Exploring factors related to delayed diagnosis for autistic girls through the Connected Bradford Cohort Database

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Abstract

Background: It is well established that autistic girls are diagnosed and supported later than boys, but a clear and grounded understanding of this problem is lacking. The Connected Bradford Cohort datasets combine health and education data for 600,000 citizens across the Bradford district, and therefore provide an excellent opportunity to document structural inequalities at a population level. Furthermore, using the Connecting Lived Experiences with Visualisation of Electronic Records (CLEVER) framework, the data findings can be combined with lived experiences in order to better our understanding and generate solutions to meet the needs of autistic girls earlier. The Early Years Foundation Stage Profile (EYFP) has been found to be an early predictor of autism diagnosis in children, but the impact of sex has not yet been investigated.

Methods: Linked health and education datasets for 2617 autistic individuals (≤18 years) in the Connected Bradford cohort were used to ascertain the impact of sex on: rates of autism diagnosis, age and likelihood of diagnosis, and the EYFSP as a potential early indicator of autism. Interviews and focus were used to add vital insights into the data findings through the lived experiences of autistic girls/women and parents of autistic girls across the district.

Results: Sex-based prevalence rates of autism were~4:1. Girls were diagnosed later than boys, and boys were three times more likely to receive an autism diagnosis. Low EYFSP scores were a strong indicator of subsequent autism diagnosis for boys, but comparatively less so for girls. Interview and focus group findings indicated that sex-based disparities were underpinned by factors such as a lack of professional knowledge about the Female Autism Phenotype and inflexible, under-resourced services.

Conclusion: There is a systemic failure to identify and support autistic girls across the Bradford district. Health and education services are currently ill-equipped and require systemic training, service revision, and a focus on needs-led support.

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ADHD:	Attention Deficit Hyperactivity Disorder
ADI-R:	Autism Diagnostic Interview – Revised
ADOS-2:	Autism Diagnostic Observation Schedule – 2nd ed.
AET:	Autism Education Trust
APA:	American Psychological Association
CAMHS:	Children and Adolescent Mental Health Services
CLEVER:	Connecting Lived Experiences with Visualisation of Electronic Records
DCD:	Developmental Coordination Disorder
DSM-5:	Diagnostic and Statistical Manual of Mental Disorders – 5th ed.
EHCP:	Education and Health Care Plan
EYFSP:	Early Years Foundation Stage Profile
FAP:	Female Autism Phenotype
FPE:	Female Protective Effect
ICD-11:	International Classification of Diseases – 11th ed.
ID:	Intellectual Disability
IR:	Intercoder Reliability
NICE:	National Institute for Health and Care Excellence
OT:	Occupational Therapy/Therapist
SALT:	Speech and Language Therapy/Therapist
SEN:	Special Educational Needs
SENCO:	Special Educational Needs Co-ordinator
SNOMED-CT:	Systemised Nomenclature of Medicine – Clinical Terms
SPD:	Sensory Processing Disorder
TA:	Thematic Analysis
WHO:	World Health Organisation

A note about language

The author respectfully acknowledges that individual preferences around the use of language in autism research may vary. The following paragraphs outline the rationale for the terminology used throughout this document.

“Autistic person” vs “Person with autism”

Autism-first language will be used throughout this document, i.e., “autistic person” rather than “person with autism”, as this moves us toward understanding autism as an integral part of an individual’s identity rather than an additional ‘condition’ (Botha et al., 2023). While further research is needed to understand how we should talk about autism in a way that reflects the preferences of *all* autistic people, e.g., speaking and non-speaking, with and without intellectual disability, current guidance from autistic advocates suggests a preference for autism-first language (Autistic Self Advocacy Network, 2021; Botha et al., 2023; National Autistic Society, 2021).

“With/without an intellectual disability” vs “Low/High Functioning”

The terms “with/without an intellectual disability” will be used throughout this document, in acknowledgement that “low/high functioning” can have ableist and stigmatising effects, perpetuate stereotypes, and does not accurately reflect the experience of autistic people (Bottema-Beutel et al., 2021). “Low/high functioning” is a value-based judgement of ability and does not adequately describe the differences between intellectual and adaptive functioning, which can vary across domains for every individual (Botha et al., 2023). Throughout this document, language will be used specifically to reflect the heterogeneity in individual profiles and the importance of social context, in line with the neurodiversity paradigm (Pellicano & den Houting, 2022).

“Sex” vs “Gender”

The UK Office of National Statistic defines the term “sex” as ‘referring to the biological aspects of an individual as determined by their anatomy, which is produced by their chromosomes, hormones, and their interactions’, and the term “gender” as ‘a social construction relating to behaviours and attributes based on labels of masculinity and femininity; gender identity is a personal, internal perception of oneself and so the gender category someone identifies with may not match the sex they were assigned at birth’ (Tolland & Evans, 2022). Throughout this document, the terms “males/females”, “boys/girls” and “men/women” will be used to refer to biological sex at birth and as it was recorded in health records at the time of this study. The researcher respectfully acknowledges the limitations of this binary stance within the context of growing literature surrounding gender diversity and autism (Warrier et al., 2020); while this highlights an important focus for future research, the role of gender is not within the remit of the current study, and biological sex is used as a focus for current structural inequalities in autism diagnosis and service provision.

Chapter 1: Introduction

1.1 Autism

Autism is a lifelong form of neurodiversity that affects how an individual experiences and interacts with the world around them (Pellicano & den Houting, 2022), and commonly underlies difficulties or differences in social understanding and interaction, verbal and/or non-verbal communication, cognitive flexibility, sensory processing, restricted and/or repetitive behaviours (RRBs), and intense interests (Hosozawa et al., 2020; Shephard et al., 2019). Autism can be understood as an individual profile of strengths and needs across different areas, which can vary according to factors such as age, environmental stressors, social demand, and the presence of co-occurring conditions (Bradshaw et al., 2021). The impact of these differences varies greatly within and between autistic people, and greater impact is associated with poorer health, social, education and employment outcomes and increased need for support (Howlin & Magiati, 2017).

Autism is officially categorised as a ‘neurodevelopmental disorder’ (World Health Organization, 2022), which is grounded in the medical model of disability (World Health Organization, 1980). Indeed, autism was first conceptualised by professionals who were working within a medical framework and comparing observed autistic behaviours to the 'typical norms’ of their time (Kanner, 1943). However, with the development of the field, critics of the medical view of autism argue that this framework is overly deficit-focused, primarily locates difficulties or differences as a ‘problem’ within the individual, leans towards interventions that are designed to ‘correct’ or bring functioning in line within neurotypical expectations, and can exclude the voices and lived experiences of autistic people (Pellicano & den Houting, 2022; Simeonsson et al., 2000). Over the last two decades, there has been growing support for viewing autism through the lens of the neurodiversity paradigm, which posits that neurodevelopment is wide ranging and naturally diverse; a spectrum on which most people will be within a ‘neurotypical’ range and others will be ‘neurodivergent’ (Chapman, 2020). The neurodiversity paradigm is closely aligned with the social model of disability (Oliver, 2013) and works on three main assumptions: first, no value-based judgements are attached to neurodivergence and there should be a focus on strengths and diversity, rather than deficits alone. Second, the neurodiversity paradigm acknowledges that many autistic people will need support and it places emphasis on the need for a social response and adaptive environments rather than locating ‘problems’ within an individual. And third, there is a focus on the lived experiences of autistic people, and the importance of centring autistic voices in conversations around decision-making, service planning and future research (Pellicano & den Houting, 2022).

Prevalence rates

It is estimated that 1% of the population are autistic, although this is considered to be a conservative estimate on the basis that not all autistic individuals will have received a formal diagnosis (Fombonne et al., 2021; Roman-Urrestarazu et al., 2021; Underwood et al., 2021; Zeidan et al., 2022).

Autism was historically thought to occur predominantly in males (Werling & Geschwind, 2013; Young et al., 2018) and current sex-based prevalence rates continue to the echo this bias; estimates have ranged from 16:1 (Werling & Geschwind, 2013) to 1.8:1 (Matttila et al., 2011), with most findings suggesting ratios around 3:1 (Loomes et al., 2017). This bias is also reflected in clinical research, with the majority of autism research based on predominantly male samples and those who have received a formal diagnosis (Mandy & Lai, 2017; Whitlock et al., 2020). Interestingly, a recent longitudinal study by Burrows et al. (2022) found that, when age- and sex- measurement biases were accounted for in their population sample, autism prevalence in males and females was an equal 1:1 ratio. Furthermore, a Norwegian population-based study of 1,701,206 adults and 804,146 children found that male to female ratios were lower in autistic adults (2.57:1) compared to autistic children (3.67:1) and that differences were influenced by diagnostic biases and late diagnosis in females (Posserud et al., 2021). These findings lend support to the theory that higher prevalence of autism in males is, at least in part, an artefact, and that autism is currently under identified in females.

Diagnostic Criteria

The International Classification of Diseases (ICD-11) (World Health Organization, 2022) and the Diagnostic and Statistical Manual of Mental Disorders

(DSM-5) (American Psychiatric Association, 2013) are used globally in the assessment and diagnosis of autism; both sets of diagnostic criteria now reflect a dyadic understanding of autism and stipulate ‘persistent deficits’ in social communication and social interaction across multiple contexts and restricted, repetitive patterns of behaviour, interests, or activities. In order to meet criteria for a diagnosis of autism, assessing clinicians must ensure that difficulties are not explained by intellectual disability and that they significantly impact an individual’s daily functioning. The diagnostic criteria also state that difficulties must be present from the early developmental period; however, there is an acknowledgement that they may not become apparent until social demands exceed an individual’s capacity, and they may be masked by learned strategies (APA, 2013; WHO, 2022). The ICD-11 and DSM-5 also provide clinicians with guidance on conditions that commonly co-occur with autism and can significantly impact an individual’s functioning (APA, 2013; WHO, 2022). Some of the most prevalent co-occurring conditions are discussed below.

Co-occurring conditions

Intellectual disability

An Intellectual Disability is defined as ‘significant limitations both in intellectual functioning and adaptive behaviours as expressed in conceptual, social and practical adaptive skills…originating in the developmental period’ (p. 2) (Schalock et al., 2021). Intellectual Disability commonly co-occurs with autism, and estimates suggest that approximately 34% of people with an intellectual disability are also autistic (Emerson & Baines, 2010; Shenouda et al., 2023). A Scottish population-based study by Dunn et al. (2019) found that approximately 18% of autistic people had a co-occurring intellectual disability and that 2.57/1000 children aged 0-15 years had co-occurring diagnoses of autism and intellectual disability. Prevalence rates of co-occurring autism and intellectual disability are otherwise limited, although Posserud et al. (2021) found that male to female ratios were lower in autistic children with a co-occurring intellectual disability (2.72:1), compared to autistic children without an intellectual disability (5.05:1).

Attention Deficit Hyperactivity Disorder (ADHD)

Attention Deficit Hyperactivity Disorder (ADHD) is characterised by difficulties with impulsivity and/or sustaining attention and has a prevalence rate of 5-7% in children in the general population (Williamson & Johnston, 2015). The co-occurrence of ADHD in autistic individuals has been found to be high, with estimates of up to 80% of autistic children experiencing ADHD, and up to 50% of children with ADHD also receiving an autism diagnosis (Mahendiran et al., 2019). A recent meta-analysis by Rong et al. (2021) found a lifetime ADHD prevalence rate of 40.2% in autistic individuals in the UK. Research has indicated that autistic individuals with ADHD are more likely to have their autism diagnosed later than those who do not have ADHD (Kentrou et al., 2019), and children who are diagnosed with ADHD first are more likely to receive their autism diagnosis after the age of six (Miodovnik et al., 2015). Interestingly, rates of ADHD in autistic individuals with an intellectual disability have been found to be lower than those without an intellectual disability (Witwer & Lecavalier, 2010). Analyses of sex differences in rates of autism and co-occurring ADHD are limited due to the preponderance of males in clinical research samples, although there is some evidence that autistic males are up to three times more likely to have a co-occurring diagnosis of ADHD than autistic females (Rong et al., 2021).

Developmental Coordination Disorder (DCD)

Developmental Coordination Disorder (DCD) is characterised by difficulties with coordination, control and planning of motor responses, along with sensory processing difficulties which impact fine and gross motor skills (Camden et al., 2022). The prevalence of motor difficulties consistent with DCD is high in autistic individuals, with a recent meta-analysis finding rates of 50-88% (Kangarani-Farahani et al., 2023). A study by Narayan Bhat (2020) found that in a sample of 11,814 autistic children aged between 0-15 years, 86.9% experienced difficulties consistent with DCD, although only 31.6% of those children were receiving appropriate support for their motor difficulties.

Research has indicated that motor delays in infancy could be an early indicator of subsequent autism diagnosis (Harris, 2017), however, studies have relied on predominantly male samples and comparatively little is known about motor skills development in autistic girls. A recent study by Gabis et al. (2020) found in their sample of 468 autistic children, early motor delay was more common in autistic girls than boys (60% of girls and 47% of boys) and concluded that motor difficulties could be an early indicator of autism in girls.

Sensory Processing Disorder (SPD)

Sensory Processing Disorder (SPD) is a heterogenous condition that impacts the way in which an individual processes, organises and responds to sensory information, and causes difficulties in their everyday functioning (Miller et al., 2009). While sensory processing has long been associated with autism (Alhage Kientz & Dunn, 1997; Talay-Ongan & Wood, 2010), it has only been recognised as a core feature in the last ten years following its inclusion in the diagnostic criteria for autism in the DSM-5 in 2013 (APA, 2013). SPD is estimated to affect between 45-95% of autistic children (Ben-Sasson et al., 2009); autistic children are more likely to experience over- and under-responsivity to sensory input, and to demonstrate sensory seeking behaviours than neurotypical peers (Ben-Sasson et al., 2019). Recent research has focused on sex-differences in SPD among autistic individuals, with mixed findings; some studies found no sex-differences in sensory profiles (Bitsika et al., 2018), while others have found that autistic girls showed increased over-responsivity to taste, smell and touch compared to autistic boys (Kumazaki et al., 2015). In recent study of 168 autistic children and 239 neurotypical children (all with similar levels of cognitive ability), Osorio et al. (2021) found that autistic girls were more likely to experience over-responsivity to sound and touch, and to have more difficulty with postural control than their neurotypical counterparts and autistic boys. Furthermore, Osorio et al. (2021) found that the magnitude of difference in sensory processing between autistic boys and girls was greater than that between neurotypical girls and boys. Taken altogether, these findings indicate that while sensory processing difficulties are a shared core feature of autism, there may be differences in how these difficulties manifest between autistic girls and boys.

Sleep Disorders

Sleep difficulties have been found to affect up to 86% of autistic children and are one of the most commonly parent-reported difficulties (Cortese et al., 2020; Estes et al., 2023). A recent systemic review of 113 studies, concluded higher rates of sleep disorders in autistic children than neurotypical peers, with the most common issues being delayed sleep, short sleep duration, irregular sleep-wake patterns, and poor sleep quality (Carmassi et al., 2019). Autistic children have also been found to experience higher levels of bedtime resistance and sleep anxiety, further impacting sleep quality, and thus their daytime functioning (Díaz-Román et al., 2018). While sleep difficulties are also common in neurotypical development, these tend to resolve by school-age, whereas autistic children continue to experience sleep difficulties throughout childhood and beyond (Sivertsen et al., 2012). Difficulties with sleep are associated with poor self-regulation, increased repetitive behaviours, and increased difficulties with communication in autistic children (Sare & Smith, 2020) and have been found to detrimentally impact parent well-being (Giallo et al., 2013). Research has indicated no differences in rates of sleep difficulties between autistic children with and without intellectual disability (Estes et al., 2023); however, early findings have indicated some sex-differences. Autistic girls have been found to experience higher rates of sleep disorders than autistic boys (Angell et al., 2021), with more difficulties in areas of bedtime resistance, sleep duration, sleep anxiety, and sleepiness (Estes et al., 2023).

Mental health difficulties

The prevalence of mental health difficulties has been found to be significantly higher in autistic people, with a recent meta-analysis of 96 studies finding pooled lifetime prevalence rates of 20% for anxiety and 11% for depression, compared to 15% and 8% respectively in the general population (Lai et al., 2019). It is estimated that up to 70% of autistic people will have at least one co-occurring mental health diagnosis and up 50% will have two or more, with anxiety and depression being the most common (Buck et al., 2014; Lever & Geurts, 2016). Estimates suggest that approximately 40% of autistic school-aged children have a co-occurring diagnosis of anxiety (Vasa et al., 2020), with factors such as Intolerance of Uncertainty (Jenkinson et al., 2020) and sensory processing difficulties (MacLennan et al., 2020) thought to mediate the relationship between autism and anxiety. Autistic females have been found to report higher levels of anxiety, but not depression, than autistic males (Sedgewick et al., 2020). Research suggests that autistic girls and women are more likely to experience internalised ‘symptoms’ that lead to anxiety, low self-esteem, depression and suicidality (Beck et al., 2020).

Mental health difficulties have been found to have detrimental effects on education and quality of life (Adams et al., 2019) and are associated with increased risk of suicide; autistic children are 28 times more likely to think about or attempt suicide than neurotypical peers (Mayes et al., 2013). Research has indicated that autistic people are nine times more likely to die by suicide than the general population, with higher prevalence of suicidal thoughts and behaviours in late diagnosed autistic people (Cassidy et al., 2014). Autistic people without an intellectual disability have been found to be at increased risk of suicidal thoughts and behaviours compared to those with an intellectual disability, and within this autistic females demonstrate the highest risk (Hirvikoski et al., 2020).

1.2 Autism Provision in the UK

Formal identification of autism can have many benefits for the individual. Confirmation of autism through a clinical diagnosis has been found to increase positive self-regard and self-identity (Corden et al., 2021). An autism assessment and diagnosis can also guide interventions to support with the impact of differences or difficulties for some people and indicates that reasonable adjustments may be required to facilitate access to health services (Brede et al., 2022; Mason et al., 2019). Furthermore, for autistic children and young people, a formal diagnosis can improve access to Special Educational Needs (SEN) support in school (Dockrell et al., 2019).

It is therefore imperative that autistic people are able to access assessment services to have their needs identified; however, there have been notable challenges to this, which were reflected in the agenda set out in the NHS Long Term Plan (NHS, 2019). Here, missions included reducing waiting times and providing timely assessments, and working with education and social care providers to develop packages of support for autistic children. A further re-commitment to achieving ‘demonstrable improvements’ in these areas was outlined in The National Strategy for Autistic Children, Young People, and Adults (UK Government, 2021). In recognition of continued service pressures, waiting times and patient dissatisfaction with services, a National Framework and Operational Guidelines were published in 2023, with a focus on improving outcomes for autism assessment in the UK (NHS England, 2023a, 2023b).

Autism assessment pathways

Autism assessments in the UK are delivered through health services. For children this is usually through Child Development Centres (Paediatrics) and Children and Adolescent Mental Health Services (CAMHS). Operational guidance for improving autism pathways (NHS England, 2023b) highlights five key stages of autism assessment, although whether, and how, these stages are delivered varies between services and according to other agencies existing involvement. The five key stages will be considered below, as understanding the distinct phases of the assessment process will be important in later determining exactly where and how potential inequalities are enacted:

Stage 1: Identification and referral

Identification of autism for children and young people relies on the system around them (e.g., family, education staff, health professionals) to notice traits, usually when there are concerns about their impact on the child's functioning and well-being (O'Reilly et al., 2017). Access to an autism assessment usually begins with parental discussions with the GP or education professionals, although it has been highlighted that lack of clarity about who is able to make a referral for an autism assessment can be barrier and cause of delay (Crane et al., 2018).

Stage 2: Screening and triage

Once received by assessment services, the referrals are first screened to assess whether they meet eligibility criteria, which can differ across services depending on how they are commissioned (NHS England, 2023b). Triage involves gathering further information about the individual and their presentation, to decide whether an autism assessment is indicated; methods of triage again vary between services with some reviewing medical notes and letters, and others using questionnaire-based screening tools. The outcome of screening and triage is usually decided by a multi-disciplinary team discussion and communicated to the individual and/or their family.

Stage 3: Pre-assessment support

The pre-assessment phase includes communication with the individual and/or their family about the waiting times for assessment. Current guidance states that assessment should take place within three months of referral (National Institute for Health and Care Excellence, 2017); however, demand and capacity means that families are often waiting for significantly longer periods of time (as addressed in the NHS Long Term Plan). It is recommended that children and young people receive interim support while they await autism assessment, including needs-led resources and input from health services, and work to identify and meet educational needs within school (NHS England, 2023b).

Stage 4: Diagnostic assessment

Diagnostic assessments are conducted by an appropriately qualified multi-disciplinary team and, as per NICE guidance, should combine corroborative information with a clinical interview with the individual, an autism specific developmental history, such as the Autism Diagnostic Interview – Revised (ADI-R) (Lord et al., 1994) with parents or caregivers and behavioural observations (National Institute for Health and Care Excellence, 2017), and many services use semi-structured behavioural observation tools, such as the ADOS-2 (Lord C et al., 2012) to support the assessment. Assessment should include the consideration of differential diagnoses and screen for conditions that commonly co-occur with autism (NHS England, 2023b).

Stage 5: Post-assessment support

Once a diagnosis has been given, post-assessment support should then be provided. This can include supporting the individual to understand their individual profile of strengths and needs, and psychoeducation about autism. Furthermore, needs-led support should be provided or signposted to, including interventions to support mental health and education (NHS England, 2023b).

Education and SEN

Educational provision for autistic children varies according to need, and can include mainstream schools, specialist provisions, and residential schools. Many autistic children without an intellectual disability will attend mainstream school provision and receive support from a Special Educational Needs Co-ordinator (SENCO). The Autism Education Trust outlined the role of the SENCO in supporting autistic children within four main areas: *understanding the individual, learning and development, providing an enabling environment and nurturing positive and effective relationships*, and these concepts were underpinned by appropriate staff training (Autism Education Trust, 2021). When a child’s individual needs exceed the capacity of the SEN provision, additional funding for support can be sought via the Local Authority through an Education and Health Care Plan (EHCP). An EHCP identifies the education, health and social needs of a child and sets out a holistic plan to meet those needs up to the age of 25, and applications can be parent or school led (UK Government, 2023). While it has been found that securing a formal diagnosis can support the EHCP application (Dockrell et al., 2019), this is not a mandatory requirement and should be based on identified needs.

The Early Years Foundation Stage Profile (EYFSP)

The Early Years Foundation Stage Profile (EYFSP) is an assessment that is conducted with all children in the first year of their education in the UK and provides information from teacher-report of educational, socioemotional, developmental, and communicative behaviours. The EYFPS has been found to be an effective indicator of children with a higher chance of requiring SEN support later in childhood (Atkinson et al., 2022). Wood et al. (in press) replicated these findings on a population level and while also investigating structural inequalities in identifying SEN needs. Findings indicated that children from minoritised ethnic backgrounds with low EYFSP scores were less likely to receive SEN support compared to their White counterparts. Furthermore, using a longitudinal birth cohort, Wright et al. (2019) investigated utility of the EYFSP as an indicator of a subsequent diagnosis of autism specifically, finding that children with a low score on the EYFSP were ~50 times more likely to go on to receive an autism diagnosis compared to children who did not have a low score. These findings are encouraging and suggest that this nationally used educational assessment could be used as an early screening tool to identify potential autism and children who are more likely to require SEN support; however, sex-differences in the efficacy of the EYFSP as a potential early indicator of autism have not yet been investigated.

Structural inequalities in autism diagnosis

Early identification of autism is associated with better health and educational outcomes through the implementation of timely support (Zwaigenbaum et al., 2013). Furthermore, delayed identification and subsequent unmet need contributes to poorer health and education outcomes and increased risk of mental health difficulties (Cassidy et al., 2014). It is therefore imperative that autistic individuals are identified as early as possible; however, there is evidence to suggest that there are structural inequalities in access to autism diagnosis and support, with certain factors associated with increased risk of delayed or missed diagnosis.

Individuals without an intellectual disability are more likely to have their autism identified later than those with an intellectual disability (Brett et al., 2016) and children from minoritised ethnic backgrounds are at increased risk of delayed and missed diagnosis compared to White peers (Tromans et al., 2020). There is some evidence to suggest that children from lower socioeconomic backgrounds are at increased risk of delayed diagnosis (Thomas et al., 2012) although, interestingly, Kelly et al. (2019) found in their birth cohort study that children of mothers with higher levels of educational attainments were twice as likely to be diagnosed than children of mothers with lower levels of education, and when maternal education was accounted for, socioeconomic status was not associated with later autism diagnosis.

Arguably the most notable disparity in autism diagnosis and support is that between males and females (Posserud et al., 2021); it is now well established that autistic girls are at increased risk of delayed or missed diagnosis compared to boys, even when there is a similar level of need (Geelhand et al., 2019).

1.3 Autism and Girls

Autism is diagnosed at higher rates in males compared to females, with current estimates of 3:1 (Loomes et al., 2017). However, there is growing evidence to suggest that these rates reflect diagnostic biases rather than true prevalence (Burrows et al., 2022), and that many autistic girls are not identified (Posserud et al., 2021). For those girls who do receive a diagnosis, this tends to occur later than boys (Geelhand et al., 2019; Lockwood Estrin et al., 2020), and risk of delayed or missed diagnosis is further increased for girls who have other pre-existing mental and/or physical health diagnoses (Zener, 2019), are from deprived socio-economic backgrounds (Grove et al., 2017; Hosozawa et al., 2020), are from minoritised ethnic backgrounds (Tromans et al., 2020), do not have a co-occurring intellectual disability (Lockwood Estrin et al., 2020) and do not present with externalised ‘behavioural difficulties’ (Duvekot et al., 2017). The issue of delayed and missed diagnosis for autistic girls has received much attention in recent years; a number of hypotheses have been developed in an attempt to understand these sex-based disparities and these will be considered in turn in below.

The Extreme Male Brain and the Female Protective Effect

Baron-Cohen (2002)’s Extreme Male Brain (EMB) theory suggests that low rates of diagnosis in females reflects the underlying aetiology of autism. The EMB relies on the theory that there are inherent sex differences in how the human mind works, i.e., on a continuum of empathising to systemising, females tend to be high ‘empathisers’ and males tend to be high ‘systemisers’ (Baron-Cohen et al., 2003). The EMB is based on data collected via a self-report scale that was developed by Baron-Cohen et al. (2003) and argues that autistic individuals tend to be high systemisers and therefore display features of an ’extreme male brain’, and so females are inherently less likely to be autistic. Similarly, the Female Protective Effect (FPE) argues that, based on genetic and environmental factors, females require a “higher etiological load in order to manifest behavioural symptoms of autism” and therefore being female is in itself a “protective factor against autism” (Robinson et al., 2013). However, recent findings of a review by Dougherty et al. (2022) found limited genetic evidence to support the FPE, and there are a number of further limitations to both the EMB and FPE theories as explanations for sex-based disparities in autism diagnosis:

First, the EMB theory relies on outdated, essentialist, gendered expectations and fails to recognise natural diversity in cognitive and emotional functioning between the sexes (Ridley, 2019). Second, the EMB and FPE rely on the assumption that current estimates of autism prevalence in males and females are accurate, and there is growing evidence to suggest that is not the case and that there are large numbers of autistic girls and women who have not received a diagnosis and are therefore not included in clinical research and prevalence rates (Burrows et al., 2022; Posserud et al., 2021). Third, the majority of autism research has included largely male clinical samples, and the relatively small number of females that have been included are those with a level of need enough to have met diagnostic criteria on standardised measures that are influenced by a stereotypically male presentation (Mandy & Lai, 2017). Little research has focused on females who are potentially autistic but have not received a diagnosis, which means that the full spectrum of autism presentations is not represented in clinical research.. This is problematic within the context of known barriers to assessment and diagnosis for girls and women (Lockwood Estrin et al., 2020). Neither the EMB nor the FPE go far in acknowledging the growing literature that suggests the core features of autism are similar in males and females, but the manifestation of these features is different between the sexes. These differences have been conceptualised as the Female Autism Phenotype (FAP), and there is growing evidence for this as a potential contributory factor for delayed or missed diagnosis in autistic girls and women (Grove et al., 2017; Hull et al., 2020; Tubio-Fungueirino et al., 2020).

The Female Autism Phenotype (FAP)

The FAP suggests that although males and females share similar core features of autism, the ways in which they present are qualitatively different, particularly in females without an intellectual disability (Hull et al., 2020). Turning first to social understanding and interaction in the FAP, there is some evidence to suggest that, overall, autistic girls without an intellectual disability may display fewer social difficulties than autistic boys, but comparatively more difficulties than neurotypical girls (Hull et al., 2020). Autistic girls have been found to show higher levels of social motivation than autistic boys (similar levels to neurotypical girls) which can make them appear more socially skilled (Lai et al., 2015). However, there is evidence to suggest that while they may appear better able to initiate social interactions, they are more likely to have difficulty managing conflict and maintaining friendships over time compared to autistic boys and neurotypical girls (Hiller et al., 2014). This may be perceived by others as dipping in and out friendship groups, or being a 'social butterfly', rather than difficulties with social interaction and maintaining relationships (Gould, 2017).

There is some debate in the literature with regard to the FAP and RRBs. Some studies suggest that autistic girls display fewer RRBs than their male counterparts (Gould, 2017), while others suggest that there are no differences in the rates of RRBs, but that autistic girls are more likely to "mask" ritualised behaviours, and hold intense interests that are more "socially acceptable" on the surface and therefore less likely to be interpreted as RRBs by others (Tint et al., 2017; Wang et al., 2017). A study by Antezana et al. (2019) found similar rates of RRBs in autistic girls compared to autistic boys, but autistic boys were more likely to present with stereotyped interests, whereas girls were more likely to display insistence on sameness and self-injurious behaviour. A recent meta-analysis of 79 studies by Saure et al. (2023) found that, compared to autistic boys, autistic girls without an intellectual disability appear to have better social communication and linguistic abilities and display fewer RRBs, but have more sensory processing and motor difficulties.

The evidence in support of the FAP as a barrier to identifying autism in girls has gathered momentum in recent years, drawing attention to the increased likelihood of autistic girls presenting with internalised symptoms and mental health difficulties, which are then more likely to be identified as primary difficulties, rather than secondary to underlying autism and unmet need (Lockwood Estrin et al., 2020; Tubio-Fungueirino et al., 2020; Zener, 2019). Furthermore, autistic girls without an intellectual disability often have insight into differences between themselves and neurotypical peers, which can lead to the development of learned coping strategies that "mask" the difficulties they are experiencing (Cook et al., 2017).

The Role of Masking

Mandy (2019) summarises ‘masking’ as a strategy to cope with “the mismatch between an individual’s natural way of being and the demands their social environment places on them” (p. 1879). For autistic people, this is a complex set of processes that can include unconscious and/or conscious imitation of peers, rote learning of social behaviours according to context, and minimising autistic characteristics in order to fit into an environment (Tubio-Fungueirino et al., 2020). In an online study by Cage and Troxell-Whitman (2019), 70% of their sample of 262 autistic individuals reported that they ‘masked’ their autism on a regular basis across different settings, and the same study found that ‘masking’ difficulties was associated with high levels of anxiety and stress.

As outlined earlier, autistic girls without an intellectual disability tend to show higher levels of social motivation than autistic boys (Lai et al., 2015). This, combined with social norms that place pressure on girls to be social (Milner et al., 2019), means that autistic girls are more likely to ‘mask’ their difficulties in order to fit in with neurotypical peers (Cook et al., 2017). Qualitative research into the experiences of autistic girls and women has revealed that they are likely to use a range of techniques to ‘mask’ their autism (Milner et al., 2019), cope with education and working environments, develop friendships (Cage & Troxell-Whitman, 2019), and avoid bullying and alienation (Hull et al., 2017). While ‘masking’ can prove an effective coping strategy in response to social demand, there is evidence to suggest that this comes at a huge cost. ‘Masking’ is reported to be an exhausting process (Cage & Troxell-Whitman, 2019), which can lead to internalised difficulties such as anxiety and depression (Livingston et al., 2019). This is reflected in some qualitative studies which have found common themes in reports of isolation, self-doubt and ‘a perpetual state of confusion’ among late diagnosed autistic girls (Tubio-Fungueirino et al., 2020; Zener, 2019). Autistic girls are less likely to be referred for an autism assessment, and those who are referred are still less likely to receive a diagnosis (Bargiela et al., 2016; Navot et al., 2017) and ‘masking’ is thought to be a contributory factor to the systems around autistic girls being less likely to identify their needs.

Limited Systemic Understanding

Limited systemic understanding of how autism presents in girls has been found to be a barrier to diagnosis and support (Leedham et al., 2020). Diagnostic criteria, assessment tools, professional training and general systemic awareness of autism tend to be representative of a 'male presentation', which presents a number of challenges to identifying autistic girls who may present differently (Hull et al., 2020).

Qualitative research into the experience of parents has found that parental awareness of autism can be a contributory factor to delayed identification for girls. For example, Rabbitte et al. (2017) found that parents of autistic girls were more likely to interpret their daughters' difficulties within more 'relatable' frameworks, such as anxiety, rather than considering the possibility of underlying autism. Similarly, in a qualitative study by Navot et al. (2017), parents of autistic girls expressed concern that they had not picked up on their daughters' difficulties earlier. This echoed the findings of Watson (2014) who concluded that parents perceived autism as a 'boy's condition'. Emotional and behavioural difficulties reported by parents, but not by teachers, have been found to increase the likelihood of girls receiving a diagnosis of autism (Duvekot et al., 2017).

Where parents do report concerns, there are often differences in how girls' difficulties are perceived by education staff (Tomlinson et al., 2019) and some parents have reported feeling their concerns were dismissed or that their daughter's difficulties were misinterpreted by education staff (Cook et al., 2017). Whitlock et al. (2020) found that education staff were less able to identify what autism 'looks like' in girls, compared to boys, when presented with case vignettes. Education staff have been found to report fewer concerns in relation to autistic girls, perhaps reflecting girls' ability to rote learn the rules, 'mask' their difficulties, and outwardly appear to manage the classroom environment (Hiller et al., 2014). Girls are therefore less likely to be referred for autism assessment (Geelhand et al., 2019)

Where girls are referred for assessment, there are further challenges to receiving a diagnosis. Autism assessment tools such as the Autism Diagnostic Observation Schedule – Second Edition (ADOS-2) (Lord C et al., 2012) utilise scoring algorithms that focus on externalised symptoms characterised by the typically 'male presentation' (Lai et al., 2015). The ADOS-2 therefore relies upon clinician’s ability to discern ‘masking’ from innate skills in behavioural assessment. Furthermore, an accurate developmental history relies upon both clinician and parental understanding of the Female Autism Phenotype in order to accurately recall and document potential autistic traits that may have been evident throughout the girls’ development. Clinician bias has also been highlighted as a potential barrier to identifying autism in girls; Lockwood Estrin et al. (2020) conducted a systematic review that concluded clinicians were more reluctant to diagnose autism in girls due to lack of awareness of the ‘female presentation’. Additionally, funding for autism assessment services within community settings is not responsive to increasing caseload (Galliver et al., 2017), therefore, in addition to waiting times which inherently contribute to delay, it is not always possible for clinicians to spend time directly observing the child across different settings at the point of assessment. Therefore, services often rely upon questionnaires, e.g., the Social Responsiveness Scale (SRS-2) (Constantino JN & CP, 2012), to triangulate assessment information. However, for girls who do not present with externalised or ‘male’ traits of autism, difficulties are less likely to be captured in teacher’s responses. These issues point to structural inequalities in *identification and referral*, *screening and triage*, and *diagnostic assessment* processes (NHS England, 2023b), which are contributing to the delayed and missed diagnosis, and unmet need, for autistic girls.

1.4 The current study

Rationale

Early identification of autism is associated with better health and educational outcomes (Zwaigenbaum et al., 2013); however, autistic girls are identified later than boys and some will go into adulthood without having their autism identified, with long term effects on mental health and well-being (Cassidy et al., 2014). It is therefore imperative that we move toward understanding how autistic girls can be identified earlier, to ensure they receive timely and appropriate support.

The issue of delayed diagnosis for autistic girls has received much attention in recent years, with research generating a number of hypotheses to understand under-identification. However, we are currently lacking a holistic understanding of exactly how and why these inequalities are enacted ‘on the ground’. One challenge to developing a holistic picture is the complex systems that surround children in the

UK. These systems often work in silos and utilise different record systems that are ring-fenced by information governance policies. This study aims to overcome these systemic barriers by focusing in on a specific population and utilising linked health, education, and social care records in order to explore exactly how and why sex-based inequalities are enacted within place-based context.

Connected Bradford

The Connected Bradford Programme is a joint initiative between local government and NHS Trusts. It links routine health, social care, and education records of over 800,000 people across the Bradford district in anonymised datasets, for the purpose of research and evaluation and to improve patient pathways and models of care (Sohal et al., 2022). Connected Bradford therefore presents an excellent opportunity to overcome systemic barriers and explore sex-based inequalities in autism diagnosis on a population level, specific to place-based context.

Study Aims

The overarching aim of this study is to better understand the structural inequalities in diagnosis and support for autistic girls and to generate solutions to identify and meet needs earlier. This study will explore these issues on a population level, using the Connected Bradford linked datasets to address four main aims:

1. To determine the average age of autism diagnosis in girls compared to boys (≤18 years old) in the Connected Bradford Cohort. This is a population-based study and so these large-scale findings will contribute to the current evidence base regarding current rates and age of autism diagnosis by sex for children in the UK.

2. To explore the role of intersectionality in access to autism diagnosis by analysing the interaction of sex, ethnicity, and autism diagnosis for individuals (≤18 years old) in the Connected Bradford Cohort.

3. To replicate the study by Wright et al. (2019) (which found the EYFSP to be an effective early indicator of subsequent autism diagnosis in a birth cohort) in the larger Connected Bradford population cohort and extend this to investigate whether the EYFSP could be an effective early indicator of autism in girls specifically.

4. To integrate these data driven insights with the lived experiences of stakeholders across the Bradford district in order to build a comprehensive understanding of the current barriers to identifying and supporting autistic girls, and to generate potential solutions.

Chapter 2: Study Design

The background, rationale and aims of this study were established in Chapter 1. This chapter will outline how the study was designed in order to address the aims.

2.1 Epistemological Position

The issue of delayed diagnosis for autistic girls is a socially situated problem and one that requires urgent action for change. In order to contribute to addressing this problem, this study takes a *Critical Realist* approach (Lawani, 2020) to develop a holistic understanding of the problem. While there is value in taking a *Positivist* approach to observe an emerging quantitative 'truth' in the datasets (Park et al., 2020), and in taking an *Constructivist* approach to consider the problem through human perception and experience (Alharahsheh & Pius, 2020), neither approach used in isolation would effectively establish a clear picture of how and why structural inequalities are enacted for autistic girls on a population level. Therefore, this study will combine both quantitative *and* qualitative methods in order to better our understanding of the current realities through analysis of datasets *and* lived experiences, and to guide actions for change and improvement.

2.2 Methodology

A mixed methods design was employed (Fàbregues et al., 2021; Timans et al., 2019), combining population level data and the lived experiences of citizens across the Bradford district in West Yorkshire, UK (Sohal et al., 2022). Full details of the methodology for each study will be outlined in the relevant chapters (3 and 4).

The CLEVER framework

The Connecting Lived Experiences with Visualisation of Electronic Records (CLEVER) framework was used to guide the design of this study. Statistical analysis of the Connected Bradford datasets was conducted first, to meet the first three aims of the study. Once these findings were established, the study then moved to meet the fourth aim – to explore the lived experiences of stakeholders across the

Bradford district to better understand the patterns observed in the data. The lived experiences of stakeholders were explored in two ways:

Interviews with autistic girls/women

Semi-structured interviews were conducted with autistic girls and women (≤16 years old) with lived experience of delayed diagnosis. The use of semi-structured interviews allowed for in-depth exploration of individual experiences, allowing the interviewer to follow-up on salient areas of discussion and participants to freely elaborate on areas of particular significance to them (Adams, 2015). A one-to-one interview design was also selected to reduce social demand, within the context of potential social interaction difficulties and anxiety (Spain et al., 2020).

Focus groups with parents of autistic girls

Focus groups were held with parents of autistic girls who had experience of navigating services and seeking support for their daughters. Focus groups have been found to be an effective method of gathering rich qualitative data in a relatively short space of time (Robinson, 2019), as the interaction between participants generates discussion and insights. Guidance around the composition of focus groups suggests anywhere between four and 12 participants is acceptable (Gundumogula, 2020); however, it was anticipated that the content of the group discussions may be emotionally evocative and a large group may have hindered honest and open contributions from participants. It was therefore decided to recruit no more than six parents; enough to promote discussion, whilst maintaining psychological safety.

Collaboration with Connected Bradford research team

This study was conducted in collaboration with members of the Connected Bradford research team. Statistical analysis of the Connected Bradford linked datasets was conducted in collaboration with qualified data scientists, and supervision was provided by qualitative researchers for quality checking of interview and focus group schedules and intercoder reliability in the thematic analysis of qualitative data.

2.3 Ethical approval

The project was conducted under the governance of the Bradford Institute for Health Research. The data were provided by the citizens of Bradford and district and collected by the NHS and other organisations as part of their care and support. HRA CAG and ethical approval was granted by the Leeds Bradford Research Ethics Committee for Connected Bradford IRAS ref: 239924, CAG ref: 18/CAG/0091 and REC ref: 18/YH/0200. The qualitative exploration was part of a larger programme of research on autism pathways (IRAS ID: 227117; REC reference: 17/EM/0254, and IRAS ID: 290135; REC reference: 20/YH/0314) and was part of a clinical audit approved by the Bradford Teaching Hospitals National Health System (NHS) Foundation Trust (IRAS Number: 233328).

Chapter 3: The Connected Bradford Datasets

The first three aims of this study were to (i) establish the average age of autism diagnosis by sex in the Connected Bradford cohort, (ii) explore the role of intersectionality in access to autism diagnosis by analysing the interaction of sex, ethnicity, and autism diagnosis, and (iii) explore the efficacy of the EYFSP as an early indicator of autism by sex. This chapter will describe three separate analyses that were conducted to meet these aims; each analysis, including methods and results, is considered in turn below followed by an overarching discussion of the findings.

3.1 Analysis 1: Demographics and age of autism diagnosis

Methods

Study Setting and Participants

Data were collated from the Connected Bradford database; a retrospectively linked database for over 800,000 citizens across the Bradford district in West Yorkshire, United Kingdom (Sohal et al., 2022). Primary care records from across the Bradford district were collated, covering the time period September 1999 to February 2022. Only those 18 years old and younger were considered in the following analyses. Please see Table 1 for demographics of the autism cohort.

Variables

Autism Diagnosis

A list of relevant SNOMED-CT codes were created to identify individuals with autism spectrum diagnoses within the Primary Care data. Autism spectrum was coded in SNOMED-CT as “Pervasive Developmental Disorder, SCTID: 35919005” (“autism spectrum disorders” are listed as a secondary preferred term under this code). There were found to be 49 descendant conditions of this code which were also used to indicate autism spectrum diagnosis. Only children with relevant SNOMED-CT codes were included in subsequent analyses. An “age at diagnosis” variable was also created reflecting the date the first autism spectrum diagnosis code appears in an individual’s records.

Ethnicity

The vast majority of the cohort were from either “White” or “Asian” backgrounds. Due to low numbers, individuals from other backgrounds were grouped as “Other” ethnic backgrounds. These were derived from census categories.

Table 1.

Demographic breakdown of individuals with an autism diagnosis

		N (%)
Total		2617
Females	**Total**	592 (22.6)
	White	346 (13.2)
	Asian	158 (6.0)
	Other	40 (1.5)
	Unknown	48 (1.8)
Males	**Total**	2022 (77.3)
	White	1198 (45.7)
	Asian	478 (18.2)
	Other	143 (5.4)
	Unknown	203 (7.7)
Sex Data Missing		3 (0.1)

Statistical Analysis

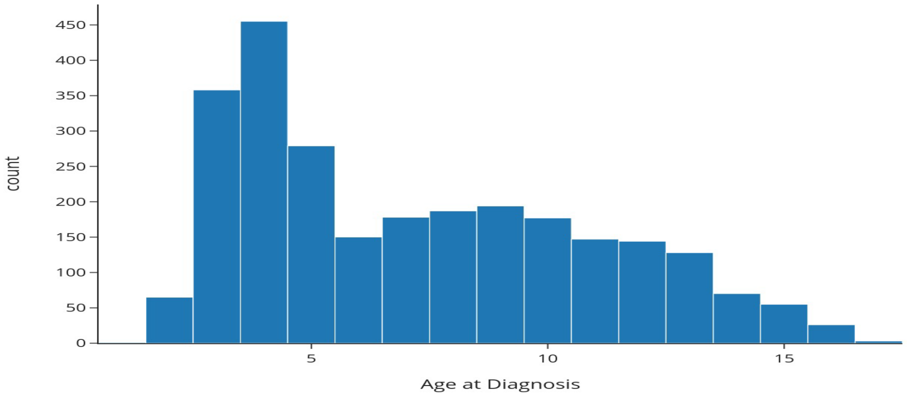
Descriptive statistics were used to ascertain the mean age of autism diagnosis between males and females in the whole sample, and across different ethnic groups. Welch’s two-sample t-tests were conducted to establish whether the differences in age of diagnosis between groups were statistically significant.

Results

Across the whole cohort, there is evidence of a bimodal distribution in the age of diagnosis. As shown in Figure 1, there is a sharp peak of diagnoses around the age of four and then another, albeit shallower, peak at around nine years of age.

Figure 1.

Distribution of age of diagnosis across the whole autism cohort

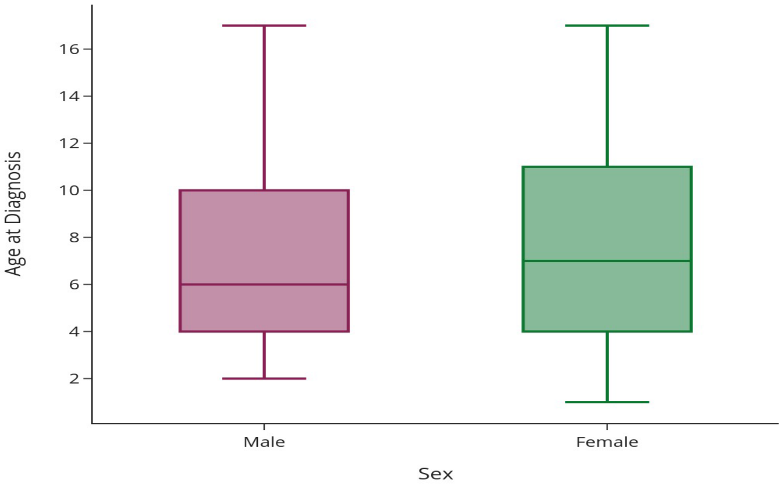


When comparing average age of autism diagnosis across the sexes, it was evident that the mean age of diagnosis was considerably younger for males (Mean = 7.02, Standard Deviation = 3.56) than females (M = 7.83, SD = 3.94). A Welch two-samples t-test revealed that this difference was statistically significant, $t(764) = 3.4$ $p= <.001$.

Figure 2 illustrates the distribution and median age of diagnosis by sex using a Box and Whisker plot (Tukey, 1977), whereby the lower and upper hinges of the box indicate the first and third quartiles, and the whiskers indicate values within 1.5 times the interquartile range.

Figure 2:

Distribution of age of autism diagnosis by sex (Median age and interquartile range)

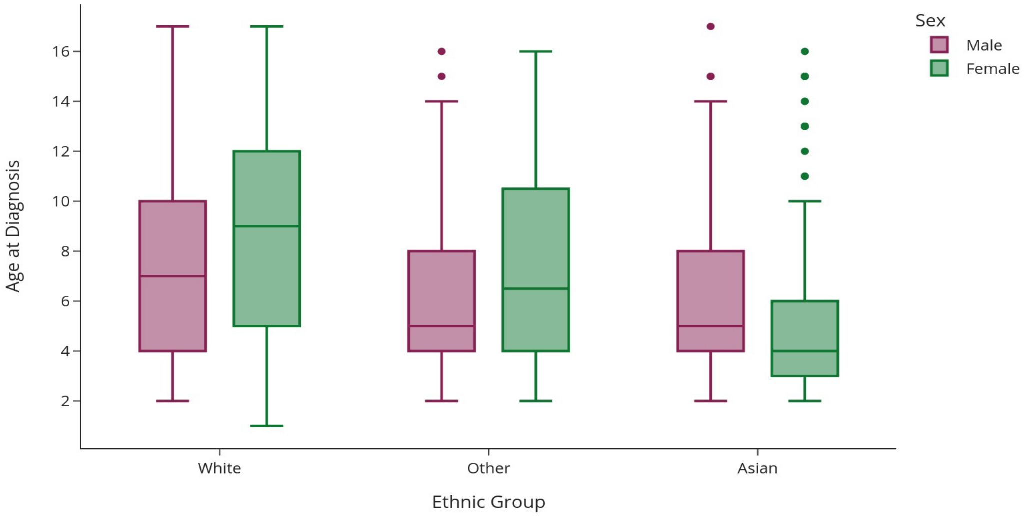


Lastly, the combination of both ethnicity and sex on age of diagnosis were considered. As shown in Figure 3, White males were diagnosed substantially younger than white females (M=7.45, SD=3.63 compared to M=8.71, SD=3.85) and this was statistically significant *t*(534) = 5.42, *p* =<0.001. Similarly, in the sample of children from Other ethnic backgrounds, males were diagnosed earlier than females (M=6.13, SD=3.24 compared to M=7.53, SD=4.13). In contrast, Asian females were diagnosed at a relatively earlier age than Asian males (M=5.53, SD=3.18 compared to M=5.98, SD=3.09), although, this difference was not statistically significant, *t*(261) = -1.58, *p* = 0.11.

Furthermore, comparison of females across ethnic groups revealed the average age of diagnosis was younger for Asian females compared to White females (M=5.53 SD=3.18 compared to M=8.71, SD=3.85) and this difference was statistically significant, *t*(363) = -9.73, *p* =<0.001. Similarly, the average of diagnosis was younger for Asian males compared to White males (M=5.98, SD=3.09 compared to M=7.45, SD=3.63), *t*(1023) = 8.32, *p* =<0.001 .

Figure 3.

Distribution of age of autism diagnosis by sex and ethnicity (Median age and interquartile range)



3.2 Analysis 2: Likelihood of autism diagnosis

Methods

Study Setting and Participants

All data were again drawn from the Connected Bradford database. To understand the likelihood of receiving a diagnosis of autism across various demographics, a non-clinical comparison group (i.e., individuals without an autism diagnosis) was needed. Therefore, information regarding individuals under the age of 18 was first collated from education records owned by the Department for Education (DfE). These data were then linked with primary care records to determine which of these children had an autism diagnosis. In total, 130778 individuals were included in analyses. Table 2 demonstrates the demographic breakdown of this cohort, along with a comparison of individuals with and without an autism diagnosis.

Table 2.

The demographic breakdown of individuals within Analysis 2

			Autism Diagnosis (%)	
		Total	**No**	**Yes**
Total		130782	128400	2382
Females	**Total**	63206 (48.3)	62673 (48.8)	533 (22.4)
	White	30104 (23.0)	29786 (23.1)	318 (13.3)
	Asian	21402 (16.3)	21266 (16.5)	136 (5.7)
	Other	4910 (3.7)	4874 (3.7)	36 (1.5)
	Ethnicity Unknown	6790 (5.1)	6747 (5.2)	43 (1.8)
Males	**Total**	67359 (51.5)	65510 (51.0)	1849 (77.6)
	White	31725 (24.2)	30621 (23.8)	1104 (46.3)
	Asian	20660 (15.7)	20237 (15.7)	423 (17.7)
	Other	5010 (3.8)	4884 (3.8)	126 (5.2)
	Ethnicity Unknown	9964 (7.6)	9768 (7.6)	196 (8.2)
Sex Data Missing		322 (0.2)	322 (0.3)	0

Statistical Analysis

Multivariate Logistic Regression (MLR) was conducted to model the relationships between the demographic variables (sex and ethnicity) and the likelihood of an autism diagnosis. MLR is widely used in health research as a robust method of assessing the association between multiple independent variables and a categorial outcome; it evaluates the independent effects of each variable on the outcome whilst adjusting for the effects of the other variables (Boateng & Abaye, 2019; Hidalgo & Goodman, 2013). Resulting odds ratios indicate the strength of the association between demographic variables and the likelihood of an autism diagnosis, compared to a baseline reference group. In this analysis, a female individual of Asian heritage was used as the baseline reference group; in line with the study aims, a pragmatic decision was made to select a baseline 'least likely' to receive an autism diagnosis based on the evidence base surrounding sex- and ethnicity- based disparities. The analysis was conducted using the statsmodel package (Version 0.13.5; Seabold and Perktold (2010)) in Python. The likelihood of diagnosis, based on the demographic features, is described, and adjusted odds of autism diagnosis and confidence intervals for each of the demographic variables are reported.

Results

Initial explorations revealed that over three-quarters of children with an autism diagnosis were male, compared to around 50% in the non-clinical sample. Meanwhile, in the non-autism sample, around 47% of the children were of White heritage compared to nearly 60% of children with a diagnosis of autism.

This was explored further by modelling the likelihood of autism diagnosis as a function of sex and ethnicity, using a female individual of Asian heritage as the baseline reference. As shown in Table 3, compared to baseline, males had approximately three times increased odds of being diagnosed with autism (OR: 3.36, 95% CI: 3.03-3.71). Meanwhile an individual of White heritage had nearly two times increased odds (OR: 1.71, 95% CI: 1.55-1.89), and an individual from the "Other" ethnic group also had increased odds (OR: 1.21, 95% CI: 1.01-1.45), compared to baseline.

Table 3.

Logistic regression table indicating likelihood of diagnosis by sex and ethnicity

Pseudo R-Squared = 0.036; LLR p-value = 0.00; SE: Standard Error CI = confidence interval; LL = lower limit; UL = upper limit.

Effect	**Estimate**	***SE***	**95% CI**		**z**	***p***
			LL	*UL*		
Coefficients						
Intercept	-5.07	.058	-5.19	-4.96	-87.43	<.001
Male	1.21	.050	1.11	1.31	23.37	<.001
White	0.54	.050	0.44	0.63	10.65	<.001
Other	0.19	.090	0.02	0.37	2.16	.031
Odds						
Intercept	-	-	-	-	-	-
Male	3.36	-	3.03	3.71	-	-
White	1.71	-	1.55	1.89	-	-
Other	1.21	-	1.01	1.45	-	-

3.3 Analysis 3: EYFSP and Autism diagnosis

Methods

Study Setting and Participants

Autism diagnosis data were again obtained from primary care records and linked to EYFSP data from education records via the Connected Bradford database. Records spanned the time period 2013-2019. This resulted in 70,277 children being included in analyses. Demographics of the sample are reported in Table 4.

Table 4.

Demographic breakdown of the sample in Analysis 3

			Grouped by Autism Diagnosis, n (%)		
		Missing	**Overall**	**No**	**Yes**
n			70277	69050	1227
Sex	**Female**	639	33607 (48.3)	33354 (48.8)	253 (20.6)
	Male	-	36031 (51.7)	35062 (51.2)	969 (79.4)
Eligible for Free School Meals	**No**	0	55725 (79.3)	54816 (79.4)	909 (74.1)
	Yes	-	14552 (20.7)	14234 (20.6)	318 (25.9)
Ethnicity	**White British**	-	35901 (54.6)	35129 (54.4)	772 (64.8)
	Pakistani	-	20509 (31.2)	20248 (31.4)	261 (21.9)
	Other	4528	9339 (14.2)	9181 (14.2)	158 (13.3)

Variables

Autism Diagnosis

A list of relevant SNOMED-CT codes were created to identify individuals with autism spectrum diagnoses within the Primary Care data. Autism spectrum was coded in SNOMED-CT as “Pervasive Developmental Disorder, SCTID: 35919005” (“autism spectrum disorders” are listed as a secondary preferred term under this code). There were found to be 49 descendant conditions of this code which were also used to indicate autism spectrum diagnosis. Only children with relevant SNOMED-CT codes were included in subsequent analyses. An "age at diagnosis" variable was also created reflecting the date the first autism spectrum diagnosis code appears in an individual's records.

Ethnicity

Data in the previous two analyses revealed that the majority of individuals from the "Asian" and "White" sample reflected Pakistani and White British populations specifically. Therefore, as this also aligns with the general bi-ethnic population of the Bradford district, it was deemed more representative to focus the following analyses on these more specific populations.

Early Years Foundation Stage Profile (EYFSP)

The EYFSP is a statutory assessment conducted in the final term of the year in which a child reaches age five and is used to support the transition into the national curriculum Key Stage 1. The EYFSP summarises and describes children's learning and development in accordance with seven areas of learning, subdivided into 17 early learning goals across seven domains (see Figure 4).

Scoring is based on an observational assessment conducted by teaching practitioners and guided by a framework set out by the UK Department for Education. Accordingly, each of the 17 Early Learning Goals scored either "2" (meeting the level of development expected), "3" (exceeding this level), or "1" (not yet reaching this level - i.e., the skill is emerging). Both total (summed) scores and sub-score were calculated for each individual. The sub-score included only five early learning goals which reflected the four key symptom areas defined by the World Health Organisation's 1992 research diagnostic criteria for autism: (i) social reciprocity, (ii) language and communication, (iii) imagination delays, and (iv) repetitive and stereotyped patterns of behaviour (see Wright et al., for more information). Consistent with the methodology of the Wright et al (2019) paper, the EYFSP scores were then dichotomised for the purposes of analysis. Children who received a total score of <25 and a sub-score of <8 were categorised as having a "low" score. Those who had scores above this threshold were said to have "not low" scores.

Figure 4.

A description of how Early Learning Goals map onto Areas of Learning of the EYFSP

Area of learning	Early Learning Goals
Communication and language development	• Listening and attention • Understanding • Speaking
Physical development	• Moving and handling • Health and self-care
Personal, social, and emotional development	• Self-confidence and self-awareness • Managing feelings and behaviour • Making relationships
Literacy	• Reading • Writing
Mathematics	• Numbers • Shape, space, and measures
Understanding of the world	• People and communities • The world • Technology
Expressive arts and design	• Exploring and using media and materials • Being imaginative

Figure 5.

A description of how the four key symptom areas of the WHO map onto the Early Learning Goals of the EYFSP

Symptom Areas	Early Learning Goal
Social reciprocity	• Communication and language: listening and attention
Language and communication	• Personal, social, and emotional: managing feelings and behaviour. • Personal, social, and emotional: making relationships
Imagination	• Expressive arts and design: being imaginative
Repetitive and stereotyped behaviour	• Physical development: health and self-care

Statistical Analysis

Univariate and multivariable logistic regression models were conducted to understand the association between EYFSP scores and autism diagnosis. All analyses were conducted using the statsmodel package (Version 0.13.5; Seabold and Perktold (2010)) in Python. Independent models were conducted for both the EYFPS total score and sub-score and reported separately. In addition to EYFSP total score/sub-score, the following variables were included in the model as covariates: sex (male/female); receipt of free school meals (yes/no); ethnicity (White British/Pakistani/Other ethnic group); and age of child at extract. Lastly, an interaction term was included in the model to disentangle the combined effect of sex and EYFSP score on autism diagnosis. In the multivariable logistic regression model, females, with a "not low" EYFSP score/sub-score, who were not in receipt of free school meals, of White British ethnicity and under ten years old were employed as the reference group.

Results

Findings demonstrated that 1.75% (1227) of the 70277 individuals in the matched cohort had a diagnosis of autism. Of the children with autism diagnoses, 64.1% (786) had a "low" EYFSP total score and 68.5% (841) had a "low" 5-item sub-score, compared with 16.5% (11359) and 14.5% (9979) respectively from the individuals without an autism diagnosis (Table 4). The univariate logistic regression suggested that children with low EYFSP total scores and sub-scores had nine- and 12-times increased odds, respectively, of being diagnosed as autistic (see Table 5).

The multivariable model demonstrated that children with a low EYFSP sub-score had over 16 times increased odds of being diagnosed as autistic than those who did not receive a low score (see Table 5). In addition, males had more than three times increased odds of being diagnosed autistic compared to baseline, while children of Pakistani heritage had approximately two times decreased odds and individuals of "Other" ethnicity had nearly two times decreased odds. Free school meal status and age (excluding age 11, which given the effect size and confidence intervals is likely a statistical anomaly) were not significant predictors of an autism diagnosis. Lastly, the interaction between sex and EYFSP score was significant for both the Total score and the sub-score; compared to the reference group, males with low EYFSP sub-scores had approximately 36 times increased odds of being diagnosed with autism.

Table 5.

*Odds ratios and 95% Confidence Intervals from logistic regression models. Total effects of EYFS scores are reported in the univariate models. Effects when controlling for covariates are reported in Multivariable models. *Interaction effect odds are calculated using a combination of the individual "male", "low score" and "male & low score" coefficients. OR = Odds ratio; CI= Confidence Intervals*

		EYFSP Total Score		EYFSP 5-item sub-score	
		OR	**95% CI**	**OR**	**95% CI**
Univariate EYFSP Score:					
EYFSP Score	**Not Low (reference)**	-	- -	-	- -
	Low	9.12	(8.08 – 10.29)	12.94	(11.42 - 14.66)
Multivariable EYFSP Score and co-variates:					
EYFSP Score	**Not Low (reference)**	-	- -	-	- -
	Low	11.09	(8.55 - 14.37)	16.50	(12.67 - 21.49)
Sex	**Female (reference)**	-	- -	-	- -
	Male	3.45	(2.75 - 4.32)	3.31	(2.61 - 4.20)
Interaction * – Male and Low Score	**No (reference)**	-	- -	-	- -
	Yes	27.64	(12.71 - 60.09)	36.34	(16.33 – 80.88)
Eligible for free school meals	**No**	-	-	-	-
	Yes	0.94	(0.82 – 1.08)	0.90	(0.78 – 1.03)
Ethnicity	**White British (reference)**	-	-	-	-
	Pakistani	0.47	(0.40 – 0.54)	0.47	(0.41 – 0.55)
	Other	0.62	(0.52 – 0.74)	0.61	(0.51 – 0.73)
Age	**<10 (reference)**	-	-	-	-
	10	0.86	(0.69 – 1.07)	0.84	(0.71 – 1.10)
	11	1.25	(1.03 – 1.53)	1.26	(1.04 – 1.54)
	12	1.15	(0.95 – 1.40)	1.17	(0.96 – 1.42)
	13	1.13	(0.93 – 1.37)	1.10	(0.91 – 1.34)
	>13	0.98	(0.81 – 1.18)	0.95	(0.79 – 1.14)

3.4 Discussion

Age and Likelihood of autism diagnosis

The prevalence of autism in the Connected Bradford cohort (≤18 years of age) is largely consistent with current national estimates of 1% (Fombonne et al., 2021) demonstrating the ecological validity of this population-based study. Within the autism cohort, 77.3% were male and 22.6% were female, which suggests that there are fewer girls with an autism diagnosis in the Connected Bradford cohort compared to national estimates of 3:1 (Loomes et al., 2017). This could indicate that there are large numbers of autistic girls in the district who have not been identified, which is consistent with research that suggests girls are more likely to be diagnosed later (or not at all) compared to boys (Zener, 2019).

Analysis of likelihood of diagnosis across demographic groups revealed that boys were most likely to have an autism diagnosis (78% males in autism cohort compared to 51% in the non-clinical sample) and boys had three times increased odds of being diagnosed autistic compared to the baseline reference group (girl from an Asian background). For those girls in the cohort with an autism diagnosis, these findings indicate that they are diagnosed later than boys on average. There were also differences in the likelihood of diagnosis based on ethnicity; overall, White British children were most likely to receive an autism diagnosis (59% of the clinical sample compared to 47% of the non-clinical sample) and had almost three times increased odds in receiving a diagnosis compared to the baseline reference group. Children from "Other" ethnicities also had increased odds of diagnosis compared to the baseline reference group.

Turning to the interaction of sex and ethnicity, girls were identified later than boys in the White British and Other ethnicity groups; however, among children from Asian backgrounds, girls were diagnosed younger than boys. Furthermore, comparing the average age of autism diagnosis across sexes and ethnic groups, girls from Asian backgrounds appear to be identified earlier than any other groups. Taken at surface level, these findings could suggest that there are no inequalities in access to autism diagnosis for Asian girls. However, this seems unlikely within the context of the wider findings around ethnicity-based inequalities in autism diagnosis and support (Tromans et al., 2020). It is more likely that that girls from an Asian background with greater difficulties (e.g., those with a co-occurring intellectual disability) are diagnosed at an early age, but those without an intellectual disability are even less likely to be identified later in childhood and more likely to be missed completely compared to their White counterparts. The relatively younger average age of diagnosis likely reflects the lack of identification of autistic girls from Asian backgrounds in late childhood and beyond. These findings suggest that ethnicity-based inequalities in autism diagnosis and support are further exacerbated for girls.

These findings are indicative of the well-documented issue autistic girls having their needs identified later than boys. Potential mechanisms underlying this delay include limited systemic awareness of the female autism phenotype (Allely, 2019; Song et al., 2021), identification and assessment tools which are biased towards a male presentation of autism, and the phenomena of masking, whereby girls are more adept at consciously and unconsciously developing coping strategies, such as imitating peers, to hide their difficulties (Halsall et al., 2021; Tubio-Fungueirino et al., 2020). There is evidence to suggest that autistic girls who are not identified, and therefore do not receive appropriate support, are more likely to have poorer educational outcomes and are at increased risk of internalised symptoms and mental health difficulties, including anxiety and depression and suicidality (Cassidy et al., 2014; Hirvikoski et al., 2020). It is therefore imperative that we move toward understanding these inequalities to ensure that autistic girls are identified earlier and receive the support they need.

EYFSP

This EYFSP analysis aimed to up-scale the study by Wright et al. (2019) to investigate the relationship between EYFSP score and autism diagnosis. The results of this study support the findings of Wright et al. (2019); children below cut-off EYFSP scores were 16 times more likely to receive an autism diagnosis than children who scored above cut-off. This is particularly the case for boys; there was a significant relationship between below cut-off EYFSP scores and autism diagnosis for boys (36 times more likely to have an autism diagnosis), suggesting that the EYFSP could function as an early indicator of autism in their first year of education. However, the strength of this relationship was more than halved for girls with a below cut-off score (16 times more likely to have an autism diagnosis), therefore while the EYFSP may detect potential autism for some girls, it may not be as reliable an early indicator of autism. This finding is not surprising as it sits within the larger problem of identification and assessment for autistic girls. It may be that features of autism within the context of the ‘Female Autism Phenotype’ do not lie within the domains assessed in the EYFSP. It may also be that the needs of autistic girls are not being captured as part of the EYFSP assessment, potentially due to ‘masking’ of difficulties (Cook et al., 2017) and assessment tools being geared toward identifying the ‘male presentation’ of autism (Lai et al., 2015; Strang et al., 2020). It is also important to note that EYFSP assessments are teacher-reported, and the limitations in terms of systemic understanding and highlighting the needs of unidentified autistic girls is well documented (Tomlinson et al., 2019; Watson, 2014). It is possible that the EYFSP captures the needs of autistic girls who present with symptoms that are consistent with the ‘male presentation’ and the needs of girls who have co-occurring difficulties such as an intellectual disability, which are more readily detected through the domains in the EYFSP assessment. However, there are gaps in our understanding in terms of identifying girls who do not present with co-occurring difficulties (Lockwood Estrin et al., 2020), who present with the ‘female autism phenotype’ (Hull et al., 2020) and who may ‘mask’ their difficulties (Zener, 2019).

Summary

These analyses have established the presence of sex-based inequalities in autism diagnosis across the Bradford district. Now, these data driven insights will be combined with the lived experiences of stakeholders across the district, in order to develop a holistic understanding of how and why these inequalities are enacted and to generate solutions to meet the needs earlier of autistic girls earlier.

Chapter 4: The lived experience of stakeholders

The previous chapter focused on the analysis of the Connected Braford datasets, which revealed sex-based disparities in age of autism diagnosis, likelihood of autism diagnosis and the efficacy of the EYFSP as an early indicator of autism. These findings suggest that autistic girls are at increased risk of delayed or missed diagnosis compared to boys across the Bradford district; however, these results alone do not go far in understanding why this is and what the barriers are to accessing diagnosis and support. In order to better understand how these inequalities are enacted, the CLEVER framework (outlined in Chapter 2.2) was utilised to combine the data-driven insights with the lived experiences of stakeholders across the Bradford district. This chapter will focus on the lived experiences of stakeholders through interviews with autistic girls and women and focus groups with parents of autistic girls.

4.1 Recruitment

Participants for interviews and focus groups were recruited through Airedale and Wharfedale Autism Resource (AWARE, 2023) - a parent-run group that supports families of autistic children across the Bradford district. A recruitment poster was developed and disseminated via AWARE social media forums, with contact details to express interest in taking part (Appendix A).

Participants and Inclusion Criteria

Autistic girls and women (≤16 years of age) with experience of delayed diagnosis were recruited to take part in semi-structured interviews. This study was particularly interested in the experiences of autistic girls/women without an intellectual disability, as this is the group at higher risk of delayed or missed diagnosis.

Parents of autistic girls (of any age) who had experience of navigating services and seeking support for their daughter were recruited to take part in focus groups. Parents who were currently in the process of seeking an assessment for their daughter were also included in this study, in acknowledgement that there will be many autistic girls in the system who have not yet been identified. Inclusion criteria can be found in Table 6.

Table 6.

Inclusion criteria for interviews and focus groups

	Inclusion Criteria
Interviews	• Girls and Women, ≥16 years old • Willing and able to discuss experiences of delayed diagnosis • Living in the Bradford district
Focus Groups	• Parent of an autistic girl • Experience of seeking assessment/support for their daughter • Living in the Bradford district

Informed Consent

Participants who expressed interest in taking part were provided with a Participant Information Sheet (PIS) (Appendix B and C) and encouraged to contact the researcher with any queries. Upon confirmation that they had read and understood the PIS, participants who were interested in taking part in the study were provided with a link to an online informed consent form (Appendix D and E). Participants completed the informed consent process independently but were encouraged to contact the researcher with queries at any stage.

4.2 Methods

Materials

A semi-structured interview schedule was developed (Appendix F); questions were guided by the current literature, the study aims, and discussion in supervision. A participant version of the interview schedule was also developed, including the questions but not the interviewer prompts (Appendix G).

A semi-structured focus group discussion schedule was developed (Appendix H); as above, discussion points were guided by the literature, study aims, and discussion in supervision. Focus group guidelines were developed to support access to the online session and to outline behavioural guidelines (Appendix I).

Procedure

Interviews with autistic girls/women

Once participants had completed informed consent, they were contacted by the researcher to arrange a convenient date and time for the interview and were emailed with a link to join the meeting. Interviews were conducted via video call on Microsoft Teams and lasted no longer than 60 minutes. All interviews were recorded for the purpose of transcription using Microsoft Teams functionality. Participants had provided informed consent for sessions to be recorded and this was confirmed in the session before recordings were started.

Reasonable adjustments

In line with current recommendations (Doherty et al., 2021) the following reasonable adjustments were made to support access to the interviews:

1. All participants were provided with the interview schedule no less than 48 hours prior to the interview, in order to reduce uncertainty and allow time to prepare their thoughts in responses to questions. Participants were given the opportunity to ‘opt out’ of any questions they did not want to be asked by emailing the researcher ahead of the interview; however, none of the participants opted out of questions.
2. All participants were provided with a photograph of the researcher and were offered the opportunity to meet ahead of the interview in order to minimise anxiety caused by uncertainty; however, none of the participants opted to meet before the interview.
3. Interviews were conducted on a 1:1 basis with the researcher, although participants could choose to attend with a trusted person for support if preferred; two participants opted to have their parent in the room with them at the time of the interview.
4. Interviews were conducted via video call; however, participants could choose to turn their camera off and/or ask the researcher to turn off theirs if preferred. All

participants preferred the researcher to have their camera on, and two participants opted to have their own camera off.

5. Participants were made aware that the interview could be paused for breaks if needed/preferred.

Focus Group with parents of autistic girls

Once participants had completed informed consent, they were contacted by the researcher to arrange a convenient date and time for the focus group. This was arranged through a link to an online poll where participants could indicate their availability. Once a mutually convenient date and time was agreed, participants were emailed a link to join the meeting, which was held via video call on Microsoft Teams. It was originally thought that one focus group would be sufficient to cover all topics of discussion; however, it was agreed with the participants that a second session was needed to ensure appropriate time was given to all topics. The focus group was therefore held over two 90-minute sessions with the same participants. Both focus groups were recorded for the purpose of transcription using Microsoft Team functionality. Participants had provided informed consent for sessions to be recorded and this was confirmed with all participants in the session before recordings were started.

Compensation

All participants received one £25 Love2Shop e-voucher per interview/focus group attended, in compensation for their time and contributions to the research.

Transcribing

Recordings from interviews and focus group sessions were manually transcribed by the researcher, resulting in seven interview transcripts and two focus group transcripts for analysis. All transcripts were anonymised, and participants were allocated pseudonyms to protect their confidentiality.

4.3 Analysis

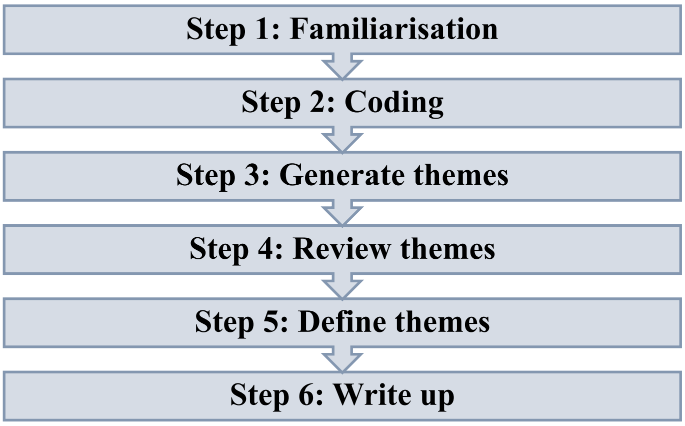
Thematic Analysis

Thematic Analysis (TA) was used to analyse the data from interviews and focus groups, as this has been found to be a systematic method of qualitative analysis that is conducive to understanding shared experiences and making meaning across a group of participants (Braun & Clarke, 2006). In line with the *Critical Realist* stance of this study (Lawani, 2020), the approach to TA included a combination of inductive and deductive processes (Proudfoot, 2022); the analysis was fundamentally exploratory and themes were determined by the raw data from participants. However, the study was designed to elicit insights into documented structural inequalities and therefore the data was also analysed with broad preconceived parameters in mind, such as barriers to accessing support.

Analysis was carried out using NVivo (version 1.6.1) for qualitative data analysis. Two separate analyses were carried out; data from interviews and focus group transcripts were analysed separately using the six steps of TA as shown in Figure 6.

Figure 6.

The six steps of Thematic Analysis (Braun & Clarke, 2006)



Positionality

It is important to consider factors which may have influenced the collection and analysis of qualitative data in order to minimise the impact of potential bias (Cruz, 2015). The researcher is a white woman from a working-class background, educated to post-graduate level, and so there are several intersectional factors that may have impacted the process of data analysis. Through access to education and a position of White Privilege (Ahsan, 2020; Ong, 2021), the researcher had benefited from social mobility and held a position of relative privilege with respect to socio-economic status and ethnicity. The researcher also had prior experience of working in a second opinion autism assessment service, where children were referred when families were challenging the outcome of their child's autism assessment with local services. As such, the researcher was witness to the damaging effects of under-funding and lack of resource on autism services. While the researcher was an 'outsider' as a health professional in relation to the group of participants (Chavez, 2008), the frustrations shared by participants in this study echoed those from the researcher's clinical experience and there was an emotional pull to align with these views. The semi-structured interview/focus group format meant that there was a risk of this influencing the direction of discussions through follow-up questions; it was therefore important to take a stance of relative neutrality and curiosity as a facilitator, through active reflection and self-awareness. A similar process was taken to minimise bias in the analysis of data analysis, and a second coder was also employed to support reliability checking.

Reliability Checking

Intercoder reliability (IR), i.e. an agreement between different coders as to how the data should be coded, is argued to promote dialogue between coders in qualitative research, which is conducive to reflexivity and transparency in the coding process (O'Connor & Joffe, 2020). In this study, IR was established by employing an experienced qualitative researcher within the Connected Bradford research team to act as a second coder in the analysis. Steps 1 to 3 of TA (*Familiarisation, Coding* and *Generating Themes*) were completed independently by the researcher and the second coder in parallel, before a meeting to discuss and calibrate initial findings.

Steps 4, 5 and 6 (*Review* and *Define Themes,* and *Write Up*) were then completed independently by the researcher.

4.4 Results

Interviews with autistic girls and women

Participants

Seven autistic girls and women expressed interest in taking part in the study, and all seven went on to complete informed consent and participate in interviews. Demographic information of interview participants can be found in Table 7.

Table 7.

Demographic breakdown of autistic girls and women who were interviewed

Participant Pseudonym	Ethnicity	Age at interview	Age at autism diagnosis	Self-reported co-occurring conditions
Anna	White British	23	8	DCD; Dyscalculia
Beth	White British	16	15	SPD; ADHD; Anxiety
Claire	White British	47	47	Depression; Anxiety; OCD
Debbie	White British	52	46	Dyslexia; Depression
Ellie	White British	23	16	Anxiety
Fran	White British	21	11	Anxiety; SPD
Georgia	White British	16	15	Anxiety

Interview themes and sub-themes

Thematic analysis of interview data generated an initial 80 codes, resulting in a final five themes and 17 sub-themes as shown in Table 8. Each of these will be discussed in turn below with example quotations to illustrate themes and subthemes.

Table 8.

Themes and Sub-themes from interviews with autistic girls and women

Interview Themes	Subthemes
1. Early experiences (pre-diagnosis)	a. Co-occurring conditions identified first
	b. Disparity between academic/social abilities
	c. The evolution of masking
2. Barriers to diagnosis and support	a. Limited professional knowledge
	b. Rigid pathways
	c. Missed opportunities
3. Experience of autism assessment	a. Fragmented routes to assessment
	b. Inappropriate assessment process/tools
	c. Reactions to diagnosis
4. Impact of delayed diagnosis	a. Mislabelling
	b. Unmet potential
	c. Mental health difficulties
	d. Difficulty adjusting to late diagnosis
5. What needs to change	a. Co-produced training for professionals
	b. Break the stigma
	c. Review autism assessment process
	d. Needs-led support, before diagnosis

Theme 1: Early experiences (pre-diagnosis)

The first theme to emerge from the interview data was that of early experiences, and within this three sub-themes emerged:

Sub-theme 1a: Co-occurring conditions identified first

All participants described features of co-occurring conditions from a young age. These ranged from specific learning needs such as 'Dyslexia' and 'Dyscalculia', to difficulties with functional motor skills. The most prevalent condition identified was anxiety, with participants describing difficulties with social anxiety:

> "I couldn't understand social cues at all… and I think that made me overly aware of how I was, like socially… I used to, like, get really upset if I had to leave the house, like I thought people would judge me just like for being there" (Beth)

and difficulties with change "I was very apprehensive; I didn't like going to new places" (Ellie). The second most common condition identified was sensory processing difficulties, with the most common experiences being over- sensitivity to sound:

> "Every Wednesday they'd put the fire alarm on and I used to dread it. I wouldn't be able to focus on anything. I wouldn't be able to do schoolwork until that went on…. I remember when I was a little it was, like, painful and I couldn't deal with it at all" (Beth)

and over-sensitivity to touch: "I can't, like, wear certain textured clothes or clothing, I have to wear soft clothes, if they're the wrong texture, then I won't wear them" (Fran). All conditions were identified as primary diagnoses, rather than secondary to autism, and participants described this as a barrier to identifying autism earlier: "It was just, like, that didn't explain everything, but it explained enough for people to just be like, well, that's just what it is then" (Georgia).

Sub-theme 1b: Disparity between academic and social abilities

The second sub-theme that emerged was that of disparities between academic and social abilities at school. Participants described academic success: "I always loved learning and I was top of the class in primary and secondary" (Claire); "it was just my norm to put so much effort it and come out with good grades" (Ellie), and that this was a barrier to education professionals seeing difficulties in other areas:

> "I was holding up to the standards they had… it was never a concern to them to look into maybe the weird things that I did do, because the only thing they were looking at was if I could get the grades" (Georgia).

The most common difficulties described, but not detected by school staff, were struggling with group-based tasks: "I struggled to work in groups… I'd always get really angry and frustrated with people" (Beth) and spending breaktimes alone: "I found that I was on my own rather a lot. I struggled to create friendships and I spent most of my time walking around the playground by myself" (Fran). Participants described the effort of managing the school day: "school was the hardest part about having autism, because you don't fit into the social demographic…so I had to pretend" (Fran) and the difference in their presentation between home and school: "the person I was at school and the person I was automatically at home were two completely different people" (Ellie).

Sub-theme 1c: The evolution of masking

The third sub-theme to emerge was that of Masking. Participants described a dawning awareness of being different: "I became aware of being a little bit different around the age of seven or eight" (Debbie); "my mum said that I would say 'I know I'm different from the other children'" (Anna), which ultimately led to motivation to try to fit in with peers: "for people to like you, you have to be kind of outwardly chatty and happy and everything, and it's just the opposite of what I felt. So, I guess really… that's when I, you know, the masking started" (Claire). Some participants explained that they didn't mask when they were younger, but that the process began with age and awareness:

> "I was running around the playground talking to myself, you know, that's kind of standing out, standing out from the crowd, so I think in primary school, no [I didn't mask] … once I had the diagnosis, that's when I did it… I wanted to hide it from people" (Anna).

Others described a transition from consciously masking when younger:

> "I'd spend the majority of the time watching people and kind of seeing how they were reacting to the teacher, what they were doing at their desk and things like that. So I'd spend about 90% of my time actually observing everyone else" (Ellie)

to it becoming an unconscious process with age:

> "I would say it did start as a conscious decision…I realized what I needed to be like, you know, in order to make friends and… then it gets to be so normal that you don't even really think about it" (Claire).

Participants commented on the energy it takes to mask their difficulties: "I spent so much time masking…. I was always just very drained, and I was always, like, tired and I didn't wanna be around people" (Georgia) and the consequences of this: "my second year at university, I now realize I had my first significant autistic burnout…I couldn't sustain the hyperactive socialite that I tried to be" (Debbie). Participants also highlighted the role of masking as a barrier to having their needs identified: "I did exactly as I should when I should have done it, I was perfect student. And a bit of an introvert. And that was it. I never put a foot wrong. So I guess, where are the signs?" (Claire)

Theme 2: Barriers to diagnosis and support

The second theme that emerged from the interview data was around barriers to accessing diagnosis and support, and within this were three sub-themes:

Sub-theme 2a: Limited professional knowledge about autism in girls

The first sub-theme was a systemic lack of knowledge and awareness of how autism presents in girls and women: "doctors and, and teachers, and, like, people who do the assessment, professionals, aren't as a clued up on diagnosing women as they are men" (Fran). Participants felt that professionals are influenced by the male-stereotype of autism: "I think they still seem to think of autism as a child, a boy, in a corner, rocking, making funny noises, hitting people, nonverbal" (Claire), and, as a result, some level of need was identified in childhood, but these were not considered through the lens of autism: "the professionals told my mum that there was something, they just didn't know what it was, and it was left at that" (Ellie). One participant described seeking support around difficulties with friendships:

> "I literally had two sessions and they said, 'What do you mean you can't talk to girls and you have to talk to boys? You know, how lucky are you that boys want to talk to you?' And that was it. And so I didn't go back after that. And then it took me years to try again" (Debbie).

Another participant described a lack of professional knowledge leading to a sense of hopelessness in seeking support: "It was just like, no matter how many people I talked to…they just didn't think anything was wrong" (Georgia).

Sub-theme 2b: Rigid service pathways

The second sub-theme related to the rigidity in both health and education systems as a barrier to accessing support. In terms of seeking support through health services, four participants shared that they had not received any input from CAMHS, despite experiencing significant levels of anxiety throughout their childhood: "I didn't even know about CAMHS until last year [age 22], and that's kind of sad that I hadn't heard about them, 'cause I could've used, erm, some support" (Fran). One participant shared that she did have contact with CAMHS but did not meet criteria for support: "We talked to a CAMHS woman and she didn't think I was bad enough to result in further, like, investigation into what was wrong" (Georgia).

Participants described some of the barriers to accessing *meaningful* support, and one such barrier was the system imposing neurotypical assumptions:

> "When you try and articulate what you think is happening in, in your head or what you're experiencing… because it's so different, they assume that it must fit this particular pattern, that they kind of understand… and often it's nothing to do with it" (Debbie).

Participants also described the impact of working with generic mental health interventions, such as Cognitive Behavioural Therapy: "Thinking of the worst thing that could happen just made me worse… I thought that it was going to happen" (Beth). One participant reflected on the rigidity of how support was delivered as a barrier to accessing support for mental health:

> "She was, like, 'the only other option is I come to your house' and I hated that. Because it's, like, crossing my boundaries… I'm already freaked out. I already don't want to be there. I don't want you to be there either. Whereas if

> I was messaging someone on the phone, I'd be a lot more comfortable." (Georgia)

In terms of seeking support through school, participants described a rigid approach to SEN provision:

> "They had a very…one route… so you go to one quiet room, but then that one quiet room had loads of people who needed that quiet room in, so it kind of defied the point. I know it works for some people, but I think, for me, learning was where I thrived the most at school and I didn't wanna be taken out of that" (Ellie)

and a focus on keeping them in the classroom environment rather than exploring individualised coping strategies:

> "So, I was just, like, sitting in a room with these two scary men and…it was a lot of 'how can we keep you here?' when sometimes all I wanted to do was go home and figure it all out, and then come back in tomorrow" (Georgia)

Sub-theme 2c: Missed opportunities

The third sub-theme to emerge within the barriers to diagnosis and support was Missed Opportunities. Participants described seeking support and raising their concerns with professionals but that those concerns were dismissed:

> "I looked into it [autism] and I was just like, yeah, this is definitely me. So, I went to a GP, and he just made me feel utterly ridiculous for even suggesting it. And I just thought, oh well, that's that then. Never followed it up" (Claire).

One participant described how her GP actively discouraged her from seeking an autism assessment:

> "Her first response was 'well, why on earth do you want to know? You seem to be doing fine' and because I wasn't in crisis, she couldn't understand why I wanted to do this. The second thing she then raised with me was that, was I sure that I want to have this on my medical record, because it would count against me in all sorts of scenarios… so that was her justification for saying 'no, I don't think you should'. And then the third response… was 'I don't think we should do anything about it' and her parting comment was, 'if you go privately, not only will it be quicker, but you are in control of the results –

> we don’t need to know’. She didn’t wink at me, but she might as well have done” (Debbie).

Theme 3: Experience of assessment process

The third theme that emerged was participants’ experience of the autism assessment process, and within this were three sub-themes:

Sub-theme 3a: Fragmented routes to assessment

Participants took various routes to autism assessment, including incidental diagnosis during assessment for other difficulties: “I ended up with an autism diagnosis…. they weren't even looking for autism, but they got it” (Fran), seeking their own diagnosis in order to support their daughter’s assessment: “I kind of thought, well, maybe I'm just a bit trait-y…but there are enough questions here, maybe if I have a diagnosis they will then take us seriously with our daughter” (Debbie), and school referrals for assessment when difficulties began to impact academic performance: “when my grades started dropping… I went to speak to this woman in school and that's when she mentioned, you know, ‘you should probably go look into it [autism] and into getting an assessment done’” (Georgia).

Sub-theme 3b: Inappropriate assessment process/tools

The second sub-theme related to experiences of the assessment process. Some participants, whose assessment took place in late childhood, described that they did not fully understand what was happening at the time: “I was having, kind of, all these tests done, all these activities where they were trying to assess me…I think that at the time I was very confused. I had no idea why. No one communicated that to me” (Ellie), and even with more awareness, participants were not clear on the rationale behind assessment processes: “I just thought some of the things they asked me to do... I was like, ‘why are you asking me this?’” (Georgia). Some participants felt that the assessment tools were not appropriate: “It was clearly aimed at children, really… I just wish it could be made more adult-y. Erm yeah, [reading from] a child's book is just really daft. I felt really stupid” (Claire), and that assessment procedures were not supported by reasonable adjustments:

> "If you're dealing with someone who's possibly autistic, there's gonna be a whole set of things that are going to be made a lot easier if you do this before the first meeting, things like how to get there, where the reception is, what's going to happen, who you talk to, where you park. All that stuff…they didn't put any of that in place" (Debbie)

Sub-theme 3c: Reactions to diagnosis

The third sub-theme was participant reactions to their diagnosis. Participants communicated mixed reactions. Most shared a sense of relief: "It was a relief to have it…it just makes a lot more sense." (Beth) and self-understanding: "…to be given permission to be, to be different and to feel different if, you know, if you can explain to yourself and think 'oh this is why I feel like that'" (Claire). Others identified that the diagnosis helped people around them to understand their difficulties: "People pay attention, now I can say 'I'm autistic' and people do things differently" (Beth), and that this triggered support: "It meant I got more support and people knew the reason behind stuff" (Georgia). One participant shared a sense of uncertainty and although receiving a diagnosis was a positive thing for them, they didn't understand what it meant: "It helped me know who I was, but…I wasn't sure what that meant… to have autism and be autistic" (Anna).

Theme 4: Impact of delayed diagnosis

The fourth theme that emerged from the interview data was around the impact of delayed diagnosis for autistic girls and women. Within this, there were four sub-themes:

Sub-theme 4a: Mislabelling

The first sub-theme was that delayed diagnosis led to the mislabelling of difficulties or behaviours. Some participants found that others described their presentation as shyness in childhood: "people said, 'oh she's just a quiet kid'" (Georgia), whereas others reflected on the accumulation of more negative labels from others: "I was called, for example, a very judgmental child and a very controlling child… they were all words that when you listen to them you can think, you know, you're not a very nice person" (Debbie). With age and increased self-awareness, this led to feeling disliked by others: "I just felt like people didn't really like me because I didn't understand and stuff" (Beth). Delayed autism diagnosis and mislabelling contributed to how participants understood themselves as they matured: "I guess I've always thought that there's something wrong with me, that the other people can cope with things just fine, but I just can't" (Claire), leading to low self-esteem and negative self-evaluation that became entrenched with age: "All this mislabelling going on… absolutely hammers your self-esteem…I feel stupid all the time" (Debbie).

Mislabelling of difficulties also led to inappropriate and ineffective interventions. One participants described how raising social interaction difficulties with her GP led to an inappropriate referral for marriage counselling:

> "My GP sent me to a Relate counsellor, even though there wasn't anything wrong with our marriage…she kept saying to me, erm, 'well, you know if you want to relate to your husband a bit better, you need to cuddle him more, you need to touch him more' and I was like, 'our relationship is fine, I'm not here for this!' Yeah. I didn't go back because she wasn't listening to me at all." (Debbie)

Another participant described how her experiences were mis-labelled as primary mental health difficulties, and she was prescribed medication with harmful effects:

> "I've been on anxiety medication and depression medication, and if somebody had probed a bit further into that instead of just being desperate to hand me a prescription for drugs that didn't do me any good… it has really angered me…the last lot of antidepressants I was on, the withdrawal was just awful, and it took over a year" (Claire)

Sub-theme 4b: Unmet potential

The second sub-theme was the impact of delayed diagnosis and subsequent lack of support on participants ability to reach their full potential. The participants in this study reflected age of diagnosis from 8 years old to 47 years old, and so findings depict the impact of lack of support from childhood and education through to adulthood and employment. Participants reflected on the deterioration in their academic performance in secondary school: "In year 7 and 8 and stuff it was 'foundation, secure, and mastery'. Back then I'd get 'mastery', which is above average, but now [year 11] I'm getting like average or like below average" (Beth) and the longstanding impact of this into adulthood: “I was really bright at school… and yet here I am in a in a basic admin job, but it's because I just I can't take on anymore. So, you know, I feel like I've massively underachieved” (Claire).

Another area within unmet potential was the impact of changing expectations as they navigated different stages of life:

> “Each of the major changes have been hugely difficult because I've, I've been ticking along, having developed a little mask that's worked, and then suddenly I would realize that what was working before isn't working now, and I don't know how to be what's expected…what I should be doing, not doing, saying, not saying” (Debbie).

One participant (Claire) reflected on the consequences of not knowing she was autistic as she made career choices:

> “I started teaching… kind of knowing that it wasn't really my thing, that I find it really tough… but I just thought, I'm sure a few months in, if I'm doing this every day…I will just get used to it. It will become the norm and it will be easy. And it didn't. After year it was still just as hard… panic attacks practically every day”

approached motherhood:

> “I found becoming a mum really, really tough…all the kind of sensory things about having a baby…the noise of the crying was just like alarm bells going off in my head. It was utterly horrendous, and it set off a really physical reaction in me of absolute panic”

and she wondered how these experiences might have been different if she had known she was autistic and had received appropriate support: “You know, massive life decisions that you think… looking back, nothing ever got easier, you know, which is probably why I'm in such a state of anxiety and everything now… I would have been easier on myself”.

Sub-theme 4c: Mental health difficulties

The third sub-theme in relation to the impact of delayed diagnosis, was experiences of subsequent mental health difficulties. The most common difficulty experienced was anxiety: “I’m just constantly anxious” (Claire). Participants also shared experiences of low mood related to high expectations of self: “I was really upset with myself that I kept getting really low grades” (Beth), depression: “I struggled really badly with anxiety and depression from eleven years old” (Ellie), low self-esteem: “so the upshot…is quite a lot of low self-esteem… low confidence” (Debbie), and suicidality: “on and off antidepressants, suicidal, a suicide attempt when I was kind of early 20s, erm, really low self-esteem” (Claire). Participants described persistent mental health difficulties that were entrenched in adulthood but started from a very young age: “I was so young so I can’t remember what I was feeling, but I know I was crying a lot. I’d wake up in the morning and I’d just cry” (Anna) and triggers included difficulties with social interaction:

> “If you don't have friends, you know, you’re not a very valuable sort of person. So it really kind of affected my self-worth. I've struggled with depression and anxiety and first signs of OCD…so, you know, it kind of started preteens, really” (Claire)

and anxiety related to sensory processing difficulties: “…it was the not knowing when it was gonna happen that really stressed me out” (Beth). Participants also commented on the impact of internalised mental health difficulties: “It is very isolating, and you just kind of live inside your own head really” (Claire).

Sub-theme 4d: Difficulty adjusting to late diagnosis.

The fourth sub-theme related to difficulty adjusting to a later diagnosis of autism. One participant, who received her diagnosis at the age of 47, described an initial euphoria followed by an ‘identity crisis’:

> “I was euphoric and kind of going ‘this makes so much sense! I’m so happy!’ and that lasted for weeks, until it didn’t, and then the wheels came off big time for nearly four years…with hindsight I would say it was a full-on identity crisis” (Debbie).

Others described the feelings of shame and embarrassment that came with a later diagnosis: “I thought I'm either gonna be really stupid or really weird… so I was, for a few weeks, quite self-conscious about it” (Ellie) which may have been ameliorated by an having an earlier diagnosis: “I guess I would have also properly come to terms with it and not be, not felt, ashamed of it or embarrassed by it, if it's something that you grow up with” (Claire).

Theme 5: What needs to change

The fifth and final theme from the interview data was participants' views on what needs to change in order to identify and support autistic girls earlier, and within this there were four sub-themes:

Sub-theme 5a: Co-produced training for professionals

The first sub-theme related to the need for professionals training in autism in girls and women. Participants felt that training was a priority for all professionals including education staff: "I think schools need a lot more training on autism in girls. I think when you get autism training, it's mainly looking at, kind of, how boys portray it, and girls can be completely different to that" (Ellie), GPs: "I wish there was an education programme for GPs to go through…especially for, you know, how autism presents in girls and women" (Claire), and CAMHS: "all professionals who are responsible for being gatekeepers… they are the people who need the training being delivered by autistic people" (Debbie). Participants felt that training should be co-produced and delivered by autistic girls and women:

> "Having someone that's been through what it's actually like, instead of just having someone who hypothetically knows what it should be like, 'cause it just feels a lot more real coming from someone who can tell you about what they've had problems with, who can tell you about how it could have been seen sooner" (Georgia)

and that training should be extensive as "an afternoon's training is not enough!" (Debbie). Participants felt that training should include how autism can present in girls and women, and a recognition that delayed identification is a system failure, rather than a feature of autism in girls and women: "I think the onus really needs to be shifted. Yes, girls have been diagnosed later, because of failings in peoples training and responsibility, not 'oh well we weren't to pick up on it 'cause it comes out later'" (Beth). Furthermore, participants highlighted that training should include a focus on seeing beyond masking: "You need to ask why they're trying to sit under the radar, and, and to then start unpacking what's going on there" (Debbie) and trying to understand what may be underlying any difficulties: "Why can't anybody put together [anxiety about] noise, difficulties concentrating, struggling with friendships…. [is] everybody really that narrow minded that they can't join all those dots up together?!" (Beth).

Sub-theme 5b: Break the stigma

The second sub-theme relating to what needs to change, was the issue of breaking the stigma around autism for girls and women. Participants reflected on the negative stereotypes surrounding autism and how it is viewed by others:

> "[peer at school] hugged me, like I had, like, cancer or something, and she said, 'I'm so sorry!'. I was like, really? I don't have an incurable life or death disease…. this is autism. I just felt a bit 'urgh' about that" (Fran)

and that how peers view autism in general can impact a girl's motivation to seek diagnosis and support:

> "If someone does something stupid or something unreasonable or whatever, it's 'God, you're so autistic' and it's this assumption that to insult somebody, you tell them they're autistic…they've realised that this thing that they are is just not acceptable" (Debbie).

Participants felt that steps towards breaking the stigma would include representation:

> "I wish we lived in a world where neurodivergence is seen as a positive thing so that people feel comfortable, kind of, revealing themselves in whatever careers they're in…to kind of fight against the stereotype of what it is to be autistic…I think that would be a game changer really" (Claire),

positive reframing of autistic behaviours:

> "There needs to be a different perspective. I mean, look at all these words and look at where they come from and give them alternative positive words…often it's a behaviour that a neurotypical also has, but they give them the positive word, they're not given the negative word" (Debbie),

and redressing the male stereotypes: "Services and schools just need education, like training, and just really trying to deal with the stereotypes" (Beth).

One participant suggested that breaking the stigma may support parents to overcome potential embarrassment around labels for their daughters:

> "I know that a lot of people are saying 'my daughter is not autistic'… and they don't want to go for the diagnosis. So, help parents to not be embarrassed about the labels. Help them to see that it's part of their [daughter's] identity and they need to know, you know, and the earlier they find out the better" (Anna).

Participants talked about the role of education and acceptance in breaking the stigma around autism and girls, in schools:

> "Especially in secondary school and stuff, doing more, like, bringing it into the curriculum. Because they do a lot about, you know, like, other things, like disabilities and stuff, and how we need to help and how we can all be aware... so I feel like it should be brought more into the curriculum" (Georgia)

and in the wider community: "Something I try and push for is just more awareness in the community…I just feel if the world accommodated us, we wouldn't have to mask… we wouldn't be burnt out" (Ellie).

Sub-theme 5c: Review assessment process

The third sub-theme relating to what needs to change, was reviewing assessment processes. Participants shared a number of recommendations to improve assessment processes and earlier identification of autistic girls. Participants suggested a process of screening for autism in the early years:

> "I think that everyone should have a little bit of an assessment when they're younger, through school, so that it doesn't have to be like a high-level assessment. But, like a small assessment to kind of pick up if there are any issues. And then if they pick up on anything, they can then refer them on to get another assessment, a more detailed one. Just something that could be implemented into the school system from an early age" (Georgia)

and documenting any concerns in a continuous record that follows the girls through education, to support referrals for assessment and support:

> "If anyone picks anything up, they have like a file online and then that gets passed up through the schools and through the years so that if any teacher, no matter how small it is, picks up on something, they make sure it's written

> down. And then, you know, a few years in the future…they can look and kind of put it all together" (Ellie).

Participants also commented upon assessment criteria:

> "I want to see you there be a development in the way that assessments are done so that they're aware of… how girls present. So they're not just to looking at a chart which says symptoms and it's the ones that boys present" (Fran),

and one participant (Debbie) suggested generic criteria that encompasses all presentations of autism, regardless of sex: "Everything should be just the generic…you know, 'they are into *something* to a point of… just an interest that is beyond what you would normally expect'. You know, so genericize everything" and the importance of recognising different presentations between environments as a potential indicator of autism for girls: "when school's turn around and say, 'we're not really seeing that behaviour in school'. Maybe that should be in the warning sign as well". Participants felt that the assessment process should be reviewed for girls and women, with the development of age-appropriate assessment methods:

> "It [should be] more about your feelings rather than just your reaction to whatever stimulus they put in front of you. I'm sure a lot of people don't get diagnosed because they've kind of learned to cover up various things, and they've done it for so many years that it's just part of who they are now. And kind of being able to kind of give concrete examples. Like, you sent me the questions beforehand… I found that really useful because I'm terrible at thinking on the spot. So, something like that… so you can come up with things, because especially if, you know, at my age, you've buried a lot of stuff, you've just forgotten about it. But if you have a few days to think about things, then it, kind of, it comes up" (Claire)

and that post-diagnostic support to understand their diagnosis should be prioritised:

> "I just think that when I was diagnosed, I should have been told about the future, what might happen, how I might feel, you know? And even if I didn't feel those things, it would've been OK, but I feel all my life I should have been more prepared really. Thinking about school, or employment, you know. I should have been prepared" (Anna).

Sub-theme 5d: Needs-led support before diagnosis

The fourth sub-theme relating to future change was a focus on needs-led support regardless of diagnosis. Participants recognised that a lack of diagnosis is a barrier to support: "unless [you've] got a physical diagnosis, schools won't support, which I completely disagree with, because if you're on the waiting list or you're trying to get that diagnosis, you're going years without support" (Ellie) and felt that there should be a move to "giving support regardless, even if they don't have a diagnosis of autism" (Fran).

Participants reflected that effective support prior to diagnosis often came from having teachers who were flexible and supportive:

> "I was quite lucky in the fact that, even without a diagnosis, I had supportive teachers. I could go and say, 'It's a bit noisy out there, I don't really wanna be talking with people. Can I just sit and read in here?'…they'd just hand me the classroom key and go 'come find me when you're done'. So, in that sense, in my school, I, kind of, didn't need a diagnosis" (Ellie)

and people who recognised areas of need without the need for a diagnosis: "I got a mentor…just like a nurture thing… before we got the diagnosis, there was a bit of time where they were treating me as if I had the diagnosis" (Beth). Participants felt that access to flexible support was important, including the option to access 'break out spaces' at school: "a place where neurodivergent individuals could go to kind of get away from the rest of the school and to communicate with other neurodiverse people" (Fran) and support in managing social interaction difficulties: "being on my own in the playground and things, you know, I think a lot more social support would have been nice" (Anna). Participants emphasised that forming connections with people they are comfortable with was a vital part of having their needs identified:

> "She was the one that I liked and so I told her stuff, and I was, like, 'this is what this is what's going on. This is how I feel. These are problems I'm having'. And she was like, 'look into it [autism]. I'll find you solutions in school' (Georgia).

Participant also highlighted the importance of speaking to the girls themselves: "I think services need to try and engage with the children as well, rather than just completely ignoring them and going to the parents" (Ellie) from a position of curiosity and kindness: "sometimes, unless somebody kind of teases it out, you don't really know that it's there…so, you know, a friendly, non-judgmental ear" (Claire).

Focus Group with parents of autistic girls

Participants

Eleven parents of autistic girls expressed interest in taking part. Of these, eight went on to complete informed consent and five participated in the focus group. Demographic information of focus group participants can be found in Table 9.

Table 9.

Demographic breakdown of parent focus group

Parent Pseudonym	Ethnicity	Sex	Age	Daughter's age at autism diagnosis
Helen	White British	Female	47	16 – awaiting assessment
Iris	White British	Female	56	8
Julie	White British	Female	63	15
Kate	White British	Female	43	9
Louise	White British	Female	44	18

Focus Group themes and sub-themes

Thematic analysis of focus group data generated 62 codes, resulting in a final six themes and 17 sub-themes, as shown in Table 10. Each will be discussed in turn below with example quotations to illustrate themes and sub-themes.

Table 10.

Themes and sub-themes from focus group with parents of autistic girls

Focus Group Themes	**Subthemes**
1. Autism was missed	a. It was just who she was! b. Co-occurring conditions identified first
2. Barriers to school support	a. Inconsistent/inexperienced education staff b. Parental concerns dismissed c. Rigid approach to SEN support
3. Barriers to CAMHS	a. Fragmented, inflexible pathways b. Limited professional knowledge c. Impact of service pressures
4. Routes to support	a. Finding 'Golden People' b. Being the 'Angry Parent' c. Seeking private support
5. Impact on parent well-being	a. Feeling blamed by the system b. Emotional distress and desperation
6. What needs to change	a. Co-produced training for professionals b. Parent voice should be heard and believed c. Needs-led support, before diagnosis d. Review autism services

Theme 1: Autism was missed

Parents discussed the reasons why autism was initially missed in their daughters, and within this there were two sub-themes:

Sub-theme 1a: It was just who she was!

The first sub-theme relates to parents noticing traits or behaviours in their daughter at a young age and not necessarily associating these with autism: "I mean, autism just was not on my radar… [there were] lots of, sort of, little peccadillos that really, sort of, made our lives quite difficult, but they just felt like they were her peccadillos" (Iris) but viewing them as part of her personality: "…enormous tantrums that seemed above and beyond what was the normal toddler tantrum. But we just said 'exuberant personality. She knows her own mind'" (Helen). Parents discussed how their daughters did not display 'classic indicators' of autism: "She walked very early. She talked very early. Her sleep has always been disordered, but it was just, you know, you just need to get on the Gina Ford" (Kate) which meant that other explanations were used to explain their presentation. Where concerns had been raised, these had been discounted by professionals: "We went to see a Paediatrician when she was two, but they said they didn't think she was autistic because…of eye contact and, you know, being able to play with the nurse and stuff" (Julie). One parent shared that it was only when co-occurring anxiety began to impact their daughter that they began to question whether there was something else underlying the traits they had noticed earlier on: "It was because of the social anxiety. I suppose that was how it became an issue for her with the traits. Up until then we could say it's just her personality" (Helen).

Sub-theme 1b: Co-occurring difficulties identified first

All parents discussed that their daughters were experiencing difficulties that led to co-occurring conditions being identified as primary diagnoses prior to the identification of autism. Parents discussed the early identification of sleep disorders: "the main the reason we, kind of, ended up down this pathway is she had extraordinarily disordered sleep and, and as a baby she didn't really sleep" (Kate), motor skills difficulties and Developmental Coordination Disorder:

> "Developmentally there were certain things that she wasn't, certain criteria she wasn't meeting and one of those was definitely with her all her motor

> skills. In Year 2 they referred her, not for autism, but to an Ed Psych and OT" (Iris)

sensory processing issues: "she had huge sensory issues, and she would quite often come home with the most horrendous migraine headaches, and she would vomit" (Julie), which for some, led to other diagnoses: "so, initially we were sent to audiology, and they actually diagnosed her with the condition, which is hyperacusis, which is extreme kind of sensitivity to sound" (Kate)

The most common co-occurring condition discussed by parents was anxiety: "She struggled with, erm, transitions. So, like, getting on to train or a bus or going out of the house or coming in the house… that was a real anxiety for her" (Julie), which for some led to self-harming behaviours: "She started internalizing it…she started saying she was stupid, and self-harming started coming into it. So, it really went downhill" (Helen)

Theme 2: Barriers to school support

The second theme to emerge from focus group data was the issue of barriers to school support when their daughters' undiagnosed autism began to impact their mental well-being and school attendance. Within this there were three sub-themes:

Sub-theme 2a: Inconsistent/inexperienced education staff

The first sub-theme relates to the inconsistency and inexperience of education staff in relation to knowledge and ability to support autistic girls. Parents discussed the variation between schools:

> "I see that there are some schools that are amazing, and the SENCOs are amazing, but there are also some schools that are absolutely dreadful. So, we're not having a universal offer. It's a bit of a post code lottery really" (Louise).

Parents raised concerns about the demands of the SENCO role and the level of training required:

> "In Bradford, they don't need SENCO specific training straight away to get the job, as long as they have had it within four years… So, you could have somebody who's been there three and a half years, doesn't have a training,

> leaves, somebody else comes in, doesn't have it for three and a half years and you've never got anybody qualified in there" (Louise).

In addition to the general demands of the SENCO role, parents discussed the specific lack of knowledge and experience with autistic girls: "our former SENCO tried to kind of wade in with her, you know, 'I'm a SENCO, I'm an official' and very quickly, she said 'I've never met an autistic girl before. Your daughter's the first autistic girl I've met" (Kate). A shared experience among some parents was finding staff members who were able to support their daughter but connections being broken internal restructures:

> "There was a year ahead…and she was absolutely brilliant… but then she got moved to [another year group] … It's frustrating because they develop those helpful relationships but then they get broken and so it just feels very fractured and disjointed" (Julie)

Sub-theme 2b: Parental concerns dismissed

The second sub-theme relates to parents attempting to raise concerns and seek support for their daughters but feeling that these concerns were dismissed by education staff. A contributory factor to this (and a shared experience by most parents) was the role masking and the difference in their daughters' presentation at school compared to home:

> "I remember bursting into tears one morning because of just getting her to school. And I said, 'I can't cope anymore with, you know, how this child behaves at home'. And they were like, 'what are you talking about? She's like the model of good behaviour at school'" (Helen).

Parents described the frustration of trying to highlight their daughters' needs but not feeling listened to:

> "I can remember going to school and saying, 'she can't come to school, that these are the reasons why' and they said to me, 'but we're looking in on her and she's smiling'. But we're telling you she's not fine! So why are you not listening?" (Louise)

and feeling blamed: "I felt like that because they thought there wasn't anything wrong, then there wasn't anything wrong. It was me, obviously" (Helen). Parents discussed the challenge of continuing to seek support for their children by educating the system: "I'm struggling with school at the moment…it just feels like such a mammoth, mammoth task to try and, kind of, educate" (Kate). As their daughter's difficulties escalated and it became more difficult for them to access school, parents discussed that, in addition to having their concerns dismissed, they felt pressure and responsibility to ensure continued attendance: "there is that feeling, you know of 'well, she should be in'. You know, it's, it's just really hard" (Julie) which exacerbated feelings of anger and desperation with the lack of support:

> "I was desperate for them to get me in front of the magistrates for a non-attendance because I thought then I'm gonna go into that Magistrates Court with all these files that show every bit of effort that I've made to get help and support over the last three years. And you could get the press there and I will tell them just how badly we've been failed at every single level" (Helen).

Sub-theme 2c: Rigid approach to SEN support

The third sub-theme related to parents' experiences of SEN support following their daughter's autism diagnosis. Parents described a rigid and prescribed approach as a barrier to support for their daughter, particularly in secondary school. One parent shared the response from school when they tried seeking accommodation around their daughter' sensory needs:

> "We explained my daughter sensory needs, the fact that she has her own kind of cobbled version of a school uniform that meets the criteria, but she's comfortable and it means she can access her education. And even though she has an EHCP, there were just like 'no - we just won't do that', you know, 'she'd have to carry her blazer with her even if she didn't wear it. She'd have to have it with her at all times'" (Kate).

Another parent described push-back from the school system when their daughter attempted to return after a period of school-resistance:

> "She's gone in as and when she can manage, now I'm getting this message from school saying, 'it's lovely to see her but she can't just come in when she wants - she has to know that it's the adults that make the decision about attendance'" (Julie).

Another parent described the lack of needs-led collaboration around support: "You come up against the 'that's not how schools operate'… they'd say, 'you know, needs a reduced timetable' and then… *they* told *her* what the timetable was gonna look like" (Helen) and that support became prescribed through the implementation of general SEN policy: "the staff are just following yet another policy of how you deal with an autistic person and forgetting that, just like any other person, that person is just a person and asking them what would work for them" (Louise). Parents discussed how this was echoed in the EHCP process: "…there is, like, this prescribed approach within the EHCP…I just worry that teachers will see it as a document of this is how we deal with your daughter. And that's not always what she's gonna need" (Kate), which becomes counterintuitive to personalised support: "it's like… we've got to make her fit into that, not that the environment needs to change to make her feel better about being there. And it just, yeah, just feels horrible" (Julie).

Theme 3: Barriers to CAMHS support & assessment

The third theme to emerge from the focus group data related to the barriers to seeking support and autism assessments for their daughters through CAMHS, and within this there were three sub-themes:

Sub-theme 3a: Fragmented, inflexible pathways

The first sub-theme within barriers to CAMHS support was the issue of fragmented and inflexible pathways. Parents first discussed the lack of clear and defined pathways to seeking support for their daughters: "it's all so bitty and, and there's no one pathway through it at all" (Helen) and an awareness that the system is disjointed and working in silos:

> "I had a conversation with psychiatrist, I'd had school involved, I'd spoken to social services and had the police involved… I cannot tell you… I've had everybody I could ring at Bradford, and they were saying 'Why isn't this team speaking to you? Why isn't this team pulling this together?'" (Helen).

Parents discussed the challenges of seeking support from CAMHS at the point of referral: "She was so scared and so unhappy. And I was on my knees… so phoned CAMHS, got told no. You know, 'your child's not known to us, you need to speak to school nursing'" (Kate) and that referrals were continually declined on the basis that their daughter did not meet the criteria for support: “I actually remember going to the director, children's director at Bradford District Care Trust, to beg them to see her because she didn't meet the criteria for any kind of support to be referred to them” (Louise). In addition to declined referrals, parents discussed the gatekeeping of relevant parent training and resources until a diagnosis of autism has been made: “You're blocked from accessing services until you get that [diagnosis]… parents are forced down this route” (Louise). Parents discussed a frustration with the reliance on diagnoses to justify any support: “they’re totally fixated on labels; it makes my blood boil” (Louise) and that not having an autism diagnosis led to inappropriate support offers:

> “I asked to go on that Cygnet course with Bradford, and they said, ‘oh, you can't go on it because she's not got a diagnosis’. They sent me on a general parenting course… it was so obvious… these aren't gonna work, we think our children might be autistic… and they said, ‘well, yeah, but we talk about more about that in the Cygnet course’. But it's like, we can't get on the Cygnet course ‘cause we haven't got a diagnosis!” (Julie).

Parents also discussed the uncontained transitions in and out of CAMHS. One parent reflected on their experience of transitioning from Paediatrics with whom they had established a good relationship:

> “The paediatrician obviously got flagged that we were now in the CAMHS system so she contacted me to say, ‘now that you're with CAMHS, I have to pass you over’… and we saw the CAMHS psychiatrist for the melatonin prescribing once only and then we didn't hear anything for months and months and months” (Kate)

and another parent reflected on the “cliff edge” (Helen) as children approach the upper age limit for CAMHS input without a planned transition to others services:

> “I really had to push for five years for CAMHS to do the [autism] assessment for her. And then she got the diagnosis the week before her 18th but she didn't get any support afterwards because she was then 18, so she was just discharged” (Louise).

Sub-theme 3b: Limited professional knowledge

The second sub-theme related to the lack of professional knowledge about autism and girls in CAMHS: “I expected a lot more than what we got, and they didn’t understand autism at all” (Kate). Parents reflected on the difficulties of working with inexperienced practitioners:

> “She was training on the job. She hadn’t had any experience prior to working with my daughter… she started to see my daughter on a weekly basis and she had a written workbook about anxiety… my daughter was getting nothing from it…she was masking her whole way through… and in the end, we kind of came to a mutual agreement with CAMHS that it really wasn’t working for anybody” (Kate)

which led to inappropriate and ineffective interventions without autism being identified: “Eventually, she did get into CAMHS, but they treated her for social anxiety for probably about four years – didn’t help at all. They didn’t pick up she was autistic.” (Louise). One parent reflected on the lasting impact of receiving inappropriate advice and support:

> “With the diagnosis came a clinician and she kept us on for a while but actually that’s the worst thing that ever happened to us because we got completely the wrong advice. The advice she gave us is that you have to be persistent, insistent, and consistent. We stuck with that for quite a few years, and my daughter still remembers it now as the worst time of her life” (Iris).

For another parent, lack of knowledge led to their daughter’s self-harm and suicidal thoughts being dismissed: “This was over the phone… I didn't even get a word in edgeways. She just told me she was attention seeking, she wouldn't kill herself, and that was that” (Helen).

For those parents whose daughters accessed an autism assessment through CAMHS, a lack of professional knowledge still posed a barrier to therapeutic input post-diagnosis: “I thought with CAMHS that they would be the experts on autism and things like that…but they actually are just the assessment tool” (Louise). Parents discussed the issue of inappropriate and limited support as being rooted in a systemic lack of knowledge: “you can't know what you don't know. And that's the problem… they don't know” (Helen) which is reflected in the language used in relation to autism: “they used the phrase ‘high functioning autism’ as well, which really annoyed me" (Kate). One parent had been involved in discussions about trying to identify autistic children earlier and shared their frustration with the lack of knowledge:

> "They'd come up with this sheet of how to identify children earlier… and it was literally something like… eye contact… and I was just like are you serious? You're putting all this money into this to help identify early and you don't understand this…" (Helen).

Another parent reflected that the lack of professional knowledge as a barrier to support is echoed throughout the wider system: "It's not just CAMHS. I'm talking health visitors, probably midwives, school nurses, social workers, across the board… we're assigned these workers who do not understand what our children need and what we need" (Julie).

Sub-theme 3c: Impact of service pressures

The third sub-theme related to the impact of service pressures, such as staffing and resources, on access to appropriate support. The first issue to arise was that of long waiting lists for autism assessments: "`She was put on [the waiting list] when she was five and we got her diagnosis last year… so she was on for nearly four and a half years" (Kate) with no interim support: "They said 'you'll be put on about a two-year waiting list'. And that I'm like, well, what happens in the meantime?" (Helen); "We were just on the waiting list…didn't have any input or contact at all from CAMHS in any way, shape or form" (Kate).

Parents discussed the issues with staffing retention in CAMHS, which impacted support provision. Staffing shortages was a barrier to seeking support for their daughter: "I ended up speaking to the team leader who said, 'yeah, we recognise your daughter needs to see someone, but I don't actually have any staff'" (Julie) and one parent commented on the lack of communication about changes to allocated workers: "We didn't hear anything for months and months and months, and I then found out that the lady I had been speaking to had left and no one had told us" (Kate). Inconsistency in CAMHS workers led to lost referrals for some parents, meaning that their daughters did not receive the support they needed:

> “She had said ‘it's very clear your daughter needs a sensory profile assessment… I also think she's got ADHD; I will put in the referral to get an assessment going for that’. But then it disappeared… I wanted to find out where she was on the waiting list and the new lady looked on the system and said, ‘oh, I can see the previous person said she was going to submit it, but I can't find any evidence of it being submitted. I will do it for you now’. She submitted it and got a response from occupational therapy saying ‘oh we don't do that anymore. So that went up in smoke and it also turns out they hadn't submitted the referral for the ADHD assessment” (Kate).

Parents discussed the pressures on CAMHS services within the context of increased demand and insufficient resources, which resulted in GPs diverting families away from CAMHS: “The GP was like, ‘there's no point going to CAMHS, it's overwhelmed, try and find a private psychologist. Would you like some antidepressants?’” (Helen) and CAMHS workers asking parents to raise concerns: “the CAMHS worker said to me, ‘we're in crisis, we're letting children down, please, can you write to your MP’ And I was like, ‘if I had time, I would do that’” (Helen). Parents reflected on the impact of working conditions on the CAMHS workers:

> “I'm sympathetic with CAMHS. They have enormous pressures on them…or actually, no, maybe I'm just being polite. Maybe I'm not sympathetic with them, but they, you know, they can't keep staff, the working conditions that staff are in is absolutely awful. Why would you go and work there? Unless you're very, very self-sacrificing…” (Kate)

and they highlighted the issues as a systemic failure, rather than individual responsibility:

> “This is why I have never put in a formal complaint against CAMHS because, who are we complaining about it? It’s the system, it’s not the workers, it’s the system. They’re not doing it maliciously, these poor people working in these services” (Helen).

Theme 4: Routes to support

The fourth theme to emerge from the focus group data was the various routes that parents took in order to obtain appropriate assessment and support for their daughters, and within this there were three sub-themes:

Sub-theme 4a: Finding 'Golden people'

The first sub-theme relates to finding people who understand autism in girls and who have the skills to support their daughters, described by parents in the focus group as 'Golden People':

> "We definitely are trying, in schools and society, to get structures in place…but it just all seems to come down to what we call 'golden people', and they're the people that somehow seem to get it, and somehow seem to be able to know how to make a difference" (Iris).

Parents discussed how 'Golden People' "actually listen to what you're trying to say, and they don't make assumptions. They're like hens teeth" (Helen), and that finding this support is often accidental, rather than reflective of a robust framework around the child: "For us, it was less about there ever being a system that helped… it's kind of happened by accident and often it's people that she has sought out herself" (Louise). In order to seek support for their daughters, parents described "always looking… my antenna is always up for that person who can make a difference" (Helen).

Sub-theme 4b: Being the 'Angry Parent'

The second sub-theme relates to the position parents had to take in order to access support and services. In order to overcome barriers to support, such as those described above in Themes 2 and 3, parents described persistence in seeking support through school: "I think, maybe, I've just ground them down and it's like, 'look, you know, just anything for an easy life to stop the [family name] from coming and asking us again'" (Kate) and a need to take the lead in sourcing support for SEN provision: "I was trying to get her an EHCP. School didn't. But I did a parental request, so all the way through primary that was also ongoing with trying to get an EHCP" (Julie). In relation to seeking support through CAMHS, parents described:

> “…[fighting] every inch of the way… I think I probably subverted every system to get her in there because I just couldn't, couldn't not… I found every workaround, every phone number…to be *so annoying* that it was easier for them to say, ‘have an appointment, leave us alone’” (Kate)

and, for two parents, access to support came from escalating their concerns to the NHS Trust out of desperation and fear for their daughters lives:

> “I got to the point where I emailed one of the directors at Bradford District Care Trust of Children Services and I sat in her office and I cried and I begged her to let my daughter go speak to somebody within CAMHS because I didn't know where we were gonna end up” (Louise).

Parents described a significant lack of support for their daughters’ needs:

> “If I hadn't gone out and just been an angry parent and found it myself, there would have been nothing. I've changed our whole life. That child is gonna thrive, but not because of services, but because of what I've done” (Helen)

Sub-theme 4c: Seeking private support

The third sub-theme relates to parents responding to the lack of support from services by seeking private therapy and assessment, peer support, and training to educate themselves and facilitate support their daughters. One parent described seeking her own training to support her daughter’s co-occurring sleep disorder, which highlighted the limitations of courses offered via CAMHS:

> “I got beyond frustrated and I actually trained as a sleep practitioner so I could support my family…when we got her diagnosis and I was finally eligible to go on the sleep training course, I’d done an awful lot of training myself by that point, …the course was so out of date, the information they were sharing with parents was so inappropriate… they were not taking into consideration any form of neurodiversity at all” (Kate).

Another parent discussed the value of peer-led parent support groups, which, for her, highlighted the discrepancy in awareness and understanding of autism in girls between parents and professionals:

> "It's mind-blowing and you feel like you're going mad because you're like, you're in…these fantastic communities and there's so many people that understand this and have educated themselves. How are we educating ourselves, and we get this, but [services] don't?" (Helen).

Other parents described the process of paying for private assessment and support, in the absence of input from services:

> "Her sensory needs impacted or her at school and I asked about having an OT assessment and they said it wasn't possible to get it done on the NHS so I arranged a private OT specialist assessment which was, you know, that was really helpful and they did a really good report" (Julie)

and the financial burden this has created: "We got a private [psychologist] who's been amazing, but we've nearly gone bankrupt. We are so up to our ears in debt. We've paid over £20,000 in advice and legal fees to get this EHCP and package" (Helen) with some parents receiving financial help from family members for private assessment: "My parents said we can't carry on waiting, this is ridiculous…they paid for her to have her assessment by Socrates. And I'm so grateful because those Socrates reports are so incredibly detailed" (Kate)

Theme 5: Impact on parent well-being

The fifth theme to emerge from the focus group data was the impact delayed diagnosis, lack of support, and navigating through services had on parental well-being. Within this there were two sub-themes:

Sub-theme 5b: Feeling blamed by the system

The first sub-theme related to parents feeling blamed for their daughters' difficulties before autism was identified, which in turn led to feelings of self-doubt and self-blame. Parents discussed the pressure to keep their daughters in education, even without support for fear of punishment:

> "They're not in because either, you know, they have got diagnosis and its unmet need or then they're undiagnosed and it's "bad behaviour", but the needs aren't being met anyway, but the parents are now being punished and taken to court and fined, and it just feels so unfair" (Julie).

Parents also felt judged by professionals for seeking autism assessment for their daughter: “Professionals are becoming resentful of parents because they think we're obsessed by getting a diagnosis and it's not that at all” (Louise). One parent shared the near catastrophic impact of feeling blamed by professionals for the difficulties their daughter was experiencing prior to the identification of autism:

> “I just thought, I can’t, I can't do this anymore. It's all my fault. It's obviously my fault. And I just thought that's it, the best thing…this is seriously what I thought at the time…. the best thing for me is that I kill myself and I kill [child] as well, because we're not gonna get any help here. I'm in such a different place now, I can't tell you…but that was honestly what CAMHS did to me in terms of… ‘this is your fault’. They’ve really traumatised us as a family” (Helen)

Sub-theme 5b: Emotional Distress and Desperation

The second sub-theme related to the emotional distress experienced by parents throughout the process of trying to obtain support for their daughter. Parents discussed the impact of navigating services for their daughter on their own mental health: “I definitely feel that it’s a road to really poor mental health for all of us as parents” (Iris). Parents described feelings of anger at not being believed and watching the system fail their child:

> “My stomach churns ‘cause it just makes me so angry that we're all going through the same thing. It's like we're rewriting it over and over again, aren't we, for each child and the amount of time that it’s taken” (Helen).

Others commented on how exhausting the process is: “I was on my knees. I just didn't. I just couldn't function” (Kate) whilst acknowledging relative privilege in being able to advocate for their daughters: “You know, we are, kind of, able, we're vocal and able to kind of fight, and say what we feel our kids need, and other parents aren't, you know, there are barriers for them to do that” (Julie). Some parents discussed feelings of anxiety when thinking about the ongoing challenges of seeking appropriate support for their daughter as they transition through different stages of the education system: “…moving up into secondary school…we haven't got to that point yet but, my God, I'm so scared about it. And I don't know how to manage that”

(Kate). And others spoke of the fear they felt for the level of distress their daughters were in, and a concern that they might harm themselves:

> "I could see such a dramatic difference and how fast she was going downhill that I wasn't prepared to let it last any longer, because I'd have lost her. It was just awful…I wasn't, I wasn't gonna let that happen" (Louise)

Theme 6: What needs to change

The sixth and final theme in the parent focus group data related to what parents feel needs to change in order to identify and support autistic girls earlier. Within this there were five sub-themes:

Sub-theme 6a: Co-produced training for all professionals

The first sub-theme related to the limited knowledge of autism in autistic girls, across both health and education settings. Parents felt that training for all professionals would be an integral part of identifying girls earlier: "Staff training again across the board on, you know, autism and what to be aware of [in girls]" (Helen) and in schools, this should be extended to all staff that come into contact with children: "I think the training needs to be wider, not just the teachers. I'm talking about the caretaker. I'm talking about the lunchtime supervisors… everybody should have all that same understanding" (Louise). Parents felt that current training would not necessarily be helpful due to the influence of male-stereotypes: "I think the system is so fundamentally male-focused that even if you say it to schools, go get the training, the training they will get will be done with a male view" (Kate) and that meaningful training should be co-produced and delivered by autistic girls and women with lived experience:

> "I think the training would be really helpful if it was put together or had people with lived experience. Because that's part of the problem. These training sessions are generally put together by someone who hasn't lived it…they need to get autistic women who are prepared to do it…" (Julie)

and would benefit from giving a realistic, balanced view of autism in girls, that avoids the 'autism is superpower' trope and equally is not too deficit-focused: "It's finding that middle ground of yes, this [girl] is successful, but equally they need this support to help them achieve this, and normalizing the fact that you might need something different to everybody else" (Kate). Parents felt that increased knowledge would lead to increased general awareness in schools, and that autism in girls should be normalised: "…getting schools to talk more about neurodiversity [in girls] … just in a normal way…it's not about othering young people. It's just it's about…inclusion, isn't it?" (Julie).

Sub-theme 6b: Parent voice should be heard and believed.

The second sub-theme was the idea that the parent voice should be heard and believed. Parents reflected on their experiences of not feeling heard by schools and health services and suggested that listening to parents is imperative: "I think really the fact that someone would have listened to me as a parent, as the expert in my child… to have actually been heard and believed …" (Louise) and that parental concerns should be acted upon, to begin supporting their daughter's needs as soon as possible:

> "As soon as there's an inkling from a parent that something's not quite right, [they should have] the information they need, or the people to go speak to, or to be signposted to, as early as possible… that's something that really needs to change" (Julie).

Importantly, parents recommended that concerns raised should be responded to with empathy: "... just a little bit of empathy and humanity… and that just shows how screwed up the system is if you just want people to be polite and understanding" (Kate).

Sub-theme 6c: Needs-led support, before diagnosis

The third sub-theme related to the need to move towards needs-led support, before autism diagnosis. Parents reflected on their frustration with the gatekeeping of autism support and suggested that all parents should have "access to training courses, definitely…having a diagnosis as a barrier to support is unbelievable. Now this is not realistic, but in an ideal world we'd have a universal offer of support" (Louise). Having waited to access autism parent training after their daughter's diagnosis, one parent shared that: "If we'd had access to Cygnet much, much earlier, you know, when she was much younger, that would have really, really helped…I would have done things completely differently" (Julie). Parents discussed the importance of meeting need before a diagnosis: "I think we're working the wrong way around. What we're doing is we're kind of awaiting this diagnosis… but actually if we put everything into place before, that diagnosis doesn't make any difference" (Louise), which may ultimately reduce pressure on assessment services in the longer-term: "Professionals…think we're obsessed by getting a diagnosis and it's not that at all, it's that we can't get [support] without it… so it's just this silly catch 22" (Kate). Parents also highlighted the importance of listening to the individual needs of the girls, who often know what support they would find helpful: "They tried to impose on her what they thought was a [helpful] way…but she was very clear on what would work for her" (Helen) and for education staff to remain open-minded and flexible in their approach to support: "even when you've got a resource provision... it's about listening to that family and that child because we're all gonna be different" (Julie).

Sub-theme 6d: Review autism services

The fourth and final sub-theme was a review of service provision in education and health settings. With regard to education, parents felt strongly that the role of the SENCO should require full training (inclusive of training in autism in girls) and should be a protected role: "The role of the SENCO needs looking at because you can't have somebody SENCO-ing and teaching half the time when you've got 2000 students to look after, it's ridiculous" (Louise). With regard to health services, parents felt that CAMHS teams are not resourced or equipped to work with autistic girls: "The clue is in the title, it's child and adolescent *mental health* service. They are a mental health service. They don't see themselves as a service for neurodiversity" (Helen) and suggested that specialist autism services, separate to CAMHS would be helpful: "If I'm asthmatic, I'd have my asthma specialist. If I had rheumatoid arthritis, I'd have my rheumatologist. Why, with a lifelong condition like this [autism], are there no specialists for people to access?" (Louise).

4.5 Discussion

The fourth aim of this study was to link the data findings in Chapter 3 with the lived experiences of stakeholders across the Bradford district in order to develop a holistic understanding of the sex-based inequalities in access to autism diagnosis and support. The findings suggest that the needs of autistic girls *are* identified at a relatively early age, but the barriers to autism diagnosis and support are structural. Interviews and focus groups findings were highly consistent, with both groups highlighting the same barriers to accessing support. Although, it is important to note the homogeneity of this sample (all White British Females); it is likely that people from minoritised ethnic backgrounds will experience different and/or further barriers to accessing autism diagnosis and support that are not reflected here.

The findings of interviews and focus groups will be discussed below within two overarching categories: *barriers to identifying autism and barriers to accessing support.*

Barriers to identifying autism

These findings support the growing evidence for the FAP in autistic girls without intellectual disability, and that limited systemic awareness of the FAP is a barrier to identification. Autism was often not considered and, in line with previous qualitative findings by Rabbitte et al. (2017), parents in this study shared that they initially explained their daughters' early presentation through more relatable frameworks, such as personality traits like 'shy' or 'exuberant' (Focus Group (FG) Theme 1a). Some of the girls/women reflected on the negative labels that were attributed to them by the wider system, such as 'controlling' and 'judgemental' as it was not recognised that behaviours were driven by underlying autism (Interview Theme 4a).

Girls/women and parents reported that there were no 'classic indicators' of autism; however, there was notable consistency in how autism presented in this cohort. In line with findings by Hull et al. (2020), most of the girls/women in this study were academically able but experienced difficulties with social interaction and maintaining friendships (Interview Theme 1b). In terms of RRBs, only one participant referred to an area of intense interest, and two referred to difficulties with change and a preference for routine. Parent findings echoed this pattern; no parents referenced areas of intense interest, but several noted difficulties with social interaction, change and transitions. This is again consistent with previous FAP research into RRBs that has found autistic girls are less likely to present with intense interests or ‘stereotyped behaviours’, but more likely to experience difficulties with change and transitions (Allely, 2019). The prevalence of self-reported sensory processing difficulties was high in this cohort, which is not surprising given that this is now included in the diagnostic criteria as a core feature of autism (American Psychiatric Association, 2013). The nature of sensory processing difficulties was congruent with previous findings that autistic girls are more likely to experience over-responsivity to sound and touch (Kumazaki et al., 2015; Osorio et al., 2021) and, in this cohort, led to subsequent anxiety connected to overstimulation and unpredictability of the sensory environment. Parents noted that sensory processing difficulties were evident from infancy, which suggests that this could be an early indicator of autism in girls.

The girls/women in this cohort shared that while their needs were not identified by others, they developed an awareness of being different to their neurotypical peers from a relatively early age. This dawning awareness was associated with the evolution of masking (Interview Theme 1c), which is congruent with the high prevalence of masking behaviours in autistic girls and women (Lai et al., 2017) and was discussed as a further barrier to having their autism identified. Masking is defined in the literature as a combination of unconscious and conscious strategies (Tubio-Fungueirino et al., 2020); interestingly, girls/women in this cohort consistently described a conscious decision to mask, through studying their peers and adopting similar behaviours in order to fit in at school, and that this became an unconscious process with time and practice. Consistent with the findings of Beck et al. (2020) masking was discussed as an exhausting process that had positive social effects, but negative consequences in terms of well-being and mental health. Participants described the fear negative social evaluation if they did not mask, and that masking their social interaction difficulties led to internalised symptoms such as anxiety and depression. The age of autism diagnosis for the girls and women in this study ranged from 8 years to 47 years and the findings from interviews indicate that mental health difficulties (and other detrimental effects of delayed diagnosis), were first evident at an early age but worsened and became more entrenched with age and the length of delay to having their needs identified. In most cases, co-occurring mental health difficulties (stemming from unmet need, masking, and sensory hyper-responsivity) were recognised first by the system around them (Interview Theme 1c; FG Theme 1b), which became a further barrier to identifying their autism as mental health diagnoses were used to as a ‘cover all’ to explain all difficulties they were experiencing.

Given that identification of autism relies on the system around the girls to notice and act upon concerns, the cumulative impact of these barriers suggest that it is limited systemic awareness of how autism presents in girls/women (the FAP) that underpins delays and inequity of access for girls in the *Identification and Referral* stage of autism assessment (NHS England, 2023b).

Barriers to accessing support

The girls/women and parents in this study shared their experiences of seeking support across different areas of the system. Experiences of accessing support in school, CAMHS and the autism assessment process will be discussed in turn below.

School

An initial barrier to accessing support in schools stemmed from the ability of autistic girls without an intellectual disability to ‘mask’ their difficulties, leading to differences in how they present across environments. Parents discussed their experiences of raising their concerns and seeking support, but being dismissed by education professionals on the basis that behaviours were not observed in the school environment (FG Theme 2b). Furthermore, the girls/women felt that schools did not recognise or support their needs until their academic attainments were directly impacted by their difficulties (Interview Theme 4b). The lack of support from school in response to parental concerns echoes the findings of Rabbitte et al. (2017), and also suggests that the systems around the girls are working in silo and support is only considered when difficulties are observable in the immediate environment. This is problematic within the context of ‘masking’, where differences are common between presentations at school, where social stakes are higher, and home, which is often a place of safety and where the ‘mask’ comes off (Interview Theme 1c).

For parents in this study, this led to a long journey of trying to have their daughters needs acknowledged in the school environment, feeling blamed and unsupported (FG Theme 5a), which is consistent with prior research that indicates parents need to advocate and ‘build a case’ for support from services (O’Reilly et al., 2017). This results in long delays and unmet need, which, for the girls in this study, led to school becoming intolerable, a deterioration in academic attainment, and considerable consequences in terms of mental health (FG Theme 5a & 5b; Interview Theme 4c). For some, effective support was implemented in school through finding ‘golden people’ (FG Theme 4a) who listened to parents’ concerns, spoke to the girls about their needs and had the skills to support them; however, this was described as ‘accidental’ rather than the result of a robust and responsive system around the girls.

A recent study by Dockrell et al. (2019) found that SEN provision tends to be driven by diagnosis rather than need, which in itself contravenes current guidance that *pre-assessment support* should be provided in education settings according to need (NHS England, 2023b). The struggle to access school support, outlined by parents and girls/women here, contributes to growing evidence that barriers to support are exacerbated for autistic girls. Prior research has found that girls are less likely to be referred for an autism assessment in order to receive ‘diagnosis driven’ support (Geelhand et al., 2019), and these findings indicate that when their needs are identified (with and without an autism diagnosis), support is impeded by lack of professional knowledge and a systemic failure to acknowledge and meet those needs.

Where needs were recognised in the school environment, systemic rigidity and lack of knowledge continued to pose barriers to effective support. The girls/women in this study discussed the challenges of a prescribed approach to SEN that often led to higher levels of anxiety and a focus on keeping them in the classroom environment at all costs (Interview Theme 2b). Parents echoed these findings and discussed the challenges of seeking adjustments for their daughters’ sensory needs, inflexibility in supporting girls back to school after a period of high-anxiety and school resistance, and a prescribed, ‘one-size fits all’ approach to SEN (FG Theme 2c). Both groups expressed the importance of implementing support in a way that is collaborative and individualised to the girls’ specific needs (Interview

Theme 5d; FG Theme 6d). However, most experiences were that SEN policy was enacted without collaboration with the girls, which led to further layers of expectation and high anxiety that further exacerbated their difficulties.

The Autism Education Trust state that SENCOs should be appropriately trained to meet the needs of autistic children by focusing on: understanding the individual, learning and development, providing an enabling environment and nurturing positive and effective relationships (Autism Education Trust, 2021). However, the experiences of girls and parents in this study suggest that current SENCO provision is not meeting these expectations. Parents highlighted concerns about the role of SENCOs in schools, including the low level of training required to be appointed to the role, and the time and attention they are able to provide whilst also holding teaching responsibilities. Furthermore, where girls had been able to connect with certain education staff and were being effectively supported, staffing restructures meant that those connections were broken, and support was again inconsistent (FG Theme 2a). Barriers to accessing support through schools point to structural inequalities for girls in the *pre-assessment* and *post-assessment support* stages of autism assessment (NHS England, 2023b).

CAMHS

A number of structural barriers were identified in terms of accessing support through CAMHS. Most parents in this cohort described multiple declined referrals on the basis that their daughter did not meet criteria for support, despite high levels of anxiety, self-harm, and suicidality. Declined referrals were often linked to the lack of evidential support from schools (the challenges of which are highlighted above) and parents were signposted back to the school nurse where their concerns had initially been dismissed. For some parents, this led to escalation to the NHS trust in order to challenge declined referrals – again highlighting the burden on parents to challenge the system in order to ensure support for their daughters (O’Reilly et al., 2017) (FG Theme 4b).

Where referrals for support were accepted, further challenges lay in the pressures on NHS services. High staff turnover and levels of staff sickness led to inconsistencies in allocated workers, which is particularly problematic for autistic girls within the context of difficulties with change and unpredictability (Allely, 2019). Staffing inconsistencies also led to broken episodes of care and lost referrals, resulting in years long delays and missed opportunities for support (Interview Theme 2c). Parents in this study reflected on the discrepancy between demand for CAMHS support and their capacity to provide it, resulting in parents and children experiencing a service that feels like a ‘conveyor belt’ and ‘lacking in humanity’.

Another highlighted barrier to accessing support for autistic girls was professionals’ lack of knowledge about how autism present in girls, and about neurodiversity more generally (Interview Theme 2a; FG Theme 3a), which reflects earlier findings by Lockwood Estrin et al. (2020) that clinicians were not confident in their ability to identify autism in girls within the context of the FAP. The girls/women in this study reflected on the impact of their difficulties being viewed through a neurotypical lens, leading to mental health interventions that were not appropriately adapted and therefore ineffective and sometimes harmful. Furthermore, they reflected on CAMHS workers becoming frustrated when interventions were not helpful, which led to discharge from services altogether. This highlighted the wider issue of working with neurodiversity in generic mental health services; both parents and participants reflected on the lack of knowledge and skills for working with neurodiversity which led to girls’ presentation being viewed solely through the lens of mental health, with a lack of reasonable adjustments to support access to the service.

Parents also reflected on the rigidity of service offers and the gatekeeping of relevant support (FG Theme 3b). At present, autism specific parent training such as the Cygnet course, which has been found to increase parent satisfaction and specific child behaviour goals (Stuttard et al., 2016), is reserved only for those whose children have received a formal diagnosis of autism. Within the context of the barriers to diagnosis for autistic girls, this means that parents are lacking vital support. Parents suggested that access to training courses should be based on a profile of need, rather than the presence of a formal diagnosis (FG Theme 6d). The cumulative impact of these barriers meant, for girls/women and parents in this study, that mental health difficulties were exacerbated, parents felt blamed by the system, and many undertook the financial burden of sourcing private psychological support from practitioners with expertise in working with autistic girls and women (FG Theme 4c). Once again, these barriers to CAMHS support signify structural inequalities in the *identification and referral*, pre-*assessment* and *post-assessment* support stages of autism assessment for girls (NHS England, 2023b).

Autism Assessment

A number of barriers were discussed in relation to the assessment and diagnosis of autistic girls without an intellectual disability. First, access to an autism assessment in this cohort was impeded by declined CAMHS referrals on the basis that school did not provide supporting information. While current guidance on autism assessment states that assessment information should be triangulated across settings (National Institute for Health and Care Excellence, 2017), the emphasis on supporting information from school can become problematic in the case of autistic girls. This study has demonstrated through analysis of the EYFSP that teacher-report assessment tools are less effective at highlighting potential autism in girls, and this, combined with girls' ability to mask their autism in school, means that assessments that require supporting information from school are a structural barrier to girls at the *screening and triage* stage of assessment (NHS England, 2023b). For the two women in this study who sought assessment as an adult, both were initially dismissed and actively discouraged from pursuing assessment by their GP, and these experiences appeared to be underpinned firstly by lack of knowledge about the FAP and secondly by a perceived stigma attached to an autism diagnosis. Stigma in autism is influenced by public and professional understanding and has been found to impact on individual and caregiver mental health (Papadopoulos et al., 2019; Turnock et al., 2022). The girls and women in this study felt that breaking the stigma attached to diagnosis would be an important step towards identifying and support autistic girls earlier (Interview Theme 5b).

For those where a referral for assessment was accepted, service pressures were a further barrier to access (Interview Theme 3a; FG Theme 3c). Parents in this study reported waiting over four years for an autism assessment for their daughter, in stark contrast to the recommended three months (National Institute for Health and Care Excellence, 2017). Barriers to accessing autism assessment meant that a number of girls/women and parents in this study sought private or outsourced assessments (FG Theme 4c).

Turning to the experience of autism assessment itself, these findings indicate that current processes are not appropriate for autistic girls and women without an intellectual disability (Interview Theme 3b) and suggest structural inequalities at the *diagnostic assessment* stage of assessment (NHS England, 2023b). Current assessment tools, such as the Gold Standard ADOS-2 (Lord C et al., 2012) are based on behavioural observations, which poses obvious challenges in the assessment of girls/women who have developed masking strategies and are unlikely to display behavioural indicators of autism (Wood-Downie et al., 2021). The girls/women in this study reflected that the experience of assessment made them 'feel stupid' and the process was child focused. Instead, they felt that assessment should be more age-appropriate, with a focus on a clinical interview which is more likely to elicit information based on their inner experiences. The girls/women also highlighted the importance of reasonable adjustments to support access to an autism assessment (Doherty et al., 2021), for example, providing interview questions ahead of time to reduce uncertainty and allow time to reflect on relevant experiences to support the assessment (Interview theme 5c; FG theme 6d). The findings also indicated that a further barrier to autism diagnosis lies within the current diagnostic criteria. The girls/women reflected that the examples provided within the criteria, which guide assessing clinicians (WHO, 2022; APA 2013), were based on a stereotypically male-presentation and they were keen to have diagnostic criteria that encompasses all presentations of autism, including elements of the FAP (e.g., stating that girls are less likely to present with 'stereotyped' RRBs).

These findings highlight structural barriers and inequalities for girls at each and every stage of the autism assessment process, i.e., *identification and referral, screening and triage, pre-assessment, diagnostic assessment,* and *post-assessment support* (NHS England, 2023b). The participants in this study made several recommendations to resolving these inequalities and meeting the needs of autistic girls earlier, and these will be outlined in the Clinical Implications (Section 5.2).

Chapter 5: Overall Discussion

5.1 Key Findings

Sex-based disparities in autism prevalence rates are higher in the Bradford district compared to national estimates, which suggests that there are large numbers of girls across the district that have not yet had their autism formally identified. Boys are statistically more likely to receive an autism diagnosis than girls, and girls who are diagnosed tend to receive their diagnosis later than boys. Autistic girls from Asian backgrounds are at further risk of delayed and missed diagnosis compared to their male peers and girls from White British backgrounds. Furthermore, while the nationally utilised EYFSP education assessment tool has demonstrated strong potential as an early indicator of autism in boys, it is comparatively less effective at indicating potential autism girls.

Using the CLEVER framework to link these data insights with the lived experiences of stakeholders, this study found that sex-based inequalities in the Bradford district are underpinned by a systemic failure to identify and support autistic girls across health and education settings, which can have devastating effects on the well-being of the girls and their parents. Contrary to the idea that autistic girls 'fly under the radar', these findings indicate that needs are identified at an early age but are mis-diagnosed or overlooked. Lack of professional knowledge about the FAP, and parental concerns subsequently being dismissed, was found to be at the root of unmet need for autistic girls in this cohort, and this was further exacerbated by services pressures including high staff turnover and lack of resource.

5.2 Clinical Implications

The findings of this study carry a number of implications for clinical practice in order to move towards redressing the sex-based inequalities in access to autism diagnosis and support for autistic girls.

Autism and Girls Training for Professionals: There is an overarching need for accurate and up-to-date training on how autism presents in autistic girls. Findings indicate the need for training across the entire health system (including health visitors, GPs, and CAMHS practitioners) and education system (including Teachers, Teaching Assistants, Headteachers, SENCOs, and Breaktime Supervisors). Current training is dominated by the ‘male stereotype’ and so professionals who have received training in autism, are unlikely to be equipped to identify the nuances of the female presentation. Therefore, an overhaul of current training packages for health and education professionals is required, with the voices of autistic girls and women at the centre. Training should be co-produced and co-delivered by girls and women with lived experiences, which will ensure the accuracy of the information provided and a meaningful, impactful training experience. As well as a focus on how autism can present for girls, training should focus on shifting the narrative around delayed diagnosis by highlighting that the delay is a systemic failure to identify and support, rather than a core feature of autism in girls.

Prioritise parental concerns: A major finding of this research was that parents were often the first to identify their daughters’ needs, but their concerns were dismissed by the health and education system, leading to years of trying to navigate services to obtain support, and delayed diagnosis. Therefore, a key recommendation from this research is that parental concerns should be prioritised and acted upon without delay. Furthermore, within the context of literature concerning the role of masking for autistic girls, discrepancy between a girl’s presentation at home and school should be seen as an indicator of potential autism, within the context of parental concerns. These recommendations have implications for education and health professionals working directly with girls and their parents, and for the wider conceptualisation, diagnostic criteria, and assessment for autism.

Needs-support before diagnosis: The issue of delayed diagnosis for autistic girls is well-established, and a key findings from this research was that receiving individualised, needs-led support is impeded by the lack of a formal diagnosis. Unmet need can have catastrophic effects for autistic girls and their families and so a key recommendation from this research is that support should be implemented based on individual need, regardless of a formal diagnosis. Gatekeeping of parent training and resources for autism is impeding access to appropriate and timely support. While there is an acknowledgement that access to autism specific training requires some level of gatekeeping to ensure parents receive appropriate training according to their children’s needs, it is suggested that access to parent training courses should be determined by a profile of need rather than the presence of a diagnosis. Similar recommendations have emerged around the process of SEN provision within schools, and the need for flexible SEN provision according to need, rather than diagnosis driven support that is directed by general policy. A key element of providing timely and needs-led support in schools is centring the voices of autistic girls and avoiding systemic neurotypical assumptions. This involves facilitating a safe environment where they can be supported to discuss their experiences and understand their needs.

Review autism assessment process for girls and women: The process of identifying and assessing autistic girls requires change, and a key direction of change is developing a process of recording concerns throughout childhood. Findings pointed toward a 'log of concerns' beginning at the outset of the education journey that would capture concerns and observations across the girls' development in order to build a picture that would support referrals to health services and the autism assessment process.

The EYFPS may function as an early screening assessment and indicator of potential autism for *some* girls in the first year of education, although it is a relatively less effective for girls compared to boys. The needs of autistic girls tend to become more noticeable to others with age, as social demands increase, therefore an education-based screening assessment across different stages of development may increase the likelihood of identifying needs as early as possible.

Current observation-based assessment tools are not appropriate for older girls and women, without an intellectual disability, who are likely to have developed masking skills. Therefore, the use of an interview-based assessment focusing on the inner experiences of autistic girls and women may be more effective. This should be supported by reasonable adjustments, including the provision of interview questions ahead of time, to allow girls and women to reflect on their experiences and bring relevant examples to support the assessment.

The findings of this research also highlighted the challenges of seeking assessment and support for autistic girls within CAMHS, within the context of rigid pathways and the lack of appropriately adapted interventions. While this recommendation is ambitious within the current economic climate, qualitative findings supported the notion of neurodiversity services, separate to CAMHS, that specialise in assessment and interventions across the lifespan.

Break the stigma: The final recommendation arising from this research was the need to 'break the stigma' around autism for girls. This includes awareness programmes in schools to highlight what autism can look like for girls, with a focus on strengths as well as potential difficulties.

Another move toward breaking the stigma also lies in the positive reframing autistic behaviours and re-evaluating the language used to describe the core features of autism. One such example is moving away from terms that can be experienced as patronising, such as "special interests", to more accurate descriptive terms, such as "areas of intense interest".

Finally, a key area to breaking the stigma around autism for girls and women is representation, which relies on environments that support and promote neurodiversity, in which autistic women feel safe enough to share their diagnosis. If younger girls see autistic women represented in their immediate environments and more widely in the media, they may be more like to recognise potential autism in themselves, which may reduce feelings of isolation and the drive to 'mask', and which would increase the likelihood of support.

5.3 Future Research

This study demonstrated the power of combining the lived experiences of stakeholders with data-driven insights in the Connected Bradford Cohort. The voices of autistic girls and women and parents of autistic girls have added vital insights into the barriers to accessing support and autism diagnosis across the district, and to recommendations for change. Future research could adopt a similar model to link these findings with the experiences of professionals across health and education settings. Adding different perspectives of stakeholders across the Bradford district would further contribute to a holistic understanding of sex-based structural inequalities in order to improve support for autistic girls. Future studies may also wish to focus specifically on the lived experiences of autistic girls and women from minoritised ethnic backgrounds to explore the role of intersectionality in barriers to accessing to autism diagnosis and support.

5.4 Strengths and Limitations

The analysis of the Connected Bradford datasets yielded large-scale findings, which contribute to the current evidence base around rates of autism diagnoses in the UK. The main strength of this study lies in the centring of autistic voices in the research; the voices of autistic girls and women, and parents of autistic girls, were the driver to understanding the structural inequalities observed in the data and recommendations for improvement. The flexibility of online recruitment and data collection meant that participants were able to take part with reduced demand in terms of time and financial cost, which may have otherwise been a barrier if required to travel (Iacobucci, 2022). The online delivery also reduced the social demands by allowing participants to take part from the safety of their own home, and it was hoped would reduce potential anxiety in this participant group. A number of reasonable adjustments were incorporated into the study design in order to support access to the research (Doherty et al., 2021), including participant choice over camera use, length of interview and questions to cover. Interview questions were also shared ahead of time, and several participants communicated that this had been helpful in reducing uncertainty and allowing them to reflect on their experiences prior to discussion in the interview.

While online delivery offered benefits for some participants, it is also important to note that this may have acted as a barrier for others. Recruitment was conducted entirely online through social media forums and interviews and focus groups were conducted via video call, which required participants to have access to an internet connection. Bradford is ranked as the fifth most income deprived local authority in the UK (City of Bradford Metropolitan District Council, 2020) and so, within the context of digital poverty (Barrantes, 2007; Seah, 2020), it is likely that the online format precluded some families from accessing this research. Furthermore, online advertising of the research was through the AWARE group and so would have reached only those who were already connected to peer-support.

The limitations to the recruitment process are perhaps reflected in the demographics of participants who took part interviews and focus groups. Both samples were entirely White British and were therefore not representative of the population across the Bradford district. This may pose some questions for the generalisability of these findings in this population, and reflects wider systemic ethnicity-based inequalities in access to health care (Patel & Hanif, 2022). With hindsight, recruitment and data collection may have benefited from a hybrid approach including advertising in community settings to widen access to those who may not have access to the internet and/or social media forums.

5.5 Conclusion

This study has highlighted the sex-based inequalities in access to autism diagnosis and support for girls across the Bradford district, and the large numbers of autistic girls that are currently being failed by the systems around them. The lived experiences of autistic girls and their families indicate that health and education services are currently ill-equipped and require systemic training and education, a review/restructure of current service provision, and a focus on needs-led support prior to diagnosis, in order to meet the needs of autistic girls earlier.

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Appendices

Full appendices can be found by copying the following link into your browser: https://www.dropbox.com/sh/clxweooesy4ubva/AADHYQEnbPvSi83grr7Lo736a?dl=0