Exploring Clinician’s Perpectives of the Female Autism Phenotype in those with Intellectual Disabilities

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From Swiss Cottage School to Artistic Autistic to Hackney Ark. This is for you.

"In the darkest times, hope is something you give yourself. That is the meaning of inner strength" – Iroh, Avatar the Last Airbender, Nickelodeon, 2005.

Abstract

Autism Spectrum Condition (ASC) presents differently across populations with an increasing recognition of its unique presentation in women. Research suggests that women are more likely to engage in masking behaviours, which may contribute to delays in diagnosis and barriers to appropriate support. Additionally, individuals with intellectual disabilities (ID) remain underrepresented in autism research, despite a high rate of co-occurrence with ASC. These historical biases and systemic barriers may further obscure the accurate identification and understanding of ASC in these populations. This thesis explores clinicians' experiences in assessing and supporting women with both ASC and ID. Health professionals working in autism and intellectual disability services participated in semi-structured interviews. Thematic analysis identified five key themes: Diagnostic Challenges, Gendered Manifestations, Intersectional Influences, Education & Awareness and Person-Centred Practices. Clinicians reported observing traits consistent with the Female Autism Phenotype in women with ID, challenging existing assumptions about the cognitive capacity required for masking behaviours. The findings from this thesis highlight the need for greater consideration of intellectual disability in autism research and clinical practice, as well as the importance of an intersectional approach to assessment and intervention. Recommendations include enhanced training for clinicians, the development of tailored diagnostic tools, and increased awareness of gendered and cognitive factors influencing autism presentation. This research contributes to evolving best practices in autism assessment and long-term support for those with ID, emphasizing the importance of individualized, inclusive, and equitable diagnosis and care.

Keywords: Intellectual Disability, Autism, Women, Masking, Female Autism Phenotype

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Chapter 1: Introduction

"There is no greater disability in society than the inability to see a person as more" – **Robert M. Hensel, author and disability advocate**

Chapter Summary

This thesis explores ASC in women with intellectual disabilities and the experiences of clinicians working with this population. The introductory chapter contextualizes human development theories, reviewing historical and contemporary perspectives on autism and intellectual disability. It examines how autism manifests across different populations and the barriers individuals with ID face in accessing appropriate assessment and support. The review of the literature highlights a significant gap in research on individuals with a dual diagnosis of autism and ID, despite consistently reported high co-occurrence rates. Furthermore, much of the existing knowledge is derived from secondary sources, such as healthcare professionals, rather than direct input from those with lived experience. This omission raises concerns about the accuracy and inclusivity of current protocols for and understanding of autism within this population. To address these gaps, a systematic review will be undertaken to inform the development of research questions and objectives guiding this thesis. The findings will contribute to improving diagnostic practices and support systems for women with autism and intellectual disabilities, promoting more inclusive and equitable clinical approaches.

How Do We Conceptualise Development?

Over the past century, academics have devoted considerable efforts and resources to unravelling the intricacies of human development, seeking to define developmental features and trajectories that characterize the concept of ‘typical’. Several seminal theories that attempt to explain and model this pathway of ‘typical development’ have been proposed over the last one-hundred years, identifying key milestones and factors that may influence it. Jean Piaget, for example, suggested four developmental stages that humans progress through where different cognitive processes emerge and mature (Piaget, 1921). By acquiring these skills, he argued, children construct an understanding of the world around them, progressing through the stages as they encounter discrepancies in their world (McLeod, 2018). Whilst, at the time of its creation, Piaget’s theories were met with praise and acclaim they nevertheless came with limitations, particularly with regards to skills presenting in distinct stages rather than developing continuously throughout childhood. It was this that brought forward concepts of social development popularised by Lev Vygotsky, who placed importance on the environment that humans inhabit and the opportunities for social interactions that arise within it (Vygotsky, 1978). Whilst these names are known to most psychology undergraduates, forming part of university teaching programmes across the United Kingdom (UK), ideas around development have reached mainstream society too, with discussions around the influence of both nature and nurture regularly being debated in relation to particular behaviours that individuals may engage in. With this research in mind, typical development may be defined as one acquiring and utilising specific skills and abilities at particular stages of their early life.

Hypotheses such as these have provided the foundations into what we now consider the typical, yet they have also inadvertently provided researchers and health professionals with an avenue to explore and support those who do not fit into this category or meet these milestones: that of the *'atypical'*. Atypical development, defined in this context as a delay, deviation or absence of meeting the milestones mentioned by those above (Brown, Parikh & Patel, 2020), brings with it a storied history of discrimination and persecution stretching beyond theories of staged or social development. Whilst researchers such as Piaget only began to define these processes in the early 1900s, documentation of society's view towards those considered atypical suggests the presence of a negative lens at least two-hundred-years prior. A 2012 book edited by researcher David Race, in partnership with clinical and research contributors, identifies a stream of UK laws suggesting that individuals who developed atypically were seen as a threat to establishments across the world, disrupting the progression brought about by the industrial revolution and the perceived need to have as many 'profitable' members of society as possible. Examples include the 1853 Lunatic Asylums Act, which gave authorities the power to *'immediately apprehend'* those considered to be atypical, as well as the 1886 Idiots Acts which permitted detention of this group within hospitals and asylums. As Malthus argues, these laws restricted the freedoms of this community, decreeing them a "drain" on valuable resources, segregating them to workhouses and placing restrictions on those that supported them (Malthus, 1798). Indeed, even the words included in these policies, *'feeble minded'*, *'idiot'*, '*fool'* and *'imbecile'* further emphasise the viewpoint of the typical towards the atypical, even defining the diagnostic labels of the Mental Health Deficiency Act, published as recently as 1913. The systemic stigma directed at this community would culminate in the popularisation of Eugenics which *'sought to improve human qualities through selective breeding'* (Galton, 1883) and, by extension, eliminate those who developmentally deviated. Across the world mass genocides were conducted on this population (Burleigh, 2000), compulsory sterilisation was implemented (Tannsjo, 1998) and further emphasis was placed on making the group an underclass, unworthy of support, empathy or health provision. This continues to be evident in the present day where UK health provisions offer checks for whether individuals with be born 'atypically'. A systematic review on the use of amniocentesis, which screens for several foetal 'abnormalities', found that 67% of expectant mothers terminated their pregnancy having received a positive result (Natoli, Ackerman, McDermott & Edwards, 2012). This evidence highlights the negative perceptions held towards those who are seen to develop atypically, both historically and in present day systems.

Despite strides being taken to challenge these problematic narratives and beliefs around those considered 'atypical', early iterations of these ideas came with problems of their own. The concept of normalisation for instance, first posited in the 1960s, aimed to integrate 'atypical' individuals into wider society, but by imposing measures on them, resulting in an assimilation into what was culturally 'normal' rather than developing specific provisions around the population's needs. A paper by Culham and Nind (2003), for example, considered the movement of normalisation and its effect on those it was hoping to impact, finding that systems and structures did not significantly adapt to meet the needs of those thought to be atypical during its implementation with many of its measures felt to be prescribed rather than chosen. Recent guidelines defining the abnormal suggest stigma towards this group still exist in modern day. The Diagnostic & Statistical Manual (DSM) and the International Classification of Diseases (ICD), documents used to identify characteristics of mental health conditions in the United States (US) and UK respectively, used the pejorative term ‘retarded’ to define atypical development up until their most recent editions published in the 2010s. This wealth of evidence highlights the historical challenges that those who fit into ‘atypical development’ have faced in being understood and supported as well as the problem-focused narratives imposed upon them by the ‘normally’ developed. Today, many of those who are viewed as having developed atypically fall into categories in the DSM-V and ICD-11 classification under the heading Neurodevelopmental Disorders.

Neurodevelopmental Disorders & Neurodivergence

Autism Spectrum Conditions

Neurodevelopmental Disorders are defined by the American Psychiatric Association (APA) and in diagnostic manuals mentioned above as a group of conditions involving challenges with the acquisition of specific skills during the aforementioned stages of typical development (World Health Organisation, 2022). However, a term commonly utilised by those with neurodevelopmental conditions is neurodivergence, popularised by neurodivergent academics such as Judy Singer in the 1990s and, more recently, author Steve Silberman to begin challenging deficit-based language and encourage acceptance as a neurological difference rather than a disorder (Singer, 1999; Siberman, 2017). As such, given that these are the terms used by many neurodivergent individuals themselves, this will be used forthwith. One such neurodivergence are those which fall under the label Autism Spectrum Conditions (ASC), referred to as Autism Spectrum Disorder (ASD) and Autism within the field. ASC, defined here as distinct differences in social communication and interaction alongside patterns of restrictive, repetitive behaviour, has been within psychological nomenclature since 1911 when it was first used alongside descriptions of severe presentations of schizophrenia (Bleuler, 1911). However, features that would go on to fit its definition were noted years prior with similar negative characterisations to atypical development made of them. John Down, for example, described in 1887 those who would subsequently fit an autism diagnosis in the future as having '*developmental retardation*' or being '*idiot savants*' who had general deficits in cognitive ability but strength in a particular area of interest (Down, 1887). Bleuler's definition would continue to be used amongst health professionals until the 1960s when, alongside the societal shift towards 'atypical' normalisation, ASC was reconceptualised as its own distinct presentation considered as an inability to fantasise rather than the more Freudian withdrawal into fantasy (Evans, 2013). Prevalence figures for ASC have rapidly increased since these initial descriptions from estimates of 1/25,000 children in the 1960s to a recent systematic review finding that 161/25,000 individuals receive a diagnosis, a 16,000% rise (Zeidan et al. 2022). This trend is further corroborated by recent data from the UK's National Health Service (NHS), which reported a 34% increase in open referrals for ASC assessment between July 2021 and July 2022, totalling over 125,000 individuals awaiting evaluation (NHS, 2022). Reasons for this increase are mixed with some suggesting the shift towards evidence-based practice resulted in ASC becoming more objective and measurable whilst others posit a reduction in stigma towards neurodivergent communities and greater accessibility of assessment and screening tools. In spite of this, over 84% of these referrals for assessment had been open for at least three months, surpassing the recommended timeframe outlined in the National Institute for Clinical Excellence (NICE) guidelines for assessment initiation (NHS, 2022). As recently as September, 2024, a publication by the National Autistic Society put these figures even higher with nearly 205,000 waiting for an assessment and nearly 200,000 waiting past the recommended timeframe (National Autistic Society, 2024). This underscores not only the challenges for UK healthcare services in meeting this burgeoning demand for assessment and diagnostic services but also continued review and redevelopment of tools, measures and services for identifying and supporting ASC populations in the UK.

The challenges professionals and their services face are compounded by differences in how ASC manifests in different individuals and the underlying historical assumptions and stigmatisation that remains today. Early in its history, Autism was thought to be primarily a male disorder with women both denounced and positioned as responsible for causing the condition rather than having the condition themselves. In one of its original classifications, Leo Kanner posited the ‘Refrigerator Mother’ theory, suggesting that Autism was caused by distant parents, particularly mothers, who failed to form secure attachments with their children (Kanner, 1943). These theories were expanded upon in the proceeding years by Bettelheim, drawing upon Freudian psychoanalytic practices which, whilst popular in post-World-War Britain, drew criticism from researchers and parents of autistic children at the time for its misogynistic language and attitudes towards women and, subsequently, trans and non-binary communities (Courcy & des Rivières, 2017; Rimland, 1968). Whilst these theories continued to be challenged by seminal writers of the time, such as Lorna Wing and Judith Gould who would go on to define the classification for ASC used still today (Wing & Gould, 1979), views around autism’s origins and its presentation still permeate the discourse with respected authors such as Simon Baron-Cohen proposing a the ‘extreme male brain’ theory of ASC as recently as the turn of the millennium (Baron-Cohen, 2002). In this, he describes how those with the condition fit into an “extreme male profile with a desire to systemise and an inability to empathise”; a postulation that has been met with similar criticism from his contemporaries (Ridley, 2019; Krahn & Fenton, 2012). It is difficult to quantify the effects that these historical and research biases have had on diagnosing both men and women with the condition. However, prevalence rates and figures suggest that men have typically been diagnosed in greater numbers compared to their female counterparts. A study by Sun and colleagues identified that, in general populations, the ratio of men to women diagnosed with the condition is approximately 3:1 (Sun et al. 2014) whilst in clinical samples, this figure is higher at 4:1 (Fombonne, 2009). In addition, research with women with ASC have suggested that this group is typically misdiagnosed with other mental health presentations prior to receiving a diagnosis of autism itself. A study by Bargiela, Steward and Mandy interviewed fourteen women with ASC who had received their diagnosis after the age of fifteen, finding through a framework analysis a theme of participants being told that they were not autistic and being given labels such as depression, anxiety and personality disorder by professionals instead (Bargiela, Steward & Mandy, 2016). More recent findings corroborate this research, with a cohort study examining sex differences in autistic adults finding that female individuals with ASC were at higher risk of psychiatric diagnoses and were nearly twice as likely to be hospitalised compared to men (Martini et al. 2022). This evidence suggests that women with ASC experience unique barriers to do with their ASC diagnoses compared to their male counterparts. As such, a new area of study has developed to better understand these idiosyncrasies and why they might exist, leading to the theorising of what is known as the Female Autism Phenotype.

The Female Autism Phenotype (FAP) was introduced as a concept as early as 1992 but has become more prominent in autism research in the past decade. Theorised by Kopp & Gilberg (1992) FAP posits that autistic women and those presenting as female have traits similar to that of their male counterparts but express them in different ways that are harder to identify. Subsequent studies comparing the experiences of men and women with autism have provided support for this initial hypothesis. A study by Rynkiewicz and colleagues (2016) compared Polish boys and girls with ASC diagnoses on sections of the Autism Diagnostic Observation Schedule (ADOS), the gold-standard of autism assessment used in the UK. Their results found that girls with ASC made use of non-verbal communication in a more neurotypical manner compared to boys, potentially leading to lower ADOS scores which the authors claim result in subsequent under-diagnosis of autism in this population. Further differences were noted by Sedgewick et al. who found that adolescent girls with ASC showed comparable motivation to adolescent girls without ASC to form friendships and engage with others. In contrast, boys with autism reported having less drive to socially connect when compared to those without, providing further evidence for the FAP's existence (Sedgewick et al. 2016). This research goes some way to explain why the prevalence rates found above are so heavily weighted towards males who exhibit ASC in not only a way that is more explicit but also fits with what professionals and researchers consider a 'typical' presentation.

Criticisms of the FAP suggest that it is too binary, inhibiting men and boys who exhibit more implicit features of ASC from being recognised. In spite of this, it has provided the foundation for experiences of women with the condition to be heard in both the research field and wider society, challenging the historical narratives regarding who can have ASC. This has, subsequently, led to the emergence of social masking as a concept, where an autistic person intentionally or unintentionally suppresses certain behaviours relating to their condition in order to avoid prejudice and judgment from 'typical' individuals (Lai et al. 2011). First-hand accounts from women with autism provide examples and experiences of masking including copying and mimicking the behaviours of those around them (Miller, Rees & Pearson, 2021), using compensatory strategies such as forcing appropriate eye contact with others (Hull et al. 2017) and even descriptions of exhaustion from prolonged periods of covering up their ASC, leading to increased risk of self-harm and suicidal ideation (Bradley et al. 2021). Indeed, a recent article published by the British Psychological Society identified a new condition relating to social masking known as ‘Autistic Burnout’ with a measure created alongside its classification (Arnold et al. 2023). Diagnostically, reports from direct caregivers of children with ASC suggest that masking may play a role in the challenges faced during assessment. A study by Navot, Jorgenson & Webb (2017) investigated the experiences of eleven mothers of girls with ASC between the ages of ten and nineteen. Their results suggested that mothers experienced exclusion from both neurotypical and ASC populations, as well as being met with scepticism from clinicians when bringing their daughters to be assessed. Further research by Mademtzi, Singh, Shic & Koenig (2018), who also interviewed parents, found that caregivers felt the need to exaggerate their female child’s difficulties in order to move through the diagnostic process, potentially suggesting the presence of clinician bias but also a greater ability for females with ASC to mask their autistic traits. Psychological thinking around the purpose and origins of masking is still in its relative infancy, but emerging ideas are closely intertwined with the stigmatized history associated with both ASC and Atypical development. Pearson and Rose completed a conceptual analysis of the phenomenon, attempting to understand masking through the lens of social identity theory where individuals form their identities based on their group memberships, comparing themselves to others both in and out of their group (Tajfel & Turner, 1979). They argued that masking was a response from women with ASC existing in the context of disparagement and the deficit narratives surrounding atypical individuals as highlighted above, leading to a tendency for individuals with this condition to mask and assimilate in order to adhere more closely to the larger ingroup of neurotypicals (Pearson & Rose, 2021). Whilst acknowledging some of Pearon & Rose’s arguments regarding masking’s aim to adhere to ingroups, other authors frame it more as a social strategy, requiring a seemingly large amount of complex cognitive processes to understand one's own feelings, those of others and their potential views regarding the label of ASC and the features it manifests. Given these deficit-focused narratives, it has been thought that this level of understanding was beyond a person with ASC's capabilities and, more broadly, beyond that of an individual believed to be developing atypically. However, the findings above began to challenge the historical negative narratives around ASC, showcasing the potential, abilities and strength of the population whilst highlighting the shortcomings of systems created by the 'typical'.

Intellectual Disability

Co-occurrence is a common feature of neurodevelopmental disorders, with significant research highlighting overlapping characteristics and frequent dual-diagnoses. One particularly prominent example is the intersection between ASC and Intellectual Disability (ID). ID is defined here as a global impairment in cognitive and adaptive functioning, present before adulthood, and affects approximately 2–3% of the general population ranging from mild to profound, though only about one in four individuals with ID fall into the severe or profound category (Patel et al., 2020). Diagnostic guidelines published by the British Psychological Society (BPS) emphasize the importance of exploring different aspects of functioning and recognizing diverse profiles strengths within the ID population. Whilst earlier research often relied on intelligence quotient (IQ) scores of 70 or below to define ID, there has been a recent move toward recognising individual areas of strength and specific needs for support (Lee, Cascella & Marwaha, 2023).The co-occurrence of ASC and ID has received sustained attention in the research field, though estimates of its prevalence vary widely depending on methodology, sampling and our evolving understanding of these conditions. For instance, an analysis of 2011 UK census data suggested that 30% of individuals with autism also had an intellectual disability (Rydzewska et al., 2018). This figure aligns with recent data from large-scale US surveillance studies, indicating that between 32-38% of children with autism also having ID (Maenner et al. 2023). However, a localised South Carolina study involving over 2,000 children reported a prevalence rate of nearly half this figure just seven years prior (Tonnsen et al., 2016) whilst older NHS data suggests that up to 70% of autistic individuals in the UK had co-occurring intellectual disabilities. It is possible that these figures reflect historical diagnostic practices rather than current trends (Newschaffer et al., 2007). Indeed, recent figures published between 2016 and 2021 by the NHS indicate that the proportion of individuals with both ID and ASC has increased from 19.8% to 28.6%, suggesting potential improvements in recognition and, perhaps, less societal stigmatisation of neurodivergence and disability as a whole (NHS, 2016; 2021). More interesting still, studies investigating the populations with ASC-ID have found differences compared to those with solely ASC, both in prevalence and behavioural presentation. Yeargin-Allsop & colleagues (2003) studied the rates of autism amongst nearly 1000 children screened and diagnosed by medical and educational bodies. They discovered that the ratio of boys to girls diagnosed with autism was 4:1, in line with Fombonne and colleague’s findings above, but this shrunk to 2:1 when an ID was also present. It is also notable that a higher proportion of females with ASC are found to have an ID when compared to males, with some studies estimating 46% of women compared to 37% of men (Children's Hospital of Philadelphia Research Institute, 2020). Further investigation into the behavioural differences noted in this population may provide some explanation as to this shrinkage. A critical review by Matson & Shoemaker (2009) aimed to collate the existing research around ASC-ID at the time of publication. They noted that individuals with ASC-ID presented with greater deficits in social and adaptive behaviour as well as greater observation of behaviours that challenge as the severity of an ID increased. When taken alongside prevalence statistics above, as well as the presentations of ASC identified without ID highlighted, these issues suggest that there may still be a risk of underrepresenting the true frequency of neurodivergence in those with ID, particularly women. This evidence implies that ASC-ID individuals, regardless of their gender identity, present in a unique manner as a result of their co-occurring presentation which may be more conducive to the current diagnostic classifications. When considered alongside the emerging field of social masking, this further emphasises the need to investigate the potential contributing factors that may result in this unique manifestation presenting.

Despite these discrepancies, it is evident that ASC-ID co-occurrence is significant and warrants attention in both clinical and research contexts. Given its prevalence, one might assume that individuals with ASC-ID would feature prominently in the field to ensure findings are representative of neurodiverse communities. However, this is not the case and research on intellectual disability has often been overlooked within clinical psychology. A review of over 500,000 abstracts spanning two decades found that, while ID was a trending topic, it was also frequently grouped with other neurodevelopmental disorders or mental health conditions like ASC and OCD, preventing individual examination of its features and nuances across its population (Wieczorek et al. 2021). This pattern extends to inclusion in autism-specific studies. A cross-sectional review by Ginny Russell and colleagues (2019) examined over 300 studies involving more than 100,000 participants published in autism-focused journals. Their findings revealed selection bias in 80% of the papers reviewed; only 6% included participants with an ASC-ID presentation and, more alarmingly still, over 100 studies failed to mention participants' intellectual abilities altogether. Similarly, Stedman et al.

(2019) observed a decline over two decades in the inclusion of participants with more pronounced deficits in cognitive ability, adaptive functioning, and communication skills. Work by Bishop and colleagues (2024) aimed to better understand why this disparity exists, with their mixed-methods study identifying barriers such as inaccessible study designs, limited knowledge about obtaining informed consent and assessing capacity in individuals with ID, and resource constraints like time and funding (Bishop et al., 2024). Although these studies have limitations such as narrow research parameters and potential bias in defining selection criteria, they underscore the urgent need for greater inclusion of ASC-ID individuals both as research participants and as a focus of investigation. Addressing this gap is essential for ensuring that findings are generalizable to neurodiverse populations and for advancing our understanding of how best to support individuals with ASC-ID specifically.

To summarise, individuals with neurodevelopmental conditions (and more broadly those considered ‘atypical’) have experienced historical stigmatisation both in the research field and wider society. Existing research suggests that two of these, ASC and ID, have a high rate of co-occurrence with one another yet are under-represented in the research literature. To compound this, first and second-hand accounts have noted differences in how typically developing women with ASC present compared to men, leading not only to a misrepresentation of the current diagnostic statistics available, but also questions raised about the quality of assessment tools for the condition across various populations. Given the limitations highlighted regarding conducting research with ID communities, very little research exists investigating whether specifically ASC-ID women present in a manner similar to that of either women or other groups with ASC diagnoses. The current paper, therefore, aims to explore how this population manifests their autistic profiles. Beginning with a systematic review of the current literature to generate appropriate research questions, the research will hope to go one step further by speaking with those working in NHS ID services, gathering their experiences of working with women with ASC-ID in clinical settings to see if the FAP is translatable to the ID population. It is hoped that both the review and synthesis of current literature, as well as the study itself, will shed some light on this under-researched group, providing further insight on what services and clinical staff can implement to improve both diagnostic and health outcomes for this group.

Chapter 2: Systematic Review of Existing Literature

"There is no one type of autism because autism is like a fruit salad. For each person diagnosed with autism the fruit pieces in that fruit salad can be many or few, big or small, exotic or common" – **Donna Williams, Australian author and autism advocate**

Chapter Summary

This chapter presents a systematic review conducted to inform the research questions and aims of the current thesis. Initial exploration of the literature revealed a scarcity of studies focusing on the direct diagnostic and therapeutic experiences of individuals with both ASC and Intellectual Disabilities. Given this limitation, the review instead examined the perspectives of clinicians involved in assessing and diagnosing ASC in the general population, using their expertise in autism and familiarity with diagnostic tools. A meta-ethnographic approach was selected to address the research question: ‘What are the experiences of health professionals assessing for Autism Spectrum Conditions?’ The review process identified 3 overarching themes emerged: Clinical Competence, Systemic Constraints, and Sociocultural Context. These themes were integrated to generate insights into the challenges and influences shaping diagnostic practices. The chapter concludes by outlining the research questions generated from the synthesis, which will guide the subsequent empirical study. These findings contribute to improving autism assessment practices, particularly in populations with co-occurring intellectual disabilities.

Rationale of Literature Review

The complex interplay between ASC and ID presented a significant challenge when considering areas for systematic review. Initial explorations into this field revealed a paucity of studies directly involving individuals with ASC-ID, particularly when considering specific aspects such as the presentation of ASC in ID individuals or its manifestation in women. Searches specifying particular aspects of ASC-ID yielded up to one hundred results from research platforms but often produced papers that either did not focus directly on this group or included participants with other neurodevelopmental comorbidities. A preliminary search including terms around ASC, ID and experiences of health services, for example, produced papers outlining prevalence studies for individuals with ID only and trials of health checks for adults with ASC only. This scarcity of research, coupled with the inherent difficulties in conducting direct interviews with the ASC-ID community, resulted in a shift towards the experiences of caregivers, specifically professionals working within services and systems involved in the assessment of individuals with ASC.

Previous research has identified the substantial level of support required by the ASC-ID community from healthcare and educational services. A study of 248 children with an ASC-ID dual-diagnosis demonstrated higher support needs across various domains, including home life, schooling, and health and safety, compared to neurotypical children and those with ASC alone (Guillén et al. 2023). Whilst the lack of reported effect sizes limits the interpretation of these differences, the findings align with broader legislative recommendations by NICE emphasizing the need for multi-disciplinary approaches to ID healthcare and specific educational plans. Focusing on the experiences of clinicians involved in screening and assessing ASC, therefore, offered several advantages. These professionals are not only able to identify barriers or challenges faced in practice but also provide a well-informed perspective on the presentation of ASC. Their training in administering assessment tools and familiarity with diagnostic criteria placed them as valuable sources of insight into the complexities of diagnosis, including that of dual or co-morbid presentations. Furthermore, investigating the experiences of this group helped to address the challenges highlighted by Steadman and colleagues (2019) in conducting research directly with the ASC-ID population, allowing for a more feasible and ethically sound method of gathering rich, informative data on the diagnostic process and its challenges. This approach not only circumvents methodological barriers but also leverages the expertise of professionals, enrichening the research field as a whole. The insights gained from the review would, therefore, hope to inform best practices, improve diagnostic accuracy, and enhance the quality of care provided to those presenting with ASC.

Design

Meta-ethnography was chosen as the most suitable approach to integrate concepts across studies, thereby answering the question: “What are the experiences of health professionals assessing for Autism Spectrum Conditions?” First posited by Noblit & Hare, meta-ethnography is one of the most frequently utilised synthesising strategies in health research (Noblit & Hare, 1988; Hannes & Macaitis, 2012). The process requires researchers to examine articles that fit with the area of exploration, using a staged process to uncover overlapping themes and create broad hypotheses. Previous research has shown that this form of synthesis is not without limitation. A review by Campbell and colleagues investigated the approach’s benefits and shortcomings, finding that due to the process’s highly interpretative nature, that it could not be considered a standardised approach as its process involves a high level of influence from the researcher conducting it (Campell et al. 2012). However, given the under-researched nature of the population investigated, meta-ethnography was deemed the most appropriate method to use as theories and concepts could still be developed despite a small number of research papers (France et al. 2014; Atkins et al. 2008).

Inclusion Criteria & Search Strategy

In an effort to develop a comprehensive understanding of the posed review question, the criteria for study inclusion were purposefully broad with the exception of including a term around gender and sex. No time limit was imposed regarding when studies could be published in order to gauge a broad representation of assessment experiences across ASC's conceptualisation. Given the nature of both the review question but also the wider contextual history of ASC as mentioned in the previous chapter, it was important that a search term connecting women with ASC was used in the hope that articles considering the experiences of autistic women were reflected. This did not factor any further into exclusion criteria with male and female clinicians being included as well as discussions around both men and women who were screened with comparisons welcomed. Qualitative studies that interviewed professionals from various disciplines, regardless of their specific roles, were included, intending to capture a diverse range of experiences and perspectives and allow for the potential identification of unique challenges faced by different fields. Recognizing the frequent co-occurrence of neurodevelopmental conditions with ASC, studies that distinctly identified and mentioned these co-occurrences were also considered. This decision was grounded in the understanding that these co-occurrences can significantly impact the presentation of social communication difficulties, a hallmark of ASC. Age restrictions were intentionally avoided, ensuring that experiences related to screening and identifying ASC in children, adolescents, and adults were all given a voice. This decision was informed by the varying reports on typical ages of diagnosis, with some studies suggesting an average age of around five years old (Howlin & Moore, 1997; Crane et al. 2018), while others point to a more recent trend of diagnosis occurring in adolescence (Russell et al. 2022). By embracing this age spectrum, the review aimed to capture the nuances and challenges that may arise at different developmental stages. Moreover, this this inclusivity acknowledged the potential for vastly different experiences between those diagnosed in childhood versus adulthood, as well as the varying durations of challenges faced by individuals with underlying ASC. Rather than viewing this as a limitation, it was seen as an opportunity to gain a deeper understanding of the broader diagnostic journey by casting a wide net and embracing diverse perspectives.

Cooke and colleagues' SPIDER tool (See Table 1.) was used to ensure that an accurate, efficient and specific search of literature was conducted (Cooke, Smith & Booth, 2012). In quantitative research, the PICO tool is a gold-standard for identifying relevant studies for review, breaking down clinical questions and characteristics into searchable words and phrases (Richardson et al. 1995). However, when translating to qualitative study, the PICO has been found to be more limiting. Alison Cooke and colleagues have highlighted how each heading of the PICO does not accurately overlap onto qualitative study and can lead to additional research time and resources eliminating quantitative papers from searches. To address this gap, the SPIDER tool was created, adapting the PICO components to make them more suitable for qualitative approaches. The research question above was separated into its components to accurately and effectively include all relevant studies during searches. Particular attention was given to the sample due to the wide range of professions potentially involved in screening, assessing and diagnosing ASC. This was completed in tandem with the generation of appropriate key words and phrases.

Table 1 Summary of Search Terms for meta-ethnographic synthesis in SPIDER format from Cook et al. (2012)

SPIDER Headlines	**Search Terms Used**
Sample	clinician* or health professional* or nurse* or physician* or doctor* or therapist* or psychologist* or practitioner*
Phenomenon of **I**nterest	(woman or women or girl* or female*) and (autis* or asd or asc or autis* spectrum disorder) and (screen* or assess* or diagnos*)
Design	interview* or survey* or focus group* or qualitative*
Evaluation	experience* or perception* or attitude* or view* or perspective*
Research Type	Qualitative Research or Qualitative Study or Qualitative Methods

The final terms were placed into an electronic search, utilising appropriate databases. These included: APA PsycArticles, APA PsycInfo, CINAHL Ultimate, MEDLINE Ultimate, OpenDissertations and E-Journals. The final search (conducted on 05/02/2025) yielded 221 works. Page and colleague's Preferred Reporting Items for Systematic Reviews & Meta-Analyses (PRISMA) tool was utilised to refine the papers that were to be included in the final review (Page et al. 2021). Initially developed in 2009, the tool provides guidelines on refining relevant papers for systematic reviews and has been found to be cited in over 60,000 published papers since its initial release (Scopus, 2020). 44 studies were identified as duplicates and removed from consideration either automatically by the search engine used or manually. Titles of each study were scrutinised in order to determine whether articles would meet the criteria for selection. If further investigation was required, abstracts were also screened.

Further exclusions took place as a result due to a variety of factors including other aspects of neurodivergence being focused on, such as ADHD, utilising solely samples of caregivers other than health professionals and clinicians such as family members and utilising methodology that did not fit a qualitative design. Upon investigating the remaining sixty-nine articles in depth, it became apparent that, whilst some referenced clinical experiences of using interventions with individuals with ASC, they did not speak directly towards the process of assessment and diagnosis. Following this process, time was given to conduct a citation search from the remaining article's reference list with nine relevant works found to meeting criteria and chosen for the final synthesis: Barbaro et al. 2023; Buck et al. 2024; Cumin, Pelaez & Mottron. 2022. Fenikilé et al. 2015; Garg et al. 2018; Hamp et al. 2022;

Hayes et al. 2022; Hurt et al. 2017 & McLinden & Sedgewick, 2022. Figure 1 summarises the process of conducting this search in a PRISMA Flow Chart below:

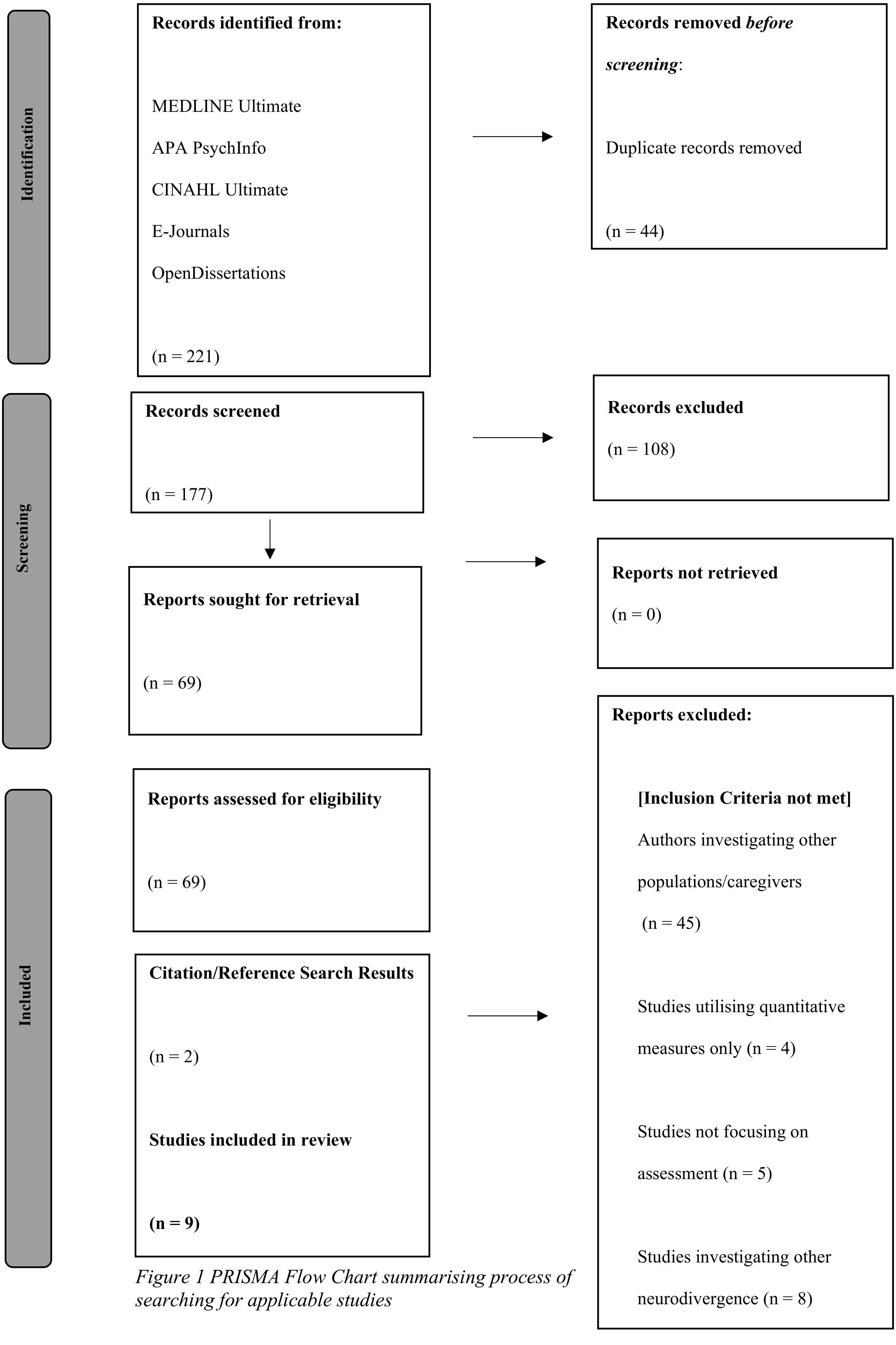


Figure 1 PRISMA Flow Chart summarising process of searching for applicable studies

Results

Quality Assessment

The nine identified studies were subject to an assessment of their quality, utilising the Critical Appraisal Skills Programme (CASP) tool (Singh, 2013). The most commonly used tool for evaluating health-related studies, CASP is recommended for researchers who are novel to qualitative study, posing ten questions to consider when analysing a research paper (Long, French & Brooks, 2020). Articles mainly fell short on questions six and seven by not reporting or considering the relationship between research teams and participants and with respect to the reporting of ethical considerations with only one study detailing some of the ethical considerations that factored into the study design and procedure whilst the majority simply cited the board which approved them. To build on the information collected from the CASP, the papers were read and re-read in order to understand other aspects where they showed strength as well as where they were lacking. On the whole, the studies defined a clear research aim, utilised a methodology appropriate to meeting it and analysed collected data rigorously. However, difficulties arose across many in terms of sampling, both in its quantity and quality. Papers were susceptible to the typical limitations of qualitative research with regards to the number of professionals included ranging from seven (McLinden & Sedgewick, 2022) to twenty-eight (Hamp et al. 2023) participants in the final samples. Furthermore, the majority of studies recruited participants from Western countries including Australia, America & the UK leaving them susceptible to sampling bias and poor generalisability. Limitations concerning the use of small samples sizes and specific countries are well documented, acknowledging both the intense nature of qualitative data collection but also its potential failure to capture the full range of experiences of a population (Nogueira &

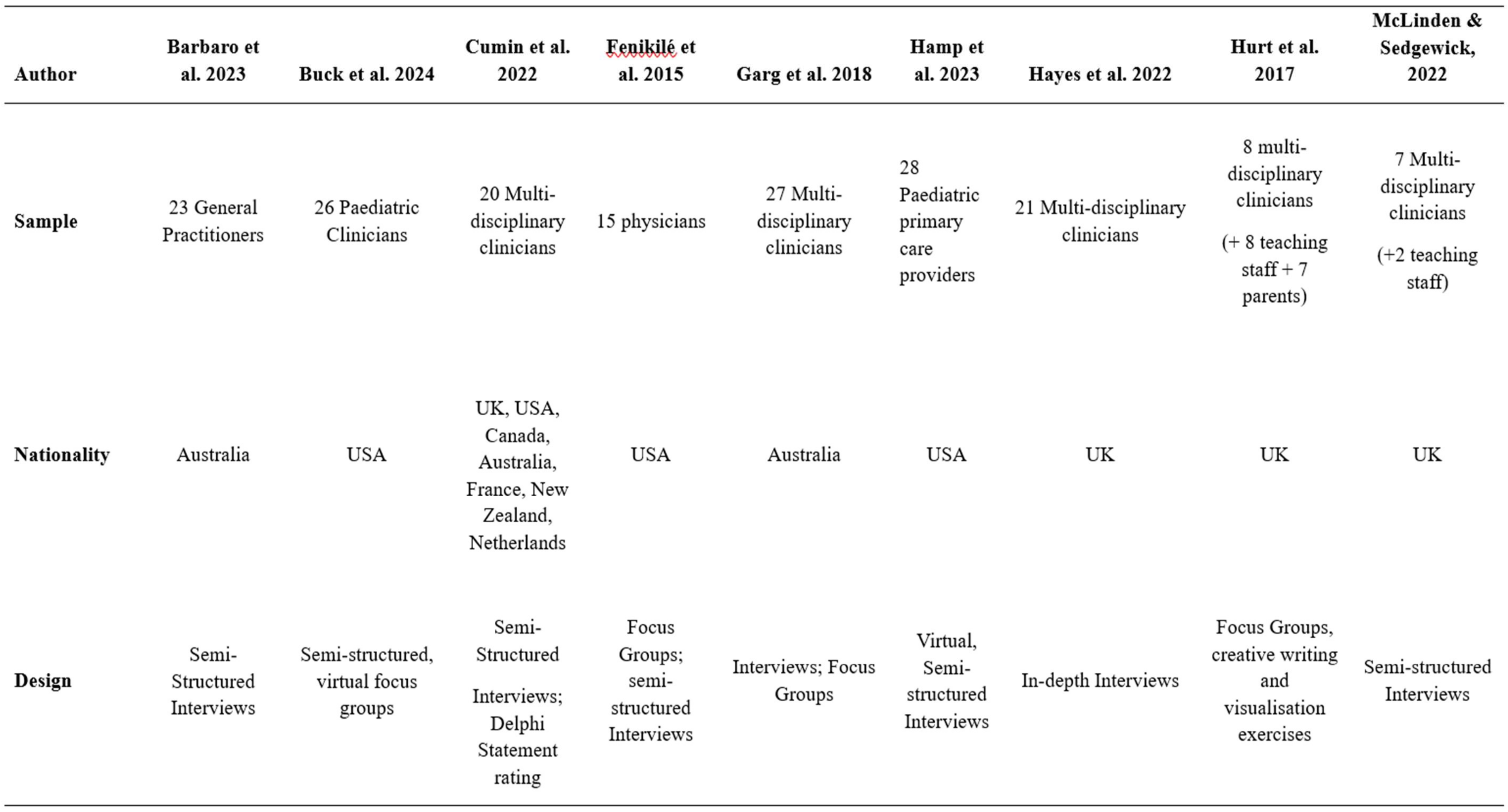
Ribiero, 2023). The use of participants solely from western, educated, industrialised, rich and democratic (WEIRD) nations has only recently been questioned. However, emerging data has identified inconsistencies in participant backgrounds represented in published works, with 80% of psychological research being from WEIRD countries despite them making up just 12% of the population (Henrich, Heine & Norezayan, 2010). Though the numbers of participants able to be recruited in qualitative research is a longstanding issue, it is clear that the articles searched could have improved in their attempts to include participants from other backgrounds.

Further issues surfaced with regards to the professions that took part in the studies. Papers either utilised a multi-disciplinary pool (Buck et al. 2024; McLinden & Sedgewick, 2022; Cumin et al. 2022; Hayes et al. 2023) or focused on one particular group of professionals such as doctors of various specialisations (Fenikilé et al. 2015; Barbaro et al. 2023; Hamp et al. 2023). Previous research has highlighted the risk of bias when using single discipline participant pools with a critical review by Levin & Herrnstein finding that its use can result in narrow, biased perspectives that fail to acknowledge other narratives or explanations (Levin & Herrnstein, 1977). A more recent paper by Levy provides further support for this argument, contending that experts bring vested interests to the research process and can be interested in particular outcomes with regards to policy or service user wellbeing (Levy, 2017). This evidence suggests that some articles, particularly those utilising one group of professionals, may be influenced by a particular narrative of said profession. The results of the CASP, combined with the more in-depth scrutiny suggest that these papers, whilst suitable in their methodology and design, demonstrate typical limitations found in qualitative research with regards to sampling as well as not clearly acknowledging potential underlying biases from researchers and participants alike. However, it is important to acknowledge the relative strengths of these works. All papers are focused on building an emerging research field, addressing gaps in the current literature specifically the diagnosis of ASC in women and the direct experiences of clinicians working with them. In addition, the use of exploratory, qualitative methodologies through semi-structured interviews have been found as helpful for allowing novel areas of study to be explored without the development of new quantitative measures that require validation and reliability tests (Weismayer & Pezenka, 2017). Holding in mind the limitations noted, the papers were deemed suitable and included in the final synthesis, representing a section of the research field that is still in its relative infancy.

Identifying Associations & Translations

Key information from the selected studies are presented below (Table 2). These were examined through repeated readings to draw out their main findings, an example of which can be found below (Table 3). Remaining tables can be found in Appendix 1. To identify common themes across the samples of health professionals, the papers were then cross-examined to see if any experiences overlapped or remained distinct from one another.

Table 2 Summarising Key Information from each article selected for meta-ethnographic synthesis



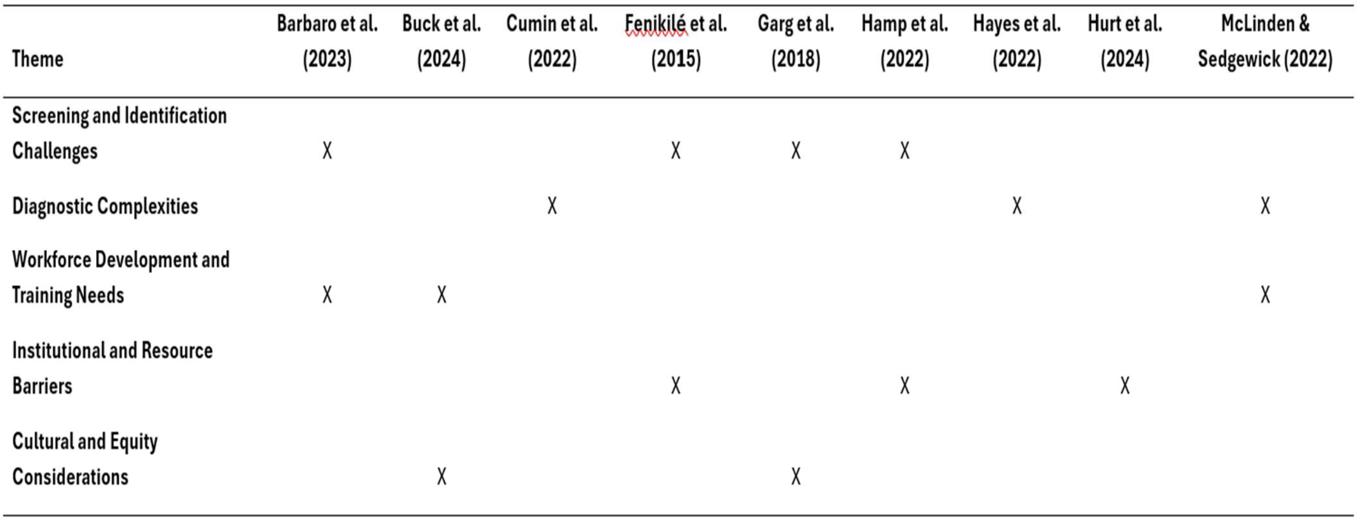
Author	**Barbaro et al. 2023**	**Buck et al. 2024**	**Cumin et al. 2022**	**Fenikilé et al. 2015**	**Garg et al. 2018**	**Hamp et al. 2023**	**Hayes et al. 2022**	**Hurt et al. 2017**	**McLinden & Sedgewick, 2022**
Sample	23 General Practitioners	26 Paediatric Clinicians	20 Multi-disciplinary clinicians	15 physicians	27 Multi-disciplinary clinicians	28 Paediatric primary care providers	21 Multi-disciplinary clinicians	8 multi-disciplinary clinicians (+ 8 teaching staff + 7 parents)	7 Multi-disciplinary clinicians (+2 teaching staff)
Nationality	Australia	USA	UK, USA, Canada, Australia, France, New Zealand, Netherlands	USA	Australia	USA	UK	UK	UK
Design	Semi-Structured Interviews	Semi-structured, virtual focus groups	Semi-Structured Interviews; Delphi Statement rating	Focus Groups; semi-structured Interviews	Interviews; Focus Groups	Virtual, Semi-structured Interviews	In-depth Interviews	Focus Groups, creative writing and visualisation exercises	Semi-structured Interviews

Table 3 Exemplifying the process of summarising key themes, findings and concepts from each chosen article

Author	**Barbaro et al. 2023**
Aims	Evaluate the implementation of an autism screening and surveillance pathway
Sample	Twenty Three General Practitioners
Nationality	Victoria & New South Wales, Australia
Design	Semi-structured Interviews
Themes	
Challenges of Screening	Limited knowledge and uptake of tools amongst GPs
Time Constraints	Lengthened screening times, implementation issues, GP schedules
Systemic Shortcomings	Lack of local workforce, complex systems, socioeconomic factors
Support Needs	Admin Support, GP training opportunities, specific resources for ASC (e.g. tools)
Findings	GPs suggest that clear open communication with staff facilitates timely screening. Systemic issues and time constraints inhibit this with training needs around skill development

The process identified several topics that were noted across the nine studies. Five common themes were uncovered, involving a broad spectrum of clinical experiences assessing and diagnosing ASC. These themes, as well as their occurrence in the articles, are tabulated below:

Table 4 Showing commonly occurring themes across nine selected articles



Theme	Barbaro et al. (2023)	Buck et al. (2024)	Cumin et al. (2022)	Fenikilé et al. (2015)	Garg et al. (2018)	Hamp et al. (2022)	Hayes et al. (2022)	Hurt et al. (2024)	McLinden & Sedgewick (2022)
Screening and Identification Challenges	X			X	X	X			
Diagnostic Complexities			X				X		X
Workforce Development and Training Needs	X	X							X
Institutional and Resource Barriers				X		X		X	
Cultural and Equity Considerations		X			X				

Topics were combined into three broader categories in order express the synthesis in a meaningful and understandable manner. Figure 2 outlines the three categories: Clinical Competence, Systemic Constraints and Sociocultural Context as well as the line of argument explaining their connections. Each broader category is paired with its function as shown in brackets.

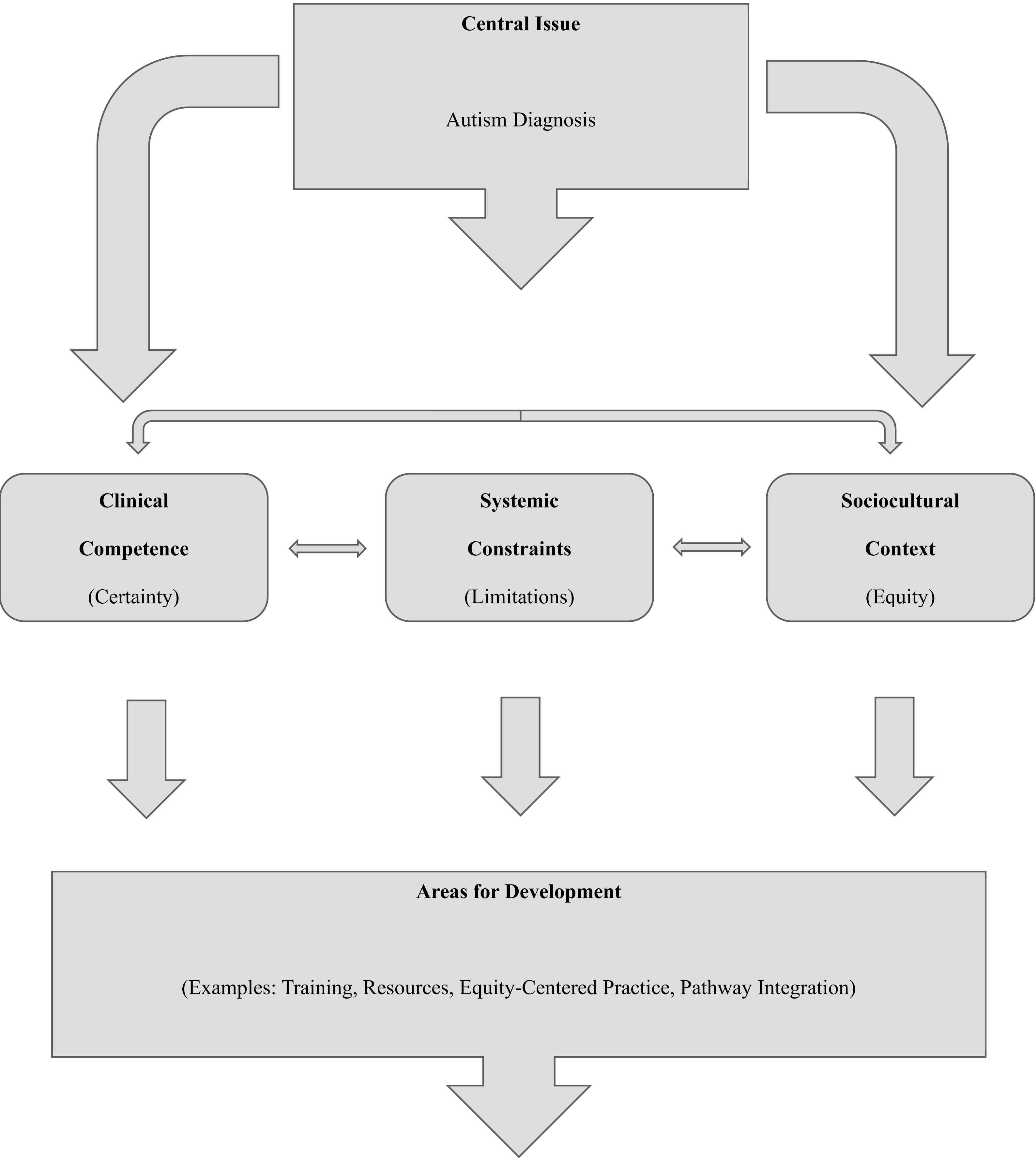

Central Issue
Autism Diagnosis
Clinical
Competence
(Certainty)
Systemic
Constraints
(Limitations)
Sociocultural
Context
(Equity)
Areas for Development
(Examples: Training, Resources, Equity-Centered Practice, Pathway Integration)

Figure 2 Line of Argument Created following identification of common themes and broader categories during ethnographic synthesis

Clinical Competence (Certainty)

Screening Challenges

The nine studies highlighted the difficulties that clinicians across disciplines face when attempting to identify features of ASC in their service users. These were varied with some citing a lack of experience and knowledge of autism-specific tools used (Barbaro et al. 2023; Fenikilé et al. 2015) whilst others commented on the busyness of their services and clinics, preventing these tools from being routinely implemented (Hamp et al. 2022). In addition, one paper provided a critique of the tools themselves, suggesting that the current ones used were not suitable for those from diverse cultural backgrounds (Garg et al. 2018). This theme suggests that professionals working with community members in primary care contexts face challenges even prior to the assessment and diagnostic process, struggling to both identify the features of ASC and effectively utilise the measures to screen for it, a concern that is particularly important given those in primary care having the most frequent contact with the general population.

Diagnostic Complexities

Alongside the challenges associated with identifying ASC in the early stages, articles also referenced the nuances clinicians can face when subsequently assessing individuals with suspected autism. Gender-specific features were noted with professionals outlining the limits of traditional diagnostic frameworks when attempting to recognise more subtle presentations found in women with ASC, particularly those who were both verbal and engaged in social masking behaviours (Cumin et al. 2022; McLinden & Sedgewick, 2022). Others spoke of the variability of guidelines used across different services and how diagnosis itself is influenced by societal norms, expectations and interactions between clinicians and family members and their views of the assessed individual (Hayes et al. 2022). This theme suggests that the prescriptive nature of the current diagnostic frameworks, whilst effective in some ways, may not capture a complete profile of an individual's ASC. In order to improve accuracy with regards to both assessment and diagnosis, it posits that a shift towards more flexible, individualised approaches that account for different contexts and service strengths, may be helpful in simplifying the current complexities.

Systemic Constraints (Limitations)

Institutional & Resource Barriers

While early identification challenges and varied presentations of ASC pose significant difficulties, sampled clinicians also spoke to the broader context of institutional and resource barriers, further complicating the diagnostic process and extending beyond individual clinical practices to encompass regional service provisions and care coordination. Hurt et al. (2024) highlighted difficulties in developing effective referral and assessment pathways, pointing to broader systemic issues in healthcare delivery for ASC. This is compounded by other researchers citing a lack of specialized practices for ASC assessment, leading to overwhelmed teams and significant time constraints placed on the clinicians working within them (Hamp et al., 2022; Fenikilé et al., 2015). This theme underscores not only the scarcity of ASC-specific assessment resources in the analysed works but also the inadequacy of existing structures to efficiently and accurately capture the level of need in the general population. It is as though these systemic barriers create a ripple effect, which does not just impact diagnostic processes but other aspects of care from initial screening to diagnosis and subsequent treatment coordination. Without additional resources, it was felt that these barriers would perpetuate inequities in assessment for ASC.

Sociocultural Context (Equity)

Workforce Development & Training Needs

Despite referencing challenges, both individual and systemic, that contribute to difficulties with provisions for ASC, clinicians also made suggestions relating to what could be provided to address these barriers, thereby developing staff teams and meeting current gaps in training. Clinicians across disciplines and services requested additional education on how diverse presentations of ASC can be, citing a ‘need to update our understanding’ of how the condition can manifest (McLinden & Sedgewick, 2022). General practitioners, who typically sit on the ‘front line’ of contact with the general population, echoed these sentiments and requested training that allowed them to improve detection of possible early signs of what could be ASC (Barbaro et al. 2022). Some participants sought to address some of the wider systemic issues present in institutions, considering how the workforce itself could be altered to ‘reflect[s] the community’ that each team was serving (Buck et al. 2024). This theme emphasize the importance of addressing the current issues within assessment services for ASC, providing ongoing professional development, specialised training and making efforts to increase diversity within the workforce to better represent the populations that are engaging with them.

Cultural & Equity Considerations

Through developing the workforce and addressing felt gaps in expertise, the synthesised articles argued that assessment services for ASC could be improved for service users trying to access it. However, they also emphasised the importance of moving beyond these individual competencies towards being culturally conscious services, thereby allowing for more equitable assessments for ASC to be completed. As stated above, articles spoke to the importance of services being representative of the communities that they encompassed, suggesting that those they worked with from different cultural backgrounds found it easier to engage with the assessment if they were working with someone from their own cultural background or with shared aspects of difference (Buck et al. 2024). Others described the need to recognise context of the individuals they worked with and the wider factors that they may be influenced by such as their location, ability to use transport to access services and the languages that they spoke (Garg et al. 2018). By holding these cultural considerations in mind, as well as the barriers that they cause, the authors believed that more personalised and meaningful assessments could be completed within their service, allowing for equitable diagnosis and provision across the population.

Expressing the Synthesis – Line of Argument

The results of the synthesis suggest a model of the factors that clinicians believe require consideration when attempting to achieve accurate and timely diagnosis for individuals with suspected ASC. They state that professionals must demonstrate competence in understanding what ASC is, the nature of its individualised presentation and the tools used to diagnose it, holding in mind their limitations. These clinicians operate within teams that are under wider systemic constraints, experiencing pressures around level of need, clinical time and lack of specialised provision for the ASC population. As they overcome these challenges, they must also hold in mind the sociocultural context present both within and outside of their services, considering members of the general public from diverse backgrounds who are typically most affected by accessibility barriers. These three pillars provide an equitable, precise and realistic model of what clinicians believe ASC assessment and diagnosis can be. However, the model also provides an understanding of what can occur when one or more of these three pillars fail to be effectively executed. The lack of clinical competence, for example, results in uncertainty amongst professionals of all disciplines, creating difficulties when attempting to identify features of ASC in the early stages. This lack of certainty interacts with systemic constraints, stretching services even further, increasing already felt time constraints and, ultimately, delaying or preventing ASC assessments from taking place. In addition, it stops services themselves from developing, resulting in those from more marginalised groups continuing to experience inequitable care resulting in further underrepresentation and underdiagnosis. The interaction between these pillars (represented by double-headed arrows in Figure 1) is crucial, showcasing not only the interconnectedness between them but also the reliance each has with one-another. This relationships reflects the current fragility clinicians felt about ASC assessment services and the negative impact the system can experience if just one pillar fails. Suggestions within the papers around areas of improvement hope to go some way to altering this model for the better, working towards scaffolding the pillars to prevent future failures and provide a more experienced, confident and representative workforce involved in the screening and assessment processes.

Discussion

The meta-ethnographic synthesis provides a comprehensive overview of clinician experiences when assessing and diagnosing ASC, identifying three overarching categories that shape their points of view: Clinical Competence, Systemic Constraints and Sociocultural Context. These encapsulate the historical and contemporary challenges faced both by the ASC community and the clinicians working with them. The line of argument provides a model for understanding the interplay between these categories, aligning with research referenced in the introduction calling for a more holistic, inclusive approach to understanding and supporting individuals with ASC, particularly those from underrepresented groups. Multi-disciplinary clinicians within the nine articles synthesised stressed the lack of competence they felt clinically when working with ASC, highlighting challenges with effectively screening individuals they encountered in their services and feeling as though the tools that they were provided did not fit the complex and varied presentations that were witnessed in their practice. When considering the evidence presented in the introduction, this finding reflects the evolving understanding of how ASC can present that has recently emerged in the research field. The lack of trust in screening tools to effectively capture all individuals with ASC reflects Rynkiewicz and colleagues' (2016) findings that those outside of the 'typical' presentation, in their case women, score lower on even the gold standard of assessments for ASC and, perhaps, is an echo of biases and stigmatisations during ASC's inception. Kanner's (1943) postulation that women were responsible for causing ASC rather than having it themselves is reflected in the uncertainty that clinicians feel towards their use of the tools with populations that do not fit a 'typical' profile of autism, labelling some as complex or part of another presentation. Based on the synthesis findings, rather than being blamed for causing ASC, women are now implicitly blamed for not fitting into what is considered to be ASC. The findings of stress the need for the continued development and discussion regarding all aspects of the assessment processes, making space for presentations such as the Female Autism Phenotype. In addition, they suggest that a greater awareness of ASC is needed regarding both the history of the condition and its subsequent impact on all individuals and groups with autism.

As well as the challenges associated with using measures required for ASC assessment, clinicians referred to the difficulties that they encountered when operating under restrictions imposed on them by the wider services that they worked in. The category of Systemic Constraints outlines barriers that clinicians faced across different healthcare services, affecting provisions nationwide rather than service-by-service. Issues were raised with regards to the lack of specialised assessment services as well as the level of busyness that professionals were under, subsequently compounding the challenges of accurate and timely diagnosis. When considered alongside the 34% increase in open referrals for ASC assessment in NHS services, the findings provide some explanation as to why timeframes within this context are repeatedly surpassed and many are left waiting for extended periods beyond NHS guidelines. They suggest that clinicians within health services are not as well informed as they could be regarding the nuances of ASC and lack the time and resources required to skill themselves up in order to identify said nuances. The compounding nature of these two factors poses a perpetual cycle that is difficult to break where clinicians continue to feel unskilled to identify features in their service users and have less and less time due to the steady increase of individuals who actively request ASC assessment. The emergence of this category provides further evidence for greater investment into both specialised services for ASC and the NHS as a whole.

Whilst the above provides opportunities for subsequent nationwide service development, the final category stressed the importance of holding in mind sociocultural context during the assessment process, both currently and in the future. Considering workforce development needs and cultural and equity considerations, the category represents clinician views that workforces not only should utilise tools that are suitable for working with individuals from diverse backgrounds but should be representative of the communities that they are working with as a whole. Professionals in the synthesised works built on their assertions regarding the limitations of the current assessment process for ASC, stating that they were not fit for those from culturally diverse backgrounds in their current state. Furthermore, clinicians who came from the same sociocultural context as these individuals highlighted the positive experiences that they had had when they were directly involved in the assessment process, citing the strong rapport that they had achieved. Whilst the previous category of Clinical Competence hints at the presence of the remnants of historical biases around ASC, the current category may imply a more positive outlook for future development of assessment and diagnostic processes for autism as well as other aspects of neurodivergence. In line with both Singer (1999) and Silberman's (2017) aims to challenge deficit-based narratives around ASC, the findings imply that there are benefits when incorporating service-user's context to create an individualised assessment provision, resulting in a more accurate and meaningful assessment experience. Alongside the storied history of the stigmatisation mentioned previously, including those with ID, this evidence notes the importance of holding in mind all aspects of difference, considering ASC as part of identity rather than the whole.

Limitations

The results of the meta-ethnography provide valuable insights into the clinical experience of assessing individuals with ASC. However, like any synthesis, it is not without its limitations, stemming from methodological constraints, the scope of the included studies and long-standing challenges mentioned above in qualitative research. Despite clinicians identifying themes of inclusion and cultural awareness when considering how to optimise diagnostic processes for ASC the papers these experiences were drawn from did not represent populations from diverse backgrounds. All nine studies were conducted in what are typically considered WEIRD countries such as the UK, Australia and the United States, subjecting them and the synthesis to geographical bias. This limitation found during the quality assessment prevents the synthesis from being generalisable to the world's population, potentially overlooking unique challenges faced by other clinicians in underrepresented regions such as few to no diagnostic services for ASC existing or being widely accessible. Future syntheses could specifically look at these regions to identify both similarities and differences identified by the results above, making space in the field for the remaining 88% of the population as highlighted by Henrich, Heine & Norezayan (2010).

Additionally the interpretative nature of the synthesis brings with it its own biases alongside the geographic. Meta-ethnographic synthesis, as highlighted by Campbell and colleagues above, requires a significant amount of interpretation from the researcher conducting it. This leaves the process susceptible to the researcher's personal and professional context and biases influencing the direction of the themes identified, categories conceptualised and line of argument proposed. Previous systematic reviews of meta-ethnographic approaches recommend a collaborative approach, involving two or more researchers in an effort to bring different perspectives during analysis (Lee, Hart, Watson & Rapley, 2015). However, in the case of the current review, this was not possible due to the individual context of the researcher and the requirements needed to achieve the qualification associated with the thesis. Despite this, more could be done with regards to the researcher's reflexivity throughout the process, to keep any potential biases in mind. Whilst Noblit & Hare's (1988) recommendations were followed with regards to repeated reading of papers to ensure that the researcher was familiar with each, this could have been built on using other reflexive techniques that have been reported to be helpful, such as a reflective journal. Future reviews will incorporate these techniques to ensure that factors potentially implicitly influencing the researcher can be acknowledged and addressed, allowing for a more comprehensive and objective synthesis of participant experiences.

Finally, the focus on the accounts of clinicians prevents the exploration of service user experiences during the assessment process. Whilst a rationale was given for the need to gather professional experiences of diagnosing individuals with ASC, due to their expertise and believed understanding of ASC, this neglected the first-hand perspectives of individuals with ASC themselves, potentially leaving some of the barriers faced by this group unheard. Given the finding that clinicians themselves felt uncertain about the tools used and the presentations that they were encountering, this makes the perspectives of this population all the more pertinent. Future research could connect both these two groups, the individuals with ASC and the professionals assessing them, in order to create a full picture of the diagnostic provisions and subsequently explore how these can be developed to be as optimal and efficient as possible.

Implications on Research Questions & Aims

With the findings of the systematic review, existing literature and the limitations of both mentioned, critical gaps continue to exist in our understanding of ASC, in particular the lack of voice of individuals with ID. Whilst the synthesis highlighted challenges in diagnosing ASC, particularly for presentations outside the traditional ASC mould, little consideration was once again, given to individuals with ID despite the previously referenced co-occurrence rates. The synthesis' finding that groups from non-WEIRD contexts presented in manners that did not fit recommended assessment tools is particularly relevant in this context, perhaps suggesting that individuals with ASC-ID may have unique presentations that would influence diagnostic and healthcare outcomes. Furthermore, historical biases surrounding autism diagnosis have disproportionately affected both women and individuals with ID and, whilst the concept of the FAP has brought attention to how women may mask or present their traits more subtly, it remains unclear whether these gendered presentations are translatable to this group. Given that clinicians in the synthesised works already report uncertainty when working with 'atypical' presentations, this lack of understanding further complicates accurate and equitable diagnosis for women with ASC.

Exploring this gap in the field has several potential implications. First, understanding how women with ASC-ID present in clinical settings can improve diagnostic accuracy and reduce delays in accessing support, a difficulty noted within the synthesis. In addition exploring these presentations could help challenge historical narratives that have marginalized both women and individuals with ID within autism research and clinical practice. By centring their experiences, this research can contribute to our understanding of not just ASC but other aspects of neurodivergence. In order to address this gap, two key research questions emerged:

1. How do women with autism and intellectual disabilities present in clinical settings?
2. Is this presentation different from how other groups (e.g., men with ASC-ID or women without ID) present?

These questions aim to explore whether the FAP is applicable to women with ID or whether unique considerations are warranted for this population, both diagnostic and beyond. Investigating them will provide valuable insights into the intersectionality of many different aspects of difference, advocating for the voices and experiences of individuals with ID who are, so often, problematised or not considered in the research field. Given the research highlighted in the introduction and the subsequent review of the available literature it is hypothesised that women with ASC-ID will present in a unique manner, exhibiting some traits associated with the FAP but in a way that is different to other groups including women with ASC but without ID. The subsequent chapters detail the process of designing an appropriate methodology to answer these research questions, considering the sampling, data collection and analysis plan.

Chapter 3: Research Design & Methodology

"I work with a few researchers, but I'm really picky who I associate with and who I'm happy publicly being named alongside… if I'm going to engage in research either as a co-creator or as a participant, I need to know who is doing it, can I trust them, what's the purpose of the research, has the research been shaped and created either by or with Autistic people and will that research have a negative impact on the lives of Autistic people" – **Kieran Rose, The Autistic Advocate**

Chapter Summary

This chapter outlines the methodological framework underpinning the study, including the researcher's epistemological stance and the rationale for selected methods. Given the exploratory nature of the research, an interpretivist approach was deemed most appropriate, using a qualitative research design. A purposive sampling strategy was used to recruit clinical health professionals from an adult NHS intellectual disability service, ensuring insights from those with direct experience in assessing and supporting individuals with autism and intellectual disabilities. Participants engaged in semi-structured interviews, with questions co-developed alongside experts by experience to enhance relevance and sensitivity. A thematic analysis approach was selected to systematically explore emerging patterns within the data. Ethical considerations, including informed consent, confidentiality, and participant well-being, were addressed throughout the study design and implementation. Plans for disseminating findings include engagement with clinical and academic professionals, as well as organizations responsible for developing guidance on supporting neurodivergent communities. The importance of this methodological approach is in the potential to enhance understanding of diagnostic and support practices for women with autism and intellectual disabilities.

Epistemological Positioning & Justification of Methodology

In order to effectively answer the research questions posited at the end of the previous chapter, it is important to first state the epistemological position of the researcher, outlining their stance on the nature of knowledge and how it is acquired. In the field of psychological study, articulating this stance is essential, guiding one’s methodological choices and influencing the manner in which data is interpreted. Through this, underlying assumptions can become more apparent, potentially enhancing the quality of the research itself. Following careful consideration, both personally and professionally, an Interpretivist epistemology was deemed most fitting for the current study. Rooted in subjectivism and developed as a response to Empiricism and Positivism, Interpretivism posits that knowledge acquisition is multifaceted and emphasizes the importance of contextualizing actions and events within societal cultures. In addition, it asserts that there is no single wholly correct way of acquiring knowledge and focuses on analysing actions and events by assigning meaning to them within context. Works investigating the benefits of an interpretivist approach have highlighted its allowances for this context and the complexity it may bring as well as its ability to facilitate understanding how and why events occur. Furthermore, when compared to positivist approaches, interpretivism allows for the researcher to be active and flexible to anything that may change as the research progresses (Clarke-Hagan & Curran, 2023).

The choice of an interpretivist stance is particularly relevant to the field of ASC and ID research, reflecting the researcher's evolving perspective as a clinical psychologist in training. While initially inclined towards a realist viewpoint in personal life, professional experiences with neurodivergent populations fostered a more relativist approach, recognizing the importance of lived experiences and contextual differences. This shift was further reinforced during clinical training, where critical evaluation of current assessment and diagnostic tools for ASC in women revealed some of the limitations of positivist approaches. Moreover, the historical and ongoing marginalization of neurodivergent and ‘atypical’ individuals in mainstream society underscores the need for greater nuance when approaching the topic. Recommendations from autistic advocates and guidelines from the National Institute for Clinical Excellence (NICE) emphasize the importance of tailoring interventions to individual needs and strengths (NICE, 2012). Given these personal and systemic factors, a relativist, interpretivist approach was deemed most appropriate for this research, allowing for a comprehensive exploration of the experiences of women with autism and learning disabilities while acknowledging the complex interplay of social, cultural, and individual factors shaping their realities.

Design

Given the epistemological positioning of the research and its researcher, it was important to explore the existing research field to best understand how the relative, lived experiences of women with autism and learning disabilities manifest. To achieve this, an investigation into studies within this field took place, hoping to find the most appropriate research design that both fit with the study’s epistemological frame and build on that which has been previously conducted. First, works investigating the female autistic phenotype were examined. Judith Gould’s pioneering 2017 paper on masking highlights the recency which the phenomenon has entered the conversation around Autism. Sex differences in the presentation of Autism Spectrum Conditions were being postulated as early as 1992, with papers such as that by Kopp & Gilberg suggesting the presence of a differing autism phenotype (Kopp & Gilberg, 1992). However, the idea of *‘camouflaging’* was initially hypothesised by Tony Attwood in 2007, subsequently being discussed at the International Meeting for Autism Research in 2008. Since then, the field has since expanded to its current stage where quantitative outcome measures are currently being developed to identify masking traits. This includes Hull and colleagues’ Camouflaging Autistic Traits Questionnaire, a twenty-five-item survey found to identify aspects of ASC presentations that are not picked up by traditional assessment tools. (Hull et al. 2019). In the exploratory stages of masking research, however, methodology was primarily qualitative utilising a variety of these methods. Dean and colleagues for example used peer nomination to compare relationships of ASC and typically developing students. Their results suggested that, whilst girls and boys with ASC were excluded in greater numbers compared to their typically developing peers, girls with the condition appeared to be more overlooked rather than rejected unlike ASC boys (Dean et al. 2014). Others used peer observation and minute-by-minute descriptions to explore sex differences in social behaviour, finding that girls use more compensatory strategies to cover up their social challenges when compared to boys during play (Dean, Harwood & Kasari, 2017).

The most widely used methodology, however, has been semi-structured interviews, mostly with individuals with autism themselves. Tierney and colleagues interviewed ten ASC adolescent females struggling with relationships, with their rich accounts describing the development of masking behaviours as a means to navigate the social landscape of adolescence (Tierney, Burns & Kilbey, 2016). Cook, Ogden & Winstone built on this research, expanding the sample to also interview members of families, in this case parents, finding that masking had pros and cons for both groups, such as giving girls a means of *'concealing their label'* but also issues specific to parents, in particular the potential risk of delayed ASC diagnosis (Cook, Ogden & Winstone, 2018). Further studies have expanded to interview other members of ASC individuals' circle of support about their experiences including clinicians (Muggleton et al. 2019), teachers (Hiller et al. 2014) and siblings (Green, 2013). This evidence suggested that a qualitative approach, given the thesis research's interpretative positioning and focus on such an event as nuanced as social behaviour, would be appropriate in effectively answering the research questions. In addition, it highlighted the importance of gathering rich qualitative data from a variety of sources and the importance of utilising a sample with a rich understanding of ASC, ID and masking whether experiential or theoretical.

Investigating the Female Autism Phenotype (FAP) led to scrutiny of research investigating the presentation of ASC in individuals with a co-occurring intellectual disability, hoping to better understand how the population has been historically studied but also how academics have involved individuals with ID in the design of the research itself. Previous works in this area were found to typically be quantitative in nature, conducted in comparison to those with autism but without a intellectual disability. A study by Russell, Steer & Golding, for instance, explored the socio-developmental factors which may influence diagnostic rates of autism by comparing retrospective longitudinal data from autistic individuals both with and without ID. They found that individuals, in particular women, with autism but no intellectual disability, were more likely to be missed during assessment and diagnosis processes compared to those who also had an ID (Russell, Steer & Golding, 2011).

This supported work prior by Murphy, Healy & Leader two years prior who used between-subjects designs to compare the characteristics of autistic children with and without ID, finding evidence suggesting that the severity of impairment related to the degree in which autism impacts individuals day-to-day functioning (Murphy, Healy & Leader, 2009).

Unlike quantitative approaches, qualitative methods to gauge the experiences of individuals with autism and intellectual disabilities directly were comparatively difficult to come by. Unlike those without an intellectual disability, where first-hand accounts have been acquired, much of the evidence with the ASC-ID community is second-hand. Hanne Sigstad has highlighted the challenges of interviewing individuals with intellectual disabilities directly, referencing the difficulties that can occur throughout the research process such as achieving informed consent and adapting communication within an interview. As a result, they argue that the richness of data collected can be severely impacted and any adaptations to research design can clash ethically with national research guidelines (Sigstad, 2014). This may go some way to explaining the mismatch in the proportion of ID community members being involved in autism-related research as mentioned by Russell and colleagues in the introduction previously. Conversely, however, research also acknowledges the issues with not making use of a research-with approach. Previous work in other health-related fields have found that failing to involve socially disadvantaged groups can result in perpetuation of accessibility issues (Rogers, 2004), reinforcement of stigmatised narratives (Singh, Azuine & Siapush, 2012) and poor generalisability and external validity of findings (Johnson, 1990). This conflicting evidence suggests that, whilst there are challenges to interviewing those from more disadvantaged communities, such as those with ASC-ID, the long term consequences of not doing so could have greater long term impacts in a variety of contexts, strengthening the notion that this group is ‘hard to reach’.

As a result of these perceived challenges, semi-structured interviews have typically taken place with family members, teachers and clinicians involved in these individuals' care. A case study by Benderix and colleagues looked at the experiences of ten parents from five families which contained children with ASC-ID, using hermeneutic phenomenological interviews to gather narrative experiences of parents before and after moving into a group home. Interviews of this type have been found to develop richer understanding of particular human experiences (van Manen, 2002) with Benedrix et al's study suggesting that parents struggled with their autistic children's emotional regulation, sleep problems and social isolation, factors that were reduced following integration into a group setting (Benedrix, Nordström & Sivberg, 2006). Further work by McKenzie, Murray and Martin explored the views of a variety of caregivers involved in supporting ASC-ID individuals during the COVID-19 pandemic. This included team leads, nurses and psychologists with a consistent interview schedule to cover key areas of experience (McKenzie, Murray & Martin, 2021). Whilst the limitations of not using direct interviews are evident, the above shows the value of second-hand experiences when understanding the presentation of ASC and ID be it through choice of sample or through comparing the group to autistic individuals without an intellectual disability.

Given the investigation of ASC-ID studies making reference to the challenges associated when developing research designs, it was important to consider the ethical issues that have arisen previously and that may subsequently arise in the current piece of work. Katherine McDonald & Colleen Kidney's seminal publication in the journal of Policy and Practice in Intellectual Disabilities systemically reviewed peer-reviewed literature on ethical practices in research with the ID community. They suggest not only ways in which to engage with communities with ID (including making appropriate decisions about research participation, ensuring ethical accountability and utilising frameworks and approaches that do not differ from those without ID diagnoses) but also highlight the dilemmas that have been present when working with the community previously. In particular, they reference the assumptions made by academics regarding intellectual disability and the gaps in knowledge that remain as a result of them (McDonald & Kidney, 2013).

This critical examination of ethical considerations aligns with a broader shift in research paradigms that have occurred over the past few decades. Traditional top-down research has been, over criticised previously for not sufficiently addressing the needs of its subjects with a lack of collaboration highlighted as being of particular issue (Kiernan, 1999; Reason, 1988; Heron, 1992; Reason & Heron, 1997). The new paradigm of research proposes a shift in the role of researcher from *'expert'* to *'facilitator'* with the investigated population positioned as co-researchers to establish aims of the research from the outset. Through this process, it is hoped that potential power imbalances present in research are reduced. The evolution from top-down approaches to more participatory methods reflects a growing recognition of the importance of involving research subjects, particularly those from vulnerable populations such as the ID community, in the research process. This shift not only addresses ethical concerns raised by scholars like McDonald and Kidney but also aligns with the principles of community-based participatory research, emphasising collaborative, equitable partnerships among researchers, stakeholders, and community members across research phases. By integrating these ethical considerations and participatory approaches, researchers can work towards more inclusive, respectful, and effective studies that better serve the needs of the ID community while advancing scientific knowledge in the field.

In summary, investigation of the above previously researched areas influenced the chosen methodology. Given the need for rich data and the current sparsity of the research field, qualitative methods were chosen in order to provide initial exploration around potential masking behaviours of women with ASC-ID. In addition whilst interviewing women with ASC-ID directly would certainly provide the most valuable accounts relating to the Female Autism Phenotype, previous research suggests that challenges may be encountered when investigating this population both in research design and ethics when considering the current study's scope. Furthermore, studies have utilised second-hand accounts of those involved in ASC-ID peoples' care to great effect. Finally, despite guidelines being developed regarding research with this vulnerable group and stressing the involvement of the population at all stages of research, communities with ASC-ID still act as the investigated rather than the investigators. These factors, as well as others identified significantly influenced the direction which the research took.

Holding these ideas in mind, a qualitative, within-subjects design utilising semi-structured interview was chosen and thought to best answer the two research questions. Taking the lead from researchers who initially investigated differing behavioural presentations in women with ASC without ID, qualitative methods have been used throughout psychological research as a means of exploring emerging research fields. Shoshanna Sofaer highlights their ability to provide rich accounts of *'rarely heard'* vulnerable groups and to generate future hypotheses for further research (Sofaer, 1999), a factor that was influential given the potential population that may be impacted by its findings. Significant thought was given to how this group of individuals could be involved. However, discussions around whether this group could form the researched sample raised several concerns from both the researcher and their supervisor. This will be discussed in greater detail in the section outlining participants.

Participants

The above highlights both the need to directly involve women with autism and learning disabilities in studies whilst also acknowledging the difficulties in doing so. However, when selecting an appropriate participant pool, the prevalence of these difficulties became more apparent. As previously stated, studies investigating the proportion of men to women with autism have found ratios of 4:1 in clinical populations and 3:1 in general populations, both in favour of men. Whilst this distribution shrinks when a comorbid intellectual disability is present to 2:1, this increased the specificity of the participants required and thus reduced the potential number available for sampling. Specificity issues were also noted when considering the age of these prospective participants. Systemic clinical issues and biases have significantly impacted the age at which girls are diagnosed with autism. An interview with Francesca Happé in a British newspaper suggested that only 20% of girls with the condition are diagnosed before the age of 11 compared to approximately 50% of boys (Hu, Devlin & Debski, 2019). As such, it was thought that conducting research with a younger age group may not only result in them not being able to articulate their experiences of how autism impacted their lives but also that they would not have received a diagnosis of Autism itself. These limitations left the study potentially focusing on adult women with a diagnosis of ASC and a co-morbid ID who were also able to accurately describe their experience of a complex social phenomenon, all whilst navigating research issues flagged by Sigstad (2014). It was decided that such a study would require a larger scale than was possible within the context and scope of the current thesis, involving work across multiple systems which support or work with women with ASC and ID and potentially resulting in difficulties when achieving ethical approval and limiting the already short period of time with which the researcher could conduct the study.

Given the perceived difficulties in recruiting women with ASC-ID mentioned above, clinicians working within ID services were thought to be able to provide rich experiences given their frequent interactions with the population with ASC-ID. Studies involving health professionals has highlighted the benefits of using such a sample when conducting research. A study by Krok-Schoen and colleagues investigated the benefits and challenges of sampling health workers in health disparity research, finding that these groups were able to integrate both their professional and personal knowledge of communities that they worked with to provide rich accounts of experiences to investigators. Furthermore, they suggested that clinicians were more readily available to implement any findings effectively into their clinical work, allowing for any communities investigated to be more efficiently impacted (Krok-Schoen et al. 2016). Explorations of research fields to determine the epistemological positioning for the study supported the use of clinicians perspectives further, finding that these views have not only been utilised in research with this community but also identified felt-biases from parents when attempting to get a diagnosis for women with autism specifically, needing to exaggerate traits to professionals. It was therefore determined that interviewing clinicians would allow for exploration into these areas as well as their direct experience of working with women and girls with ASC-ID. An inclusion criterion was developed to ensure that participants had suitable experience working with ASC-ID individuals. It was decided that participants would need to have worked with at least two women with a diagnosis of ASC-ID in their capacity as an employee within NHS services. This allowed for clinicians to have experience of several ASC-ID presentations as well as for a wide variety of NHS employees to be recruited rather than limiting the participant pool to just one discipline, increasing the generalisability of the findings. To recruit these clinicians, a research advertisement was created, summarising the focus of the study, inclusion criteria of its prospective participants and contact details of the research team if there were any expressions of interest. An email script was constructed to achieve this, circulated around the disability service's team via internal mailing lists as well as word of mouth. A copy of this email script can be found in Appendix 2

Measures

Whilst involving women with both ASC and ID proved to be not possible in a participatory capacity, developing the measures presented an opportunity to collaborate with these communities in a research and design capacity, in line with McDonald and Kidney's recommendations. Experts by experience were consulted in order to develop the measures that were to be used with research participants. Here experts by experience, as outlined by the Care & Quality Commission (CQC), are defined as those whose knowledge about the topic comes directly from their experiences of it, in this case Autism and Intellectual Disability (CQC, 2024). Co-production with these experts has been increasingly implemented by professional, educational and research bodies in order to develop and evaluate services and systems. A recent study by Ashburner and colleagues used participatory action research to develop a picture-based goal setting, involving autistic individuals throughout the design and evaluation process. Their results suggested that the participation of this community as co-researchers significantly improved the outcome of the final product, in particular how easily understandable and relevant it was to the needs of the ASC community (Ashburner et al. 2023). More specific to the current research, a study by Emerson and colleagues (2005) spoke with individuals with intellectual disabilities in order to determine survey questions to be posed to participants, a strategy that has been replicated in future research (Bunning, Proudman & Wyborn 2017). This evidence highlights the value of expert accounts when designing research that could benefit their community. As such initial consultations were set up with women with ASC and ID presentations in order to decide on and refine the questions on the interview schedule.

Experts were recruited primarily through the researcher's supervisor through professional links that they held with intellectual disability services. Experts were women, occupied a variety of roles within these services including support practitioners, mental health nurses and health access champions and each had differing aspects of neurodivergence including autism and learning disabilities. Consultations lasted for approximately one hour and themes discussed included the experts' experiences of living with autism and intellectual disabilities, the challenges they faced working in clinical services, and what they felt professionals should be aware of regarding having ASC and ID. These took place up until the interview schedule was finalised, at which time said experts who had agreed to be contacted during consultation were asked to review the interview schedule to ensure that their views had been accurately represented, thus ensuring alignment with the guidelines posited above. The consultation produced an interview schedule of six open-ended questions to be put to the study's participants:

1. *From your experience can you share what difficulties clinicians might face when trying to figure out if a woman has autism and a learning disability?*

2. *From your experience why do you think some women with autism and learning disabilities don't get diagnosed properly, and how can we help fix this?*

3. *Can you share any clinical experiences you've had in your role with autism in women that might be different from what's usually seen in men, especially when they also have a learning disability?*

4. *From what you've seen in your role, what unique challenges do women with autism and learning disabilities face compared to men with the same conditions?*

5. *How can we make sure women with autism and learning disabilities feel accepted and celebrated, both in healthcare and in the wider community?*

6. *When working with women with Autism and a learning disability, what has surprised you about this group?*

Alongside each of these questions, a series of follow-up questions were created. Recommendations for conducting interviews by Nick Fox state that using prompts alongside asking questions can be helpful in encouraging an interviewee to give more detailed responses and allow them to consider points of discussion further (Fox, 2009). Three prompts were generated for each question in case of this eventuality and were to be used in case responses were brief or participants did not expand on topics that came to their mind during conversations. An example of the full interview schedule as well as these prompts, can be found in Appendix 3. Alongside the main component of the interview, questions were asked prior and following the interview regarding whether participants had read and signed the consent form, any questions they had, their understanding of the study and anything else that they felt was important to acknowledge that had not been covered in the interview itself.

Settings

A decision was made for interviews to be conducted virtually, via video consultation platforms. A recent review of 22 studies found that adults with ID have positive feelings towards virtual healthcare settings in particular when sufficient adaptations and scaffolding is in place for them such as having a support person present, good internet speeds and confidential spaces for work (Selick et al. 2021). Similar positive feelings have been shared by the prospective participant pool. A recent narrative synthesis by Walthall and colleagues highlighted the flexibility and accessibility of using virtual consultation for both clinicians and patients, though they are careful to note issues and barriers that can arise too, such as with technology and equipment (Walthall et al. 2022). With these recent reviews in mind, the study sought to utilise this setting and the considerations that came with it, ensuring participants were sufficiently scaffolded to access the interviews. Following discussions within the research team, it was decided that Microsoft (MS) Teams would be the most appropriate platform due to its use across the investigated service and its functionality, possessing recording software and tools for transcribing. It was thought that this would be most accessible to participants, reducing time pressures around commuting, fitting in more idiosyncratically into work schedules and utilising laptops and systems already provided by their attached service. In doing so, this would hope to address issues highlighted in Walthall and colleagues' review, yet using such a platform did produce its own ethical issues, which will be discussed in more detail below.

Procedure

A purposive sampling technique was utilised to recruit clinicians working in a National Health Service (NHS) Adult Intellectual Disability Service. A non-probability means of sampling, purposive techniques involve deliberate choices by the researcher to identify particular qualities in a research participant (Etikan, Musa & Alkassim, 2016). A 2020 review of sampling methods found that sampling via these means is useful in qualitative research which has multiple phases or aims as well as helping investigators justify participant selection based on theoretical grounds (Berndt, 2020). Participants who responded to the study advertisement were able to register their interest to the research team via the provided contact details. This also presented an opportunity to address any questions regarding any aspect of the design or the procedure itself. Clinicians that were still interested were given the chance to share their email addresses to which a participant information and consent form was sent for consideration. A 'cooling off period' of seven days was then implemented to decide whether they would still like to take part before being contacted by the researcher to organise a time for interview. These were individual in nature, ensuring flexibility with when interviews could be offered and that they could be completed in a confidential space that aligned with participant work schedules. At the time of interview, participants and researcher would join a meeting via an online link, sent to their email address, to MS teams. All research forms were sent to the chief investigator prior to interviews taking place, ensuring that this had been completed by checking with the participant prior to the interview commencing.

Introductions as well as checks regarding achieving consent mentioned above were finalized before the core six questions and potential prompts were posed.

Analysis

Interviews were recorded via software embedded into Microsoft Teams itself and stored on a password protected USB storage. Participants were given a number and pseudonym to accurately track their interviews and research forms as well as ensuring anonymity when conducting analysis. These files were then transferred to Box, a secure cloud storage system provided by the researcher's connected institution. Each participant's information was protected with a password known only to the researcher. Whilst a tool for transcription was available within the consultation platform, the researcher did not rely on this feature when writing up, ensuring that final transcripts were accurate to the recordings of each interviewed clinician. A thematic analysis was deemed most appropriate to be conducted when holding the epistemological position and design of the research. A widely used method of qualitative data analysis in psychological research, the six step process, involving familiarisation, generation of codes, search, reviewing and defining themes, is both a powerful and flexible approach to help researchers understand the thoughts and experiences of research participants, identify and analyse any repeating patterns within experiences and express them in an understandable and categorised manner (Braun & Clarke, 2006). Reviews of this form of analysis have showcased its value when exploring emerging research areas as well as its accessibility for researchers new to qualitative study. A publication by Nigel King compiling research and recommendations relating to thematic analysis highlighted the formulaic nature of the process, allowing it to be easily grasped by prospective researchers (King, 2004). In addition, when chosen in conjunction with an explicitly stated epistemological position, it has been found to be more flexible than other forms of data analysis (Holloway & Todres, 2003). When considered with the relative interpretivist nature of the research, this approach was thought to allow for exploration and interpretation of a diverse range of experiences from a variety of contexts, allowing for multiple meanings within the prospective data set to be explored.

Ethical Considerations

As referred to above, several ethical issues arose when conceptualising different aspects of the research design involving the researcher, participants and setting. To ensure transparency and model the research around individuals with ID, it was important to reflect on each of these dilemmas, their potential impacts and how they might be addressed prior to applying for ethical approval.

Potential Coercion of Participants

Perhaps what the research team were most aware of was their own vested interests in Autism Spectrum Condition and in particular, social masking behaviours. The chief investigator in particular held preconceived beliefs regarding the importance of the differences in female presentations of ASC and, by proxy, social masking behaviours as a whole. Furthermore, the potential impact that research such as this could have for this population and on UK assessment tools may have influenced how research materials were developed and phrased. As such, the decision to involve ASC-ID individuals in the research design held further weight so as to hear the voice of this community and not let the researcher hold all the power in structuring questions to clinicians. Consideration was still needed around how the consultation was structured so as to maintain impartiality and not sway experts by experience when they shared their views. In addition, research participants would need to be made aware that they would be participating on a voluntary basis, reducing potential feelings of coercion.

Assessing Participant Capacity to Understand & Consent

The study made suitable adaptations to the research process to ensure that participants were able to understand and consent to the study. Materials were presented in a clear style with frequent check-ins with participants to check understanding what was required of them during the research procedure. This was of particular relevance when consulting with experts by experience, whose aspects of neurodivergence and learning disabilities may have resulted in traditional methods of research not being appropriate. As such, additional measures were taken to check that these experts were aware of how they would be involved in the research, scaffolding these conversations around their individual needs to achieve informed consent. This led to one expert by experience being joined by a colleague for support when speaking to the research team with discussions held to ensure that this colleague was there for support only, rather than to influence responses in any way.

Research Setting & Means of Interviewing

Whilst MS Teams had helpful features, such as built-in recording systems and transcript generators and being regularly used in NHS services, as well as offering greater flexibility regarding timing of interviews, control of the research setting was deemed to be limited. Given that consultations could be completed in other settings outside of their clinical environment, there was deemed to be a greater risk of interruptions from others as well as the location not being confidential. In addition, the use of an online consultation platform presented issues regarding what may happen if interviews disconnected or if information was disclosed (relating to the participant or others) that implied a level of risk. To address these concerns, information forms were adapted to state in detail the necessity for participants to find a space where they feel safe and comfortable to share their experiences openly. The researcher was then able to double check this prior to interviews taking place as an additional 'safety net' and collaborate with each participant with a plan if the research space was breached in any way. If risk-related information was disclosed during the interview, it would be terminated at this time and information above would be shared with the participant, with any collected data being excluded from final analyses.

Whistleblowing & Safeguarding Queries

In addition to planning for any disclosures regarding risk, it was thought that participants may also raise safeguarding issues or even whistle-blow about the service itself given the research's procedure and its pooled sample. Frederic Reamer's peer reviewed article on whistleblowing gathered data from several noteworthy academics in the past thirty years, highlighting difficulties that can arise when working in clinical health settings, including practitioners engaging in unethical practices, lack of appropriate training leading to care that is below standards and personal contexts unintentionally causing harm to clients (Reamer, 2019). In addition, policies outlined in the British Psychological Society (BPS) code of ethics regarding whistleblowing as well as the NHS trust chosen for sampling, emphasise timely raising of concerns and ensuring that workers are believed and treated sensitively (BPS, 2021). Whilst it was not anticipated that the researcher would come across such practices when speaking to clinicians, it was important to ensure that measures were in place in case this arose at any point during data collection. It was agreed that the researcher and their supervisors would regularly check in regarding whether any disclosures had been made. It was thought that, if any concerns arose, the research team would elevate this concern to service management and senior leadership. Moreover, a protocol was developed in anticipation of participants raising safeguarding issues about service users that they work with in any capacity. In this case, the chief investigator held sensitive information and would utilise supervision once again to discuss options for whether information needed to be taken forward.

Having considered these ethical dilemmas and appropriate means of managing them, the researcher sought ethical approval from the Health Research Authority (HRA) for conducting research within the NHS via the Integrated Research Application System (IRAS). In addition, contact was made with the proposed research site and their research lead in order to inform them of the potential piece of work that was to be conducted and anything that the researcher could do to help facilitate this process if ethical approval was achieved. A favourable opinion was given by the HRA on 23rd November, 2023 leading to a second application to the researcher's connected university and their ethics committee. A further favourable outcome was given by the University of Essex's ethics officer on the 28th November, 2023, allowing for the next phase of the research to commence. Documents relating to seeking ethical approval can be found in Appendix 4.

Dissemination Plan

In developing the methodology for this study, a comprehensive plan was formulated to disseminate its findings across academic, clinical, and political spheres. The researcher prioritized the involvement of three distinct groups in this dissemination process, with particular emphasis on the involvement of both the autistic and intellectual disability communities. Previous research advocates for implementing a range of strategies to share study findings with patients. A 2015 review of twenty-one quantitative and qualitative research articles provided recommendations for disseminating results to service users and organizations, stressing the importance of combining various approaches, such as developing a robust plan early in the research process and creating lay versions tailored to the target audience, to achieve optimal results (Schipper et al. 2015). As such, discussions took place in research supervision about how and where the findings could be shared to achieve the most impact for women with autism and learning disabilities. The NHS trust chosen for sampling felt like a suitable starting point, sharing the findings back to participants about what they felt were the challenges the community faced as well as the strategies that they utilised when working with them. When considering the limited mandatory training present in the NHS with regards to both autism and learning disabilities, it was hoped that this would present an opportunity to share clinical expertise, provide information about how patients can be better supported when working in health services and identify presentations that are unique to women with autism and learning disabilities. This could then be adapted and shared both internally amongst colleagues and externally to other NHS trusts that work with these communities.

Given the focus on populations with autism and intellectual disabilities in this study, the production of lay dissemination materials also felt particularly relevant, requiring the materials to be adapted in a clear and comprehensible manner for the community being indirectly investigated. Whilst the study was not aiming to directly investigate the experiences of women with ASC-ID, ensuring that these findings were accessible and easy to understand for the community still held importance. Rather than develop just one set of dissemination materials, it was decided that each intended audience would receive a tailored document summarising and framing the results. For example, for women with ASC-ID, results were presented concisely utilising easy to understand language that presented the key findings as they related to the community. Moreover, given the indirect nature of ASC-ID investigation implemented, any findings presented to the community were not presented as fact so as not to impose narratives or assumptions around their behaviours and motivations. In contrast, whilst clinicians were also provided with clear and concise dissemination materials, different information would be highlighted as it related to their healthcare context.

Finally, thought was given to where the research findings could be published in the academic field so as to inform policy, practice and improve quality of life for women with ASC-ID. Internal discussions between the researcher and their supervisor concluded that academic journals covering both ASC and ID could be considered, hoping to highlight the higher rates of comorbidity present between the two presentations than has been currently found in the field as mentioned previously. The Journals of Autism & Developmental Disorders (JADD) and of Intellectual Disability Research (JIDR) stood out as obvious suitable candidates. JADD's mission statement encourages *'research submissions on the causes of ASDs and related disorders, including genetic, immunological, and environmental factors; diagnosis and assessment tools… and prevention and treatment options'* whilst JIDR aims *'to provide a platform for sharing knowledge and advancing the understanding of intellectual disabilities and promoting better outcomes for individuals with these conditions.'* Whilst it appeared the current research fit more with publication in the JIDR, it was thought that the research could be submitted to JADD in an effort to highlight issues with current diagnostic processes as well as provide a less male-centric lens on autism and its implications on treatment options, particularly for women with autism. Furthermore, in order to distribute the research beyond clinicians working within the sampled service, the British Psychological Society (BPS) Bulletin of the Faculty for People with Intellectual Disabilities was selected. Published three times per year, the bulletin aims to inform clinical psychologists working with ID service users about new practices, recommendations and updates on service provisions. Through this combined and targeted approach to specific journals and publications, it was thought that the dissemination plan would both have significant reach and impact as well as being realistic with regards to the scope of this research. Having investigated potential journals where the findings could be distributed, the researcher and their supervisor agreed to review the dissemination plan after the Viva examination to identify the journal most suitable for publication.

Conclusion

This chapter has outlined the methodological approach for the current study, aiming to explore the experiences of women with autism and learning disabilities through the perspectives of clinicians working in NHS Adult Intellectual Disability Services. An interpretivist epistemology was taken with qualitative, semi-structured interviews used on a purposive sample of experienced clinicians working with the target population. The interview schedule was developed in collaboration with experts by experience, ensuring relevance and sensitivity to the needs of women with autism and intellectual disabilities. Ethical considerations were carefully addressed, including potential coercion, capacity to consent, and safeguarding issues. Thematic analysis was selected as the most appropriate method for data analysis. The study's dissemination plan hopes to share findings with participants, the NHS trust, and the wider academic community through publications in relevant journals aiming to contribute valuable insights into the unique challenges faced by women with autism and learning disabilities, potentially informing future clinical practice and research in this understudied area. Prior to undergoing data collection, it was hypothesised by the chief investigator and their team that women with autism and learning disabilities present with unique challenges when coming into contact with NHS intellectual disability services. In addition, in line with autistic women without ID, this population will have been observed to present in a manner that is different to other autistic groups, including men with ASC-ID with similar mannerisms and behaviours that may be considered as socially masking. Having made this hypothesis, data collection could begin.

Chapter 4: Results

[in] society there is still an expectation of... women to some degree... It has changed and it is constantly changing, but there is an expectation of femaleness and there's a lot of autistic women who struggle with… identity and struggle to understand where they fit into societal expectations in a societal narrative… For autistic reasons, but for other reasons as well, but… especially if they've got a learning disability as well, so they are kind of a double whammy” – **‘Steph’, Clinical Psychologist and participant**

Chapter Summary

This chapter presents the results of semi-structured interviews conducted with participants, the rigorous coding and categorisation that took place and the themes which were constructed, providing insight into the previously stated research questions:

1. How do women with autism and intellectual disabilities present in clinical settings?

2. Is this presentation different from how other groups (e.g., men with ASC-ID or women without ID) present?

Five major themes were defined following analysis, outlined in the table below with relevant sub-themes attached.

Table 5 Outlining 5 defined themes and their relevant sub-themes

Theme	**Sub Themes**
Diagnostic Challenges	*Masking Mannerisms*
	Overshadowing
Gendered Manifestations	*Covert Expression*
	Socially Driven
Intersectional Influences	*Societal Expectations*
	Historical Bias
Education & Awareness	*Professional Training Gaps*
	Community Consciousness
Person-Centred Practices	*Strength Recognition*
	Individualised Intervention

Each theme is explored in detail, supported by relevant quotes across the interviews with participants and contextualised within the wider research field where appropriate. The sub-themes are also outlined and discussed to deepen the analysis and highlight differing viewpoints and experiences captured during data collection, with interconnections examined to provide as comprehensive an understanding of the health professional perspective of women with ASC-ID as possible. The analysis not only suggests some answers to the research questions, but also highlights some unexpected lines of enquiry for further consideration in the future to provide greater insight into this population's experience. The chapter will conclude by summarising the key findings, laying the foundation for further interpretation and reflection in the final discussion chapter.

Sample

A total of sixteen participants were successfully recruited and interviewed for the study during the phase of data collection. Each participant met the requirements outlined in the previous chapter and served as the primary source of research data with all recruited from a single NHS service for adults with ID. The service in question was part of a wider NHS trust working across multiple sites in the Southeast region of England, both inpatient and community based. The diversity of adults with ID who used the service, and the geographical spread of the teams provided a variety of perspectives and experiences across those interviewed, somewhat increasing generalisability of results.

Data Collection & Analysis

Descriptives

Demographics

The initial phase of data collection aimed to establish a comprehensive understanding of the disciplinary distribution within ID services and assess the representativeness of the study sample. Descriptive statistics were gathered through brief introductions, focusing on participants' gender identity and current clinical roles. Table 6 below summarizes these findings with each participant under a pseudonym to anonymise their responses.

Gender Distribution

Analysis of the data revealed a significant predominance of female clinicians in the sample, aligning with broader trends in the NHS workforce where women consistently comprise approximately 77% of the total workforce (National Health Service, 2018). The observed gender ratio in this study likely represents an accurate depiction of staff composition in NHS services for individuals with ID, although specific data for this subspecialty is limited.

Clinical Roles

The study sample encompassed a diverse range of clinical disciplines, reflecting the multi-disciplinary nature of service for those with ID. Psychology emerged as the most frequently represented profession, accounting for 25% of the participant pool. Guidelines published by the National Institute for Health & Care Excellence (NICE) have recently recommended a shift towards psychological interventions when working with adults with ID, potentially leading to an increase in this discipline working in these services (NICE, 2022). In addition, whilst training for assessment and diagnosis of ASC is open to a wide variety of professions and is encouraged to be conducted in a multi-disciplinary manner, psychologists tend to play a key role in this process. Thus, it may be the case that this group was more interested in taking part in the study compared to other professions who encountered the advertisement. Beyond this, the diversity of clinical roles present in the sample suggests a high degree of representativeness of the multi-disciplinary nature of LD services, crucial for capturing the complexity of service provision and enhancing the generalizability of the study findings.

Table 6 Summarising Descriptive Statistics of Participants

Pseudonym	**Gender**	**Role/Profession**
Rosie	F	Community Nurse
Katie	F	Charge Nurse
Steph	F	Clinical Psychologist
Lauren	F	Speech & Language Therapist
Yana	F	Clinical Psychologist in Training
Sara	F	Healthcare Assistant
Flo	F	Senior Nurse Practitioner
Talia	F	Clinical Psychologist
Shiren	F	Art Therapist
Dan	M	Speech & Language Therapist
Megan	F	Occupational Therapist
Caroline	F	Psychiatrist
Ruth	F	Occupational Therapist
Esther	F	Dietician
Melina	F	Clinical Psychologist
Kiki	F	Dietician

Qualitative Findings

Transcribing & Data Familiarisation

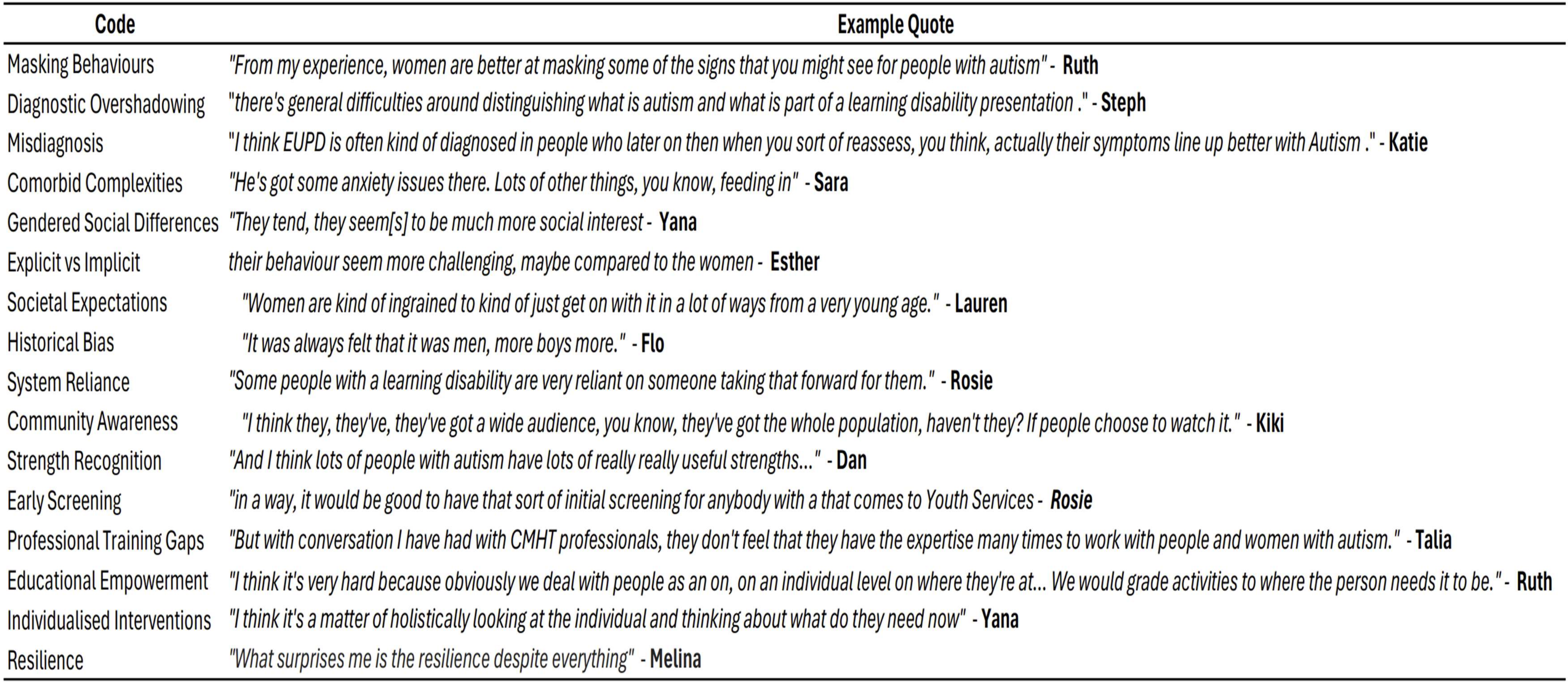
Interview recordings were revisited following the data collection phase in order to accurately transcribe for the purpose of analysis. A denaturalized transcription approach was deemed most appropriate for the collected data, focusing on the content of the interviews and omitting unnecessary words or grammar. Seminal papers on denaturalised transcription have highlighted its use when analysing data thematically. A 2005 publication suggests that the approach's deconstruction of speech into its meanings and perceptions aligns well with the goals of thematic analysis which aims to identify meanings across a dataset (Oliver et al. 2005; Braun & Clarke, 2006). In addition, denaturalised transcriptions have been found to enhance readability compared to its naturalised counterpart, helping to facilitate coding processes and allow for better engagement and familiarisation with the data during the stages of thematic analysis (Davidson, 2009). Interviews were transcribed over a period of seven days following the closure of the data collection phase. Guidelines recommend that interviews should be written up in a timely manner in order to accurately recall contextual details and nuances that may not be captured in recordings alone (Powers, 2005). In addition, it provides the opportunity for ongoing analysis of the data set, allowing for the identification of emerging themes early in the research process. However, given the practical constraints placed on the researcher, immediate transcription was not possible. In order to mitigate the potential variation in transcription quality that this presented, all interviews were transcribed in the same timeframe, assisted by the recordings being captured on video. This allowed for the opportunity for initial codes and themes to still arise across the transcripts but also for some of the non-verbal cues and particulars of the interviews to still be noted and accounted for.

The process of transcribing interviews marked the initial stage of systematic data analysis in this study. Following Braun & Clarke's (2006) approach to thematic analysis, the researcher began by immersing themselves in the dataset to gain a comprehensive understanding of its content and nuances, involving multiple iterations of reading and re-reading the transcripts while simultaneously listening to the original audio recordings. This dual-sensory approach allowed for a deeper engagement with the data, capturing not only the verbal content but also the subtle nuances in tone, emphasis, and emotional inflections that might not be immediately apparent in written form. In line with best practices in qualitative research (Maguire, 2017), summary sheets were crafted for each participant, representing comprehensive accounts of data collected during the interviews. They included key points discussed, potential areas of interest for further exploration, and initial observations that could inform subsequent stages of analysis. This process of creating summary sheets not only aided in data organization but also facilitated the identification of emerging patterns and themes across the dataset. In addition, the researcher kept a reflexive journal throughout this phase, documenting initial thoughts, reactions, and potential biases. This aimed to enhance the transparency and rigor of the analysis process providing insight into the researcher's evolving understanding of the data and served as a tool for critical self-reflection. This comprehensive familiarization process grounded the analysis in a thorough knowledge of the data set, positioning the researcher to proceed with subsequent stages of analysis. Examples of these processes can be found in Appendix 5.

Generating Codes

With this foundation in place, systematic generation of initial codes began, identifying meaningful segments of text and assigning descriptive labels. This process was both iterative and inductive, involving multiple passes through the transcripts to refine and develop codes which emerged from the data (Fereday & Muir-Cochrane, 2006). Descriptive, line-by-line coding was implemented in the first instance, summarising the content of scrutinised data in the form of a noun. This approach aimed to both acknowledge the context of the responses given while also categorizing large amounts of data present in the sample. Throughout the coding process, awareness of potential biases influencing code identification was maintained. Previous research has identified the influence that such bias can have on this process, focusing on particular aspects of data that fit with what is believed to be 'positive' or 'correct' by the coder themselves (Jalava, Griffiths, Larsen & Alcott, 2021). These can result in either over or under-coding, leading to data fragmentation or loss of context and richness in data sets. To mitigate these potential issues, several strategies were employed. The reflexive journal mentioned earlier continued to be used, providing a means of documenting decision-making processes and maintaining awareness of potential biases. Additionally, the iterative coding process helped to continuously refine and recalibrate the codes, reducing the risk of inappropriate coding strategies. The combination of this as well as line-by-line coding sought to balance detailed analysis with preservation of contextual richness. By implementing these measures, the study aimed to ensure a rigorous and balanced approach to code generation and data analysis, minimizing the impact of potential biases while maximizing the depth and breadth of insights derived from the data. Codes were recorded in a codebook as they were documented and refined. In the first instance, over 400 unique codes were identified, subsequently cut down to twelve across the sixteen transcripts which can be found in Table 2. An example of one transcript and the coding of another can be found in Appendix 6.

Table 7 Showing results of initial coding and twelve codes that were developed across the sixteen participant transcript



Code	Example Quote
Masking Behaviours	*"From my experience, women are better at masking some of the signs that you might see for people with autism"* - **Ruth**
Diagnostic Overshadowing	*"there's general difficulties around distinguishing what is autism and what is part of a learning disability presentation ."* - **Steph**
Misdiagnosis	*"I think EUPD is often kind of diagnosed in people who later on then when you sort of reassess, you think, actually their symptoms line up better with Autism ."* - **Katie**
Comorbid Complexities	*"He's got some anxiety issues there. Lots of other things, you know, feeding in"* - **Sara**
Gendered Social Differences	*"They tend, they seem[s] to be much more social interest* - **Yana**
Explicit vs Implicit	*their behaviour seem more challenging, maybe compared to the women* - **Esther**
Societal Expectations	*"Women are kind of ingrained to kind of just get on with it in a lot of ways from a very young age."* - **Lauren**
Historical Bias	*"It was always felt that it was men, more boys more."* - **Flo**
System Reliance	*"Some people with a learning disability are very reliant on someone taking that forward for them."* - **Rosie**
Community Awareness	*"I think they, they've, they've got a wide audience, you know, they've got the whole population, haven't they? If people choose to watch it."* - **Kiki**
Strength Recognition	*"And I think lots of people with autism have lots of really really useful strengths..."* - **Dan**
Early Screening	*"in a way, it would be good to have that sort of initial screening for anybody with a that comes to Youth Services* - ***Rosie***
Professional Training Gaps	*"But with conversation I have had with CMHT professionals, they don't feel that they have the expertise many times to work with people and women with autism."* - **Talia**
Educational Empowerment	*"I think it's very hard because obviously we deal with people as an on, on an individual level on where they're at... We would grade activities to where the person needs it to be."* - **Ruth**
Individualised Interventions	*"I think it's a matter of holistically looking at the individual and thinking about what do they need now"* - **Yana**
Resilience	*"What surprises me is the resilience despite everything"* - **Melina**

Generating Themes & Sub-Themes

Broader patterns across the dataset were explored in order to identify any potential themes which encapsulated several of the codes identified previously. Codes that shared similar underlying concepts were synthesised with one another, with consideration given to the researcher's own assumptions and biases so as not to influence the final result. Steps taken in the prior phases with regards to reflexivity and data familiarisation helped to minimise the common errors typically found during this stage (Braun & Clarke, 2022). However, due to constraints placed on the researcher, inter-rater reliability was not able to be conducted leaving the themes susceptible to investigator bias. The process resulted in five main themes being constructed, with sub-themes providing further detail when attempting to answer the research questions, illustrated in Figure 2 below. The themes provide insight into answering the research questions surrounding the presentation of ASC in this population. Each theme, and its corresponding sub-themes, will be discussed in detail both individually and how it relates and connects to others found during this stage of analysis.

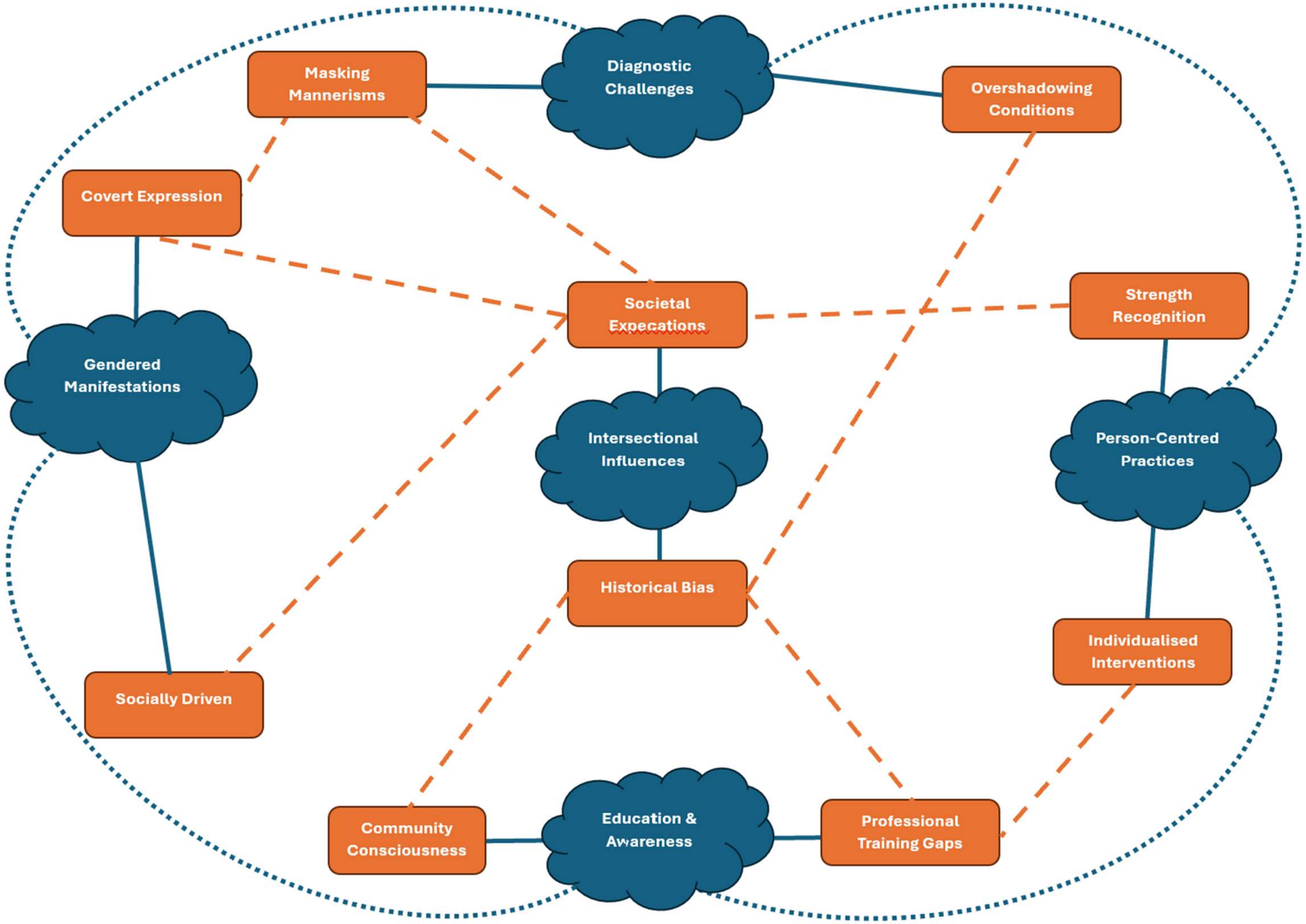


Figure 3 Thematic Map showing constructed Themes (Blue Clouds) and Sub-Themes (Orange). Solid Lines Represent connections between themes and their relevant subthemes whilst Dotted Lines Represent Semantic Connections between all themes and subthemes created.

Theme One: Diagnostic Challenges

The theme of diagnostic challenges relates to participants citing key issues in the accurate identification and diagnosis of ASC in women with ID. In doing so, they also highlighted what they believed to be the current impact of these challenges on women with ASC given their more subtle presentation. Several of the aforementioned challenges were of particular importance to the ID community, with participants feeling that unique challenges were experienced when a query of ASC in an individual with ID was raised in their services:

Sub-Theme One: Masking Mannerisms

Masking, and its potential role in misdiagnosis, among women with ASC and ID was frequently referred to by participants. The term ‘masking’ was explicitly used by several clinicians. Ruth, an Occupational Therapist, observed that in her experience “*women are better at masking some of the signs*” that people might commonly associate with ASC. This sentiment was echoed by Speech & Language Therapist (SaLT), Lauren, who elaborated that women not only *“mask more”* than other groups but also how it was a *“strategy that a lot of women use… especially [those with] mild learning disabilities”*. Professionals used alternative terminology to describe this phenomenon. Dan, another SaLT, described how masking entailed “*covering up some… social difficulties*” that women with ASC-ID experience, whilst Clinical Psychologist Steph used the metaphor of a “*veneer*” to describe the surface-level presentation that she observed in the population leading “*the person [to appear] quite reciprocal*”.

There was general consensus among participants that the aspects of ASC that female service users with ID mask were primarily social in nature. These masking behaviours were both directly observed by clinicians and reported by patients or their support systems. Mimicry emerged as a frequently referenced form of direct masking. In this context, mimicry refers to the tendency of individuals to imitate or adopt behaviours, speech patterns, and social cues from those around them. Dietician Esther described mimicry that she had witnessed:

"I would say, it's that maybe echolalia, if they're verbal, but also copying behaviours of what others do. And kind of really following things based on what their mum or their brother or their sisters doing but doing it because they think that's the way to do it, not necessarily because that's the way they're thinking."

Clinical Psychologist Melina and Occupational Therapist (OT) Megan corroborated Esther's view. Melina suggested that, of the women with ASC-ID that she had worked with, this group typically found themselves "*in positions of being socially exploited*" not "*because of unstable emotional pattern[s]*" but instead because "*they [were] copying or modelling [themselves] by other people*". Megan, meanwhile, highlighted her view that social abilities that she observed tended to occur more in women compared to men:

"I think it's the things like social skills… I think women in general, you know, in the general population, women have better… So well actually let's reframe that… Women tend to be happier with social interaction just innately. And I think… Because a woman with learning disabilities and autism might well have learnt some of those skills."

The interviews suggest some variation in perspectives regarding the intentionality of mimicry as a masking strategy for this population. Some participants believed that women with autism and intellectual disability actively copied others they were close to, such as family members, while others attributed the difference to an innate ability to navigate social interactions compared to men, both with and without ASC or ID. These results highlight a critical area for consideration in the assessment and diagnosis of ASC in women with ID, as this group may be subject to similar challenges with regards to underdiagnosis of misdiagnosis found in other populations with autism.

Overshadowing Conditions

The presence of co-morbid conditions that obscured or delayed the diagnostic process for women with ID was observed by the sample, effectively acting as its own form of clinical masking in conjunction with social masking behaviours mentioned above. Notably, the most prominent comorbidity contributing to clinical masking in the view of participants, was the intellectual disability itself. Yana, a Clinical Psychologist in Training, outlined how, "*depending on the severity of the learning disabilities*" clinicians may find it "*easier to dismiss*" any queries regarding ASC. Rosie, a Community Nurse, corroborated Yana's observation, stating that it may be the case that "*an overshadowing of the learning disability*" takes place where professionals believe that "*they've got a learning disability and that's that*". This precedence of ID and the manner in which this encompassed a person's difficulties was summarised by Katie, also a Nurse:

"Other priorities... social circumstances that might be put first because they're kind of seen as the things that need addressing sort of more urgently than an autism diagnosis... maybe that lot of stuff will just get put down to the LD."

The data suggested that this overshadowing effect influenced the care decisions of various professionals working with this population throughout their lives. Flo, a Senior Nurse Practitioner, provided a poignant example from her own experience when working with staff in primary care:

"Totally diagnostic overshadowing with a lot of people, especially GPs. If you try to get somebody seen, sometimes they'll say, 'Oh well, they've got a learning disability, that's normal.' You know, and it can be a battle sometimes of actually that's not normal behaviour for that person. Yes, they might have a learning disability, but actually there's something else going on."

Whilst Flo described this bias across other services, Healthcare Assistant Sara acknowledged that even in ID services, there was the potential for bias towards the ID aspect of a women's identity, sharing her experience that ID "*is our main focus*" and that, as a result she and her colleagues may not "*take into account other things*". When considering alternative explanations as to why this bias was present, Art Therapist Shiren raised systemic issues that she believed contributed to this problem:

"I think we've got a limited resource of learning disability and autism services anyway so I think that particularly if people, you know, women are presenting quite able and they

then go into adult mental health services, I don't think they're always equipped to pick up on learning disabilities… as a starting point."

Caroline, the only Psychiatrist interviewed, also shared her view on this topic, noting that ID was "*a diagnosis that is given*" in earlier childhood and is an "*already established diagnosis*" compared to ASC. Beyond these frequent observations around the impact of ID itself, participants also acknowledged other differential diagnoses that could overshadow assessment for ASC, particularly mental health presentations. Talia, a Clinical Psychologist, highlighted the ease at *which "someone could think whether this is autism"* in a person they might be assessing or something different "*like personality disorder or… attachment difficulties".* Kiki, another Dietician, reported her experience of the overlap with traits of ASC and those in Obsessive Compulsive Disorder (OCD):

"That's typically what is explored, first of all around their behaviours it's almost like some traits of OCD sometimes, and I think people kind of grasp onto that OCD mental health side of things rather than actually has this been a lifelong issue rather than just an acute issue that's coming up now."

These findings suggest a complex interplay of factors contributing to diagnostic overshadowing in women with ASC and ID. The presence of a learning disability, often diagnosed earlier in life, appears to create a significant barrier to the exploration of other potential issues such as autism. This overshadowing effect is compounded by the presence of mental health comorbidities, which may present with overlapping symptoms.

Theme Two: Gendered Manifestations

Gendered Manifestations refers to clinicians observing that women with both ASC and ID exhibit behaviours and symptoms of autism that are different compared to that which they would typically see in men with the same conditions. Whilst the diagnostic challenges related to one phase of clinical input, this theme refers to life-long differences in autistic presentation which have been observed by clinicians, providing further context in our understanding of how autism can present in the ID population, both for women and for men.

Sub-Theme One: Covert Expression:

Participants reported witnessing more covert features in women with ASC and ID that they had worked with, contrasting significantly with the more overt manifestations observed in men. Consistent accounts were given with regards to how men with ASC-ID tended to express distress and dysregulation, utilising more externalised observable means. Melina described witnessing *"a lot of agitation"* including "*rushing… punching walls"* and "*verbal and physical aggression*" when her male clients were more dysregulated. Yana and Esther's experiences aligned with this, sharing how "*it's still the case that lot of.. male service users tend[ed] to display aggressive behaviour*" and how men "*could often have more outbursts*" describing behaviours such as "*throwing things… stimming… pacing and twirling"*. Differences were also reported regarding the openness to engage in emotional expression. Women with ASC and ID were reported to internalize their emotional experiences, often resulting in self-directed regulation strategies and disengagement from support. Katie and Lauren described this phenomenon in women whom they had worked with, sharing how they had "completely shut down" when in periods of severe distress and how much harder it was to know how they were feeling as *"they [didn't] really know how to express it*", whilst men *"[wore] their heart on their sleeves"* making it *"easy to see"* how they were feeling. When exploring what the impact of this internalisation was, Rosie shared how women that she had worked with would be seen as "*withdrawing", "going into herself*" or even *"disengaging"* from support sessions entirely.

As well as emotional externalisation, clinicians shared their feelings that men with ASC-ID tended to behave in manners more indicative of traditional profiles of ASC whilst women were believed to exhibit these less frequently. Melina shared how women's *"stereotypical behaviour tend[ed] to be less there"* compared to men that she had come across in her work, whilst Steph provided a more concrete example of the differing interests that she had observed and how they made ASC harder to spot:

"I mean, ladies, women do wear makeup, so if they spend hours now is putting on their makeup, you kind of think, oh, why it's a function to this they're just slow, whereas with boys, you know if they know the bus timetables, frontwards and backwards…"

Talia shared an example of her experiences of conversing both men and women with ASC-ID, reflecting on the differences that she had encountered providing further evidence for the more 'typical' features of ASC observed in men compared to women:

"And so, you know, the conversation was quite one way really conversation. And you could see that the person would only want to talk about their own interests and they would go into great lengths to talk about their own interests… So we could see very clearly signs of autism. I'm comparing that with a woman I'm working with LD"

These findings suggest that women with ASC-ID express themselves in a manner that is less typical of ASC than men, both due to the content of the manifestations and the way in which they are observed and interpreted by those around them. When these covert expressions are missed, clinicians reported emotional overwhelm and dysregulation for this group, often manifesting in more intense and self-directed ways. Lauren shared that "*the levels of self-harm are miles more severe in women than men*" that she had worked with. Shiren expanded on these points, sharing how a woman that she had worked with experienced difficulties in her daily life:

> *"Her ability to sort of adapt and transition and to perform changes at work that are really difficult to her, and so this has led to her, unfortunately being disadvantaged at work and that those needs not being fully understood and it's caused a lot of distress for her."*

This sub-theme underscores the need for greater consideration when working with women with ASC and ID whom, from a professional perspective, internalise their experiences and express themselves in less overt ways. Whilst this may also contribute to underdiagnosis or misdiagnosis, aligning with the challenges discussed in the previous theme, it also highlights the extent of the unknowns relating to women with ASC-ID and their emotional experiences compared to men. Reports that this group may disengage and withdraw from support services highlights not only the potential level of distress this group needs to be under before overtly expressing themselves (and the risks associated with this) but also reveals the need to identify early signs that internalisation may be taking place, allowing for support to be given at a more helpful stage.

Sub-Theme Two: Socially Driven

Whilst women with ASC-ID were described to engage in more internalised forms of emotional expression and held less rigid and more culturally normalised interests, clinicians contrastingly reported a difference in how socially driven women with ASC-ID were compared to men. Participants reported observing a greater desire and effort among women with autism and intellectual disabilities to seek out and engage in social interactions, despite potential difficulties in execution. Lauren highlighted the contrast in social engagement during assessments:

"Sometimes the conversations are a bit more insightful. When I've worked with men, what we often will find is that they just say they don't know to a lot of the answers in the ADOS, whereas I think girls will try and answer and get themselves tied up in knots a little bit more."

Whilst Yana and Dan noted the heightened social interest that they had observed in women with ASC-ID that they had worked with:

"They tend or they seem to be much more social[ly] interest[ed] so they may look like they are wanting to go out all the time or being really friendly to people and wanting to build a connection or social media." - Yana

"So I think well, well, well women and they're kind of that social having more of those kinds of sort of social drive to build relationships… That that would be my gut feeling is that actually that's where the difference lies" – Dan

When comparing these experiences to male service users, professionals reported a feeling of them being less interested in social connection. Talia shared how, during her work with one such individual, her interactions felt one-sided:

"There was no kind of response or no curiosity from the person about, you know, how it was. And so, you know, the conversation was quite limited and one way conversation. And you could see that the person would only want to talk about their own interests"

This single-way interaction was also corroborated when comparing how men and women managed being by themselves. Caroline noted how patients that she saw who were men were *"happy being by themselves"* and were content with *"sitting in their rooms"* as a means of coping whilst women were reported to *"want more attention"*. While this heightened social drive was viewed as a potential strength for women with ASC and ID, clinicians expressed concerns about potential vulnerabilities that could arise. Megan highlighted the challenges of navigating complex social situations:

"I used to go in as an OT to a special needs college. And you know during break times, it's like rampant hormones and actual friends actually figure and who you know, who's broken up. But it's like there was no… they didn't have the maturity of understanding and the misinterpretation. So I think they're likely to misinterpret what people are saying"

This risk of misinterpretation of social interactions and situations was echoed by Shiren, who shared:

"Perhaps they may not understand certain social cues, but they might be perceived as to understand them and then they can be vulnerable in, you know, in all kinds of relationships. And you know, a lot of the time, unfortunately, we see kind of narratives around sexual abuse and around financial abuse as well where that person is perceived to have a good understanding but may not necessarily be perceiving that information or may not be taking that in"

This sub-theme implies a significant gender difference in the manifestation of autism in individuals with intellectual disability, particularly with regards to social engagement. It suggests that women with these presentations may exhibit a stronger drive for social connection, potentially masking some of their difficulties and leading to unique vulnerabilities. These observed differences in social drive underscore the need for greater understanding around these conditions and the importance of considering gender and intersectionality to understand and support this population, thereby improving quality of life and healthcare provision.

Theme Three: Intersectional Influences

Previously defined themes have highlighted how different aspects of ASC and ID in women manifest, setting them apart from other populations. Intersectional Influences, whilst acknowledging these thematic similarities, are defined as factors that relate to living as a woman with autism and intellectual disabilities in mainstream society and culture. The theme encapsulates the impact that clinicians believed the context of being a woman and having an intellectual disability or aspect of neurodivergence, both historically and presently, has had in manifesting the differences noted above. In this way, the theme posits, women with ASC and ID utilise traits similar to that of the FAP which is maintained by the wider systemic context.

Sub-Theme One: Societal Expectations

Societal expectations refer to factors which professionals believed resulted in the behaviours and experiences observed in women with ASC-ID. These expectations, both implicit and explicit, were found to compel these women to conform to traditional gender roles, resulting in the more subtle manifestations of ASC. Lauren shared her perspective around how quickly these expectations are placed on women suggesting *that "from an early age"* they was a sense of *"just getting on with it… fitting in and making do"* a message which Steph believed impacted women with ASC to a greater degree, affecting identity formation itself:

"In society there is still an expectation of what women, to some degree… It has changed and it is constantly changing, but there is an expectation of femaleness and there's a lot of autistic women who struggle with gender identity and sexual identity and struggle to understand where they fit."

The data defined some of these expectations under what could be called 'femaleness' which they argued women with ASC-ID gravitated towards, possible as a means of conforming to Western societal norms. Caroline provided her own example of a woman she had worked with:

"My lady. She is the one of the patients she wanted to have a baby, and she is now all about having a baby… So it's all, it's all different for female, and they have different needs. I suppose she wants to be a mother and she is trying to make it happen."

Kiki noted another societal pressure that she believed was more gendered, this time regarding physical appearance:

“There’s definitely more pressure on women when they are overweight to lose weight. And if a man that I see with the same diagnosis doesn’t care, loves his big belly, then that’s fine. Whereas I almost feel that there’s definitely more pressure on women to make adjustments.”

These distinct societal pressures, the data suggested, resulted in different standards being applied to men and women with ASC-ID. Melina spoke on the impact of these standards and how it applied to men and women’s role in Western society:

"The role expected of them is different. So I think socially men who are quite… mildly inappropriate in what they say. I think it’s still attributed to the gender and accept it… If you have a girl who is quiet, who does not talk and does not have behavioural problems as a child is often praised and seen as good."

Whilst these pressures were certainly viewed to apply to wider society, some participants observed their own services and professions also falling victim to these stereotypes. Kiki shared her experience of practices implemented in ID services and the assumptions that were made about women with ID's health needs based on their age:

> *"But you know, people with a learning disability especially, you know, moderate to severe learning disability, they will be put on contraceptive pill and when they reach the age of 50, it will automatically be stopped and they will have and they will be kind of tested as to whether they're going through the menopause. It kind of just seems like a blanket rule at the age of 50, they come off their contraceptive pill."*

In summary, despite evolving societal norms, clinicians believed that expectations around women have persisted, creating a culture of resilience to stigma and conformity mediated by patriarchal notions of what it means to be a woman. The data, shows that women with ASC-ID may gravitate towards these more tangible norms, resulting in a societal mask that further complicates the diagnostic process and access to provision. This sub-theme highlights the complex interplay between societal expectations and the lived experiences of women with ASC-ID, emphasising the need for clinicians and researchers to consider these influences when developing assessment tools and interventions, as well as the importance of challenging restrictive gender norms to create more inclusive environments for neurodivergent individuals.

Sub-Theme Two: Historical Bias

Intertwined with the previous sub-theme is that of historical bias, representing the contextual history of ASC and ID that resulted in the formation of the expectations highlighted above. Participants' views highlighted how this historical context may affect the diagnosis and presentation of ASC and ID in women with frequent reference made to the historical beliefs regarding ASC. Flo spoke of how professionals *“didn’t tend to look for [ASC] in women”* in the past, stating how *“it was always felt that it was men [and] boys more”*. This historical male-centric view of Autism has had lasting implications on the diagnostic process. Ruth elaborated on Flo’s perspective regarding the diagnostic focus, speaking about the historical prioritisation of ID:

> *"I think it is more likely that somebody will get an autism diagnosis from a young age but maybe you know, back 20-30 years ago it was more about just having them diagnosed, you know, having them diagnosed with a learning disability and getting the right schooling for them."*

The impact of these historical biases was felt to extend to the diagnostic tools used for autism and intellectual disability assessment, given their conceptualisation at the time these preconceptions were held. Esther echoed findings from the systematic review, stating that *“so much of the diagnosis criteria [was] aimed at men”,* meaning that, when women with ID and ASC enter services *“they don’t fit”*. Yana went on to emphasise this point, sharing her point of view that *“a lot of the measures”* used that have attempted to typify what is known about ASC are *“more relevant for males”* than females. The historical attitudes towards intellectual disabilities were also discussed, providing insight into views which may have necessitated behaviours aligning with the themes & sub-themes above. Megan reflected on this as well as how the current environment may have changed for the better:

> *"I think it's getting better. It's something that is being talked about more… Never used to be. I mean, when I was young, you know, people were just, you know, it was institutions*

and everything and he didn't talk about it all, you know. And they use terms like they were simple or not right in the head, you know, and it's not politically correct, but that is the language they used."

Given the impact that these historical biases were believed to have had on all aspects of provisions for ASC, it is perhaps unsurprising that clinicians believed that these resulted in some of the diagnostic challenges stated in Theme One. Lauren highlighted this connection, describing the difficulties that she had encountered regarding the differentiation of ASC-ID presentations from other conditions such as personality and eating disorders:

"There's the diagnostic overshadowing part, but there is also the attitudes and historically what we see with women. So lots of women are misdiagnosed with eating disorders or psychosis or personality disorder, and I think part of that is kind of probably society based and kind of what we would expect rather than thinking outside the box."

The emergence of this sub-theme underscores the profound impact of historical perspectives on current diagnostic practices and societal attitudes towards autism and intellectual disabilities in women. It highlights the need for a more nuanced, gender-informed approach to assessment and diagnosis, as well as the importance of challenging long-standing biases in clinical practice.

Theme Four: Education & Awareness

The previously constructed themes highlight the current and historical challenges that women with ASC-ID face in being effectively supported and understood, both in a clinical context but also in wider society. To address these issues, participants stressed the need to learning and development opportunities in these contexts, encapsulated in the current theme: Education and Awareness. By filling these gaps, participants hoped that staff and families would be able to more accurately recognise the traits of autism in women with ID mentioned above as well as reducing the societal stigma associated with the diagnoses. This would, it was hoped, increase the awareness of more subtle presentations of ASC clinically whilst reducing the need to use strategies such as masking in wider society.

Sub-Theme One: Professional Training Gaps

A lack of specialized training in identifying and understanding Autism Spectrum Conditions in women with Intellectual Disabilities was noted across the data set. This deficiency was reported across various healthcare disciplines, suggesting a systemic issue in professional development. Healthcare Assistant Sara articulated the reliance on experiential learning due to limited formal training:

"We don't always necessarily get lots and lots of training... we get very little training really so lots of what, you know, we do is kind of based on experience and going out and meeting people... we get kind of the least amount of, you know, training and things, but we may be the people that see the person the most."

This absence of suitable training was not only observed directly by Sara but indirectly by Talia, a clinical psychologist which, as previously stated, is typically routinely involved in the assessment and diagnosis of ASC. She shared that, in conversations that she had had with members of a community mental health team that *"they [didn't] feel that they have* *expertise… to work with people and women with autism"*. For other clinicians, such as SaLT, Dan, this lack of "expertise" resulted in some services having "*a reluctance to work with people with autism",* believing that it did not encapsulate their *"sort of skill set"* at this time. Whilst some mandatory e-learning resources were referenced to, such as the Oliver McGowan Training, their effectiveness and accessibility were questioned by members of the sample. Esther expressed concerns about the perfunctory nature of this training, sharing whilst *"training is great and… really good in regards to understanding"* she worried that some professionals viewed it as *"another mandatory training that you just tick box and do"* rather than something to fully engage with and learn from. Flo echoed Esther's view, stating her own reliance on self-directed learning:

> *"We haven't ever been given, you know, training on autism. It's more what we... the information we get that we would then take out to families or to the carers or to the clients to assist them in understanding their diagnosis."*

Accessibility to training resources also differed across services that clinicians worked in. Ruth stated that, whilst some mandatory training materials were available to all, others were only available to a select few depending on the region they worked in:

> *"Yes Oliver McGowan training. Yeah, yeah. So obviously we've done the first part of that, but there should be a roll out. There's a second stage to that, but I know full well that [UK Region] clinicians haven't accessed that training because currently it's only available in [Different UK Region], so I don't know whether that training will cover, you know, autism in women as well, or whether it's just general autism training."*

As well as gaps relating to adequate training, others were noted regarding the current confusion when navigating pathways of support. Esther spoke more to the difficulties women with ASC-ID and their families can have when navigating service systems and achieving the most appropriate support:

"It's just that I think it's one of the biggest, like the systemic issues is that they keep getting battered back and forth between services and I think it's important that we hone on specific pathways for these service users who want that support."

Participants expressed that addressing these training gaps could significantly improve diagnostic accuracy and early intervention. Megan suggested that greater involvement of experts-by-experience in *"interviewing staff"* would help to create a more inclusive and ID-conscious environment for both clinicians and service users. Talia suggested targeting professionals in other disciplines such as primary care providers:

"...do you target GPs perhaps? And you know if they if they've got, if they have people who visit them and they are on the LD register, they do inform them about autism? And then you know our GPs well enough trained to spot whether a person with a learning disability might show autistic traits."

Katie emphasized her belief that enhanced training could empower professionals to challenge established diagnoses and increase feelings of autism and intellectual disability confidence:

"I think it's that kind of that confidence, almost in challenging it, isn't it, if you've sort of, you know, you're meeting someone who's in their 30s and they've had reports for years from all these psychologists and psychiatrists saying that they've got EUPD or they've got this to actually stand up and then say, actually, I think all of that is wrong. You know… it take… it takes a bit of guts to do that, doesn't it?"

This subtheme underscores the critical need for comprehensive, accessible, and effective training programs across all healthcare disciplines to improve the identification and support of women with autism and intellectual disabilities.

Sub-Theme Two: Community Consciousness

Rather than solely addressing gaps in professional development and, by extension, services working with women with ASC-ID, participants also recognised the need to extend awareness and understanding of both conditions to families and the wider community leading to the defining of the sub-theme Community Consciousness. The data collected revealed a perceived lack of awareness of services suitable for women with ASC-ID and suggestions for how this might be improved. Participants emphasized the importance of dedicated events and initiatives to promote awareness and connection with the broader society. Shiren highlighted the potential for an autism awareness week, similar to an existing awareness event present in her service:

"I know we've got the LD Awareness Week, but we could also have an autism awareness week... You know, we can have spaces that are available for that groups that are available for that, but also kind of coming together as teams and in the community like in the

LD Awareness Week where we can raise awareness of it and also kind be able to point out what there is available in the Community as well, and signpost people and families to those."

Lauren and Esther corroborated this view, stressing the importance of educating families and how it can improve understanding for both the family and women with ASC-ID themselves:

"I think encouraging families to first do that learning because a lot of families do not understand autism. Do not understand a learning disability even so, I think that education is the most important step and providing them with the community." - Lauren

"I think part of it is building that awareness and understanding. So the individual can understand their condition more, they feel supported in how to manage that and can cope with that and feel independent within that as well." – Esther

Megan highlighted how this lack of understanding can lead to problem-saturated narratives:

"It could be very difficult because families will just turn round and say they're just being difficult, you know… Because they haven't got that level of understanding… And particularly, you know, going into families where you've got young women who are being put down by the families and actually saying, but actually she's doing really well."

Flo provided support for this point, providing an example of the long-term impacts of a lack of community consciousness and how it can continue to feed into these narratives:

"I remember getting referrals of people in their 50s or 60s that we knew nothing about because they'd lived with elderly family who, you know, a parent had then died and suddenly it was crisis because nobody knew about them because they were hidden away because that's what they were told to do in the, you know, previous days. And they didn't want services involved because they thought you'd take them away from them. I've had that said to me before"

Participants offered suggestions for increasing awareness, including early screening in youth services and leveraging social media and popular culture. Rosie proposed:

"in a way, it would be good to have that sort of initial screening for anybody with a that comes to Youth Services in the beginning like, because we have very basic screening tools to start with and then it goes to a bigger assessment."

The role of media in normalizing ASC-ID and reducing stigma was also discussed. Katie and Ruth reflected on the impact of documentaries and television content:

"there's that recent documentary and it isn't it is it Paddy McGuinness's wife, who's kind of shared her… So there's, you know, there's a lot of positive stuff kind of in the mainstream around it which, you know, both staff and patients see" - Katie

"I'm a documentary person, I love a good documentary. And I've learned an awful lot from watching documentaries about women with autism, I don't know. You're probably totally aware of the Chris Packham series that was on. I found that really enlightening… I think

they, they've, they've got a wide audience, you know, they've got the whole population, haven't they? If people choose to watch it." - Ruth

The inclusion of the Community Consciousness sub-theme in the analysis highlights the perceived gap between professional understanding and public awareness of ASC and its manifestation in women with ID. The consistent emphasis on the need for broader societal recognition and understanding of these conditions, which was believed would lead to improved diagnosis, support, and overall quality of life for affected individuals, reveals the multifaceted approach required to address this issue. By incorporating this sub-theme, the analysis recognises of the vital role participants believed that community awareness plays in breaking down stigma, improving support systems, and fostering a more inclusive society for women with ASC-ID where specific presentations highlighted in other themes above can be acknowledged. This aligns with the broader theme of Education & Awareness, demonstrating the interconnectedness of professional development and community engagement in addressing the complex needs of this population.

Theme Five: Person-Centred Practices

Person-Centred Practices refer to participants describing a need for co-produced, holistic packages of support and care for this population. By focusing on strength profiles, areas of need and goals of individual service users, it was felt that a greater understanding of ASC and ID could be achieved. This, it was believed, helped to mitigate some of the challenges faced by the population in the present and could address more long term consequences of FAP behaviours in the future.

Sub-Theme One: Strength Recognition

One particular person-centred practice emphasised by clinicians was ensuring recognition and acknowledgment of strengths observed in women with ASC-ID that they had worked with. In doing so, they attempted to challenge problem-saturated narratives and presentations typically placed on this group by focusing on their individual capabilities. One such strength that was consistently recognised was the resilience that women with ASC-ID were believed to have shown throughout their lives. Lauren spoke of *"how resilient… and creative"* the women she had worked with were and, despite *"how… exhausting"* it must be to navigate the 'typical' world, she had seen her service users "*just get on"* with their lives. Sara further elaborated on Lauren's perspective, reflecting on the numerous challenges faced by the population:

> *"They're dealing with a whole lot of things that the rest of us would really struggle with, that the expectation for them to be functioning in the community or make decisions or be independent or… added with the autism and LD… I Think lots of them are amazing some of the things [they] are presented with the rest of us would struggle with and they're doing it. You know, they're really doing their best to function in in society and get on with their lives"*

These observations underscore the often-overlooked positive attributes of these individuals. Others spoke about how they altered their descriptions and language around ASC and ID in an effort to positively reframe service users' lives. Caroline, for example described how, when outlining a diagnosis of ASC to her clients, that she would describe it as *"a superpower… especially if… patients have both learning disabilities and autism".* Through use of this language, Melina believed this would help to *"enhance self-esteem and enable* *them* [women with ASC-ID] *to participate in any way they can."* Yana also referenced this in her responses, describing how she incorporates strengths recognition into her practice and the role that clinicians have in challenging deficit-focused narratives:

"I guess it speaks about thinking about the strengths a bit more and when we're thinking about the deficits or the challenges, it's thinking… how can I use the strengths that this person obviously has to help them to support them. How can they use them but its more for us - how can we empower them to use those strengths?"

In summary, Strength Recognition aligns closely with person-centred approaches by emphasizing individual capabilities, reframing narratives positively, and empowering clients through the recognition and utilization of their unique strengths. This approach moves away from problem-focused interventions and towards more holistic, empowering strategies that respect the individuality and potential of each person.

Sub-Theme Two: Individualised Intervention

By respecting the individuality of each person and their unique profiles of strength and areas of need, participants believed that individualised packages of provision could be created for this population, thereby making services more person-centred. Flo spoke of the assumptions made by clinicians when a new person comes into the service. She spoke of how "sometimes when we get a referral, we go in expecting something" but actually, once she had met the person *"it's something totally different"* despite fully recognising that *"everyone's an individual"* who aren't *"all going to present the same".* In order to recognise one's individuality in care provision, Rosie spoke of the need for a "*very holistic*" approach that considers *“everything that’s going on for that person”*. This applied, as Yana described, to all types of intervention rather than supporting a woman with ASC-ID through one particular discipline:

> *"Some people may need psychology input and may want psychology input. Some people may not want psychology input and then you can't force them. But some people may need occupational therapy. Some people may need speech and language therapy. Some people may need just nursing"*

Each profession was thought to need to make their own individual adaptations to their input depending on where the service user felt they were at when support was requested. Ruth and Lauren provided their own examples of adaptations they make such as to *“grade activities to where the person needs to be”* or *“making sure that its really structured”* with *“lots of visuals… tailored to the individual person”*. Through these individualised interventions, clinicians felt there was a direct impact on the relationship between themselves and their female service users with ASC-ID. They spoke of the impact on therapeutic rapport that was felt by working in this way. Shiren, for example, remarked on the strength of the relationship she had been able to create when time was given to individualise an intervention:

> *“but you really have to spend a lot of time with someone to know the ways in which they work and you know what's helpful with, you know, in terms of communication style for them, what aren't materials they like to use? And I think after all of that then then it's possible, it's really, you know, it has surprised me how quickly you can get to that stage once you really attune to what someone's presenting and what their needs are.”*

This sub-theme suggests that, by creatively adapting clinical work to suit women with ASC-ID and their individual needs, be it different communication strategies or grading activities in line with ability, that the population would have more positive experiences with clinical services, thus allowing greater feelings of safety and, potentially, greater externalised expressions of traits associated with ASC and ID.

Conclusion

The analysis of interviews with NHS healthcare professionals revealed five interconnected themes, providing insight into the unique presentation and experiences of women with autism and intellectual disabilities. These collectively paint a complex picture of the challenges and considerations needed when supporting this population, both diagnostically and therapeutically. The theme of Diagnostic Challenges, in particular the sub-theme of Masking Mannerisms, emerged as a central issue, intersecting with and influencing other themes. Behaviours typically associated with the Female Autism Phenotype, viewed through the lens of Gendered Manifestations and Intersectional Influences, highlights how societal expectations of femininity may inadvertently contribute to underdiagnosis, misdiagnosis and current presentations observed by clinicians working with women with ASC-ID. Themes of Education & Awareness and Person-Centred Practices underscore the importance of increased understanding of these factors and autism more widely, thereby allowing for tailoring service provisions to each individual.

Whilst these overarching themes highlight the systemic changes that clinicians believed are necessary to improve quality of life and provision for women with ASC-ID, the defined sub-themes provide deeper insight into the behavioural manifestations of the community more directly as well as the influences that they are impacted by. Sub-themes of Strength Recognition and Socially Driven challenge conventional narratives of global impairment associated with intellectual disability, suggesting that women with ASC-ID have been observed to exhibit both resilience from the world around them and skill to operate socially within it. The sub-theme of Historical Biases, emphasise these strengths further, showcasing the unique systemic challenges that women with ASC-ID have had to navigate throughout both autism and intellectual disability's storied history. The findings, therefore, imply that systemic changes are needed to all aspects of ASC and ID provision in the UK, centring these strength-based narratives of women with these diagnoses to re-evaluate healthcare provisions. Through scrutiny of diagnostic processes, implementing service-wide training programmes and increasing public awareness and support campaigns, it is hoped that the findings can support a greater quality of life for this population moving forward. Further discussion, along with reflections on the research process itself, will be discussed in the subsequent chapter.

Chapter Five: Discussion

"No, autism is not a 'gift'. For most, it is an endless fight against schools, workplaces, and bullies. But, under the right circumstances, given the right adjustments, it CAN be a superpower" – **Greta Thunberg, Neurodivergent Activist**

Chapter Summary

This chapter presents a discussion of the research findings showing how they contribute to current knowledge on ASC and Intellectual Disabilities (ID). The results reveal a complex interplay of factors shaping the experiences of women with ASC-ID, highlighting both shared and unique challenges compared to individuals with ASC alone. Drawing on the literature outlined in the introductory chapter, this analysis situates the findings within the broader historical and clinical context of autism and intellectual disability research. A key focus is the intersectionality of gender, autism, and intellectual disability, particularly how this influences behaviours associated with the Female Autism Phenotype. The study's findings challenge existing assumptions and call for a more nuanced understanding of diagnostic and support practices for this population. The potential implications extend across clinical practice, research methodologies, and policy development, emphasizing the need for more inclusive and individualized approaches. The chapter also critically reflects on the strengths and limitations of the approaches used in this thesis, considering how these factors may shape future research in the field. Finally, the position of the researcher is examined, alongside strategies for effectively disseminating the findings to clinical, academic, and policy-making audiences, ensuring meaningful contributions to the evolving discourse on autism and intellectual disabilities.

Summary of Results

The study set out to better understand women with ID and how ASC might present in a woman with a dual diagnosis of these from the perspective of clinicians working with them, in the hope of providing more appropriate support to this and other neurodivergent communities in both clinical and non-clinical environments. From interviews conducted with clinicians, five main themes were constructed: Diagnostic Challenges, Gendered Manifestations, Intersectional Influences, Education & Awareness & Person-Centred Practices each of which enrichens our understanding of the challenges that clinicians believe this population face.

The theme of Diagnostic Challenges and its relevant sub-themes underscore the persistent difficulties in identifying ASC in women with ID. In line with the findings of the meta-ethnographic synthesis, a parallel was drawn between the concept of 'Diagnostic Complexities' and the constructed theme of 'Diagnostic Challenges'. Similar to professionals interviewed in Cumin et al. and McLinden & Sedgewick's 2022 works, clinicians in the current study reiterated the difficulties they encountered when working with the more subtle presentations of ASC they had witnessed in their female clients with ID. Particular reference was given to mannerisms considered to be involved in masking an aspect of their ASC, corroborating previous findings by Miller, Rees & Pearson (2021) suggesting that women with ASC engaged in more copying behaviours to blend in with the social norms of their environment compared to men. These more nuanced means of social communication echoes Kopp & Gilberg's proposition of the Female Autism Phenotype (FAP) in 1992, connecting to accounts of women with ASC without ID found in the field previously (Hull et al. 2017; Lai et al. 2011). However, clinicians also identified unique factors relating to populations of women with ID and how aspects outside of the individual factored into ASC remaining undiagnosed. Whilst previous research has highlighted the difficulties with differential diagnoses, such as that by Bargiela and colleagues whose interviews with women suggested assignment of mental health labels before diagnoses of ASC, clinicians suggested that the diagnosis of ID acted as a form of ASC masking itself, concealing women with ID's neurodivergence and leading to the former encompassing all aspects of their identities. Clinicians thought that, due to their experiences of ID being identified earlier in a person's life, that this could prevent them and other professionals from considering autism as a co-occurring presentation, believing that a diagnosis of ID may be 'good enough' for a woman to get appropriate support regardless of underlying ASC traits. Whilst prevalence studies outlined in the introduction suggest a closer split between men and women with ASC-ID diagnoses compared to those without ID, the current findings suggest that a ratio of 2:1 in favour of men may still be inaccurate due to clinicians focusing on ID above all other potential aspects of a woman's identity, a legacy of historical biases against those believing to be developing 'atypically' (Race, 2012; Malthus, 1798).

Gendered Manifestations as a theme built upon the diagnostic challenges clinicians attribute to women with ASC-ID, revealing how traditional gender roles and norms may shape ASC-ID presentations. Existing research discussed in the introduction showcased how women with ASC have been observed to adopt compensatory strategies to navigate societal expectations such as forcing eye contact and scripting dialogue (Sedgewick et al. 2016; Miller et al. 2021). Clinicians working with ID populations mirrored these findings, suggesting that women expressed themselves more covertly and had a higher social drive compared to their male counterparts, seeking out others rather than being comfortable on their own. Whilst these findings are similar to that previously found in women with ASC and no ID, they challenge notions that behaviours associated with the FAP require high cognitive ability to execute and disrupt Baron-Cohen's (2002) "extreme male brain theory" of a greater ability to systemise. Instead, professionals believed that women with ASC and in this case ID, may utilise behaviours associated with the FAP as a means of socialising to the expectations of what it means to be a woman in western society, reflecting broader sociocultural pressures on women to conform to what is acceptable, whilst men were given more license to express themselves and externalise behaviours believed to be associated with ASC. This revelation has implications for the current understanding of autistic burnout in those with ASC-ID as posited by Arnold et al. (2023). Several clinicians described sustained emotional exhaustion, social withdrawal, and marked difficulty coping with everyday change among their female service users, a constellation of experiences that align with recent conceptualizations of autistic burnout. While existing literature on autistic burnout has largely excluded those with intellectual disabilities, participants in this research reported observing periods of withdrawal, 'shut down', and even self-injurious behaviour in women with ASC-ID, particularly following prolonged efforts at social masking or adapting to neurotypical expectations. These observations suggest that autistic burnout may be both relevant and under-recognized in this group, with unique risk factors stemming from the intersection of intellectual disability, gendered social pressures, and challenges accessing tailored support. The implications underscore the need for further study and clinical attention towards autistic burnout in women with co-occurring ASC and ID, including the development of supportive strategies that minimize masking demands and promote authentic self-expression.

The wider context of what it meant to be a woman with ID and ASC led to the conceptualisation of the theme of Intersectional Influences, revealing how societal norms and historical biases converge to marginalise these communities. Participants consistently noted that this population faced heightened vulnerabilities due to the intersection of their multiple identities (gender, neurodivergence & disability), potentially leading to greater risk of misunderstanding and exploitation. This created, in the view of professionals, a compounded marginalisation where the coalescence of these identities resulted in greater marginalisation, discrimination and barriers faced in accessing appropriate care and support. When reflecting on the findings in the meta-ethnographic synthesis, as well as the wider literature in the introduction, this aligns with the historical marginalisation of both women and individuals with ID in autism research. Considered alongside Garg et al. (2018) who suggested that diagnostic tools were not suitable for those from diverse cultural backgrounds, the findings suggest that other aspects of difference that a person may identify with complicates the process even further, perpetuating historical stereotypes about particular groups, in this case those with ID, identified by Race (2012). This theme supports the need for a more nuanced understanding of how different aspects of identity interact, emphasizing the importance in moving beyond binary approaches to autism research and practice towards more holistic, intersectional frameworks which can better capture the lived experiences of this population.

One of the main barriers that clinicians believed prevented them from moving beyond these binary approaches was a need to bridge the gap in the understanding of the presentation of ASC in women with ID and lack of awareness of the challenges that they faced as noted above, encapsulated in the theme of Education & Awareness. Whilst the study aimed to focus on professionals to provide an informed and experienced perspective on women with ASC-ID, clinicians interviewed generally felt as though they were not appropriately skilled to recognise and support the population, citing gaps in their professional development and training. Whilst mandatory options were offered by services that participants worked in, such as the Oliver McGowan training, participants felt that this was insufficient, citing a belief that its mandatory nature prevented other professionals from actively engaging with its content. As a result, professionals tended to rely on their own experiences or resources that were shared between them, leading to inconsistencies in terms of the knowledge regarding how diverse presentations of ASC can be and what factors influence this. This finding echoes the systemic limitations highlighted by McLinden & Sedgewick (2022) in the meta-ethnographic synthesis, reinforcing the desire for more information regarding how ASC can manifest and the need for health services and systems to implement appropriate and comprehensive training packages for staff involved across all aspects of provision for both ASC and ID. When considered alongside Buck et al.'s (2024) call for greater representation within the workforce itself, the findings suggest that involvement and input of women with ASC and ID in said services could also help address this perceived gap, providing first-hand accounts and experiences of what having these aspects of their identity is like to live with and experience. This would allow training packages to include manifestations that comprise FAP in ID populations specifically, supporting Silberman's (2015) push for neurodiversity-informed training through collaboration and co-production. The second tier of the Oliver McGowan Training, involving in-person training lasting for one day, could represent a foundation for such trainings to build from, already involving facilitators with lived experience of both ASC and ID. Whilst this theme does identify a barrier that clinicians believe prevent them from fully understanding the presentation of ASC in women with ID, it also offers an aspect of service development that, if addressed, could result in the creation of more ASC-ID-informed practices and services.

Whilst the themes above may suggest that women with ASC-ID face significant challenges according to clinicians, whom themselves feel unskilled in effectively recognising and supporting them, the findings offer promising avenues for development and growth if the appropriate forms of support are offered. Person-Centred Practices, despite their potential limitations in addressing the systemic issues highlighted above such as overshadowing and lack of training, provide a solid foundation for enhancing service delivery both within and beyond neurodevelopmental services. Clinicians consistently emphasised the importance of recognising the strengths of women with ASC-ID in clinical settings, challenging narratives of those considered to be “atypical” highlighted previously. This approach, it was thought, acknowledged the resilience that these individuals have developed in navigating the social challenges they face. By focusing on strengths, clinicians believed they could develop more effective, personalised strategies to support their clients, aligning with guidelines put forward by the National Institute for Clinical Excellence (2018), but expanding them to prioritise neuro-affirmative practices. The finding that women with ASC-ID were thought to exhibit more culturally and socially normative interests compared to men suggests that clinicians are confident in bringing in these strengths into therapeutic and diagnostic practices, providing a sufficient foundation to build on. A strengths-based, personalised approach, could be instrumental in challenging negative intersectional narratives surrounding this community around their ability and place in society as being ‘unworthy of support’ as referenced by Tannsjo (1998). Moreover, this approach aligns well with the findings from the meta-ethnography emphasising the need for heterogeneous screening strategies for autism that go beyond the ADOS or other gold-standard assessment tools. By focusing on individual strengths and needs, services can transcend the one-size-fits-all approach that has historically failed to capture the diverse presentations of ASC. This shift could potentially address the 'clinical mask' effect noted above, encouraging professionals to explore other aspects of neurodivergence even in the presence of a learning disability. In essence, while the challenges are significant, the person-centred approach, combined with increased education and awareness among professionals, offers a promising direction for improving the lives of women with ASC-ID, providing a framework for more nuanced, individualized care that can better accommodate the complex intersectionality of autism, intellectual disability, and females.

These themes above collectively affirm a professional belief that the FAP can be applied to women with ID whilst also exposing unique intersectional challenges compared to other groups. The persistence of behaviours associated with masking, even in cognitively diverse populations, challenges assumptions that social camouflaging is reliant on intellectual capacity, instead emerging as a survival strategy shaped by gendered and ableist societal norms. These norms are perpetuated, it is believed, by rigidity in systems who operate closer to a one-size fits all approach to ASC assessment, diagnosis and provision with limited training opportunities for its professionals. By acknowledging the historical critiques and pairing these with the contemporary insights of the interviewed clinicians, the findings suggest a potential roadmap for dismantling these systemic barriers and fostering equitable, individualised care for this marginalised population with ASC.

Implications

Policy and Guideline Adjustment

As alluded to above, the findings of the current study could have implications across various domains, encompassing clinical practice, research methodology and future policy development when working with individuals with ASC-ID. With regards to the latter, the results challenge existing guidelines and suggestions for recognising, referring and diagnosing autism spectrum conditions. Recommendations set out by NICE (2011) were written prior to much of the research surrounding FAP and its behavioural manifestations being published and, currently, do not specify specific tools to use within the assessment process, instead utilising broad descriptors on what may be helpful when considering ASC as a potential diagnosis. This includes ASC being "*under-recognised in girls leading to underdiagnosis"*, the need for *'improving early recognition of autism by raising awareness of the features suggesting possible autism through multi-agency training'* and, pertinent to the ID community, an increased prevalence if an intellectual disability is also present. Whilst the lack of specification regarding assessment may allow for a wide range of measures to be utilized, some of which may be helpful in identifying aspects of the FAP, the results suggest that, in practice, those which have historically been used continue to be relied on despite their limitations. In addition, it may result in nationwide inconsistencies in the assessment processes for ASC where some make use of these measures such as Hull et al.'s (2017) Camouflaging Autistic Traits Questionnaire (CAT-Q), which itself is not validated for use with individuals with ID, whilst others do not, leading to a disconnect forming between presentations specific to populations. Reflecting on this with the construed theme of Education & Awareness and the professional gaps it noted, a need for change within these guidelines becomes all the more pertinent as clinicians report a lack of confidence with the 'gold standard' tools currently used. Future guidelines should embrace the famous quote by Dr Stephen Shore, professor of special education with ASC, that *"if you've met one person with autism, you've met one person with autism"* and be more specific in the potential presentations and diagnostic tools utilized (Ambitious about Autism, 2017). Through this more detailed approach, with the support of rigorous multi-disciplinary trainings on ASC, ID and its impact on each's manifestation, more consistent assessments utilising specific masking-related questionnaires can be conducted and a greater level of confidence for health professionals can be achieved to better recognise features of autism in females with intellectual disabilities.

Future Research and Service Development

Alongside a greater ability to accurately identify autism in the female ID community, the results also underscore a necessity for developing screening and assessment tools tailored to populations with ID specifically. As noted in the introduction, the Autism Diagnostic Observation Schedule (ADOS), while considered the gold standard for assessment for ASC by NICE, has limitations in detecting ASC presentations more commonly observed in women, girls and, from the perspective of clinicians in the current study, women with ID. Whilst the finding of these limitations led to the creation of the CAT-Q by Hull and colleagues mentioned above, without significant adaptations, the implementation of these measures for women with ID remains problematic for researchers, professionals and, most importantly, women with ASC-ID themselves. Exemplified by Lovett and Lewandowski's (2015) study on educational accommodations for students with learning disabilities, the results suggested that while adaptations to measures and questionnaires could be made, such modifications often compromised the validity and reliability of the collected data. Further compounding this issue, research on the use of outcome measures in health services reveals additional barriers for individuals with ID. Jahagirdar, Kroll, Ritchie, and Wyke (2012) demonstrated that without adequate explanation of the purpose and content of measures, patients with ID struggled to accurately complete screeners and assessments compared to other groups. This finding emphasizes the importance of clear communication and support when administering such tools to this population. The current study's emphasis on Person-Centred Practices, combined with the observed overlap of camouflaging behaviours across individuals with and without ID, underscores the urgent need for collaboration with the communities with ASC-ID to develop a specific, accessible measure for identifying and assessing masking behaviours. Such a tool would need to be sensitive to the unique characteristics and needs of individuals with both ASC and ID, while maintaining validity and reliability. To achieve this goal, it is recommended that future research emulate the participatory methodology employed in this study to ensure that the created measure is user-friendly and relevant to the lived experiences of women with ASC and ID. This collaborative approach would help address the current shortcomings of widely used assessment tools whilst potentially providing a foundational evidence base that supports the use of person-centred approaches in the process. In doing so, this may lead to more accurate identification and support for women with ASC and ID who are currently being missed by diagnostic practices.

The development of ID-specific screening tools, it is hoped, will have implications on both clinical and research areas involving work with this community. However, perhaps a more significant impact on future research design and methodology is how it shapes understanding of theories behind autistic camouflaging. Typically, two reasons for masking have been posited in the emerging research field: to fit into a neurotypical world and to maintain relationships within the individuals' systems. These social theories, as referenced by Milton (2017), Blumer (1986) and more recently by Pearson & Rose (2021), are influenced by autism's problematic history, resulting in stigmatisation and a need for neurodivergent groups to align themselves with neurotypicals. As previously stated, the findings suggested that clinicians interviewed believed that women with ASC-ID engaged in behaviours and masking consistent with the FAP, challenging notions around the cognitive abilities believed to be required. In addition, this group held interests that have been normalised for women and girls to hold, such as Disney princess toys and make up, and behaved in ways that were socially acceptable for women and girls, aligning themselves with female members of their family and systems. When considered alongside references made by clinicians to the historical and modern context that they felt women with ASC-ID have had to operate in, the results may suggest that the population may be more susceptible to conforming to societal norms and narratives, engaging in masking not because of a desire or intention to avoid social stigma but instead because it aligns with equally subtle societal expectations around gender and ID. Future research should examine these aspects of identity and their interactions with ASC, re-evaluating the theories that are currently held about neurodivergence to include both the intersectional and the contextual. While social theories have provided valuable insights, they may need to be expanded to account for the unconscious, gender-specific aspects of masking hinted at by the clinicians who participated in this study, leading to a more comprehensive understanding of masking behaviours across the autism spectrum and inform more inclusive and effective support strategies for women with ASC-ID.

Strengths & Limitations

Evaluation and reflection of the research's design and implementation yielded relative strengths, limitations and considerations for how these could be addressed in future research to enrich the field of study and subsequently the lives of women with ID. First, the study's very existence provides a foundation for further work focusing in greater detail on the ASC-ID community as a whole and what individual challenges they face. As described in the introduction, individuals with ID are typically under-represented in the autism research field, with only one in every twenty participants having a dual-diagnosis despite the lower end of prevalence estimates suggesting one in every five individuals with ASC also have ID in the general population. As a result, studies have typically looked at these conditions in isolation when investigating their nuances, leading to research focusing on the FAP and, by extension, the presentation of ASC in populations with solely this diagnosis. Whilst this certainly has its benefits in understanding the impact of ASC on behavioural manifestations and cognitive processes, it neglects the experiences of co-occurrence and, to a degree, the wider shift towards neurodiversity and neurodivergence. Through continued involvement in the research designs, it is hoped that individuals with ASC-ID can be included within autism studies and be represented in a manner that is more in line with the prevalence figures stated above.

Collaboration with women with ASC and ID diagnoses in the design of the interview schedule and positioning them as experts by experience helped to make the study more relevant and meaningful to the community it was intended to impact. Addressing concerns found in McDonald & Kidney's seminal review (2012), the direct involvement of women with ASC and ID challenged the assumptions academics have made about the community previously, believing that they held valuable insights into what would be helpful to pose to clinicians who may work with women with ASC-ID across the lifespan. By framing the interview questions around these consultations, this helped to ensure that the research questions were not only addressed but considered in a manner that covered topics of genuine importance to the population being studied rather than solely the interests of the authors and wider academia. Whilst accounts collected in semi-structured interviews were second-hand in nature, the format built on the above, facilitating detailed accounts from those with extensive experiences of working with men and women with ASC-ID. The resulting dataset provided rich descriptions of clinical observations and experiences, enabling the identification of patterns, both new and old, in how ASC manifests in women with ID that might not be captured through more structured methods. In turn, this allowed for a deeper understanding of the complex interplay between autism, intellectual disability, and gender which may not have been achieved without this expert involvement and the interview methods used.

The varied perspective on research design provided by experts by experience was replicated in the diversity of professions collected in the sample. A purposive sampling technique was utilised to find individuals who would, it was felt, best answer the research questions. This resulted in clinicians working in an NHS adult intellectual disability service being chosen as the most appropriate participant pool, providing their perspectives of their work with the female population with ASC-ID. Whilst some NHS teams are specialised and focus on providing one particular model or type of provision, by focusing sampling on this service and its professionals, a variety of clinicians were recruited including those from psychology, psychiatry and nursing. This allowed for different perspectives to be shared and heard during the data collection process, providing a more holistic pattern of experiences to be analysed and widening the lens away from one particular discipline. Given the number of professionals that individuals with ASC-ID may come across and work with throughout their lives, the results collected felt more generalisable to the population across different aspects of their lives rather than just within a clinical setting. In spite of this, it is important to state that the sample, whilst diverse, was small, comprising of less than twenty clinicians and primarily represented by the discipline of clinical psychology, reducing the likelihood of the results being representative of these professions as a whole. The finding that said professionals reported feeling less confident and inexperienced when thinking about differing presentations of ASC and ID emphasises this point further. Future research could use the foundation that this study has created and then extend this by either looking at a profession's perspective in isolation or increase the sample size to improve generalisability to multi-disciplinary teams. This would, it is hoped, provide better understanding through uncovering the individual strengths and needs of each profession when supporting neurodivergent populations. Despite the scope of the current study not allowing for an increased sample size, the diversity of the clinicians interviewed is considered a relative strength of the research, representative of the professionals that work both frequently and closely with women with ASC-ID.

Though the above showcases the numerous and varied strengths of the study, it is important to consider the limitations in the research, primarily with regards to the chosen methodology. Whilst steps were taken to involve women with ASC-ID in the research design as experts by experience, data collection itself relied on second-hand accounts of those who have worked with this population, thought to fit the purposive nature of the chosen method of sampling. It is also important to emphasise that the study focused specifically on exploring professionals' perceptions of working with women with ASC-ID rather than gathering their accounts of first-hand experiences of these women themselves. Although this approach fit with the research's scope and other means of collaboration were implemented, the data itself relies on the indirect perspective of clinicians rather than women with ASC-ID directly. Previous research has highlighted the risks of relying on second-hand accounts from historically marginalised groups, potentially impacting reliability and validity of results. In particular, the slogan *'nothing about us without us'* has been widely used in both UK health services and by global human rights groups to encourage the direct participation of communities with discriminated aspects of difference, including ID. When reflecting on the construed theme of Education & Awareness, as well as its relevant sub-themes, further concerns arise. Participants referred to their own gaps in professional experience, relying on their own research and other sources for guidance in their understanding of ASC such as media or having family members with aspects of neurodivergence. It is possible, therefore, that these sources reinforced stereotypes about ASC and how it manifests in different groups, women included. As a result, clinicians may have been biased towards thinking about masking as a presentation but not other behaviours that could be specific to those with ID, confirming previously identified characteristics whilst distancing their accounts from women with ASC-ID themselves. If the study was to be repeated with the findings considered, a more flexible and person-centred approach would be recommended, directly engaging with women with ASC-ID using diverse data collection measures that fit with their individual profiles of communication as highlighted in previous research (Gibson, 2018). In addition, the interview schedule could be adapted to more explicitly examine the layers of perception noted above, providing an additional lens and insights into how clinicians interpret, construct and possibly shape their understandings of the lived realities of women with ASC-ID. This, it is hoped, would provide a more accurate picture of the lived experiences of women with ASC-ID as well as professionals who work with them, contributing meaningfully both to the research field and the quality of life of this population. However, at the time of the study's design and implementation, the chief investigator's capacity was limited due to the requirements of their doctoral training in clinical psychology. This prevented them from having the time and capabilities to identify women with ASC-ID who were suitable for the study, adapt resources to fit each of their individual strengths and areas of need as well as ensuring that appropriate consent and understanding of the study itself was achieved. As a result, whilst the research is limited by these second-hand accounts it is justified by its positioning of women with ASC-ID as experts by experience during its design.

As well as being susceptible to confirmatory bias, participants also relied on retrospective experiences of working with women with ASC-ID, leaving them subject to recall bias. Participants were asked to, in their experience, draw on clinical interactions that they had had in their roles and wider careers when working with individuals with autism and intellectual disabilities. Their descriptions wee then utilised as the core data to construct themes during analysis. Rather than getting a complete picture of this population, it is possible that the retrospective nature of these accounts would emphasise memorable or unusual presentations over typical encounters. When considering the theme of Gendered Manifestations, this may explain why clinicians were able to recall the interactions that they'd had with men with ASC-ID more readily, identifying their more expressive behaviours and rigid interests. Given that, in their view, women with the same presentation utilised more internalised means of self-expression, this may have resulted in other behaviours unique to this group being missed or not recalled during interviews. This limitation amplifies the need for direct accounts as, without them, it is also possible unique masking behaviours that are so successful in concealing autistic traits are being used which are currently not being picked up by health professionals or family members. With the finding that health professionals felt that there were gaps in their professional understanding when trying to accurately identify different autistic presentations, this provides further support for the need for first-hand accounts of the experiences of women with autism and learning disabilities to share their own experiences of their behaviours. This will, it is hoped, provide not only further understanding around the behaviours that may be being overlooked or attributed to other aspects of identity, but also consider how intentional the use of these behaviours are when operating in a neurotypical world.

Reflection of Self & Positioning During Research

When thinking about the strengths and limitations of the study, it is also crucial to consider my own position, views and biases and how these may have influenced the research process and analysis. In this context, reflexive writing involves connecting personal experiences with the research process to better understand and reflect on how these interacted when conducting the study and its analysis (Behrens & Rosen. 2007). At the forefront of my reflections is the potential interaction between my professional experience with individuals with ASC and ID and my relative inexperience in qualitative research. The choice to focus on supporting and understanding people with autism was an easy one for me, having worked with communities with Special Educational Needs (SEN) since the age of sixteen. These experiences continued into academia, where my integrated master's degree in Psychology concentrated on Developmental Disorders & Clinical Practice, looking at the assessment criteria and presentation of aspects of neurodivergence as well as intellectual disability. As a result of these experiences, I was exposed directly to both a significant amount of academic information relating to the presentation of ASC but also many individuals directly, each of whom had their own profiles of ASC and challenges that they were facing in their lives. Whilst this provided me with a comprehensive understanding of autism both clinically and scholastically, my direct experience in completing research was focused on quantitative analysis and smaller scale research projects, rather than qualitative approaches. I wonder, therefore, if this personal interest in the research topic and the desire to better understand and support the population in my clinical work, resulted in my own biases shifting my focus towards particular questions and discussion points during semi-structured interviews. Similar to that of participant efforts to lean on person-centred approaches to cover up gaps in professional understanding, it is probable that my clinical experience and knowledge of the history of autism and the current issues faced today covered my research shortcomings. I find myself feeling stuck on clinicians sharing experiences around mandatory training being, for some, something to be completed rather than immersed in. I wonder if this has occurred in any capacity for me, limiting the research's scope and missing aspects that did not feel, to me as relevant as others. I am grateful that we were able to involve experts by experience in the process of designing interview questions as well as consulting with my thesis supervisors which, I hope, has gone some way to addressing the impact of these potential biases I hold.

The influence of my personal and professional investment in the topic, as well as the ability to be fully immersed in the research process, leads me to consider my context at the time of writing and the limitations that this placed on the research. As a clinical psychologist in training, one is required to not only produce a doctoral thesis, exploring a new (or furthering an existing) area of study but also take part in clinical placements to develop and refine their therapeutic skills as well as better understand the role and its place in health services upon qualification. To achieve this, a trainee's time is split between both academic days and clinical placements with a requirement to fulfil a certain number of days on each whilst also needing to complete related assignments as alluded to above. When considering how this dynamic influenced the current research, the dual-task management led me to not consider methodologies that may prove difficult and disrupt this balance. The chosen sample for this project is one such example. As stated previously, recommendations for working and conducting research with individuals with learning disabilities suggests making suitable adaptations to methodologies and work practices. However, ethical practices such as that posited by the Health Research Authority (HRA) stress the importance of achieving informed consent from participants and as reported by Iacono (2006), may be conservative with approving studies where this is not achieved in the typical ways. These narratives around potential research groups that may be difficult to access may have led me to consider alternatives that fit closer with my context at the time of conducting the research. In doing so, I wonder if this has led to some of the limitations around interpreting the results and themes from the indirect accounts mentioned above and how much of issue this is to the wider field of psychological research conducted by trainees. I would be lying if I did not feel some guilt in this respect for not putting more time and energy into the research and striving more to reach this ‘difficult to access’ population, utilizing some of the adaptations referenced above. As I was finalizing the themes, I had a conversation with a family member who described the findings of this thesis as *“what will be referenced in the paper that makes a significant impact and meaningful change”*. At a similar time, whilst working clinically with those with ID, I took time to reflect on ideas around meaningful change within these services and with this community and how measures of progress are different to that found in other services. I hope to remind myself of the foundational and exploratory nature of the study and how it lays the groundwork for future researchers, perhaps future clinical psychologists in training passionate in this area, to expand on its findings and better support all communities with ASC-ID moving forward.

With both my long-standing personal investment in populations with autism and intellectual disabilities and the context of clinical training, I have considered how this impacted the analysis and interpretation of the results that were collected. As I progressed through training, I not only became more accustomed to the research process but also had a range of experiences working with women with ASC-ID and the clinicians who provide provisions for them. This exposed me to the population in both community and hospital contexts and the challenges that not only they directly face but also the narratives and beliefs cultivated about them by professionals and family members. Having this exposure to these systemic influences, particularly at a time when I was both collecting and analysing the study data, I wonder if this further shifted my focus to consider these more environmental impacts on women with ASC-ID, producing the results highlighting intersectional influences. In addition, given that I was becoming more confident with both my research skills and my practice, I wonder if there was consistency across the interviews conducted or whether my approach changed as I gained more experience in discussing topics and a greater clinical understanding of the contexts that health professionals were operating in. As well as impacting my professional life, systemic influences entered my consciousness in my personal life. Having grown up as part of a white, wealthy and privately educated family and identifying as a cisgender man from birth, I had few and far between come into contact with those from other backgrounds and had not knowingly had any direct experiences of discrimination. During data collection and analysis process, however, a rupture took place in my friendship group where a neurodivergent person of colour began more openly discussing systemic racism and discrimination and how it applied to myself and my friends. This led to me exploring aspects of social justice in greater detail as well as personal reflection on my own aspects of difference and how these contributed to my own biases and assumptions about others. Despite taking steps during the coding process to mitigate the influences of these factors and remind myself of these biases, I'm mindful that this may have been done as it was what I believed was the right thing to do methodologically given my relative infancy in qualitative study rather than to consider the impacts of my own context on the analysis process. It is also important to acknowledge that, whilst I held these ideas in mind during data analysis, they were less prevalent for me throughout other parts of the process and most likely influenced my decision-making throughout this time. When conducting research in the future, I hope to immerse myself more wholly in the process, allowing space for more honest reflections of how my context influences decision making and analysis of any collected results and greater involvement of investigated population members across the stages of research.

Dissemination

As highlighted in Chapter 3, a plan to disseminate the findings was constructed in order to maximise impact across the academic, clinical and political spectrums. First, with regards to the clinical setting, the NHS trust where participants were sampled from felt as though it was a primary target for these efforts. It was important to the researcher to recognise the valuable contribution all participants had made in providing their perspectives regarding their work with ID communities. Moreover, given the single service sampling that took place, it was thought that the findings would be most generalisable to their work patterns and provisions that they offered. Given references made to the limited nature of mandatory training in the NHS of ASC and ID, it was thought that these findings provided an opportunity not just to share clinical expertise but to increase confidence around the work currently being completed whilst providing further information about how service users can be better supported within the service itself. A plan has been made to preliminarily feedback to participants, as well as the wider team, in the near future with a confirmed date. Materials for this feedback session (see Appendix 7) will be adapted to ensure information is relevant to the healthcare context, emphasising practical applications of the findings which can then be shared amongst colleagues and through word of mouth with other NHS trusts working with these communities.

Whilst clinicians interviewed were thought to be a primary target for dissemination, communities of women with ASC-ID were just as important to inform given the research's focus. Experts by experience who supported the design of the interview schedule were sought out to share the findings with, with sufficient adaptations once again made to ensure that they were presented in a manner that fit with each expert by experience's profile of neurodivergence, strengths and needs. Following the preliminary feedback to participants mentioned above, it was thought that these professionals could help to facilitate the distribution of the findings to populations with ASC-ID that they worked with. This would help to connect parts of systems that work with these communities together, providing each with valuable insight for these groups themselves as well as others who are typically directly involved in their care.

Finally, in order to inform policy, practice and improve quality of life for women with ASC on a macro level, findings will be submitted to academic journals covering autism and intellectual disability research. As highlighted in the Methodology chapter, discussions will be had regarding which journals will be pursued following submission and completion of the viva examination. However, further avenues will be explored regarding presenting at appropriate conferences or within other settings where individuals involved in developing and implementing policy will be present such as trainings or university events. Through this comprehensive dissemination strategy, the findings regarding the presentation of autism in women with intellectual disabilities will reach those who can implement changes in clinical practice, inform future research directions, and ultimately improve outcomes for this historically underrepresented population.

Conclusion

This thesis has attempted to address a critical gap in the literature, exploring how autism manifests in a population that has been historically marginalised and under-represented in the research field. Its findings demonstrate that according to perspectives of clinicians, women with intellectual disabilities exhibit behaviours typical of the Female Autism Phenotype despite preconceived notions of the cognitive faculties required to do so. The five themes developed from the analysis illustrate the interplay between gender, neurodevelopmental conditions and societal expectations, contributing to our understanding of communities with Intellectual Disabilities, ASC's heterogeneity and highlighting the importance of both moving beyond binary understandings of its manifestations and recognising the uniqueness of its manifestation in these communities. They support the hypothesis that women with ASC-ID exhibit traits consistent with the FAP whilst going further to implicate socialisation patterns and gender-based expectations and their role in why said traits have been observed, supporting social theories of masking. Furthermore, they call for a reconsideration of the current diagnostic frameworks, historically shaped by male-centric normative research, with adjustments made to diagnostic tools and clinical training to accommodate the more nuanced experiences of communities with ID. Several avenues for future enquiry have been discussed with the potential to enhance our understanding of ASC in women with ID Priority should be given to involving the population directly in future study to uncover whether the observations of clinicians hold validity.

When I began this piece of research, I considered myself more knowledgeable than most about autism and its spectrum of presentations. My clinical experiences, which began in the UK educational system, had shaped my understanding of neurodivergence throughout my professional development. As I entered clinical training, I sought to distinguish myself as someone with a deep understanding of neurodivergence, its challenges, and the necessary adaptations to support the community effectively. This area felt like a natural choice for further exploration in a research capacity, given my perceived expertise compared to my peers. What I had yet to consider was the clinical experiences that I had had with those with ID. Through SEN and subsequently Child & Adolescent Services for those with Disabilities I had also been gathering my own perspectives on intellectual disability, its manifestation and the importance of recognising it within a person's identity. In spite of this, I had also unknowingly put it behind the presentation of autism that I was interested by, unconsciously conforming to the narratives around working with communities with such a diagnosis. The findings, therefore are both a culmination of a near fifteen-year journey with autism and a challenge to such narratives, aiming to centre the experiences of women with ID. They highlight the strengths, challenges, and recommendations for better support and understanding, underscoring the unique experiences and assumptions faced by this population and the influences such historical biases and discrimination continue to have. Moreover, they emphasize the significant role of environmental factors in masking behaviours and challenge prevailing narratives about the capabilities and engagement potential of this community. Through this process, I have come to reconsider my notions of knowledge or competency with ASC that I believed I held prior to training through my developing understanding of those with ID. I have concluded that true expertise is elusive, and one is always growing and developing understanding through encounters with individuals who possess different experiences and insights. Furthermore, I am left contemplating the implications of who holds the position of 'expert' and how researchers, professionals and others may wield influence to create assumptions about marginalized communities that may or may not be accurate but are accepted due to perceived authority and power.

I am grateful for the opportunities I have had to witness the experiences of women with ASC and ID first hand, through conversations with experts-by-experience and during my clinical placements. These interactions have provided invaluable insights into the realities of the FAP, its benefits, and the challenges it presents those exhibiting behaviours associated with it. The research contributes to a growing body of evidence calling for more nuanced, intersectional approaches to understanding autism across diverse populations. By centring the experiences of women with intellectual disabilities, this work not only advances our theoretical understanding of autism but also advocates for more equitable clinical practices that recognize the full spectrum of neurodiversity. It is my sincere hope that this work has underscored the need for further direct investigation into this community, not just by clinical psychologists in training but also by the wider academic community. In doing so, we may continue to challenge our assumptions, amplify unheard voices, and contribute to a more respectful knowledge of both autism and intellectual disability. As our understanding continues to evolve, we can continue our push towards a richer understanding of this fascinating neurodivergence.

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Appendices

Appendix One: Summary Tables of Papers Suitable for Systematic Review

The following provides summary tables for each of the nine studies which met criteria for systematic review. Each table summarises the aims of the articles, the professions and nationalities sampled, emerging themes and suggestions regarding to findings as they relate to the literature review questions.

Author	**Barbaro et al. 2023**
Aims	Evaluate the implementation of an autism screening and surveillance pathway
Sample	Twenty Three General Practitioners
Nationality	Victoria & New South Wales, Australia
Design	Semi-structured Interviews
Themes	
Challenges of Screening	Limited knowledge and uptake of tools amongst GPs
Time Constraints	Lengthened screening times, implementation issues, GP schedules
Systemic Shortcomings	Lack of local workforce, complex systems, socioeconomic factors
Support Needs	Admin Support, GP training opportunities, specific resources for ASC (e.g. tools)
Findings	GPs suggest that clear open communication with staff facilitates timely screening. Systemic issues and time constraints inhibit this with training needs around skill development

Author	**Buck, Hurewitz & Franklin (2024)**
Aims	Gather clinical insight on barrier to achieving equitable autism provision
Sample	Twenty-Six multi-disciplinary paediatric clinicians ('autism experts')
Nationality	United States of America
Design	Semi-Structured, virtual focus groups
Themes	
Workforce Composition	More representative workforce would help accessibility
Workforce Capacity	Limited workforce in number and training
Impact of COVID-19	Assessment tools not appropriately matched to context of COVID-19
Findings	Authors state that workforce diversity, autism education and sufficient interventions for staff burnout are necessary to address barriers to autism assessment & diagnosis

Author	**Cumin, Pelaez & Mottron (2022)**
Aims	Describe clinical expertise involved in making decisions regarding autism diagnosis in women
Sample	Twenty Clinicians with between 5-40 years' experience assessing + diagnosing autism
Nationality	Not stated
Design	Delphi Survey (Content Analysis)
Themes	
Diagnostic Challenges	Diagnostic criteria vague and does not acknowledge complex presentations
Differential Diagnosis	Mental Health presentations mimic traits of autism
Strategies for Assessment	Taking time and using patient-centred approaches are helpful
Findings	Clinicians observe complex presentations in their clients that do not fit the criteria provided by manuals and guidelines

Author	**Fenikilé et al. (2015)**
Aims	Explore barriers to implementiong screening for autism at 18 and 24 months
Sample	Fifteen family physicians
Nationality	Kansas, United States of America
Design	Three focus groups & six semi-structured interviews
Themes	
Screening Barriers	Physicians working with limited resources and lack of training around use of screening tools and autism
Tool Preference	Physicians preferred general developmental assessments over specific autism tools
Findings	Clinicians did not feel confident using autism screeners and preferred more general assessments. Time constraints and limited resources facilitated this

Author	Garg et al. (2018)
Aims	Explore the use of screening tools by health professionals to understand barriers and facilitators to autism diagnosis
Sample	Thirty-Seven Primary Health Care Providers
Nationality	Sydney, Australia
Design	Semi-structured Interviews
Themes	
Barriers to Access	Issues regarding transport to services and language used in screening tools
Barriers for screening use	Limited knowledge of tools reported by clinicians, suggesting it is too specific and preference for more traditional milestone-based measures
Findings	Study suggests a lack of confidence using screening tools by clinicians and barriers experienced by those from different contextual backgrounds

Author	**Hamp et al. (2023)**
Aims	Explore experiences of care providers around identifying and managing autism
Sample	Twenty-Eight Primary Care Providers
Nationality	United States of America
Design	Semi-structured Interviews via Zoom
Themes	
Identification Challenges	Concerns regarding use of standardised screening tools. Lack of knowledge of both parents and clinicians regarding signs of autism
Process Barriers	Long wait times, processes and complicated systems made navigating autism diagnosis challenging
Findings	Study suggests clinicians lack capacity and confidence in communicating and delivering autism-related information to families

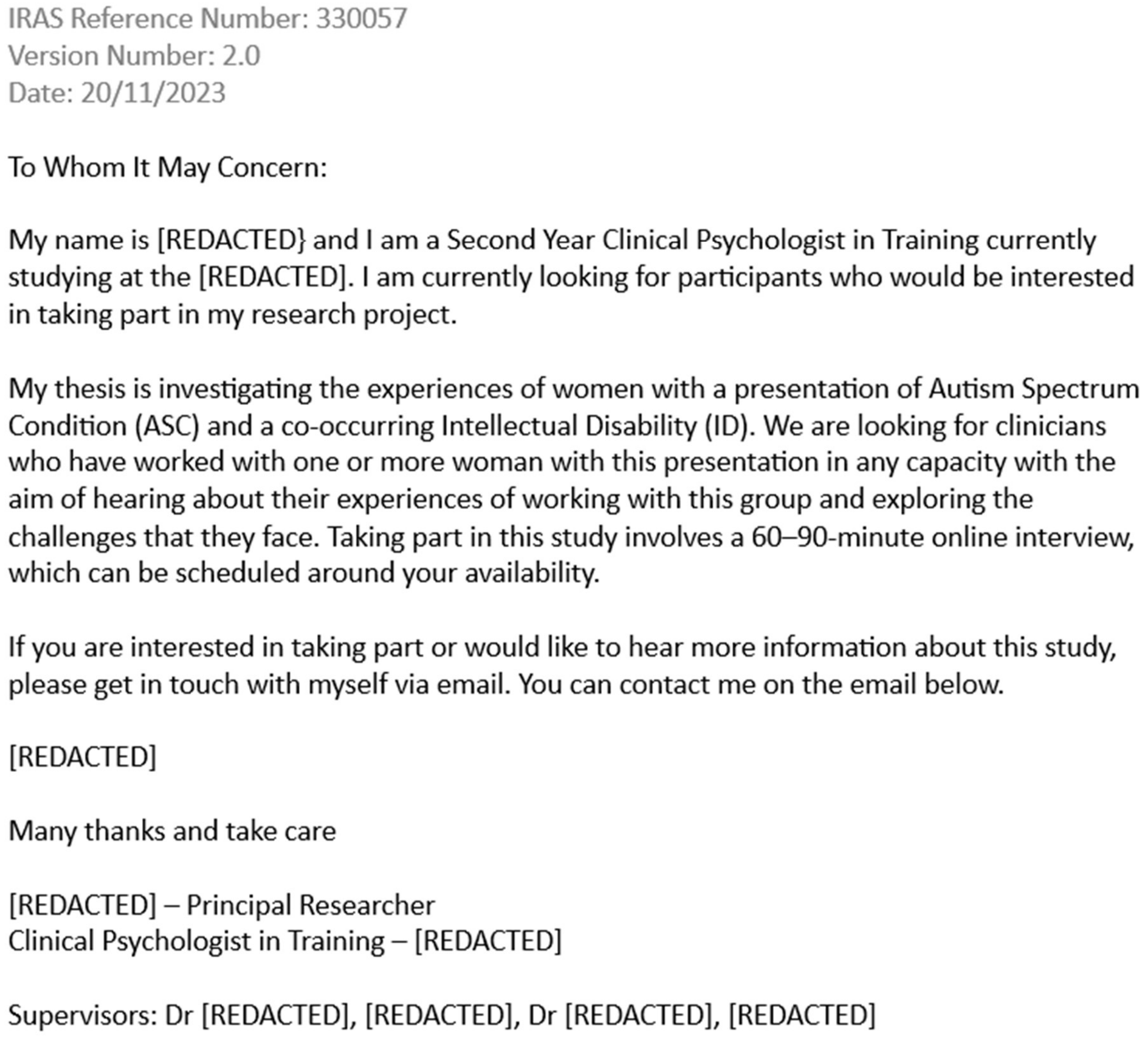
Author	**Hayes et al. (2022)**
Aims	Explore experiences of care providers around identifying and managing autism
Sample	Twenty-One Clinicians working in Autism Assessment Services
Nationality	England
Design	Semi-structured Interviews
Themes	
Institutional Pressures	Reports of increased referrals, time pressures and limited expert support both during and post assessment
Tool Limitations	Tools reported as limited when assessing particular groups (women + girls) and forming only one part of assessment process
Diagnostic Challenges	Reliance on professional understanding of autism and the difficulty of diagnosing it within a 'spectrum'
Findings	Clinicians believe autism assessment is a lengthy, contextual process, involving pressures and challenges due to the context of services administering them

Author	**Hurt et al. (2017)**
Aims	To understand clinician experiences of the pathways for children with autism
Sample	Eight Health Multi-Disciplinary Professionals
Nationality	South Wales, United Kingdom
Design	Focus Groups, creative writing workshops and visualisation exercises
Themes	
Clear Provisions	Clinicians believed structured, clear systems benefitted families accessing autism assessment and support
Limited Communication	Information shared with clinicians was poorly communicated when children are referred
Family Expectations	Clinicians struggled with managing parental expectations regarding diagnosis and the limited provision they had following assessment
Findings	Clinicians believe that healthcare systems communicate in manners that prevent efficient and accurate autism diagnosis from taking place

Author	**McLinden & Sedgewick (2022)**
Aims	To understand how autism diagnostic services and professionals have changed to accommodate for women with autism
Sample	Nine Multi-Disciplinary Health Professionals
Nationality	United Kingdom
Design	Semi-structured Interviews
Themes	
Gender Differences	Clinicians felt that women deviated from the norn of what autism typically had been defined as
Informal adaptations	Clinicians had adapted their practice in their own settings without official policy guidance
Service Limitations	Clinicians felt that there was a lack of services available for assessing women with autism
Findings	Clinicians believe that healthcare systems communicate in manners that prevent efficient and accurate autism diagnosis from taking place

Appendix Two: Email Script for Adertising Research to Potential Participants

The following provides the email script that was used to advertise the study to clinicians working in the sampled service for adults with intellectual disabilities. Some names and affiliated institutions have been redacted to maintain confidentiality.



IRAS Reference Number: 330057
Version Number: 2.0
Date: 20/11/2023

To Whom It May Concern:

My name is [REDACTED} and I am a Second Year Clinical Psychologist in Training currently studying at the [REDACTED]. I am currently looking for participants who would be interested in taking part in my research project.

My thesis is investigating the experiences of women with a presentation of Autism Spectrum Condition (ASC) and a co-occurring Intellectual Disability (ID). We are looking for clinicians who have worked with one or more woman with this presentation in any capacity with the aim of hearing about their experiences of working with this group and exploring the challenges that they face. Taking part in this study involves a 60–90-minute online interview, which can be scheduled around your availability.

If you are interested in taking part or would like to hear more information about this study, please get in touch with myself via email. You can contact me on the email below.

[REDACTED]

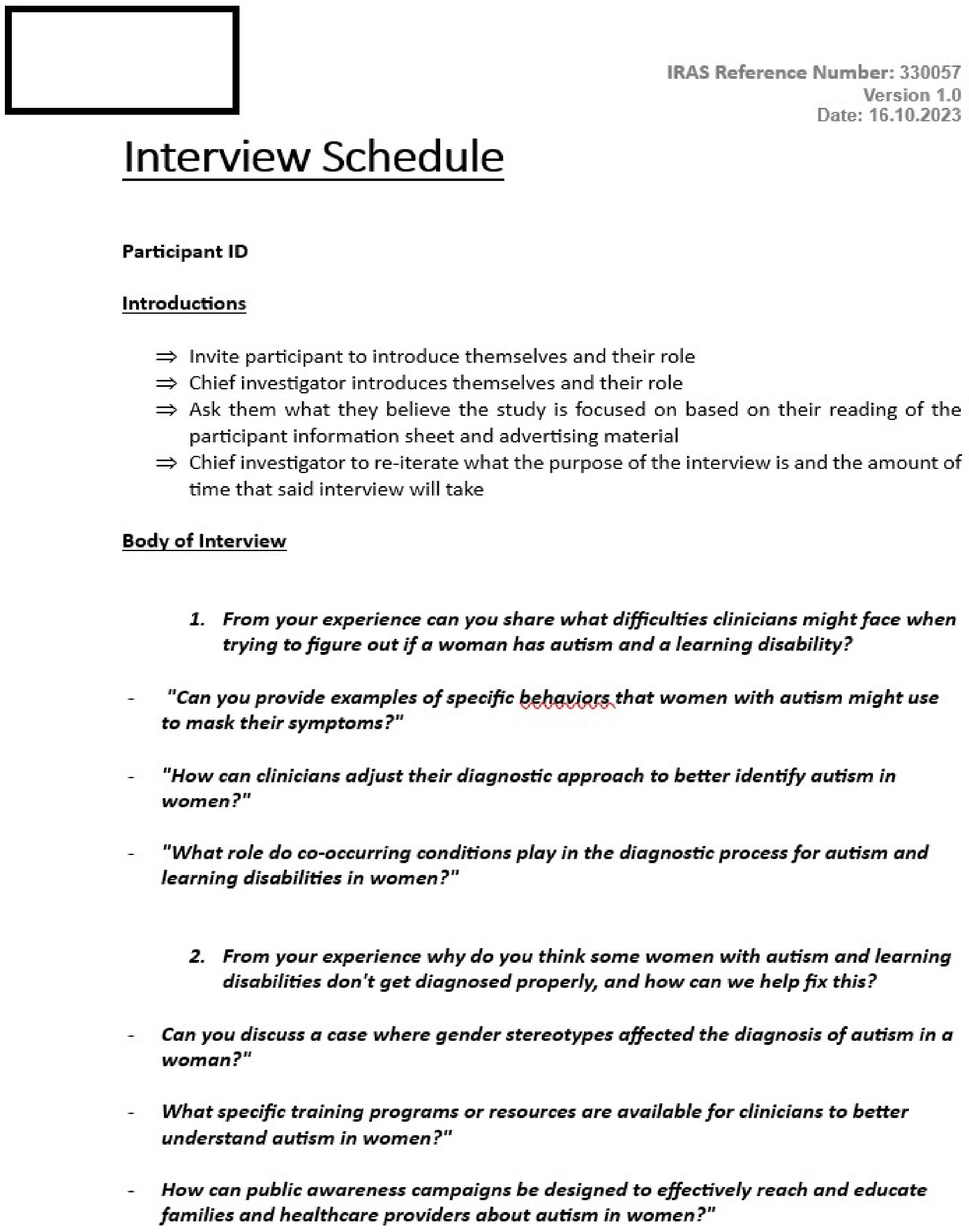
Many thanks and take care

[REDACTED] – Principal Researcher
Clinical Psychologist in Training – [REDACTED]

Supervisors: Dr [REDACTED], [REDACTED], Dr [REDACTED], [REDACTED]

Appendix Three: Interview Schedule for Qualitative Data Collection

The following outlines the schedule developed in collaboration with experts by experience that was used during semi-structured interviews with participants. Six questions, which made up the core of the interview, were paired with prompts to facilitate conversation. Some information regarding the chief investigator's institution is redacted.



IRAS Reference Number: 330057
Version 1.0
Date: 16.10.2023

Interview Schedule

Participant ID

Introductions

- ⇒ Invite participant to introduce themselves and their role
- ⇒ Chief investigator introduces themselves and their role
- ⇒ Ask them what they believe the study is focused on based on their reading of the participant information sheet and advertising material
- ⇒ Chief investigator to re-iterate what the purpose of the interview is and the amount of time that said interview will take

Body of Interview

1. ***From your experience can you share what difficulties clinicians might face when trying to figure out if a woman has autism and a learning disability?***

- ***"Can you provide examples of specific behaviors that women with autism might use to mask their symptoms?"***

- ***"How can clinicians adjust their diagnostic approach to better identify autism in women?"***

- ***"What role do co-occurring conditions play in the diagnostic process for autism and learning disabilities in women?"***

2. ***From your experience why do you think some women with autism and learning disabilities don't get diagnosed properly, and how can we help fix this?***

- ***Can you discuss a case where gender stereotypes affected the diagnosis of autism in a woman?"***

- ***What specific training programs or resources are available for clinicians to better understand autism in women?"***

- ***How can public awareness campaigns be designed to effectively reach and educate families and healthcare providers about autism in women?"***

3. ***Can you share any clinical experiences you've had in your role with autism in women that might be different from what's usually seen in men, especially when they also have a learning disability?***

- ***"Can you share a clinical experience where a woman's subtle social difficulties led to a delayed diagnosis of autism?"***

- ***"What strategies have you found effective in identifying autism in women with co-occurring mental health conditions?"***

- ***"How do the coping mechanisms of women with autism differ from those typically seen in men?"***

4. ***From what you've seen in your role, what unique challenges do women with autism and learning disabilities face compared to men with the same conditions?***

- ***"What are some common social challenges women with autism and learning disabilities face that are different from men?"***

- ***"How do these challenges impact their daily lives and relationships?"***

- ***"What support systems or interventions have proven effective in addressing these unique challenges?"***

5. ***How can we make sure women with autism and learning disabilities feel accepted and celebrated, both in healthcare and in the wider community?***

- ***What initiatives have you seen that successfully promote acceptance of women with autism and learning disabilities in healthcare settings?"***
- ***How can communities create more inclusive environments for women with autism?"***

- ***"What role can media and public figures play in celebrating and raising awareness about women with autism and learning disabilities?"***

6. **When working with women with Autism and a learning disability, what has surprised you about this group?**

- ***Can you share an instance where a woman's strengths or abilities surprised you during your work with her?"***

- ***What unexpected challenges have you encountered when working with women with autism and learning disabilities?"***

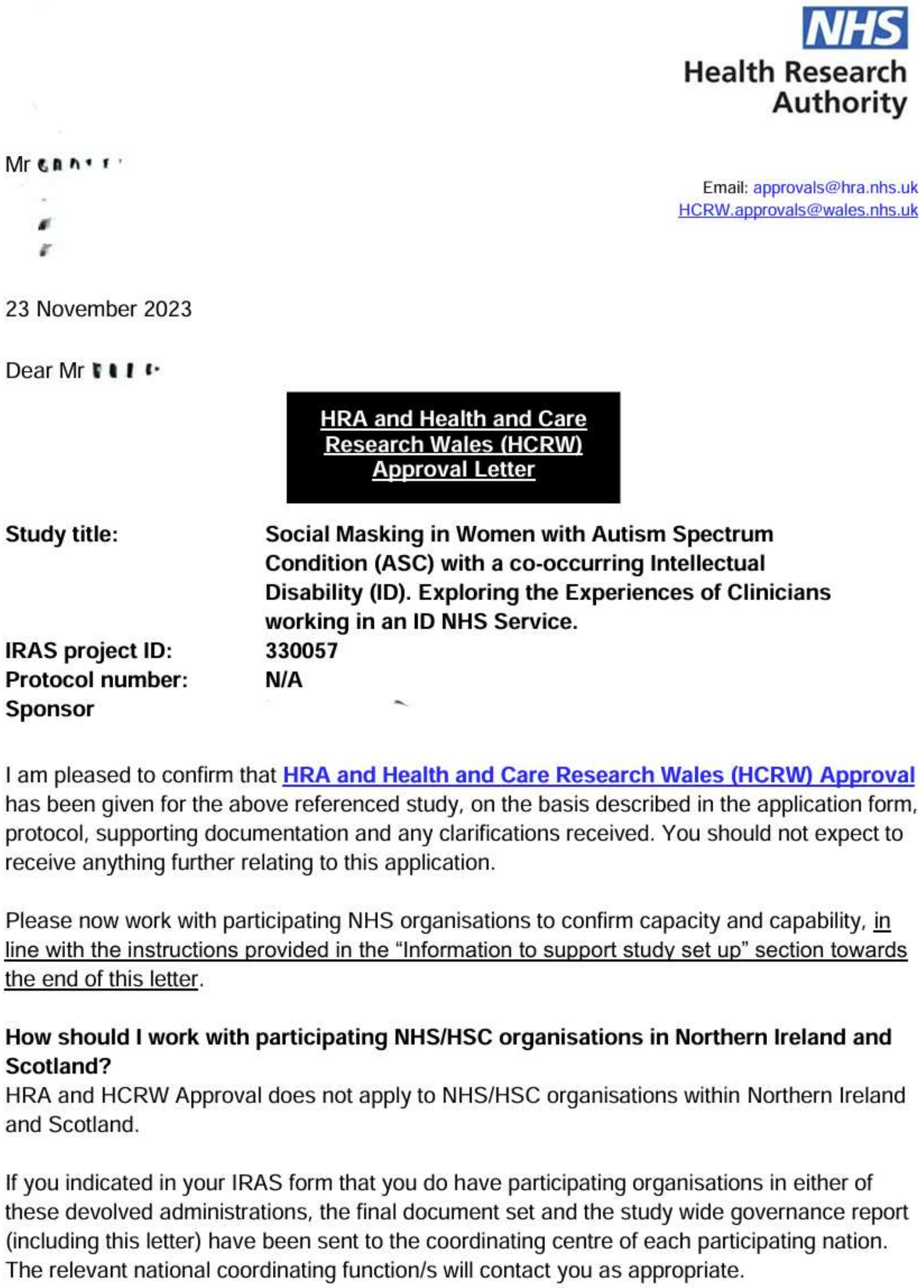
- ***How have these surprises influenced your approach to care and support for this group?"***

End of Interview

- ⇒ Chief investigator to inform participant of the end of the interview
- ⇒ Invite participant to ask any questions
- ⇒ Inform participant of next steps
- ⇒ End interview

Appendix Four: Documents Confirming Ethical Approval for Conduction of Thesis Research

The following provides evidence of documents confirming ethical approval from relevant bodies to conduct the thesis research. This includes approval from the Integrated Research Application System, used to apply for UK National Health Service Ethics, as well as from the Chief Investigator's attached institution.



NHS
Health Research
Authority

Mr [redacted]

[redacted]

Email: approvals@hra.nhs.uk
HCRW.approvals@wales.nhs.uk

23 November 2023

Dear Mr [redacted]

HRA and Health and Care Research Wales (HCRW) Approval Letter

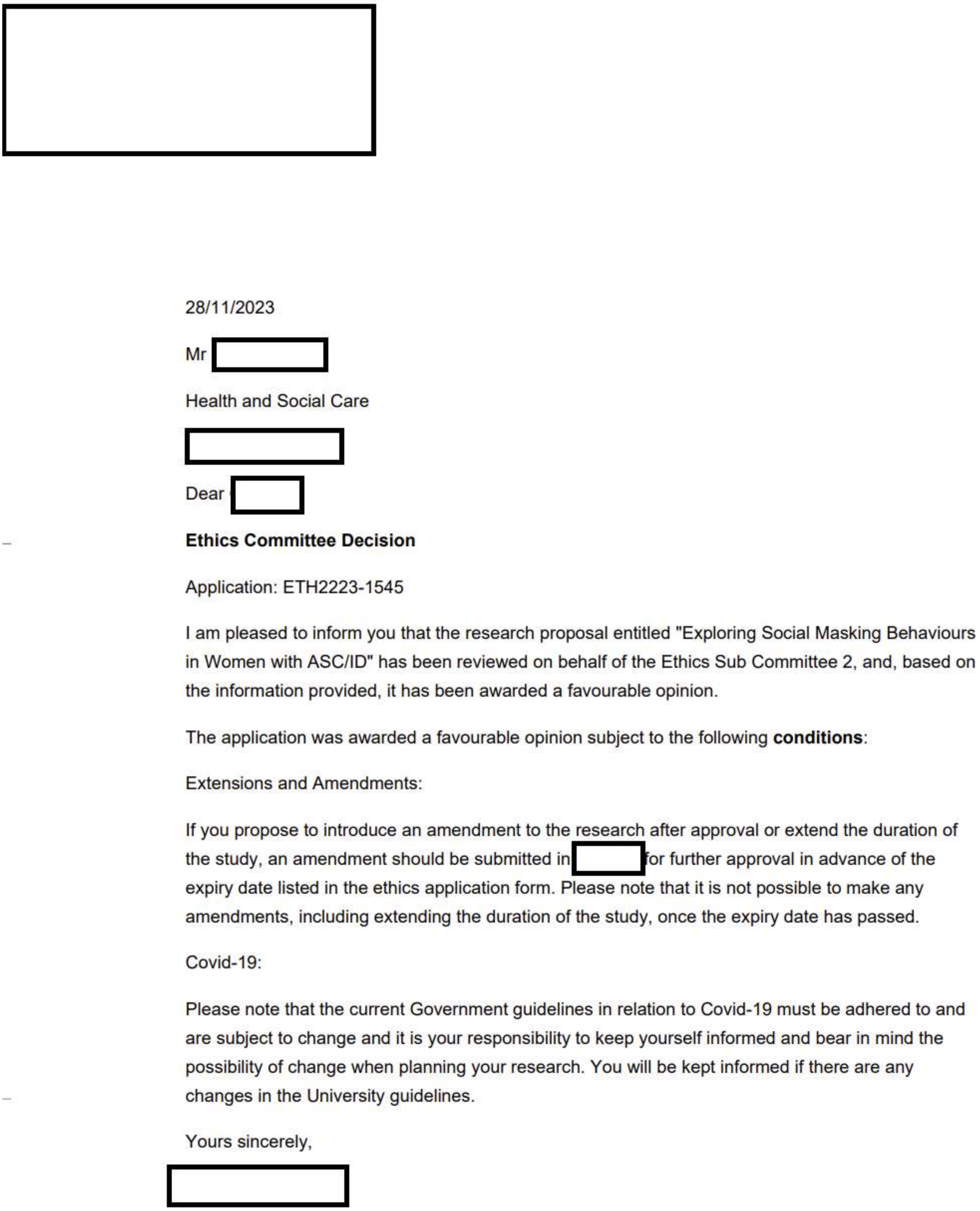
Study title: **Social Masking in Women with Autism Spectrum Condition (ASC) with a co-occurring Intellectual Disability (ID). Exploring the Experiences of Clinicians working in an ID NHS Service.**
IRAS project ID: **330057**
Protocol number: **N/A**
Sponsor

I am pleased to confirm that **HRA and Health and Care Research Wales (HCRW) Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

Please now work with participating NHS organisations to confirm capacity and capability, in line with the instructions provided in the "Information to support study set up" section towards the end of this letter.

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?
HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) have been sent to the coordinating centre of each participating nation. The relevant national coordinating function/s will contact you as appropriate.



[redacted]

28/11/2023

Mr [redacted]

Health and Social Care

[redacted]

Dear [redacted]

Ethics Committee Decision

Application: ETH2223-1545

I am pleased to inform you that the research proposal entitled "Exploring Social Masking Behaviours in Women with ASC/ID" has been reviewed on behalf of the Ethics Sub Committee 2, and, based on the information provided, it has been awarded a favourable opinion.

The application was awarded a favourable opinion subject to the following **conditions**:

Extensions and Amendments:

If you propose to introduce an amendment to the research after approval or extend the duration of the study, an amendment should be submitted in [redacted] for further approval in advance of the expiry date listed in the ethics application form. Please note that it is not possible to make any amendments, including extending the duration of the study, once the expiry date has passed.

Covid-19:

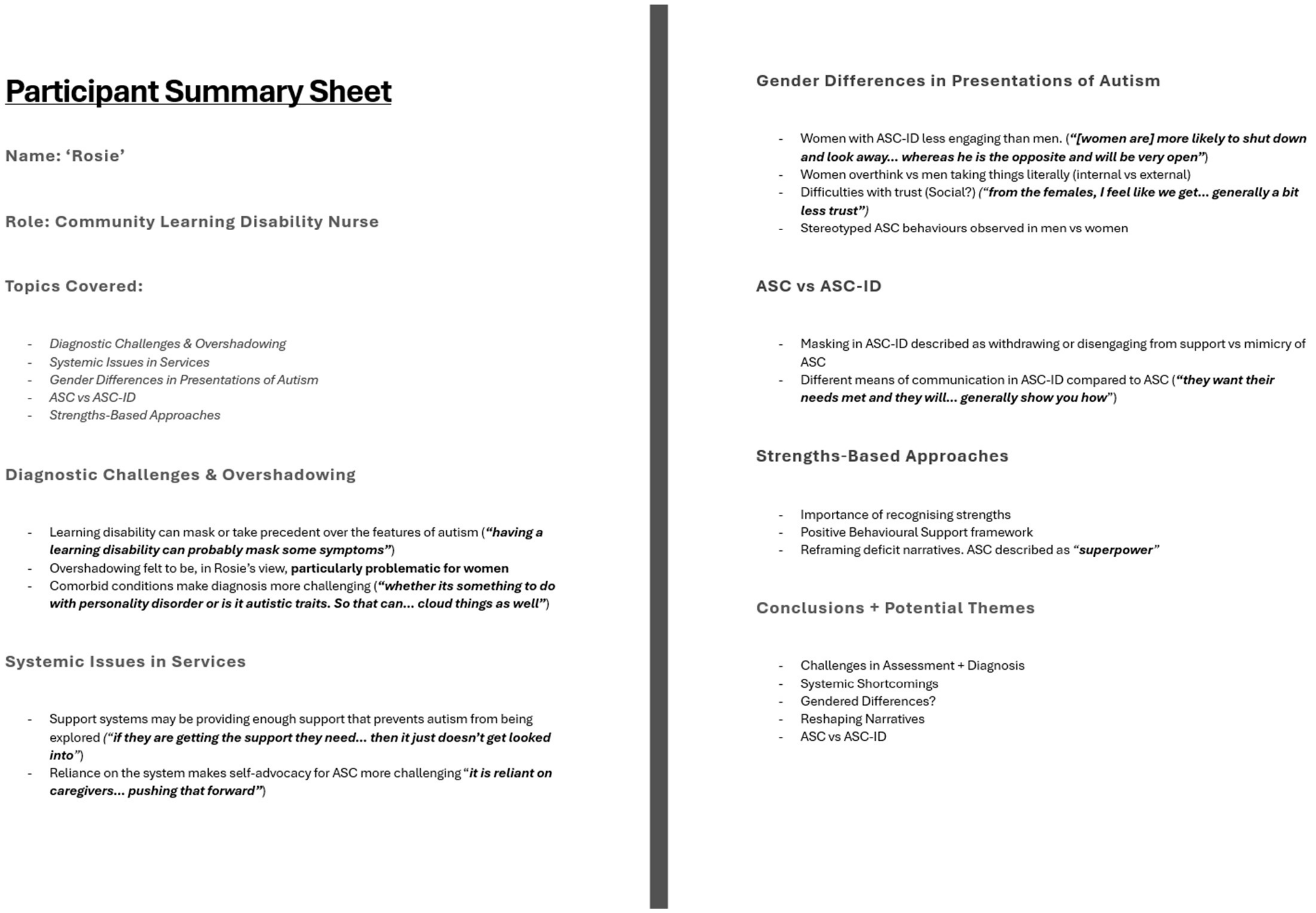
Please note that the current Government guidelines in relation to Covid-19 must be adhered to and are subject to change and it is your responsibility to keep yourself informed and bear in mind the possibility of change when planning your research. You will be kept informed if there are any changes in the University guidelines.

Yours sincerely,

[redacted]

Appendix Five: Examples of Processes Involved in Data Familiarisation and Transcription

The following appendix contains examples of strategies utilised by the chief investigator during analysis. This includes participant summary sheets and pages from the researcher's reflective journal, kept throughout transcription and construction of themes.



Participant Summary Sheet

Name: 'Rosie'

Role: Community Learning Disability Nurse

Topics Covered:

- *Diagnostic Challenges & Overshadowing*
- *Systemic Issues in Services*
- *Gender Differences in Presentations of Autism*
- *ASC vs ASC-ID*
- *Strengths-Based Approaches*

Diagnostic Challenges & Overshadowing

- Learning disability can mask or take precedent over the features of autism (***"having a learning disability can probably mask some symptoms"***)
- Overshadowing felt to be, in Rosie's view, **particularly problematic for women**
- Comorbid conditions make diagnosis more challenging (***"whether its something to do with personality disorder or is it autistic traits. So that can... cloud things as well"***)

Systemic Issues in Services

- Support systems may be providing enough support that prevents autism from being explored *("**if they are getting the support they need... then it just doesn't get looked into**")*
- Reliance on the system makes self-advocacy for ASC more challenging "***it is reliant on caregivers... pushing that forward"***)

Gender Differences in Presentations of Autism

- Women with ASC-ID less engaging than men. (***"[women are] more likely to shut down and look away... whereas he is the opposite and will be very open"***)
- Women overthink vs men taking things literally (internal vs external)
- Difficulties with trust (Social?) *("**from the females, I feel like we get... generally a bit less trust"**)*
- Stereotyped ASC behaviours observed in men vs women

ASC vs ASC-ID

- Masking in ASC-ID described as withdrawing or disengaging from support vs mimicry of ASC
- Different means of communication in ASC-ID compared to ASC (***"they want their needs met and they will... generally show you how"***)

Strengths-Based Approaches

- Importance of recognising strengths
- Positive Behavioural Support framework
- Reframing deficit narratives. ASC described as *"**superpower**"*

Conclusions + Potential Themes

- Challenges in Assessment + Diagnosis
- Systemic Shortcomings
- Gendered Differences?
- Reshaping Narratives
- ASC vs ASC-ID

Friday 30th August, 2024

Had another session with [redacted] today. We were doing some psychoeducation around autism and the desire and need to plan activities in greater detail than first realised. It struck me today that the initial referral for him was for managing grief, something which I considered to be relatively common in ID services. Reminded me of the overshadowing that's kept coming up during interviews except in this case its not a common MH condition it's a presentation. Don't get me wrong, anxiety I guess would also be present for him and contribute to that grief in some way it just seems like grief was mum's feeling rather than his priority. Makes me think about how for women w/ASC, mental health conditions are assigned to those masking over ASC. In this case, despite [redacted] having a diagnosis of both ASC and ID, the ASC has been forgotten with the ID and the beliefs that come with it, taking precedence. It makes me wonder about the ID in particular I think one ppt said something about the ID being diagnosed earlier so encompasses the presentation more. Wonder if this is unique to those with ID?

Sunday, 1st September 2024

Supposed to be going on AL in the next few days and feeling guilty about not working on the analysis. Might be making me feel like I should stick with what I've got rather than go deeper. Wonder if that's why resilience is sticking in my mind today. I found this word quite difficult during interviews. It made me angry that people with ID had to be resilient. Whenever I heard it, I kept thinking about people that I worked with at [redacted] How resilient they have had to be when, if they were understood and recognised, they may not need to. Resilience masks the challenges in that way maybe? I feel like my brain is really stuck on masking too. It feels at the moment like every challenge to the negative narratives mask them in some way. Resilience, therefore, doesn't feel like an appropriate theme. Feels like strength kind of does it justice. That acknowledges the creativity and all the amazing things noted in interviews? Will probably do some more whilst on AL.

Wednesday, 4th September 2024

One day. One day into AL and Im back… Resilience to doing analysis or resilience to not doing analysis? You be the judge. Its still in my brain I feel like its starting to cloud my judgments of the other themes. Its starting to feel frustrating and anger inducing to not only make sense of this data but also consider what it means for the ID community. I think this is making me view each 'theme' negatively. Overshadowing is bad. Wider society is bad. Men with ASC-ID bad. I think that's what made me write this. That feeling. It feels a bit like ive lost my way with it, not remembering why I decided to do this in the first place. I find myself worrying if, by centring the

Appendix Six: Examples of Interview Transcript and Coding

The following contains an interview transcript from a participant of the study. The name given for the participant is pseudonymized as in the thesis Results chapter. Some information has been redacted as a means of preserving confidentiality regarding services that the participant is attached to.

Chief Investigator: That's looking good. So just for the purposes of the recording and the transcript, I thought we could start with some introductions. So my name's [Chief Investigator]. I am a second, although going on 3rd year clinical psychologist in training, studying at the [attached academic institution], I don't know if you want to introduce yourself.

That's fine. Yes, I'm [Talia]. I'm a clinical psychologist and I'm working in the [NHS Adult Disability Service].

Chief Investigator: Brilliant. Talia, thank you so much for giving your time for the interview today. Just before we start again for the purposes of the transcript, I wanted to make sure that you'd had a chance to read through the information sheet and consent form that I've sent through. And if you had any questions around anything on there?

Talia: I don't have any questions. Everything was very clear.

Chief Investigator: Oh, that's the answer I like to hear and get great feedback as well. And lastly, I just wanted to get a sense from you as to what you think we're going to be speaking about for the next hour or so.

Talia: So my understanding is it's going to be around autism in women with learning disabilities. That’s the generic idea I've got in my mind.

Chief Investigator: Yeah, it's broad.

Talia: Quite broad, yeah.

Chief Investigator: Yeah. So you're absolutely right. We're going to be speaking about the community of women with autism and learning disabilities and just kind of get a bit more of an understanding of how we might be able to understand and support the group moving forward both clinically but in the wider community as well. I've got six questions for you today. There may be times where we're talking about something and I ask a follow up question… So we may feel like we go off topic and it may feel like we're repeating ourselves and I can only apologise in advance for that. I might also be taking notes here and there just so I can pick up on some of the things that you've said. Does that all sound OK, [Talia]?

Talia: OK. Yeah, that's fine. Yeah.

Chief Investigator: Fabulous. So if we start with the first question, from your experience, can you share what difficulties clinicians might face when trying to figure out if a woman has autism and a learning disability?

Talia: Oh, to find out whether they have what is autism and learning disability that’s quite broad, isn't it? OK. Just… I'm writing down and I'll let you know what I think.
So is it are we talking then about the time when you start a therapeutic relationship with someone or are we talking about the time when you don't know anything about the person and you've got the person that you're trying to figure out whether they have LD and Autism. So at which stage of the process are we talking about? So are we talking about people who are already known in the service and they already have a diagnosis of LD and Autism or are we talking about people who are relatively new, so you get into the process of figuring out and doing assessments around LD and autism?

Chief Investigator: I wonder if you can speak to both a little bit, if that's OK, because I think as you say there might be, there might be differences, I don't know from your perspective. Yeah. So I'm just thinking, let's start from the beginning. So when we receive a referral, so first of course, we have to check whether the person has a learning disability. Unless you take that for granted, unless you take that, you know that the person has a learning disability, a woman, because we're talking about women with learning disabilities. Unless you take for granted that we know that the person has a learning disability and you need to figure out about autism because that's probably what you're looking for, I'm assuming that, you know, that the person has a learning disability and is the autism that… Let's start with that, because then it becomes too messy. I think so. Let's say we see, we know that the person has a learning disability and we are not sure whether the person has autism or not. Now I think with women particularly it can be, it seems to be usually trickier than with males. And yeah, I'm... I'm just thinking about, you know, you would probably go. We'll do an assessment we would do a D-BAS to start with, with the screening for autism, and then if they meet, if they are above the cut off for social communication and stereotyped [behaviours] and the total score. Then you would go on and do a more in depth assessment, like usually it's the ADOS. And the ADI-R that we're doing our service. I think where the difficulty is that you may not necessarily spot the signs in the very beginning, even before doing the screening, because they can… I mean, I'm thinking about two women that I'm working with… and actually it's interesting because with one of them, an autism assessment was done and she didn't meet the threshold. However, she presents us quite autistic. And in the very beginning, when you meet with her, you do not necessarily think that she's that she has autism because socially she has the skills, she has some good skills to communicate with people, and she seems quite chatty. And you know, she seems interested in you… And I wouldn't necessarily think if I met with her, I think probably I started thinking about autism at 2-3 months in the therapeutic relationship that 'OK, something is happening here'. So socially, I think she was able to communicate. So I didn't think of that aspect. But then I realised that there was quite a lot of rigidity in her thinking and rigid thinking styles couldn't really think of alternative explanations to describe situations… Couldn't really understand the more kind of the more kind of. New- more… how to say that subtle communication or could easily misinterpret other people's behaviours, but this came after in session after we had thorough conversations initially, the way she interacted with me and the assistant working with me, we didn't think that was the case. So I I think then starting from the beginning. Probably clinicians we should be a bit more curious and probably not to… Just what we see doesn't mean that this is what it is, you know? Don't take things as a face value. That's what I'm what I'm trying to say. So I think it it's quite tricky in the beginning if you if people do not have knowledge around autism in women or the differences that can exist between males and females… Yeah. Eye contact for example. I'm just thinking eye contact is, you know, I'm thinking of the people I'm working with, the two women, they do make eye contact. And it's it's. I just also wonder because then the assessment was done and it was found that she doesn't meet the threshold. It makes me won- But however, I can say clearly that there are quite a lot of autistic traits and it makes me wonder whether the tools we use are not quite appropriate for women with autism and LD. Yeah. So that's what came to my mind as an initial thought. The other thing is that, very easily, someone could think whether this is autism or whether this is other things like personality disorder or, you know, attachment difficulties. And I think there is quite a lot of overlap and clinicians get into this kind of conflict in their mind and in my mind as well, sometimes about whether it's autism, whether it's EUPD or PD or trying to give labels and that doesn't help really because it can be both. But at the end of the day, you know, giving a label doesn't necessarily explain how the person is. So it's about thinking what is the meaning of the behaviour rather than giving a label as well, if that makes sense, yeah.

Chief Investigator: Thank you for that. I'm struck by something that you said early on in your response around, I guess the process towards someone either gaining or at least being assessed for autism, there's an assumption we started with the assumption that there's a learning disability present and it got me thinking about the process of the sort of diagnostic journey for a woman with a learning disability. I wondered from your experience or from the experience of working in the area with women with autism what that process is like is there are. Are there things that are diagnosed more early on in a journey throughout life for women compared to some other conditions? I think you alluded to some there around mental around kind of other mental health presentations and those comorbidities. Is that something that you've seen in your work?

Talia: I've seen that there are dilemmas when it comes to diagnostic categories.
Usually people come to us, it's well, they are given. If we start from childhood, usually

they're given something like a diagnosis of global developmental delay. They won't say learning disabilities early on and when there is a transition from children to adult services the transition team will do a kind of brief assessment to see whether they meet the criteria for learning disabilities, and this is really when they're given the learning disability label. Unless the GP and I'm not sure how it works unless that they are on the LD register already from the GP, so usually they come to us. We're, because we're not a diagnostic service, so people should have it. It should be very clear kind that they meet the LD criteria to come to our service. Of course, we've got people that it's not so clear and then this is when we become involved but I have to say in, in, in general we don't do quite a lot of eligibility assessments in psychology because we've got the way in team who, they know they have some guidelines around how to kind and some criteria to follow around how to distinguish people that might not have LD, so usually we are involved when they come. However, I have to say, with the eligibility assessments that I am that I have been involved, it has been quite tricky and actually they did not have some of them did not have LD but did meet the criteria for autism. And this is when you know they don't meet the criteria for our service because we they have to have a learning disability and we need to signpost them somewhere else, and this is a difficult journey for people. And I mean, we're talking about women and for women with autism without the LD label. Because then which are the services that can support therapeutically people and women with autism without LD and actually the support is very limited and usually they will have to go to mainstream mental health services which are expected to make reasonable adjustments. But with conversation I have had with CMHT professionals, they don't feel that they have the expertise many times to work with people and women with autism. So I think there is a gap there. So I think people are quite, yeah, they fall into the gaps if they don't have LD and they just have the autism label... Yeah... In terms of the other mental health conditions. I think it depends on which stage they are in their life…

It's usually in adulthood, and when they come to our services that when the LD is established and we see signs of autism and signs of other possible, let's call it personality disorder it might be trauma. I mean, what we're talking quite frequently is the overlap really between trauma and autism. And that that trauma might be given a label as a personality disorder, disorder or EUPD and I think this is where it becomes a bit more complicated. So it's trying to understand, you know whether it's autism and or whether it's whether the behaviour is the outcome of trauma. Yeah, we have a tool for that which can help and it shows what kind of manifestations may be because of the one because of the other. But still you know it's I think you need to. If you know that if you take a detailed history and you see that there is trauma in a person's life, it's very difficult to know which comes from what, if that makes sense.

Chief Investigator: That's really helpful. Thank you. I'm mindful that with this next question, it may overlap and some of the things that we're already speaking about.
So I apologise if there's some repetition here. From your experience, why do you think that some women with autism and learning disabilities don't get diagnosed properly? And how can we help to fix this?

Talia: It's a very good question. I'm just wondering about the tools we use. I have two specific women in mind that did not meet the threshold and I've been working with them for years. So, you know, I have got to know them quite good. But it's still there… The kind of… for them, the label of autism makes sense, although they don't have it, so the language should be very careful. So I use 'autistic traits', but they say 'I'm autistic', so in their mind they are autistic. However, the tools that the ADOS and the ADI-R that we use, they did not meet the threshold of autism. So it makes me wonder whether certain tools need to be developed differently… Specific category of people… I also believe that perhaps we need to have a more comprehensive and detailed assessment… For example, the ADI-R takes into account developmental milestones and how they were early in life, but I wonder if… And every clinician is different… For example, I will ask about family context and family circumstances early in life, and I will try to take a detailed, almost doing a timeline with the person about how they were in the beginning, how things changed in the family. Also seeking for any kind of traumatic experience… Might be there… Which is it takes a bit more time. It's not like doing the ADI and the ADOS it's probably more comprehensive assessment. And I wonder if that would help. It's quite a difficult question.

Chief Investigator: I wonder just with what you were saying there around the assessment process being more thorough and being more, I guess, fuller in that sense. And I and I'm drawn to what we were speaking about earlier in terms of how… early the process can start for this group. I think you described how women can get diagnosed with a learning disability or global developmental delay in childhood. For you, is there anything not just about the, I guess, the fullness of the assessment process, but also when it's done so frequency as well as content

Talia: The timing?

Chief Investigator: Yeah.

Talia: Yeah, the timing. There is quite frequently a sense of injustice in these women and in sense of unfairness that things were not picked up early enough. One of the women I'm working with who is the one that did not meet the threshold… But she believes she calls herself autistic. She talks about how things were not picked up at school and how she felt that other people, because of their more physical disability, they were treated differently and she didn't get receive the support she needed. And that has followed her in her life, even now, thinking that people do not understand her and the difficulties that she's experiencing. And actually this is because she she's masking and she shows quite able and she can converse with people, but her understanding and her the way she interprets it in the information is very autistic and she struggles with that. So I would say from stories of people I've heard, there is this sense that things were not done right when they were young. For some of them, the learning disability was also not picked up early enough, and this was done later in life. And that could be for various different reasons. Could be that because there back then the schools were not so… What's the word… They did that. They were not, did not know how to. They were they would just call people lazy without seeking what is underneath it, or could have been the family views around services and almost thinking that if their daughter or if their children are kept under the radar or they would be safe because social services wouldn't become involved, to take them away from their parents. So there are there are these narratives as well in some of the families. But yeah, I think it. Yeah, it in most cases it wasn't picked up early. I think the autism diagnosis was probably given by adult services yea.

Chief Investigator: You spoke about changes to the tools or some I guess reflection on the tools that are used. I don't know if there are any that you're aware of that you feel would be helpful to include or perhaps standardise across assessment services for autism.

Talia: I am not, I believe that almost it has to be seen sometimes as a separate so probably… Because of the social interaction element, because I think they show they might show sterility of typical characteristics, they might show rigidity. I think in the social communication element there are two levels, almost the one which is about what you see the external that they can converse. They might use quite a lot of body language as well to converse sometimes. But it's more when it comes to interpreting people's behaviours and intentions. So I think if there is something that can almost break down the social communication element would help. The Social Communication Questionnaire is something that we sometimes use but I wouldn't say it goes in great depth and it relies on information given by third parties. So it's another tool to use with the person. And I don't know what the research is in this domain in terms of developing tools which are a bit more sensitive to the social communication aspect in women, but I would probably think… I would think if I were a researcher, I would probably think this way breaking down the elements of social communication aspect… And from that, probably giving more weight or more focus to the more subtle signs. So I think this is this is where someone can distinguish between how women and men with autism can present, but as I said, I'm not very familiar with up to date research.

Chief Investigator: And I'm mindful that we're speaking about, I guess, clinical.
Sort of clinical adjustments and adaptations that can be done. I wondered from your perspective if there's anything that can be done in terms of the wider community to educate families and support systems about autism in women and what that might look like.

Talia: But because in general I wonder whether the community is… We're talking specifically about community with people with learning disabilities. Whether there is anything currently happening or a campaign, but I'm not sure because I'm just thinking whether now our service. For example, I'm not aware of any easy read leaflets or anything that could help families or people with LD be a bit more aware of autism. It's usually when we receive a referral and the referrals usually come from professionals, from social workers, from carers or managers who are a bit more geared or you know, they have an idea about autism. When it comes to families, I don't think we receive referrals. You know, it may be. It's usually professional that picks it up. So I think this is an area we are lacking really. It might be that you know, is it really leaflets around what autism is? And I know there are quite a lot on the Internet which come from organisations like Mencap but this is only if a person has access to a day centre. That information may be readily available and I'm not sure as a service we do that I'm not sure we inform a person that, OK, you know, this is some information about autism. Just have a read. Yeah. I think probably we're not so good in doing that. But also it's about thinking how to do it. Let's say OK as a service we develop an easy leaflet around what autism is. How do you go about targeting people? Do you like send it to all the people that you you're working with? And this takes careful thought how to do it? Or do you just target people that you think that might be on the spectrum? Or do you target GPs perhaps? And you know if they if they've got, if they have people who visit them and they are on the LD register, they do inform them about autism. And then you know our GPs well enough trained to spot whether a person with a learning disability might show autistic traits. Or do they just see the LD label and they say, OK, that's it, and they don't go any further. It's a very specific category of people, isn't it? Yeah.

Chief Investigator: Thank you. You've sort of already alluded to the next question and we're thinking about some of the differences and similarities across what's seen in men and women with autism and learning disabilities. So can you share any clinical experiences you've had in your role with autism in women that might be different from what's usually seen in men, especially when they also have a learning disability?

Talia: Mm hmm. Yeah, I think probably I have kind of answered that. But in my experience it's a bit more… With men with learning disability, it's usually a bit more clear that… I'm just thinking about, for example, recently me and the other psychologists in the service, we've done an autism assessment with a man with learning disabilities and his 30s and it was quite evident in the ADOS that the person was quite treated and his responses, and it was quite clear that, you know, he showed autistic traits. And the information was consistent in the ADIR as well so you could see that… he did not respond to humour or the examiner. He was not interested in, for example, they were talking about holidays and the Examiner shared his own… that he went on a holiday recently, but there was no kind of response or no curiosity from the person about, you know, how it was. And so, you know, the conversation was quite limited and one… One way really conversation. And you could see that the person would only want to talk about their own interests and they would go into great lengths to talk about their own interests… So we could see very clearly signs of autism. I'm comparing that with a woman I'm working with with LD, she's the one that shows autistic traits and does believe that she's got autism… And… She can respond to humour and there is quite a lot of two way conversation. I'm just thinking about another person because this clinical example she didn't meet threshold, although we're thinking she does have what I'm thinking about, another person I'm working with for quite a while… that... I think there is the two way conversation is easier. So if I say something 'cause I'm seeing her for therapy. It's different than an assessment though. But I can… there can be a conversation with her. There will be an expression of emotion a bit more easily. We can have times that there is humour and response in humour. She will share, for example, her thoughts about a song that makes her feel in a specific way, so she will go into more depth around her emotions, not in the level in the same level as a person without autism, of course. But there are differences. So she would she would show a bit more emotion than males with autism… I think the similarities I see is in terms of the difficulties in understanding people's intentions. And they may for that, they may be taken advantage [of] quite easily, and that is both for men and women. But I think the changes are mainly around the emotion, the response to humour and the way they converse with people. Yeah, that's what I'm thinking… Just trying to think of other people have worked with. It's the question that you're asking. More males come to my mind, which is interesting and… the females are either with a question mark, whether they've got autism or not or they are very limited in my mind. The women with autism have worked with, which is interesting.

Chief Investigator: If you were to hypothesise why do you think that might be?

Talia: Now I'm just wondering now because I'm making the connection I'm thinking well, I have in mind 2-3 women that the assessment was done and they didn't meet the threshold with the tools that we use. However, they show very intense restricted behaviours and they do identify themselves as autistic because they feel that this label suits them and explains their characteristics. And in my mind, I can say more about males because I have worked with males that they had the label of autism very clear. But not so much with women. And that makes me wonder if, exactly, that whether we… There's something missed… And it could be because the different present, in my opinion, you know that there is a different presentation.

Chief Investigator: And I think you've alluded to some of this already, but you've spoken a lot about the social communication differences and I'm mindful that in autism diagnosis, it's just one side of the of the dyad, I guess. Now, I wonder if there's anything that you've noted from that other side in terms of similarities or differences around the restrictive, repetitive patterns of behaviour or thinking. I think you alluded to earlier.

Talia: Yeah. No, in terms of the thinking, I've seen rigidity in both repetitive patterns. That would be difficult to say. I'm just thinking about recent autism assessments we've done.

They were mainly with males. And there were some repetitive patterns or things that they'd done, for example. A person had an intense interest around loom bands and making loom bands, and if someone was to disrupt the routine, they would become argumentative and they would end up in conflict, or they would become aggressive after a while when they were younger. But I'm thinking similarly with the person I'm working with a woman she also has repetitive tendencies, and if she wants to talk about the specific actor that she likes and if people try to interrupt her she will also become argumentative. But I'm just wondering if in women it is manifested in a more repetitive pattern, but in terms of what they think or what they say rather than what they do in terms of more kind of ritualistic thinking or verbal rituals that they do. I'm just thinking, for example, I can think of men having interests that are more practical, that if you try to disturb their routine they will not like it. But I'm thinking with women, the women I know, it is more around thinking ritual or a verbal ritual. Yeah, I'm. I'm not sure what other clinicians will say about that, but that's probably something I have observed. And saying that my experience with autism assessments is mainly with males for some reason, not so many women, but my therapeutic experience in in my, in therapy, I have experience with both LD and autism in, in, in male and female with assessments. I've mainly seen men.

Chief Investigator: Thank you. Again, I'm mindful you may have spoken about some of these things already. From what you've seen in your role, what unique challenges the women with autism and learning disabilities face compared to men with the same conditions?

Talia: I think they frequently feel not understood they feel missed out or left out.
Especially when there is, I'm just thinking of families that they have children, that they all had LD and some had autism and some didn't have autism… I'm just thinking of a person I'm

working with who has LD and autism And her sister has only autism without the LD label. And the sister managed to go to university. But she stayed behind and how she compares herself with her sister. But you know that we're talking about the LD here, which is missing. I'm just trying to think about the opposite. If you've got, then people with LD. And one has autism and the other one doesn't have autism. They're not picked up early. Usually I think the autism is not picked up early. It's quite late in their life and when you give the label, sometimes it does make sense. It makes people almost… they almost feel like a burden is lifted off their shoulders if they've got the diagnosis. But in cases where a diagnosis is not given whilst they identify themselves as autistic, I think this is quite difficult. They feel that the families do not understand them. And they feel that there are some gaps, that there's a sense of injustice from the society in general and unfairness and sometimes… Well, if it is just the autism without the LD, I think it is, it is much more complicate if it is autism with associated mental health issues. But without learning disabilities. I think this is a very difficult territory for people where they need to access mental health services that need to make reasonable adjustments, but they don't have the expertise… I think also sometimes we see people that in terms of their functional ability skills, they might be in kind of a good level. So they will be able to cook, they will be able to maintain their hygiene in the house. So practically they can show that they are fine, they can they can do it on their own, they can survive. And I think this also makes it hard because people assume, ‘OK, you know they can cook, they can clean themselves. It's fine.’ They're able to, to have a conversation with people. But this is just a surface. It's a sense of not being understood really.

Chief Investigator: And what I think you've alluded to this already, what vulnerabilities does that lack of understanding creating sort of women with autism and learning disabilities daily lives and relationships?

Talia: Oh. I think in and out in terms of the relationship, it's a it's a very, very difficult territory. I think they find it hard to understand. They usually get into very difficult situations in terms of being taken advantage [of]… Frequently. It might be that you know, especially when it comes to romantic or sexual relationships, I think they find it quite hard to understand that people's why a person has asked them to go out or they say, for example, had a person from, I don't know, the north of England who is coming to visit me and they may not understand why this is strange to have someone to just come and see you in Colchester from the north of England. What the intentions might be or I remember a person who came and said… that they've asked me. I think it was something that was exposing or something like seeing the underwear. Or, but it wasn't very clear because she showed me the texts. And she said the way she interpreted it is that he wanted a picture of her, but it was very clear in the text that he wanted her to show her underwear. But she didn't understand that and her response was something like, OK, that's fine. But why do you want a picture of me? Since you can see it on my profile. So she couldn't understand the sexual intention behind it. I think that's some- sometimes they also do not understand the implications of what might happen? For example, I'm I have a person in mind who did not, who was not aware that the other person was trying to exploit her because he had? He was on the sexual offenders register and she could not see that he was using an exploiting her as a way to get access to his children, with whom he had to have supervised contact. But she was using her as a means almost to. To what's the word to satisfy his sexual desires and she couldn't see that. I think that that is where autism comes in and we had to spend quite a lot of time in the session to really break it down and help her understand that she hadn't thought that there can be an alternative explanation. So I think when it comes to relationships, it's they are quite vulnerable and they cannot say that the intentions of the other person. Might not be good. Similarly, I think there are difficulties around. When they come to an understanding of their own behaviour, this might make them feel quite sad and devastated and might lead to suicidal thoughts. I'm just thinking of an interpretation of a social situation from a woman with autism who could not think that her father's behaviour was related to the stroke that he had. And she interpreted it as her dad not caring about her. So when her sister told her that, you know, that might be behaving this way because of the stroke and explained the kind of neurological manifestations of it, behavioural manifestations of a stroke she became very distressed to find out that and she couldn't believe how she could think that her dad doesn't care about her. And that made her feel very overwhelmed. And may have suicidal thoughts and thinking that, oh, I'm bad, I shouldn't be thinking this way. So it's really thinking about it's like almost like they are locked… Locked in their world, and when you try to open and help them see, this has to happen very carefully as well. I think it becomes even more difficult when you've got two people without small, two women with autism in the family and trying to help them see what they said, how it impacted the other person and vice versa. This is quite a complex thing to understand.

Chief Investigator: Thank you. So for the next question, how can we make sure we're always learning disabilities, feel accepted and celebrated both in healthcare and in the wider community?

Talia: I Have to think about that. Well, I think first of all is curiosity and respect.
As individual professionals… Well… Regardless of the labels, it's about thinking people as human beings. I think… so… When you see a person, I would say be curious about the person's behaviours but not stick to the label so much. So be curious about why the person shows the behaviour that they do and try to understand them. So we're talking about basic

human characteristics. I think it's about spending quite a lot of time… Especially with women with LD and autism. To understand them, it may take months. To try to, yeah, to try. I'm just thinking of a person and I feel like eight months, nine months in, I really started to understand what's going on. I would say probably it would help not making assumptions about people. And… Sometimes I've seen professionals being scared because of them. Because they see the surface. For example, I'm thinking they might see. A person's sexual behaviours that might be deemed as inappropriate and I had professionals who, especially when they were talking about childhood sexual abuse or possibility of becoming a perpetrator, professionals can get still quite fearful of that? But it's about thinking what is behind it so start to not make assumptions and see what is behind. Because behind is usually a person who is quite vulnerable and might have been exploited like in the example that I mentioned previously. So I would say definitely spending time with a person to get to know them. Not making hypothesis early enough but being curious about what the person shows. I think probably it would help if there was a group. Oh, there were groups of women with LD and autism that they should come together because that would help having a shared experience. And I'm thinking that for some of the people I'm working with that were quite lucky enough to meet other women with autism. They some of them have reported very, very strong friendships because they feel that the other person can understand them. So I'm not sure you know, perhaps it could be as a service or other charitable organisations arranging some groups specifically for women with autism. To perhaps, you know, share which can be either like activities and socialising, or it could be more structured such as sharing experiences. But in a safe way. I'm just trying to think what else which got me there. I haven't thought about that before. I think it would help. If people were learning disabilities and their families were a bit more aware of the differences in how women with LD and autism present differently with males. Because first is about awareness. I think if we almost fix the gaps around awareness and assessment I think that would be a first port of call. But I'm thinking in terms of more helping them win their day-to-day life. I think probably it would be group specifically for women with Autism and LD They feel quite isolated what is there? The sense I've got from the women I've worked with is isolation. Quite a lot of isolation. So the more we can help make connections with others, I think the better their quality of life will be.

Chief Investigator: And one of the ways that people have found connection with others is through social media. And I wondered, from your perspective if there's any role that social media, but also the figures on social media and mainstream media. Can play in celebrating and raising awareness about women with autism and learning disabilities as well.

It could be. We're talking about big campaigns. Yeah, well, it could be, you know, people who are actors or famous TV personas and they have autism. But you know, they could help, but that's in a bigger scale, isn't it? So far the only thing I can think about is yes, they do have. They do find almost like solace, so they're comforted in social media but at the same time They become victims because of the social media. It's easier for them to become victim and it's and it's not like, you know, it's not like when you have children and you have parental control and you can control what they are doing and what they're not doing. Or its they don't necessarily have someone to guide them through what is right and what is not. They might be quite isolated. They might live on their own. But it could be. It could be that awareness is raised through social media around what is a you know what to notice. For example, what is appropriate? What is not appropriate, you know. And I think we're talking about very big and different categories, but at least you know I think people could raise awareness, especially if people with autism raise awareness in social media about, oh, and share their own experiences, perhaps about… For example, things that they didn't know and they were caught victims… Or what to be mindful of. If it comes from people without LD, it might sound a bit more didactic, but if it comes from people who have the lived experience, I think that would help. Or it could be a collaboration actually between a person with autism and someone. Who can talk about electronic safety? I'm just thinking, you know, there is a very famous. In [UK Area] there is a very famous programme which is for parents of children around electronic safety. And there were two ex-police officers they were working with this part of electronic crime and then they left the police and they now raise awareness. In terms of safety and Internet safety for the children and they have done a big campaign and I wonder, you know, because you need expertise in terms of electronic crime and Internet safety, but you also need expertise in people who have lived experience of autism. A collaboration could happen, you know, to raise awareness. That would be great.

Chief Investigator: Thank you. And last question for today. When working with women with autism and a learning disability, what has surprised you about this group?

Talia: They are very strong. I think their difficulties have made them be so strong. I quite admire them because they have managed to survive all these difficulties and. I think that I have learned quite a lot by them in terms of life and how to overcome difficulties. So yes, the strength and determination is something that comes very strong. Yeah, and their survival skills, definitely that. I'm just thinking about finishing off after four years with their in therapy and you know the things that she has been through and how she survived and how she has been remarkable. What else surprised me? But… It's not a surprising, but it's something that I quite enjoy when I work with women with autism is that they are very sincere and very honest. And that there isn't anything hidden. You know what they want to say, they will say it and you can work with that. And that's positive. It's positive for therapeutic relationship. It's negative for other things when they are for example saying everything they think to taxi driver is not that helpful, but for a therapeutic relationship, I think you've got the raw material in front of you and you can work well with that. So it's, it's not so much what surprised me, but it's what I like is their honesty and being sincere.

Chief Investigator: All of those. So you've spoken about something that has surprised you in terms of that strength that women with autism and learning disabilities show, but also something that you enjoy about working with the group. How have they influenced your approach to care and support for women with autism and learning disabilities moving forward.

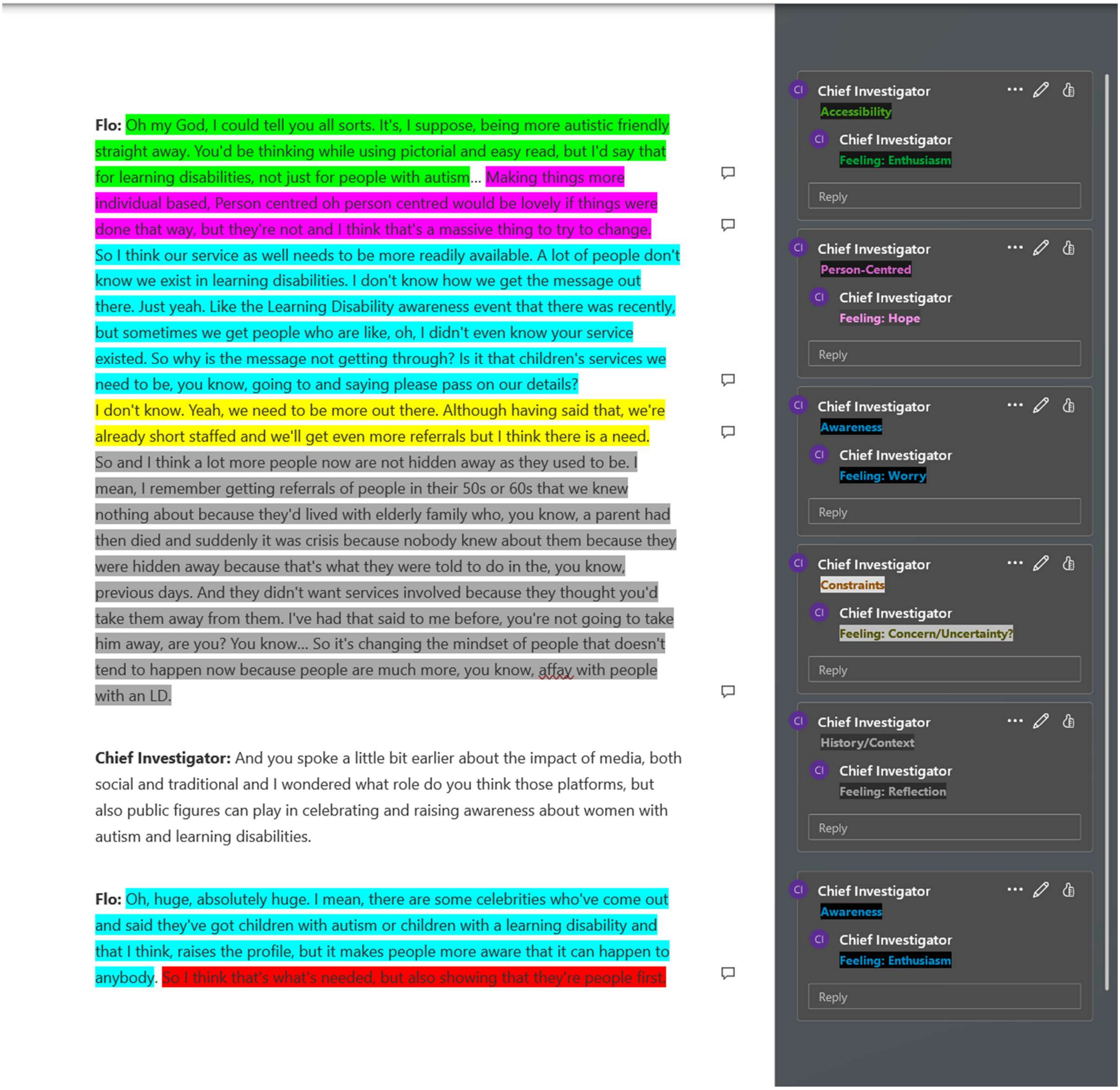
Talia: With the in terms of their honesty and sincerity, I think. You… You can work very easily with what they bring, so they tell you what they think and you start breaking down and you start making them think what is behind it? So it helps moving the process of therapy forward. In terms of the strength and determination that they've shown, I think that has helped me as well. Keep up my hopes because it's quite easy sometimes to get into that loop of you know of losing hope sometimes and It was. It's. It's a long process and it takes quite a lot of time. And sometimes you feel that things are static and they are not moving on. Because they will, they will bring the something that they are depressed about or something that's like trying to work out. And then the next time they will bring a similar thing and next time is the same. And sometimes you become a bit. But see now it's… you want to see more, but the process is very slow. And I think the hope and determination that they show, I keep me going sometimes as well, you know? So I'm just thinking, you know, they've managed to go through all these difficult moments in their lives. So, you know, I'll hold their hand almost and go together. Yeah. So it's this strength is, is very positive for the therapeutic relationship and for the process.

Chief Investigator: [Talia], that's all the questions that I had for today. I don't know, before we finish, if you have anything either to add to the questions that we've spoken about or if there's anything that we haven't spoken about that you feel is important to share before we finish.

Talia: I definitely think some of your questions made me thinking. Especially around how they can be accepted and celebrated. Anything that we haven't spoken about? I think probably it's more about my curiosity. So it's probably not going to help you in your. It's my curiosity about what the research says is my curiosity about, you know.
What made you be interested in in the in this particular aspect? So it's more my curiosity questions might come up after we finish the interview, you know. Yeah.

Chief Investigator: OK. Well I wonder if for the purposes of the transcript, if we pause and then you can have an opportunity to ask those questions, does that sound OK?

Talia: Yeah, that's fine.



Flo: Oh my God, I could tell you all sorts. It's, I suppose, being more autistic friendly straight away. You'd be thinking while using pictorial and easy read, but I'd say that for learning disabilities, not just for people with autism... Making things more individual based, Person centred oh person centred would be lovely if things were done that way, but they're not and I think that's a massive thing to try to change. So I think our service as well needs to be more readily available. A lot of people don't know we exist in learning disabilities. I don't know how we get the message out there. Just yeah. Like the Learning Disability awareness event that there was recently, but sometimes we get people who are like, oh, I didn't even know your service existed. So why is the message not getting through? Is it that children's services we need to be, you know, going to and saying please pass on our details? I don't know. Yeah, we need to be more out there. Although having said that, we're already short staffed and we'll get even more referrals but I think there is a need. So and I think a lot more people now are not hidden away as they used to be. I mean, I remember getting referrals of people in their 50s or 60s that we knew nothing about because they'd lived with elderly family who, you know, a parent had then died and suddenly it was crisis because nobody knew about them because they were hidden away because that's what they were told to do in the, you know, previous days. And they didn't want services involved because they thought you'd take them away from them. I've had that said to me before, you're not going to take him away, are you? You know... So it's changing the mindset of people that doesn't tend to happen now because people are much more, you know, affay with people with an LD.

Chief Investigator: And you spoke a little bit earlier about the impact of media, both social and traditional and I wondered what role do you think those platforms, but also public figures can play in celebrating and raising awareness about women with autism and learning disabilities.

Flo: Oh, huge, absolutely huge. I mean, there are some celebrities who've come out and said they've got children with autism or children with a learning disability and that I think, raises the profile, but it makes people more aware that it can happen to anybody. So I think that's what's needed, but also showing that they're people first.

Chief Investigator
Accessibility
Chief Investigator
Feeling: Enthusiasm

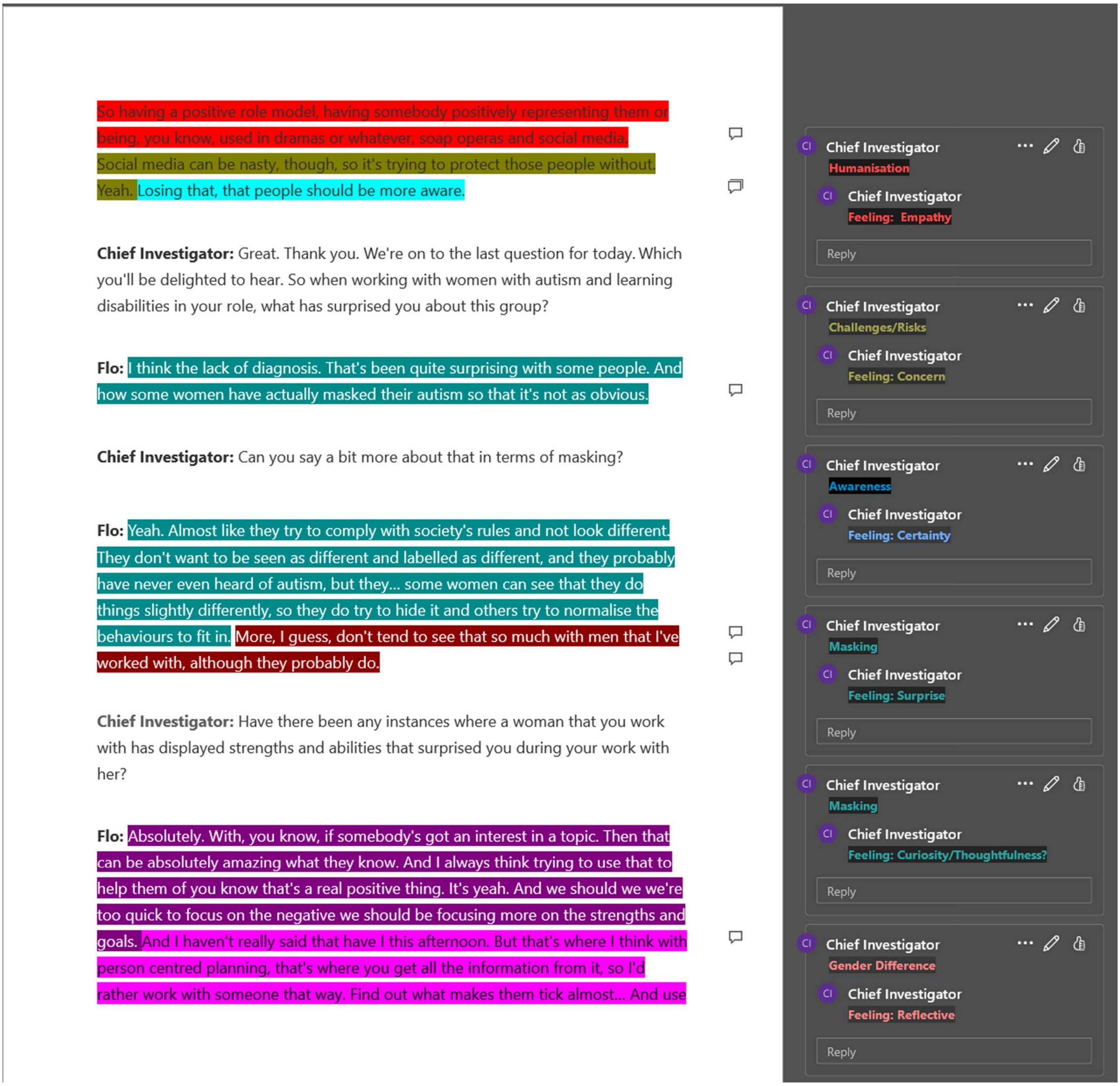
Chief Investigator
Person-Centred
Chief Investigator
Feeling: Hope

Chief Investigator
Awareness
Chief Investigator
Feeling: Worry

Chief Investigator
Constraints
Chief Investigator
Feeling: Concern/Uncertainty?

Chief Investigator
History/Context
Chief Investigator
Feeling: Reflection

Chief Investigator
Awareness
Chief Investigator
Feeling: Enthusiasm



So having a positive role model, having somebody positively representing them or being, you know, used in dramas or whatever, soap operas and social media. Social media can be nasty, though, so it's trying to protect those people without. Yeah. Losing that, that people should be more aware.

Chief Investigator: Great. Thank you. We're on to the last question for today. Which you'll be delighted to hear. So when working with women with autism and learning disabilities in your role, what has surprised you about this group?

Flo: I think the lack of diagnosis. That's been quite surprising with some people. And how some women have actually masked their autism so that it's not as obvious.

Chief Investigator: Can you say a bit more about that in terms of masking?

Flo: Yeah. Almost like they try to comply with society's rules and not look different. They don't want to be seen as different and labelled as different, and they probably have never even heard of autism, but they... some women can see that they do things slightly differently, so they do try to hide it and others try to normalise the behaviours to fit in. More, I guess, don't tend to see that so much with men that I've worked with, although they probably do.

Chief Investigator: Have there been any instances where a woman that you work with has displayed strengths and abilities that surprised you during your work with her?

Flo: Absolutely. With, you know, if somebody's got an interest in a topic. Then that can be absolutely amazing what they know. And I always think trying to use that to help them of you know that's a real positive thing. It's yeah. And we should we we're too quick to focus on the negative we should be focusing more on the strengths and goals. And I haven't really said that have I this afternoon. But that's where I think with person centred planning, that's where you get all the information from it, so I'd rather work with someone that way. Find out what makes them tick almost... And use

Chief Investigator
Humanisation
Chief Investigator
Feeling: Empathy

Chief Investigator
Challenges/Risks
Chief Investigator
Feeling: Concern

Chief Investigator
Awareness
Chief Investigator
Feeling: Certainty

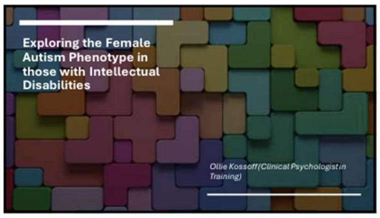
Chief Investigator
Masking
Chief Investigator
Feeling: Surprise

Chief Investigator
Masking
Chief Investigator
Feeling: Curiosity/Thoughtfulness?

Chief Investigator
Gender Difference
Chief Investigator
Feeling: Reflective

Appendix Seven: Slides to be Used for Dissemination of Results

The following details materials used for dissemination to staff and participants working at the sampled adult intellectual disability service. Said materials are due to be subsequently adapted into easy-read in order for these to be shared with both individuals with ASC-ID and their families:

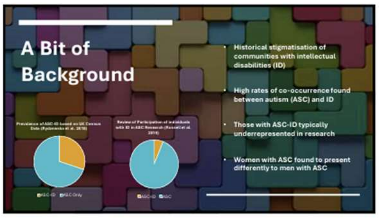


Exploring the Female Autism Phenotype in those with Intellectual Disabilities

Ollie Kossoff (Clinical Psychologist in Training)

First Thing's First

Thank you so much!



A Bit of Background

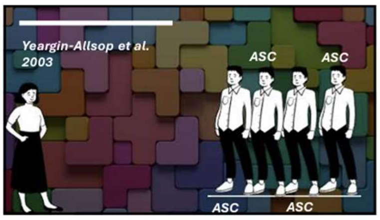
- Historical stigmatisation of communities with intellectual disabilities (ID)
- High rates of co-occurrence found between autism (ASC) and ID
- Those with ASC-ID typically underrepresented in research
- Women with ASC found to present differently to men with ASC

More likely to be diagnosed with mental health conditions over ASC

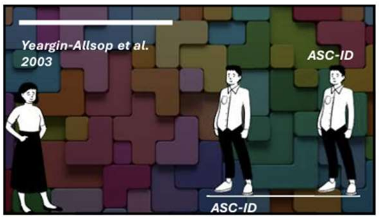
Typically diagnosed with ASC later in their life

More motivated to form friendships & relationships

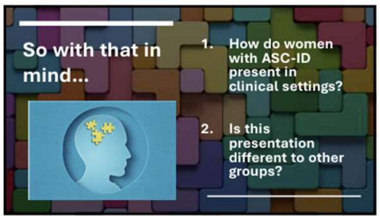
Engage in 'masking' at a greater rate than men



Yeargin-Allsop et al. 2003

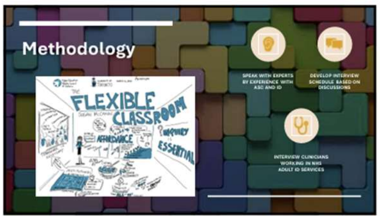


Yeargin-Allsop et al. 2003



So with that in mind…

1. How do women with ASC-ID present in clinical settings?
2. Is this presentation different to other groups?



Methodology

SPEAK WITH EXPERTS BY EXPERIENCE WITH ASC AND ID

DEVELOP INTERVIEW SCHEDULE BASED ON DISCUSSIONS

INTERVIEW CLINICIANS WORKING IN NHS ADULT ID SERVICES

Participants

16 in total representing a variety of disciplines working with individuals with ASC and ID

Psychology

Health Care Assistance

Psychiatry

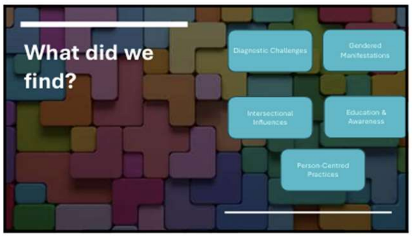
Nursing

Dietetics

Speech & Language

Occupational Therapy

Art Therapy



What did we find?

Diagnostic Challenges

Gendered Manifestations

Intersectional Influences

Education & Awareness

Person-Centred Practices

10

"Other priorities... social circumstances that might be put first because they're kind of seen as the things that need addressing sort of more urgently than an autism diagnosis... maybe that lot of stuff will just get put down to the LD."

- Clinicians observed challenges in accurately identifying and diagnosing Autism in women with ID

- Belief that women with ID engaged in masking behaviours picked up from other female family members

- In addition, clinicians felt as though ID itself overshadowed potential exploration of a diagnosis of Autism (both for family members and professionals working with women with ID)

Diagnostic Challenges

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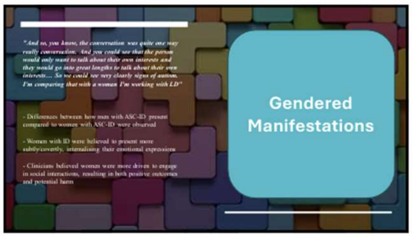

"And so, you know, the conversation was quite one way really conversation. And you could see that the person would only want to talk about their own interests and they would go into great lengths to talk about their own interests… So we could see very clearly signs of autism. I'm comparing that with a woman I'm working with LD"

- Differences between how men with ASC-ID present compared to women with ASC-ID were observed

- Women with ID were believed to present more subtly/covertly, internalising their emotional expressions

- Clinicians believed women were more driven to engage in social interactions, resulting in both positive outcomes and potential harm

Gendered Manifestations

12

"In society there is still an expectation of what women, to some degree… It has changed and it is constantly changing, but there is an expectation of femaleness and there's a lot of autistic women who struggle with gender identity and sexual identity and struggle to understand where they fit."

- Clinicians believed that different aspects of a woman with ASC-ID's identity and the context they provide resulted in some of the behaviours noted in the previous themes

- Clinicians believed that the historical biases around gender, ASC and ID may result in greater conformity to traditional gender roles

- Historical stigmatisation of those with ID resulted in ASC not being acknowledged

Intersectional Influences

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"We haven't ever been given, you know, training on autism. It's more what we... the information we get that we would then take out to families or to the carers or to the clients to assist them in understanding their diagnosis."

- Discrepancy amongst clinicians regarding the amount of training about ASC and how it can present that they received

- Clinicians reported seeking out their own learning on ASC, creating inconsistencies with confidence when identifying ASC in women with ID

- Importance of raising awareness in the community via awareness week and engaging with families to share knowledge

Education & Awareness

14

"They're dealing with a whole lot of things that the rest of us would really struggle with, that the expectation for them to be functioning in the community or make decisions or be independent or… added with the autism and LD… I Think lots of them are amazing some of the things [they] are presented with the rest of us would struggle with and they're doing it. You know, they're really doing their best to function in in society and get on with their lives"

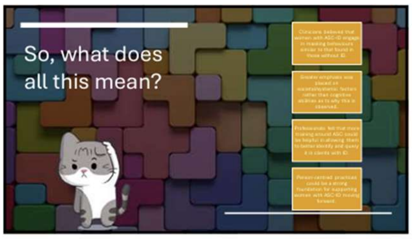
- Clinicians believed working with women with ASC-ID in a person-centred way helped to address the challenges they highlighted in the other themes

- Working in a strengths-based way was thought to help support women with ASC-ID

- This allowed for the creation of individualised packages of support which helped to reduce need for masking

Person-Centred Practices

15



So, what does all this mean?

Clinicians believed that women with ASC-ID engage in masking behaviours similar to that found in those without ID.

Greater emphasis was placed on societal/systemic factors rather than cognitive abilities as to why this is observed.

Professionals felt that more training around ASC could be helpful in allowing them to better identify and query it in clients with ID.

Person-centred practices could be a strong foundation for supporting women with ASC-ID moving forward.

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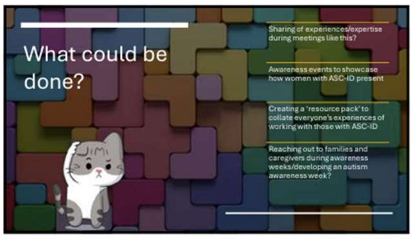

What could be done?

Sharing of experiences/expertise during meetings like this?

Awareness events to showcase how women with ASC-ID present

Creating a 'resource pack' to collate everyone's experiences of working with those with ASC-ID

Reaching out to families and caregivers during awareness weeks/developing an autism awareness week?

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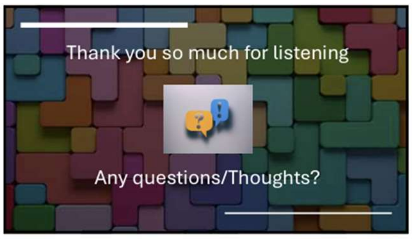

Thank you so much for listening

Any questions/Thoughts?

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