feedback to each panel. You will then be invited to take part in the next round. Your responses will be anonymised, other panels will not know what you have said or who you are, only myself and my supervisors will have access to your responses.

What are the potential benefits of taking part?

This study will provide us with information on how to improve the FASST screening tool before it is piloted. The FASST aims to support the much-needed earlier identification of autism in females.

What are the potential risks if I take part?

This study requires the use of your time in relation to completing the questionnaires for each round, however we have designed the questionnaires to be as brief and easy to complete as possible. The use of online questionnaires means that you can complete them whenever is convenient for you within a two-week period.

Your option to take part in the study.

Your participation is completely voluntary. If you choose to take part and then later change your mind then that is ok and you can withdraw your information at any time. Your participation in the study will remain completely anonymised. Any information you provide will be confidential, you will be assigned a unique reference number in order for us to store your information.

You will be asked to provide your contact details (name, telephone number and email address) to enable me to contact you throughout the study, however these details will be stored securely in a locked filing cabinet. Your personal information will then be destroyed at the end of the study. Information such as your location area and background will be used to summarise participant information in our study write ups, but we will not discuss or present your individual information, all your private information will remain anonymous.

The next steps

If you would like to take part as a panel member for this study, please complete and sign the attached consent form to me by email. If you have any questions, please contact me on the details below.

Main Researcher:	Lizzie Gale	eeg6@kent.ac.uk
Academic supervisors:	Dr Jill Bradshaw	J.Bradshaw@kent.ac.uk
	Dr Fiona Gullon-Scott	F.Scott-256@kent.ac.uk
	Prof Peter Langdon	P.E.Langdon@kent.ac.uk

Address: Tizard Centre, University of Kent, Cornwallis North East, Canterbury, Kent, CT2 7NF

Thank you for taking the time to read this information.

Complaints and Comments Procedure

Developing a screening tool for autism spectrum conditions (ASC): A Delphi Consultation.

You will be given a form at the end of your involvement so that you can provide feedback or make a complaint. In addition, at any time you are welcome to contact us.

If you have any questions, concerns or complaints regarding this study, please do not hesitate to get in contact.

In the first instance please speak to the main researcher:

Lizzie Gale (eeg6@kent.ac.uk, Address: Tizard Centre, University of Kent, Cornwallis North East, Canterbury, Kent, CT2 7NF)

If this is not appropriate, you can contact my supervisor:

Dr Jill Bradshaw (J.Bradshaw@kent.ac.uk, Address: Tizard Centre, University of Kent, Cornwallis North East, Canterbury, Kent, CT2 7NF)

Alternatively, you can contact the Secretary of the Tizard Centre's Ethic Committee:

Jo Ruffles (J.Ruffles@kent.ac.uk, Tel: 01227 827373, Address: Tizard Centre, University of Kent, Cornwallis North East, Canterbury, Kent, CT2 7NF)

Thank you.

Appendix 4.3: Delphi – Consent Form

Consent Form

Developing a screening tool for autism spectrum conditions (ASC): A Delphi Consultation.

Please initial

- I have read the information sheet relating to the Delphi Consultation. I understand what participation in this study will involve and have had my questions answered. ☐
- I understand that I will be asked to complete questionnaires electronically up to three times during the study and will return these within 2 weeks each time. ☐
- I understand that my answers to the questionnaires will remain confidential and that I will not be identifiable in any reports or publications about the Delphi Consultation. ☐
- I **would** like to take part in this study. ☐

Name:
Date:
Signed:

Please provide the following details to allow the researcher to contact you during the study.

Email address:
Telephone number:

Thank you for taking the time to complete this form.

Appendix 4.4: Delphi – Comments and Feedback Form

Feedback/Comments Form

Developing a screening tool for autism spectrum conditions (ASC): A Delphi Consultation.

Thank you for agreeing to take part in the Delphi Consultations run by Lizzie Gale as part of her research into the design of a screening tool for autism, which focuses on earlier identification of autism in women and girls.
We hope that everything was alright during your participation in the study with Lizzie. We would be interested in any comments you would like to make, positive or negative.
When things go well, we like to encourage researchers by giving them good feedback. But if things don't go well, it will help us to know this.
Please send any comments you have to:

> **Jo Ruffles** (J.Ruffles@kent.ac.uk, Tel: 01227 827373, Address: Tizard Centre, University of Kent, Cornwallis North East, Canterbury, Kent, CT2 7NF)

Contact Information:

Main Researcher:	Lizzie Gale	eeg6@kent.ac.uk
Academic supervisors:	Dr Jill Bradshaw	J.Bradshaw@kent.ac.uk
	Dr Fiona Gullon-Scott	F.Scott-256@kent.ac.uk
	Prof Peter Langdon	P.E.Langdon@kent.ac.uk

Address: Tizard Centre, University of Kent, Cornwallis North East, Canterbury, Kent, CT2 7NF

Thank you once again for helping the Tizard Centre with our research.

Appendix 5: Pilot Study

Appendix 5.1: Ethical Approval – for Pilot Study

TIZARD
University of Kent

Tizard Ethics Feedback Form

Student Name:	Lizzie Gale
Supervisor:	Jill Bradshaw
Title:	**Developing a screening tool for autism spectrum conditions (ASC): Study Three – Piloting the FASST**

The Tizard Ethics Committee has considered the above proposal. The decision of the Committee is:

Your ethics amendments have now been approved.

Signed: **L Lukehurst** **Date:** **04/11/2019**

On behalf of Tizard Ethics Committee

Alterations approved by Supervisor	**Signature**	**Date**
Final approval On behalf of Tizard Ethics Committee	**Michelle McCarthy** **Signature**	**Date**

Appendix 5.2: Pilot Study – Participant Information Sheet

TIZARD
University of Kent

Participant Information Sheet

Developing a screening tool for autism spectrum conditions (ASC): Study Three – Piloting the FASST

My name is Lizzie Gale and I am PhD student in Intellectual and Developmental Disabilities at the Tizard Centre, University of Kent. My PhD is supervised by Dr Jill Bradshaw, Dr Fiona Gullon-Scott and Prof Peter Langdon (contact details below). We are designing a screening tool for autism, which focuses on earlier identification of autism in women and girls. Please read the following information provided below, so you can decide if you would like to take part. Please do contact me on the details below if you have any questions.

What is the project about?

This study relates to the use of a female specific screening tool, and whether this will help to identify autistic women and girls. Currently we know:

- Males are more likely to be diagnosed with autism than females
- Females are often diagnosed later, either during adolescence or adulthood.
- Later diagnosis causes problems for women and girls and autistic women say that their lives would have been improved if they had been diagnosed sooner.

We have developed a screening tool called the FASST (Female Autism Spectrum Screening Tool) and we are now at the stage where we want to pilot our screening tool. We have recently finished study two where several Focus Groups and Delphi Consultations were held; this proved immensely beneficial as were able to refine the content of the FASST based upon the feedback from autistic people, those who self-identify as autistic, parents/carers and professionals. We are proud to say that the FASST has been co-produced with autistic people.

For study three, we now want to pilot the FASST to ascertain whether or not the FASST can successfully screen for autism in females, thus supporting the earlier identification of autism in women and girls.

What will the project involve?

In order to take part in the study you must either have a diagnosis of autism or self-identify as autistic. We will also be asking non-autistic people to take part in the study.

Please note, you MUST have an informant (somebody who knows you well) who would be willing to take part in the study. An informant can be a family member, friend, carer or similar that knows you well.

Study three will involve the use of a battery of self-reports (which you will complete) and an informant report (which your informant will complete) including:

The Autism Spectrum Quotient (AQ) – Self-Report
The Empathy Quotient (EQ) – Self-Report
The Friendship Questionnaire (FQ) – Self Report
The Camouflaging Autistic Traits Questionnaire (CAT-Q) – Self Report
The Female Autism Spectrum Screening Tool (FASST) – Informant Report

We will also be asking you to provide some information about yourself, including your location area and background.

The researcher will be looking to recruit three groups of participants: autistic people, people who self-identify as autistic and non-autistic people). We will be aiming to recruit at least 20 participants for each group.

If you decide to take part, you will be sent a link to complete the assessments electronically. You will be asked to complete all four self-report questionnaires and your informant **(someone who knows you well)** will be asked to complete the FASST. ***Please note that in order to take part in the study you must have a friend, relative carer or similar, who will be willing to take part and complete the FASST questionnaire.***

It is expected that each self-report will take approximately 20-30 minutes for you to complete and the FASST will take approximately 30-40 minutes for the informant to complete the FASST. Further, your informant will need to complete the FASST twice online, separated by no more than two weeks.

Please note – you will need to pass on the relevant information sheet and consent form to your informant. If you encounter any difficulties with this, please contact the lead researcher who will be happy to assist you with this.

At the end of the study we will provide a summary document detailing the findings of our research.

What are the potential benefits of taking part?

The aim of this study is to find out whether or not the FASST can reliably screen for autism in females, thus supporting the much-needed earlier identification of autism in women and girls.

What are the potential risks if I take part?

This study requires the use of your time in relation to completing the questionnaires in our battery of assessments. The use of completing the assessment online means that you can complete them whenever is convenient for you within a two-week period.

Your option to take part in the study.

Your participation is completely voluntary. If you choose to take part and then later change your mind then that is ok and you can withdraw your information at any time. Your participation in the study will remain completely anonymised. Any information you provide will be confidential, you will be assigned a unique reference number in order for us to store your information.

You will be asked to provide your contact details (name, telephone number and email address) to enable me to contact you throughout the study, however these details will be stored securely in a locked filing cabinet. Your personal information will then be destroyed at the end of the study. Information such as your location area and background will be used to summarise participant information in our study write ups, but we will not discuss or present your individual information, all your private information will remain anonymous.

The next steps

If you would like to take part in our study, please complete and sign the attached consent form to me by email. If you have any questions, please contact me on the details below.

Main Researcher:	Lizzie Gale	eeg6@kent.ac.uk
Academic supervisors:	Dr Jill Bradshaw	J.Bradshaw@kent.ac.uk
	Dr Fiona Gullon-Scott	F.Scott-256@kent.ac.uk
	Prof Peter Langdon	P.E.Langdon@kent.ac.uk

Address: Tizard Centre, University of Kent, Cornwallis North East, Canterbury, Kent, CT2 7NF

Ethical Approval

This study has received ethical approval from the Tizard Centre Ethics Committee.
Contact details:

Liz Lukehurst – Secretary to Tizard Centre Ethics Committee, University of Kent, Cornwallis North East, Canterbury, Kent, CT2 7NF.
Email: E.Lukehurst@kent.ac.uk

Thank you for taking the time to read this information.

General Data Protection Regulation (GDPR) Privacy Notice for Research

The University of Kent is the Data Controller for this study.
As a university we use personally-identifiable information to conduct research, including to improve health, care and services. As a publicly-funded organisation, we have to ensure that it is in the public interest when we use personally-identifiable information from people who have agreed to take part in research. This means that when you agree to take part in a research study, we will use your data in the wats needed to conduct and analyse the research study. Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable

and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information as possible.

The University Charter:

https://www.kent.ac.uk/governance/about/consitutionandmanagement.html sets out that 'the objects of the University are to advance education and disseminate knowledge by teaching, scholarship and research for the public benefit' (paragraph 3).

Health and care research should serve the public interest, which means that we have to demonstrate that our research serves the interest of society as a whole. We do this by following the UK Policy Framework for Health and Social Care Research https://www.hra.nhs.uk/planning-and-improving-research/policies-standards-legislation/uk-policy-framework-health-social-care-research/

If you wish to raise a complaint on how we have handled your personal data, you can contact our Data Protection Officer who will investigate the matter. If you are not satisfied with our response or believe we are processing your personal data in a wat that is not lawful you can complain to the Information Commissioner's Office (ICO).

The University of Kent's Data Protection Officer can be contacted at:
Information Compliance, Darwin College, University of Kent, Canterbury, CT2 7NY
+44(0)1227 823671.

The University of Kent's full privacy notice can be found here:
https://research.kent.ac.uk/researchservices/wp-content/uploads/sites/51/2018/05/GDPR-Privacy-Notice-Research.pdf

Comments Procedure

Developing a screening tool for autism spectrum conditions (ASC): Study Three – Piloting the FASST

You will be given a form at the end of your involvement so that you can provide feedback or comments on your involvement with the research. In addition, at any time you are welcome to contact us.

If you have any questions, concerns or complaints regarding this study, please do not hesitate to get in contact.

In the first instance please speak to the main researcher:

Lizzie Gale (eeg6@kent.ac.uk, Address: Tizard Centre, University of Kent, Cornwallis North East, Canterbury, Kent, CT2 7NF)

If this is not appropriate, you can contact my supervisor:

Dr Jill Bradshaw (J.Bradshaw@kent.ac.uk, Address: Tizard Centre, University of Kent, Cornwallis North East, Canterbury, Kent, CT2 7NF)

Alternatively, you can contact the Secretary of the Tizard Centre's Ethic Committee:

Address: Tizard Centre, University of Kent, Cornwallis North East, Canterbury, Kent, CT2 7NF).
Tel: 01227 827373

Thank you.

TIZARD
University of Kent

Appendix 5.3: Pilot Study – Consent Form – Self-Report

Consent Form – Participants completing Self-Reports
Developing a screening tool for autism spectrum conditions (ASC): Study Three – Piloting the FASST

Please initial

- I have read the information sheet relating to Study three – Piloting The FASST. I understand what participation in this study will involve and have had my questions answered. ☐
- I understand that the information I provide throughout the battery of assessments will be used to analyse the FASST and its reliability as a new screening tool. ☐
- I understand that all of the information I provide will remain confidential and that I will not be identifiable in any reports or publications about Study three – Piloting the FASST. ☐
- I confirm that I have an informant who is willing to take part in the study ☐
- I **would** like to take part in this study. ☐

Name:
Date:
Signed:
Please provide the following details to allow the researcher to contact you during the study.
Email address:
Telephone number:

Thank you for taking the time to complete this form.

Appendix 5.4: Pilot Study – Consent Form – Informant

TIZARD
University of Kent

Consent Form – Participants completing Informant Report

Developing a screening tool for autism spectrum conditions (ASC): Study Three – Piloting the FASST

Please initial

- I have read the information sheet relating to Study three – Piloting The FASST. I understand what participation in this study will involve and have had my questions answered. ☐
- I understand that the information I provide throughout the battery of assessments will be used to analyse the FASST and its reliability as a new screening tool. ☐
- I understand that all of the information I provide will remain confidential and that I will not be identifiable in any reports or publications about Study three – Piloting the FASST. ☐
- I **would** like to take part in this study. ☐

Name:
Date:
Signed:

Please provide the following details to allow the researcher to contact you during the study.

Email address:
Telephone number:

Thank you for taking the time to complete this form.

Appendix 5.5: Pilot Study – Comments and Feedback Form

TIZARD
University of Kent

Feedback/Comments Form

Developing a screening tool for autism spectrum conditions (ASC): Study Three – Piloting the FASST

Thank you for agreeing to take part in Study Three – Piloting the FASST run by Lizzie Gale as part of her research into the design of a screening tool for autism, which focuses on earlier identification of autism in women and girls.

We hope that everything was alright during your participation in the study with Lizzie. We would be interested in any comments you would like to make, positive or negative.

When things go well, we like to encourage researchers by giving them good feedback. But if things don't go well, it will help us to know this.

Please send any comments you have to:

Liz Lukehurst – Secretary to Tizard Centre Ethics Committee, University of Kent, Cornwallis North East, Canterbury, Kent, CT2 7NF.

Email: E.Lukehurst@kent.ac.uk

Thank you once again for helping the Tizard Centre with our research.

Appendix 5.6: Pilot Study – Research Advert

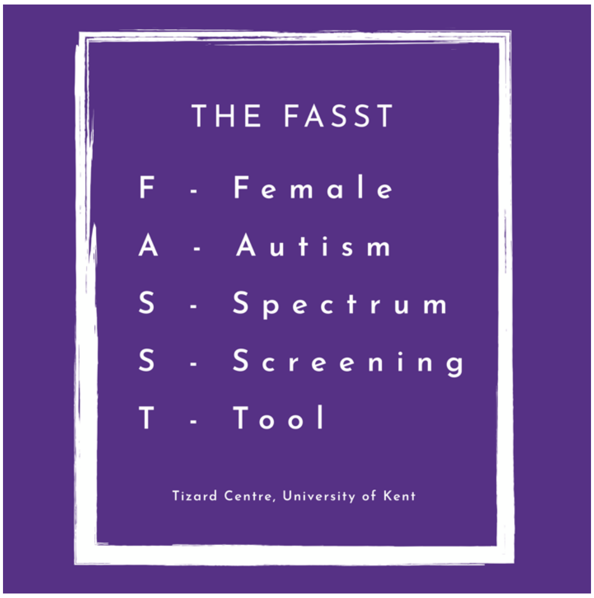
TIZARD
University of Kent

Participants Wanted!

Are you a late-diagnosed autistic woman*?

Do you self-identify as an autistic woman?

If so, we want to hear from you!


THE FASST
F - Female
A - Autism
S - Spectrum
S - Screening
T - Tool
Tizard Centre, University of Kent

Researchers at the Tizard Centre, University of Kent are designing a screening tool for autism, which focuses on earlier identification of autism in women and girls.

What is the project about?

This study relates to the use of a female specific screening tool, and whether this will help to identify autistic women and girls. Currently we know:

- Males are more likely to be diagnosed as autistic than females
- Females are often diagnosed later, either during adolescence or adulthood.
- Autistic women say that their lives would have been improved if they had been diagnosed sooner.

We have developed a screening tool called the FASST (Female Autism Spectrum Screening Tool) and we are now at the stage where we want to pilot our screening tool. We are proud to say that the FASST has been co-produced with autistic people.

For study three, we now want to pilot the FASST to ascertain whether or not the FASST can successfully screen for autism in females, thus supporting the earlier identification of autism in women and girls. We are also looking to recruit non-autistic people to help us with our research.

The study will involve you and your informant taking part in a series of online questionnaires which you can access at any time and complete at your own convenience.

Please note, you MUST have an informant (somebody who knows you well) who would be willing to take part in the study. An informant can be a family member, friend, carer or similar that knows you well.

If you think you would be interested in taking part in the study, or simply want to find out more, please contact Lizzie Gale (eeg6@kent.ac.uk) who will be happy to talk to you and provide you with more information about the research.

***The researchers would like to acknowledge that the complexities of gender and autism and the person's lived experience of such is a topic that cannot be fully covered within the scope of this PhD Research Project.** During the research process we have been inclusive with our criteria but at this stage we have unfortunately had to limit this to cisgender women and girls for study three. Despite this I believe it is important to continue to explore the area of gender identity and autism and we hope to secure funding post-PhD to research the use of the FASST with a wider range of people not only cisgender women and girls. **Please do follow @LiziGale on Twitter for future updates on how the project expands.**

Appendix 6: Delphi Results
Appendix 6.1: Delphi Results – Amendments to FASST items across Focus Groups and Delphi

*This table details original wording of items and details at what stage the item was either amended, retained or excluded.

	Presented to the Focus Groups	**Wording amendments from Focus Group Participants**	**Presented to the Delphi in Round 1**	**Met consensus? Re-presented? Or retained?**	**Wording amendments from all Delphi rounds**	**Presented to the Delphi in Round 4**
1	She is able to chat about anything with you.	Add 'almost"	She is able to chat about almost anything with you	Presented in round 2		
2	She is good at listening to others.		She is good at listening to others	Presented in round 2		
3	She enjoys meeting new people.		She enjoys meeting new people	Presented in round 2 Item retained R3	'Enjoys' is a difficult word to use – perhaps use 'comfortable'	They feel comfortable meeting new people
4	When other people meet her they find her really easy to talk to.		When other people meet her they find her really easy to talk to	Presented in round 2		
5	She can join in easily with group chats, when more than three people are talking together.		She can join in easily with group chats, when more than three people are talking together	Met consensus in R1	Need to define 'group chats' – face to face or online	They can join in easily with group chats, face to face and/or online, when more than three people are talking together
6	She will always show consideration for other people.		She will always show consideration for other people	Presented in round 2		
7	She is careful not to say things that could cause offence.		She is careful not to say things that could cause offence	Presented in round 2 Item retained R3	Would be better worded as 'they often do not understand when or why they have caused offence'	They often do not understand when or why they have caused offence
8	She will often do things that others		She will often do things that others	Presented in round 2 Met consensus in R2	Change 'often' to 'sometimes'	They sometimes do things that others think are rude or inappropriate without

	think are rude or inappropriate.		think are rude or inappropriate		Explain that it is likely to be unintentional or understanding why they have caused offence	understanding why this has caused offence
9	She has several people who would call her a real 'friend'.		She has several people who would call her a real friend	Presented in round 2 Item retained R3	How do you define several? It needs to be more specific What is a real friend?	They have a few close friends rather than a large and varied group of friends
10	She has at least one friend that she has stayed in touch with and regularly communicates with, whom she has known for years.		She has at least one friend that she has stayed in touch with and regularly communicates with, whom she has known for years	Presented in round 2		
11	When she does things, she is considerate of the impact on other people's feelings.		When she does things, she is considerate of the impact on other people's feelings	Presented in round 2 Item retained R3	'think' would be better than 'considerate' 'often can't predict what people will feel or respond' should be added	When they do things, they often do not think of the impact on other people's feelings and often cannot predict how other people will feel or respond This item was split into two item 52 and item 58 on the FASST.
12	She has excessively intense attachments to others that are not reciprocated.		She has excessively intense attachments to others that are not reciprocated	Presented in round 2 Met consensus in R2	Add in 'are not reciprocated to the same extent' Remove 'excessively' Change to 'they have friendships with people that aren't reciprocated'	They have friendships with people that are not always reciprocated to the same extent
13	She has at least one close relationship that seems genuinely shared.		She has at least one close relationship that seems genuinely shared	Presented in round 2 Item retained R3	This doesn't differentiate between relationships outside the family – this should be clearer	They have at least one close relationship outside of the household/family

						that seems genuinely shared
14	She tends to have lots of fleeting relationships.	Change ‘fleeting’ to short-lived.	She tends to have lots of short-lived relationships	Presented in round 2 Item retained R3	You do not need to have ‘lots of’ This is an issue around maintaining friendships	They tend to have short-lived relationships due to difficulties in maintaining relationships
15	It is easy to feel a comfortable connection with her.	This should not be a personal observation, change to ‘Do other people’	Do other people feel a comfortable connection with her	Presented in round 2		
16	She is able to adjust her behaviour in different social situations.		She is able to adjust her behaviour in different social situations	Met consensus in R1	Easily adjust her behaviour in different social situations without difficulty	They can easily adjust their behaviour in different social situations without difficulty
17	She seems particularly socially naive for her age.		She seems particularly socially naive for her age	Met consensus in R1	Take out ‘particularly, she either is or isn’t. Would be better described as ‘social behaviour is unconventional or different to non-autistic people of her age	They sometimes seem socially naïve for their age
18	When other people meet her, they find it easy to get on with her.		When other people meet her, they find it easy to get on with her	Presented in round 2		
19	She tends to be quiet and does not initiate.		She tends to be quiet and does not initiate	Presented in round 2		
20	She tends to be outgoing and sociable.		She tends to be outgoing and sociable	Presented in round 2		
21	She is highly organised and likes lists, special arrangement of	There is no need to comment on whether or not she is highly organised – remove.	She likes lists, special arrangements of objects, or ordering things	Met consensus in R1	Needs more descriptors ‘has a set way of doing things’ ‘Careful’ would be a better word than ‘special’	They have a set way of doing things such as careful arrangement of objects and/or organise

	objects, or ordering things.				'Organised system' is also helpful to include	things systematically, for example lists
22	She has specific routines that she HAS to stick to or she becomes upset.	It should not be 'has' or 'needs' – there could be a lot of reasons.	She gets upset if she cannot follow specific routines	Met consensus in R1	Using 'unexpected events' would also be important – this is covered in a different item – have added in 'unexpected changes' 'upset' is not the best word to use	They may find it difficult if they cannot follow specific routines or unexpected changes occur
23	She has really focussed interests or passions which she will spend hours pursuing.	There could be many interests at any one time – phrase with 'particular'	She can spend long periods of time focused on a particular activity	Met consensus in R1		They can spend long periods of time focused on a particular activity
24	Her interests can lead to her neglecting other activities or duties.		Her interests can lead to her neglecting other activities or duties	Met consensus in R1	Change 'neglecting' to 'forgetting'	Their interests can lead to them forgetting other activities or duties
25	She prefers social and shared activities and interests.		She prefers social and shared activities and interests	Presented in round 2		
26	She prefers solo activities and interests which she can do on her own.		She prefers solo activities and interests which she can do on her own	Met consensus in R1	Add 'mostly'	They mostly prefer solo activities and interests which they can do on their own
27	She seems excessively bothered by noises that do not bother others.	Using 'excessive' demeans what the person is experiencing.	She is distressed by noises that do not bother others	Met consensus in R1	Use distressed or distracted – as it might not always be distress 'Overwhelmed' might be a better word	They can be distressed, distracted or overwhelmed by noises that do not bother others
28	She has excessively intense dislike of specific textures, tastes, or smells.	Using 'excessive' demeans what the person is experiencing.	She has unusually intense like/dislike of specific textures, tastes, smells or places/spaces	Met consensus in R1	Need to distinguish between over and under responsive	They have unusually intense like/dislike of specific textures, tastes, smells, temperatures or places/spaces. They may

						be under or over responsive to these things
29	She becomes anxious and upset when something unexpected happens.		She becomes anxious and upset when something unexpected happens	Met consensus in R1	It isn't always so negative adding in 'unsettled' is important	They become anxious, upset and/or unsettled when something unexpected happens
30	She has an explosive temper that comes out of nowhere.		She has an explosive temper that appears to come out of nowhere	Presented in round 2		
31	She is a really calm, content person.	There is no need for the word 'content' – split into two questions	She is a really calm person	Presented in round 2		
32	Other people think she takes things too literally.	Clarifying the question by stating 'she can'	Other people think she can take things too literally	Met consensus in R1	Take away 'other people' Take away 'too'	They can take things literally
33	She doesn't seem to understand subtle social cues.		She doesn't seem to understand subtle social cues	Met consensus in R1		They do not seem to understand subtle social cues
34	She can rage, or cry, or laugh with little apparent trigger.		She can rage, or cry, or laugh with little apparent trigger	Presented in round 2 Item retained R3	'little apparent trigger' is not helpful Suggestions for: 'with triggers that do not bother most people' or 'she has strong emotions and it can be hard for me to work out what she is responding to' or 'they will express extreme emotion to apparently small triggers'	They express extreme emotion to apparently small triggers which, can be hard to work out what they are responding to
35	She complains of feeling different to other people.	Does not need the negative associations with the word 'complains'	She mentions or talks about feeling different to other people	Presented in round 2 Met consensus in R2		They talk about feeling like they are different to other people

36	She seems very anxious compared to others.		She seems very anxious compared to others	Met consensus in R1	What others? This isn't needed 'very' isn't needed as anxiety can be present on many levels	They often appear and/or describe feeling anxious
37	She seems really calm and confident compared to others.		She seems really calm and confident compared to others	Presented in round 2		
38	When people meet her they find her engaging and friendly.		When people meet her they find her engaging and friendly	Presented in round 2		
39	She has always had a great fashion sense.		She has always had a great fashion sense	Presented in round 2		
40	She has at least one really intense or obsessive interest.		She has at least one really intense or obsessive interest	Presented in round 2 Met consensus in R2	Please do not use 'obsessive' as it has negative connotations and associations with the deficit model 'Passion' would be better than obsessive Needs quantifying 'at any one time'	They have at least one intense interest and/or passion at any one time
41	She is really easy-going and flexible.		She is really easy-going and flexible	Presented in round 2		
42	She has really low self-esteem.		She has really low self-esteem	Presented in round 2 Item retained R3	Don't need to use the word 'really'	They often appear and/or describe having low self-esteem
43	She doesn't seem to pick up on other people's feelings or intentions.		She doesn't seem to pick up easily on other people's intentions	Met consensus in R1	'Doesn't always notice or pick up on' would be better 'If people are not always direct and honest' – although it may not always be about honesty	They do not always pick up easily on other people's intentions, especially if information is not direct

44	She seems to stare too long at people and this makes her seem hostile or intense.		She seems to stare too long at people and this makes her seem hostile or intense	Presented in round 2		
45	She doesn’t hold your eye when she talks to you.		She doesn't hold your eye when she talks to you	Presented in round 2		
46	She can really express herself clearly through gesture and intonation.		She can really express herself clearly through gesture and intonation	Presented in round 2		
47	It is always easy to tell how she is feeling just by her facial expressions.		It is always easy to tell how she is feeling just by her facial expressions	Presented in round 2		
48	She can easily pick up on and respond appropriately to other people’s feelings.	Separate into two questions.	She can easily respond appropriately to other people's feelings	Presented in round 2	Some comments for ‘easily’ to be removed – however this was kept in as it is possible to be able to respond, but doesn’t account for how difficult the person might find this to do – this was also reflected in other comments.	They can easily respond appropriately to other people’s feelings
49	She feels exhausted after social situations.		She feels exhausted after social situations	Met consensus in R1	Important to get this right with more explanation, words like appears exhausted and describes being exhausted is important. Not just situations – should be more specific to interactions, situations	They often appear and/or describe feeling exhausted after some social interactions

					implies certain environments.	
50	She has difficulty managing conflict.		She has difficulty managing conflict	Met consensus in R1		They have difficulty managing conflict
51	She experiences difficulties developing and maintaining friendships.		She experiences difficulties developing and maintaining friendships	Met consensus in R1	Split into two items that asks about developing and maintaining individually They are two separate questions Use 'has' instead of experiences – experience implies less	They have difficulties developing friendships
						They have difficulties maintaining friendships
52	She is able to engage in 'small talk'.		She is able to engage in 'small talk'	Presented in round 2 Item retained R3	Change 'able to' to 'maintain' or 'finds it easy' Also a separate question to qualify whether she actually enjoys it or not	They find it easy to maintain and engage in 'small talk'
						They enjoy 'small talk'
53	She finds it easier to form friendships with males.		She finds it easier to form friendships with males	Presented in round 2		
54	She has more shared interests with males and may be described as a 'tomboy'.		She has more shared interests with males and may be described as a 'tomboy'	Presented in round 2		
55	She experiences high levels of stress.		She experiences high levels of stress	Met consensus in R1	Higher than what?	They often appear and/or describe feeling stressed
56	She is skilful at imitating the behaviours of others around her.		She is skilful at imitating the behaviours of others around her	Presented in round 2 Met consensus in R2		They are skilful at imitating the behaviours of others around them
57	She uses online platforms to develop		She uses online platforms to develop	Presented in round 2		

	and maintain friendships.		and maintain friendships			
58	She experiences difficulties with romantic relationships.	Add in 'likely to' as well.	She experiences difficulties or is likely to experience difficulties with romantic relationships	Presented in round 2		
59	She experiences difficulties with school work.	Add in 'previously experienced'	She experiences difficulties or previously experienced difficulties with school work	Presented in round 2 Item retained R3	This needs to be school environment – not just the work aspect	They experience difficulties or previously experienced difficulties with the school environment (this may include aspects of school work)
60	She experiences difficulties with employment.	Add in 'likely to' as well.	She experiences difficulties or is likely to experience difficulties with employment	Presented in round 2 Met consensus in R2	Needs to be more specific – but no specific comments for change of wording	They experience and/or is likely to experience difficulties with employment (this may include the social interaction and communication demands and/or sensory needs of the environment)
61	She expresses feelings of loneliness and isolation.		She expresses feelings of loneliness and isolation	Presented in round 2 Met consensus in R2	'sometimes' or 'frequently' – something additional in here is needed	They often appear and/or describe feeling lonely and/or isolated
62	She experiences bullying.	Add in 'previously experienced'	She experiences or previously experienced bullying	Presented in round 2 Met consensus in R2		They experience or previously experienced bullying
63	She feels pressured to fit in with social expectations of 'being female'.		She feels pressured to fit in with social expectations of 'being female'	Presented in round 2 Item retained R3	General consensus that the 'being female' should be removed and it's the pressures of social expectations in general	They are aware of and/or feel uncomfortable with the pressures to fit in with social expectations

					Feeling the pressure is not the same as succumbing to the pressure	
64	She experiences mental health conditions.	Add in 'previously experienced'	She experiences or previously experienced mental health conditions	Met consensus in R1	Is this only diagnosed conditions? This could affect how an informant answers	They experience or previously experienced mental health conditions. This may include self-identified conditions also
65	Adolescence is/was a difficult period.		Adolescence is/was a difficult period	Met consensus in R1	Adolescence is difficult for everyone – adding 'noticeably' is important here	Adolescence is/was a noticeably difficult period
66			She is always direct, blunt and to the point	Presented in round 2 Met consensus in R2	Use 'has a tendency to be' rather than 'always' Use the word 'usually' was a common theme	They are usually direct, blunt and to the point
67			She is described as overbearing and/or intense	Presented in round 2 Met consensus in R2	Don't use the word 'described' Overbearing is very different Controlling would be a better word.	They can be controlling and/or intense
68			She has a smaller number of friends that she trusts	Presented in round 2 Item retained R3	Smaller than what? Should just be 'small' – keep it simple – 'few' Is it about friendship necessarily?	They have a small number of people that they trust
69			She is very conscious of her impact on her environment	Presented in round 2		
70			She has intense attachments to objects	Presented in round 2 Item retained R3	The wording needs to include 'specific' To include attachments in general and animals	They have intense attachments which may include specific objects and/or animals
71			She has intense attachments to animals	Presented in round 2		Made into one item as above.

72			She has an intense reaction to things on the tv that others find acceptable	Presented in round 2 Item retained R3	Extreme emotions is a good indicator – but should be expanded to include newspapers and social media Experiencing intense reactions to things they hear, see or experience is important Don't compare to others – this isn't important	They sometimes experience intense emotional reactions to things they hear, see or experiencing (including things on the tv, newspapers and social media)
73			She has difficulties with proprioception	Presented in round 2 Item retained R3	Proprioception is too complex a word – needs a definition	They are usually able to sense the movement and position of their body
74			She is sensitive to temperature	Presented in round 2 Item retained R3	Incorporated into item: 28	
75			She has difficulties understanding her own emotions	Met consensus in R1	Understanding or 'describing useful here 'She sometimes seems unaware or why she feels a certain way'?	They sometimes seem unaware of their emotions; can appear and/or describe having difficulties understanding their own emotions
76			She is a content person	Presented in round 2 Item retained R3		
77			She has a strong sense of justice, of right and wrong and seeking the truth	Met consensus in R1		They have a strong sense of justice, of right and wrong and seeking the truth
78			Other people think she can take things too seriously	Met consensus in R1	Take away 'other people'	They can take things too seriously
79			She can easily pick up on other people's feelings	Presented in round 2 Met consensus in R2	Its more about responding rather than picking up on –	They appear and/or describe finding it difficult

					this is covered by a previous item already included Feelings can be misinterpreted Can pick up on the emotion, but will have difficulty assigning that emotion and figuring out what it means 'Notice' is better than 'pick up on' May be confused what they are picking up	to notice or understand other people's emotions
80			She can spend a long-time ruminating	Met consensus in R1	This needs more description Some people may not know what ruminating is – change the language	They can appear and/or describe spending a long time thinking/worrying about situations
81			She has difficulties understanding boundaries in relationships	Met consensus in R1	May not be always	They sometimes have difficulties understanding boundaries in relationships
82			Does she isolate herself from others	Met consensus in R1	Using additional descriptors such as 'sometimes' 'all the time' is important	They sometimes seem to isolate themselves from others
83			Do people complain about how she treats others	Presented in round 2 Item retained R3	'Complain' is not the right word 'concerns is better Phrase as 'Other people sometimes raise/have concerns about how she treats others'	Other people sometimes raise/have concerns about how they treat others

Appendix 6.2: Delphi Results – Amendments to items from Delphi to final draft

	Item wording after completion of the Delphi Rounds	Final draft - FASST Items
1	They can join in easily with group chats, face to face and/or online, when more than three people are talking together	They can join in easily with face to face chats, when more than three people are talking together
2	They can easily adjust their behaviour in different social situations without difficulty	They can easily adjust their behaviour in different social situations without difficulty
3	They mostly prefer solo activities and interests which they can do on their own	They mostly prefer solo activities and interests which they can do on their own
4	They can take things literally	They can take things literally
5	They do not seem to understand subtle social cues	They do not seem to understand subtle social cues
6	They often appear and/or describe feeling exhausted after some social interactions	They often appear exhausted after some social interactions
7	They have difficulty managing conflict	They have difficulty managing conflict
8	They have difficulties developing friendships	They have difficulties developing friendships
9	They have difficulties maintaining friendships	They have difficulties maintaining friendships
10	They can take things too seriously	They can take things too seriously
11	They sometimes have difficulties understanding boundaries in relationships	They sometimes have difficulties understanding boundaries in relationships
12	They sometimes do things that others think are rude or inappropriate without understanding why this has caused offence	They sometimes do things that others think are rude or inappropriate without understanding why this has caused offence
13	They are skilful at imitating the behaviours of others around them	They are skilful at imitating the behaviours of others around them
14	They are usually direct, blunt and to the point	They are usually direct, blunt and to the point
15	They can be controlling and/or intense	They can be controlling and/or intense
16	They have friendships with people that are not always reciprocated to the same extent	They have friendships with people that are not always reciprocated to the same extent
17	They can easily respond appropriately to other people's feelings	They can easily respond appropriately to other people's feelings
18	They find it easy to maintain and engage in 'small talk'	They find it easy to maintain and engage in 'small talk'
19	They enjoy 'small talk'	They enjoy 'small talk'
20	They have a small number of people that they trust	They have a small number of people that they trust
21	They feel comfortable meeting new people	They feel comfortable meeting new people
22	They tend to have short-lived relationships due to difficulties in maintaining relationships	They tend to have short-lived relationships due to difficulties in maintaining relationships
23	They have at least one close relationship outside of the household/family that seems genuinely shared	They have at least one close relationship outside of the household/family that seems genuinely shared

24	They have a few close friends rather than a large and varied group of friends	They have a few close friends rather than a large and varied group of friends
25	They can be distressed, distracted or overwhelmed by noises that do not bother others	They can be distressed, distracted or overwhelmed by noises that do not bother others
26	They have unusually intense like/dislike of specific textures, tastes, smells, temperatures or places/spaces. They may be under or over responsive to these things	They can be under or over responsive to sensations e.g. specific textures, tastes, smells or temperatures
27	They are usually able to sense the movement and position of their body	They are usually able to sense the movement and position of their body
28	They often appear and/or describe feeling stressed	They are often stressed
29	They experience or previously experienced mental health conditions. This may include self-identified conditions also	They experience or previously experienced mental health conditions
30	They often appear and/or describe feeling anxious	They are often anxious
31	They often appear and/or describe feeling lonely and/or isolated	They often appear lonely and/or isolated
32	They experience or previously experienced bullying	They experience or previously experienced bullying
33	They can appear and/or describe spending a long time thinking/worrying about situations	They often spend a long time thinking/worrying about situations
34	They sometimes seem to isolate themselves from others	They sometimes seem to isolate themselves from others
35	They talk about feeling like they are different to other people	They talk about feeling like they are different to other people
36	They often appear and/or describe having low self-esteem	They often have low self-esteem
37	They have a set way of doing things such as careful arrangement of objects and/or organise things systematically, for example lists	They have a set way of doing things such as careful arrangement of objects and/or organise things systematically e.g. lists
38	They may find it difficult if they cannot follow specific routines or unexpected changes occur	They may find it difficult if they cannot follow specific routines or unexpected changes occur
39	They can spend long periods of time focused on a particular activity	They can spend long periods of time focused on a particular activity
40	Their interests can lead to them forgetting other activities or duties	Their interests can lead to them forgetting other activities or duties
41	They become anxious, upset and/or unsettled when something unexpected happens	They become anxious, upset and/or unsettled when something unexpected happens
42	They have a strong sense of justice, of right and wrong and seeking the truth	They have a strong sense of justice, of right and wrong and seeking the truth
43	They have at least one intense interest and/or passion at any one time	They have at least one intense interest at any one time
44	They express extreme emotion to apparently small triggers which, can be hard to work out what they are responding to	They can rage, cry or laugh with little apparent trigger
45	They have intense attachments which may include specific objects and/or animals	They have intense attachments which may include specific objects and/or animals
46	They sometimes experience intense emotional reactions to things they hear, see or experiencing (including things on the tv, newspapers and social media)	They sometimes experience intense emotional reactions to things they hear or see (e.g. things on the tv, newspapers and social media), which others may not share

47	Other people sometimes raise/have concerns about how they treat others	Other people sometimes raise/have concerns about how they treat others
48	They do not always pick up easily on other people's intentions, especially if information is not direct	They do not always pick up easily on other people's intentions
49	They sometimes seem socially naïve for their age	They sometimes seem socially naïve for their age
50	They sometimes seem unaware of their emotions; can appear and/or describe having difficulties understanding their own emotions	They sometimes have difficulty understanding or describing their own emotions
51	They appear and/or describe finding it difficult to notice or understand other people's emotions	They often find it difficult to notice or understand other people's emotions
52	When they do things, they often do not think of the impact on other people's feelings and often cannot predict how other people will feel or respond Split into two items 52 and 58	When they do things, they often do not think of the impact on other people's feelings
53	They often do not understand when or why they have caused offence	They often do not understand when or why they have caused offence
54	Adolescence is/was a noticeably difficult period	Adolescence is/was a noticeably difficult period
55	They experience and/or is likely to experience difficulties with employment (this may include the social interaction and communication demands and/or sensory needs of the environment)	They experience difficulties or are likely to experience difficulties with employment
56		It is always easy to tell how they are feeling just by their facial expressions
57	They experience difficulties or previously experienced difficulties with the school environment (this may include aspects of school work)	They experience difficulties or previously experienced difficulties with school
58	When they do things, they often do not think of the impact on other people's feelings and often cannot predict how other people will feel or respond Split into two items 52 and 58	They find it difficult to predict how other people will feel or respond