Exploring the underlying factors behind internalising conditions in autistic adolescents

Kofi Yeboah

Submitted in accordance with the requirements for the degree of Doctor of Clinical Psychology (D. Clin. Psychol.)

The University of Leeds
School of Medicine
Division of Psychological and Social Medicine

March 2026

Acknowledgments

I would first of all like to thank everyone who contributed to this thesis, starting with those who participated in the study. None of this would have been possible without you and I thank you all for your time and contributions. I am glad to have the opportunity to share your experiences and voices to start this process of influencing change.

To my thesis supervisors, Professor Mark Mon-Williams and Dr Simon Pini. Thank you so much for all your guidance, support, feedback and kindness throughout; from the early stages of planning this project, through to the data collection process up until write up. As you both know, it has been a journey of some rewarding ups and so pretty tough downs. However, you have both stuck behind me through every step of this journey. To Matthew, Megan and everyone at the Connected Bradford team. Thank you for your help with the dataset analyses and feedback on the write up of the quantitative study. Thanks to all of you, I am slightly less scared of quantitative research now!

Thank you to my DClin family class of 2025. We have experienced every part of this journey together right from the outset. We have laughed together, we have cried together, we have suffered together for these last three years but the key word here is ‘together’ and there is no way I would have been able to make it to the end without you all. It was an honour and joy being part of such a special cohort of trainees and I cannot wait to watch every one of your stories unfold as we head into qualified life. You are all going to be brilliant psychologists!

To all my family and close friends. Too many to name here but special shout outs to my sister Abena, Auntie Anne, Auntie Wendy, Cousin Fiifi, Cousin Koby, Albert, Uriel and Afolabi. Thank you all especially for being my support network and space away from the DClin to unwind, spend weekends and holidays with and for being able to rant about all things Arsenal! You are as much a part of this journey and I cannot thank you all enough.

To my wonderful other (and better) half Julia, my rock. Thank you so much for standing with me through everything. Through all the highs and lows, yet your love, kindness and understanding towards me has never changed. We met just as I was getting this thesis off the ground and you have been there every step of the way since then to see it all to its conclusion. Thank you for always pushing and encouraging me even when I struggled to do so for myself. Thank you for your patience in tolerating all my challenges and stressful moments which I know was not always easy, especially in these last few months. Thank you for all your prayers and for all your sacrifices during this journey. This paragraph can never express how much I love you, but it is only fitting that I end it on that note because those are the three words that sum it all up.

Thank you Mum, my biggest inspiration behind this whole DClin journey and in life in general. It is still difficult accepting the reality that you are no longer here and that your passing came right before the final stages of this project. However, I take comfort knowing you are continuing to watch from above and even more so, without any pain, suffering or illness. Without you, none of this ever happens so for that I say thank you, I love you and I miss you, more than words can ever do justice. I dedicate this to you. Continue to rest in perfect peace until we meet again.

Finally, and most importantly, thank you God for your everlasting love, guidance and for providing me with the strength and courage to see this thesis through to completion, even when I doubted myself. You reminded me once again that through you, all things are possible and I give all praise and glory to you. Thank you for the gift of life and for allowing me to conduct this important piece of research that I hope will go far in helping to address the inequalities faced by marginalised groups. I am only ever in this position because of you my Lord.

Abstract

Background:

Previous research has indicated that autistic children and adolescents could be at risk of experiencing mental health difficulties in later life, with females and minority ethnic groups in particular being more at risk. Suggested reasons behind this revolve around sex and ethnicity-based inequalities in autism identification and diagnosis, resulting in delays and disparities in meeting needs across demographic groups. The aims of the current study were to investigate the relationship between autism and internalising conditions across sex and ethnic groups and then use these findings to help understand the lived experiences of adolescent females pre-diagnosis, during diagnosis and post-diagnosis. Furthermore, the aim was to use the findings from the current study to inform recommendations for reducing structural inequalities in autism diagnosis and support going forward.

Method:

The study adopted a mixed-methods design informed by the Connecting Lived Experiences with Visualisation of Electronic Records (CLEVER) framework. A logistic regression analysis was carried out on linked education and health records of 17,523 individuals aged 20-22 within the Bradford district in the UK. Systematised Nomenclature of Medicine Clinical Terms (SNOMED-CT) codes were used to identify individuals with a diagnosis of autism and/or an internalising condition (anxiety and/or depression). Focus groups were conducted with 15 adolescent females (≤ 18 years) from an autistic residential school to understand lived experiences across different time periods and explore possible underlying factors behind the relationship between autism and internalising conditions. Participants were split between two focus groups which occurred face-to-face and back-to-back.

Results:

Autism was found to be significantly associated with internalising conditions with autistic individuals around three times more likely to have an internalising condition compared to neurotypical individuals. Autistic females were the most likely have an internalising condition when factoring in sex and autistic South Asian individuals were the most likely of all ethnic groups to have an internalising condition. Focus group findings highlighted potential factors behind internalising conditions in autistic females such as difficulties with school pre-diagnosis, lack of understanding and meaningful support from education and healthcare staff and masking to conceal difficulties to try and fit in socially and avoid discrimination.

Conclusion:

Findings around the increased risk of internalising conditions for autistic female and South Asian individuals combined with themes from the lived experiences of adolescent females suggest that autism may well be a predictor of internalising conditions in later life. This aligns with previous research findings around sex and ethnicity-based inequalities in autism understanding, identification, diagnostic procedures and support. This has implications for future research as well as training, healthcare, educational, community and systemic recommendations for improving timely support for autistic children and adolescents going forward.

Table of Contents

List of Tables

List of Figures

A Note About Language

The author is aware of the ongoing debate surrounding use of language regarding autism and its characteristics. To date, language used to describe autism has been dependent on what people believe it to be. Some favour person-first language such as “person with autism”, whereas others prefer identity-first language such as “autistic person”. Kenny et al. (2016) found that there was not a universally preferred way to describe autism according to a survey with UK autism community members.

The National Autistic Society (NAS) have provided guidance around preferable language when talking and writing about autism based on their own research with autistic individuals, families and professionals on language preferences. Out of respect towards the power language can hold and the extent to which certain words can impact, influence and change the attitudes people have towards a subject, the language used throughout this paper will be in line with the NAS guidelines (see Table 1).

Table 1.

Guidance on autism language (NAS, 2025)

Do say	Avoid saying
• Autistic person • Autistic adult/child/people • Is autistic • Has an autism diagnosis • Adult/child/people/person on the autism spectrum • Autism is a spectrum condition • Terminology used in the current medical manuals DSM-5 and ICD-11 (i.e. Autism Spectrum Disorder). Only use ‘disorder’ when specifically referring to terminology in the medical manuals • Condition (i.e. Autism Spectrum Condition or ‘autism is a spectrum condition’ etc.) • Disability (Some autistic people feel they are disabled by society due to	• Person with autism • Adult/child/people with autism • Has autism • Suffers from autism • Living with autism • An autistic • ‘Everyone is on the spectrum somewhere’ • Disorder • Has autism spectrum disorder (unless referring to medical manual terminology) • Dysfunction • Syndrome • Disease/illness/mental illness • ‘Normal’ people • Autism is a neurological disorder • Deficit/impairment

social barriers towards autistic people) • Not autistic/non-autistic Neurotypical people • Autism is a form of neurodivergence • Autistic people are neurodivergent Difference	• High/low functioning autistic person • Mild/severe autism • Treatment/cure for autism • People living with autism • Symptoms of autism • Signs of autism

With this, the term ‘autism spectrum disorder’ will only be used when referencing terminology found in medical manuals such as the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) (APA, 2013) and the International Classification of Diseases, eleventh edition (ICD-11) (WHO, 2022). It is also important to acknowledge the language used in reference to race and ethnicity throughout this paper. The author fully supports and upholds the use of anti-racist and anti-discriminatory language. For this reason, terms such as ‘BAME’ (Black, Asian and Minority Ethnic), ‘ethnic minorities’ and ‘non-white’ will not be used as these do not reflect the cultural, social and religious differences that define ethnicity (Khunti et al., 2020). Instead, the term ‘minority ethnic’ will be used to describe individuals/groups from diverse ethnic backgrounds throughout this paper as this better acknowledges that everyone belongs to ethnic group, including individuals/groups categorized as ‘White’ (Aspinall, 2020). Certain terms such as ‘South Asian’ and ‘Other’ have been used when referring to minority ethnic groups in the *Results* and *Discussion* sections due to the data using census categories by default. Efforts have otherwise been made not to generalise different ethnic groups and specify individuals’/groups’ specific ethnic identities where possible.

Chapter 1: Introduction

1.1: Autism Background

Definition

Autism is a spectrum condition that describes a diverse group of conditions related to brain development (World Health Organization [WHO], 2023). It is a life-long condition typically identified in early childhood, characterised by differences in 'neurotypical' functioning such as social communication, interaction and understanding (Hahler & Elsabbagh, 2015). Other differences typically include sensory responses such as hypersensitivity/hyposensitivity to light, sound, and/or touch, repetitive behaviours, special interests and varying cognitive functioning (Lord et al., 2020). Every autistic person is unique, bringing their own strengths and this is key in autism being seen by some as a 'different ability' rather than a disability (Buijsman et al., 2023; Ripamonti, 2016).

Medical Model vs. Social Model of Autism

Autism was first defined as a medical condition, describing a pattern of behaviours related to emotional dysregulation from parental rejection during childhood (Bettelheim, 1967; Kanner, 1943; 1949). Following a collation of research to establish its validity, autism was officially recognised as a medical diagnosis in the third edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-III) under the names 'infantile autism' and 'residual infantile autism' (American Psychiatric Association [APA], 1980). Both were listed under the cluster, Pervasive Developmental Disorders (PDD) (APA, 1980) to reflect the pervasive lack of social responsiveness described in the initial classification and that this 'infantile' trait was not fixed and autistic individuals could in fact change over time (Rosen et al., 2021).

Since then, the way in which autism is defined and perceived by society has been the subject of mass debate. Today, it is classified as a neurodevelopmental disorder under Autism

Spectrum Disorder in the DSM-5 and the ICD-11 both of which are largely grounded in a Westernized medical model (Anderson-Chavarria, 2022). However, over time, autism itself has been in a state of flux, with language used to define it constantly changing. This is in large part down to the joint efforts of the disability rights and autism rights movements, both born out of opposition to the medical view of autism as a disease that needs to be cured or prevented (Barnes et al., 1999; Charlton, 1998).

Supporters of both movements argue that this model promotes a problem-focused view of autism where autistic individuals' capacity to be autonomous in shaping their life is brought into question, which can be deemed dehumanising (Shapiro, 1994; Williams, 1996). Some supporters also argue that this problem-focused view leads to autistic individuals being defined solely by their diagnosis and neglects some of the unique strengths and talents they possess, serving to reinforce an ablelist society in which autistic individuals struggle to navigate (Armstrong, 2010; Anderson-Chavarria, 2022; Shakespeare, 2006).

Instead, both the disability rights and autism rights movements have pushed for a social model towards understanding autism that rejects the condition itself as disabling, but rather the barriers and lack of response from society to an individual's specific needs as the disabling factor (Baker, 2011; Oliver, 1990). Criticisms of this model have suggested that it can be over-reliant on criticising systems, proposing it can lead to 'othering' of autistic individuals as different, alien or non-human (Hacking, 2009; Peters, 2000). The social model on this basis can be perceived as failing to account for the diverse experiences of autistic individuals.

Predicament Model of Autism

Due to the criticism levelled at both of these models, a third model, the predicament model towards understanding autism has been proposed (Anderson-Chavarria, 2022). This model in contrast to the medical and social models, suggests that autism be seen as a ‘predicament’ where the diverse experiences of autistic individuals are acknowledged and contextualised (Anderson-Chavarria, 2022). The predicament model, also known as the neurodiversity paradigm, pushes for greater focus on how the environment can be changed to be more inclusive and accommodating for autistic people rather than placing all the responsibility on them to change (Chapman & Botha, 2023).

There are benefits to this predicament model as highlighted: “A benefit of this model is that it disregards the spectrum metaphor which ranks autistic persons on a low-to-high functioning scale. Instead, the predicament model of autism embraces the individuality of each autistic experience without comparing it to a standard of normal. Thinking of autism as an individualized predicament allows for more answers to the question, what does being autistic mean?” (Anderson-Chavarria, 2022, p. 1321-1322). Despite this ongoing debate however, the medical model still remains the dominant model of autism among clinicians today (Graby, 2015).

Autism in Popular Culture

Autism and neurodiversity more broadly has increasingly gained recognition in popular culture. Since the 1970s, autism has largely been portrayed in the media through fictional characters in books, biographies, movies and TV shows (Murray, 2006). For example, many characters have been portrayed as having atypical abilities such as being capable of multiplying large numbers without a calculator and having enhanced problem-solving skills (Bethune, 2009). Bethune (2009) and McGrath (2019) both argue that this stereotype of autistic individuals in mainstream media is rather overrepresented. They state this stereotype lends itself to misinterpretation from the public eye as accurate portrayals of autism and all autistic people, failing to acknowledge that every autistic person is different (Bethune, 2009; McGrath, 2019). Media portrayals of autism have the potential to have either a positive or negative influence on autistic people’s lives (Jones et al., 2023). For example, they have the potential to educate and increase understanding among the general public on the strengths and challenges autistic people face or reinforce negative stereotypes and stigma surrounding autism (Nordahl-Hansen et al., 2018).

Today, public awareness of autism continues to increase through increased representations of autism in the media (Conn & Bhugra, 2012). Media representations of autism reach the public in a way that goes beyond academic journals (Garner et al., 2015). However, Dean & Nordahl-Hansen (2021) also highlight that these representations may serve as a double-edged sword. On one hand, they have the potential to increase education, awareness and inclusion and on the other hand, they can spread inaccurate portrayals and continue to preserve misinformation (Dean & Nordahl-Hansen, 2021). A common criticism with media portrayals is that many of them represent a limited proportion of autistic individuals with only White males in their 20s and 30s with savant skills (Singer, 2017). Therefore, these representations may be less applicable to cross cultural audiences (Dean & Nordahl-Hansen, 2021).

A future direction for mainstream media would be to aim for a more realistic representation of autistic people that takes into account viewers' feelings towards these representations and their constructive feedback (Steiner-Hofbauer et al., 2025). Additionally, mainstream media may benefit from considering how these preferences relate to individual characteristics, for example, viewers' own autistic characteristics (Steiner-Hofbauer et al., 2025).

1.2: Autism Prevalence

An estimated 1 in 100 children are diagnosed with autism both in the UK and globally (National Autistic Society, 2023; Zeidan et al., 2022). Many studies have found a difference in prevalence rates across populations (Zeidan et al., 2022). Increasing evidence suggests this variation may reflect disparities linked to broader demographic variables such as sex, race, ethnicity and socioeconomic status (SES).

Autism and Sex

Studies on sex-based differences in autism for example, would suggest that autism has a higher prevalence in males compared to females (e.g. Fombonne, 2009; Loomes et al., 2017), with ratios said to be around 4:1 (Baio et al., 2018). However, research has also suggested that this may be due to masking in females as well as current assessment and diagnostic processes not being tailored towards identifying female traits (e.g. Fombonne, 2009; Kirkovski et al., 2013; Lai et al., 2016; Loomes et al., 2017). The camouflaging theory hypothesises that autistic females tend to mask some of their autistic traits due to increased sensitivity to social pressure to fit in, gendered expectations around social behaviour and strengths in particular social skills (Lai et al., 2015; 2016).

Looking at contributing factors towards sex biases in current autism diagnostic procedures, Cook et al. (2024) highlighted differences in behaviours between autistic males and females. Diagnosis of autism is based on the core features specified in the DSM-5 and ICD-11. However, these diagnostic criteria are geared more towards behaviours commonly observed in autistic males due to being derived from majority-male samples and the same applies to current autism assessment tools and procedures (Cook et al., 2024). Therefore, variation in these core features, which is commonly observed in autistic females, increases the likelihood of variation in meeting diagnostic criteria (Cook et al., 2024). This can ultimately lead to variation in autism diagnosis between males and females, with females being at greater risk of going undiagnosed (Cook et al., 2024). Other contributing factors include co-occurring mental health conditions such as anxiety, which may overshadow autism diagnoses (Cook et al., 2024). Anxiety is found to be more prevalent in autistic females compared to autistic males, possibly stemming from factors such as being in poorly adapted environments, sensory overstimulation and difficulty coping with uncertainty or unfamiliar surroundings (Ambrose et al., 2020). Undiagnosed autistic females who experience high levels of anxiety may have their autistic traits misdiagnosed or misinterpreted as anxiety and therefore be more likely to experience delays in autism diagnosis (Cook et al., 2024). Research has found that females are diagnosed with autism at significantly later ages and experience longer delays in time from initial evaluation to diagnosis (e.g. Begeer et al., 2013; Shattuck et al., 2009).

As a result of the above research, the sex-imbalance in autism prevalence rates is likely to be exaggerated (Halladay et al., 2015; Kirkovski et al., 2013; Loomes et al., 2017) and ratios are likely to be closer to 3:1 (Loomes et al., 2017).

Autism and Socioeconomic Status (SES)

Access to quality services and clinical evaluations may influence the likelihood of an autism diagnosis being made (Thomas et al., 2012). Studies have shown mixed findings on the relationship between autism and SES. A study by Bhasin & Schendel (2007) found a relationship between autism diagnoses and higher SES in Atlanta, Georgia, USA. Kogan et al. (2009) carried out a nationally representative telephone survey of parents in the USA and found an autism prevalence rate of 110/10,000 children, where rates were lower in families where parents had lower number of years of education. The study by Thomas et al. (2012) found autism prevalence to be higher in non-Hispanic white and Asian children and lower in non-Hispanic black and Hispanic children. The same study also found higher prevalence rates in families with higher median incomes and that children from said families received their diagnoses at a younger age compared to children from lower income families. A study carried out in Denmark however, found no relationship between autism prevalence and SES (Larsson et al., 2005).

Thomas et al.’s (2012) study was unable to explore underlying factors beneath the relationship between autism diagnosis and SES. However, as well as access to quality services and clinical evaluations, some researchers speculate that children with autism and behavioural difficulties may be identified earlier in higher SES regions compared to children in lower SES regions. This is due to access to greater resources and potentially greater awareness of autism by parents and teachers (Croen et al., 2002; Johnson et al., 2007). Furthermore, parents in lower SES regions may not identify differences in development and behaviour as quickly as parents from higher SES backgrounds (Thomas et al., 2012). Other factors related to SES such as educational background may also explain the relationship with autism diagnosis. Highly educated parents may be more likely to make an assessment referral for their child if they are behind academically and/or developmentally (Thomas et al., 2012).

The absence of a relationship between autism and SES in the Larsson et al. (2005) study suggests disparity in healthcare access may be an important factor in prevalence rates. Additionally, the difference in findings compared to the studies by Kogan et al. (2009) and Thomas et al. (2012) may reflect more parity in income within the Danish population compared to the USA. The difference in healthcare systems between the USA and Denmark (USA and Denmark having predominantly private and universal healthcare systems respectively) may also be a factor towards this difference in findings. The UK also has a predominantly universal healthcare system and so the findings from the USA based studies may not be wholly generalizable. Nonetheless, the impact of SES on access to quality services, resources and education and the link this might have to autism prevalence can be generalizable.

A study by Kelly et al. (2019) utilised data from the Born in Bradford Cohort, a longitudinal birth cohort study based in Bradford, UK that tracks the health outcomes of nearly 14,000 children and their families from pregnancy to adulthood. Data is routinely collected through citizen health and education records. Kelly et al. (2019) found that autism diagnoses in children of mothers of higher education status was significantly higher than those of mothers of lower education status, suggesting a considerable level of underdiagnoses in children of lower education status mothers. Another UK based study in the South Thames region found evidence for lower prevalence of autism diagnosis in children of lower SES (Baird et al., 2006). A study based in Cambridgeshire however found no significant relationship between autism and SES (Sun et al., 2014). At the time of this study, the difference in findings compared to the Baird et al. (2006) study was potentially attributed to differences in study samples and design, geographical differences or that the link between autism and SES was not as significant in the UK nearly a decade later. The study by Kelly et al. (2019) however provides evidence to suggest this may not be the case and that socioeconomic inequalities in autism diagnosis among children in the UK still exist. Additionally, Cambridgeshire generally is known to be quite an affluent region, which may mean that the relationship between autism and SES in the Sun et al. (2014) study would not be as pronounced due to the likelihood of greater access to services and assessments as well as increased awareness and detection of autism.

Autism and Ethnicity

The relationship between autism and ethnicity has also provided mixed findings. A couple of studies for example, have found a lower prevalence of autism diagnosis in Latino children compared to other children (Croen et al., 2002; Liptak et al., 2008). Mandell et al. (2009) in another USA based study found that following adjusted analysis, children of Black, Hispanic or other non-White ethnicities were less likely than White children to have an autism diagnosis on their health or education records and also found a relationship between minority ethnicity and later age at diagnosis. The authors' findings were in line with previous research that has found Black children with autism are diagnosed at older ages compared to

White children and that Hispanic children are less likely to be diagnosed with autism compared to White children (Centers for Disease Control and Prevention, 2006; Mandell et al., 2002). Mandell et al. (2009) acknowledge however that this study was subject to questions around the inclusion criteria, as some of the records included children with a presumed autism diagnosis but with no further examination. Previous research (e.g. Fombonne et al., 2004) has found that this method can lend itself to the inclusion of some false positives and Mandell et al.'s (2009) study did not test this assumption.

Tromans et al. (2021) found in their literature review that autism identification generally seems to be lower in children from minority ethnic groups compared to majority groups across various countries. Some studies however (e.g. Kogan et al., 2009; Thomas et al., 2012; Yeargin-Allsopp et al., 2003) have found no association between autism prevalence and race/ethnicity.

Several reasons have been put forward as to why autism prevalence rates might differ in children of minority ethnic backgrounds. Minority ethnic children may be more likely to live in poorer regions and have unequal access to quality healthcare services, leading to later age of diagnosis (Thomas et al., 2012). Referral biases among healthcare professionals and institutional racism could also be factors behind disparities in autism identification across ethnic groups (Gourdine et al., 2011). Healthcare professionals could be more likely to attribute social and communication difficulties in a child to their ethnic background, resulting in under-diagnosis of autism in children from minority groups as well as being denied the support they need (Billstedt et al., 2011). Diagnostic tools such as the Autism Diagnostic Interview-Revised (ADI-R) (Lord et al., 1994) and Autism Diagnostic Observation Schedule (ADOS) (Lord et al., 2000) may also be biased towards the culture and ethnicity of the tool developers and normative population (Tromans et al., 2021).

Similarly, norms/expectations around social skills, eye contact and language development differ across cultures, which will likely influence how much weight parents and caregivers place on observed differences in social cues (Perepa, 2014). This is further emphasised by research carried out by Wilford (2013), who underlined the importance of differences in cultural norms, perceptions and social structures in minority ethnic populations. Wilford for example, detailed how eye contact norms differ in the Zulu tribe in South Africa. In Zulu culture, it is deemed rude for a child to look into the eyes of an adult speaking to them (Wilford, 2013). A lack of cultural awareness from healthcare professionals could have an impact on diagnostic decision-making as well as a lack of culturally adapted diagnostic tools/instruments tailored towards the ethnicity of the individual being assessed (Tromans et al., 2021).

Awareness of neurodevelopmental conditions and spoken languages among minority ethnic populations influence ethnic parents' detection of autism and subsequently seeking of a diagnostic assessment, also contributing to disparities in prevalence rates (Bailey & Arciuli, 2020). Dickerson & Dickerson (2020) found that autism prevalence rates were significantly lower in non-English speaking White children compared to English speaking White children. A survey of families of children with autism by Zuckerman et al. (2017) found English proficiency (or lack of) to be an important barrier to diagnosis within the Latino community. It has been mentioned previously how parental education level can be an important factor in detection of autism. Tromans et al. (2021) suggest that language difficulties along with the aforementioned in certain ethnic groups can present a barrier to getting an assessment and ultimately a diagnosis. This is because parents/caregivers may struggle to articulate themselves sufficiently to obtain said or lack familiarity with the condition to detect it in others (Tromans et al., 2021). Other factors such as negative belief systems and stigma around autism within ethnic groups may also contribute to a delay in seeking an autism assessment and the difference in diagnostic rates as a result (Burkett et al., 2015).

1.3: Autism Assessment Guidelines

Autism assessment guidelines in the UK are based around the diagnostic criteria set in the DSM-5 and ICD-11. For a diagnosis of autism to be made, symptoms must include persistent deficits in social communication and social interaction across multiple contexts and restricted, repetitive patterns of behaviour, interests or activities that are clearly atypical or excessive for the individual's age and sociocultural context (APA, 2013; WHO, 2022). The diagnostic criteria also state that symptoms must be present in the early developmental period, cause significant impairment in social, occupational or other areas of functioning and are not better explained by intellectual disability or developmental delay (APA, 2013).

A comprehensive autism assessment typically includes considering the primary features of autism according to both the DSM-5 and ICD-11 as well as developmental history, behavioural difficulties, functioning at home, school or work, special interests, attention to detail, hyper-or-hypo sensory sensitivities and consideration of other diagnoses or coexisting conditions (NICE, 2012). This can be gathered through direct observation in a particular setting, at school for example, clinical interview, supporting documents from other professionals such as teachers, Special Educational Needs Coordinators (SENCo) and doctors and autism assessment tools where required (Hayes et al., 2022). Commonly used diagnostic tools include the ADOS and a clinical interview tool such as the ADI-R.

Current Autism Pathway in the UK

The current pathway to an autism assessment through the NHS involves a referral from a professional such as a GP, paediatrician, SENCo or social worker to a secondary service such as a neurodevelopmental or specialist autism service (for adults) or Child and Adolescent Mental Health Service (CAMHS) or community paediatric service (for those younger than 19 years old) (NHS, 2022; Russell et al., 2022). Some services may also accept referrals directly from adolescents/adults, parents or families. Next, subject to the referral being accepted, the case will go through screening/triage and pre-assessment support before subsequently being assessed by a multidisciplinary team (MDT) to determine whether or not a diagnosis is warranted (NHS England [NHSE], 2023; Russell et al., 2022). Some services may also offer post-diagnostic support to service users following diagnosis in the form of signposting to other appropriate service and support around accepting and understanding an autism diagnosis, which may be delivered through evidence-based interventions or general educational and emotional support (NHSE, 2023).

The autism referral and assessment process for children however, remains a major challenge for a large number of parents/carers in the UK. A UK based study by Crane et al. (2016) found that on average, there was a 3-year gap between first contact with a healthcare professional and an autism diagnosis, with just over half of parents reporting dissatisfaction with the process. It is well documented that services have had to contend with increasingly restricted resources in the form of reduced healthcare budgets as part of austerity in recent years (Iacobacci, 2016). This has therefore impacted on the provision of child and adolescent autism services (Crowe & Salt, 2015). There are still significant disparities between the structures in place for meeting diagnostic needs and the level of demand, with targets for assessment timescales in child and adolescent services frequently being missed (British Medical Association [BMA], 2019). Due to the long waiting lists, parents and families may look towards private services for an autism assessment but this obviously presents a financial barrier for many, particularly those of lower SES. Additionally, diagnoses by private services may not always be fed back to GPs but rather clients (parents and adults) are free to use them as they please, which can also contribute to underreporting of autism diagnoses (Russell et al., 2022).

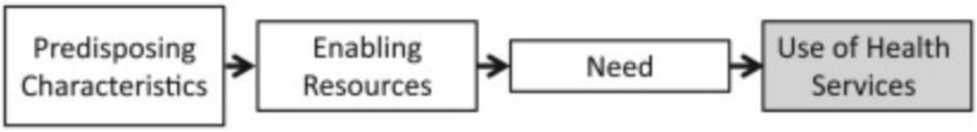
Another challenge services face is the overlap in traits of autism with other conditions such as intellectual disability or developmental delay, which can lead to obscurity when observing behaviours (Hayes et al., 2022; Huerta & Lord, 2012). Diagnostic procedures also tend to differ across services (NICE, 2012), which presents a multi-faceted challenge for diagnosing autism. Considering all of this information, it is understandable how parents, particularly those from minority and disadvantaged groups, may struggle to navigate through these obstacles in attaining an autism diagnosis for their child.

1.4: Healthcare Utilization Model

In trying to make sense of all the different factors that contribute to inequalities in autism diagnosis, the healthcare utilization model (Andersen & Newman, 1973) provides a theoretical understanding towards factors that influence use of healthcare services. These come under three areas according to Andersen and Newman (1973): *Predisposing Characteristics*, *Enabling Resources* and *Need*. *Predisposing Characteristics* include demographic categories such as race, ethnicity, sex, age and health beliefs. *Enabling Resources* include resources that encourage people to use services such as level of income, family support, access to services and cultural and community attitudes. *Need* refers to both the perceived and actual need for healthcare services regarding physical and mental health and clinical assessments. A depiction of the model is shown in Figure 1.

Figure 1.

Configuration of Healthcare Utilization Model (Andersen & Newman, 1973)



Studies that have focused on the application of the healthcare utilization model have found awareness of conditions and education level among adults to be associated with use of healthcare services (e.g. Jiang et al., 2020; Kim et al., 2020; von Heymann-Horan et al., 2013;). A Turkish-based study by McManus (2016) found that people living in urban areas were more likely to use healthcare services compared to those living in rural areas, with Başar et al.(2018) reporting that in Turkey, place of residence is among the statistically most important factors behind people's use of healthcare services.

Some studies (e.g. Alkhawaldeh et al., 2014; Jiang et al., 2020) have found perceived general health among people to be an important factor in determining how likely they are to use healthcare services. For example, in Alkhawaldeh et al.'s (2014) study, those who perceived their health as poor tended to use healthcare services more. This is noteworthy in the application of autism because how minority ethnic groups in particular perceive it, such as through a medical, social or predicament lens, cultural norms and belief systems around autism can all influence whether they feel the need to access services for an assessment or support. Furthermore, whether or not individuals experience co-occurring conditions in the form of other neurodevelopmental conditions such as attention-deficit hyperactivity disorder (ADHD), intellectual disability or mental health difficulties such as anxiety and depression, will also impact perceived general health among both disadvantaged groups and need for services.

The model can be criticised for being too simplistic however, vaguely covering the factors that influence healthcare service utilization and perhaps failing to acknowledge the wide diversity of factors and needs of people behind using health services. Some studies for example (e.g. Andrasik et al., 2008; Bayuo, 2017) highlighted that the model does not account for cultural or psychosocial factors as well as structural inequalities that influence healthcare use, particularly among minority ethnic groups. Nonetheless, it does help in putting a lot of what has been discussed into context.

Going back to autism detection in females and minority ethnic groups discussed earlier, increasing autism literacy through enabling access to information and resources around autism could help raise awareness. It can also improve detection and facilitate better judgement among parents/families of females and minority ethnic groups on whether or not they wish to utilise services to seek an autism assessment for their child. Continuing to look at how accessibility to services for females and minority groups can be improved can result in greater service utilization. This in turn could lead to a difference in reported prevalence rates.

1.5: Autism and Mental Health

Research has shown a high prevalence of mental health difficulties in autistic people and that young people particularly are at increased risk of experiencing a mental health crisis (Vasa et al., 2020). A literature review of 23 studies across the USA, Canada, UK, Australia, Belgium, China and Japan found significant reports of mental health conditions such as anxiety, depression and loneliness in autistic university students (Kuder et al., 2021). A case review by Russell et al. (2016) found a high prevalence of anxiety disorders, obsessive compulsive disorder (OCD) and depression in autistic adults and other studies have further shown a high prevalence of anxiety and depression in autistic adolescents and adults (e.g. Hofvander et al., 2009; Howlin & Moss, 2012; Solomon et al., 2012).

Behavioural difficulties and self-harm rates are also prevalent in autistic adolescents, with a reported 56% directing aggression towards parents/caregivers (Kanne & Mazurek, 2011), 30% engaging in self-harm (Soke et al., 2017) and 49% engaging in elopement (Anderson et al., 2012). Suicide rates are also reported to be higher in autistic adolescents and adults compared to the neurotypical population (Culpin et al., 2018). In the study by Vasa et al. (2020), parents reported anxiety, self-harm, verbal and physical aggression as the most harmful behaviours observed in autistic children, adolescents and adults.

An NAS (2010) report provided a comprehensive summary of the mental health challenges faced by autistic children and adolescents in the UK and some of the factors that contributed towards this. The findings included reports from parents of autistic children and adolescents around the numerous occasions they had come across CAMHS professionals who lacked basic understanding of autism, often leading to ineffective and inappropriate treatment of their child’s mental health needs (NAS, 2010). This same report documented that CAMHS Professionals reported how many of their colleagues had not had basic training in autism, meaning they did not feel confident in attending to autistic children and adolescents’ mental health difficulties (NAS, 2010). A lack of understanding from others was also a considerable source of stress and anxiety among autistic children and adolescents, with 83% believing that their difficulties were as a result of not being understood by others (NAS, 2010). Finally, a previous NAS (2006) report found that 34% of parents of autistic children felt that a delay in appropriate support from school had a negative impact on their child’s mental health. These findings suggest a lack of autism understanding across systems as a significant factor behind children and adolescents not getting the right support for their needs and subsequent mental health difficulties.

A study by Ashworth et al. (2025) also looked at the experiences of parents/carers of autistic children and adolescents in seeking support from CAMHS for their child’s mental health needs, with findings indicating the ongoing struggles parents/carers faced accessing necessary support. Parents/carers reported diagnostic overshadowing and lack of professional knowledge about autism as some of the main barriers to referral for CAMHS support for their child (Ashworth et al., 2025). Furthermore, parents/carers who did manage to get a referral reported a lack of reasonable adjustments and offers of ineffective/inappropriate therapies, resulting in their child disengaging and ultimately not benefitting from the service (Ashworth et al., 2025).

Crane et al. (2019) conducted a survey and semi-structured interviews with autistic young adults in the UK and found that a number of them were unsure whether their mental health difficulties were directly linked to their autism, whereas some believed that the longer their autistic needs remained unmet, the more likely it could lead to the start of mental health challenges at some point. Some participants reported difficulty with identifying whether changes in their thoughts, feelings and behaviour were a sign of mental health problems due to experiencing fluctuations in these prior to their mental health difficulties anyway (Crane et al., 2019). Furthermore, some participants felt that any support they were to receive needed to address both their autistic and mental health needs as they felt they were interconnected (Crane et al., 2019). Crane et al. (2019) also found high levels of stigma, struggling to navigate a neurotypical world, delays in receiving an autism diagnosis and barriers to accessing support such as lack of available services, lengthy waiting times and poor transitions from CAMHS to Adult Mental Health Services (AMHS) to be among the most common reports by participants linked to their mental health difficulties.

It is not uncommon for autistic people to have challenges with identifying/describing emotions or understanding and expressing their needs (Hill et al., 2004; Nicolaidis et al., 2014), which in turn can impact their ability to identify the signs of mental health difficulties. Involving autistic people in the design and implementation of interventions aimed at improving mental health literacy can help towards addressing this (Crane et al., 2019). Successful interventions are also heavily dependent on the extent to which they are tailored towards the target audience's needs (Noar, 2006). Following improved mental health literacy among autistic people, seeking and receiving support tailored to their needs can continue the shift towards improved outcomes (Crane et al., 2019).

A limitation of Crane et al.'s (2019) study is the lack of ethnic diversity in the participant sample, with the large majority being of White background. It would be beneficial to understand the mental health experiences of autistic individuals of minority ethnic backgrounds in a bid to reduce structural inequalities concerning autism diagnosis and support. Additionally, greater stigma may be attached to mental health difficulties in minority ethnic groups compared to non-minority groups (Gary, 2005), meaning autistic individuals from minority groups may be even less likely to seek support for their mental health difficulties or unable to access support tailored to their particular needs (Crane et al., 2019).

1.6: Autism and Education

Over the last couple decades, the number of autistic pupils in mainstream schools has increased significantly (Roberts & Webster, 2020). In England, an estimated 70% of autistic children and adolescents are enrolled in a mainstream school (Department for Education [DFE], 2014). With this, a key challenge for many mainstream schools is providing an inclusive, child-centred approach that successfully educates all pupils, including autistic pupils (Roberts & Webster, 2020; UNESCO, 1994). The profiles of autistic people in academic settings varies, most having particular strengths and difficulties which can result in excelling in some academic areas whilst experiencing particular challenges in others (Keen et al., 2016).

Autistic People's Experiences in Education

As reported earlier, autistic people experience high incidences of co-occuring conditions, including mental health and other neurodevelopmental conditions, which can impact on executive functioning and self-regulation (Saggers et al., 2016). This makes the learning environment especially challenging for autistic pupils, where there is an increased expectation to manage these areas of functioning. As a result, mainstream schools often struggle to support the needs of autistic pupils (Roberts & Webster, 2020).

Research has indicated that autistic pupils are not receiving the support they need and tend to have difficulty experiencing successes both in school and beyond (e.g. Burgess &

Cimera, 2014; MacNeil et al., 2009; van Steensel et al., 2011;). Some of the consequences of this include high exclusion rates for autistic pupils, autistic pupils being more likely to receive suspensions or pupils dropping out of school entirely (Brede et al., 2017; MacNeil et al., 2009; Sciutto et al., 2012; van Steensel et al., 2011). Teachers often report feeling ill-equipped, stressed and anxious about meeting the needs of autistic pupils in their classrooms (Roberts & Simpson, 2016). Furthermore, research that has explored environmental factors (e.g. loud noises, curriculum demands and changes in routine) which impact on learning suggests that education professionals require a greater understanding of this as well as the ways these factors exacerbate already high levels of stress and anxiety (Roberts & Simpson, 2016).

Research looking into the school experiences of autistic pupils across demographic groups has also raised interesting findings. Autistic females in particular have reported feeling lonely, isolated and misunderstood in the school environment (e.g. Goodall & MacKenzie, 2019; Honeybourne, 2015), challenges with managing the impact of late diagnosis and coping in a mainstream high school environment (Cridland et al., 2014). Further research focusing on the negative impact of delayed diagnosis and unmet needs of autistic females in school settings has highlighted the high risk of mental health difficulties, feelings of social exclusion and isolation in the long-term through to adulthood (e.g. Baldwin & Costly, 2016).

Tomlinson et al. (2021) found in their study involving interviews with autistic girls that many reported several difficulties in the school environment such as sensory issues, social interaction difficulties and inconsistencies among staff regarding awareness and understanding of their needs. Nelson & Lichwa (2025) interviewed black autistic girls about their experiences in education and found that feelings of racism, ableism and sexism contributed towards feelings of rejection and isolation and also towards disengagement with their learning. Findings also indicated how masking served as a means of navigating a predominantly neurotypical society for these girls, including navigating the complexities of racism, gendered expectations and ableism (Nelson & Lichwa, 2025).

Effective Education Practice for Autistic Pupils

Researchers have suggested a number of effective practices that can support autistic pupils with their learning in school. These include family involvement and collaboration, adapted environment, curriculum and routine, availability of resources, specific staff/pupil support, staff training to increase awareness and knowledge of autism, functional approach towards managing challenging behaviour and transition support (Dawson & Osterling, 1997; Iovannone et al., 2003; Simpson et al., 2003). Tomlinson et al. (2021) concluded from their study that effective collaboration and sharing of information about individual needs and specialised support around social skills development are essential to helping autistic girls navigate everyday interactions and relationships. Tomlinson et al. (2021) also found in their study that positive and trustful relationships between participants and school staff were linked to staff knowledge about their individual needs. This emphasises the need for greater education and awareness around autism for school staff, which could be addressed through appropriate staff training.

In the UK, Special Educational Needs (SEN) schools are also available to autistic pupils with an Education, Health and Care Plan (EHCP) and whose needs cannot be met at a mainstream school (El-Salahi et al., 2023). These schools differ considerably to mainstream schools regarding their provision for SEN pupils, including autistic pupils. Whilst mainstream schools often take an inclusive approach, aiming to integrate SEN pupils into mainstream classes, SEN schools provide specialised and tailored support which may not be readily accessible at a mainstream school (Now Education, 2025). The systematic review by El-Salahi et al. (2023) included papers which highlighted what an inclusive school environment should include, such as improving autism awareness across school and including autistic children and adolescents in classroom-based tasks with peers. In a study that aimed to include autistic children and adolescent voices in the design and implementation of neuro-inclusive school environments, suggestions included natural lighting, mild wall colours, access to large indoor/outdoor spaces, installing classroom windows for green space views, spacious and structured learning environments (Bahrami & Nejad, 2024). These are all steps both mainstream, SEN and specialist autism schools can adopt to be more neuro-inclusive and support autistic pupils.

The partnerships for inclusion of neurodiversity in schools (PINS) (DFE, 2025) also sets out provision for neuro-inclusion in mainstream schools across the UK. This is a national programme that aims to bring together specialist health and education professionals along with expert parents/carers to shape neuro- and SEN-inclusive practice within schools, increase accessibility to early interventions within schools, oversee staff training and increase collaboration between schools and parents/carers (DFE, 2025). In doing so, the programme aims to move away from a diagnostic lens and more towards a strengths-based approach by focusing on developing key strengths/skills and enhancing the school environment to better meet the needs of all pupils, including those who are neurodiverse, such as providing sensory tools and multiple ways of accessing learning (DFE, 2025). By achieving this, the programme aims to demonstrate how a structured learning environment and well-equipped school can lead to improved outcomes for neurodiverse children and help maximise their learning opportunities (DFE, 2025).

Resource provision (RP) in mainstream schools is another important step in moving towards inclusive education practice. RP involves providing specialist facilities and support within a mainstream setting to pupils with an EHCP (Bradford Schools Online, 2025). This approach can either take the form of an Inclusive Service Model (ISM) or a Safe Space

Model (SSM) (Special Needs Jungle, 2025). With a ISM, pupils spend the majority of their learning time in the classroom, with support from RP staff and said staff work closely with teachers, parents and other professionals (e.g. Speech and Language Therapists) to adapt lessons and tailor learning objectives to best support neurodiverse and SEN pupils (Special Needs Jungle, 2025). In contrast, a SSM treats RP as a separate classroom within the school, where pupils primarily learn in a separate, controlled space, only joining mainstream classes for certain subjects and activities, such as those that do not require additional support (Special Needs Jungle, 2025).

Schools may opt to use a mix of the two approaches, but the SSM tends to be more common (Special Needs Jungle, 2025). With this however, comes the risk of isolation from peers and missing out on valuable learning opportunities. To help address this, mainstream schools could benefit from considering the use of a RP toolkit, which focuses on a whole school approach, support with transitioning from RP to mainstream classrooms, further collaboration between schools, parents and external professionals and additional support to develop peer relationships as examples of reducing this gap (Special Needs Jungle, 2025).

1.7: Benefits of Early Autism Diagnosis and Support

Receiving an autism diagnosis alone can be beneficial for a number of reasons. Firstly, a diagnosis can be validating for many individuals in helping them make sense of their experiences, fostering positive self-identity and connections with the autistic community (NHSE, 2023). Secondly, it can enable clinicians to recommend to individuals, evidence-based interventions targeted at improving particular skills and abilities linked to autistic traits such as speech, language and communication as well as wellbeing outcomes (NHSE, 2023). Thirdly, an autism diagnosis can facilitate access to academic support for children in the form of an EHCP to help identify their education, health and social needs and create a plan tailored towards meeting these (NHSE, 2023). Additionally, when it comes to future employment and workplace support, having an autism diagnosis can help with advocating for reasonable adjustments (NHSE, 2023).

Early autism identification and diagnosis however can have even greater benefits and this has been supported by several studies. Early autism intervention has been found to be linked with improvements in daily living and social skills (e.g. Remington et al., 2007), suggesting that early diagnosis and intervention are essential to long-term outcomes for autistic children (Elder, 2017). Okoye et al. (2023) particularly highlighted how receiving an autism diagnosis between the ages of 2 and 5 can facilitate early access to intervention focused around these skills as well as enhancing quality of life and reducing parental stress. As a child's brain is still developing during the early stages of life, early intervention may have a greater positive impact than in later life (Okoye et al., 2023). Grzadzinski et al. (2021) also found lower levels of parental stress and anxiety in those who received an early autism diagnosis for their child, improving family functioning more broadly. Taylor et al. (2015) found that greater social outcomes and independence in adulthood were observed in children who received early autism diagnoses and intervention.

According to NHSE (2023), delayed or undiagnosed autism can increase the risk of poorer outcomes in later life, abuse, mental health difficulties, suicide or hospital admission. Autistic people therefore make up a significant proportion of the mental health inpatient population in England (NHSE, 2023).

1.8: The Current Study

Rationale

Based on the literature review, we can establish that disparities exist in autism diagnoses across different demographics, with a number of factors suggested by the research authors that can possibly account for this such as sex and racial biases in autism diagnostic procedures, differences in understanding of autism among White and minority ethnic communities and access to services across different SES groups. Additionally, high rates of mental health difficulties (primarily anxiety and depression) have been reported in autistic adolescents especially. What is not so clear however, is the extent to which autism may be a predictor of mental health difficulties in later life and the underlying factors which may account for this. This is especially the case with autistic individuals from minority ethnic backgrounds. The study by Crane et al. (2019) for example, suggested delayed diagnosis and therefore delayed support as a primary reason behind the mental health reports from their sample.

Study Aims

The current study aims to explore the relationship between autism and internalising conditions and if there are any significant differences between demographic groups such as sex and ethnicity. The study also aims to use this contextual data to help understand the lived experiences of autistic adolescent females across different time periods. This will be done in the following ways:

1) Determine the rate of diagnosis of autism and internalising conditions by sex and ethnicity within the Bradford region.
2) Establish the likelihood of internalising conditions for individuals with an autism diagnosis across sex and ethnicity.
3) Use this contextual data to better understand the lived experiences of autistic adolescent females pre-diagnosis, during diagnosis and post-diagnosis and generate practical solutions for future support.

Chapter 2: Method

2.1: Study Design

The study adopted a mixed-methods approach, using an explanatory sequential design (Creswell & Creswell, 2018). That is, collecting quantitative data to begin with followed by collection of qualitative data to help explain the quantitative findings, including findings that may not be entirely consistent with the collected data (Creswell et al., 2011). This is usually done through seven steps (Toyon, 2021):

1) Setting up ontological and epistemological position.
2) Establishing an approach to inquiry.
3) Collecting data.
4) Analysing quantitative data.
5) Recollecting data.
6) Analysing qualitative data.
7) Integrating and reporting the results.

2.2: Setting up Ontological and Epistemological Position

Ontology

Ontology is defined as the study of truth, reality and existence, concerned with what actually exists in the world that humans can acquire knowledge about through scientific methods (Moon & Blackman, 2014). It refers to an individual's view of reality, the extent to which they believe in that reality and how they contend with that reality when different and conflicting ideas of reality emerge (Moon & Blackman, 2014). Many different ontological positions exist but two fundamental examples are defined by Moon & Blackman (2014):

1. ***Realism*** – Reality is universal, existing independent of human experience and social, cultural, political and historical context.

2. ***Relativism*** – Reality is subject to individual experience situated within social, cultural, political and historical context; no universal truth exists.

Ontological Position of Current Study

The current study adopted a realist ontological position to address study aims 1-2 through the gathering and analysis of quantitative data to determine whether a relationship exists between autism and internalising conditions at district level.

Epistemology

Epistemology is defined as the study of knowledge and how exactly we go about acquiring it (Moon & Blackman, 2014). It focuses on what constitutes knowledge, how scientific methods can be used to both produce and develop knowledge and the extent to which knowledge is applicable to the wider world (Moon & Blackman, 2014). The major epistemological positions are defined below:

1. ***Positivism*** – Knowledge is factual and a product of a universal reality that can only be gained through empirical and observable means such as quantitative methodology (Armstrong, 2013).
2. ***Critical*** – Knowledge is shaped by the social, cultural, political and historical context of the reality it is generated in and is not faultless; it can be subject to change over time. It is measured through interpretive, reflexive and contextual means such as qualitative methodology (Farias et al., 2016).
3. ***Constructivism*** – Knowledge is not factual but instead a product of a socially and culturally constructed reality determined by individual experience; it is measured through subjective and interpretive means such as qualitative methodology (Armstrong, 2013).
4. ***Pragmatism*** – Knowledge is not fixed; it evolves over time and through experience. Reality is truthful or meaningful if it helps provide solutions to

real-world issues. It is measured through the most practical and suitable means for addressing a particular issue, such as quantitative or qualitative methodology or a combination of both in the form of mixed-methods (Johnson & Onwuegbuzie, 2004; Tashakorri & Teddlie, 1998).

Epistemological Position of Current Study

The current study adopted a critical epistemological position to address study aim 3, through the gathering and analysis of qualitative data to explore the lived experiences of participants. This was done with the aim of uncovering contextual and structural factors which might help explain any relationships found in the quantitative data.

Overall Position of Current Study

Based on the ontological and epistemological positions adopted above, the current study is underpinned by a critical realist approach (Stutchbury, 2021) to try and get an understanding of the link between autism and internalising conditions from a holistic perspective. A critical realist approach in the context of this study aims to highlight the relationship between autism and internalising conditions among particular demographic groups through objective quantitative data and combine this with the personal experiences of autistic adolescents to suggest possible underlying factors behind this relationship to guide recommendations for change and improvement. Whilst a positivist approach (Park et al., 2020) would allow for identifying hard facts regarding the link between autism and internalising conditions between demographic groups at population level and a constructivist approach (Badie, 2017) would enable us to explore this relationship at an individual level through personal experience, neither approach in isolation would provide a holistic picture of the issue. Therefore, a critical realist approach was deemed to be the most suitable means of achieving the study aims, making it particularly ideal for a mixed-methods approach.

2.3: Establishing an Approach to Inquiry

CLEVER Framework

The study design was informed by The Connecting Lived Experiences with Visualisation of Electronic Records (CLEVER) framework (Elshehaly et al., 2023) by combining the statistical analysis of Connected Bradford datasets (Aims 1 – 2) with the lived experiences of adolescent females (Aim 3). The CLEVER framework is a theoretical framework designed to combine quantitative data in the form of linked electronic records, with qualitative data in the form of lived experiences of individuals and communities (Elshehaly et al., 2023). It aims to add context to routinely gathered electronic datasets through the application of lived-experience data to help inform both decision- and policy-making procedures across multiple contexts such as healthcare, social care and education (Elshehaly et al., 2023).

It was hoped that the findings from the current study could be used to help inform the development of future interventions and policies aimed at reducing structural inequalities in autism identification, diagnosis and support among children and adolescents across demographic groups. This in turn could help increase the likelihood of improved outcomes in future. Therefore, it made sense to use the CLEVER framework to inform the design of this study.

Connected Bradford

Connected Bradford is a database that links together a number of routinely collected datasets, including primary and secondary care, community care, education, and social records collated over a period of over 40 years (Sohal et al., 2022). This includes health and social data for around 800,000 citizens of the Bradford region from 5 NHS Trusts, 86 general practitioner services and 200 schools (Sohal et al., 2022). The datasets include information around appointment history, prescriptions and clinical data (primary care), maternity, inpatient, outpatient and emergency service data (secondary care), mental health, school nurse and health visitor interactions (community care), children's social care data, adult social care data and data from the DFE (Sohal et al., 2022). Examples of studies that have used the Connected Bradford datasets include a study exploring the effect of older age and frailty on timing of cancer diagnosis (Summerfield et al. 2022), a study looking at the underlying factors that contribute towards poor reading skills in children, such as an ophthalmic deficit (Mon-Williams et al., 2022) and a study looking at the effectiveness of using the Connected Bradford datasets to identify undiagnosed autism in children (Wright et al., 2019).

Bradford is a multicultural city in West Yorkshire, UK with a large multi-ethnic population and high levels of social, economic, health and education inequality (Sohal et al., 2022). Therefore, using Bradford as the population setting for the contextual research provides a good opportunity to explore the relationship of autism and internalising conditions, whether there are disparities according to certain demographics, and the potential factors behind this. It also provides the opportunity to explore this at district level to begin with and then, hopefully on a wider scale, help generate practical solutions aimed at reducing these factors.

Collaboration with Connected Bradford Research Team

The study was conducted in collaboration with members of the Connected Bradford research team. It was agreed by both the primary research supervisor (who is part of the Connected Bradford team) and the researcher that statistical analysis of anonymised Connected Bradford datasets would be carried out by a Data Analyst within the Connected Bradford research team. Conversely, variables from the datasets for analysis and reporting and interpretation of results would be chosen and conducted respectively by the researcher. For security and confidentiality purposes, these are standard procedures for external researchers who wish to use information from Connected Bradford datasets.

Focus Groups

It was mutually agreed by the researcher and research supervisors that focus groups would be a suitable method for Aim 3 of the study (Use the contextual data to better understand the lived experiences of autistic adolescent females pre-diagnosis, during diagnosis and post-diagnosis and generate practical solutions for future support). The benefit of using focus groups is that they can elicit information in a way that enables researchers to explore why a particular issue is significant and what is significant about it (Morgan, 1988), invite participants to share their ideas and experiences and also build on these through facilitated discussion (Leung & Savithiri, 2009). Secondly, focus groups allow researchers to explore a particular issue in a group dynamic and encourage a collaborative space for participants to bounce off each other (Leung & Savithiri, 2009). Finally, focus groups can be empowering for participants as they are consulted as experts by experience and are given the opportunity to collaborate with researchers to try and influence change in a given area (Gibbs, 1997).

Guidance around running focus groups recommends having around 7 to 10 participants per group (Leung & Savithiri, 2009). The focus groups in the present study aimed to adopt this same recommendation as having this number in a group would give participants the best chance of feeling comfortable sharing their experiences and maintaining psychological safety.

Interviews

Semi-structured interviews were initially planned with participants and their parents/carers as a follow up to the focus groups to gather further data and explore key messages and themes that arose from the focus groups in greater depth. The benefit of semi-structured interviews is that they offer flexibility and autonomy for the researcher to explore key themes and messages whilst also providing rich, in-depth data (Adeoye-Olatunde & Olenik, 2021). However, due to the recruitment challenges, this was unfortunately not possible given the remaining timeframe for the project. A one-to-one interview design would have been used in order to give priority to the interviewer-interviewee relationship and minimise the influence of external voices (e.g. parents/carers) over the voices of participants. Additionally, this design helps to reduce stress/threats to the interviewee and make the environment as comfortable as possible for them (Legard et al., 2003). Reflections around interviews not going ahead as hoped are covered in more detail in the *Self-Reflexivity* section.

Ethical Approval

Contextual data was provided by the citizens of Bradford and district and collected by the NHS and other organisations as part of their care and support. As a result, ethical approval for the study was covered under pre-existing Data Sharing Agreements and ethical arrangements for the Connected Bradford datasets. University ethics for the qualitative study was granted by the University of Leeds School of Medicine Research Ethics Committee (SoMREC): MREC 23-074.

2.4: Collecting Data

Contextual Data

Contextual data was initially collected from the Connected Bradford dataset through the analysis of citizen primary care records (n = 1,114,364). However, due to the broad criteria of this search term (everyone with a primary care record), people of all ages were included in this sample. This poses a particular issue given that diagnosis rates have changed over time; such that older individuals may be less likely to have a diagnosis even if the underlying incidence rates have not changed. A similar issue applies for the diagnoses of an anxiety and/or depression; many in this cohort would have been too young to receive a diagnosis related to either.

To address this, the primary care records were only considered for individuals who had Reception year records available in the 2006/2007 and 2007/2008 academic years (one individual without sex information was excluded; final n = 17,523), meaning those individuals will be around 20-22 years old today. This ensured that the data covered a similar time period, ensuring that censoring and any changes in diagnosis rates over time should affect individuals to a similar extent. Please see Table 2 for full demographics.

Table 2.

Demographics of quantitative sample

Variable	N	%
Total	17523	100
Internalising condition		
No internalising condition	15194	86.7
Anxiety only	771	4.4
Depression only	752	4.3
Anxiety and depression	806	4.6
Autism		
False	17169	98.0
True	354	2.0
Ethnicity		
White British	9402	53.7
South Asian	6405	36.5
Other	1716	9.8
Sex		
Female	8417	48.0
Male	9106	52.0

Variables

Autism and Internalising Conditions

Systematised Nomenclature of Medicine Clinical Terms (SNOMED-CT) codes were used to identify individuals with any of the diagnoses of interest from their primary care records. Those with autism were identified using codes provided by NHS Digital (49 codes). Those with an internalising condition (anxiety or depression) were identified using codes from the MULTIPLY initiative (109 codes for anxiety, 151 codes for depression). Individuals were classed as having autism or an internalising condition if any code in the code list matched one listed in their primary care record.

Sex

Both males and females were included in the final cohort gathered from the dataset. An individual's sex was determined from the primary care registration details. The majority of individuals (52%) were male.

Ethnicity

Ethnicity information was partially provided by primary care registration details. Where this information was missing from primary care records, the modal ethnicity listed across school census records was used. When available, the two provided good agreement (92%). Given the major ethnicities present in Bradford, ethnicities were categorised by White British, South Asian, and other ethnicities, with the latter category required due to the small number of individuals in more specific categories contained within.

Contextual Data Analysis

Statistical analysis

The datasets were analysed using logistic regression analysis. Logistic regression is ideal for exploring relationships between one or more independent variables and a single dichotomous dependent variable (Leon, 1998). The dependent variable in this case was dichotomous (i.e. yes/no, true/false etc.). For this reason, logistic regression was deemed a more suitable analysis for this study than other analyses such as linear regression, which is best suited for a continuous dependent variable (Leon, 1998).

The first model only included whether an individual had autism and an internalising condition as the independent and dependent variables respectively. Two additional regressions were performed that included sex and ethnicity as moderating variables, whereby they were interacted with whether an individual had autism. This was then used to determine whether the relationship between autism and internalising conditions was stronger for individuals of a particular sex and/or ethnicity.

Focus Groups Data Collection and Participants

Inclusion Criteria

Adolescents aged 11-18 years who either had a diagnosis of autism or who were on the waiting list for an autism assessment at the time, were invited to take part in the research. The research was particularly interested in the experiences of this target group as they are at higher risk of experiencing delays in autism assessment and unmet needs.

Recruitment

Participants were recruited from a residential specialist school for autistic girls aged 11-16. Multiple recruitment routes were targeted in the hope of recruiting a diverse sample of participants. Other target organisations included a parent-led group for autistic children and young people and a mainstream school, both of which the research supervisors had connections to. However, due to recruitment challenges throughout the project, recruiting a diverse sample proved difficult, meaning sex ended up being the main demographic of focus for the focus groups study.

A letter was drafted to share with the headteacher at the school (who the primary research supervisor had connections with), explaining the purpose of the research and asking whether they would be willing/have capacity to support the project. The letter also asked for help with approaching pupils at the school to share the participant information sheet with them so they could decide whether they would be willing to participate subject to confirmation from the headteacher that the school could support the project. Once headteacher approval was given for the study to go ahead, an email was sent to the assistant headteacher (delegated by the headteacher with making all the necessary arrangements for the focus groups to take place) explaining the project. A copy of the participant information sheet and consent form was included in the email so the assistant headteacher could share with interested pupils to make them aware of the study and decide if they would like to participate.

Informed Consent

Participants who expressed an interest in taking part in the research were provided with a participant information sheet (Appendix A) by the school assistant headteacher. Pupils were encouraged to contact the assistant headteacher with any questions before making a final decision as to whether or not they would like to take part in the study.

Upon confirmation that they had read and understood the purpose of the study, pupils who confirmed their interest in taking part gave verbal consent to the assistant headteacher. A paper copy of the informed consent form (Appendix B) was then signed off by the assistant headteacher on behalf of the participants and approved by the headteacher, who had a duty of care for the pupils. Participants were still encouraged to contact the assistant headteacher with queries at any stage and were informed that these would be passed onto the researcher.

Materials

A semi-structured focus group schedule (Appendix C) was developed to facilitate the discussion of the focus groups. Questions were informed by the literature, study aims and discussions during supervision. Examples of these questions included those around participants' experiences pre-diagnosis, whether participants felt their needs were met in a timely fashion and if not, what impact this had on them, and what changes participants felt are needed to help identify and support autistic adolescents earlier.

Procedure

Focus Groups

Once the assistant headteacher had completed the informed consent form on behalf of the participants, they coordinated with the researcher, pupils and headteacher to arrange a convenient date and time for the focus groups. Once a convenient date and time was agreed, a confirmation email was sent to the researcher. Both focus groups took place face-to-face at the school on the morning of 21st July 2025. The groups ran back-to-back, lasting 40 minutes and 50 minutes respectively. The researcher began the focus groups by introducing themselves, their role and providing a short summary to the participants about the research and what they hoped to achieve from talking to them.

To help with engagement and the flow of discussion, it was planned for the focus group schedule be used flexibly to introduce questions, as a prompt and follow up on important discussion points and to help keep participants on track if necessary. As such, the researcher aimed to adopt more of a facilitator role and for the discussions to be participant led and conversational as much as possible. Reflections around group facilitation and managing dynamics are covered further in the *Self-Reflexivity* section.

Ethical Considerations

It was acknowledged prior to the study that the focus group discussions may bring up sensitive topics for participants. Participants were made aware of this at this stage through the participant information sheet and that they had the right to withdraw from the research at any point up to two weeks after the focus groups should they wish. This was also reiterated to participants before the focus groups began and that they should only share what they feel comfortable sharing. The researcher also double checked with participants to get their consent about whether they would still like to go ahead with the groups.

Each focus group included the assistant headteacher and another teacher from the school sitting in and helping facilitate both focus groups where appropriate. It was felt that having staff members who participants were familiar with would help in making them feel comfortable and be readily available to participants for support during discussions should it be needed. Participants were encouraged to let the researcher and/or the assistant headteacher and teacher know if they had any questions, concerns or needed support at any moment during the discussions. Time was also left at the end of the focus groups to address any questions/concerns participants had and offer additional support if needed.

The focus groups also took place in a sensory-friendly classroom at the school. This was important both for providing familiarity and to minimise the risk of sensory aversions among participants, in turn reducing the risk of dysregulation and disengagement.

Recording and Transcription

Both focus groups were audio recorded on an encrypted device for the purpose of transcription using Microsoft Teams. Participants had given their consent prior for the focus groups to be recorded and this was confirmed with all participants in the session before starting recordings. Recordings from both groups were transcribed via Microsoft Teams initially and then checked and refined for accuracy using TP Transcription, a professional transcription service. Following this, all transcripts were anonymised and participants were given pseudonyms to maintain confidentiality.

Participants

Fifteen autistic pupils expressed an interest in taking part in the focus groups and all fifteen went on to give their consent to participate in the focus groups. Per the recommendation by Leung and Savithiri (2009), the participants were split between two focus groups, with 7 participants in the first group and 8 participants in the second group. Group participants were sorted according to proximity of age, trying to get as many participants around the same age in each group. The aim here was to aid group dynamics and facilitate conversation/understanding between similar aged peers. Demographic information of focus group participants is displayed in Table 3. Age when diagnosed with autism is not presented in the demographic information but varied across the groups, ranging from ages 4 to 11.

Table 3.

Demographics of focus group participants

Participant Pseudonym	**Sex**	**Ethnicity**	**Age at focus group**
Bulma	Female	White British	14
Launch	Female	White British	13
Chi-Chi	Female	White British	14
Zangya	Female	White British	12
Videl	Female	White British	13
Pan	Female	White British	15
Bulla	Female	White British	13
Marron	Female	White British	13
Kale	Female	White British	13
Coco	Female	White British	15
Erasa	Female	White British	12
Fasha	Female	White British	13
Gine	Female	White British	15
Caulifla	Female	White British	13
Suno	Female	White British	14

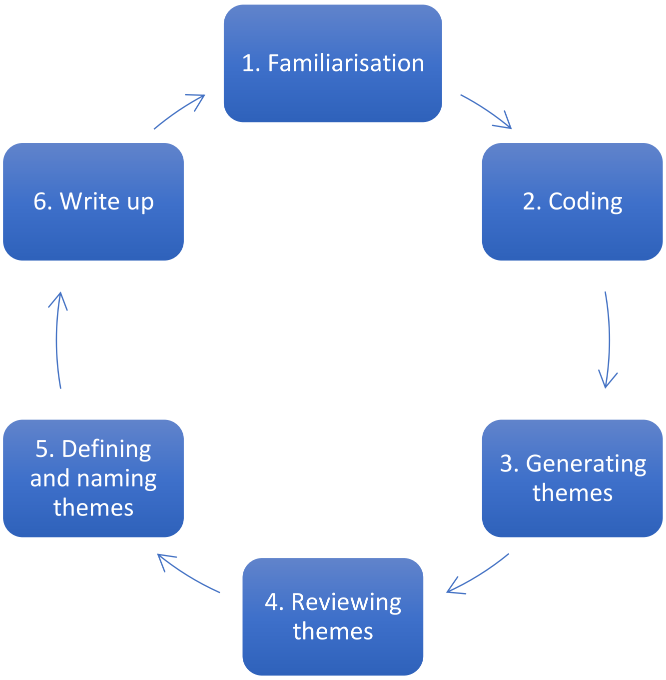
Focus Group Data Analysis

Thematic Analysis

Thematic Analysis (TA) was used to analyse the data from focus groups. TA offers a highly flexible approach to qualitative analysis whilst still providing a rich and detailed account of the data (Braun & Clarke, 2021). TA also offers a valuable approach towards analysing the various perspectives participants bring, highlighting similarities and differences and the unforeseen insights that can come from this (Braun & Clarke, 2021; King, 2004). In line with the critical realist approach this study adopted (Stutchbury, 2021), inductive TA was utilised in order to adopt an exploratory approach and allow for data-driven themes and insights to emerge without any pre-existing notions and theories. The data from focus groups was analysed with the aim of prioritising the voices of a marginalised group in the context of autism diagnosis and support and the risk of internalising conditions. Therefore, using an inductive approach was deemed to be the best approach towards eliciting insights into participant experiences and reducing interpretation bias that could potentially arise from drawing on pre-existing notions and theories. It was also felt that this would increase the likelihood of informing meaningful recommendations targeted at different systemic levels. Data from the focus groups were analysed using the six steps of TA (see Figure 6).

Figure 6.

The six steps of thematic analysis (Braun & Clarke, 2021)



Following a process of familiarisation, which involved transcribing the focus groups and reading through the transcribed data a couple times, initial coding began. This involved attaching labels to parts of the data which best described their content. Codes were regularly reviewed and edited throughout the initial coding process and codes that were closely related in content or that highlighted similar messages/patterns were colour coded. From here, initial themes and sub-themes were generated which captured the overarching message of these codes. An example of this process is illustrated in Appendix D.

Credibility Checks

Given the existing literature on the disparities in autism diagnoses and timely assessments between demographic groups, some of the potential reasons behind these disparities, high incidences of mental health conditions among autistic people and high incidences of masking particularly among autistic females, it would have been easy to assume that these might be some of the reports to emerge from participants in the focus groups. The researcher was aware of the possibility of this bias influencing the focus group schedule and final data and took steps to minimise this where possible.

To ensure themes and sub-themes generated during analysis were both reliable and credible, credibility checks were carried out by a Qualitative Researcher and Trainee Clinical Psychologist, both independent to the study. This process involved the Qualitative Researcher and Trainee Clinical Psychologist completing Steps 1 to 3 of TA (*Familiarisation, Coding and Generating Themes)* independently before the researcher met with both separately to compare initial themes and sub-themes. Following both meetings, the researcher completed Steps 4 to 6 of TA (*Reviewing Themes, Defining and Naming Themes and Write Up)* independently, with particular focus on grounding in the data during Steps 4 and 5 by re-analysing it all to uncover any new themes whilst amending initial themes to see what new theories and understanding might emerge. This process involved listening back to the audio recordings for the purpose of checking for accuracy of existing themes as well as looking out for any new emerging themes.

Chapter 3: Results

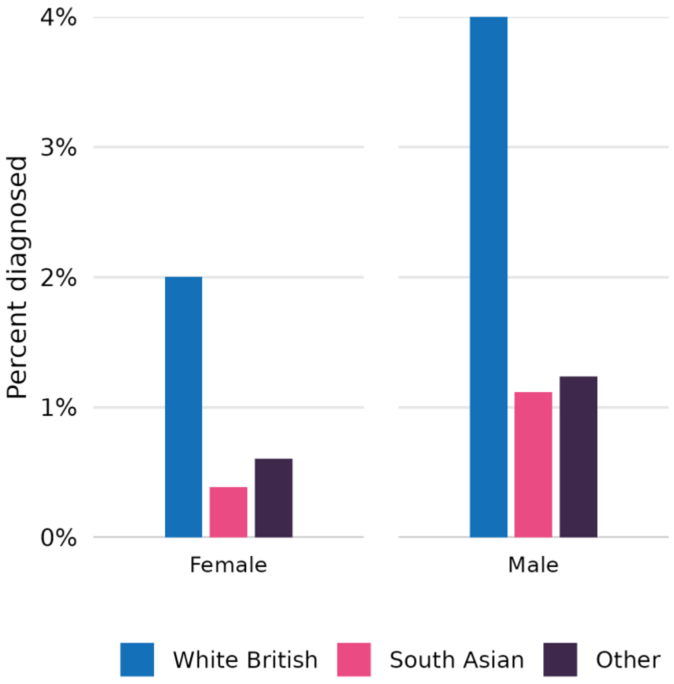
3.1: Contextual Data

Rate of Diagnosis - Autism

When looking at whether the rate of diagnosis of autism differs across sex and ethnicity, White British individuals were most likely to be diagnosed with autism, with males being more likely to be diagnosed compared to females. Figures 2 illustrates this distribution.

Figure 2.

Rate of diagnosis of autism across sex and ethnic groups

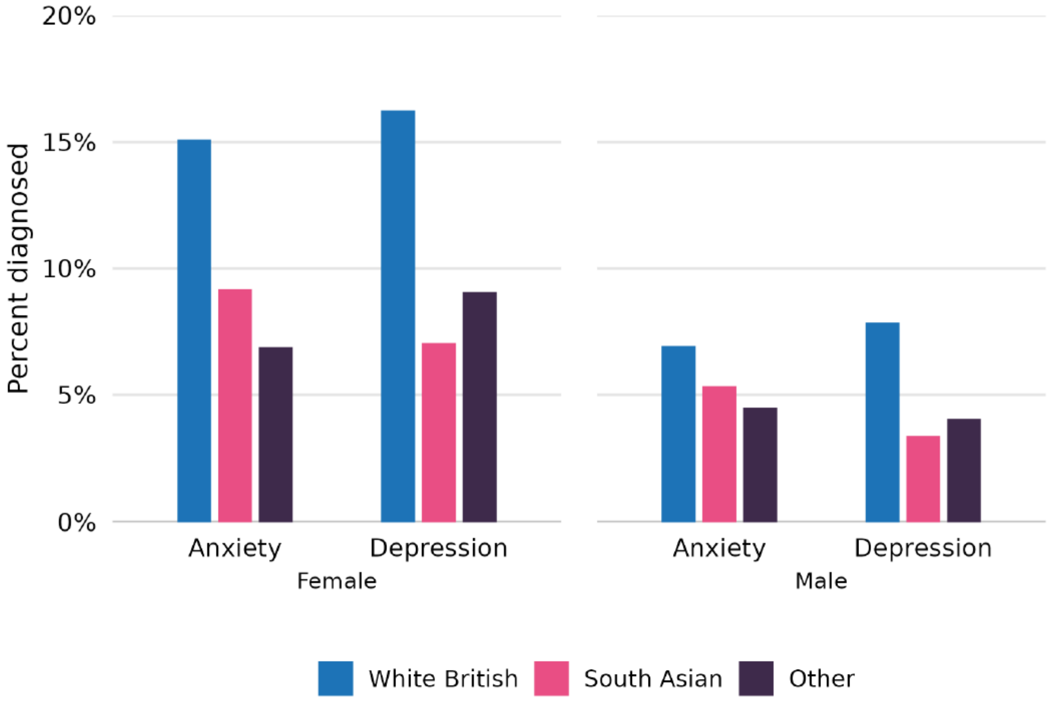


Rate of Diagnosis – Internalising Condition

Looking at the rate of diagnosis of internalising conditions across sex and ethnicity, females were found to be more likely to have an internalising condition compared to males. Moreover, White British individuals were found to be more likely to have an internalising condition compared to South Asian and Other groups of individuals. This appeared most prevalent in White British Females. These comparisons are shown in Figure 3.

Figure 3.

Rate of diagnosis of internalising conditions across sex and ethnic groups



Relationship between Autism and Internalising Conditions

Pulling everything together, is autism related to internalising conditions? Table 4 shows that the rate of internalising conditions for individuals with an autism diagnosis was higher (42%) compared to individuals without an autism diagnosis (13%). This suggests that within the Connected Bradford cohort, individuals with an autism diagnosis were around three times more likely to have an internalising condition compared to those who did not ($\beta = 1.61$, $p < .001$).

Table 4.

Number of individuals with diagnoses relating to internalising conditions and/or autism

	Autism	
Internalising	**False - N (%)**	**True - N (%)**

False – N (%)	14,989 (87.2%)	205 (57.9%)
True – N (%)	2,180 (12.7%)	149 (42.1%)
Total	**17,169**	**354**

Comparisons can also be drawn when factoring in sex and ethnicity. Starting with sex, autistic females were the most likely to have an condition ($\beta = 2.18$, $p < .001$).

With ethnicity, White British individuals with an autism diagnosis had a higher probability of having an internalising condition ($\beta = 1.32$, $p < .001$) and autistic South Asians were the most likely of all ethnicities to have an internalising condition ($\beta = 0.99$, $p < .001$).

3.2: Summary

This contextual data has demonstrated a positive relationship between autism and internalising conditions, with autistic individuals being almost three times more likely to have an internalising condition compared to neurotypical individuals. This suggests that autism could well be a predictor of internalising conditions in later life. Through this study, we were able to demonstrate the value of using routinely collected data from citizen records to investigate this relationship. These findings have important implications for future quantitative research and also for the qualitative part of this study, which will explore the relationship between autism and internalising conditions further and the underlying factors that may contribute towards this. This is important given the implications it can have for the long-term outcomes of the autistic community.

3.3: Focus Group Study Results

The previous section focused on the analysis of Connected Bradford datasets and revealed a significant positive relationship between autism and internalising conditions, with autistic females and autistic individuals from South Asian backgrounds being the most likely groups to have an internalising condition when factoring in sex and ethnicity respectively.

The findings suggest that autistic individuals are at increased risk of internalising conditions compared to neurotypical individuals across the Bradford district.

However, these findings alone are not sufficient in explaining this relationship and the differences between demographic groups nor do they suggest some of the possible factors behind this relationship. In order to better understand this relationship, the CLEVER framework (Elshehaly et al., 2023) was applied to combine these statistical analyses with the lived experiences of adolescents. This section will focus on the lived experiences of autistic adolescent females during different time periods in their lives, including any experiences of internalising conditions and how autistic people can be better supported going forward.

Focus Group Themes and Sub-Themes

The initial TA of focus group data generated 6 themes and 20 sub-themes. Following Steps 4 and 5 of TA (*Reviewing Themes* and *Defining and Naming Themes*), themes and sub-themes which closely aligned with each other were merged to form new ones. During this process, it also became apparent that a diagnostic timeline emerged which captured participants' experiences during different time points in their lives. This helped to shape the final thematic structure from pre-diagnosis to post-diagnosis as shown in Appendix E. This resulted in the final 5 themes and 10 sub-themes shown in Table 5. Each theme and sub-theme will be discussed below with supporting quotes to illustrate each one. The group dynamic varied in both groups with some participants having more to say in response to questions than others, which is reflected in the supporting quotes under each theme.

Table 5.

Themes and sub-themes from focus groups with participants

Focus Group Themes	Subthemes
1. Life pre-diagnosis	a. Challenges of being undiagnosed in school b. Assessment experience
2. Life during diagnosis	a. Quality of support b. Unseen and unheard
3. Life post-diagnosis	a. Importance of school environment b. Positive role models c. Moving forward d. Top tips
4. Understanding of autism	a. Misrepresentation and stereotyping
5. Masking and concealing difficulties	a. Fear of discrimination

Theme 1: Life pre-diagnosis

Most participants discussed their life prior to being diagnosed with autism, giving examples of some of their experiences. Within this, there were two subthemes:

Sub-theme 1a: Challenges of being undiagnosed in school

The first sub-theme relates to the impact of being undiagnosed on participants' school attendance, learning and wellbeing. A couple of participants highlighted their school attendance in particular, stating how much it had *dropped* due to the struggles of coping with the challenges of being undiagnosed:

"*Yeah, my school attendance was awful before I got diagnosed*" (Bulma)

"*My attendance dropped very low. I didn't come in for about two years*" (Videl)

A couple of participants also spoke about their experiences at their previous school and their difficulty coping with the mainstream environment, stating *loud* noises, especially from their classmates:

"*Yeah so it really stopped me from being able to go in because it was so loud and noisy in there, I couldn't cope*" (Bulma)

"*They're (classmates) so loud and they kept going on and on and on. It was awful, I did not like it*" (Videl)

A couple of participants went on to speak about feeling isolated and excluded as a result of their needs. One spoke about the difficulty of going to a school different to their friends, the burden of carrying the label of *special needs* and withdrawing from social interaction as a result:

"*It was kind of difficult going into high school because everybody else went to the same school and I didn't because of the special needs. Everybody knew that like after Year 6, so it was really kind of difficult to talk about it to other people*" (Coco)

One spoke also about their difficult experience at their first primary school, being separated from peers and kept inside during break times due to what was described as *behavioural issues* by their teachers. They reflected on the impact of feeling isolated and bored, stating that it left them feeling tired and distressed with little sympathy and understanding from their teachers regarding their neurodevelopmental needs:

"*I went to two primary schools because the one before was horrible because of my autism so- to the point that they would just keep me inside during playtime not only because I* *was bad but just because it would be better for other students. So, every single playtime, I would be in the hallway sitting on my own. When everyone else would come back in, I'd also be allowed back in but I'd be really bored and tired because I would have done nothing all playtime. Then I'd be stressed out, crying and having a breakdown. Then they would just blame it on me, saying I have behavioural issues*" (Gine)

Overall, this sub-theme highlights some of the challenges and consequences that autistic adolescents, particularly females, commonly experience in mainstream education whilst undiagnosed. The impact of this on adolescents' wellbeing and social interactions can have implications for their school attendance and learning opportunities. Additionally, the lack of understanding from teachers regarding their needs can further compound these challenges for autistic adolescents, potentially leading to instances of masking that will be discussed later in this section.

Sub-theme 1b: Assessment experience

The second sub-theme touched on participants' recollection of their autism assessment experience and what it involved. One participant recalled feeling *awkward* during their assessment, highlighting the different tasks they undertook and how they were unable to make eye contact with the assessor throughout. They also spoke about how it felt to receive an autism diagnosis following the assessment, despite it not coming as a surprise:

"*Mine was really awkward. He set loads of toys in front of me and was just like, 'play with them', and I just laid them out and ordered them. Then he told me to read a story to him and I just couldn't make eye contact or anything. He then called later that night and said I had autism. We kind of knew it, but it was still a bit weird to like think*" (Marron)

A couple of others mentioned different assessment experiences which mostly involved speaking to their parents. One participant recalled playing with one of the clinicians whilst their parents were speaking with the assessor, where the clinician seemingly determined they were autistic due to being controlling during play:

"I think most of the time they just spoke to my parents, and then one of the doctor guys was playing with me and I just kept taking control of everything and he was like, 'yeah, you're definitely autistic'" (Chi-Chi)

Another participant spoke about their assessment mostly involving speaking to their mum. Furthermore, they spoke about how their lack of interaction and eye contact was immediately interpreted as autism by the assessing clinician:

"There was a room and she had a notebook and she was talking to my mum about stuff I did when I was a kid. I was like just sitting there, like not making eye contact, not speaking to her and she said, 'yeah, you've got autism'" (Gine)

This sub-theme highlights the differences regarding what autism assessments might involve and how brief or comprehensive they can be. The sub-theme also highlights how involved participants were in the assessment and some of their feelings towards the assessment at the time. It also suggests how clinicians' preconceived notions around autism can play out and influence their clinical judgement when conducting assessments. This has links to the theme around how autism is understood among family members and professionals which will be discussed further on in this section.

Theme 2: Life during diagnosis

The second theme saw participants reflect on their experiences whilst waiting for the outcome of their assessment or just after receiving their autism diagnosis. There were two subthemes under this theme:

Sub-theme 2a: Quality of support

The first sub-theme captures some of the support participants reported receiving both prior to being diagnosed and soon after receiving a diagnosis. Different levels of support from family and professionals was noted by participants, with some receiving more support than others whilst some also received more helpful support than others.

One participant recalled how their parents had to keep pushing for a diagnosis and reasonable adjustments for them at their school whilst they were on the waiting list for an autism assessment. Ultimately however, they did not receive much support from school:

"*They (parents) did as best as they could. They kept pushing for a diagnosis and support, even though the school was not being helpful. So yeah, they did help a lot*" (Bulma)

Another participant mentioned receiving support from CAMHS in the form of therapy whilst they were on the waiting list for an autism assessment due to reported behavioural difficulties at school. The participant did not find the support too helpful however, finding it difficult to stay engaged over the course of sessions:

"*They (CAMHS) didn't really help but I had like a ton of therapy sessions but that was about it. I found them really boring. I think because I'd done so many I just got really sick and tired of it and I kind of stopped listening to them*" (Launch)

One participant mentioned feeling supported and understood by their primary school at the time after being ignored by their previous school. So much so that they recalled being suggested for an autism assessment by school staff less than a week since they joined the school. They also recalled how accommodating school staff were in implementing reasonable adjustments for them such as scheduled breaks:

"*I was at a primary school and my mum said, 'There's something different going on', and they're like, 'No, there's nothing wrong'. Then I moved to a private school at the beginning of Year 5 and within a week they were like, 'There's something different, you should see if she has autism', and they supported me and said if you need anything, like if you need to go outside, you can*" (Marron)

This sub-theme highlights the varying levels of support participants received both pre- and post-diagnosis from family and professionals. One participant mentioned how much their parents were pushing for an autism diagnosis for them in the hope it would get support for them from school, despite school seemingly not cooperating in putting reasonable adjustments in place. The importance of receiving such support and understanding from parents was highlighted by the participant when they recalled how grateful they were towards them for it. Others forms of support highlighted in this sub-theme also include that from CAMHS for another participant due to reported behavioural difficulties at school. The participant reflected on receiving therapy whilst they were on the waiting list for an autism assessment but not finding them particularly helpful and ultimately disengaged.

Within this sub-theme, there was also a positive report from a participant about how supportive a private school they attended was in suggesting they be assessed for autism following their observations and implementing reasonable adjustments for them in the meantime, such as time outside when needed. This once again highlights the importance of understanding of autism at school level in delivering the right support for pupils.

Sub-theme 2b: Unseen and unheard

The second sub-theme explains how some participants continued to have their needs overlooked at school even after they received an autism diagnosis.

One participant for example, recalled how the lack of support and understanding from teachers towards them at their old school got so bad to the point where it affected them personally and they no longer felt able to attend:

"*When I first got diagnosed I didn't really think much of it but then I think because I knew I had it, I started to realise what I was doing was because of autism but my school just didn't understand. They just couldn't seem to give me the help I needed and it got so bad to the point where I just couldn't physically go*" (Kale)

Another participant also cited a lack of support from their previous school despite being aware of their autism diagnosis. They mentioned how their school failed to deliver on a number of promises regarding reasonable adjustments, such as being allowed to go outside when needed:

"School said they were going to do a bunch of stuff but then they didn't. They said they each time they would give me like 10 minutes outside and stuff. They said like, 'I don't know, just play with paper or something' and then like they just never did that" (Fasha)

This sub-theme indicates how some participants experienced their voices continuing to go unheard at their previous school even once they had been diagnosed with autism. It also speaks to a continued lack of understanding from school staff around autism and how that contributed to their inability to provide appropriate support for them, having detrimental effects on participants such as impacting on their school attendance. This highlights some of the reports shared by participants pre-diagnosis where their school attendance and wellbeing were significantly impacted due to the school environment and lack of understanding and support regarding participant needs.

Theme 3: Life post-diagnosis

The third theme saw participants reflect on their life currently, to living with an autism diagnosis and discussing future aspirations, to some advice they would share with other autistic adolescents who may be going through similar experiences to what they have. There were four sub-themes under this theme:

Sub-theme 3a: Importance of school environment

The first sub-theme captures reflections from some participants about their experiences at their current school and discussing how it compares to their previous schools. They went on to speak about the difference in school environment and how much they feel they benefit from the structured, relatable environment.

One participant for example, mentioned their surprise when they first arrived at the number of pupils that shared similar experiences to them. However, they mentioned how this contributed towards a safe space to share these with each other as well as their feelings:

"*When I came to this school I realised, wow, there's so many people that are going through the same thing as me and I guess I can talk about it. I just kind of can open up about like how I feel and then also about what I have*" (Coco)

Another participant underlined the understanding amongst peers and school staff towards every pupil's individual needs which they felt makes it easy for them to be themselves. They also mentioned how helpful the school are in always trying to provide a solution to each pupil's problem, including if they feel they struggle to be themselves for any reason:

"*I think you just feel understood. Even if you're struggling they find it so easy to just figure out what's wrong and they always seem to have a solution. I just feel at ease here. You kind of feel you can be yourself and if you can't, they help you*" (Caulifla)

It was also stated how beneficial the structured environment at the school was for pupils in settling in and having the best opportunity to engage with their learning. One participant for example, mentioned how much they are benefitting from the smaller class sizes, finding the environment quieter and easier to focus as a result:

"*I like that the class sizes are small. It's just so much more peaceful and it's easier to work with the class because it's so small. It's just easier to cope*" (Suno)

Overall, this sub-theme underlines the importance of the school environment in autistic pupils feeling supported and having their needs met, ultimately giving them the best possible chance of experiencing positive outcomes. The sub-theme describes the different factors that participants highlighted at their current school which they feel contributes towards such an environment such as relatable peers, having a safe space to share experiences and feelings, understanding and support from school staff and structured learning environment such as smaller class sizes.

Sub-theme 3b: Positive role models

The second sub-theme highlighted some of the protective factors participants currently draw on whenever times get difficult for them. Namely, participants spoke about some positive role models they look up to for inspiration and validation. These role models ranged from family, friends and acquaintances, to celebrities and content creators.

One participant mentioned looking up to the footballer, Lucy Bronze as a role model for example. Being autistic herself, the participant mentioned how she especially looked up to Bronze and how her revealing herself to be autistic gave them confidence to do the same and be proud of it. They also spoke about how a celebrity identifying as autistic brought some 'normality' to the condition:

"*When I saw Lucy Bronze, one of my favourite footballers come out and say she's autistic, that made me say to some people that I am. Like, she's really good and it's different when someone like her comes out and says that. Makes you think like, normal people can have it*" (Fasha)

Another participant mentioned their mum as their biggest role model due to how much she had fought and stood by them over the years. They reflected on how she especially did so during a time when there was a lack of understanding and acceptance of autism within their family. Additionally, she reflected on how she never treated them any differently to their siblings and how she did not define them by their diagnosis, which they greatly appreciated:

"*I think my role model is my mum because when I was younger, my dad didn't want me to get diagnosed. She always wanted me to and I know it's because she wanted answers not just for herself but for me too. Some of my family didn't really understand what autism* *was, didn't really accept it. She has always stood by me, never treated me differently because of my autism nor has she treated me any differently to my sisters. I just admire that you know*" (Erasa)

One other participant mentioned someone from their cadet group as their biggest role model. The participant mentioned how the person has been quite supportive towards them, seemingly understanding of everything due to having a best friend who is also autistic and how they have also been offering close support to that same friend:

"*It's just someone I know in my cadet group, but her best mate is autistic and she also has high levels of anxiety, which I have as well, so she's quite helpful. She helps me with pretty much everything. So I think I look up to her*" (Kale)

This sub-theme speaks to positive role models that are seen as protective factors in the lives of some participants. These range from family, friends and acquaintances to public figures and are seen as role models to participants for different reasons. For public figures who are also autistic, this was empowering for one participant particularly as for them, it helped normalise being autistic. Other role models mentioned by participants included parents who took a keen interest in understanding their child's autism and wanted to support them by all means necessary, and peers from local groups such as cadet groups. This was the case for one of the participants who had received close support from a peer whose best friend is autistic and therefore had good insight into their needs. The findings from this sub-theme offer good reason to suggest that having positive role models can be a source of empowerment for autistic people and ensure they continue to appreciate and work towards their strengths.

Sub-theme 3c: Moving forward

The third sub-theme saw participants look towards the future. This included thinking about what they would like to do career wise and what changes they hope to see when it comes to support for autistic people going forward in order to help meet needs earlier and increase the likelihood of better outcomes long-term.

Many participants shared examples of the careers that were of interest to them at this stage with some speaking about the inspiration behind them. A couple of participants for example spoke about wanting to pursue psychology-related careers. The first was keen to understand more about the biology behind the human brain and why everyone functions differently, particularly autistic people:

"*I want to do something with psychology, like understand people's brains and how they work. Like being autistic and understanding that you know every brain's different and it functions differently. They don't have the same biology; I think they're all different and understanding all that, I find it really interesting*" (Marron)

The second was keen to pursue a career in criminal psychology to become an advocate and help challenge the current justice system, which they deem to be unfair:

"*I want to do something like criminal psychology. Just because sometimes when I look on the news and like you know with the justice system, it can be a little bit unfair. I really want to do something where I could help with that because I think that there's a lot of issues in the world. I'd like to be an advocate for that, or like fight for it, because I think it really needs to change*" (Suno)

The other half of this sub-theme brought up points around the changes some participants would like to see in place in future to improve support for autistic people. One of the participants reflected on the system as a whole and their experiences of navigating the complexities of getting into a specialist school. They recalled how much their parents fought to get them into the school and felt the process towards gaining admission to specialist autism schools in general could be improved:

"I think maybe just making like the whole system a lot easier and understandable, because my parents had to fight to get me into this school. I think just making the support and help I need a lot easier to access and not taking as long as it did" (Marron)

The same participant also felt the current referral process for an autism assessment is not the most accessible and needs to change:

"I think just, like the application process isn't that great and the assessment process as a whole was horrible. I got diagnosed pretty quickly but a lot of people didn't, or it took quite a long time to pick up on it. I think it should be like an initial thing they do not necessarily for everyone, but it could be an option to do it from a certain age onwards. Like you could have the assessment and stuff" (Marron)

This sub-theme continues on from the last sub-theme in exploring the positives in participants lives by looking at their future career aspirations and some of the reasons behind these. Career options involving psychology were of particular appeal to a couple participants for reasons related to understanding individual differences and social justice, both of which are common issues related to autism. The second half of this sub-theme brought up suggestions from participants around what needs to be done differently going forward to support and help meet the needs of autistic people in a timely manner. Examples included increased accessibility to specialist schools and a smoother autism assessment pathway. The themes that emerged here may have implications for the *Discussion* section later on.

Sub-theme 3d: Top tips

The fourth sub-theme saw participants share some of their top tips for helping fellow autistic adolescents who may be experiencing similar challenges to what they have done throughout their lives.

One participant shared advice around mixing with peers who are similar in personality and who share similar interests as this makes it easier for one to be themselves and reduces the need to mask:

"*If you struggle to mask, find some friends that are equally as weird as you because it's a lot easier to be around them than people that act like kind of weird*" (Bulla)

Another participant advised others to say away from toxicity and to know their limits when it comes to engaging in certain situations:

"*Don't go near people who are toxic, they're just awful, and don't be by yourself in situations that you can't cope with. We have a growth mindset but don't force yourself into doing things you know you cannot cope with*" (Bulma)

This sub-theme revealed some of the coping strategies participants have utilised to help themselves when faced with challenging situations and to provide tips for other autistic adolescents to help them do the same. A lot of the tips centred around connecting with similar peers and not feeling pressured into situations that have the potential to become too overwhelming, despite the pressure one can find themselves under to develop a growth mindset. These reports therefore form some of the protective factors among participants, adding to the other ones previously discussed. The reports from this sub-theme also begin to acknowledge the difficulty that can come with masking and concealing difficulties as the opening quote from one of the participants takes into account that this can be a struggle for some autistic people. The impact that can come with masking will be discussed in more detail later in this section.

Theme 4: Understanding of autism

The fourth theme was found to be present across all three periods in participants' lives (pre-diagnosis, during diagnosis and post-diagnosis). Participants reflected on both their own understanding of autism and those around them such as family, peers and teachers during these time points. For some participants, it was about how they made sense of their needs before they became aware of what autism is and for others it was the understanding, or lack of from family, peers and school and how this influenced their response towards participant needs. One sub-theme emerged from this theme but most of the reports fell under the main theme, which will be discussed first.

Reports emerged from the focus groups which suggested that a number of participants were not aware they had autism prior to being diagnosed. For one participant, it was particularly the case where they struggled to make sense of their experiences and why they felt so different to their peers. In their words, this led to them not feeling *normal*:

"I just remember like thinking that something was wrong. Like I didn't feel normal or like one of the pupils. 'Oh, it's behavioural issues', but I knew that it was something deeper. I don't think I knew what was going on, but I knew it wasn't normal, it didn't feel right" (Erasa)

Another participant reflected on the understanding their parents had of autism due to the participant's brother being autistic. As such, they mentioned that their parents tried to get them diagnosed from the moment they noticed certain behaviours when they were younger. However, they were denied a diagnosis for a long time as clinicians seemingly could not detect any signs of autism during assessment:

"My parents tried to get me diagnosed when I was very little because my brother's also autistic, so they kind of knew I had something but everyone refused to diagnose me because they thought I was normal" (Caulifla)

For another participant, they spoke about the lack of understanding from school staff despite being aware that they had recently been diagnosed. The participant recalled how their teacher continued to mislabel them as having behavioural issues and the struggle of trying to get them to understand that their needs and behaviours were down to them being autistic rather than anything intentional:

"I think there was a teacher that was very wrong about me having behavioural issues, even though he knew that I was diagnosed, and it was still like battling to get them to understand that I wasn't doing it intentionally and that it was just the way I reacted to things" (Kale)

The reports under this main theme highlight the levels to which autism was understood by participants, parents and teachers. Importantly, for participants, how they felt in comparison to their peers before they were diagnosed was a key in determining whether they felt 'normal'. Understanding from parents towards one participant was seemingly present due to them becoming familiar with autistic traits through the participant's brother. However, they were missed for a long time by clinicians due to them thinking they were normal. Misunderstandings towards participants from teachers was also present within this theme despite being aware that they had an autism diagnosis.

These reports possibly speak to a mixed level of understanding among people of the different ways autism may present across different demographics of individuals which will be interpreted further in the *Discussion* section. The perception of what is 'normal' highlighted in this theme may also link to the sub-theme that will be discussed next.

Sub-theme 4a: Misrepresentation and stereotyping

The sole sub-theme here links to the general theme of understanding of autism as it brought up notions of how autism has been and continues to be subject to misrepresentation and stereotyping in society. Participants reflected on times in their lives where this has played out, bringing up different examples involving comments from others regarding how they look/behave and media coverage of autism they have been exposed to.

One participant gave an example of a movie they recently watched involving a school. The movie which involved portrayals of autistic people, was subject to a fair bit of scrutiny and misrepresentation from the participant as they not only felt they were inaccurate, but also failed to take into consideration how every autistic person is different:

"This school with autistic people, they aren't even autistic. It's so confusing. Like all the misrepresentation, and then there's also some of the movie that are misrepresenting how all autistic people are different, which makes it even worse. So just making a movie and making all autistic people the same gives such a strong stereotype of what they are, but they're often very different" (Pan)

Another participant spoke about how stereotyping plays out in everyday life when meeting new people. They mentioned how people are often surprised to hear that they are autistic based on their appearance and mannerisms and how this may be linked to some of the preconceived notions they have of how autistic people present:

"When I'm meeting people, I won't necessarily tell them I'm autistic straight away and when I do, they can actually be quite surprised by it. I think maybe that's also because autism can be quite like stereotyped into people with severe learning difficulties and that kind of thing, whereas I think here at this school we're all quite high functioning and we're actually like capable. I don't think a lot of people realise that" (Marron)

Overall, this sub-theme draws attention to the different forms of misrepresentation and stereotyping that frequently occur regarding autism in both social interactions and the media. Participants expressed their views on these stereotypes, with many feeling they lead to a false representation of autistic people that fail to account for individual differences or lead to inaccurate comparisons to other conditions such as learning difficulties.

The sub-theme links back to how autism is understood within society in general and has implications for when it comes to interpreting these findings and suggesting some of the factors that may influence these misrepresentations and stereotypes. It also has implications for the potential impact these misrepresentations and stereotypes might have on autistic people. For example, it may influence the degree to which some of them mask and conceal their difficulties, which will be discussed further in the next theme.

Theme 5: Masking and concealing difficulties

The fifth and final theme to emerge from the focus groups was again found to be present in participants' lives pre-diagnosis, during diagnosis and post diagnosis as they reflected on how much they mask and conceal their feelings. For a number of participants, this served as a coping strategy that helped them navigate the social world and still does to a degree for others. It came with a cost however in terms of the emotional impact it would often have on participants as well as those around them. One sub-theme emerged from this theme. Reports under the main theme will be discussed prior to this.

Participants were first asked if they ever went through a period where they masked to hide their difficulties and get through the day. Nearly all participants recalled at least one point in their lives where they would mask with most occurring pre-diagnosis. For one participant, they reflected on how much they used to mask when they were younger pre-diagnosis and how they sometimes still mask now to try and feel *normal*. They mentioned how this comes at the expense of not feeling like themselves however and spoke about how it can affect them mentally, which was especially the case when they were younger:

"*I think masking never really made me feel like myself, I just felt like another person. I think I did it so much that I almost believed it. I think I lost myself, especially when I was younger, because I was really trying to be someone that I wasn't and it drained me. I just wasn't myself and I think it really affected me mentally as well. I didn't really start being myself probably until I came here and sometimes I don't always act like myself; I still mask because I'm trying to be normal*" (Suno)

Another participant mentioned how they still used to mask after they changed primary schools because they were expecting it to be like their previous school where they had some difficult experiences detailed previously. Therefore, they felt the need to mask initially as a means of protecting themselves against what they expected. The participant explained how this would often lead to breakdowns after school however due to the exhaustion of concealing their true self, impacting both on themselves and those around them:

"*When I first went to my good primary school, I thought they would be the same as my old school. So I started masking but then I'd come home afterwards and have a full-on breakdown and not be very nice to my family because I'd just be so tired and exhausted from acting like a whole different person all day. It kind of just destroyed my personality*" (Gine)

For another participant, they reflected on a period at their primary school where the school felt they were not academically capable and appointed a number of teaching assistants to support them in class. According to the participant, the school also disclosed their autism diagnosis. They recalled feeling embarrassed during this time as their classmates quickly would go on to tease them about it, to which the participant would conceal their true feelings due to the embarrassment and because it was easier than expressing how they really felt:

"*My primary school thought I wasn't smart. So they put loads of different teachers to come and sit with me every day and help me do my work. Everybody in my class would notice so it was really embarrassing for me and embarrassment is such a big thing for me. The school also kind of told everybody when I was diagnosed so everybody kind of knew everything and made fun of me for it. So I would just laugh along with them because it was easier than saying that I was hurt*" (Erasa)

The reports from this theme underline some participants' experiences of masking and concealing difficulties during their lives and the factors behind it. For most, it served as a defence mechanism to help navigate the complexities of everyday life and protect against feelings such as disappointment and embarrassment. The mental, emotional and physical effects of masking were revealed by participants, with exhaustion and emotional breakdowns among the reports, impacting both participants and others around them such as family. It was also noted how some participants felt like they lost their sense of self whilst masking in an effort to be 'normal', with one participant admitting to still masking at times at present to feel normal.

The reports here suggest a short term vs. long-term dilemma of masking for participants. In the short-term, it can help autistic people overcome challenging social situations but at the expense of physical and emotional fatigue, therefore having important implications for the wellbeing of autistic people in the long-term.

Sub-theme 5a: Fear of discrimination

The sub-theme under this main theme emerged as a result of reports from some participants about concealing their difficulties out of fear of being treated differently by both peers and teachers.

This was the exact case for one participant, who was worried about being treated differently at school and not in a positive way:

"I think if I raised the whole thing about being autistic and thinking I'm not the same, I was worried I would get treated differently and not in the right way" (Zangya)

Other participants spoke about the fear of being bullied by their classmates as a reason for masking and concealing difficulties. For one participant, they did not speak to anyone about their needs when at primary school as they did not feel the environment was the most supportive due to the nature of their peers:

"I tried my hardest to be as normal as possible because I didn't want anyone at school knowing that I had special needs. My school weren't the nicest group of children, like they weren't very supportive. So I didn't really speak to anyone about it" (Coco)

The same participant mentioned how they still mask at present predominantly outside of school due to some negative experiences in primary school where they revealed their autism diagnosis to peers and got bullied for it:

"Well for me, I still don't really talk to people about it outside of school, because in Year 6, when I did start telling people about it I got really badly bullied. So I just then kind of kept it to myself" (Coco)

This sub-theme reveals how masking was used by some participants to protect against potential discrimination by their peers and teachers both in the past and presently. This was based off factors such as not feeling like their school environment was a safe space due to fear and past experiences of being bullied. As a result, a number kept their difficulties to themselves. The sub-theme once again brings up the short-term vs. long-term dilemma notion as the fear of discrimination led to participants' masking for protection in the short-term but potentially experiencing some of the long-term effects of masking mentioned under the main theme.

3.4: Overall Summary

Themes and sub-themes that emerged from the qualitative study covered a range of lived experiences of autistic participants across different time periods, with similarities and differences between participants from each focus group. The central themes revolved around the challenges of engaging with learning and social relationships in school and everyday life whilst undiagnosed, the varying quality of support and understanding participants received from family, school and professionals before, during and after diagnosis, the misrepresentation and stereotypes of autistic people within the media and the need among participants to mask and conceal difficulties to help overcome tricky personal situations and avoid being bullied. The themes from this study have significant implications for the autistic community in general, which are to be discussed further in the following section.

Chapter 4: Discussion

The aims of the current study were to (i) determine the rate of diagnosis of autism and internalising conditions by sex and ethnicity within the Bradford region (ii) establish the likelihood of internalising conditions for individuals with an autism diagnosis across sex and ethnicity (iii) Use this contextual data to better understand the lived experiences of autistic adolescent females pre-diagnosis, during diagnosis and post-diagnosis and generate practical solutions for future support. Findings from both the contextual and focus groups studies will be contextualised under two overarching categories (*relationship between autism and internalising conditions* and *lived experiences of adolescents*), with additional sub-categories under each to organise the contextualisation of findings according to each topic/theme. Quantitative findings addressing Aims 1 – 2 will be grouped and contextualised under *relationship between autism and internalising conditions*, and qualitative findings addressing Aim 3 will be contextualised under *lived experiences of adolescents*.

4.1: Relationship Between Autism and Internalising Conditions

Risk of Internalising Conditions for Autistic Individuals

White British males were found to be the demographic group with the highest percentage of autism diagnoses in the Connected Bradford cohort and White British females were the group with the highest percentage of diagnosis of an internalising condition (anxiety and/or depression). Findings also suggested that being autistic is linked to a greater risk of internalising conditions as the rate of internalising conditions for autistic individuals was around three times higher than that for non-autistic individuals in the cohort. This relationship was most apparent for females when factoring in sex and South Asians when factoring in ethnicity. White British individuals with an autism diagnosis also had a higher probability of having an internalising condition. These findings are consistent with previous research that has found an increased risk and prevalence of mental health difficulties, particularly internalising conditions, in autistic individuals (e.g. Hofvander et al., 2009; Howlin & Moss, 2012; Kuder et al., 2021; Solomon et al., 2012; Vasa et al., 2020) and a lower prevalence of autism diagnoses in females compared to males (e.g. Fombonne, 2009; Loomes et al., 2017). The findings would also appear to be consistent with previous research that has found a higher prevalence of autism diagnoses in White individuals compared to individuals of minority ethnic backgrounds (e.g. Mandell et al, 2002; Mandell et al., 2009; Tromans et al., 2021).

In trying to contextualise these findings, various factors from the literature review may explain why autistic females especially were found to be more likely to have an internalising condition, such as the barriers to autism diagnosis for this demographic group. These include sex biases that exist in autism diagnostic tools and procedures and a high prevalence of co-occurring mental health conditions in females that can overshadow autism such as anxiety, thus increasing the likelihood of delayed diagnosis (Cook et al., 2024). Masking, which commonly occurs in autistic females, may also explain these findings as it can not only make identifying autism challenging, but also increase the risk of anxiety, stress and depression due to the significant cognitive strain it places (Lai et al., 2016).

Another explanation which can also apply to the finding of diagnostic rates being lower in South Asian and Other ethnicities is the location of study. As mentioned earlier, Bradford is a city with a large multi-ethnic (particularly South Asian) population and a high level of socioeconomic inequality. This is therefore likely to impact on equality of access to healthcare services for this population, particularly in the context of autism assessments, which can lead to underdiagnoses or delayed diagnosis as Thomas et al. (2012).

Although the population setting of the qualitative study differed, some of the themes that emerged may still apply to the quantitative findings around the positive relationship between autistic females and internalising conditions. Reports from autistic adolescent females in the qualitative study included difficulties with school and social interactions whilst undiagnosed, exacerbated by not receiving the needed support from school and healthcare staff. These experiences pre-diagnosis especially were linked to many participants masking to suppress their difficulties and get by. The impact of all these factors as reported, included exhaustion and reduced school attendance for many participants due to feeling unable to cope in the mainstream environment. Whilst reflecting on future support for autistic people, one participant mentioned the need for improvements to the autism assessment process due to the number of autistic females who experience delayed identification and diagnosis. These are difficulties many autistic females across the globe face as highlighted by the previous research presented earlier (e.g. Cook et al., 2024; Lai et al., 2016), particularly in disadvantaged areas. Therefore, it is possible many autistic females in the Bradford district would also have faced these same difficulties during their lives, thus increasing the likelihood of experiencing internalising conditions.

Various other suggestions were presented earlier in the paper around why autism diagnostic rates may vary in both females and individuals from minority ethnic backgrounds. These include females commonly being diagnosed at later ages and experiencing longer delays from initial screening to diagnosis (e.g. Begeer et al., 2013; Shattuck et al., 2009), potential referral biases and institutional racism among healthcare professionals (e.g. Billstedt et al., 2011; Gourdine et al., 2011), cultural bias of diagnostic tools such as the ADI-R and ADOS (e.g. Tromans et al., 2021), differences in norms and expectations around social skills across cultures (e.g. Perepa, 2014), awareness of neurodevelopmental conditions and language barriers within minority ethnic communities (e.g. Tromans et al., 2021). The extent to which these factors may have contributed to the findings from the current study are unknown. However, it would not be implausible to suggest that they may have based on the literature review.

The Healthcare Utilization Model (Andersen & Newman, 1973) discussed earlier can be applicable in contextualising these findings within the Bradford district. When considering the factors this model suggest influence use of healthcare services (*Predisposing Characteristics*, *Enabling Resources* and *Need*), *Enabling Resources* are what encourage people to use healthcare services. This includes factors such as income level, access to services and cultural and community attitudes (Andersen & Newman, 1973). It is highly likely there will be differences between families of lower SES and minority ethnic backgrounds compared to those of White and higher SES backgrounds in level of income, Subsequently, this will mean differences in terms of how easily they can access healthcare services as highlighted in previous research. There could also be differences in attitudes towards autism and education/awareness of autism. Therefore, for families of autistic children and adolescents of lower SES and minority ethnic backgrounds, this will influence the level of *Need* regarding an autism assessment and referring their child to said services ultimately. Thus, this can increase the likelihood of delayed autism diagnosis and identification, increasing the risk of untimely meeting of needs and internalising conditions for autistic individuals of lower SES and minority ethnic demographics.

When thinking more about the significant relationship observed between autism and internalising conditions, current issues around the autism assessment pathway in the UK must be considered. In the study by Crane et al. (2019), some participants reported feeling they could be prone to mental health difficulties in future if their autistic needs remained unmet. Delays in receiving an autism diagnosis and barriers to support such as lengthy waiting times and lack of smooth transitions between child and adult services were also among common factors linked to mental health difficulties reported by participants. NHSE (2023) highlighted some of the long-term risks associated with delayed or undiagnosed autism.

On the other hand, several studies also highlighted the benefit of early diagnosis and support for the long-term outcomes of autistic individuals (e.g. Okoye et al., 2023; Remington et al., 2007; Taylor et al., 2015). On this basis, it would not be implausible to suggest structural inequalities around autism assessment/diagnosis can impact mood and anxiety levels and may have contributed towards the relationship between autism and internalising conditions observed in the current study, especially in females and minority ethnic groups.

Overall, the findings from the statistical analyses of datasets and focus group themes provide real time evidence that highlight the risk of poorer outcomes for autistic individuals in both the short and long term, especially those of female, minority ethnic and lower SES background, should they continue to experience untimely support regarding their needs. This has important implications both for future practice and research.

4.2: Lived Experiences of Adolescents

Life Pre-Diagnosis

Findings from focus groups with autistic adolescent females drew some valuable insights around some of their experiences before, during and after diagnosis. Participants mentioned some of the challenges they experienced in primary school prior to being diagnosed. This included poor school attendance which was linked to difficulty coping with the "noisy" classroom environment as well as feeling isolated, excluded and misunderstood by peers and teachers due to their needs, often leaving participants feeling tired and distressed (Focus Group Theme 1a). Participants also reflected on their experience of their autism assessment, which included descriptions such as "awkward", not being too involved in the process and recollections of being diagnosed off the basis of being observed as controlling and lacking social interaction and eye contact by assessors (Focus Group Theme 1b).

These reports are consistent with findings from previous research which has explored the mainstream school experiences of autistic females. These include reports of feelings of isolation, loneliness and being misunderstood (e.g. Goodall & MacKenzie, 2019; Honeybourne, 2015) and managing the challenges of delayed diagnosis in a mainstream high school environment (Cridland et al., 2014). They also align with some of the findings from Tomlinson et al. (2021), where autistic females reported difficulties they had in their mainstream environment such as sensory difficulties, difficulty with social interactions and inconsistencies among school staff regarding awareness and understanding of their needs.

The consistency in findings may suggest a wider issue of a lack of an inclusive environment in mainstream school settings, particularly for autistic pupils. As the number of autistic pupils in mainstream schools continues to rise as reported by Roberts and Webster (2020) and the DFE (2014). This has implications for how mainstream schools move forward to move closer towards promoting an inclusive environment for all pupils rather than expecting everyone to fit into their structure. The consequence of not doing so may not only further impact on the short-term wellbeing of autistic pupils in the form of isolation, fatigue and distress as reported by participants in the current study, but also increase the likelihood of this continuing long-term into adulthood. Previous research focusing on the long-term impact of unmet needs of autistic female pupils included a higher risk of mental health difficulties (e.g. Baldwin & Costly, 2016). Therefore, it is important that the practical suggestions to be discussed further in the *Clinical Implications* section include those targeted at promoting an inclusive school environment in line with the predicament model of autism/neurodiversity paradigm (Anderson-Chavarria, 2022; Chapman & Botha, 2023), to reduce the likelihood of long-term mental health difficulties (including internalising conditions) for autistic adolescents.

Life During Diagnosis

Focus group participants also reflected on the quality of support they received from those around them just before being diagnosed as well as soon after diagnosis. This included support from both family and professionals. One participant for example recalled how much their parents pushed for reasonable adjustments at their primary school prior to their autism assessment despite school not being very accommodating (Focus Group Theme 2a). Another mentioned receiving CAMHS intervention whilst on the waiting list for an autism assessment due to reported behavioural difficulties at school. However, they did not find CAMHS helpful in providing effective support, ultimately leading to disengagement (Focus Group Theme 2a).

These findings echo those from the NAS (2010), which included several reports from parents of autistic children and adolescents about their experiences of CAMHS professionals lacking sufficient understanding of autism, leading to ineffective support for their child's mental health and behavioural needs. As highlighted by this same report, parents mentioned not getting the right support and professionals lacking sufficient understanding of autism as the biggest contributors to their autistic child's mental health difficulties (NAS, 2010). The findings from this theme are also in line with those from the study by Ashworth et al. (2025), where parents of autistic children and adolescents reported a lack of effective and appropriate therapies offered by CAMHS to their child, resulting in them struggling to engage and ultimately not benefitting from intervention.

The fact that the findings from this theme closely align with those by Ashworth et al. (2025) and the NAS (2010) report comes as a concern, indicating that little has changed in the last fifteen years regarding accessibility of CAMHS services for autistic children and adolescents. Noar (2006) stated how the success of interventions is heavily influenced by the extent to which they are tailored towards individual needs. The longer CAMHS interventions and services continue to lack accessibility will only result in longer delays in meeting the needs of autistic children and adolescents, increasing the likelihood of experiencing internalising conditions and other mental health conditions in the short-term and/or long-term. Therefore, it is important that procedures are put into place aimed at improving both CAMHS and general support available to autistic individuals in future.

It emerged from the focus groups that some participants' needs continued to be neglected by teachers at their previous school even once they had received their autism diagnosis. A continued lack of understanding by school as well as failing to deliver on promises of reasonable adjustments was noted, with this impacting one participant to the point where they no longer felt able to attend school (Focus Group Theme 2b).

This continued sense of feeling unseen and unheard can be interpreted as presenting yet another barrier for autistic adolescents to overcome in the mainstream environment on top of those highlighted previously. Additionally, these findings align with previous research which found that autistic pupils are not receiving the support they need in mainstream schools, often impacting on their ability to experience successes in these environments (e.g. Burgess & Cimera, 2014; MacNeil et al., 2009; van Steensel et al., 2011). Reports from one participant about feeling they could no longer attend school due to their needs continuing to be neglected is reminiscent of examples of the consequences of autistic pupils not receiving the necessary support highlighted by previous research, such as dropping out of school completely (e.g. Brede et al., 2017; MacNeil et al., 2009; Sciutto et al., 2012; van Steensel et al., 2011). A report by the NAS (2006) found that 34% of parents stated that a delay in appropriate support from school had a negative impact on their child's mental health. Autistic pupils continuing to have their voices go unheard is likely to increase feelings of despair, frustration and marginalisation, potentially leading to increased mental health difficulties and higher school dropout rates ultimately. This theme also raises queries around the extent to which school staff understanding of autism ultimately influences the level of support schools feel able to provide to autistic pupils, which will be discussed further later on.

Life Post-Diagnosis

Focus group participants also shared some of their experiences post-diagnosis, including at present. This included reflecting on their time at their current school so far. The school environment was especially favourable with participants, with relatable peers, smaller and quieter classes, quality of understanding and support from school staff and enablement of a safe space to share personal experiences among the key factors that contributed towards such (Focus Group Theme 3a). As a result, many participants felt they were in the ideal environment to support their individual needs and experience successes with their learning.

The findings are line with some of the suggestions from previous research around adapting school environments to be more neuro-inclusive (e.g. Bahrami & Nejad, 2024; El-Salahi et al., 2023). The high level of understanding school staff have around autism is likely to be a significant factor behind how supported focus group participants felt by them, contributing to overall positive relationships. Tomlinson et al. (2021) found in their study that trusting relationships between autistic girls and school staff were underpinned by the level of knowledge among staff regarding their needs. Therefore, this theme not only once again emphasises the importance of appropriate understanding of autism among school staff but underlines the importance of the school environment in pupils' needs being met and reducing the risk of internalising conditions.

Focus group participants mentioned some of the role models in their lives that they look up to for inspiration and validation, particularly during challenging moments (Focus Group Theme 3b). Examples included parents, friends/acquaintances and celebrities. For one participant, their role model was the professional footballer, Lucy Bronze. The participant felt she had helped 'normalise' being autistic by revealing herself to be autistic, feeling it served as inspiration for the autistic community given everything she has achieved in her career. One participant mentioned their mum as their role model having fought to support them over the years when there was little understanding towards them from others. Another participant mentioned a member of their cadet group as their role model due to the support and understanding they received from them. The participant felt a lot of this understanding stemmed from the cadet member having a best friend who is autistic.

These findings shed light on some of the protective factors focus group participants have in their lives. They are in line with a neuroaffirmative approach (Walker, 2021), which promotes an inclusive understanding of autism that recognises the individual differences and strengths every autistic person brings by encouraging practices and initiatives that help bring autistic people closer to these strengths and protective factors within their lives. By having positive role models, especially in the form of successful public figures who identify as autistic, it can both inspire and reassure focus group participants and the autistic community as a whole that their goals and ambitions are attainable and that they are not defined by their diagnosis. This can encourage more autistic adolescents to embrace their neurodiversity and reduce the need to mask in an attempt to conform to societal standards of ‘normal’, which has implications in terms of reducing internalising conditions and other mental health difficulties experienced by autistic people in the long-term.

Reflecting on their lives post-diagnosis also saw participants look towards the future at their career aspirations and what changes they feel are needed to better meet the needs of autistic people going forward (Focus Group Theme 3c). A couple participants for example, expressed an interest in psychology-related careers such as biological and criminal psychology to understand more behind individual differences and social justice respectively. In terms of changes needed to better support autistic people, suggestions from participants included easier access to specialist schools and improvements to the current autism assessment pathway, including the autism assessment process itself. One participant in particular highlighted the inconsistencies in timing of diagnosis and delays in identification of autistic children and adolescents, particularly among females.

These reports reflect some of the issues in the current UK autism assessment pathway as found in previous research such as lengthy waiting times (3-year gap on average) between first contact and autism assessment (e.g. Crane et al., 2016), challenges with supply and demand resulting in difficulties meeting assessment timescales (e.g. BMA, 2019), limited resources and budgets impacting on service delivery (e.g. Crowe & Salt, 2015; Iacobacci, 2016) and current assessment processes and tools being geared more towards identifying autistic traits in certain demographics such as White males (e.g. Cook et al., 2024; Fombonne, 2009; Loomes et al., 2017; Tromans et al., 2021), thus increasing the likelihood of delayed identification in females and minority ethnic groups. Differences in autism assessment procedures between services (NICE, 2012) will inevitably result in variability in thoroughness of autism assessments, which can also contribute towards variations in autism assessment experiences, identification and diagnoses among children and adolescents.

Further delays in autism diagnoses can also have implications for accessibility to specialist schools. Currently, access to specialist schools and an EHCP for pupils in the UK is facilitated by having a relevant diagnosis such as an autism diagnosis. If accessibility regarding these is to be improved in future, which will have implications on timely meeting of needs for autistic children and adolescents, it is fundamental that the current structural inequalities in autism assessment pathways are addressed sooner rather than later.

Some participants shared some key tips to help fellow autistic adolescents who may be going through similar challenges to what they have pre- and post-diagnosis. These included mixing with relatable peers who individuals can feel comfortable around which may reduce the feeling of needing to mask and knowing which peers and situations not to get involved with, especially ones that can be anxiety provoking. These sharing of tips can prove to be useful protective factors against experiencing internalising conditions.

Understanding of Autism

Findings from the focus groups brought up some themes around how well autism is understood at both a micro level (i.e. individual, family, school and healthcare services) and a macro level (i.e. mass media). Participants reflected on their own understanding of their autism pre-diagnosis as well as that from family and teachers (Focus Group Theme 4). Reports included participants struggling to make sense of their experiences, wondering why they did not feel 'normal' compared to their peers. Other reports included one participant reflecting on how quickly their parents identified their autistic traits and looked to get them diagnosed due to having a good understanding of autism. Within this report, the same participant recalled being denied a diagnosis for a long time as they did not align with clinicians' presentation of autism. Another participant however, reflected on the struggle to get teachers to understand their needs despite them being aware of their autism diagnosis, stating how they continued to mislabel them as having behavioural issues.

The findings around participants having difficulty understanding what they were experiencing is similar to previous research which has reported how autistic people can struggle with identifying and/or labelling emotions as well as understanding and/or expressing their needs (e.g. Hill et al., 2004; Nicolaidis et al., 2014). Findings around parent understanding of autism and push for diagnosis again aligns with Andersen and Newman's (1973) Healthcare Utilization Model, with family support and education around autism being the *Enabling Resources* which drove the *Need* for parents to refer the participant for an autism assessment as soon as possible. Findings around teachers continuing to neglect a participant's autistic needs despite being aware of their diagnosis may indicate a deeper need for greater understanding of autism among school staff in order to feel confident meeting these needs. Previous research has suggested that teachers often report feeling under-equipped, stressed and anxious about meeting the needs of autistic pupils in mainstream classrooms (Roberts & Simpson, 2016). Therefore, it is possible understanding of autism among school staff ultimately influences the level of support schools feel able to provide to autistic pupils, as may have been a factor in the participant report highlighted above.

All these findings have implications for the importance of continued developing of resources that increase education and awareness of autism for autistic people, school staff and general public.

Participants also recalled several times where they had been exposed to media material that portrayed false representations and stereotypes of autistic people in society (Focus Group Theme 4a). One participant for example, recalled a movie they recently watched and scrutinised due to its inaccurate portrayals of autistic people and failure to consider individual differences, only reinforcing stereotypes. Within this theme, also came reflections of when participants had been subjected to stereotyping from others. One participant spoke about how they are subject to stereotyping when meeting new people, stating how others tend to be surprised when they hear they are autistic based on their appearance and mannerisms. This was potentially linked to some of the preconceived notions others had about how autistic people present.

These findings have similarities to the different portrayals of autistic people in the media over the years, with many instances of stereotyping, overrepresentations and little acknowledgment that every autistic person is different (e.g. Bethune, 2009; McGrath, 2019; Singer, 2017). Garner et al. (2015) and Dean and Nordahl-Hansen (2021) mentioned how media representations of autism have the power to influence the public in a way academic material cannot. If portrayed accurately, they can increase education, awareness and inclusion but if not, can continue to preserve stereotyping and misrepresentation in society (Dean &

Nordahl-Hansen, 2021). This demonstrates how media coverage of autism over the years may continue to influence understanding of autism at a macro level in society today. This will therefore influence how autism is understood among individuals, families, schools and healthcare services at a micro level. This may account for some of the themes in the focus groups on the lack of understanding around autism, namely from those outside of participants such as school and healthcare staff. In turn, this may influence how able professionals feel in providing meaningful support to autistic individuals and stresses the importance of providing means to improve understanding of autism.

Masking and Concealing Difficulties

Masking was found to be a key theme across different periods in participants' lives within the focus groups (Focus Group Theme 5). Most participants revealed going through a period where they concealed their difficulties to help them get through challenging situations. Reflections included masking both pre-diagnosis and currently to try and feel *normal*. Other factors beneath masking that emerged included protection against anticipated difficulties based on past experiences and protection from embarrassment and being teased by peers due to them being aware of participants' diagnosis. For many participants however, this came at a cost, with reports of mental breakdowns, exhaustion and not feeling themselves noted, impacting on both participants and others around them. For other participants, masking served as a protective factor against potential discrimination from peers and teachers due to reasons such as their school environment not being very supportive and past experiences of being discriminated against due to their needs. This resulted in participants not speaking to anyone about their needs.

The findings from this theme are similar to some of the risks associated with masking highlighted in previous research such as anxiety, stress and depression due to the cognitive strain it can have (e.g. Lai et al., 2016). The findings also align with previous research by

Nelson and Lichwa (2025) who found that masking served as a coping strategy among autistic females as a means of navigating the challenges they encountered in their mainstream school experiences and a predominantly neurotypical society as a whole. The internal struggle within participants to mask in order to feel ‘normal’ can suggest a sense from participants that their needs and experiences were not in line with societal standards of normal as implied by the medical model of autism (Anderson-Chavarria, 2022). For many autistic children and adolescents, they may feel this same pressure to fit this standard and begin looking at being autistic as a problem that needs to be fixed. This pressure coupled with a pressure to mask to meet this need can therefore increase the risk of internalising conditions due to the cognitive and emotional strain that can ensue.

4.3: Strengths and Limitations

Strengths

The current study drew on data from just under a million citizens in the Bradford district from infancy up to young adulthood, underlining the significance of linking education and health records to explore the relationship between autism and internalising conditions. As the datasets were drawn from the Bradford district, it provides real time data on a diverse sample of autistic individuals and individuals with an internalising condition. This lends itself to suggestions around some of the structural and demographic inequalities around autism identification and diagnosis highlighted by previous research that can explain some of the findings from the current study.

This study involved a sample of autistic adolescent females, capturing their voices and experiences. The findings from focus groups further contribute to the evidence base around structural inequalities females face concerning autism identification and diagnosis. Themes from focus groups also uncovered some factors in the lived experiences of participants that can explain the increased risk of internalising conditions in autistic females.

The focus groups took place in-person at participants' school. This meant participants were in an environment and surrounded by peers they were familiar with. This would have helped to make participants feel as comfortable as possible, increasing likelihood of better engagement. Focus groups taking place in-person would also have contributed to better engagement, rapport-building and response to social cues between participants and the researcher.

Limitations

Whilst the current study has some key strengths, it also has some notable limitations. Firstly, challenges throughout the recruitment process were reflected in the demographic sample of focus group participants, with all participants being White British females. This lends itself to sample bias as recruiting from an autistic girls' school increased the probability of such bias occurring. This will therefore raise question marks over the generalisability of these findings, including to minority ethnic groups. The same limitation may also apply to minority ethnic groups other than South Asians, who were highly represented within the statistical datasets cohort due to Bradford's large South Asian community (Office for National Statistics [ONS], 2023). The difference in population settings between the quantitative (Bradford) and qualitative (Surrey) studies may also raise generalisability questions, particularly as the participant demographics in the qualitative study are not representative of the Bradford district. Nonetheless, this study still represents important value in capturing the voices of autistic females and highlighting the demographic inequalities regarding meeting the needs of autistic individuals and the risks that come with this.

Secondly, as mentioned earlier, follow-up interviews did not occur due to the recruitment issues faced and remaining timeframe for the project. This meant that important themes that emerged from the focus groups such as experiences pre-/post-diagnosis and masking could not be explored in more detail with participants. This could have added to the depth of analysis regarding these experiences and impact on participant wellbeing to further understand the factors that increase the risk of internalising conditions. However, focus group themes from the current study have laid important groundwork for future research in this area, which may be explored through interviews.

Thirdly, although in the quantitative study, it was suggested that most internalising conditions co-occurring with autism may have been preceded by the autism diagnosis, the data does not include any contextual information regarding individuals' internalising conditions. As a result, it is unknown the extent to which their internalising conditions were directly linked to their autism or if they stemmed from other factors in individuals' life. Findings from the qualitative study however, provide reason to suggest internalising conditions may have been a result of factors related to autism.

Finally, the use of SNOMED-CT codes to identify individuals with a diagnosis of autism and/or an internalising condition may not have been the most reliable method as it depends on the availability of citizen primary care records. However, this was the best available method at the time of study.

4.4: Clinical Implications

The findings from this study have several training, healthcare, educational, community and systemic implications to help address the sex and ethnicity-based inequalities in meeting autistic children and adolescents' needs in a timely manner, therefore reducing the risk of internalising conditions in both the short-term and long-term.

Training Recommendations

Findings from the current study highlight a critical need for further autism training for education staff (Headteachers, Teachers, Teaching Assistants, SENCos, Nursey Managers, Nursey Assistants and Early Years Practitioners etc.) and healthcare staff (Doctors, Nurses, Psychologists, CAMHS Practitioners, Allied Health Professionals etc.):

- Training should focus on awareness and identification of autism, particularly in females and minority ethnic groups. This should also include training on detecting signs of masking/camouflaging
- Training on how mental health difficulties may present differently in autistic individuals. Additionally, how to differentiate between overlapping mental health and neurodevelopmental conditions such as anxiety and ADHD by developing differential diagnosis frameworks
- Training should be co-delivered and co-produced by facilitators with lived experience from diverse demographic backgrounds. This can improve the quality of training for staff by ensuring they receive advice and suggestions from experts by experience, facilitating the delivery of effective and meaningful support to autistic children and adolescents in future
- Training should draw attention to the current structural inequalities in autism assessment procedures and timely support. Training should stress that these inequalities stem from systemic failures in understanding and identifying autism across diverse demographic groups, rather than from challenges exclusive to said groups
- Training should also highlight the consequences of these structural inequalities and untimely meeting of needs, such as the increased risk of internalising conditions and poorer mental health generally
- Training for education staff on best practice guidance for making school environments as neuro-inclusive as possible to support learning needs. This should include reduction of sensory triggers (loud noises and bright lights), smaller class sizes, 1-to-1 support with neurodiversity-informed staff, flexible

seating, scheduled breaks and increasing access to sensory tools (sensory toys/games and noise-cancelling headphones for example)

- Training for education staff on adopting a neuroaffirmative approach to learning that builds on autistic pupils' strengths and interests. This will help create a more engaging and meaningful learning experience and build self-esteem for autistic pupils
- Training for healthcare staff on developing neuro-inclusive evidence-based interventions to deliver more person-centred, needs based care to autistic individuals
- Further training opportunities for CAMHS Practitioners and Allied Health Professionals (Occupational Therapists, Speech and Language Therapists, Mental Health and Wellbeing Practitioners etc.) to be involved in autism assessment procedures to help reduce assessment waiting times

Healthcare Recommendations

Healthcare services should consider the following recommendations to reduce existing inequalities in autism diagnostic procedures and improve timely support for children and adolescents:

- Further collaboration between healthcare and education staff at both nurseries and schools to offer initial autism screenings/assessments and joint consultations with parents/carers and families where possible
- Increase in post-diagnostic support for individuals and their families around understanding their autism diagnosis, the assessment report and recommendations and how best to support with applying these. Additionally, further resources for signposting to additional educational, wellbeing and specialist community support if necessary. This can be particularly helpful for

increasing awareness, education and support for individuals and families of minority ethnic backgrounds

- Increase in developing community CAMHS satellite services aimed at supporting autistic children and adolescents experiencing mental health difficulties, including internalising conditions
- Continuous audit of autism assessment pathways for evaluation of procedures to identify where improvements can be made to reduce waiting times and structural inequalities. For example, determining whether particular screening/assessment steps can be streamlined and any sex/ethnicity-based inequalities in diagnostic tools and procedures that can be addressed
- Increase in support offered to individuals and families whilst on the waiting list for an autism assessment to prevent difficulties worsening. Examples might include increasing signposting to support for concerns possibly linked to autism such as speech and language support, learning support and/or mental health support

Educational Recommendations

Nurseries and schools should consider the following recommendations for improving support for autistic children and adolescents and moving closer towards a neuro-inclusive environment for all:

- Mainstream schools taking further steps towards adapting their environments to be more neuro-inclusive. This includes classroom adaptations such as sensory-friendly adjustments (adjustable lighting, natural coloured walls, acoustic wall panels, flexible seating options etc.), access to quiet and sensory spaces, increased 1-to-1 support, smaller class sizes and visual timetables

- Promoting neuro-inclusive teaching practices in mainstream schools such as combination of verbal, visual and auditory material, breaking down tasks into steps, summarising written information, additional processing time, scheduled breaks and offering a balance of academic, physical and vocational lessons. Schools should consult autistic pupils and parents/carers for feedback on their teaching methods and how they can be improved to ensure learning needs are met
- Continued investment in establishing wellbeing hubs within schools where autistic pupils have access to evidence-based interventions from neurodiversity-informed practitioners to support their wellbeing
- Nurseries and schools may look to offer information/consultation sessions and provide resources for parents/carers of children showing early autistic traits. This will help with improving detection from early and reducing delays in appropriate support
- Increased collaboration between mainstream and specialist schools to facilitate access and transition to specialist schools for autistic pupils where appropriate. This will help with supporting the application process to specialist schools
- Improved relationships between SENDCos and parents/carers of autistic pupils to support with the EHCP application process and facilitate access

Community Recommendations

Community-based services and organisations can take the following steps to improve support for autistic children and adolescents and their families:

- Culturally-inclusive autism resources for minority ethnic communities to increase awareness, understanding and reduce stigma. South Asian communities in particular may benefit from these resources based on quantitative findings from the current study. In line with the Healthcare Utilization Model (Andersen & Newman, 1973), this enabling of resources can influence cultural and community attitudes towards autism through greater awareness. This can then instil a greater need among minority ethnic families to seek access to services for an autism assessment for their child

- Continued identification and collaboration with positive autistic role models in the community that children and adolescents can access. This can serve as a protective factor by empowering children and adolescents to embrace being autistic and celebrate their individual qualities. This can have implications for reducing masking and impact on personal wellbeing as a result
- Peer support groups for autistic children and adolescents that provide opportunities for social interaction, connection and group activities with peers with shared experiences

Systemic Recommendations

Some general recommendations aimed at improving macro level support and understanding around autism are also suggested. This will influence changes to support for autistic children and adolescents at micro level going forward:

- Continued government investment in NHS services for improvements in autism assessment pathways and diagnostic procedures. The government could benefit from further use of local population data to detect disparities in autism diagnoses across diverse demographic groups. They can then use this data to inform strategies aimed at increasing accessibility to autism assessments and timely diagnosis
- Increased government investment in nurseries and schools around autism provision and development of screening/assessment tools for improved early

detection. This will prevent difficulties escalating from a delay in meeting children’s needs

- Government investment in autism training for healthcare services, nurseries and schools nationwide that addresses structural inequalities in autism detection. This includes training that covers how autism can present differently in females and minority ethnic groups and adapting diagnostic procedures to reduce sex and racial biases. This is important for upholding anti-discriminatory practice and ensuring autistic individuals of particular demographics who are at greater risk of poorer outcomes in later life receive timely intervention.

Initiatives from broadcasting companies that air and produce TV shows and films on autism that aim to gather feedback from autistic viewers on these media representations, whether they feel they are accurate or misleading/stereotypical and how they can better reflect the reality and diversity of autistic people. This is important for improving awareness and understanding of autism at a societal level and influencing how it is understood at micro level, in turn influencing how support is delivered in future.

Chapter 5: Conclusion and Future Research

The current study has shown that a positive relationship exists between autism and internalising conditions within the Bradford district, with females and South Asians at particular risk when comparing demographic groups. The lived experiences of autistic adolescents highlighted some possible underlying factors behind this relationship such as difficulties with school pre-diagnosis, lack of understanding and meaningful support from education staff and clinicians and masking to conceal difficulties, fit in socially and protect against discrimination. On the other hand, themes around the importance of the school environment, positive role models and changes moving forward were seen as factors that could help improve outcomes of adolescents in later life.

Despite the qualitative study including participants not wholly representative of the Bradford region, the findings are in line with previous research on the sex-based inequalities females commonly face in autism identification and diagnostic procedures. This may be one explanation behind why females were found to have lower diagnostic rates in the Connected Bradford datasets. Furthermore, it may explain why females were also one of the demographic groups most at risk of internalising conditions. Future research would benefit from further exploration of the potential factors behind higher risk of internalising conditions for females through a more in-depth method such as interviews. Future research should also take steps to explore the lived experiences of autistic individuals from minority ethnic groups to understand if some of the findings align with previous research findings on the ethnic-based inequalities in autism identification and diagnostic procedures.

The current study demonstrated the benefit of using regional data to identify disparities and relationships and integrating this with the lived experiences of adolescents through the CLEVER framework. Future research could look to adopt this same method in other UK cities with high socioeconomic inequalities. This will help with building a national picture of the disparities in autism identification and diagnoses across the country and inform solutions aimed at resolving this and improving the outcomes of autistic individuals going forward.

Chapter 6: Self-Reflexivity

As this thesis draws to a close, I will share a few reflections on my position throughout the research process, as well as the rewards and challenges faced, both personally and professionally.

As the lead researcher of this project, although every effort was made to reduce bias and be as neutral as possible, I fully acknowledge my position as a university educated Black neurotypical male and the potential impact of this on my approach towards this research. I understand that with my identity may come multiple positions of power and privilege, particularly from the perspective of a participant group that has faced numerous barriers in society regarding access to healthcare and educational support and equal opportunities. Being of Black African ethnicity, although I too can consider myself to be of a marginalised group, I also appreciate my privilege in the opportunities I have been afforded. As such, I acknowledge that as much as I could sympathise with this participant group, I could not truly empathise with them given the sheer difference in experiences between us. This especially felt the case when considering my position as a neurotypical male and the privileges that come with this regarding not being subjected to many of the systemic inequalities that autistic females face.

Upon reflection, this may have impacted on my ability to explore certain points of discussion, as I would have liked such as masking among participants and their understanding of autism. This was due to me still developing my own understanding of masking and how differently autism can present in females. Nonetheless, as the focus groups progressed, I found myself becoming more comfortable with this uncertainty; adopting a curious, non-judgemental position through active listening and follow-up questions to invite participants to elaborate further on some of their reports.

Whilst the possibility of neglecting, minimising or completely missing personal views and important points during discussions remained, I was keen to strike a fine balance between asking the relevant questions from the focus group schedule, whilst still being guided by participants. To help with this, rather than being the one to ask several questions and do most of the speaking, I adopted a facilitating role between topic questions, allowing participants more autonomy over the flow of conversation and any other helpful points of discussion. This was particularly apparent through the discussions around participants' role models and future aspirations. I felt this was key for making the focus group experience for participants as engaging as possible and for rapport building, as well as empowering them to feel that they had an influence in discussion matters. I believe this flexible approach ultimately proved successful not only for those reasons, but because it allowed for some important themes to emerge which still had implications for the research question.

As highlighted in the *Results* section, the dynamics in both focus groups varied, with some participants having a lot more to say than others. The exact reasons for this on the day were unknown, with several possibilities such as differences in personalities, shyness, social anxiety or unfamiliarity of me possibly accounting for this. The differences in contributions from others however, did lead to some long pauses of silence particularly during the first group (where this dynamic varied the most). Efforts were made to create a safe space where the group felt as comfortable and conversational as possible as mentioned previously. However, on reflection, it may have been helpful to consider inviting participant views on doing small breakout groups for some of the discussion topics. This may have encouraged quieter participants to open up in smaller groups with peers they are more familiar with and share responses/ideas which they could have then brought back to the wider group. This would be something to consider trailing if running such groups again in future. Being more comfortable with the pauses of silence and not feeling the urge to say something to fill the silence could also have helped. Waiting a bit longer and giving participants every opportunity to fill the silence may have resulted in some of the more reserved ones speaking up more. This is another consideration for future practice.

As my understanding of the sex, SES and ethnicity-based inequalities faced by autistic individuals and the long-term implications of this for health and wellbeing increased through undertaking this research, I was keen to ensure this was reflected in the focus group schedule and in qualitative data analysis. Personal supervision was helpful for gaining feedback on focus group schedule designs. Equally, consultations with a Qualitative Researcher and Trainee Clinical Psychologist, independent to the project, were used to compare initial themes and sub-themes. This helped in consolidating these, whilst also helping inform new themes and sub-themes that were missed in the initial analysis. This ensured that the voices of a marginalised demographic of participants were captured and represented as accurately as possible in the final analysis and report.

This project has been a beneficial and rewarding learning experience. It has been helpful in developing my understanding of the relationship between autism and mental health, namely internalising conditions, and some of the key contributors towards this in the form of sex and ethnicity-based inequalities regarding autism detection, diagnostic procedures, and access to timely support. Through interpreting dataset analysis, I have gained an understanding of the benefits and efficacy of using linked regional health and education data to identify disparities in autism diagnoses between demographic groups, particularly in deprived regions. It has been valuable in understanding how the intersection between socioeconomic inequalities and access to appropriate services/resources can contribute towards the sex and ethnicity-based inequalities observed and how the use of regional data can inform future research aimed at reducing such inequalities. For me, this is a critical next step in protecting the future outcomes of autistic children and adolescents across the UK by preventing further delays in meeting needs and increasing their risk of poorer mental health and quality of life overall.

This project has also been rewarding in getting my first experience of conducting research with lived experience participants. Aside from the reflections previously mentioned, it helped provide insight into the lives of autistic adolescent females and some of the challenges/barriers they have had to navigate in school and social environments. With this, came insight into the impact these challenges had on self-esteem and wellbeing and the need to adopt coping strategies such as masking to protect against this, which also came with its consequences. It was intriguing to witness first-hand how some of the inequalities and experiences of autistic females I had come across through my background research were reflected in the accounts of many participants. It was also helpful in using these accounts to inform my understanding and make sense of some of the relationships found in the analysis of linked datasets. This has inspired me to keep an eye out for further future research opportunities within this area and help contribute towards tackling inequalities and ensuring the voices of autistic individual from marginalised groups continue to be heard.

Despite these rewards however, there have also been some significant challenges. The first of these as touched on previously, revolves around recruitment difficulties faced throughout this process. Despite targeting multiple recruitment organisations early on and advertising the project through different avenues, such as recruitment posters, letters, and by contacting multiple school headteachers and SENCos, recruitment proved challenging. It was not until late in the process that we were able to recruit enough participants for this project. This impacted on the demographic sample of participants as well as data collection.

As previously mentioned, semi-structured interviews were planned as a follow-up to the focus groups which would have allowed for further exploration of key themes from the focus groups. Due to the delays and the remaining timescale for the project once enough participants had been recruited for the focus groups however, this was not possible. This impacted on proceedings in terms of ensuring we captured sufficient data from the focus groups and ensuring this was reflected in the analysis. However, this also had a personal impact. It was disappointing not to have the opportunity for further exploration through interviews given some of the themes that arose from focus groups. I believe this could have been valuable in adding further insight into potential factors behind the relationships established in the quantitative study, particularly in a one-to-one setting where the experiences of adolescents could have been explored in such a way that is difficult in focus groups settings.

It was also disappointing that recruiting a diverse sample of participants proved challenging for reasons above, where different experiences and themes would have likely emerged. This could have provided an opportunity to understand whether some of the suggested reasons behind ethnicity-based inequalities in autism identification/diagnosis highlighted by previous research were also reflected in the accounts of minority ethnic adolescents and how these might be addressed going forward. Being a minority ethnic individual myself, there is perhaps an underlying bias on my part that contributes towards this disappointment, not just for sentimental reasons. I was already aware of the challenges minority ethnic groups face in having their voices heard, particularly through research. However, I was determined to use the disappointment from this experience in ensuring the voices of another marginalised group in autistic females was not minimised and represented as much as possible in this thesis.

With these challenges, also came anxiety. As time passed and the deadline for this project drew increasingly closer, it became difficult to remain calm amid all the delays and not wonder whether I would complete everything in time. This meant being in a position of uncertainty whilst making every effort to ensure this did not have an impact on my application during this research. Thankfully, time was left at the end of each supervision session for a reflective space to acknowledge these challenges and feelings which helped with navigating through this uncertainty/anxiety. Additionally, it allowed my supervisors and I to come together to brainstorm solutions to these difficulties, which led to the opportunity to collaborate with the school for the qualitative part of this study. Finally, these spaces allowed for valuable reflection on the realities of being a researcher and some of the challenges and disappointments commonly faced. These are reflections that I can hold onto and use as a learning experience to identify what might be done differently going forward.

References

Adeoye-Olatunde, O. A., & Olenik, N. L. (2021). Research and scholarly methods: Semi-structured interviews. *Journal of the American College of Clinical Pharmacy*, *4(*10), 1358-1367. https://doi.org/10.1002/jac5.1441

Alkhawaldeh, A., Holm, M. B., Qaddumi, J., Petro, W., Jaghbir, M., & Al Omari, O. (2014). A cross-sectional study to examine factors associated with primary health care service utilization among older adults in the Irbid Governorate of Jordan. *Current gerontology and geriatrics research*,

Ambrose, K., Adams, D., Simpson, K., & Keen, D. (2020). Exploring profiles of anxiety symptoms in male and female children on the autism spectrum. *Research in Autism Spectrum Disorders*, 76, 101601. https://doi.org/10.1016/j.rasd.2020.101601

American Psychiatric Association. (1980). *Diagnostic and Statistical Manual of Mental Disorders* (3rd ed.).

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). https://doi.org/https://doi.org/10.1176/appi.books.9780890425596

Andersen, R., & Newman, J. F. (1973). Societal and individual determinants of medical care utilization in the United States. *The Milbank Memorial Fund quarterly. Health and society*, *51*(1), 95–124.

Anderson-Chavarria, M. (2022). The autism predicament: Models of autism and their impact on autistic identity. *Disability & Society*, *37*(8), 1321-1341. https://doi.org/10.1080/09687599.2021.1877117

Anderson, C., Law, J. K., Daniels, A., Rice, C., Mandell, D. S., Hagopian, L., & Law, P. A. (2012). Occurrence and family impact of elopement in children with autism spectrum disorders. *Paediatrics*, *130*, 870–877.

Andrasik, M. P., Rose, R., Pereira, D., & Antoni, M. (2008). Barriers to cervical cancer screening among low-income HIV-positive African American women. *Journal of health care for the poor and underserved*, *19*(3), 912-925. 10.1353/hpu.0.0037

Armstrong, J. (2013). *Positivism and constructivism*. In J. Arm-strong (Ed.), Improving international capacity development: Bright spots (pp. 28–37). Palgrave Macmillan. https://doi.org/10.1057/9781137310118_3

Armstrong, T. (2010). *The power of neurodiversity*. De Capo Press.

Ashworth, E., Bray, L., Hanlon, C., Stanway, H., Pavlopoulou, G., Moore, D., Donaghy, B., Coen, E., & Firth, E. (2025). 'Accumulating harm and waiting for crisis': Parents' perspectives of accessing Child and Adolescent Mental Health Services for their autistic child experiencing mental health difficulties. *Autism*, *29*(8), 2111-2122. https://doi.org/10.1177/13623613251335715

Aspinall, P. J. (2020). Ethnic/racial terminology as a form of representation: A critical review of the lexicon of collective and specific terms in use in Britain. *Genealogy*, *4*(3), 87. https://doi.org/10.3390/genealogy4030087

Badie, F. (2017). *From Concepts to Predicates Within Constructivist Epistemology*. In A. Baltag, J. Seligman, & T. Yamada (Eds.), Logic, Rationality, and Interaction (LORI 2017, Sapporo, Japan). *Springer.* https://doi.org/10.1007/978-3-662-55665-8_53

Bahrami, B., & Nejad, N. M. H. (2024). Designing autism-friendly schools: Bridging the perspectives of children with ASD and the perspectives of adult stakeholders. *International Journal of Architecture, Engineering and Urban Planning, 34*(1), 1-15. https://dx.doi.org/ijaup.844

Bailey, B., & Arciuli, J. (2020). Indigenous Australians with autism: A scoping review. *Autism*, *24*(5), 1031-1046. https://doi.org/10.1177/1362361319894829

Baio, J., Wiggins, L., Christensen, D. L., Maenner, M. J., Daniels, J., Warren, Z., Kurzius-Spencer, M., Zahorodny, W., Robinson, C., White, T., Durkin, M. S., Imm, P., Nikolaou, L., Yeargin-Allsopp, M., Lee, L. C., Harrington, R., Lopez, M., Fitzgerald, R. T., Hewitt, A., … Dowling, N. F. (2018). Prevalence of autism spectrum disorder among children aged 8 years—Autism and developmental disabilities monitoring network, 11 sites, United States, 2014. *MMWR Surveillance Summaries*, *67*(6), 1–23.

Baird, G., Simonoff, E., Pickles, A., Chandler, S., Loucas, T., Meldrum, D., & Charman, T. (2006). Prevalence of disorders of the autism spectrum in a population cohort of children in South Thames: The Special Needs and Autism Project (SNAP). *Lancet (London, England)*, *368*(9531), 210–215. https://doi.org/10.1016/S0140-6736(06)69041-7

Baker, D. L. (2011). *The politics of neurodiversity: Why public policy matters*. Lynne Rienner Publishers.

Baldwin, S., & Costley, D. (2016). The experiences and needs of female adults with high-functioning autism spectrum disorder. *Autism, 20*(4), 483–495. https://doi.org/10.1177/1362361315590805

Barnes, C. M., Mercer, G. & Shakespeare, G. T. (1999). *Exploring disability: A sociological introduction* (1st ed.). Polity.

Başar, D., Öztürk, S., & Cakmak, İsmail. (2018). An Application of the Behavioral Model to the Utilization of Health Care Services in Turkey: A Focus on Equity. *Panoeconomicus*, *68*(1), 129–146. https://doi.org/10.2298/PAN171121006B

Bayuo, J. (2017). Experiences with out-patient hospital service utilisation among older persons in the Asante Akyem North District-Ghana. *BMC health services research*, *17*(1), 652. https://doi.org/10.1186/s12913-017-2604-6

Begeer, S., Mandell, D., Wijnker-Holmes, B., Venderbosch, S., Rem, D., Stekelenburg, F., & Koot, H. M. (2013). Sex differences in the timing of identification among children and adults with autism spectrum disorders. *Journal of Autism and Developmental Disorders, 43*(5), 1151–1156. https://doi.org/10.1007/s10803-012-1656-z

Bethune, B. (2009). *Autistic License*. https://macleans.ca/culture/autistic-licence/

Bettelheim, B. (1967). *The empty fortress: Infantile autism and the birth of the self.* Free Press of Glencoe.

Bhasin, T. K., & Schendel, D. (2007). Sociodemographic risk factors for autism in a US metropolitan area. *Journal of Autism and Developmental Disorders*, *37*(4), 667–677. https://doi.org/10.1007/s10803-006-0194-y

Billstedt, E., Gillberg, I. C., & Gillberg, C. (2011). Aspects of quality of life in adults diagnosed with autism in childhood: A population-based study. *Autism*, *15*(1), 7–20. https://doi.org/10.1177/1362361309346066

Bishop, F. L. (2015). Using mixed methods research designs in health psychology: an illustrated discussion from a pragmatist perspective. *British journal of health psychology*, *20*(1), 5–20. https://doi.org/10.1111/bjhp.12122

Bradford Schools Online. (2025). *Local authority led Resourced provisions*. https://bso.bradford.gov.uk/content/special-educational-needs-and-disabilities/specialist-provision/local-authority-resourced-provisions

Braun, V., & Clarke, V. (2021). *Thematic analysis: A practical guide*. SAGE.

Brede, J., Remington, A., Kenny, L., Warren, K., & Pellicano, E. (2017). Excluded from school: Autistic students' experiences of school exclusion and subsequent re-integration into school. *Autism & Developmental Language Impairments, 2*, 2396941517737511. https://doi.org/10.1177/2396941517737511

British Medical Association. (2019). *Failing a generation: Delays in waiting times from referral to diagnostic assessment for autism spectrum disorder*. https://www.bma.org.uk/media/2056/autism-briefing.pdf

Brugha, T. S., McManus, S., Bankart, J., Scott, F. E., Purdon, S., Smith, J. E., Bebbington, P., Jenkins, R., & Meltzer, H. (2011). Epidemiology of autism spectrum disorders in adults in the community in England. *Archives of General Psychiatry*, 68(5), 459-465. https://doi.org/10.1001/archgenpsychiatry.2011.38

Buijsman, R., Begeer, S., & Scheeren, A. M. (2023). 'Autistic person' or 'person with autism'? Person-first language preference in Dutch adults with autism and parents. *Autism*, *27*(3), 788-795. https://doi.org/10.1177/13623613221117914

Burgess, S., & Cimera, R. E. (2014). Employment outcomes of transition-aged adults with autism spectrum disorders: A state of the states report. *American Journal on Intellectual and Developmental Disabilities, 119*(1), 64–83. https://doi.org/10.1352/1944-7558-119.1.64

Burkett, K., Morris, E., Manning-Courtney, P., Anthony, J. and Shambley-Ebron, D. (2015). African American families on autism diagnosis and treatment: The influence of culture. *Journal of Autism and Developmental Disorders*, *45*(10), 3244-3254.

Centers for Disease Control and Prevention. (2006). Mental health in the United States: parental report of diagnosed autism in children aged 4-17 years--United States, 2003-2004. *MMWR. Morbidity and mortality weekly report*, *55*(17), 481-486.

Chapman, R., & Botha, M. (2023). Neurodivergence-informed therapy. *Developmental Medicine & Child Neurology*, *65*(3), 310-317. https://doi.org/10.1111/dmcn.15384

Charlton, J. I. (1998). *Nothing about us without us: Disability oppression and empowerment*. University of California Press.

Conn, R., & Bhugra, D. (2012). The portrayal of autism in Hollywood flms. International Journal of Culture and Mental Health, *5*(1), 54–62. https://doi.org/10.1080/17542863.2011.553369

Cook, J., Hull, L., & Mandy, W. (2024). Improving diagnostic procedures in autism for girls and women: A narrative review. *Neuropsychiatric Disease and Treatment*, *20*, 505–514. https://doi.org/10.2147/NDT.S372723

Crane, L., Adams, F., Harper, G., Welch, J., & Pellicano, E. (2019). 'Something needs to change': Mental health experiences of young autistic adults in England. *Autism*, *23*(2), 477-493. https://doi.org/10.1177/1362361318757048

Crane, L., Chester, J. W., Goddard, L., Henry, L. A., & Hill, E. (2016). Experiences of autism diagnosis: A survey of over 1000 parents in the United Kingdom. *Autism*, *20*(2), 153-162. https://doi.org/10.1177/1362361315573636

Creswell, J. W., & Creswell, J. D. (2018). *Research design: Qualitative, quantitative, and mixed methods approaches* (5th ed.). SAGE.

Creswell, J. W., & Plano Clark, V. L. (2011). *Designing and conducting mixed methods research* (2nd ed.). SAGE Publications.

Cridland, E. K., Jones, S. C., Caputi, P., & Magee, C. A. (2014). Being a girl in a boys' world: Investigating the experiences of girls with autism spectrum disorders during adolescence. *Journal of Autism and Developmental Disorders, 44*(6), 1261–1274. https://doi.org/10.1007/s10803-013-1985-6

Croen, L. A., Grether, J. K., Hoogstrate, J., & Selvin, S. (2002). The changing prevalence of autism in California. *Journal of Autism and Developmental Disorders*, *32*(3), 207–215. https://doi.org/10.1023/a:1015453830880

Crowe, BHA., Salt, A. T. (2015) Autism: the management and support of children and young people on the autism spectrum (NICE Clinical Guideline 170). *Archives of Disease in Childhood – Education and Practice* 100(1): 20–23.

Culpin, I., Mars, B., Pearson, R. M., Golding, J., Heron, J.,Bubak,I., & Rai, D. (2018). Autistic traits and suicidal thoughts, plans and self-harm in late adolescence: Population-based cohort study. *Journal of the American Academy of Child and Adolescent Psychiatry*, *57*, 313–320. https://doi.org/10.1101/165860

Daniels, A. M., & Mandell, D. S. (2014). Explaining differences in age at autism spectrum disorder diagnosis: A critical review. *Autism,* 18(5), 583–597. https://doi.org/10.1177/1362361313480277

Dawson, G., & Osterling, J. (1997). Early intervention in autism: Effectiveness and common elements of current approaches. In M. Guralnick (Ed.), *The effectiveness of early intervention: Second-generation research* (pp. 307–326). Baltimore, MD: Brookes.

Dean, M., & Nordahl-Hansen, A. (2021). A review of research studying film and television representations of ASD. *Review Journal of Autism and Developmental Disorders, 9*(4), 470-479. https://doi.org/10.1007/s40489-021-00273-8

Department for Education. (2014). *Special educational needs in England.* https://assets.publishing.service.gov.uk/media/5a749976ed915d0e8bf199d6/SFR26-2014_SEN_06102014.pdf

Department for Education. (2025). *Partnerships for inclusion of neurodiversity in schools (PINS) programme. https://www.gov.uk/government/publications/partnerships-for-inclusion-of-neurodiversity-in-schools-pins/partnerships-for-inclusion-of-neurodiversity-in-schools-pins-programme*

Dickerson, A. S., & Dickerson, A. S. (2020). Brief report: Texas school district autism prevalence in children from non-english-speaking homes. *Journal of Autism and Developmental Disorders*, *50*(4), 1411–1417. https://doi.org/10.1007/s10803-018-3676-9

El-Salahi, S., Khaki, Z., & Vohora, R. (2023). Experiences of inclusive school settings for children and young people on the autism spectrum in the UK: A systematic review. *Review Journal of Autism and Developmental Disorders, 12*(3), 517–534. https://doi.org/10.1007/s40489-023-00405-2

Elder, J. H., Kreider, C. M., Brasher, S. N., & Ansell, M. (2017). Clinical impact of early diagnosis of autism on the prognosis and parent-child relationships. *Psychology research and behavior management*, *10*, 283–292. https://doi.org/10.2147/PRBM.S117499

Elshehaly, M., Eddy, L., & Mon-Williams, M. (2023). CLEVER: A Framework for Connecting Lived Experiences with Visualisation of Electronic Records, *2023 IEEE Visualization & Visual Analytics (VIS), Melbourne, Australia,* 126-130, https://doi.org/10.1109/VIS54172.2023.00034

Farias, L., Laliberté Rudman, D., & Magalhães, L. (2016). Illustrating the importance of critical epistemology to realize the promise of occupational justice. *OTJR: Occupation, Participation and Health*, 36(4), 234-243. https://doi.org/10.1177/1539449216665561

Fombonne, E. (2009). Epidemiology of pervasive developmental disorders. *Paediatric Research*, *65*(6), 591–598. https://doi.org/10.1203/PDR.0b013e31819e7203

Fombonne, E., Heavey, L., Smeeth, L., Rodrigues, L. C., Cook, C., Smith, P. G., Meng, L., & Hall, A. J. (2004). Validation of the diagnosis of autism in general practitioner records. *BMC Public Health*, *4*, 5. https://doi.org/10.1186/1471-2458-4-5

Garner, A., Jones, S., & Harwood, V. (2015). Authentic representations or stereotyped 'outliers': Using the CARS2 to assess film portrayals of Autism Spectrum Disorders. *International Journal of Culture and Mental Health, 8*(4), 414-425. https://doi.org/10.1080/17542863.2015.1041993

Gary, F. A. (2005). Stigma: Barrier to mental health care among ethnic minorities. *Issues in mental health nursing*, *26*(10), 979-999. https://doi.org/10.1080/01612840500280638

Gibbs, A. (1997). Focus groups. *Social research update*, *19*(8), 1-8.

Goodall, C., & MacKenzie, A. (2019). What about my voice? Autistic young girls' experiences of mainstream school. *European Journal of Special Needs Education*, 34(4), 499–513. https://doi.org/10.1080/08856257.2018.1553138

Gourdine, R. M., Baffour, T. D., & Teasley, M. (2011). Autism and the African American community. *Social work in public health*, *26*(4), 454–470. https://doi.org/10.1080/19371918.2011.579499

Graby, S. (2015). Access to work or liberation from work? Disabled people, autonomy, and post-work politics. *Canadian Journal of Disability Studies*, *4*(2), 132–161. https://doi.org/10.15353/cjds.v4i2.212

Grzadzinski, R., Amso, D., Landa, R., Watson, L., Guralnick, M., Zwaigenbaum, L., Deák, G., Estes, A., Brian, J., Bath, K., Elison, J., Abbeduto, L., Wolff, J., & Piven, J. (2021). Pre-symptomatic intervention for autism spectrum disorder (ASD): Defining a research agenda. *Journal of neurodevelopmental disorders*, *13*(1), 49. https://doi.org/10.1186/s11689-021-09393-y

Hacking, I. (2009). Humans, aliens & autism. *Daedalus*, *138*(3), 44–59. http://www.jstor.org/stable/40543987

Hahler, E. M., & Elsabbagh, M. (2015). Autism: A global perspective. *Current Developmental Disorders Reports*, *2*, 58-64. https://doi.org/10.1007/s40474-014-0033-3

Halladay, A. K., Bishop, S., Constantino, J. N., Daniels, A. M., Koenig, K., Palmer, K., … Szatmari, P. (2015). Sex and gender differences in autism spectrum disorder: Summarizing evidence gaps and identifying emerging areas of priority. *Molecular Autism, 6*(1), 36. https://doi.org/10.1186/s13229-015-0019-y.

Harvey-Jordan, S., & Long, S. (2001). The process and the pitfalls of semi-structured interviews: The Journal of the Health Visitors' Association. *Community*

Practitioner, 74(6), 219. https://www.proquest.com/scholarly-journals/process-pitfalls-semi-structured-interviews/docview/213313284/se-2

Hayes, J., Ford, T., McCabe, R., & Russell, G. (2022). Autism diagnosis as a social process. *Autism*, *26*(2), 488-498. https://doi.org/10.1177/13623613211030392

Hill, E., Berthoz, S., & Frith, U. (2004). Brief report: Cognitive processing of own emotions in individuals with autistic spectrum disorder and in their relatives. *Journal of autism and developmental disorders*, *34*, 229-235. https://doi.org/10.1023/B:JADD.0000022613.41399.14

Hofvander, B., Delorme, R., Chaste, P., Nydén, A., Wentz, E., Ståhlberg, O., Herbrecht, E., Stopin, A., Anckarsäter, H., Gillberg, C., Råstam, M., & Leboyer, M. (2009). Psychiatric and psychosocial problems in adults with normal-intelligence autism spectrum disorders. *BMC psychiatry*, *9*(35). https://doi.org/10.1186/1471-244X-9-35

Honeybourne, V. (2015). Girls on the autism spectrum: Hidden difficulties and how to help. *Good Autism Practice*, *16*(2), 11–20.

Howlin, P., & Moss, P. (2012). Adults with autism spectrum disorders. *Canadian Journal of Psychiatry, 57*(5), 275–283. https://doi.org/10.1177/070674371205700502

Huerta M., Lord C. (2012). Diagnostic evaluation of autism spectrum disorders. *Paediatric Clinics of North America*, *59*(1), 103–111. https://doi.org/10.1016/j.pcl.2011.10.018

Iacobucci, G. (2016). Public health—the frontline cuts begin. *Bmj*, *352*

Iovannone, R., Dunlap, G., Huber, H., & Kincaid, D. (2003). Effective educational practices for students with autism spectrum disorders. *Focus on Autism and Other Developmental Disabilities*, 18(2), 150–165. https://doi.org/10.1177/10883576030180030301

Jiang, L., Ye, L., Dai, M., Zhou, J., & Li, Q. (2020). Use Andersen's behavior model to explain non-urgent visits in emergency department: A single center study in southwest China. *International emergency nursing*, *52*, 100845. https://doi.org/10.1016/j.ienj.2020.100845

Johnson, C. P., Myers, S. M., & American Academy of Pediatrics Council on Children With Disabilities (2007). Identification and evaluation of children with autism spectrum disorders. *Paediatrics*, *120*(5), 1183–1215. https://doi.org/10.1542/peds.2007-236

Johnson, R. B., & Onwuegbuzie, A. J. (2004). Mixed methods research: A research paradigm whose time has come. *Educational Researcher*, 33(7), 14–26. https://doi.org/10.3102/0013189X033007014

Jones, S. C., Gordon, C. S., & Mizzi, S. (2023). Representation of autism in fictional media: A systematic review of media content and its impact on viewer knowledge and understanding of autism. *Autism*, *27*(8), 2205–2217. https://doi.org/10.1177/13623613231155770

Kanne, S. M., & Mazurek, M. O. (2011). Aggression in childrenand adolescents with ASD: prevalence and risk factors. Jour-nal of Autism and Developmental Disorders, 41, 926–937. https://doi.org/10.1007/s10803-010-1118-4

Kanner, L. (1943). Autistic disturbances of affective contact. *Nervous Child, 2,* 217–250.

Kanner, L. (1949). Problems of nosology and psychodynamics of early infantile autism. *American Journal of Orthopsychiatry, 19*(3), 416–426. https://doi.org/10.1111/j.1939-0025.1949.tb05441.x

Keen, D., Webster, A., & Ridley, G. (2016). How well are children with autism spectrum disorder doing academically at school? An overview of the literature. *Autism: The International Journal of Research and Practice, 20*(3), 276-294. https://doi.org/10.1177/1362361315580962

Kelly, B., Williams, S., Collins, S., Mushtaq, F., Mon-Williams, M., Wright, B., Mason, D., & Wright, J. (2019). The association between socioeconomic status and autism diagnosis in the United Kingdom for children aged 5–8 years of age: Findings from the Born in Bradford cohort. *Autism*, *23*(1), 131-140. https://doi.org/10.1177/1362361317733182

Kenny, L., Hattersley, C., Molins, B., Buckley, C., Povey, C., & Pellicano, E. (2016). Which terms should be used to describe autism? Perspectives from the UK autism community. *Autism, 20*(4), 442–462. https://doi.org/10.1177/1362361315588200

Khunti, K., Routen, A., Pareek, M., Treweek, S., & Platt, L. (2020). The language of ethnicity: Collective terms BAME and BME should be abandoned. *BMJ*, 371, m4493. https://doi.org/10.1136/bmj.m4493

Kim, K. Y., Lee, E., & Cho, J. (2020). Factors Affecting Healthcare Utilization among Patients with Single and Multiple Chronic Diseases. *Iranian journal of public health*, *49*(12), 2367–2375. https://doi.org/10.18502/ijph.v49i12.4820

King, N. (2004). *Using templates in the thematic analysis of text.* In C. Cassell & G. Symon (Eds.), Essential guide to qualitative methods in organizational research (pp. 256–270). SAGE Publications.

Kirkovski, M., Enticott, P. G., & Fitzgerald, P. B. (2013). A review of the role of female gender in autism spectrum disorders. *Journal of Autism and Developmental Disorders, 43*, 2584–2603. https://doi.org/10.1007/s10803-013-1811-1

Kogan, M. D., Blumberg, S. J., Schieve, L. A., Boyle, C. A., Perrin, J. M., Ghandour, R. M., Singh, G. K., Strickland, B. B., Trevathan, E., & van Dyck, P. C. (2009). Prevalence of parent-reported diagnosis of autism spectrum disorder among children in the US, 2007. *Paediatrics*, *124*(5), 1395–1403. https://doi.org/10.1542/peds.2009-1522

Kuder, S.J., Accardo, A.L. & Bomgardner, E.M. Mental Health and University Students on the Autism Spectrum: a Literature Review. *Rev J Autism Dev Disord, 8*, 421–435 (2021). https://doi.org/10.1007/s40489-020-00222-x

Lai, M.-C., Baron-Cohen, S., & Buxbaum, J. D. (2015). Understanding autism in the light of sex/gender. Molecular Autism, *6*(1). https://doi.org/10.1186/s13229-015-0021-4

Lai, M.-C., Lombardo, M. V., Ruigrok, A. N., Chakrabarti, B., Auyeung, B., Szatmari, P. … MRC AIMS Consortium. (2016). Quantifying and exploring camouflaging in men and women with autism. Autism. https://doi.org/10.1177/1362361316671012

Larsson, H. J., Eaton, W. W., Madsen, K. M., Vestergaard, M., Olesen, A. V., Agerbo, E., Schendel, D., Thorsen, P., & Mortensen, P. B. (2005). Risk factors for autism: perinatal factors, parental psychiatric history, and socioeconomic status. *American Journal of Epidemiology*, *161*(10), 916–928. https://doi.org/10.1093/aje/kwi123

Legard, R., Keegan, J., & Ward, K. (2003). *In-depth interviews*. In J. Ritchie & J. Lewis (Eds.), Qualitative research practice: A guide for social science students and researchers (pp. 138-169). SAGE.

Leon, A. C. (1998). Logistic regression. *Comprehensive Clinical Psychology* (Vol. 3, pp. 243–285). Elsevier. https://doi.org/10.1016/B0080-4270(73)00264-9

Leung, F. H., & Savithiri, R. (2009). Spotlight on focus groups. *Canadian Family Physician*, *55*(2), 218–219.

Liptak, G. S., Benzoni, L. B., Mruzek, D. W., Nolan, K. W., Thingvoll, M. A., Wade, C. M., & Fryer, G. E. (2008). Disparities in diagnosis and access to health services for children with autism: data from the National Survey of Children's Health. *Journal of Developmental and Behavioral Paediatric: JDBP*, *29*(3), 152–160. https://doi.org/10.1097/DBP.0b013e318165c7a0

Loomes, R., Hull, L., & Mandy, W. P. L. (2017). What is the male-to-female ratio in autism spectrum disorder? A systematic review and meta-analysis. *Journal of the American Academy of Child & Adolescent Psychiatry*, *56*(6), 466-474. https://doi.org/10.1016/j.jaac.2017.03.013

Lord C., Rutter M., Le Couteur A. (1994). Autism diagnostic interview-revised: A revised version of a diagnostic interview for caregivers of individuals with possible pervasive developmental disorders. *Journal of Autism and Developmental Disorders*, *24*(5), 659–685. https://doi.org/10.1007/BF02172145

Lord, C., Brugha, T. S., Charman, T., Cusack, J., Dumas, G., Frazier, T., Jones, E. J. H., Jones, R. M., Pickles, A., State, M. W., Taylor, J. L., & Veenstra-VanderWeele, J. (2020). Autism spectrum disorder. *Nature reviews. Disease primers*, *6*(1), 5. https://doi.org/10.1038/s41572-019-0138-4

Lord, C., Risi, S., Lambrecht, L., Cook, E. H., Jr, Leventhal, B. L., DiLavore, P. C., Pickles, A., & Rutter, M. (2000). The autism diagnostic observation schedule-generic: A standard measure of social and communication deficits associated with the spectrum of autism. *Journal of Autism and Developmental Disorders*, *30*(3), 205–223. https://doi.org/10.1023/A:1005592401947

MacNeil, B. M., Lopes, V. A., & Minnes, P. M. (2009). Anxiety in children and adolescents with autism spectrum disorders. *Research in Autism Spectrum Disorders*, *3*(1), 1-21. https://doi.org/10.1016/j.rasd.2008.06.001

Mandell, D. S., Listerud, J., Levy, S. E., & Pinto-Martin, J. A. (2002). Race differences in the age at diagnosis among medicaid-eligible children with autism. *Journal of the American Academy of Child and Adolescent Psychiatry*, *41*(12), 1447–1453. https://doi.org/10.1097/00004583-200212000-00016

Mandell, D. S., Wiggins, L. D., Carpenter, L. A., Daniels, J., DiGuiseppi, C., Durkin, M. S., Giarelli, E., Morrier, M. J., Nicholas, J. S., Pinto-Martin, J. A., Shattuck, P. T., Thomas, K. C., Yeargin-Allsopp, M., & Kirby, R. S. (2009). Racial/ethnic disparities in the identification of children with autism spectrum disorders. *American Journal of Public Health*, *99*(3), 493–498. https://doi.org/10.2105/AJPH.2007.131243

Mandy, W., Midouhas, E., Hosozawa, M., Cable, N., Sacker, A., & Flouri, E. (2022). Mental health and social difficulties of late-diagnosed autistic children, across childhood and adolescence. *Journal of Child Psychology and Psychiatry*, *63*(11), 1405–1414. https://doi.org/10.1111/jcpp.13587

Maxcy, S. J. (1985). The democratic "Myth" and the search for a rational concept of education. *Educational Philosophy and Theory*, *17*(1), 22-37.

McGrath, J. (2019). *Not all autistic people are good at maths and science – despite the stereotypes*. https://theconversation.com/not-all-autistic-people-are-good-at-maths-and-science-despite-the-stereotypes-114128

McManus, M. C. (2016). *A test of the behavioral model of health services use on non-emergent emergency department use* (Order No. 10246106). Available from Health Research Premium Collection. (1868416718). https://www.proquest.com/dissertations-theses/test-behavioral-model-health-services-use-on-non/docview/1868416718/se-2

Mon-Williams, M., Elshehaly, M., & Sohal, K. (2022). *Connected data for connected services that reflect the complexities of childhood*. In Education Data Futures: Critical, Regulatory and Practical Reflections. 5Rights Foundation. Retrieved from https://educationdatafutures.5rightsfoundation.com/essays/competing-interests-in-education-data/connected-data-connected-services/

Moon, K., & Blackman, D. (2014). A guide to understanding social science research for natural scientists. *Conservation Biology*, 28(5), 1167-1177. https://doi.org/10.1111/cobi.12326

Morgan, D. L. (1988). *Focus groups as qualitative research*. SAGE.

Murray, S. (2006). Autism and the Contemporary Sentimental: Fiction and the Narrative Fascination of the Present. *Literature and Medicine*, *25*(1), 24-45. https://dx.doi.org/10.1353/lm.2006.0025

National Autistic Society. (2006). *Make school make sense*. https://media.autism.org.uk/m/39c53d7b7816c3fe/original/Make-School-Make-Sense-Report.pdf

National Autistic Society. (2010). *You need to know*. https://media.autism.org.uk/m/4668e2c6a9db7f1d/original/You-Need-To-Know-Campaignreport.pdf

National Autistic Society. (2023). *What is autism?* https://www.autism.org.uk/advice-and-guidance/what-is-autism#:~:text=More%20than%20one%20in%20100,and%20children%20in%20the%20UK

National Autistic Society. (2025). *How to write and talk about autism*. https://nas.chorus.thirdlight.com/file/24/w2nAKE4w2MLxnl9w2LQ-w11_8C/How%20to%20talk%20and%20write%20about%20autism%20guide%20-%20June%202025.pdf

National Institute for Health and Care Excellence. (2012). *Autism spectrum disorder in adults: Diagnosis and management*. https://www.nice.org.uk/guidance/cg142/resources/autism-spectrum-disorder-in-adults-diagnosis-and-management-pdf-35109567475909

Nelson, T., & Lichwa, H. (2025). The lived experiences of masking black autistic girls in uk education: “before people see the autism, they see my race.”. *Educational Psychology in Practice.* Advance online publication. https://doi.org/10.1080/02667363.2025.2541211

NHS England. (2023). *A national framework to deliver improved outcomes in all-age autism assessment pathways: guidance for integrated care boards*. https://www.england.nhs.uk/long-read/a-national-framework-to-deliver-improved-outcomes-in-all-age-autism-assessment-pathways-guidance-for-integrated-care-boards/

NHS. (2022). *Getting diagnosed as autistic*. https://www.nhs.uk/conditions/autism/getting-diagnosed/

Nicolaidis, C., Kripke, C. C., & Raymaker, D. (2014). Primary care for adults on the autism spectrum. *Medical Clinics*, *98*(5), 1169-1191. https://doi.org/10.1016/j.mcna.2014.06.011

Noar, S. M. (2006). A 10-year retrospective of research in health mass media campaigns: Where do we go from here? *Journal of health communication*, *11*(1), 21-42. https://doi.org/10.1080/10810730500461059

Nordahl-Hansen A., Øien R. A., Fletcher-Watson S. (2018). Pros and cons of character portrayals of autism on TV and film. *Journal of Autism and Developmental Disorders*, 48(2), 635–636. https://doi.org/10.1007/s10803-017-3390-z

Now Education. (2025). *SEND schools*. https://noweducation.co.uk/send-schools/

Office for National Statistics. (2023). *Ethnic group, England and Wales: Census 2021 (ONS).* https://www.ons.gov.uk/peoplepopulationandcommunity/culturalidentity/ethnicity

Okoye, C., Obialo-Ibeawuchi, C. M., Obajeun, O. A., Sarwar, S., Tawfik, C., Waleed, M. S., Wasim, A. U., Mohamoud, I., Afolayan, A. Y., & Mbaezue, R. N. (2023). Early diagnosis of autism spectrum disorder: A Review and Analysis of the Risks and Benefits. *Cureus*, *15*(8), e43226. https://doi.org/10.7759/cureus.43226

Oliver, M. (1990). *The politics of disablement*. Macmillan Education.

Park, Y. S., Konge, L., & Artino, A. R. Jr. (2020). The positivism paradigm of research. *Academic Medicine*, 95(5), 690-694. https://doi.org/10.1097/ACM.0000000000003093

Perepa, P. (2014). Cultural basis of social 'deficits' in autism spectrum disorders. *European Journal of Special Needs Education*, *29*(3), 313-326.

Peters, S. (2000). Is there a disability culture? A syncretisation of three possible world views. *Disability & Society*, *15*(4), 583–601. https://doi.org/10.1080/09687590050058198

Remington, B., Hastings, R. P., Kovshoff, H., degli Espinosa, F., Jahr, E., Brown, T., & Ward, N. (2007). Early intensive behavioral intervention: Outcomes for children with autism and their parents after two years. *American Journal on Mental Retardation*, *112*(6), 418-438. https://doi.org/10.1352/0895-8017(2007)112[418:EIBIOF]2.0.CO;2

Ripamonti, L. (2016). Disability, diversity, and autism: Philosophical perspectives on health. *The New bioethics: a multidisciplinary journal of biotechnology and the body*, *22*(1), 56–70. https://doi.org/10.1080/20502877.2016.1151256

Roberts, J., & Simpson, K. (2016). A review of research into stakeholder perspectives on inclusion of students with autism in mainstream schools. *International Journal of Inclusive Education, 20*(10), 1084–1096. https://doi.org/10.1080/13603116.2016.1145267

Roberts, J., & Webster, A. (2020). Including students with autism in schools: A whole school approach to improve outcomes for students with autism. *International Journal of Inclusive Education, 26*(7), 701-718. https://doi.org/10.1080/13603116.2020.1712622

Rosen, N. E., Lord, C., & Volkmar, F. R. (2021). The Diagnosis of Autism: From Kanner to DSM-III to DSM-5 and beyond. *Journal of Autism and Developmental Disorders, 51*, 4253–4270. https://doi.org/10.1007/s10803-021-04904-1

Russell, A. J., Murphy, C. M., Wilson, E., Gillan, N., Brown, C., Robertson, D. M., Craig, M. C., Deeley, Q., Zinkstok, J., Johnston, K., McAlonan, G. M., Spain, D., & Murphy, D. G. (2016). The mental health of individuals referred for assessment of autism spectrum disorder in adulthood: A clinic report. *Autism*, *20*(5), 623-627. https://doi.org/10.1177/1362361315604271

Russell, G., Stapley, S., Newlove-Delgado, T., Salmon, A., White, R., Warren, F., Pearson, A., & Ford, T. (2022). Time trends in autism diagnosis over 20 years: A UK population-based cohort study. *Journal of Child Psychology and Psychiatry, and Allied Disciplines*, *63*(6), 674–682. https://doi.org/10.1111/jcpp.13505

Saggers, B., D. Klug, K. Harper-Hill, J. Ashburner, D. Costley, T. Clark, S. Bruck, D. Trembath,A. Webster, & S. Carrington. (2016). *Australian Autism Educational Needs Analysis –What are the needs of schools, parents and students on the autism spectrum? Final report*. https://www.autismcrc.com.au/sites/default/files/inline-files/Educational%20needs%20analysis%20-%20Final%20report.pdf

Sciutto, M. J., Richwine, S., Mentrikoski, J., & Niedzwiecki, K. (2012). A qualitative analysis of the school experiences of students with Asperger syndrome. *Focus on Autism and Other Developmental Disabilities, 27*(3), 177–188. https://doi.org/10.1177/1088357612450511

Shakespeare, T. (2006). *Disability rights and wrongs* (1st ed.). Routledge. https://doi.org/10.4324/9780203640098

Shapiro, J. P. (1994). *No pity: People with disabilities forging a new civil rights movement*. Crown.

Shattuck, P. T., Durkin, M., Maenner, M., Newschaffer, C., Mandell, D. S., Wiggins, L., Lee, L.-C., Rice, C., Giarelli, E., Kirby, R., Baio, J., Pinto-Martin, J., & Cuniff, C. (2009). Timing of identification among children with an autism spectrum disorder: Findings from a population-based surveillance study. *Journal of the American Academy of Child & Adolescent Psychiatry, 48*(5), 474–483. https://doi.org/10.1097/CHI.0b013e31819b3848

Simpson, R. L., de Boer-Ott, S. R., & Smith-Myles, B. (2003). Inclusion of learners with autism spectrum disorders in general education settings. *Topics in Language Disorders, 23*(2), 116–133. https://doi.org/10.1097/00011363-200304000-00005

Singer, A. (2017). *Portrayals of autism on television don't showcase full spectrum*. https://www.thetransmitter.org/spectrum/portrayals-autism-television-dont-showcase-full-spectrum/

Sohal, K., Mason, D., Birkinshaw, J., West, J., McEachan, R., Elshehaly, M., Cooper, D., Shore, R., McCooe, M., Lawton, T., Mon-Williams, M., Sheldon, T., Bates, C., Wood, M., & Wright, J. (2022). Connected Bradford: A Whole System Data Linkage Accelerator. *Wellcome Open Research, 7*. https://doi.org/10.12688/wellcomeopenres.17526.1

Soke, G. N., Rosenberg, S. A., Hamman, R. F., Fingerlin, T.,Rosenberg, C. R., Carpenter, L., Lee, L. C., Giarelli, E., Wiggins, L. D., Durkin M. S., Reynolds A., & DiGuiseppi, C. (2017). Factors associated with self-injurious behaviors in children with autism spectrum disorder: Findings from two large national samples. *Journal of Autism and Developmental Disorders*, *47*, 285–296. 10.1007/s10803-016-2951-x

Solomon, M., Miller, M., Taylor, S.L., Hinshaw, S.P., & Carter, C.S. (2012). Autism Symptoms and Internalizing Psychopathology in Girls and Boys with Autism Spectrum Disorders. *Journal of Autism and Developmental Disorders*, 42, 48–59. https://doi.org/10.1007/s10803-011-1215-z

Special Needs Jungle. (2025). *A resourced provision toolkit to boost mainstream SEND inclusion. https://www.specialneedsjungle.com/resourced-provision-toolkit-mainstream-schools/*

Steiner-Hofbauer, V., Pintér, Y. A., & Mittmann, G. (2025). Comparing the portrayal of #autism and #neurodiversity on TikTok: Creators, content, and representation. *Wiener Medizinische Wochenschrift*, *175*(9-10), 245-252. https://doi.org/10.1007/s10354-025-01076-w

Stutchbury, K. (2021). *Critical realist research: Ethical issues and dilemmas as illustrated through a doctoral study in an African university*. In A. Fox, H. Busher, & C. Capewell (Eds.), Thinking critically and ethically about research for education: Engaging with voice and empowerment in international contexts (pp. 154–170). Routledge

Summerfield, C., Smith, L., Todd, O., Renzi, C., Lyratzopoulos, G., Neal, R. D., & Jones, D. (2022). The effect of older age and frailty on the time to diagnosis of cancer: A Connected Bradford electronic health records study. *Cancers*, 14(22), 5666. https://doi.org/10.3390/cancers14225666

Sun, X., Allison, C., Auyeung, B., Baron-Cohen, S., & Brayne, C. (2014). Parental concerns, socioeconomic status, and the risk of autism spectrum conditions in a population-based study. *Research in Developmental Disabilities*, *35*(12), 3678–3688. https://doi.org/10.1016/j.ridd.2014.07.037

Tashakkori, A., & Teddlie, C. B. (1998). *Mixed methodology: Combining qualitative and quantitative approaches* (Applied Social Research Methods Series, Vol. 46). SAGE.

Taylor, J. L., Henninger, N. A., & Mailick, M. R. (2015). Longitudinal patterns of employment and postsecondary education for adults with autism and average-range IQ. *Autism*, *19*(7), 785-793. https://doi.org/10.1177/1362361315585643

Thomas, P., Zahorodny, W., Peng, B., Kim, S., Jani, N., Halperin, W., & Brimacombe, M. (2012). The association of autism diagnosis with socioeconomic status. *Autism*, *16*(2), 201-213. https://doi.org/10.1177/1362361311413397

Tomlinson, C., Bond, C., & Hebron, J. (2021). The mainstream school experiences of adolescent autistic girls. *European Journal of Special Needs Education*, *37*(2), 323–339. https://doi.org/10.1080/08856257.2021.1878657

Toyon, M. A. S. (2021). Explanatory sequential design of mixed methods research: Phases and challenges. *International Journal of Research in Business & Social Science*, 10(5), 253–260. https://doi.org/10.20525/ijrbs.v10i5.1262

Tromans, S., Chester, V., Gemegah, E., Roberts, K., Morgan, Z., Yao, G. L., & Brugha, T. (2021). Autism identification across ethnic groups: A narrative review. *Advances in Autism*, *7*(3), 241-255. https://doi.org/10.1108/aia-03-2020-0017

UNESCO. (1994). *The Salamanca statement and framework for action on special needs education*. UNESCO. https://unesdoc.unesco.org/ark:/48223/pf0000098427

van Steensel, F. J. A., Bögels, S. M., & Perrin, S. (2011). Anxiety disorders in children and adolescents with autistic spectrum disorders: A meta-analysis. *Clinical Child and Family Psychology Review*, *14*(3), 302–317. https://doi.org/10.1007/s10567-011-0097-0

Vasa, R. A., Hagopian, L., & Kalb, L. G. (2020). Investigating mental health crisis in youth with autism spectrum disorder. *Autism Research: Official Journal of the International Society for Autism Research*, *13*(1), 112–121. https://doi.org/10.1002/aur.2224

von Heymann-Horan, A. B., Dalton, S. O., Dziekanska, A., Christensen, J., Andersen, I., Mertz, B. G., Olsen, M. H., Johansen, C., & Bidstrup, P. E. (2013). Unmet needs of women with breast cancer during and after primary treatment: A prospective study in Denmark. *Acta Oncologica*, 52(2), 382–390. https://doi.org/10.3109/0284186X.2012.746468

Walker, N. (2021). *Neuroqueer heresies: Notes on the neurodiversity paradigm, autistic empowerment, and postnormal possibilities*. Autonomous Press.

Wilford, A. (2013). Cultural variations in behaviours related to ASD in South African children. Available at https://repository.hsrc.ac.za/bitstream/handle/20.500.11910/2756/7958.pdf?sequence=1&isAllowed=y

Williams, G. (1996). Representing disability: Some questions of phenomenology and politics. In C. Barnes & G. Mercer (Eds.), *Exploring the Divide* (pp. 1194 – 1212). The Disability Press.

World Health Organization. (2022). *ICD-11: International classification of diseases (11th revision)*. https://icd.who.int/en

World Health Organization. (2023). *Autism*. https://www.who.int/news-room/fact-sheets/detail/autism-spectrum-disorders?gclid=CjwKCAiAgeeqBhBAEiwAoDDhn-5LDYXUJjw-Pkxl_lsOZxyqNFuDuo8YixYCfKED6FrHY5wdbLxVGBoCMCIQAvD_BwE

Wright, B. J. D., Mon-Williams, M., Kelly, B., Williams, S., Sims, D. W., Mushtaq, F., Sohal, K., Blackwell, J. E., & Wright, J. (2019). Investigating the association between Early Years Foundation Stage Profile scores and subsequent diagnosis of an autism spectrum disorder: A retrospective study of linked healthcare and education data. *BMJ Paediatrics Open, 3*(1), e000483. https://doi.org/10.1136/bmjpo-2019-000483

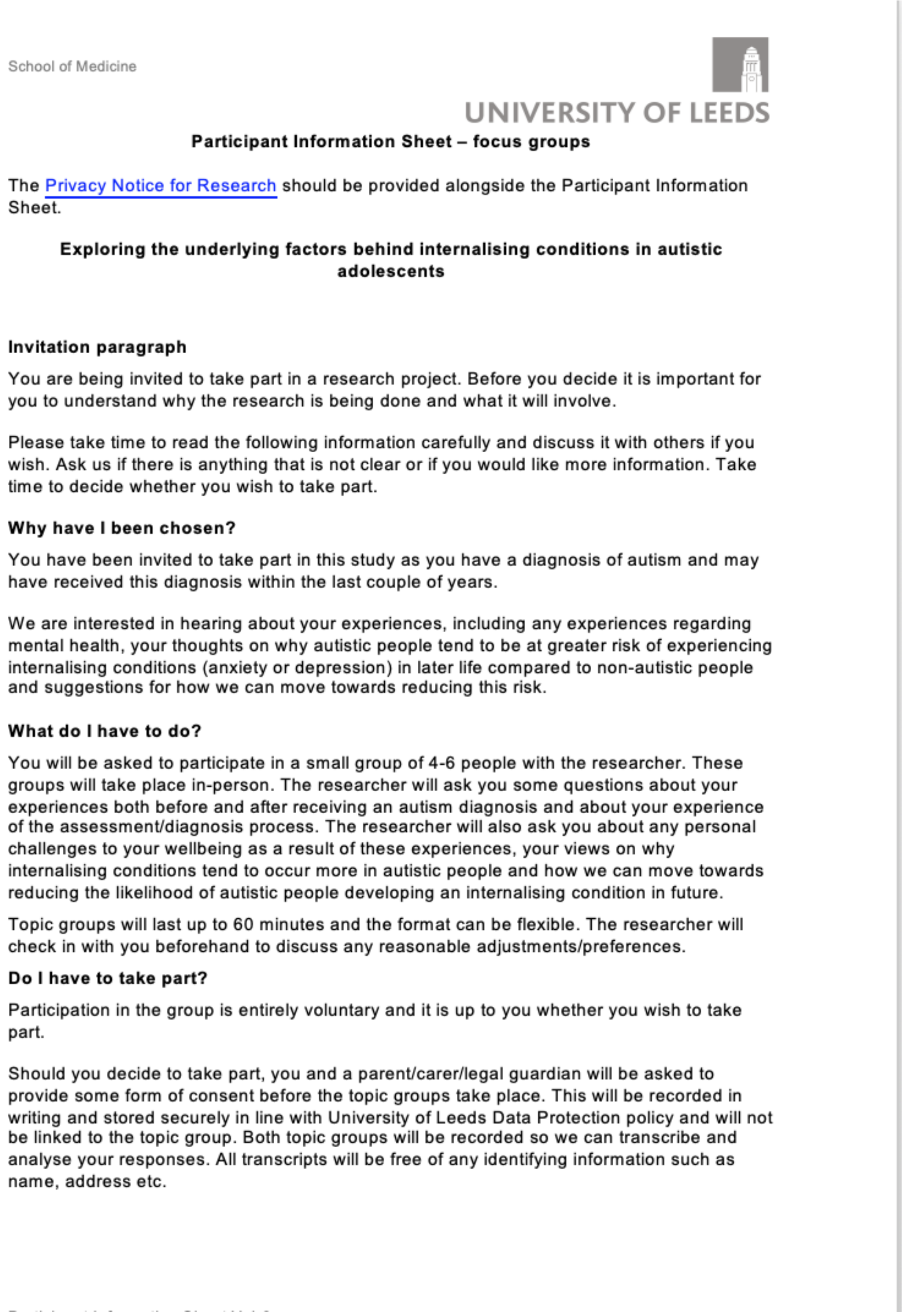
Yeargin-Allsopp, M., Rice, C., Karapurkar, T., Doernberg, N., Boyle, C., & Murphy, C. (2003). Prevalence of autism in a US metropolitan area. *JAMA: Journal of the American Medical Association, 289*(1), 49–55. https://doi.org/10.1001/jama.289.1.49

Zeidan, J., Fombonne, E., Scorah, J., Ibrahim, A., Durkin, M. S., Saxena, S., Yusuf, A., Shih, A., & Elsabbagh, M. (2022). Global prevalence of autism: A systematic review update. *Autism Research*, *15*(5), 778-790. https://doi.org/10.1002/aur.2696

Zuckerman, K. E., Lindly, O. J., Reyes, N. M., Chavez, A. E., Macias, K., Smith, K. N., & Reynolds, A. (2017). Disparities in diagnosis and treatment of autism in Latino and non-Latino white families. *Paediatrics*, *139*(5), e20163010. https://doi.org/10.1542/peds.2016-3010

Appendices

Appendix A – Participant Information Sheet (focus groups)



School of Medicine

UNIVERSITY OF LEEDS

Participant Information Sheet – focus groups

The Privacy Notice for Research should be provided alongside the Participant Information Sheet.

Exploring the underlying factors behind internalising conditions in autistic adolescents

Invitation paragraph

You are being invited to take part in a research project. Before you decide it is important for you to understand why the research is being done and what it will involve.

Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether you wish to take part.

Why have I been chosen?

You have been invited to take part in this study as you have a diagnosis of autism and may have received this diagnosis within the last couple of years.

We are interested in hearing about your experiences, including any experiences regarding mental health, your thoughts on why autistic people tend to be at greater risk of experiencing internalising conditions (anxiety or depression) in later life compared to non-autistic people and suggestions for how we can move towards reducing this risk.

What do I have to do?

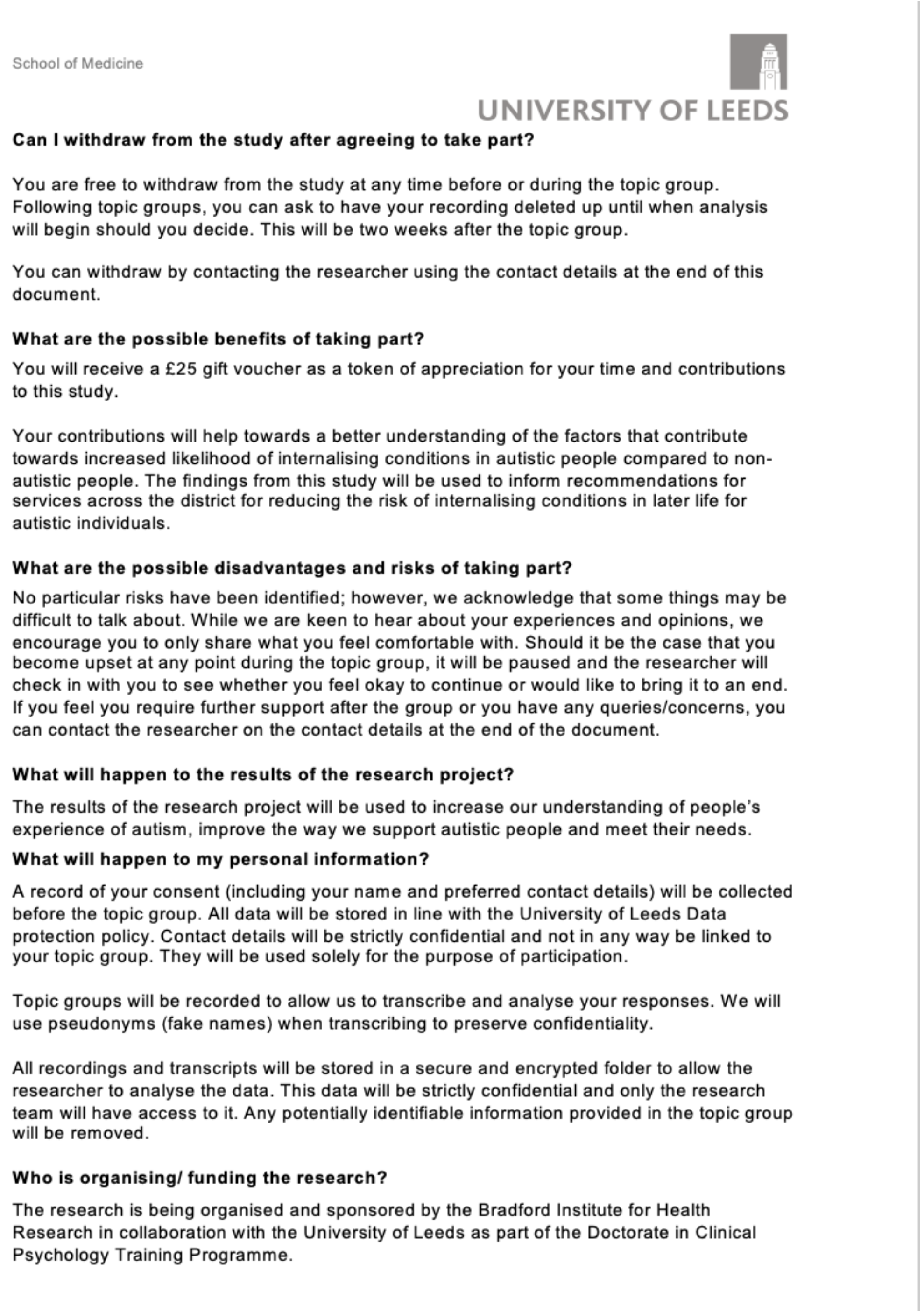
You will be asked to participate in a small group of 4-6 people with the researcher. These groups will take place in-person. The researcher will ask you some questions about your experiences both before and after receiving an autism diagnosis and about your experience of the assessment/diagnosis process. The researcher will also ask you about any personal challenges to your wellbeing as a result of these experiences, your views on why internalising conditions tend to occur more in autistic people and how we can move towards reducing the likelihood of autistic people developing an internalising condition in future.

Topic groups will last up to 60 minutes and the format can be flexible. The researcher will check in with you beforehand to discuss any reasonable adjustments/preferences.

Do I have to take part?

Participation in the group is entirely voluntary and it is up to you whether you wish to take part.

Should you decide to take part, you and a parent/carer/legal guardian will be asked to provide some form of consent before the topic groups take place. This will be recorded in writing and stored securely in line with University of Leeds Data Protection policy and will not be linked to the topic group. Both topic groups will be recorded so we can transcribe and analyse your responses. All transcripts will be free of any identifying information such as name, address etc.



Can I withdraw from the study after agreeing to take part?

You are free to withdraw from the study at any time before or during the topic group. Following topic groups, you can ask to have your recording deleted up until when analysis will begin should you decide. This will be two weeks after the topic group.

You can withdraw by contacting the researcher using the contact details at the end of this document.

What are the possible benefits of taking part?

You will receive a £25 gift voucher as a token of appreciation for your time and contributions to this study.

Your contributions will help towards a better understanding of the factors that contribute towards increased likelihood of internalising conditions in autistic people compared to non-autistic people. The findings from this study will be used to inform recommendations for services across the district for reducing the risk of internalising conditions in later life for autistic individuals.

What are the possible disadvantages and risks of taking part?

No particular risks have been identified; however, we acknowledge that some things may be difficult to talk about. While we are keen to hear about your experiences and opinions, we encourage you to only share what you feel comfortable with. Should it be the case that you become upset at any point during the topic group, it will be paused and the researcher will check in with you to see whether you feel okay to continue or would like to bring it to an end. If you feel you require further support after the group or you have any queries/concerns, you can contact the researcher on the contact details at the end of the document.

What will happen to the results of the research project?

The results of the research project will be used to increase our understanding of people's experience of autism, improve the way we support autistic people and meet their needs.

What will happen to my personal information?

A record of your consent (including your name and preferred contact details) will be collected before the topic group. All data will be stored in line with the University of Leeds Data protection policy. Contact details will be strictly confidential and not in any way be linked to your topic group. They will be used solely for the purpose of participation.

Topic groups will be recorded to allow us to transcribe and analyse your responses. We will use pseudonyms (fake names) when transcribing to preserve confidentiality.

All recordings and transcripts will be stored in a secure and encrypted folder to allow the researcher to analyse the data. This data will be strictly confidential and only the research team will have access to it. Any potentially identifiable information provided in the topic group will be removed.

Who is organising/ funding the research?

The research is being organised and sponsored by the Bradford Institute for Health Research in collaboration with the University of Leeds as part of the Doctorate in Clinical Psychology Training Programme.

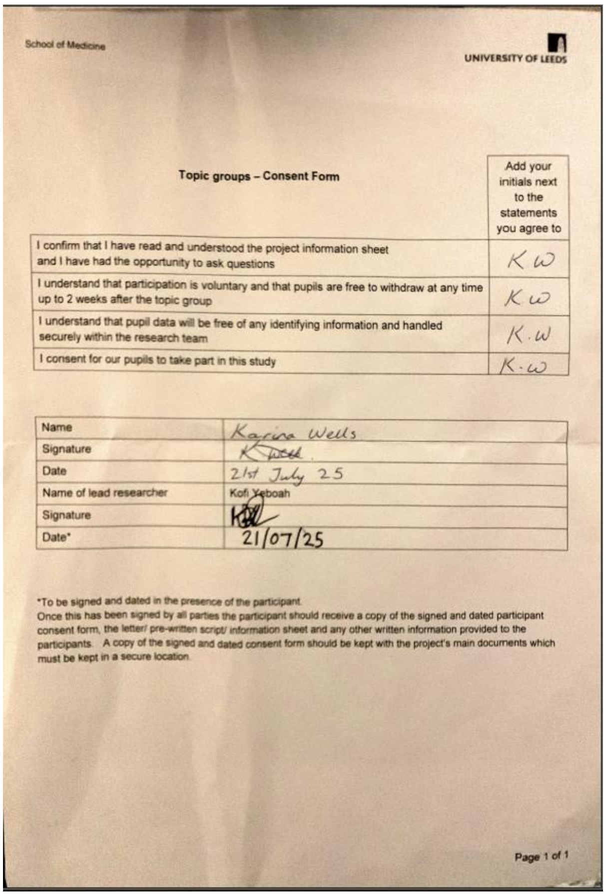
Contact for further information

Researcher:
Kofi Yeboah, Trainee Clinical Psychologist
Doctorate in Clinical Psychology Training Programme
Leeds Institute of Health Science, Worsley Building
University of Leeds
Leeds, LS2 9NL
Email: umky@leeds.ac.uk

Research Supervisors:
Professor Mark Mon-Williams
School of Psychology
Medicine and Health
University of Leeds, LS2 9NL
Tel: 0113 343 5725
Email: M.Mon-Williams@leeds.ac.uk

Dr Simon Pini
School of Medicine
Medicine and Health
University of Leeds, LS2 9NL
Tel: 0113 206 7628
Email: S.Pini@leeds.ac.uk

Appendix B – Participant Consent Form (focus groups)



School of Medicine

UNIVERSITY OF LEEDS

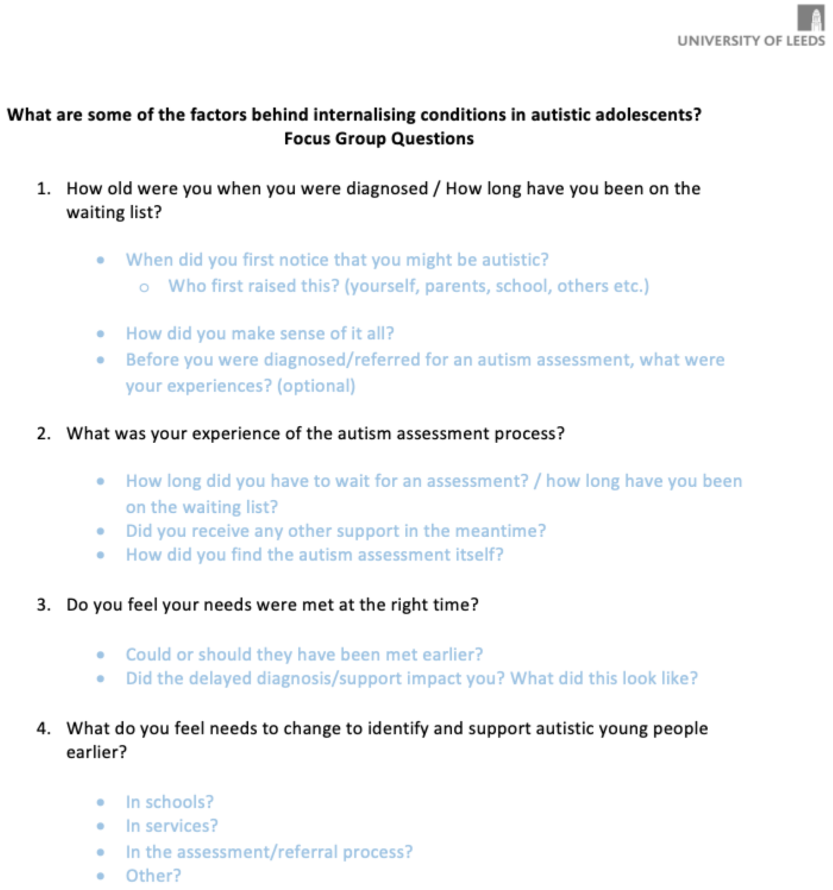
Topic groups – Consent Form	Add your initials next to the statements you agree to
I confirm that I have read and understood the project information sheet and I have had the opportunity to ask questions	K W
I understand that participation is voluntary and that pupils are free to withdraw at any time up to 2 weeks after the topic group	K W
I understand that pupil data will be free of any identifying information and handled securely within the research team	K.W
I consent for our pupils to take part in this study	K.W

Name	Karina Wells
Signature	
Date	21st July 25
Name of lead researcher	Kofi Yeboah
Signature	
Date*	21/07/25

*To be signed and dated in the presence of the participant.
Once this has been signed by all parties the participant should receive a copy of the signed and dated participant consent form, the letter/ pre-written script/ information sheet and any other written information provided to the participants. A copy of the signed and dated consent form should be kept with the project's main documents which must be kept in a secure location.

Page 1 of 1

Appendix C – Focus Group Schedule

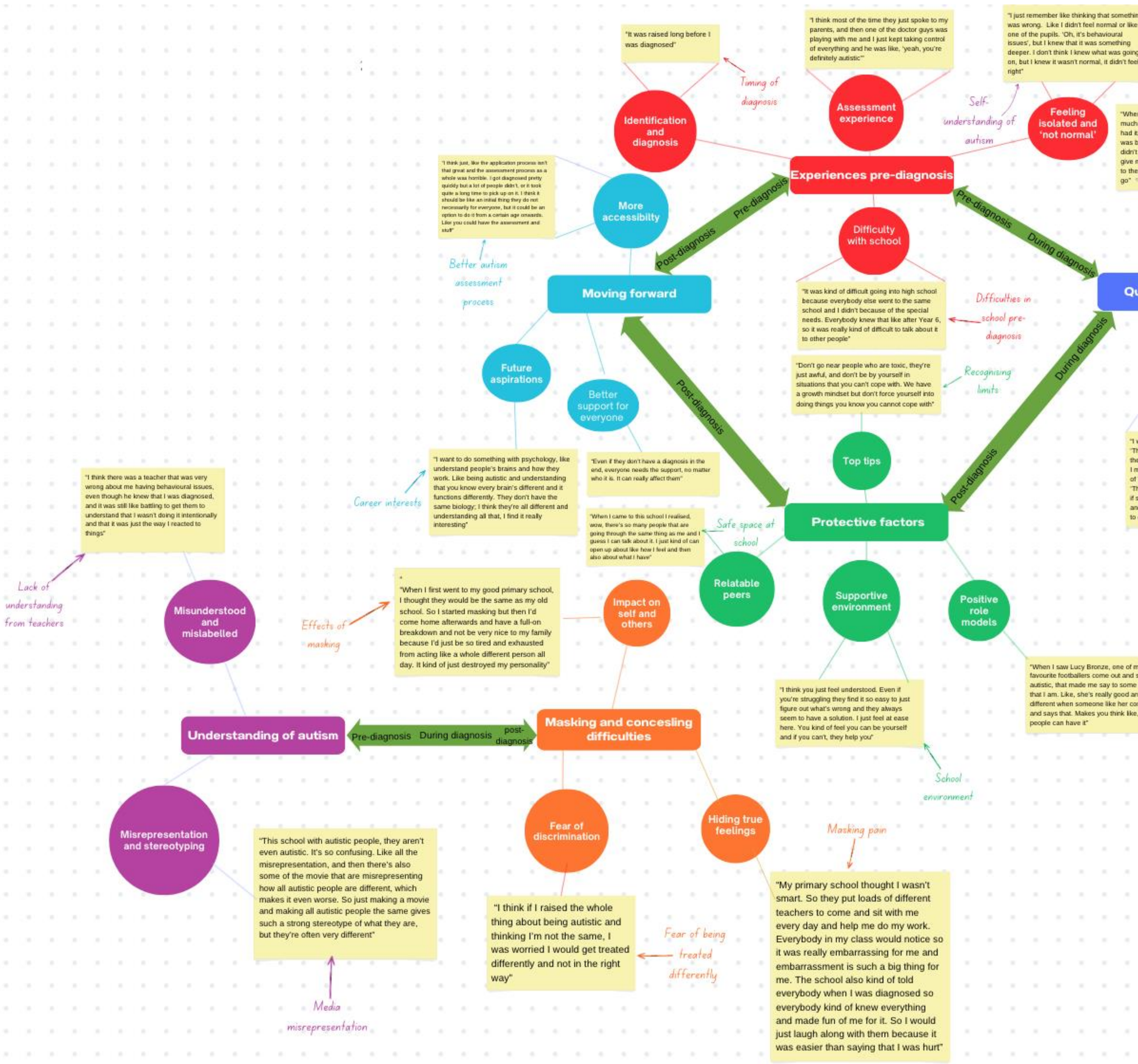


UNIVERSITY OF LEEDS

What are some of the factors behind internalising conditions in autistic adolescents?
Focus Group Questions

1. How old were you when you were diagnosed / How long have you been on the waiting list?
   - When did you first notice that you might be autistic?
     - Who first raised this? (yourself, parents, school, others etc.)
   - How did you make sense of it all?
   - Before you were diagnosed/referred for an autism assessment, what were your experiences? (optional)
2. What was your experience of the autism assessment process?
   - How long did you have to wait for an assessment? / how long have you been on the waiting list?
   - Did you receive any other support in the meantime?
   - How did you find the autism assessment itself?
3. Do you feel your needs were met at the right time?
   - Could or should they have been met earlier?
   - Did the delayed diagnosis/support impact you? What did this look like?
4. What do you feel needs to change to identify and support autistic young people earlier?
   - In schools?
   - In services?
   - In the assessment/referral process?
   - Other?

Appendix D – Illustration of Initial Focus Groups Codes and Themes



"It was raised long before I was diagnosed"

"I think most of the time they just spoke to my parents, and then one of the doctor guys was playing with me and I just kept taking control of everything and he was like, 'yeah, you're definitely autistic'"

"I just remember like thinking that somethin
was wrong. Like I didn't feel normal or like
one of the pupils. 'Oh, it's behavioural
issues', but I knew that it was something
deeper. I don't think I knew what was going
on, but I knew it wasn't normal, it didn't feel
right"

"Whe
much
had it
was b
didn't
give n
to the
go"

"I think just, like the application process isn't that great and the assessment process as a whole was horrible. I got diagnosed pretty quickly but a lot of people didn't, or it took quite a long time to pick up on it. I think it should be like an initial thing they do not necessarily for everyone, but it could be an option to do it from a certain age onwards. Like you could have the assessment and stuff"

"It was kind of difficult going into high school because everybody else went to the same school and I didn't because of the special needs. Everybody knew that like after Year 6, so it was really kind of difficult to talk about it to other people"

"Don't go near people who are toxic, they're just awful, and don't be by yourself in situations that you can't cope with. We have a growth mindset but don't force yourself into doing things you know you cannot cope with"

"I want to do something with psychology, like understand people's brains and how they work. Like being autistic and understanding that you know every brain's different and it functions differently. They don't have the same biology; I think they're all different and understanding all that, I find it really interesting"

"Even if they don't have a diagnosis in the end, everyone needs the support, no matter who it is. It can really affect them"

"When I came to this school I realised, wow, there's so many people that are going through the same thing as me and I guess I can talk about it. I just kind of can open up about like how I feel and then also about what I have"

"I w
"Th
the
I m
of
"Th
if s
an
to

"I think there was a teacher that was very wrong about me having behavioural issues, even though he knew that I was diagnosed, and it was still like battling to get them to understand that I wasn't doing it intentionally and that it was just the way I reacted to things"

"When I first went to my good primary school, I thought they would be the same as my old school. So I started masking but then I'd come home afterwards and have a full-on breakdown and not be very nice to my family because I'd just be so tired and exhausted from acting like a whole different person all day. It kind of just destroyed my personality"

"When I saw Lucy Bronze, one of m
favourite footballers come out and s
autistic, that made me say to some
that I am. Like, she's really good an
different when someone like her co
and says that. Makes you think like,
people can have it"

"I think you just feel understood. Even if you're struggling they find it so easy to just figure out what's wrong and they always seem to have a solution. I just feel at ease here. You kind of feel you can be yourself and if you can't, they help you"

"This school with autistic people, they aren't even autistic. It's so confusing. Like all the misrepresentation, and then there's also some of the movie that are misrepresenting how all autistic people are different, which makes it even worse. So just making a movie and making all autistic people the same gives such a strong stereotype of what they are, but they're often very different"

"I think if I raised the whole thing about being autistic and thinking I'm not the same, I was worried I would get treated differently and not in the right way"

"My primary school thought I wasn't smart. So they put loads of different teachers to come and sit with me every day and help me do my work. Everybody in my class would notice so it was really embarrassing for me and embarrassment is such a big thing for me. The school also kind of told everybody when I was diagnosed so everybody kind of knew everything and made fun of me for it. So I would just laugh along with them because it was easier than saying that I was hurt"

Appendix E – Diagnostic Timeline