# A district level population-based study of structural inequalities in autism pathways

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# Abstract

Studies show that early identification of autism improves developmental outcomes, but current pathways to diagnosis and support are dysfunctional, with systemic problems and inequalities at each ‘stage’ of the pathway. This project aimed to understand inequalities relating to ethnicity by combining data and lived experience information about autism pathways within the Bradford district. Analysis 1 explored the prevalence of autism diagnoses across different demographic groups and showed a lower diagnosis rate in South Asian children in comparison to white children. It also showed boys being diagnosed earlier than girls, however this finding only applied to boys from white and other ethnic groups. In Asian ethnic groups, girls were found to be diagnosed earlier than males. Analysis 2 investigated the power of the Early Years Foundation Stage Profile (EYFSP) to predict autism diagnosis by ethnicity, sex, and socioeconomic position. The analysis replicated Wright et al. (2019) but further showed children of Pakistani heritage with a low EYFSP score had two times decreased odds of being diagnosed with autism relative to children from white ethnic groups. Finally, qualitative analyses combined these data insights with the lived experiences of South Asian heritage parents and the views of Bradford autism service providers (including practitioners) and policymakers. Thematic analysis identified three overarching themes: (i) identification and diagnosis barriers and facilitators; (ii) barriers and facilitators of support and provision; (iii) suggestions for improving identification, diagnosis, and support. Together, these findings show population level inequalities for South Asian children within Bradford, increase our understanding of these inequalities, and indicate possible solutions. Recommendations include optimising community practices, healthcare, education, and the wider system. Further research on the inequalities operating in different areas of England is needed, and would benefit from similar use of connected data and qualitative techniques to explore the impact of multiple coexisting difficulties on likelihood of timely diagnosis across different ethnicities.

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# List of Abbreviations

ADHD – Attention Deficit Hyperactivity Disorder

ASD – Autism Spectrum Disorder

BiB – Born in Bradford

CAER – Centre for Applied Education Research

CAMHS – Child and Adolescent Mental Health Service

EYFSP – Early Years Foundation Stage Profile

EHCP – Education and Healthcare Plan

DfE – Department for Education (UK Government)

DSM-5 – Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition

ICD-11 – International Classification of Diseases, Eleventh Edition

ID – Intellectual Disability

NAS – National Autistic Society

NCCWCH - National Collaborating Centre for Women's and Children's Health

NHS – National Health Service

NHSE – National Health Service England

NICE – National Institute for Health and Care Excellence

MDT – Multidisciplinary team

ONS – Office of National Statistics

SEN – Special Educational Needs

WHO – World Health Organisation

APA – American Psychiatric Association

# Introduction

## Language

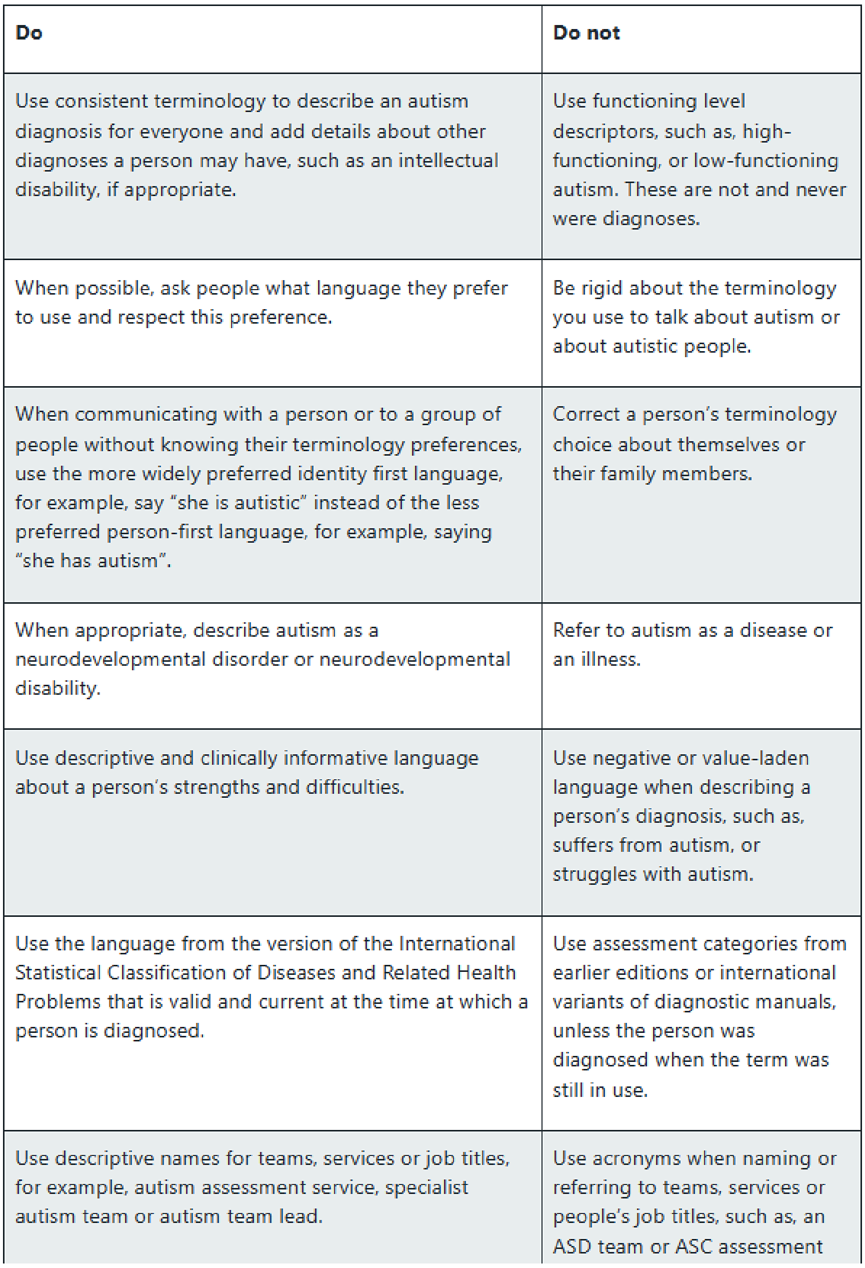
There has been considerable debate and disagreement in the last ten years around the language that is, and should be, used to describe autism and its associated characteristics. Research conducted by the National Autistic Society (NAS) with UK autism community members and relevant stakeholders highlighted differences in the preferences of parents and professionals, with professionals endorsing the term ‘person with autism’ (a person-centred approach), and parents preferring the term ‘autistic’. The authors concluded that there is “no single way of describing autism that is universally accepted” (Kenny et. al., 2016, p. 442). However, the guidance provided by the NAS emphasises the need to use positive language, ask specific individuals or groups how they would like to be described, and recognise that for many autistic people, autism is an integral part of who they are (NAS, n.d.).

In recognition of the power of words to influence people’s attitudes and beliefs, this report aims to use considerate, respectful, inclusive, and destigmatising language throughout. Furthermore, it will follow the guidance of the NAS and the language principles set out by the NHS England (NHSE) national autism assessment framework guidance document (NHSE, 2023) (see Figure 1 below).

Furthermore, it is important to be aware of the language used to describe differences in ethnicity in research. In order to use intentionally anti-racist language, throughout this report I will refer to collective groups/communities of individuals from diverse ethnic backgrounds as ‘racially minoritized’. Unlike other terms such as ‘BAME’ (Black, Asian and Minority Ethnic) or ‘ethnic minorities’, this term actively de-centres whiteness and recognises that minoritisation is a social process shaped by power done to groups of people (rather than groups naturally existing as a minority (Gunaratnam, 2003, Milner & Jumbe, 2020, Predelli et. al., 2012). Also, whilst the collective descriptive term ‘South Asian’ has been used in this report as the most straightforward way to discuss the relevant ethnic groups, it is recognised that there is significant cultural heterogeneity encompassed by this grouping, which includes individuals from Pakistan, India, Nepal, Bangladesh, Sri Lanka, and Bhutan. To avoid homogenising individuals and to acknowledge the differences and subtleties in cultural beliefs, practices and attitudes of the subgroups, efforts have been made to identify and describe participants' specific ethnic identities where possible. Finally, in accordance with governmental guidelines on writing about ethnicity (2021), terms used to describe ethnic groups (such as 'black' or 'white') will not be capitalised unless that group name refers to a geographical place.

**Figure 1.**

*NHSE Autism Language principles.*



| **Do** | **Do not** |
|---|---|
| Use consistent terminology to describe an autism diagnosis for everyone and add details about other diagnoses a person may have, such as an intellectual disability, if appropriate. | Use functioning level descriptors, such as, high-functioning, or low-functioning autism. These are not and never were diagnoses. |
| When possible, ask people what language they prefer to use and respect this preference. | Be rigid about the terminology you use to talk about autism or about autistic people. |
| When communicating with a person or to a group of people without knowing their terminology preferences, use the more widely preferred identity first language, for example, say "she is autistic" instead of the less preferred person-first language, for example, saying "she has autism". | Correct a person's terminology choice about themselves or their family members. |
| When appropriate, describe autism as a neurodevelopmental disorder or neurodevelopmental disability. | Refer to autism as a disease or an illness. |
| Use descriptive and clinically informative language about a person's strengths and difficulties. | Use negative or value-laden language when describing a person's diagnosis, such as, suffers from autism, or struggles with autism. |
| Use the language from the version of the International Statistical Classification of Diseases and Related Health Problems that is valid and current at the time at which a person is diagnosed. | Use assessment categories from earlier editions or international variants of diagnostic manuals, unless the person was diagnosed when the term was still in use. |
| Use descriptive names for teams, services or job titles, for example, autism assessment service, specialist autism team or autism team lead. | Use acronyms when naming or referring to teams, services or people's job titles, such as, an ASD team or ASC assessment |

*Note.* This image is taken from *A national framework to deliver improved outcomes in all-age autism assessment pathways: guidance for integrated care boards, by NHSE, 2023.* In the public domain.

## Autism background

Autism is a neurodevelopmental condition characterized by persistent difficulties in social communication and interaction, and repetitive and restricted patterns of behaviour, interests or activities which present in the early developmental period (American Psychiatric Association, 2013). The difficulties that individuals experience can vary in severity and impact, with greater impairment resulting in poorer functioning and increased need for support. Identified risk factors for autism include having a sibling with autism, parental mental health difficulties, and low birth weight. Autism is strongly associated with coexisting conditions such as intellectual disability, down's syndrome, foetal alcohol syndrome and cerebral palsy (National Collaborating Centre for Women's and Children's Health; [NCCWCH], 2011).

### Prevalence rates

Current research indicates that Autism occurs in 1-2% of children (NCCWCH, 2011) with recent findings from a large sample of school pupils across England indicating an estimated prevalence rate of 1.75% (Roman-Urrestarazu et al., 2021). Data from two districts in 2010 showed autism referrals for around 3% of the population and diagnosis in 1.5-2% of primary or preschool children (NCCWCH, 2011).

### Coexisting difficulties and outcomes

Autism has been associated with poor long term outcomes in social and individual functioning in adolescence and adulthood (Steinhausen et. al., 2016) and high rates of comorbid difficulties (Casanova et. al., 2020, Lai et. al., 2019). Research has identified that autistic individuals are at higher risk than the general population of sleep difficulties (Henderson et. al., 2021), mental ill health (Woolfenden et. al., 2012; Lai et. al., 2019) and physical health difficulties such as epilepsy (Lukmanji et. al., 2019). Furthermore autism is associated with an increased prevalence of co-occurring conditions such as Attention Deficit Hyperactivity Disorder (Rong et. al., 2021), learning difficulties (Brimo et. al., 2021), and Intellectual Disability (ID) (Peters-Scheffer et. al., 2016). Due to the complexity of needs autistic individuals often present with, and the increased need for specialist support from multiple services across the lifespan, Buescher et. al. (2014) estimated the lifetime cost of supporting an autistic person in the UK to be £1.5 million.

## Early intervention research

The early identification and diagnosis of autism is crucial for enabling children to access early intervention and support to improve their developmental outcomes. Recent research has shown that, in a sample of 131 children, 65% of those who were diagnosed (and received support) before 2.5 years of age showed significant improvements in core autism symptoms after 1-2 years. These improvements were nearly three times more likely to occur in this age group than those diagnosed at an older age (Gabbay-Dizdar et al., 2021). In addition, Clark et. al (2017) compared the cognitive and behavioural outcomes of children aged 7-9 years who had been diagnosed at 24 months to their peers who had been diagnosed after the age of three years old. They found that an earlier diagnosis was significantly associated with increased access to intervention, better overall cognitive abilities and lower incidence of ID, and increased likelihood of remaining in mainstream school. These benefits are likely due to children receiving targeted interventions in the optimum period of development for peak brain plasticity and behavioural flexibility (Gabbay-Dizdar et al., 2021), an explanation which is supported by neuroscience research (see Dawson, 2008).

These findings are consistent with the mounting evidence base highlighting the effectiveness of early intervention programs for autism (Reichow, 2011; Reichow et al., 2018; Zachor et al., 2007; Zwaigenbaum et al., 2015), thus stressing the importance of investing in programmes/tools/strategies to increase the early identification and diagnosis of autism in at risk groups. Indeed, various studies show promising evidence for the efficacy of screening methods for identifying autism in infants from the age of 18 months, for example, the Modified Checklist for Autism in Toddlers (M-CHAT) (Robins et al., 2001; Sunita & Bilszta, 2013; Towle & Patrick, 2016).

Despite the mounting evidence that children can be diagnosed from the age of 18 months, longitudinal studies exploring the average age of diagnosis over time have shown variable findings. Currently, the average age of diagnosis is between 3-6 years (Clark et al., 2017; Daniels & Mandell, 2014; Loubersac et al., 2021; van't Hof et al., 2021). Daniels and Mandell (2014) reviewed studies between 1990-2012 and found that the average age of diagnosis had decreased over time, whereas Russell et. al (2021) found in their 1998-2018 population-based study that the mean age of diagnosis rose from 9.6 years in 1998 to 14.5 years in 2018, as well as within every age band. In contrast, other studies have found no evidence of a change in diagnostic age over time (Brett et al., 2016; Loubersac et al., 2021).

## Role of diagnosis

### Diagnostic criteria

In the UK the International Classification of Diseases, version 11 (ICD-11, World Health Organisation, 2019) is the most commonly used diagnostic manual for determining whether to give an autism diagnosis after assessment. It defines Autism Spectrum Disorder as being characterised by "persistent deficits in the ability to initiate and to sustain reciprocal social interaction and social communication, and by a range of restricted, repetitive, and inflexible patterns of behaviour, interests or activities that are clearly atypical or excessive for the individual's age and socio-cultural context" (chapter 06 Mental, behavioural or neurodevelopmental disorders, section 6A02 Autism Spectrum Disorder). The criteria for determining whether an individual should be given a diagnosis is given in Figure 2. The ICD-11 also considers co-occurring disorders, developmental presentations, cultural variations, and additional clinical features (see ICD-11, 6A02, WHO, 2019).

**Figure 2.**

*The ICD-11 Autism Spectrum Disorder diagnostic criteria.*

### Diagnostic Requirements

Essential (Required) Features:

- Persistent deficits in initiating and sustaining social communication and reciprocal social interactions that are outside the expected range of typical functioning given the individual’s age and level of intellectual development. Specific manifestations of these deficits vary according to chronological age, verbal and intellectual ability, and disorder severity. Manifestations may include limitations in the following:
    - Understanding of, interest in, or inappropriate responses to the verbal or non-verbal social communications of others.
    - Integration of spoken language with typical complimentary non-verbal cues, such as eye contact, gestures, facial expressions and body language. These non-verbal behaviours may also be reduced in frequency or intensity.
    - Understanding and use of language in social contexts and ability to initiate and sustain reciprocal social conversations.
    - Social awareness, leading to behaviour that is not appropriately modulated according to the social context.
    - Ability to imagine and respond to the feelings, emotional states, and attitudes of others.
    - Mutual sharing of interests.
    - Ability to make and sustain typical peer relationships.
- Persistent restricted, repetitive, and inflexible patterns of behaviour, interests, or activities that are clearly atypical or excessive for the individual’s age and sociocultural context. These may include:
    - Lack of adaptability to new experiences and circumstances, with associated distress, that can be evoked by trivial changes to a familiar environment or in response to unanticipated events.
    - Inflexible adherence to particular routines; for example, these may be geographic such as following familiar routes, or may require precise timing such as mealtimes or transport.
    - Excessive adherence to rules (e.g., when playing games).
    - Excessive and persistent ritualized patterns of behaviour (e.g., preoccupation with lining up or sorting objects in a particular way) that serve no apparent external purpose.
    - Repetitive and stereotyped motor movements, such as whole body movements (e.g., rocking), atypical gait (e.g., walking on tiptoes), unusual hand or finger movements and posturing. These behaviours are particularly common during early childhood.
    - Persistent preoccupation with one or more special interests, parts of objects, or specific types of stimuli (including media) or an unusually strong attachment to particular objects (excluding typical comforters).
    - Lifelong excessive and persistent hypersensitivity or hyposensitivity to sensory stimuli or unusual interest in a sensory stimulus, which may include actual or anticipated sounds, light, textures (especially clothing and food), odours and tastes, heat, cold, or pain.

## Benefits

A formal diagnosis of autism can be beneficial to children and their families in helping them understand their difficulties and access advice and support from education, health, social care and third sector services. In healthcare, having a diagnosis enables clinicians to recommend specific evidence-based interventions for autistic children (NHS, 2023), and can ensure that reasonable adjustments are made to the support provided by physical (Mason et. al, 2019) and mental health services (Brede et. al., 2022). Having a diagnosis can also facilitate access to support and provision in education even in a 'needs led' system (Dockrell et. al., 2019), reasonable adjustments in the workplace, social care services, and entitlement to protection under the Equality Act 2010 (NHS, 2023). Furthermore, receiving a diagnosis has been shown to be beneficial to the formation of a positive self-identity, which can also increase self-esteem (Corden et. al., 2021). Indeed, as stated in recent NHS guidance "delayed or unequal access to autism assessment can result in missed opportunities for support from education, social care, voluntary, community and social enterprise…For these reasons, it is important that Integrated Care Boards do not restrict or withhold access to an autism diagnosis" (2023, paragraph titled 'the purpose of an autism diagnosis).

## Service organisation

Many health services are under increasing pressure to provide support for a growing number of children and have tried to manage this demand by requiring a diagnosis as evidence of need (despite being legally required to provide support based on need). Many services are also only commissioned to provide support for those with a diagnosis, which has further increased the demand for assessments. Whilst this commissioning model can be useful for services for the planning and distribution of resources, it creates a barrier for families with children without a diagnosis in accessing support from the appropriate health services. Consequently, many parent voices, services and government organisations across the UK are calling for the system to be reformed towards a person-centred, needs-led approach (Bristol, North Somerset and South Gloucestershire Parent Carer Forum, 2022; Holtom & Lloyd-Jones, 2022; NHSE, 2023) whereby services are mandated to provide support if needs are identified regardless of whether there is a formal diagnosis or not.

## Current pathways to a diagnosis in the UK

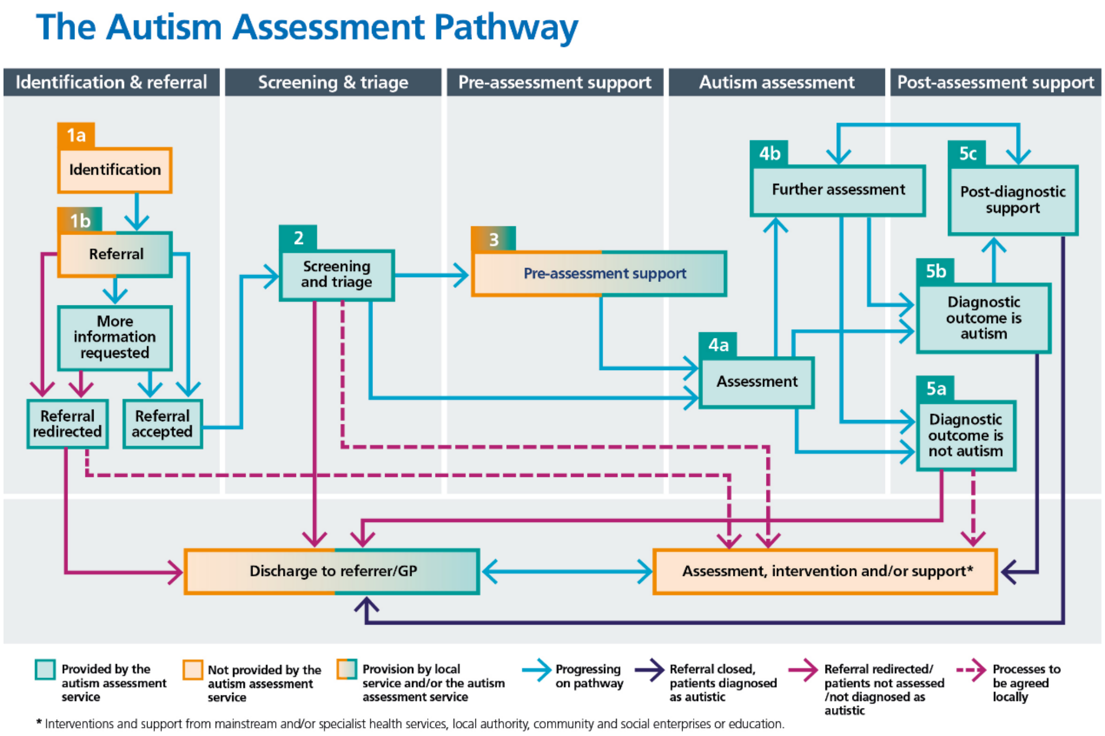
### NHS services

> Recognition and diagnosis of Autism is important for children and young people as it leads to the provision of Autism-specific support to families and appropriate education, which can in turn lead to more positive outcomes for the individual... An appropriate and timely diagnosis contributes significantly to this process (NCCWCH, 2011, p. 35).

In the UK, the current route/pathway to diagnosis in the NHS starts with a referral for assessment usually made by either a GP, educational professional, social worker, or directly by the young person or family. If this referral is accepted, diagnostic assessment is carried out by a multidisciplinary team within a secondary care service, CAMHS, a specialist neurodevelopmental or autism service, or a community paediatric team (if the child is under the age of 4 years). Families may also seek assessment from private services/practitioners due to long wait times within the NHS. Indeed, studies have reported an average wait time of 3 years to receiving a diagnosis after first concerns were raised (Crane et al., 2016), with older children found to wait longer for a diagnosis than younger children (Bent et al., 2020).

**Figure 3.**

*The five stages of the autism assessment pathway.*



*Note.* This image is taken from *Operational guidance to deliver improved outcomes in all-age autism assessment pathways: Guidance for integrated care boards, by NHSE, 2023* In the public domain.

NICE guidelines describe the autism pathway for under 19 year olds as consisting of the universal stages of identification, referral, assessment, diagnosis, and management. Whilst they highlight the crucial role of health services in recognising and diagnosing autism, they also refer to geographical differences in access routes, service provision and levels of understanding of autism, particularly among children and young people (CYP) with co-existing conditions (NCCWCH, 2011; NICE, 2017). To address these inequalities and improve the pathways to diagnosis and support, guidelines have recommended the implementation of local multidisciplinary strategy groups (whose tasks include delivering training to improve early recognition of autism, supporting CYP transitioning to adult services, and conducting relevant evaluations and audits of data) and diagnostic assessment teams that can be accessed through a single point of referral. The roles of these teams include advising on referrals for assessment, deciding on assessment needs/signposting to alternative services, completing diagnostic assessments and sharing the outcome, and providing information on available support (NICE, 2017). Prior to these recommendations, neurodevelopmental assessments were generally carried out by generic CAMHS district teams. Research has identified that since the publication of the National Autism Plan for Children (NAP-C; Le Couteur, 2003), there has been a 22% increase in the number of district teams with a formal autism assessment protocol, and of these teams 93% have adopted an MDT approach compared to 48% in 2001 (Palmer et al., 2010).

NHSE guidelines (2023) state that the assessment process should involve collecting detailed information on parents' and the child/young persons' concerns, their experiences at home, education and social care, their developmental history focusing on medical history and early autism features consistent with the diagnostic criteria listed in either the ICD-11 (WHO, 2019, used in the UK) or DSM-5 (APA, 2013, used in the US). This information gathering process should be followed by direct interaction with and observation of the CYP, to assess their social and communication skills and behaviours. The assessment should also include consideration of potential differential diagnoses, and result in the development of an individualised profile of strengths, skills and needs, which is then discussed with the family and child/young person once the outcome of the assessment has been decided (NCCWCH, 2011; NICE, 2017).

In the UK, the current recommended maximum wait time between referral and first diagnostic assessment is 3 months (NICE, 2014) with no further guidance on the recommended duration of assessment or adaptations to the assessment process in highly complex cases (Rutherford et al., 2017). However, evidence indicates that current wait time standards are far from being met, with under 18 year olds waiting one year for a diagnosis following the initial referral (NHS Digital, 2020). Whilst pre-pandemic wait times also exceeded targets (Crane et al., 2016; Palmer et al., 2010) it is important to recognise that "the true nature of the impact COVID-19 has had on Autism waiting time statistics will not be understood in full for some time" (NHS Digital, 2020, paragraph titled 'summary').

The NHS long term plan (2019) outlines a commitment to finding ways to reduce wait times for Autism diagnostic assessments and specialist support services, and research showing significant reductions in waiting times following a pathway improvement programme suggests that this can be achieved with a targeted approach (Rutherford et al., 2017). The government has also recognised the importance of reducing waiting times for children and young people with suspected Autism in their National Autism Strategy (HM Government, 2021), and has committed to investing £10.5 million to improve diagnostic pathways and early identification programs. Notably, a recent longitudinal study utilising linked healthcare and education data in a large Bradford based population of children and young people has shown favourable results in the use of Early Years Foundation Profile Scores to improve access to diagnostic services (Wright et al., 2019).

## Wider system and pathway issues

### Fragmentation of the system

There are significant issues with current pathways to a diagnosis. Firstly, the term ‘pathway’ is misleading, as there is not currently a single pathway to a diagnosis operating across the UK. Instead, there are myriad complex routes to a diagnosis involving multiple services (including community nursing, Paediatrics, GP surgeries, schools, Speech and Language, Educational Psychology etc.) which fall under the separate sectors of health and education. These sectors work in silos, and there is currently no system in place to enable cross-sector communication (UK Government, 2021, UK Government 2023).

Health services alone operate across several different NHS trusts and settings, with GPs having their own policies, practices and procedures, and schools can also be run by different academy trusts or the local authority. Within Bradford, autism assessment services alone fall under three different NHS trusts (Bradford District Care Trust, Bradford Teaching Hospitals Foundation Trust, and Airedale Foundation Trust) with no shared system of communication and data linkage. Furthermore, how health and education services are organised varies dramatically across different areas of the UK, meaning there can be a ‘postcode lottery’ situation for many families needing specialist support around neurodevelopmental needs.

Together this means the wider system is not working in a coherent manner, but there is not currently an understanding of what is happening in different geographical areas that have a unique demographic makeup and service configuration. These geographical differences also create significant difficulties in the process of ‘disentangling’ the underlying issues at a national level. There is therefore a need for place-based research which enables exploration of the available services, and how they are organised and interact with each other to identify ways to address the issues in the pathways specific to different geographical areas.

## Connected datasets

Little research to date has used routinely collected administrative data to better understand the inequalities at a population level. Therefore, the established system of data linkage in Bradford, Connected Bradford (cBradford, Sohal et. al., 2022) provides a unique opportunity to harness the power of these data to explore the issues in the autism pathways specific to children and families in the Bradford district. Building on the success of the Born in Bradford Birth Cohort study (Wright et. al., 2013), cBradford was established by the local authority and five regional NHS Trusts in a joint initiative linking pseudonymised routine health, education, social care, environmental, and other government data records of over 800,000 people across the Bradford district (Sohal et al., 2022). It has been shown to be representative of the wider Bradford population in ethnic diversity (45% are of Pakistani origin) and levels of deprivation (Wright et al., 2013), and represents an innovative whole system data linkage framework.

There is emerging evidence that routine education data, specifically Early Years Foundation Profile Scores (EYFSP), could be used to address some of the issues around early identification of autism (Wright et. al., 2019) and other special educational needs (Atkinson et. al, 2022; Wood et. al., IN PRESS). This research highlights the potential to use pre-existing routinely connected data to provide valuable insights which can inform how to improve current systems.

## Inequalities in the autism pathways

A number of different clinical, demographic and familial factors (including symptom severity, parental concern, and having a sibling with autism) have been found to be significantly associated with Autism diagnostic rates, and age at diagnosis (for a review, see Nowell et al., 2015). Gender affects the likelihood of receiving an autism diagnosis, with studies consistently reporting that boys are more likely to be diagnosed than girls (Duvekot et al., 2017; Kelly et al., 2019; Kuhn et al., 2021) and are more likely to be diagnosed earlier (Duvekot et al., 2017). Duvekot et al (2017) suggest that the under-identification of autism in girls may be due to differences in clinical presentation which lead to an exaggerated male-female ratio in diagnosis, and argue that "a better understanding of how gender influences the expression and diagnosis of autism is needed to improve the identification and treatment of girls with autism." (p. 647). Whilst these factors are all worthy of further discussion and investigation, this thesis will focus specifically on ethnicity, socioeconomic status and systemic factors.

### Socioeconomic position (SEP)

In this project, the term SEP will be used in line with the suggestion of Krieger et. al. (1997). SEP refers to the multiple factors that influence the positions held by individuals or groups in society and the resources and vulnerabilities that affect health access and outcomes (see Galobardes et. al., 2006).

Studies exploring the impact of SEP on autism diagnosis have used a variety of measures to identify SEP, including parental education level, household income, and ecological measures of neighbourhood deprivation, and the current evidence base is conflicting. Whilst some studies (generally from the US) have shown increased diagnosis rates in children of a higher SEP (Durkin et al., 2017; Durkin et al., 2010; Thomas et al., 2012), others (generally from European countries) have shown the opposite effect, i.e. increased prevalence of autism in those from a lower SEP background (Baird et al., 2006; Rai et al., 2012; Roman-Urrestarazu et al., 2021). Evidence is also inconsistent as to whether SEP is associated with earlier diagnosis (Bent et al., 2020; Brett et al., 2016; Daniels & Mandell, 2014), and some studies indicate that the presence of an ID may mediate the effect of SES on autism prevalence (Delobel-Ayoub et al., 2015). It has been suggested that these conflicting findings are due to biases in the identification of autism (Delobel-Ayoub et al., 2015) and differences in how SEP is measured across studies (e.g. using area based vs individual information) (Loubersac et al., 2021).

However, higher maternal education level (when analysed as a separate variable to other SEP measures) has been consistently associated with earlier autism diagnosis (Baird et al., 2006; Hrdlicka et al., 2016; Kelly et al., 2019; Rosenberg et al., 2011), even when other measures of SEP show no relationship to diagnosis rates (Kelly et al., 2019). As maternal education level is likely to affect parental awareness of autism and ability to navigate the increasingly complex service pathways, clearly “there is the potential for socioeconomic inequalities in diagnosis, and so inequalities in access to intervention and differential outcomes for children” (Kelly et al., 2019, p. 132).

## Ethnicity

Research has also highlighted ethnic disparities in the identification and diagnosis of autism. A review by Tromans et al. (2021) indicates lower rates of identification in children and young people from racially minoritized groups, and that when identified, this population present with more severe forms of autism. Constantino et al. (2020) focused on autism in African American children, and found that this group experienced higher rates of misdiagnosis, later diagnosis and twice the rate of comorbid ID than non-Hispanic white children.

Similarly, Mandell et al. (2009) found that children from black, Hispanic or other racially minoritised backgrounds were less likely to have an autism diagnosis than white children, and Kelly et al. (2019) found that children of Pakistani mothers were around 70% less likely to have an autism diagnosis than children of white British mothers. The disparities in diagnostic rates have been shown to persist even after a positive autism screen, with Hispanic families being less likely to receive a diagnostic assessment and diagnosis than white/non-Hispanic families (Kuhn et al., 2021). Furthermore, a study by Begeer et al. (2009) showed that ethnic minorities were underrepresented in referrals and underdiagnosed, a finding which was attributed to ethnic bias in autism assessment. The potential for bias was highlighted in the NCC report (2011) which recommended that professionals should not assume variations in behaviour are due to cultural differences and should endeavour to be aware of and address lack of cultural competence in autism assessment. However, in contrast to the above findings, other studies have actually indicated higher diagnostic rates and a lower age of diagnosis in children from minority ethnic backgrounds (Abdullahi et al., 2019; Roman-Urrestarazu et al., 2021). A review by Daniels and Mandell (2014) showed inconclusive and conflicting findings on ethnic disparities in the age of autism diagnosis, but it was acknowledged that this could be due to methodological differences between key studies (such as location, sample, and study period).

The interactions between ethnicity and socioeconomic position have also been explored in a few key studies. Durkin et al. (2017) investigated whether differences in SEP could account for differences in the autism prevalence rates in racially minoritized groups between 2002-2010, and found that although overall there was a positive association between SEP and autism prevalence, racial and ethnic disparities in prevalence rates persisted and were especially noticeable in low SEP groups. The authors argued that their findings suggest differences in SEP cannot fully account for the lower prevalence rates among racially minoritized groups, and stated that if low prevalence reflects under ascertainment of autism, “the negative impacts of poverty and being Black or Hispanic on autism ascertainment are additive rather than confounded” (p. 1824). The ‘additive’ nature of these factors is supported by the findings of Parikh et al. (2018) who examined class memberships in relation to age at autism diagnosis. They found that the children with the earliest age of diagnosis (around age 3 years) were most likely to have known language delays, come from a white ethnic group rather than a minority ethnic group, and have a more advantaged SE background. Furthermore, although the largest cohort study in England showed the highest prevalence rates of autism in Black and mixed race pupils, only around 12% of this variance could be explained by socioeconomic factors related to ethnicity (relative social disadvantage) when compared with white pupils (Roman-Urrestarazu et al., 2021). This means that 88% of the variance in prevalence of Autism in minority ethnic groups was due to other unidentified factors.

One of the factors which could explain the ethnic disparities in autism prevalence is clinical profile. A study by Becerra et al. (2014) compared children of mothers from a white background to children of mothers from a minority ethnic background and found that the latter group were more likely to be diagnosed with autism and to present with a more severe form of the condition (involving severe emotional outbursts and poorer expressive language ability). Higher rates of ID and poorer language and social and communication skills have also been reported in diagnosed children of immigrant mothers compared to diagnosed children of white mothers (Abdullahi et al., 2019), and in diagnosed black children compared to diagnosed white children (Fombonne & Zuckerman, 2021). These findings suggest that children from racially minoritized groups with less severe presentations of autism are being under detected (Fombonne & Zuckerman, 2021) and indicate possible racial bias in the assessment of autism symptom severity by clinicians and/or parents (see Harrison et al., 2017).

Tromans et al. (2021) reviewed the literature on other possible factors that could explain the ethnic disparities in autism identification and found that explanations could be grouped under the categories of health care, environment, culture and biology. For a full list of these explanations, see Table 1.

**Table 1.**

*Possible explanations of the ethnic disparities in autism identification rates.*

| Healthcare | Environment | Culture | Biology |
|---|---|---|---|
| Clinician bias<br>Bias in diagnostic measures and research<br>Reduced awareness of health services<br>Reduced service availability and access<br>Lack of complete health/education records | Rates of immigration/migration to areas with varying levels of access<br>Differences in SES, language ability and parental education<br>Different environmental exposure among certain ethnic groups (e.g. prenatal vitamin D deficiency)<br>Urban vs rural living | Belief systems around diagnosis and autism symptoms<br>Social stigma<br>Cultural norms/expectations of CYP's social behaviour and ability levels<br>Language<br>Symptom descriptions<br>Media portrayals of autism | Maternal age<br>Differences in genetic risk<br>Rates of parental consanguinity amongst certain ethnic groups |

Based on these explanations, Tromans et al. (2021) made several valuable clinical practice recommendations to address these disparities, such as training programs for healthcare professionals to increase understanding of autism presentation in racially minoritized groups, universal screening for all children, the development of culturally sensitive interventions, and increasing the representation of individuals with autism from diverse ethnic groups in media and public health campaigns. Research recommendations include recording ethnicity data in all prevalence studies, and further qualitative research exploring autism belief systems and diagnostic experiences for racially minoritized individuals and their families, which will "help inform approaches to ensuring equitable access to diagnostic and support services across ethnic groups, improving the lives of autistic persons and their caregivers, irrespective of ethnic group status" (Tromans et al., 2021, p. 251).

## Systemic factors

Various research studies have highlighted the influence of system interactions in the identification and diagnosis of autism, with the type and number of interactions proving to be significant factors in autism pathways. For example, increased overall number of contacts with professionals prior to diagnosis has been consistently associated with later age at diagnosis, whereas involvement with early intervention programs has been linked to earlier age of diagnosis (see Daniels & Mandell, 2014), and higher likelihood of autism assessment in children with identified autism symptoms (Kuhn et al., 2021). Furthermore, professionals' responses to initial concerns have also been shown to impact age at diagnosis, with passive 'wait and see' responses associated with later diagnoses, and a more proactive approach (e.g., involving onward referrals to specialist teams, use of screening tools and developmental assessments and fewer consultations) associated with earlier diagnoses (Bent et al., 2020).

Many studies have also found geographical variations in prevalence rates and age of diagnosis (Bent et al., 2015; Daniels & Mandell, 2014; Roman-Urrestarazu et al., 2021).  Multiple possible explanations for this variation have been suggested, including place-based differences in the use of diagnostic measures/screening tools, educational provision and SEND support and thresholds for accessing support (Roman-Urrestarazu et al., 2021), community resources and policies on early identification (Daniels & Mandell, 2014). The National Autism Society report (National Autistic Society, 2019) recognised the importance of addressing geographical inequalities in autism pathways, highlighting that many local authorities lack an adequate understanding of good commissioning. The report also stated the need to collect accurate linked local population data in order to provide the essential education, health and care services required by children and young people with autism, and it has been recognised that "this absence of data and analysis hides local patterns, renders some groups completely invisible, and precludes investigation of the key drivers of health disadvantage" (Pickett et al., 2021, p. 48). Clearly as with all care services, the issues with routine data collection in UK autism services (e.g., incomplete data, missing data from private clinics/community paediatrics etc.) (Russell et al., 2021; Rutherford et al., 2017) need to be addressed to support strategic place-based service improvement programs.

A key report by the NCC in 2011 concluded that the benefits of correctly identifying children with autism would outweigh the costs, and stated that "the priority is to avoid the risk of failing to recognise those who do have the condition" (NCCWCH, 2011, p. 54). Since then, research has shown a substantial increase in the incidence of autism diagnoses in the UK (Russell et al., 2021) which suggests an improvement in the overall awareness and identification of autism. However, clear inequalities remain for children and young people from differing sociodemographic backgrounds. In the current context of service cuts, increasing demand for autism assessments, and growing waiting times (further worsened by the pandemic), services are at risk of being "swamped" (Russell et al., 2021, p. 6) if they have not been already. While this will impact all children with autism, those with existing vulnerabilities will inevitably be disproportionately affected, and existing inequalities will widen if not directly addressed.

## Summary of literature review

Significant inequalities have been identified across health, education, and social care pathways (Hanson, 2019; Pickett et al., 2021). Whilst the wider pathway issues are impacting children and families of all backgrounds, they are disproportionately impacting those from minority ethnic backgrounds in areas of high deprivation. Evidence of the impact of these inequalities has been found at all stages of the autism pathway, with children from racially minoritized backgrounds less likely to be identified, referred, and diagnosed with autism (Begeer et al., 2009; Constantino et al., 2020; Kelly et al., 2019; Kuhn et al., 2021; Tromans et al., 2021). Although clinical guidelines and recommendations reflect attempts to improve the autism pathway and reduce wait times for all children and young people, research continues to highlight several sociodemographic and systemic factors that impact diagnosis rates and likelihood of an earlier diagnosis including gender, symptom severity, parental concern, socioeconomic position, and system interactions (Daniels & Mandell, 2014; Duvekot et al., 2017; Kelly et al., 2019; Kuhn et al., 2021; Loubersac et al., 2021, Nowell et. al, 2015). Clearly more needs to be done to understand and address these inequalities.

## Project rationale

It is important to recognise that within existing inequalities research distinct ethnic groups have become homogenized, meaning the differential impact of the inequalities for specific ethnic groups and the role of intersectionality with the above factors is currently not well understood on a national scale. While general patterns determined by averaged data collected from large and diverse populations provide useful insights into the wider inequalities, they can also project a biased understanding which masks the real picture and nuances of what is happening at a local level for specific minority groups. Therefore, achieving a more thorough understanding of the issues unique to different ethnic groups requires an exploration ***grounded in place***. It is crucial to adopt a place-based approach to enable the development of recommendations that will address the needs unique to the individuals and families in those areas, rather than a centralised ‘one size fits all’ approach which often perpetuates the inequalities.

Furthermore, previous studies have not used connected routine administrative data to better understand inequalities at a population level. Thus, the established system of data linkage in Bradford (cBradford, Sohal, 2022) provides a unique opportunity to harness the power of these data to explore the issues in the autism pathways specific to children and families in the Bradford district. However, it is also important to test data-driven insights with relevant stakeholders to explore whether the data resonates with lived experiences, why identified patterns might be occurring, and explore qualitatively how the data could be used to improve the pathways. Taking a district level approach enables greater focus on aspects specific to the district and might help with understanding some of the common problems in the pathways playing out across the country. As Edbrooke-childs et al. (2016) state, “future research should continue to explore reasons for these differences to understand the best way of ensuring services that are equally accessible to all children and young people" (p. 545).

## Research aims and questions

Building on previous research highlighting general ethnic inequalities, this project aimed to combine data and lived experiences to identify and understand the inequalities in the autism pathways in Bradford. It used a methodology which could facilitate a deeper and more accurate understanding of what is happening 'on the ground' for the most disadvantaged populations. The project had two mains aims with associated research questions:

Aim 1. To use routine data to identify structural inequalities in the Autism pathways.

- What is the average age at referral for an autism assessment and how does this differ by ethnicity?
- What is the demographic makeup (gender, ethnicity, SEP (using receipt of free school meals as a proxy), of the CYP (<age 18 years) in the cBradford dataset who had received a diagnosis by the point of data sampling at the end of February 2023?
- What is the average age of diagnosis in this cohort and how does this differ by ethnicity?
- How do waiting times between referral and diagnosis differ by ethnicity?
- What are the pathways through services – how many in the cohort accessed health visitors, speech and language services, paediatric services and CAMHS prior to receiving a diagnosis? How does this differ by ethnicity?
- How many children with a diagnosis also have an additional prior diagnosis of ID, mental health need or ADHD? How might this differ by ethnicity? E.g., are children from white ethnic groups more likely to have multiple diagnoses and does having an ID increase or reduce the likelihood of an autism diagnosis?

Aim 2. Using objective data descriptions as a starting point, gain an understanding of the structural inequalities in the autism pathways through collecting the views and lived experiences of parents/caregivers and autism service providers.

- What is the lived experience of the journey to an autism diagnosis and support for parents from a minority ethnic background?
- What are service providers’ views of the pathway and the identified ethnic inequalities?
- What are the barriers for CYP from minority ethnic backgrounds and how can they be addressed?

# Quantitative work

## Methods

This section describes the project’s overall design, epistemology, and ethics, followed by a specific focus on the quantitative studies. The studies involved two statistical analyses on different data types within the cBradford dataset to identify ethnic inequalities in the autism pathways in the Bradford district. The analyses are labelled as Analysis 1 (A and B) and Analysis 2, and under these headings the methods will first be outlined and then the results of each analysis described.

### Design

The project employed a convergent mixed methods design (see Tariq & Woodman, 2013) whereby quantitative and qualitative methods were used in combination. The original aim was to use both methods concurrently in an iterative-inductive approach, however in reality due to practical and methodological difficulties gaining access to relevant data and conducting the analysis, the qualitative work took place before the quantitative results were finalised. Despite this delay in the quantitative method, initial findings from the preliminary data analyses did influence the development of the qualitative research, for example the interview and focus group questions asked.

The Connecting Lived Experiences with Visualisation of Electronic Records (CLEVER) framework (Elshehaly et al., 2023 [in press]) was used to address the research aims. The CLEVER framework is a novel methodology which combines analysis of population level data with the information perspective of a stakeholder in a way which addresses the limitations of traditional approaches to data analytics that rely upon the use of cross-organisational datasets and interpretation of patterns by domain specific experts. Traditional approaches are unsuitable for research involving datasets which cross organisational boundaries and involve exploring the complexity of human experiences of interacting with multiple services. This is due to explicit information being shared between several stakeholders and the biases held by domain specific experts that can distort the interpretation of the data (Elshehaly et al., 2023 [in press]).

The CLEVER framework calibrates the analysis of routine administrative data with ‘lived experiences’ to provide an accurate and holistic picture of the system that enables policymakers and practitioners to make better informed decisions. The benefits of the approach are that it provides a powerful approach to take advantage of data driven insights, formalise these insights using well established qualitative scientific techniques, and then combine the quantitative and qualitative information in a robust manner (for further discussion of the approach, see Elshehaly et al., 2023 [in press]). The quantitative aspect of the project involved analysis of data from the Connected Bradford database to explore autism diagnosis by different demographic factors at a population level.

## Epistemology

The research design is based on pragmatism, which prioritises addressing the research question through using the best suited methods, theories, and perspectives. As this project aims to identify inequalities in autism pathways at population level through data analysis, and understand the lived experiences of navigating these pathways through qualitative data collection methods, it requires a flexible mixed methods approach which pragmatism supports. Also, as Pragmatism is centred on the concept of action and recognises that reality is shaped by the combination of actions, experiences, beliefs and consequences (Goldkuhl, 2012), this especially suits the qualitative component of the research which will focus on these aspects, and the primary aim which is to improve autism pathways through the process of inquiry. Finally, a pragmatist approach complements this research due to its concern with issues of social justice (Collins, 2012) and orientation toward “…solving practical problems in the real world” (Kaushik & Walsh, 2019, p. 4).

## Ethical clearance

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

## Analysis 1 - Age and likelihood of diagnosis by demographics

### Analysis 1. A. – Age at diagnosis by demographics

Analysis 1. A. aimed to identify the distribution of autism diagnoses across different demographic groups, including identifying the differences in the age at which the diagnosis was received.

#### Method

Study Setting and Participants

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

**Table 2.**

*Demographic breakdown of individuals with autism diagnoses.*

| | n | % |
|---|---|---|
| Total | 2617 | |
| Sex | | |
| Male | 2022 | 77.3 |
| Female | 592 | 22.6 |
| Missing | 3 | 0.1 |
| Ethnicity | | |
| white | 1547 | 59.1 |
| Asian | 636 | 24.3 |

|  |  |  |
|---|---|---|
| Other | 183 | 7.0 |
| Missing | 251 | 9.6 |

Variables

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

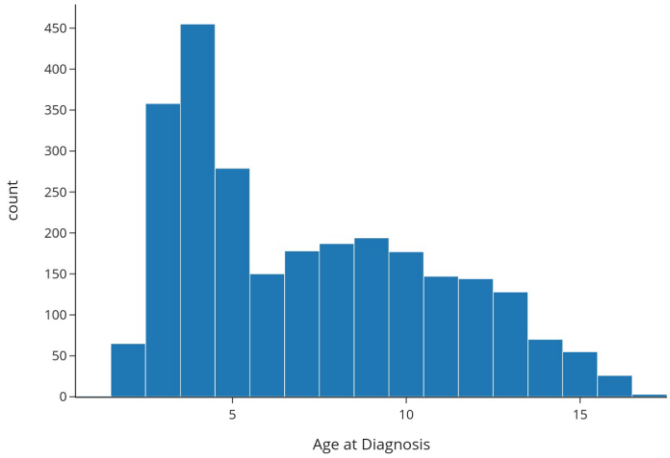
*Ethnicity*
The vast majority of the cohort were from either “white” or “Asian” ethnic groups. Due to low numbers of other ethnic groups, individuals outside the other ethnicities have been grouped into an “All Other” ethnic group. These were derived from census categories.

## Results

Across the whole cohort, there is evidence of a bimodal distribution in the age of diagnosis (see Figure 4). It is apparent that there is a sharp peak of diagnoses at age four and then another (albeit shallower) peak at around nine years of age.

**Figure 4.**

*Distribution of age of diagnosis across the cohort.*

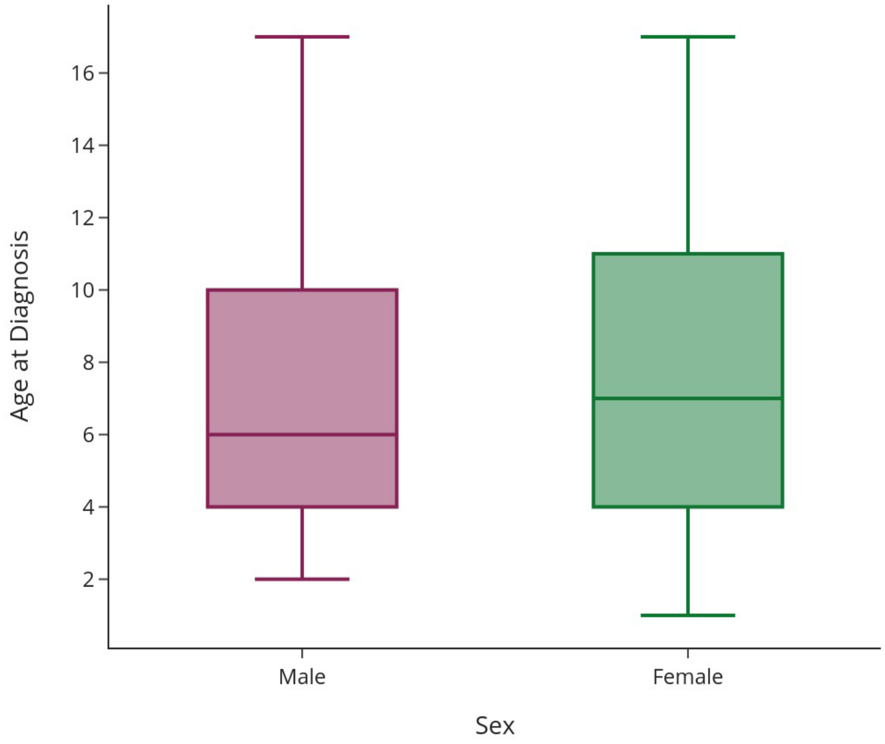


Sex differences

When comparing across the sexes, it was evident that the mean age of diagnosis was considerably younger for males (Mean = 7.02, Standard Deviation = 3.56) than females (M = 7.83, SD= 3.94) (see Figure 5).

**Figure 5.**

*Distribution of age of diagnosis split by sex.*



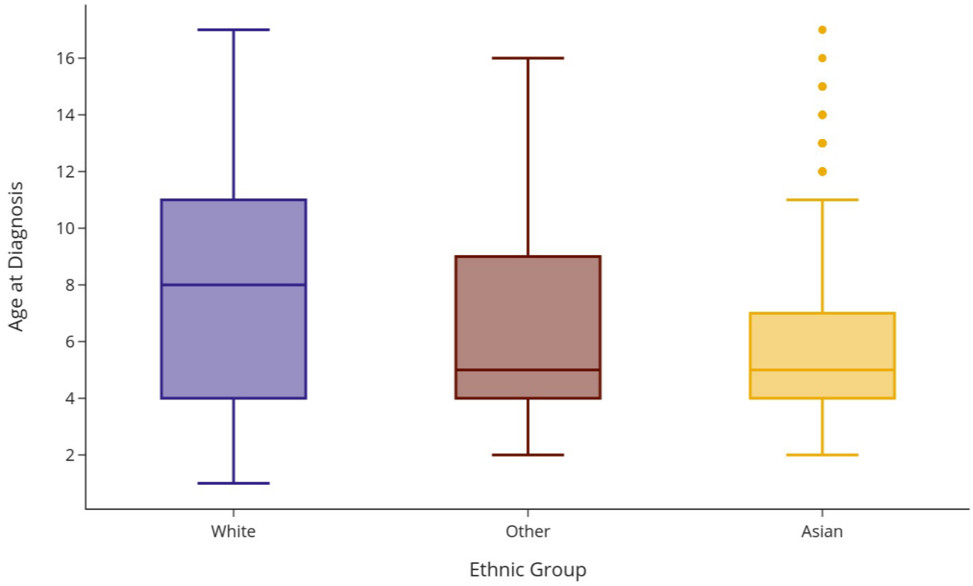
*Note*. This figure denotes the median age at diagnosis by sex.

Differences by ethnicity

When comparing age of diagnosis across ethnicities, children of Asian heritage (M = 5.87, SD = 3.12) are typically diagnosed younger than their white peers (M = 7.73, SD =3.71) and slightly younger than their peers from the “Other” ethnic group (M=6.44, SD=3.49). However, as Figure 6 illustrates, there are considerably more anomalies within the Asian sample.

**Figure 6.**

*Distribution of age of diagnosis split by ethnic group.*



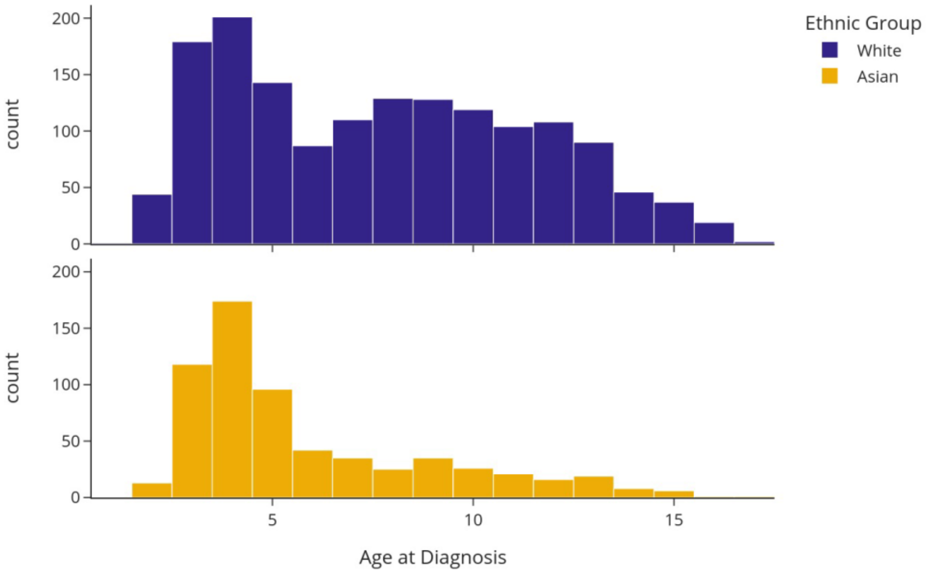
*Note*. This figure denotes the median age at diagnosis.

When exploring the distribution of ages by ethnicity, interesting patterns become apparent. While a similar bimodal distribution was found for children of white heritage, this was not the case for children of Asian heritage (see Figure 8). Indeed, for children of Asian heritage, there is a unimodal distribution of the age of diagnosis, with a peak around four years of age.

After this peak, there is a sharp decline in children being diagnosed with autism spectrum, and considerably fewer than the white heritage sample.

**Figure 7.**

*Comparison of the distribution of age of diagnosis in children of Asian and white heritage.*

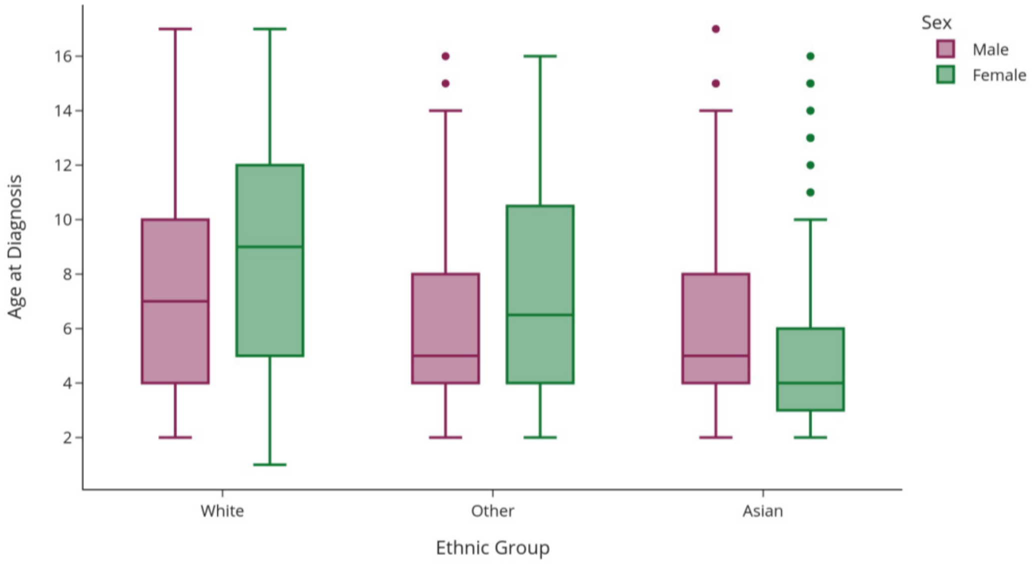


Differences by ethnicity and sex

Lastly, the combination of both ethnicity and sex on age of diagnosis were considered. As Figure 9 illustrates, males were substantially younger at diagnosis in the white heritage (M = 7.45, SD = 3.63) and Other ethnic groups (M = 6.13, SD = 3.24) compared to females (M = 8.71, SD = 3.85 and M = 7.53, SD = 4.13, respectively). In contrast, for children of Asian heritage, females (M = 5.53, SD = 3.18) received an autism spectrum diagnosis at a younger age on average compared to their male peers (M = 5.98, SD = 3.09).

**Figure 8.**

*Distribution of age of diagnosis split by ethnic group and sex.*



*Note*. This figure denotes the median age at diagnosis.

## Analysis 1. B. - likelihood of diagnosis by demographics

Analysis 1. B. explored the likelihood of receiving a diagnosis of autism across various demographics using a non-clinical comparison group (i.e., individuals without an autism diagnosis) taken from education records which were then linked with primary care records.

### Method

Study Setting and Participants

To understand the likelihood of receiving a diagnosis of autism across various demographics, a non-clinical comparison group (i.e., individuals without an autism diagnosis) was needed. Therefore, information regarding individuals under the age of 18 was first collated from education records owned by the DfE. These data were then linked with primary care records to determine which of these children had an autism diagnosis. In total, 13,0778 individuals were included in analyses. Table 2 demonstrates the demographic breakdown of this cohort, along with a comparison of individuals with/without an autism spectrum diagnosis.

**Table 3.**

*The demographic breakdown of individuals within Analysis 1.B.*

| Autism spectrum Diagnosis | Total | | No | | Yes | |
|---|---|---|---|---|---|---|
| | n | % | n | % | n | % |
| Total | 130778 | | 128396 | | 2382 | |
| Sex | | | | | | |
| Female | 63156 | 48.3 | 62623 | 48.8 | 533 | 22.4 |
| Male | 67300 | 51.5 | 65451 | 51.0 | 1849 | 77.6 |
| Missing | 322 | 0.2 | 322 | 0.3 | 0 | |
| Ethnicity | | | | | | |
| white | 61982 | 47.4 | 60560 | 47.2 | 1422 | 59.7 |
| Asian | 42069 | 32.2 | 41510 | 32.3 | 559 | 23.5 |
| Other | 9922 | 7.6 | 9760 | 7.6 | 162 | 6.8 |
| Missing | 16805 | 12.9 | 16566 | 12.9 | 239 | 10.0 |

Statistical Analysis

The likelihood of diagnosis, based on the demographic features, is described. Multivariable logistic regression was conducted to model the relationships between likelihood of diagnosis, sex, and ethnicity. Adjusted odds of autism spectrum diagnosis and confidence intervals for each of the demographic variables are reported (see Table 4).

### Results

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

This was explored further by modelling the likelihood of autism spectrum diagnosis as a function of sex and ethnicity. The reference group was a female individual of Asian heritage. Compared to baseline, males had approximately three times increased odds of being diagnosed with autism (OR: 3.36, 95% CI: 3.03-3.71). Meanwhile an individual of white heritage had nearly two times increased odds

(OR: 1.71, 95% CI: 1.55-1.89), and an individual from the “Other” ethnic group also had increased odds (OR: 1.21, 95% CI: 1.01-1.45), compared to baseline.

**Table 4.**

*Logistic regression table indicating likelihood of diagnosis by sex and ethnic group.*

| Effect | Estimate | *SE* | 95% CI | | z | *p* |
|---|---|---|---|---|---|---|
| | | | *LL* | *UL* | | |
| Coefficients | | | | | | |
| Intercept | -5.07 | .058 | -5.19 | -4.96 | -87.43 | .000 |
| Male | 1.21 | .050 | 1.11 | 1.31 | 23.37 | .000 |
| white | 0.54 | .050 | 0.44 | 0.636 | 10.65 | .000 |
| Other | 0.19 | .090 | 0.02 | 0.37 | 2.16 | .031 |
| Odds | | | | | | |
| Intercept | | | | | | |
| Male | 3.36 | | 3.03 | 3.71 | | |
| white | 1.71 | | 1.55 | 1.89 | | |
| Other | 1.21 | | 1.01 | 1.45 | | |

*Note.* Pseudo R-Squared = 0.036, LLR p-value = .00. CI = confidence interval; *LL* = lower limit; *UL* = upper limit, *SE* = standard error.

**Summary of Analysis 1 results**

The results of analysis 1.A. showed that, children from white ethnic groups were more likely to have a diagnosis (59%) than children from Asian and other ethnic groups (24% and 7% respectively). Across the whole cohort diagnosis rates by age showed a bimodal distribution, peaking around the age of 4 and 9 years. However when ethnicity was considered differential patterns of distribution were observed; a unimodal distribution in the age of diagnosis was seen in children from Asian backgrounds, with a peak at the age of 4 and then a sharp decline in diagnosis rates with significantly fewer children diagnosed after this age in comparison to children of white heritage. Furthermore, sex differences in the age of diagnosis were identified across the whole cohort, with boys having a younger age of diagnosis than females. Yet when these differences were analysed by ethnicity, this finding only applied to boys from white and other ethnic groups; in children from Asian ethnic groups, females were found to be diagnosed younger than males.

The results of analysis 1.B. showed differences in the likelihood of receiving a diagnosis across different demographic groups. Individuals most likely to have an autism diagnosis were male (78% in the clinical sample compared to 51% in the non-clinical sample) and from a white ethnic group (60% in the clinical sample compared to 47%). Compared to the baseline reference characteristics of being female and of Asian heritage, males had approximately three times increased odds of being diagnosed with autism (OR: 3.36, 95% CI: 3.03-3.71), children of white heritage had nearly two times increased odds (OR: 1.71, 95% CI: 1.55-1.89), and children from the "other" ethnic group also had increased odds (OR: 1.21, 95% CI: 1.01-1.45).

## Analysis 2 - EYFS and Autism diagnosis

Analysis 2 aimed to repeat the work of Wright et al. (2019) investigating the value of using the EYFS to predict autism diagnosis, focusing specifically on the predictive value by ethnicity, sex, and socioeconomic position (using free school meals status as a proxy measure).

### Method

#### Study Setting and Participants

Autism diagnosis data were again obtained from primary care records and linked to EYFS data from education records via the cBradford database. Records spanned the time period 2013-2019. This resulted in 70,277 children being included in analyses (including the 8935 children from the original study; Wright et al., 2019). Demographics of the sample are reported in Table 5.

**Table 5.**

*Analysis 2 Sample demographics.*

| Characteristics grouped by autism diagnosis | Missing | Overall | | No | | Yes | |
|---|---|---|---|---|---|---|---|
| | | n | % | n | % | n | % |
| Total | 0 | 70277 | | 69050 | | 1227 | |
| Sex | | | | | | | |
| Female | 639 | 33607 | 48.3 | 33354 | 48.8 | 253 | 20.6 |
| Male | 0 | 36031 | 51.7 | 35062 | 51.2 | 969 | 79.4 |
| Free School Meals Eligible | | | | | | | |
| No | 0 | 55725 | 79.3 | 54816 | 79.4 | 909 | 74.1 |
| Yes | 0 | 14552 | 20.7 | 14234 | 20.6 | 318 | 25.9 |
| Ethnicity | | | | | | | |
| white British | 0 | 35901 | 54.6 | 35129 | 54.4 | 772 | 64.8 |
| Pakistani | 0 | 20509 | 31.2 | 20248 | 31.4 | 261 | 21.9 |
| Other | 4528 | 9339 | 14.2 | 9181 | 14.2 | 158 | 13.3 |
| Has Low Total EYFS Score | | | | | | | |
| No | 0 | 58132 | 82.7 | 57691 | 83.5 | 441 | 35.9 |
| Yes | 0 | 12145 | 17.3 | 11359 | 16.5 | 786 | 64.1 |
| Has Low EYFS Subscore | | | | | | | |
| No | 0 | 59457 | 84.6 | 59071 | 85.5 | 386 | 31.5 |
| Yes | 0 | 10820 | 15.4 | 9979 | 14.5 | 841 | 68.5 |

Variables

*Autism Diagnosis*

As described above in Analysis 1.A, a list of relevant SNOMED-CT codes were created to identify individuals with autism spectrum disorders within the Primary Care data. Only children with relevant SNOMED-CT codes were included in subsequent analyses. An “age at diagnosis” variable was also created reflecting the date the first autism spectrum code appears in an individual’s records.

### *Ethnicity*

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

### *Early Years Foundation Stage Profile*

The EYFSP is a statutory assessment conducted in the final term of the year in which a child reaches age five and is used to support the transition into the national curriculum Key Stage 1. See Table 6 for a description of the areas of learning and early learning goals.

**Table 6.**

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

| Area of learning | Early Learning Goals |
|---|---|
| Communication and language development | Listening and attention<br>Understanding<br>Speaking |
| Physical development | Moving and handling<br>Health and self-care |
| Personal, social and emotional development | Self-confidence and self-awareness<br>Managing feelings and behaviour<br>Making relationships |
| Literacy | Reading<br>Writing |
| Mathematics | Numbers<br>Shape, space and measures |

| | |
|---|---|
| Understanding of the world | People and communities<br>The world<br>Technology |
| Expressive arts and design | Exploring and using media and materials<br>Being imaginative |

Scoring is based on an observational assessment conducted by teaching practitioners and guided by a framework set out by the UK Department for Education. Accordingly, each of the 17 Early Learning Goals scored either “2” (meeting the level of development expected), “3” (exceeding this level), or “1” (not yet reaching this level - i.e., the skill is emerging). Both total (summed) scores and sub-score were calculated for each individual.

The sub-score included only five early learning goals which reflected the four key symptom areas defined by the World Health Organisation’s 1992 research diagnostic criteria for autism spectrum: (i) social reciprocity, (ii) language and communication, (iii) imagination delays, and (iv) repetitive and stereotyped patterns of behaviour (see Wright et al., for more information). Table 7 maps the four key symptom areas to the related Early Learning Goals.

**Table 7.**

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

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

Consistent with the methodology of the Wright et al (2019) paper, the EYFSP scores were then dichotomised for the purposes of analysis. Children who received a total score of <25 and a sub-score of <8 were categorised as having a "low" score. Those who had scores above this threshold were said to have "not low" scores (for more information, see Wright el al., 2017).

### Statistical Analysis

Univariate and multivariable logistic regression models were conducted to understand the association between EYFSP scores and autism spectrum diagnosis. All analyses were conducted using the statsmodels package (Version 0.13.5, Seabold & Perktold, 2010) in Python. Independent models were conducted for both the EYFPS total score and sub-score and reported separately.

In addition to EYFSP total score/sub-score, the following variables were included in the model as covariates: sex (male/female); receipt of free school meals (yes/no); ethnicity (white British/Pakistani/Other ethnic group); and age of child at extract. Lastly, an interaction term was included in the model to disentangle the combined effect of sex and EYFSP score on autism spectrum diagnosis. In the multivariable logistic regression model, females, with a "not low" EYFSP score/subscore, who were not in receipt of free school meals, of white British ethnicity and under ten years old were employed as the reference group.

### Results

Findings demonstrated that 1.75% (1227) of the 70277 individuals in the matched cohort had a diagnosis of autism. Of the children with autism diagnoses, 64.1% (786) had a "low" EYFSP total score and 68.5% (841) had a "low" 5-item subscore, compared with 16.5% (11359) and 14.5% (9979) respectively from the individuals without an autism spectrum diagnosis (Table 4).

The univariate logistic regression suggested that children with low EYFSP total scores and sub-scores had nine and 12 times increased odds, respectively, of being diagnosed with autism spectrum (see Table 8).

The multivariable model demonstrated that children with a low EYFSP subscore had over 16 times increased odds of being diagnosed with autism than those who did not receive a low score (Table 8). In addition, males had more than three times increased odds of being diagnosed with autism compared to baseline, while children of Pakistani heritage had approximately two times decreased odds and individuals of other ethnicity had nearly two times decreased odds of being diagnosed with autism. Free school meal status and age (excluding age 11, which given the effect size and confidence intervals is likely a statistical anomaly) were not significant predictors of autism diagnosis. Lastly, the interaction between sex and EYFS score was significant for both the Total score and the sub-score. Indeed, compared to the reference group, males with low EYFS sub-scores had approximately 36 times increased odds of being diagnosed with autism.

**Table 8.**

*Odds ratios and 95% Confidence Intervals from logistic regression models.*

| | EYFSP Total Score | | | EYFSP 5 Item Sub-Score | | |
|---|---|---|---|---|---|---|
| | Odds ratio | 95% CI | | Odds ratio | 95% CI | |
| | | *LL* | *UL* | | *LL* | *UL* |
| Univariate – EYFSP score: | | | | | | |
| EYFSP score: | | | | | | |
| Not Low (reference) | - | - | | - | - | |
| Low | 9.121 | 8.085 | 10.29 | 12.943 | 11.427 | 14.661 |
| Multivariable – EYFSP Score and covariates: | | | | | | |
| EYFSP score: | | | | | | |
| Not Low (reference) | - | - | | - | - | |
| Low | 11.090 | 8.557 | 14.374 | 16.504 | 12.676 | 21.49 |
| Gender: | | | | | | |
| Female (reference) | - | - | | - | - | |
| Male | 3.454 | 2.758 | 4.326 | 3.317 | 2.618 | 4.206 |
| Interaction – Male and Low Score*: | | | | | | |
| No (reference) | - | - | | - | - | |
| Yes | 27.643 | 12.718 | 60.099 | 36.342 | 16.33 | 80.88 |
| Free School Meals Eligible: | | | | | | |

| | | | | | | |
|---|---|---|---|---|---|---|
| No | - | - | | - | - | |
| Yes | 0.943 | 0.823 | 1.081 | 0.902 | 0.787 | 1.035 |
| Ethnicity: | | | | | | |
| white British (reference) | - | - | | - | - | |
| Pakistani | 0.473 | 0.409 | 0.548 | 0.476 | 0.412 | 0.551 |
| Other | 0.621 | 0.521 | 0.741 | 0.616 | 0.516 | 0.736 |
| Age: | | | | | | |
| < 10 (reference) | - | - | | - | - | |
| 10 | 0.866 | 0.698 | 1.077 | 0.844 | 0.711 | 1.100 |
| 11 | 1.256 | 1.032 | 1.531 | 1.269 | 1.041 | 1.549 |
| 12 | 1.156 | 0.950 | 1.408 | 1.170 | 0.960 | 1.428 |
| 13 | 1.134 | 0.936 | 1.375 | 1.104 | 0.910 | 1.340 |
| < 13 (reference) | 0.985 | 0.819 | 1.186 | 0.953 | 0.792 | 1.148 |

*Note*. Effects when controlling for covariates are reported in Multivariable models. *****Interaction effect odds are calculated using a combination of the individual “male”, “low score” and “male & low score” coefficients.

## Summary of results and discussion

The results from the first analysis indicate prevalence rates of autism in the cBradford cohort which are largely consistent with current national estimates of 1% (Fombonne et al., 2021), demonstrating the ecological validity of this population-based study. In terms of children with an autism diagnosis, there was a male to female ratio of 4:1, which may suggest that there are fewer girls who have received an autism diagnosis in the Bradford district compared to broad national estimates of 3:1 (Loomes et al., 2017).

The results show that overall children from white ethnic groups were more likely to have a diagnosis than children from Asian and Other ethnic groups. The children most likely to have a diagnosis were male and from a white ethnic group, with males being three times more likely to be diagnosed than girls from an Asian ethnic group (the baseline), and children from white ethnic groups being nearly twice as likely to be diagnosed. Children from other ethnic groups were also more likely to be diagnosed.

Across the whole cohort diagnosis rates by age showed a bimodal distribution, peaking around the age of 4 and 9 years. However, when ethnicity was considered differential patterns of distribution were observed; a unimodal distribution in the age of diagnosis was seen in children from Asian backgrounds, with a peak at the age of 4 and then a sharp decline in diagnosis rates with significantly fewer children diagnosed after this age in comparison to children of white heritage. Furthermore, sex differences in the age of diagnosis were identified across the whole cohort, with boys having a younger age of diagnosis than females. Yet when these differences were analysed by ethnicity, this finding only applied to boys from white and other ethnic groups; in children from Asian ethnic groups, females were found to be diagnosed younger than males.

The results of analysis 2 support the findings of Wright et al. (2019); children below cut-off EYFSP scores were 16 times more likely to receive an autism diagnosis than children who scored above cut-off. This is particularly the case for boys; there was a significant relationship between below cut-off EYFPS scores and autism diagnosis for boys (36.3 times more likely to have an autism diagnosis), suggesting that the EYFSP could function as an early indicator of neurodiversity in their first year of education. However, the strength of this relationship was more than halved for girls with a below cut-off score (16.3 times more likely to have an autism diagnosis), therefore while the EYFSP may detect potential autism for some girls, it may not be a reliable indicator of potential neurodiversity. This finding is not surprising and sits within the larger problem of identification and assessment for autistic girls. The results also highlight ethnic differences in whether EYFS scores predicted later autism diagnosis. Compared to children of white British heritage, children of Pakistani heritage with a low EYFS score had approximately two times *decreased* odds and individuals of other ethnicity had nearly two times *decreased* odds of being diagnosed with autism. This indicates that despite receiving a low EYFS score, children from racially minoritized groups (especially those from a Pakistani background) are less likely to go on to be identified as having possible autism and access the pathway to a diagnostic assessment than white British children.

Consistent with current research, this difference is likely to be driven by the general inequalities faced by children of Pakistani heritage in accessing support for healthcare (Kapadia et. al, 2022), SEND in general (Akbar & Woods, 2019; Akbar & Woods, 2020; Fazil et. al., 2010) and autism (Crowther, 2019). These findings suggest that the EYFSP could act as a useful indicator to identify autistic children of SA heritage who are otherwise 'slipping through the net' (as shown in analyses 1 and 2). It will be important for further research to be conducted with education staff responsible for conducting the EYFSP, to understand the reasons *why* children from SA heritage with a low EYFS score are less likely to be diagnosed with autism, and *how* the EYFSP could be used to improve early identification and diagnosis for this population.

A possible explanation for the ethnic differences found in analysis 1 (especially the peak at age 4 years and sharp subsequent decline in children from Asian groups), could be that only the children from Asian backgrounds with more severe difficulties are identified and diagnosed, and the increased severity of difficulties is therefore more apparent at a younger age accounting for the peak in diagnosis around age 4 years. This could also account for the findings of analysis 2; a lower likelihood of being identified and diagnosed with autism after having a low EYFS score. Children from Asian groups with a higher severity of needs (and low EYFS score) may be more likely to be identified immediately after the EYFS, but it seems that those with a low score and less severe needs are being missed from early primary age onwards.

This explanation is supported by previous research which showed that children from mothers from racially minoritized groups were more likely to be diagnosed with autism and to present with a more severe form of autism (involving severe emotional outbursts and poorer expressive language ability) than children from mothers from white ethnic backgrounds (Becerra et al., 2014). Similarly higher rates of ID and poorer language and social and communication skills have also been reported in diagnosed children of immigrant mothers compared to diagnosed children of white mothers (Abdullahi et al., 2019), and in diagnosed Black children compared to diagnosed white children (Fombonne & Zuckerman, 2021).

Together with these previous findings, the results from this study support the conclusions of Fombonne & Zuckerman (2021) that children from racially minoritized groups with less severe presentations of autism are being under detected. If this is indeed the case, the under detection of 'milder' presentations of autism in racially minoritized groups is perhaps most likely due to structural biases in the identification and assessment of autism 'symptoms' by clinicians and/or parents (see Harrison et al., 2017). Consistent with this, Tromans et. al. (2021) identified clinician bias and bias in autism diagnostic measures and in research as some of the key healthcare factors which could explain the ethnic disparities in autism identification.

Other explanations suggested to explain the disparities in diagnosis rates relate to the influence of intertwined sociodemographic factors operating at an individual, family, culture, and systems level. Factors such as socioeconomic status can impact the availability of financial and educational resources and result in reduced health literacy, knowledge of the routes to care and awareness of autism. Language and cultural barriers such as cultural norms and expectations of children's behaviour and fear of stigma and discrimination are also understood to be contributory factors. Furthermore the lack of research on how autism can present differently in diverse populations and the reliance of the majority of research studies and assessment measures on white, western, middle class samples continues to perpetuate the lower awareness and understanding of autism in diverse ethnic groups. This lack of representation in the existing evidence base is likely to mean that what is considered and accepted as 'truth' in relation to autism does not accurately reflect the experiences of families from diverse ethnic backgrounds. It is most likely that the disparities identified in this analysis cannot be explained by a single factor, but rather are caused and maintained by multiple co-existing factors (for a full discussion of the possible explanations and the literature see Aylward et. al., 2021).

The subsequent qualitative component of this mixed-methods research project aimed to understand possible explanations for the findings of the above studies (and test out the validity of the possible 'higher severity=earlier diagnosis' explanation) by conducting interviews with South Asian parents with experience of navigating the pathways to a diagnosis, and national and regional focus groups with professionals across education and social care responsible for identifying and assessing children with possible autism. By combining these population-based study results with the lived experience of these stakeholders, the primary aim was to gain an understanding of *how* and *why* these identified ethnic disparities in the autism pathways are happening. A secondary aim was then to use these findings to identify possible solutions to recognizing need and implementing timely support for children from South Asian (and other) ethnic backgrounds in Bradford.

# Qualitative work

Two different data collection approaches were used (interviews with parents and focus groups with professionals) so the methodology used for each approach will be described below under the headings of ‘parent interviews’ and ‘focus groups’.

## Methods

### Sample and setting

#### Parent interviews

Potential participants were identified using voluntary response sampling and convenience sampling. To be included in the research, participants needed to self-identify as being a parent from a South Asian background living in Bradford, with at least one child who had previously been diagnosed, or was awaiting, an autism diagnosis. This inclusion criteria was used due to the project requiring participants who could talk about their experiences of navigating the pathways and the inequalities they encountered through these different stages. Parents from this specific ethnic group were targeted due to being the second largest ethnic group in Bradford (ONS, 2022) yet on a national level representing a racially minoritized group shown to experience significant inequalities in the Autism pathways as well as across health, education and social care pathways more widely (Kapadia et al., 2022). Initial analyses of data at a local level across Bradford had also identified inequalities in this population (see quantitative analyses further above). It was therefore important to capture the views and experiences of a group that would be more representative of the Bradford population.

Parents were recruited using a research poster and advert shared with members of a regional parent support group by the group director in a seasonal newsletter and via social media. The advert and poster requested potential participants wishing to take part in the project to contact the researcher by email and recruitment continued until theoretical saturation was achieved. Saturation was deemed to be achieved through ongoing monitoring and comparison of key topics/themes arising after each interview, and noting the lack of new topics/themes after the seven interviews had taken place. Six participants from the group and one participant recruited via convenience sampling in June (through a co-production coordinator in the Bradford Institute of Health Research) emailed wanting to take part, and they were then sent the participant information sheet and a link to the online consent form. After completing the online form, a mutually convenient time for the interview was arranged.

### Focus groups

Potential participants were recruited using purposive sampling. Separate national and regional focus group were used to enable collection of information on the key research questions at different levels; the focus group with DfE participants enabled discussion of topics of interest at a national level, whereas the focus group with professionals and service providers from the Bradford district enabled discussion around views and issues at a local level, specific to the Bradford population.

Participants contacted to take part in the national focus group were civil servants working for the for the Department for Education Autism pathway projects around the UK who had existing links with the Bradford Institute of Health Research and the Centre for Applied Education Research. Within this group, nine participants took part in the focus group.

For the regional focus group, professionals working across health, education and third sector services in the Bradford district who were already part of an existing advisory group were invited to take part. Nineteen participants took part in this focus group.

## Data collection procedures

### Parent interviews

Data was collected via semi-structured interviews. This method was chosen as it enabled the use of specific questions relating to parents’ experiences of the autism pathways, whilst also allowing for participants to spontaneously contribute additional information not explicitly related to the questions asked. The same questions were asked of all participants, although some participants directly answered the questions in the narratives they provided without needing to be asked, meaning the interview questions were then adapted in response to what was shared.

The semi structured interview questions were designed to capture parents' experiences of different stages of the autism pathway (from first identification of needs to post-diagnosis), and their views of the barriers and how to improve the pathways. Whilst efforts were made to ensure the questions were worded in a non-pathologizing and accessible way, my own ethnicity (white British) and education level was recognised as having influenced the interview design. Therefore feedback from a parent from a South Asian background with two children with Autism was sought via the Bradford Institute of Health Research Co-production team to check whether the wording of questions and language used was culturally appropriate and accessible to the target population of participants. This feedback confirmed that the questions were sufficiently thorough to cover the important topics, and no comments were made regarding needing to change the phrasing of questions.

The interviews took place between July and November 2022 on Microsoft Teams and lasted up to one hour. Participants were given a preference of either face to face or online interviews, but all interviewees opted for online interviews for convenience. After the interviews participants were emailed a £25 LovetoShop voucher to compensate for their time and contributions.

### Focus groups

Two focus groups were conducted, one with DfE civil servants (national group) and one with autism service providers working across the Bradford district (regional group). Focus groups were chosen to gather shared perspectives on the care pathways and experiences of services, barriers to care, and how to address the inequalities by improving the pathways. Focus groups are recommended when the research aim is "to understand issues related to consensus and diversity across participants" (Morgan & Hoffman, 2018, p.3.). They involve group interaction which is useful in the exploration of shared knowledge and experiences, can facilitate discussion of stigmatised topics, and can examine "not only what people think, but how they think and why they think that way" (Kitzinger, 1995, p. 299).

#### National focus group

Ten civil servants working were invited by email to attend a one hour in person focus group on the 12th July 2022. The focus group was facilitated by the researcher and an Assistant Director of Autistic Children's Services within Bradford District Care Trust, and involved discussion of specific questions aimed at exploring the structural inequalities in the autism pathways, lessons learned, and ways to address the barriers.

### Regional focus group

Professionals working across health, education and third sector autism services were invited to attend a one hour online focus group on 8th August 2022 to discuss the autism pathways in Bradford and what changes were needed to address the existing inequalities. This focus group was facilitated by the researcher and project supervisor who presented the quantitative data findings on the identified inequalities at the start of the group as the foundation for discussion. Focus group questions were informed by the wider evidence base on structural inequalities within autism pathways, and the initial data analyses highlighting disparities at a local level. Specific questions were designed in collaboration with the project supervisor to aid discussion of key topics of interest.

### Recording and transcription

Interviews and focus groups were audio recorded and transcribed using the Teams function which was also checked against the original recording for accuracy.

### Data analysis

The data collected from the focus groups and interviews was analysed using Thematic Analysis (TA). Whilst there are similarities and differences between TA and framework analysis (such as both focusing on identifying patterns and relationships between different sets of data but only framework analysis involving creating and applying an explicit analytic framework to interpret data), TA was chosen due to the project involving smaller datasets, being more widely used in referenced literature, and being a more familiar approach than framework analysis (whereas TA was a method explicitly taught on the DClin programme). The six phase method of TA was applied:(i) familiarizing self with the data, (ii) generating initial codes, (iii) searching for themes, (iv) reviewing themes, (v) defining and naming themes, and (vi) producing the report (Braun & Clarke, 2006). An inductive coding approach was used and the analysis adhered to the quality criteria outlined by Tracey (2010) and Nowell et. al., (2017).

The data from the parent interviews was analysed first to attempt to prioritise representing the voices of a minority, as minority groups are frequently underrepresented and under-heard in research (and indeed in wider societal organisations and institutions). It was also important to attempt to reduce the influence of bias in interpreting the data which may have been caused by analysing the professional focus groups first. Whilst both the focus groups and parent interviews involved exploring perceptions of the autism pathways and structural inequalities, the parent interviews were focused more on lived experience of the pathways, and it was felt best to analyse these sources of data separately to clearly represent the voices of two different populations and enable comparison of identified themes. It was anticipated that these unique themes could then be integrated to inform recommendations targeted at different levels of the system.

After a process of familiarisation with the data which involved transcribing the interviews, reading each interview twice, and taking notes on reflections and key points of interest in the data, initial codes were generated for each interview using the software program NVivo (March 2020). Two rounds of coding were completed, with the first round following the order the interviews took place (1-7), and the second round involving coding from the middle of the data set starting with interview 4 and going in reverse order to interview 1, and then from interview 5 to 7. Initial codes were regularly reviewed and edited throughout the coding process, resulting in a final list of codes. The same approach was then followed with the focus group data. An independent second coder also coded both sets of data and the findings were discussed to reduce the influence of coder bias. Initial themes and subthemes were generated from the combined final lists of codes from both the parent interviews and professionals focus groups due to their being several areas of similarity in the identified themes. After the process of theme generation was also completed by the second coder and agreement reached, themes were renamed and refined to produce the final set of themes and subthemes.

## Self reflexivity

Whilst efforts were made to recognise and address issues of bias (for example meeting with the university Equality and Diversity Lead to discuss the issues below prior to recruitment), it is important to acknowledge relevant aspects of my identity as the lead researcher and how they may have influenced the project design and findings.

As a university educated female of white British origin raised in a white British middle class family, I hold multiple positions of power and privilege in relation to ethnicity and socioeconomic status. Whilst the doctorate training in Clinical Psychology and my own self-study has increased my awareness of these positions, they will have undoubtedly influenced the research aims and my approach to data collection and analysis. However, it felt important to be mindful of my positioning as an outsider in relation to the parent participants (see Kanuha, 2000), and to practice cultural humility, taking a curious, non-judgemental, and open stance. I was particularly aware of my position whilst designing the interview questions and analysing the qualitative data, and the possibility I might ignore, overlook, or minimise certain views/ideas raised in the interviews. As my knowledge of the ethnic inequalities grew through undertaking the project, it also became increasingly important to me to ensure that the voices and views of racially minoritized participants were prioritised, heard, and accurately represented in this report, which I have endeavoured to do to the best of my ability.

I also became pregnant with our first child whilst analysing and writing up this report. This undoubtedly changed my perspective as I started to think about becoming a parent myself, and meant I felt more able to understand and identify with parents in the interviews who shared their views about needing to protect and advocate for their children. I also felt inspired by parents who talked about recognising the need to change their parenting approach to meet their child’s needs, and a sense of respect for them in their role as parents for the efforts they had gone to to ensure their children accessed the support they needed within the health and education systems, despite the significant barriers they had faced in doing this.

Finally in my role as a Trainee Clinical Psychologist I also adopted an insider position in relation to the focus group participants who were professionals and clinicians working in autism services nationally and in the Bradford district. Having learnt about neurodevelopmental conditions and having worked in a neurodevelopmental assessment service previously and currently undertaking neurodevelopmental assessments with children who have experienced developmental trauma, I found I could identify with some of the views raised by assessing clinicians around the challenges of conducting diagnostic assessments in an under resourced system, and reaching a conclusion in the context of increasing levels of complexity relating to co-occurring difficulties and traumatic life experiences. I recognised that at different times and with different participant groups I was holding both an insider and outsider position with regard to my professional status and researcher status, being a parent (but not a parent with autism), and my ethnicity (an insider position with the focus groups who were predominantly white ethnicity, but an outsider with the parent participants who were of South Asian ethnicity). This meant that at different times I felt emotionally pulled towards identifying with the views of one group over another. However, the benefit of holding both of these positions meant I could keep multiple perspectives in mind, maintain a curious and open stance, and draw on my own experiences and knowledge to increasing understanding where appropriate.

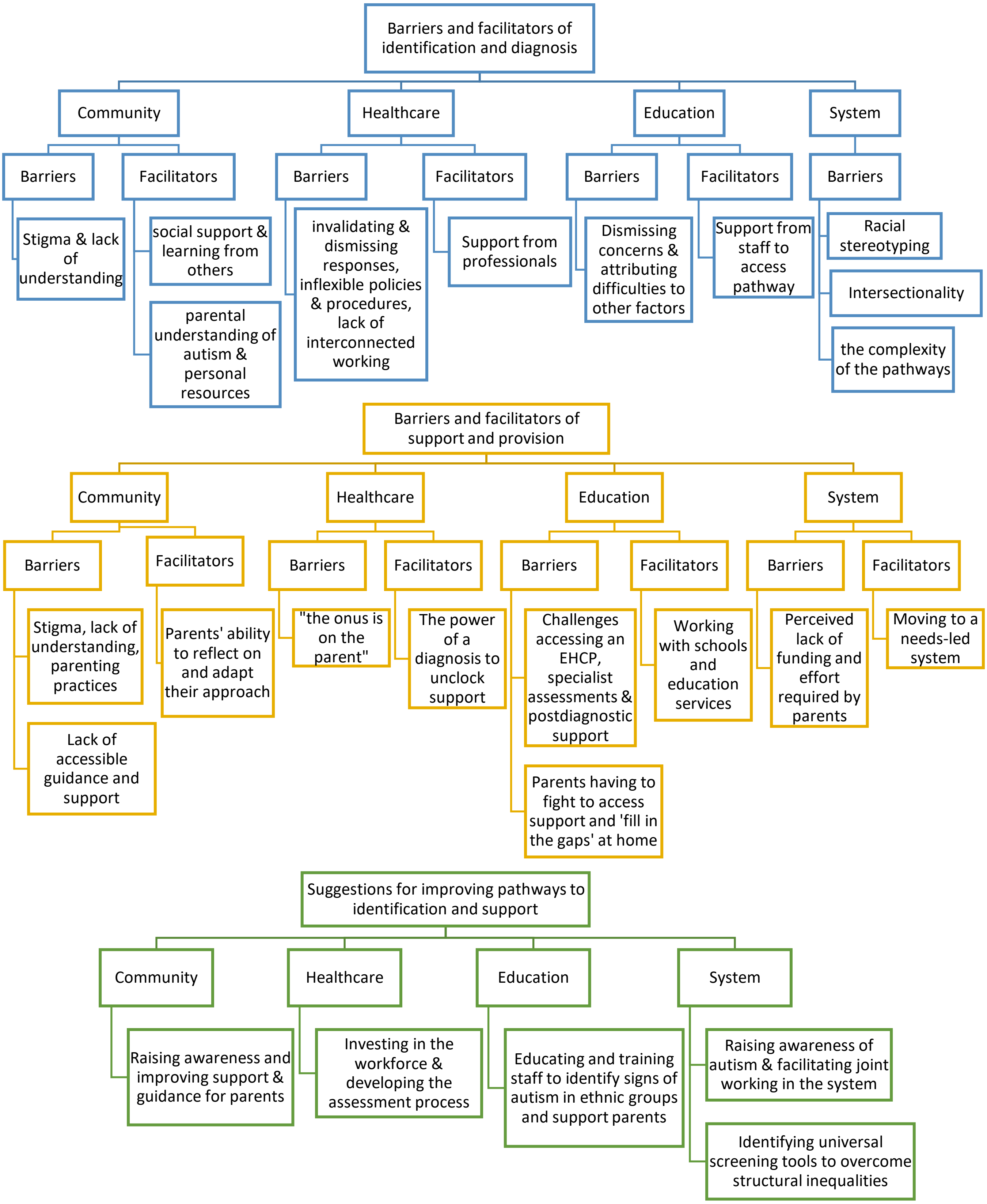
## Results

Thematic analysis of the parent interviews and focus groups identified three overarching themes: (i) barriers and facilitators of identification and diagnosis, (ii) barriers and facilitators of support and provision, and (iii) recommendations for improving identification, diagnosis and support. The settings of community, healthcare, education, and the wider system were inductively chosen from the interview and focus group data, and were used to organise the subthemes within the three overarching themes. One to three subthemes were identified for each setting. Whilst there are areas of overlap, it felt important to delineate the points and examples raised specifically for each setting. A total of 26 subthemes were identified and are described below. For an overview of all the themes and subthemes, see Figure 9 below. To illustrate each subtheme, one quote is included in the text for brevity, but more examples are included in the supplementary materials section.

The setting ‘community’ is used in this context to encompass experiences, values, and beliefs specific to South Asian parents, their immediate families and wider family network, and local community networks/groups. ‘Healthcare’ refers to NHS services within the Bradford district and across the UK, including speech and language therapy, paediatrics, health visiting services, and CAMHS. ‘Education’ refers to experiences and views relating to educational settings such as nurseries, primary schools and secondary schools, and includes mainstream and specialist provisions and services involved in education (e.g., the local authority). ‘System’ includes views and experiences that relate to the overall pathways, organisational structures, and general socioeconomic, cultural and environmental factors operating within the wider context.

**Figure 9.**

Visual representation of themes and subthemes.



## Theme 1 – Barriers and facilitators of identification and diagnosis

This theme describes the challenges parents experienced in recognising their child's needs, seeking support from their families and professionals in healthcare and education, and having these needs recognised. It also describes their experiences of accessing a referral for a diagnostic assessment of autism for their child. The facilitators in this theme refer to parents' experiences of what helped them in the process of identifying their child's needs and accessing support. This theme also integrates the views of autism professionals working at a local and national level regarding the key issues affecting autism identification and diagnosis in ethnically diverse groups.

### Community

#### Barriers

1) **Stigma and lack of understanding of autism in parents, families and the wider community.**

Parents and focus group participants referred frequently to issues around stigma and lack of understanding of the needs and behaviours of autistic children in the South Asian community. In the parent interviews, participants referred to their families and wider community holding stigmatised views of what autism is (e.g., a mental illness that can be cured, just bad behaviour, a 'phase' that will go away on its own) and what 'caused' it (e.g., black magic, and bad parenting).

> *I understand there's a lot of there's a kind of stigma attached to be like, nobody really wants to admit that their children are different. So it kind of, that's why I think, you know, mentality, the common mentality in South Asian communities "ahh it'll work out", you know, "it'll happen when it's meant to happen", and you know, "he'll talk when he's ready. He'll do that when he's ready", and absolutely there is that to a point, but not to the point where you*

> *don't seek help if you know what I mean so I think that's why it gets left quite as long as it does in a lot of families and it doesn't get picked up on in a lot of families – Parent 1*

One parent shared the view that some members of the South Asian community only hold these alternative explanations or beliefs in the absence of any other explanations or solutions, which should be provided by education and healthcare professionals.

> *I think it's, it's not a matter of educating parents about these issues, the priority is the professionals to stop gaslighting the children, say and explain to the parents that he's got learning difficulties or he's autistic and getting the right channels or referrals or signposts to treatment than to say "oh it's family problems." Or "it's black magic" ...the services are not willing to accept that they're autistic... Any Asian parent if you explain to them what autism is, they will not have any issue accepting that and you know, going down any other avenue of treatment. It's like it's not just Asian, nothing to do with Asian, it's just human beings. You know we as parents want what's best for our children and if scientifically we haven't got a diagnosis or we're not willing to talk about, you know the issue, then you know as parents we will look at alternatives – Parent 7*

Some parents talked about how the culture of privacy and stigma in their community led them to feel blamed by others, struggle to accept their child's needs and share concerns with others, including family members and education staff. Participants in the government focus group gave examples of this stigma affecting how open parents are with healthcare professionals.

> *Some of our families don't, but they show a certain face to schools, so there's certain respect that "we think the school know what they're talking about", so there's a bit of a reluctance to communicate what they think might be going wrong with a sort of feeling of blame within the family – Participant 5, DfE focus group*

> *We've run a contract…this was, quite poor, I would say, yeah, some of the families there's quite a bit of poverty in the area, a lot of Asian families, and I think just to echo what you were saying, I think we found that certain well feedback from paediatricians and psychiatrists was a lot of families were potentially answering questions in a certain way because they didn't, there was a stigma around diagnosis – Participant 1, DfE focus group*

Focus group participants also discussed the lack of role models and positive representation of autistic individuals from South Asian backgrounds on social media. They discussed how this has contributed to the lack of understanding of the spectrum of needs and abilities related to autism and meant the negative stereotypes/beliefs of autism have gone unchallenged.

> *I'm just thinking about the direct work that I do with young people who are neuro diverse and part of that work, looking at the self-esteem work around that, is looking at famous people and role models and people who we can say are neurodiverse and look how well they've done and what they've got and what they've achieved. When I'm sat here thinking I honestly cannot think of anybody from a South Asian background who is very prominent in my mind that meets that criteria that I could say to a South Asian young person, "this person is very famous they've done…" and I really struggle to do that. And*

> *that's perhaps because I haven't gone and looked into it that's also a possibility, but I wonder if that's part of it as well. – Participant 6, Bradford focus group*

Participants in the government focus group also talked about how the lack of support from services and stigma in the wider community act as compound barriers for autistic children and their families to identification and diagnosis.

> *I think that gateway, kind of who's actually supporting these families to say, "actually there might be something to investigate further", if you've then got a secondary barrier, of like, "why would you want to investigate that? because what you find out might not be very well received in your community", it's like as you say it's at every stage from the very earliest identification" – Participant 2, DfE focus group*

Many parents also talked about their own lack of knowledge and understanding of autism, and how they had identified several early indicators of possible autism when their children were younger but had not recognised these as such at the time. For example, six out of seven of the parents spoke about their child having had language delay/speech and language difficulties and social and emotional communication difficulties, five referred to sensory processing difficulties, and other signs mentioned included difficulties with sleep, behaviour, and toileting. This self-proclaimed lack of knowledge meant that parents often did not know whether they should be concerned about their child's behaviours, what help was available to them and how they could access this help.

> *I didn't really know what to do because nobody else was in a similar position to tell me what to do. I thought he just would, I thought, you know, he's gonna*

> *start nursery and then obviously he'll see the other children and they have the teachers there and he'll pick up – Parent 6*

Finally, parents and professionals in both focus groups talked about how language can act as a barrier to identification and diagnosis. Although most parents interviewed did not believe having English being an additional language was a barrier for themselves, they recognised it may be a barrier for other parents from a South Asian background. Those less fluent in English who are not able to communicate with professionals in English as easily as they would in their first spoken language are likely to find it even harder to share their concerns and seek help to enable their child needs to be identified sooner. Professionals in the focus groups also discussed specifically how children with autism who are the first to speak English in their family may be more disadvantaged than children who interact with at least one English speaker in the home, This is due to being less able to overcome the language barriers through the support of other family members. Furthermore, those less proficient in English often need more support from education and health professionals to access the pathways to identification and diagnosis.

> *My little boy who's in reception and he has seen, there's a there's a Pakistani teacher there and there's an English teacher there, and they both sort of, and I've seen like they make a bee line for the lady that speaks the language because it's easier for them to explain. Whereas if they, they can speak English to get by, but if there's something specific, like if you're raising concerns about your child, it's gonna be easier to speak to someone in your own language to do that, isn't it? Rather than trying to pull it together in English, that's hard, isn't it?" – Parent 1*

> *There is Cygnet courses going on in Urdu but these are after diagnosis…we are going to start our first Urdu course for pre diagnosis parents in*

> *November… this is for pre diagnosed family because I know the parents are struggling when they feel like first language is not English… there should be awareness everywhere with the with other languages as well…if you talk about other languages they still don't know about these, but yeah maybe they have acceptance of this thing but maybe there's a language barrier. It's hard to know how to avail these opportunities and how to help – Parent 4*

> *I had to battle, I speak English quite clearly. I can express myself quite clearly. Yet it was a battle for me so how hard is it for those parents, those parents that don't speak the language, don't understand autism, don't understand ADHD, don't understand that it's genetic. May well have needs of their own may have other needs like social and housing and being disadvantaged areas and things like that. Well how do they fit in the equation? – Parent 5*

### Facilitators

### 2) Having social support and learning from the experiences of others.

Within this subtheme, parents talked about how being able to share experiences and learn from others has helped them (and continues to help them) navigate the pathways to an autism diagnosis and feel understood. Parents spoke about specific parent support groups in Bradford such as the AWARE group (Airedale and Wharfedale Autism Resource) and Bradford Stronger Together as being helpful spaces for them to access information, advice and emotional support from other parents who had also been through, or were going through, the process of seeking an autism assessment. Several parents expressed a desire to use their experiences to also help other parents navigate the pathways, and two parents had taken on voluntary roles to support parents from South Asian backgrounds in direct (through offering 1:1 advice) and indirect ways (e.g., through engaging in consultation work).

> *…like every other parent, when they sit down, they talk about the difficulties and woes and how you know, the system at every stage is, you know, telling them there's nothing wrong with the child, or you know it's their problem or the family's problem or how they've had to circumnavigate the whole system to get to where they are and the journey they've gone through, and you don't want to wish it on anybody, but having you know a group of people together just talking about it I suppose it's more of therapeutic in that sense, and it makes you feel that you're not the only one who had to go through this – Parent 7*

### 3) Parental understanding of autism, previous experiences of the process and personal resources.

Parents described how their own personal qualities and skills had helped them to navigate the pathways to a diagnosis and support. They spoke about having the communication skills, confidence and assertiveness to challenge the views of professionals when their concerns were dismissed and having the wherewithal to find needed information about their child and the support available to them. Parents also shared how knowledge of the system, and of autism, is crucial in empowering them to share their concerns and ensure their views are heard and acted upon in a system where they can often feel disempowered.

> *I'm quite a confident parent who can find my way through all this jungle of things that you need to do, and I know a lot of parents are not gonna know what to do…we have done it ourselves, but I just feel for some of these parents*

> *that probably don't know how to find this information and they’re struggling, because we did, we struggled and even though I could find stuff out, I struggled. – Parent 2*

## Healthcare

### Barriers

### 4) Receiving invalidating and dismissing responses from healthcare professionals.

Within this setting, six out of seven parents talked about their experiences of sharing their concerns with healthcare professionals and having these concerns dismissed and/or normalised. They described having to convince professionals to take their concerns seriously, and how these concerns tended to be attributed to other explanations such as behavioural difficulties rather than being viewed as signs of potential autism.

> *…the GP kind of batted it back to me saying he's too young for it to be diagnosed at this age. You know, he needs to be a little bit older before you know, we can be sure, and I says, “well, here's the family history. Here's the signs we're seeing. So if you start the process, by the time it comes to assessment, it will be urgent, he will be showing more of, or displaying more of these symptoms and signs so you know, please don’t make us wait another year for something that we as a family know from experience, and it's hereditary, and you can't deny that…I just found it that the services don't want to know…So you have to do your homework, and its taking the evidences only for them to accept your statement, you know what you are saying and then “OK, well, we'll start the process rolling and we'll make the*

> *referral" – Parent 7*

### 5) Inflexible policies and procedures, staffing issues, and lack of interconnected working across services.

Within the professional focus groups, a key area of discussion was around services enforcing blanket policies and procedures around attendance which do not consider a child or families individual circumstances and can act as barrier to families accessing assessments. They also talked about the delays to assessments which can be caused by delays in collecting the evidence needed for decision making, and the lack of paediatricians and other health professionals who typically provide diagnostic assessments.

> *I went back to the paediatrician, and I said, "look, I think we need an assessment, and I would have thought that the Psychologist would have picked up on this when they did the assessment for learning difficulties". But she kind of said, "well, if they're doing it for the healthcare plan, they don't look, that's a separate kind of an assessment for autism", so she put it back into the system… - Parent 2*

Parents talked about issues relating to service errors, poor communication about waiting times, and being given conflicting information. They also described having to seek multiple assessments from different services for their child's additional needs, and having autism and these co-existing needs overlooked by assessing clinicians who tended to only focus on their specific area of assessment.

> *Then after that I got the diagnosis that he's got autism, but they didn't put down that he's got learning disability as well, which this is a learning disability as well. They didn't mention that. They didn't see, and also I was a bit confused*

*because they didn't check him for something like ADHD either. It's now noticed that he got that, but you know, he hasn't been assessed for that. – Parent 6*

*…when I moved to Bradford, I spoke to my GP and gave him the evidence he had no problem making a referral to CAMHS [for an autism assessment]. Only problem is that, uh, you know two weeks later I get a letter to say, you know, we've received a referral from your GP and you know you're in the system and we'll invite you for an interview because of the waiting list closer to the day. Now I've had to basically wait eight months. I got a letter from the hospital to say you've got an appointment, you know, in four weeks time, or you know four months time I can't remember. But you know two weeks before the date I got a letter of cancellation from the hospital saying your GP's made referral to the wrong services. So the admin team in the GP office instead of sending it to Bradford District Care Trust in the speech and language therapy, they've sent the letter to Bradford teaching hospitals, which is primary care. So what do you do? ... You know oh they say "we're sorry, it's just an admin error", [but I'm thinking] "where it's your admin error my sons, you know, gone back a year in the waiting list". So you know, he said "I will ring the services up to explain to them that this has been an error to try to fast track you"…and I know Bradford District Care CAMHS don't give a hoot, your problem, your job to sort it right. You're joining the queue at the back of the queue so it doesn't mean nothing to them. – Parent 7*

### Facilitators

#### 6) Parents being supported by healthcare professionals with identifying needs and accessing assessments.

Within this subtheme parents mentioned how having a pre-existing relationship or involvement with a healthcare professional, especially a paediatrician and health visitor was beneficial in having their child's needs recognised and accessing a referral for a diagnostic assessment. Parents also shared positive experiences of having their concerns validated and actioned by professionals who took the time to listen to them and advise them on how to access support. In the Bradford/regional focus group, participants also discussed the importance of healthcare professionals actively engaging with and supporting South Asian families who may have less understanding of the referral process in order to have their child's needs identified.

> *My youngest because he was born quite premature he was under the care of a paediatrician already so she was able to make the referral so I think that kind of helped a little bit, the fact that she'd got involved and sort of pushed things forward a little bit. – Parent 1*

## Education

### Barriers

#### 7) School staff dismissing concerns and attributing difficulties to other factors instead of autism.

Parents provided multiple examples of situations where they had shared their concerns related to potential signs of autism with school staff and felt that the response had been dismissing and invalidating. Parents described feeling that their children's additional learning needs were often not considered, and that the difficulties they reported were frequently attributed to their parenting, traumatic life events, their family circumstances or assumptions around language (i.e., English being an additional language). These experiences tended to result in a breakdown in the relationships parents had with their child's school.

> *As he grew up, the autistic side, you know traits were beginning to show, so I brought that to the attention of the school and the school just batted it away saying "no boys struggle with English as a subject anyway. And you know it will get better as we progress…There's nothing wrong with him"… that was the kind of feedback from school that they would you know they tried to deflect it to some other issue and you know they tried to sort of fob me off. I don't know if that's, you know the right, but you know they're kind of assigning it to my physical appearance or 'he's Southeast Asian background therefore English must be his second language' … I'd written down all those needs and gave to the teaching staff in the school… and they weren't taking note of that or the school wasn't, the class teacher wasn't supportive. And (son's name) would come back home and he would say this has happened, this has happened. And so I've had to go and go in and have a meeting again and again, you know there was a breakdown of communication – Parent 7*

### Facilitators

#### 8) Parents being supported by staff with identifying needs and accessing assessments.

Parents spoke about some of their positive experiences of being supported by school staff such as SENCos in the process of accessing and going through the diagnostic assessment process. Both parents and professionals in the government focus groups also spoke about the importance of schools and nurseries recognising children’s needs at the earliest opportunity and discussing observations of any possible signs of autism with parents. It was felt to be particularly important for schools to take this active role for families with less access to other services and/or less understanding of how to access support.

> *The expectations on schools are really important, and again, it was certainly the case in Chatfield that more of those disadvantaged families were perhaps not registered with the GP or didn't know how to seek support from health services. So if the school isn't doing it and you know early help type services were not being made available because school weren’t recognizing that there might be an issue, who is helping that family actually get on that pathway? – Participant 2, DfE focus group*

## System

### Barriers

Professionals in the Bradford focus group gave numerous examples of disparities in referral rates across different areas and services in Bradford, and in access to EHCPs. They also discussed anecdotal evidence that more children from South Asian backgrounds (aged two to four) are seen for assessment in the preschool clinic than children from white British backgrounds. Possible explanations for this centred around whether greater identification and diagnosis rates in this age group could be due to those children having a higher severity of needs, or to the education system identifying and then meeting their needs, reducing the requirement for a diagnosis. They also highlighted the poor quality of routine ethnicity data collection and monitoring in local data records.

> *Anecdotally, we are receiving probably at least three times more referrals from South Asian families from [Bradford hospital] than white British (pre 5s); this is obviously NOT the case with our referrals from Airedale nor from CAMHS. – Participant 2, Bradford focus group*

### 9) Racial stereotyping by professionals

Another possible explanation for the identified disparities highlighted by parents and professionals from both focus groups is that the needs of South Asian children are being missed due to racial stereotyping. Focus group professionals described their experiences of coming across systemic racial stereotypes, and how these perceptions prevent a more in-depth exploration of the difficulties that may be underlying a child's behaviour. They also spoke about how parents from racially minoritized groups are more likely to be blamed for the behaviours of their child, and that and their difficulties are more likely to be 'explained away' by other factors. As described above, parent's views matched those of the professionals, with numerous examples given of structural biases playing out in their interactions with health and education professionals. One parent in particular described the personal wrestle he encountered in not wanting to assume he was being subjected to racism, but eventually concluding that this was clearly underpinning his negative experiences. This parent went on to talk about how the shared negative experiences of South Asian parents of navigating the autism pathways reflects the broken state of the wider system.

> *I think there's a kind of, call it what it is it's structural racism, really in the attitudes that will say "this type of child from this type of family may display more challenging behaviour" or certainly in schools "our families don't teach their children the norms of pro social behaviour", just like you know, I've heard that said and you know, that would be describing, say, families from a Pakistani*

> *background… the staff in that school [were] kind of like, you know, "Asian boys are high spirited, naughty and don't respond to female authority figures because they don't have that at home. As soon as a man walks into the room, if it's an Asian Muslim man, so much the better and says calm down and sit down they're all perfectly behaved" but that was the kind of stereotype that was still being promulgated…actually the family was really struggling with the child's behaviour at home and you know in the end they end up with an ADHD diagnosis, or an Autism diagnosis and no family on earth would be expected to manage that without support.– Participant 2, DfE focus group*

### 10) The complex intersections between multiple aspects of identity which increase systemic disadvantage.

In both focus groups, professionals highlighted the complex nature of the interactions between socioeconomic position, ethnicity and severity of needs, giving examples from different areas of the UK of how these interactions are impacting identification and diagnosis rates in children from diverse ethnic backgrounds. They discussed how multiple areas of disadvantage can affect how a child's difficulties are viewed by others, how easily parents navigate the pathways, and how likely they are to be given an early diagnosis. These intersections also increase complexity in diagnostic decision making.

> *…the areas that I work predominantly in have quite a lot of social deprivation, and I would say that many of the late diagnoses that we come across come down to the parent blaming aspect again of the situation, whereby the parenting style of the parent is often assumed to be the issue as opposed to there being an unrecognised diagnostic need, and a lot of that very often*

> *comes from the parents perhaps not being as well read or as well educated in the area of autism. – Participant 6 – Bradford district focus group*

One participant also shared her view that systems are expecting too much of disadvantaged families in relation to being able to manage and navigate the structural complexities in the pathways to achieve support for their children.

> *The families with the least capacity to make those things happen are the ones that we expect the most of which I think is a massive barrier…it's definitely about that social capital. – Participant 2, DfE focus group*

### 11) The complexity of the pathways to referral and diagnosis involving multiple routes and services

The final subtheme refers to the complexities in the pathways as a whole which were described by both parents and professionals. Parents highlighted how these complexities delay access to support and create confusion around the 'right' routes to accessing support. Professionals discussed the geographical differences in service and pathway configuration across the UK and how this adds to the overall confusion and maintains the inequalities in the system.

> *I think it just needs to be easier, if it was easier [to access help], I think more people would pick up on the signs a bit earlier…whereas if it's just left, that's why these kids are getting left until they're, you know, they're older and by that time they've missed out on all those years when they could have had help and they could've, you know, developed more, they could've developed their skills more. – Parent 1*

## Theme 2 – Barriers and facilitators of support and provision

This theme describes parents' experiences of what helped and hindered them in accessing support and provision to meet their child's needs whilst waiting for a diagnostic assessment, and after their child received a diagnosis of autism (post-diagnostic support). It also includes the views of autism professionals on the issues operating within the wider system to impact the availability and accessibility of post-diagnostic support and provision.

### Community

#### Barriers

#### 12) Stigma, lack of understanding and parenting strategies/practices.

In discussing the barriers to support and provision, parents described how the stigma and lack of understanding in the community and in family members' home countries had impacted on help seeking and on parenting approaches. Parents described some of the different cultural parenting practices occurring in the South Asian community that are based on a lack of acceptance and understanding of autistic behaviours, and stigmatised views that autism can be 'cured' or 'treated' through physical punishment, forced marriage and spiritual healing.

> *…he [participant's husband] is from Pakistan. And he said, "oh, I remember a child when we were younger and, you know, he used to do a certain thing all the time and his dad used to get, you know, really angry with him and they used to tie him to the tree and stuff like that". I said "what?" And he says, "yeah, but now you're telling me, I'm thinking maybe he were autistic, but we didn't know. We're just thinking, oh, he's carrying on and, you know, no matter how many times I told him, he still did it, you know this kid", and I said "yeah, because maybe that's autism, but they're not aware of it." ... he said this*

> *particular kid, he used to be very vocal, apparently. But then they tied him to a tree and they wouldn't listen to him, they'd just keep him tied there, feed him there, and then they would open him on the night, lock him in his room, and he said he just went very quiet this child, after a while he wouldn't speak … So he says now you're telling me this is what it is and maybe this what it was, but he says they still don't have the understanding there [in Pakistan] of autism. But he said right that's what it must have been then, so it it's quite hard to, I think understand autism." – Parent 2*

Some parents also reflected on their own lack of understanding which had meant they struggled to know how to respond to their child's behaviours, and felt they would have been able to manage the challenges differently (in a more patient and helpful way for their child) if they'd had more understanding.

> *… I get quite upset about it because I'm thinking, you know, I used to get really mad with him sometimes because we didn't know. We didn't know how to deal with him or what to do, we're just thinking yeah he's got learning difficulties but why are you now having a paddy in the middle of a shopping centre because nothing's happened and you just now starting to bloody cry over no reason at all. We can't even take you out anywhere because you start throwing a tantrum. It's because we didn't know. And I think if we'd known, we would have reacted differently – Parent 2*

13) **Lack of accessible guidance and support for parents about how to understand their child's behaviours and respond to their needs.**

Another related barrier to accessing support and provision shared by parents was the lack of accessible information and support in helping them learn about autism, how it was affecting their child, and how to understand and respond in helpful ways to autistic behaviours. Parents gave numerous examples of having to educate themselves to support their child, and having to find their own strategies and solutions to manage more challenging behaviours.

> *I started learning by myself. I didn't have any support. I did online courses. I started with behaviour course and yeah, challenging behaviour so I started with this. The techniques they mentioned there I tried with him…one thing I read about autism, they don't like change. So…what I did because I was with in laws, I was living in one room. We were four. So what I did I started changing the room settings by changing the curtains, changing the bed sheets. Changing the chair even the moving the furniture around the room whenever he came back he picked up quickly like did you change this did you change this and I said yes I did that and then he slowly, slowly, he adapt this like change is good, but still he struggled with something like if change happened in school… it does bother him, like if there's a change of plan but not, you know, he does not react too much…And that's how I, me and my husband we helped him... – Parent 4*

### Facilitators

#### 14) Parents ability to reflect on and adapt their parenting approach to meet their child’s needs.

Within this theme, a key facilitator for parents in being able to effectively support their child related to their capacity to reflect on the effectiveness and helpfulness of their parenting approaches, learn from others, and change their expectations and responses to suit the unique needs of their child.

> *The lady that did the consultation with my son, her daughter had autism. And she said it were a long time before she could get her head around it, and she was in the job. And she said, "look, you've got to change your way of thinking, you can't expect him to be like, you know that kid or that kid or that kid, because this kid is unique to himself. You've gotta think the way he thinks, you're gonna do things, you can't sort of expect him to change, you've got to change, which is really difficult" ... I had to change. You know, I had to change my way of thinking and I think that was the turning point for me because of what she was telling me as a person who had had experience of it and how difficult it was so she didn't make it out like it were easy, she said you know, "it is a really difficult process to change your way of thinking onto his level, but don't expect him to change. You need to change." – Parent 2*

## Healthcare

### Barriers

#### 15) "The onus is on the parent".

In every interview, parents described having to fight to access support and provision for their child, and feeling that their voices were unheard and their child's needs not accepted unless they had the backing of a professional report. They described how often the outcome of the diagnostic assessment and what it meant for their child was not explained to them, and that in the absence of any post diagnostic support, they had to be the ones to action the recommendations outlined in the diagnostic report.

> *When the reports came through, there were some recommendations and things like that, but then that was that, so I got the report, but there wasn't anything*

> *else like support or there was nothing. It was like, "yeah, you got the report here, go through it and then make of it what you want", I suppose, let's put it that way. So the onus was on me as a parent to kind of pick it up and do what I needed with it…getting that report, yes, we know he's got autism, yes, they made some recommendations, but where is, what are the next steps? There isn't anything there to say, "Well, actually, you know, here is what it is" … there's nothing after that. You've got to find it yourself as a parent. – Parent 2*

### Facilitators

#### 16) The power of a diagnosis in 'unlocking' support.

Parents and professionals both talked about how powerful having a diagnosis is in the current system in opening up previously locked doors to support and provision. Parents recognised the limitations of a diagnosis in describing it as 'not a magic wand' and shared helpful experiences of having the diagnosis and the assessment report explained to them in a meaningful way. Professionals discussed how a diagnosis can increase understanding in others, act as a quick way to flag up a child's needs, empower parents in planning school provision, and help with the process of identity formation for young people.

> *A lot of people think that when you get a diagnosis for autism it's like a magic wand, you know all it is is a gateway. All it is is a gateway for extra support and that's all you want really. I don't think you're asking for a great deal, what you're asking for is for them to have maybe somebody around that understands, you know, tries to understand how their minds work, what might trigger them, when to try and maybe take them away and what might help… I just felt like, at least now I can say this is what it is, and I've pinpointed it and*

> *then now we can sort of start the process of schools and making sure that they get the right help – Parent 1*

## Education

What became clear through parents' accounts of their experiences was the direct impact of delayed or lack of support in childhood on children's learning and experience in the education system. Parents gave several examples of issues their children were experiencing at school that the education professionals they were interacting with on a daily basis did not fully understand, and how these issues were displayed through their behaviours. Parents also talked about their concerns relating to how the lack of provision in primary school would continue to affect their learning and transition to high school.

> *My oldest never, he didn't eat a thing, when he was at nursery all day he wouldn't eat a thing, and maybe if he'd had that support… they would say "well we can't feed him", [but] if that was in his EHCP, maybe they might have been able to, but he spent his whole days starving because he didn't understand how to do it himself, but they felt like they couldn't do it for him either – Parent 1*

> *When he hit year 8, by January, he was refusing school. And so by year nine, he was refusing more school. You know it were because he were struggling… then he started to abscond from school because he was still struggling. He'd get up and leave high school and nobody [would] know [he] had gone home. – Parent 5*

> *…the school's taken three years for something simple as dyslexia which can easily be diagnosed in classroom… [and now] he's leaving Primary school, he's not best equipped to go to secondary school 'cause you [school] haven't done anything to support him. – Parent 7*

### Barriers

### 17) Challenges accessing an EHCP, specialist assessments and other forms of post diagnostic support.

In this subtheme, parents described their experiences of trying to access an EHCP as another ‘hoop’ to jump through to get support even after all the hoops they had to navigate to get a diagnosis for their child. They also talked about the limitations of the EHCP, finding that even with one in place their child's needs were often not well managed and their learning and wellbeing continued to be affected. In relation to the process, parents described a lack of understanding about the process, and poor communication from schools about how the application was progressing. A DfE professional explained their perception that the high demand for EHCPs is due to parents not trusting schools to provide required the support needed for their child.

> *I've got a diagnosis from CAMHS to say he's autistic, I've got a professional report to say he's dyslexic. But unless I complete this, another piece of paper, which is going to take eight months, you know the services are in essence gaslighting, and this is why I'm saying the school won't put any support in place because he hasn't been diagnosed. Or if I'm to be correct, he's been misdiagnosed by the school… Even now, you know, the education Bradford is saying well until we have an EHCP all written out, we can't accept your child*

> *is autistic and these are the people who are supposed to be putting, you know, services in place to help me. - Parent 7*

Parents also spoke specifically about the challenges accessing specialist assessments and that specialist educational provisions were better able to meet their child's needs once they were recognised. They described feeling a sense of pressure from the system to accept any provision offered due to the shortage of places even if this was not suitable for them, and having to pay to access private assessments of specific learning needs such as Dyslexia due to lack of provision for this in schools themselves.

> *I get a phone call to say, "oh, there's a place available in Keighley, [schools name]", I said, "well, I've not even been to see the school so I don't know anything about it, the one I want is in in Bradford" ...and the other thing in my head is there's a commute here. How long is it gonna take him to get to Keighley and back? And I'm not, I'm thinking in my head I'm not having him commuting for three hours a day. So she said, "right well, we'll leave it with you, but can you just give us a response because there's only one place" and it was a bit like a sales patter, like if you don't buy now, you'll be missing out... And then I was told, "well, if you don't take the school, you're gonna be on a waiting list"... even the SEN teacher said to me she said, you know, "when they offered Keighley, and if I was the parent, I would have taken it. I would not have said no", she said "when you said no, I just thought oh my God, what's gonna happen here now because she's said no?"' – Parent 2*

> *...the school said it themselves "we can't always meet his needs because he's got, like sensory needs cause his autism, and we haven't got the resources or the, you know, everything in place for him". So that's why then they had to send him to a*

> *special school. – Parent 6*

> *There were an assessment in school when he was in year 9 or 10, and because they didn't, they don't have the qualification to assess, they can screen, but they don't have the qualification to assess. They then say that he may well be dyslexic. They will never [formally diagnose it], because they don't have that qualification, and then when it was in his education psychology [assessment] that he is showing signs of dyslexia, well "what do you mean? He's, he's either dyslexic or he isn't, you can't show signs can you?" And then I realized that school can't diagnose because they don't have the qualification I had to go private and pay £350 for that private testing and it was confirmed that he's dyslexic… – Parent 5*

In line with their reports about the lack of post diagnostic support from health services, and the onus being on parents to find their own sources of support and guidance, parents also spoke about the lack of general post diagnostic provision in the education system. They referred specifically to the lack of provision their children faced in school holidays in the Bradford district, and how they felt their children were frequently excluded from holiday clubs and activities due to assumptions about their level of need and the lack of funding for extra staff support to enable them to be included.

> *We really struggle on school holidays. It's such a long time… they wake up in the morning when it's a Monday morning expecting that they're going to school and all Christmas and if it's a one week holiday, you could sort of manage to a point, you can do things, but with the six weeks, it's hard because especially if there's nothing really out there to do with them…you have summer clubs available for children, but not for children with autism… because what they'll say to you is well,*

> *if you have a child with autism they need 1:1, we can't, we don't have the funding to pay for the one to one… I mean, there's so much money out there and you know, like being put into, autism and autism support. But I wish that there were just more services available for them…in all honesty, there's hardly anything in Bradford… our kids are the ones that struggle the most, but they get the least services offered to them. – Parent 1*

### 18) Parents having to fight to access support and provision and "fill in the gaps" at home.

The second barrier to support and provision in education described by parents and professionals was about parents having to fight to access support, and being required to provide the support being missed at school in the home environment. Parents described the lack of resources available in schools (including the lack of specialist school places), their perceptions of the lack of funding in the Bradford district being the causative factor for this, and their experiences of not being offered the support themselves and their child needed.

> *They'd allocated him a mainstream school even though I had my EHCP, I had a psychologist do another report to say, to categorically say that he cannot go into mainstream, he needs specialist provision, but they kind of just didn't even bother reading it I think, and they just gave me the nearest mainstream school to my house. – Parent 2*

These factors all increased the pressure on parents to have to 'fill in the gaps' and find their own solutions, and exasperated the feeling of having to fight for support. However, it was highlighted that parents ability to do this (i.e., to question and challenge decisions made by those in positions of greater relative power) was entirely dependent on their personal resources and social capital (e.g., their ability to know where to find appropriate support, their confidence in asking for help etc.).

> *I was trying to support him at home and I realised he was struggling, you know, and the school recognized and they encouraged that we do some more work with him at home to support him to make sure he meets the, you know, the national average criteria…I've had to go over and above, you know to try to keep him up to speed because I know if children are not up to speed in primary school, secondary school, they're going to drop out. – Parent 6*

### Facilitators

#### 19) Being supported by and working with schools and education services to access and implement provision.

Some parents shared positive examples of their experiences of being supported by schools to access educational provision for their child. These examples included being helped by SENCos specifically, the school proactively applying for the EHCP after the autism diagnosis was given, and the EHCP process being explained by council staff. Parents also described the impact receiving this support had had not only on their child's wellbeing, but also on their own.

> *My son's school now they just had a new provision built and it's on the back of the school, so they try to encourage them to go into class as much as possible…but they also have that safe space then…they've got that available to them… where he is now, the lady that runs the provision who's in charge, she has two children who are autistic herself, so she [understands them]…*

> *they know how to deal with them. So that's good for a parent because you don't spend your whole day thinking well, "God, what's happened?", you know, "what have they been up to? Have they had a good day have they had a bad day?" – Parent 1*

## System

### Barriers

#### 20) Perceived lack of adequate funding for services and the effort required by parents in navigating the pathways to support.

Parents and professionals both described the inherently long waiting times in the support and provision of the autism pathways, and that this pattern of extended waiting continues even after diagnosis. Parents shared their views regarding the perceived lack of autism provision and funding in the Bradford district, and professionals in the Bradford district focus group highlighted the pattern of interventions being implemented, found to be effective in reducing inequalities, and then stopped due to lack of attention and repeat funding.

*What we're actually doing most of the time, we put them on a waiting list to get the diagnosis and then when we get the diagnosis, we put them on a waiting list to receive the support. – Participant 2, DfE focus group*

Parents also gave numerous examples of having to navigate multiple services and the efforts required to access support.

*Everything's like a struggle, to be honest. It's constantly, like constant phone calls, constant chasing, nothing is sort of simple and I think that's part of the barrier as well – Parent 1*

Professionals highlighted the lack of a joined up approach between different sectors, and discussed how the ineffective systems that are currently in place can leave parents in the position of holding all the responsibility for organising support for their child.

> *I think a challenge that will come up soon will be creating the relationship with health and education to accept that we've, you know, we've given the diagnosis, well the clinicians have in collaboration with local authority, and in terms of NICE guidelines as well, and then how that's going to look moving forward and how health are going to now help these children that might need to be referred for maybe an ADHD assessment because they've got autism. – Participant 6, DfE focus group*

*IT was an absolute nightmare. So, our systems in health and our systems in education don't link and can't talk, and we can't transfer things over and things had to be logged in one place and not another. – Participant 5, DfE focus group*

> *What strikes me about this system is the child's been awaiting us quite a long time, the clinicians seek the information from education, to know more about how the child presents and then six months later, with a diagnosis in place, the school applies for an EHC and asks the clinician for their reports. The only person who is holding everything is the parent, which then puts all the emphasis on the parents to be this active player in the process, collating this package of support around their child…And that's one of the reasons I think, why parents always talk about having to fight for support…you hear that language all of the time…because most of the time parents are just absolutely knackered…if the parent can't come up with the goods the child is disadvantaged as a result because our systems don't work very well – Participant 2, DfE focus group*

**Facilitators**

### 21) Moving to a needs-led rather than diagnostic-driven system.

Professionals in both focus groups discussed the current diagnostic driven approach to funding and service provision, and how the system needs to be reformed to ensure services can be provided on a needs-led basis. A participant in the Bradford district focus group also shared their view that improving post diagnostic support would encourage others to access the pathway by overcoming doubts over the availability of support and the capacity for change.

> *I think that's where you got to come at it from both angles, because it's a broken system that we need to reset because it's identifying and supporting need, no matter what that is, without that necessity for EHCP or a diagnosis. – Participant 4, DfE focus group*

## Theme 3 – Suggestions for improving the pathways to identification, diagnosis, and support.

This theme refers to the specific strategies, actions and areas for development at the community, service and system levels which were described by parents and professionals. Together with the quantitative results, these suggestions informed the overall recommendations described in the discussion section of this report. These recommendations aim to guide services, policy makers, and service commissioners on how to address the existing barriers specific to the Bradford district to improve the autism pathways at all stages from identification to post diagnostic support, thereby overcoming the inequalities significantly disadvantaging autistic children and families from ethnically diverse groups.

When asked what needs to happen in the system going forward to address the inequalities in the Bradford district, one participant highlighted the need to learn from what has worked or not worked before, and working with and alongside families to make the changes.

> *I think learning from, I want to say mistakes and it's not mistakes, it's learning from what's happened before that's not been positive, and I think involving families and communities in everything you ask the person that you're doing to do, rather than do to the person. – Participant 5, Bradford district focus group*

## Community

### 22) Raising awareness in SA communities and improving support and guidance for parents.

Parents and professionals all shared the view that there needs to be more awareness in South Asian communities to tackle stigma and increase acceptance of autism, and suggested various strategies that would be helpful for South Asian families. These strategies included working with community leaders and using community spaces, increasing the accessibility of information and support, increasing positive representation of South Asian autistic individuals on social media, and creating supportive communities.

> *I think it is about education and training for me and it is about targeting those community leaders, now we have tried in the past to do that with awareness around autism, you know we've gone to mosques, but we've really really struggled so you know a lot of, I mean, I'm Muslim and I know Muslims within Bradford, they actually, you know they actually look up to their local mosques or they look up to, you know, their community leaders, so it should, the drive*

> *should come from them as well – Participant 9, Bradford district focus group*

Parents and professionals also discussed the need for professionals to take a more active role in identifying children's needs, guiding parents through the pathways, and offering more post-diagnostic support to South Asian families to address stigma. Professionals talked about the need to make it easier for parents to ask for help earlier and providing support to parents through creating specific key worker roles.

> *I think the biggest way that we could help people in terms of starting off at the beginning, which is asking for help, so we have to make that easier. We have to make it easier for people to come forward and say I'm worried about my child, this is what I'm worried about, where do I go from here? -Parent 1*

## Healthcare

### 23) Investing in the workforce and developing the assessment process.

Parents and professionals highlighted the need to train and develop the workforce at all stages of the pathway, and across services, to identify autism and provide support earlier. Particular staff groups referred to included health visitors and paediatricians. Professionals explained the more general need for staff able to conduct diagnostic assessments to reduce the waiting times. Furthermore, professionals in the government/national focus group described how effective their project involving doing assessments in schools had been and how they would take this model forward. This view was also shared by professionals in the Bradford/regional focus group.

> *One of the things that we've picked up on is that actually under fives a lot of the reason why they're struggling to diagnose under fives is actually lack of resource to get paediatricians that are available. I think within a lot of*

> *CAMHS services, there's a lot of psychiatrists a lot of time, but to get them young, they're going to need additional health checks and things like that and I think… I think we need potentially…we need to train more paediatricians.. and also I think just in general… the courses for ADI-Rs and ADOSs, they don't cost huge amounts of money and I think upskilling our staff across the board is actually a really good solution to help get faster access to diagnosis. –Participant 1, DfE focus group*

## Education

### 24) Educating and training staff to be able to identify possible signs of autism in other ethnic groups and offer support to children and parents.

Within the education system, professionals specifically highlighted the need to establish a school-based workforce to support parents and school staff, and use the expertise of other education staff such as specialist teachers.

> *one thing that I would like to explore further is having, you know, people like …psychology graduates… working within settings, working within schools… to support school staff in terms of the neurodiversity and the profiling tool and just having that deep understanding of what it looks like, what it might look like, and just working through that so you're on call to support the staff and parents to… to identify need and then book provision in to support that need. But I'd like to see that within the schools, that you guys support in, with that on a day-to-day basis- Participant 4, DfE focus group*

Parents spoke about the need to educate teaching staff, enabling staff to hold a more holistic view of a child’s needs, increasing acceptance of autism in schools, and employing community workers to overcome language barriers.

> *It's not just the parents. I think teachers need, what do you call it, CPD, around noticing you know ... because there's different things that these kids fall into [on] the spectrum, so they need to know, you know that it's certain things that kids do could fall under that, so it's also in, I think, educating teachers and educators around what it is and how to spot the signs and symptoms. – Parent 2*

Parents and professionals also talked about the importance of building positive relationships with parents by increasing trust, improving communication and creating accessible spaces in schools specific to the South Asian community which parents can be invited to.

> *I think the relationships built between the parents and the school have been so valuable. And I think that is really going to last these coming years, even if we ignore diagnosis and focus on the needs driven, that's what we can focus on now… The relationship between the school and the parents is so important. – Participant 3, DfE focus group*

### System

**25) Raising awareness of autism and facilitating joint working in the wider system.**

Within the national focus group, professionals raised the need to take a place-based approach to service organization and simplify the pathways by developing one universal pathway across the UK.

> *I think one…one pathway that's uniform across the country would be the way forward. Because then it doesn't matter where you live, doesn't matter how many times you move, the support is still there that should you need it – Participant 4, DfE focus group*

Professionals in the Bradford/regional focus group talked about the need for a single source of information on autism and available sources of support and increasing understanding in all levels of the system.

*…access to sort of a single source of information whether that be service users or professionals or anybody else who might want to look at information around neuro diversity – Participant 13, Bradford district focus group*

Government professionals also discussed the need to establish systems, processes and procedures that facilitate joint working across the different sectors of health and education, and the need for schools especially as key settings for addressing inequalities to be supported by other organisations.

> *You do sometimes need the top down. So you absolutely have to have a governance… governance in place so that health, education, social care do work together and are prepared to share their budgets and be flexible in their approach. – Participant 9, DfE focus group*

> *I'm starting to see a lot of different organizations… that have got similar kind of ideas around SEN, around autism and all those things. My worry is that…it's going be too complicated for schools to get their head around. And to my mind,*

> *they shouldn't need to know the difference between all these. It should all be around how can us as these different organizations work with the school and make it transferable to them rather than schools and parents having to kind of think well, is it the mental health pathway or the autism one… - Participant 8, DfE focus group*

### 26) Identifying universal screening tools which can overcome the structural inequalities and simplifying the pathway.

Professionals talked about the need to remove the burden of responsibility of identifying needs and accessing support from parents. This would work to overcome inequalities by reducing the extent to which the ability to access support is dependent on parental resources/skills/experiences/community support (which in turn is often largely determined by sociodemographic factors). This can be done by utilising population data and simplifying the system.

> *I think one…one pathway that's uniform across the country would be the way forward. Because then it doesn't matter where you live, doesn't matter how many times you move, the support is still there that should you need it. – Participant 4, DfE focus group*

# Discussion

In every interview parents described their experiences of having to invest significant time, effort, and energy to access support for their child, and the feeling of having to shoulder the burden and responsibility for ensuring this support was provided. This was a consistent theme across the settings of community, healthcare, education, and the wider system, and is consistent with the findings of other recent qualitative research into parents' experiences. Without the support and knowledge of how to navigate the pathways to a diagnosis and provision, parents are often left feeling confused, frustrated, and unsure of where to go to seek help. This means often the only available option is to try find their own ways of accessing information, guidance, and parenting strategies (e.g., through parent support groups, their local community or the internet), however depending on their own resources and additional barriers parents will differ greatly in their ability to source the required information and strategies and implement these at home.

Furthermore, the lack of resources currently available in the healthcare and education systems for autistic children and their parents increases the pressure and responsibility on parents to understand what is going on for their child and provide the support themselves in the absence of other available options. When resources are scarce in systems, individual groups can respond in different ways (see Cannon, Goldsmith, & Roux's model of resource scarcity, 2018). Those in greater positions of power (in this case health and education settings) can often tend to take a preservation approach due to feeling the need to protect the few resources they have, and others with less power (in this case parents) taking a combative approach due to feeling the need to have to fight/compete against others to access what is needed to survive. These conditions and responses can perpetuate the 'them and us' mentality that was present in many of the parent interviews and maintain the systemic inequalities and understandable sense of injustice many parents described (see Relative Deprivation Theory; Bernstein & Crosby, 1980).

There were some interesting similarities and differences between the themes identified in the professional focus groups and parent interviews. Both parents and professionals discussed issues relating to stigma in the South Asian community, the lack of support available to parents to help them navigate the pathways, the dismissing responses of professionals in health and education, and the common experience of signs of autism being attributed to other explanations. Parents and professionals talked about the benefits of a diagnosis in opening doors to provision in education, but also that this involved lengthy delays and meant that identified needs were often not acknowledged and interventions provided prior to receiving a diagnosis. Furthermore the lack of available tailored support post diagnosis was a topic discussed by both groups. These findings are consistent with literature exploring parents' experiences of autism pathways, services and provision in the UK (Crane et. al., 2016, Howlin et al., 1997, Legg et. al., 2019, Ryan & Salisbury, 2012) and internationally (Makino et. al., 2021, Martinez et. al., Gibbs et. al., 2019). However, in the UK based research studies listed above the majority of participants reporting these barriers were female and of white British ethnicity, therefore it is reasonable to assume that if those without the additional disadvantage of being from a racially minoritized group are facing these barriers, it is significantly more difficult for parents and children from ethnically diverse groups. Clearly the findings of this project and the wider literature indicates that more needs to be done on a local and national level to improve the pathways and address the inequalities in the availability and accessibility of support.

In terms of the differences, there were more in-depth discussions in the professionals focus groups about the impact of intersectionality that in the parent interviews. Although some parents briefly referred to the impact other aspects of identity (such as having a mental health diagnosis) and socioeconomic conditions such as lack of education and poverty would likely have on their ability to access support for their autistic child, this topic was a strong theme for professionals. This fits with the 'outsider' positioning of professionals in relation to their work with children and families which can make it easier for them to observe the patterns and interactions occurring between different aspects of identity than for those on the 'inside' who perhaps have become desensitized to the ways multiple areas of disadvantage might be impacting them. Whilst this project has not explicitly taken an intersectional approach (focusing predominantly on ethnicity), it is important to recognise the possible multiple identities held by participants in both the quantitative and qualitive studies, how these are likely to have influenced their experiences of navigating the systems.

# Overall Discussion

## Summary of quantitative and qualitative studies

This project aimed to investigate the ethnic inequalities in the autism pathways highlighted in previous research specific to the South Asian population in the Bradford district. This population was focused on due to being the second largest ethnic group in the Bradford district (comprising 32.1% of the Bradford population in comparison to 9.6% in the wider England population; ONS, 2022) and being a group that previous research has indicated experiences unique disadvantages in relation to accessing an autism diagnosis and support (Kapadia et al., 2022).

Whilst research has identified ethnic inequalities in health and social care pathways and autism pathways on a national level, there is not currently a complete, data-driven understanding of what these inequalities look like and how they impact specific ethnic groups at a local level. Therefore, by taking a place-based approach, this project provided a unique opportunity to do an in-depth exploration of the disparities unique to a specified ethnic group in the Bradford district. It also provided the opportunity to demonstrate how regional connected datasets can be used to understand and address complex real world problems.

To investigate the inequalities, the CLEVER framework approach was used which integrates the findings of population level data analysis with the lived experiences of relevant stakeholders, utilising both methods in conjunction to elicit a greater understanding of the problems ‘on the ground’. The CLEVER framework recognises the value of analysing large scale connected datasets to create insights into the patterns occurring in populations at a local level, but also emphasises that data analysis alone is not sufficient to generate a comprehensive understanding of the patterns. Therefore, it is important to also conduct qualitative research building on the data findings to understand the factors underpinning the patterns and identify possible explanations for what is happening on the ground.

The project aimed to (i) use routine data to identify structural inequalities in the Autism pathways, and (ii) to gain an understanding of the structural inequalities in the autism pathways through collecting the views and lived experiences of parents/caregivers and autism service providers. These aims were addressed using quantitative (statistical data analysis) and qualitative (interviews and focus groups) methods.

These studies used the cBradford database to explore autism diagnosis by different demographic factors at a population level.

### Analysis 1. A – Age and likelihood of diagnosis by demographics

These results showed that overall children from white ethnic groups were more likely to have a diagnosis (59%) than children from Asian and other ethnic groups (24% and 7% respectively). Across the whole cohort diagnosis rates by age showed a bimodal distribution, peaking around the age of 4 and 9. However when ethnicity was considered differential patterns of distribution were observed; a unimodal distribution in the age of diagnosis was seen in children from Asian backgrounds, with a peak at the age of 4 years and then a sharp decline in diagnosis rates with significantly fewer children diagnosed after this age in comparison to children of white heritage. Furthermore, sex differences in the age of diagnosis were identified across the whole cohort, with boys having a younger age of diagnosis than females. Yet when these differences were analysed by ethnicity, this finding only applied to boys from white and Other ethnic groups; in children from Asian ethnic groups, females were found to be diagnosed younger than males.

### Analysis 1. B – likelihood of diagnosis

These results showed significant differences in the likelihood of receiving a diagnosis across different demographic groups. Individuals most likely to have an autism diagnosis were male (78% in the clinical sample compared to 51% in the non-clinical sample) and from a white ethnic group (60% in the clinical sample compared to 47%). Compared to the baseline reference characteristics of being female and of Asian heritage, males had approximately three times increased odds of being diagnosed with autism (OR: 3.36, 95% CI: 3.03-3.71), children of white heritage had nearly two times increased odds (OR: 1.71, 95% CI: 1.55-1.89), and children from the “other” ethnic group also had increased odds (OR: 1.21, 95% CI: 1.01-1.45).

### Analysis 2 – EYFS and Autism diagnosis

Findings demonstrated that 1.75% (1227) of the 70277 individuals in the matched cohort had a diagnosis of autism. Of the children with autism diagnoses, 64.1% (786) had a “low” EYFSP total score and 68.5% (841) had a “low” 5-item subscore, compared with 16.5% (11359) and 14.5% (9979) respectively from the individuals without an autism diagnosis. The univariate logistic regression suggested that children with low EYFSP total scores and sub-scores had nine and 12 times increased odds, respectively, of being diagnosed with autism. The multivariable model demonstrated that children with a low EYFSP subscore had over 16 times increased odds of being diagnosed with autism than those who did not receive a low score. In the multivariate logistic regression model the reference baseline characteristics were having a “not low” EYFSP score/subscore, not receiving free school meals, being of white British ethnicity and under ten years old. Compared to baseline, males had more than three times increased odds of being diagnosed with autism, while children of Pakistani heritage had approximately two times decreased odds and individuals of Other ethnicity had nearly two times decreased odds of being diagnosed with autism. Free school meal status and age (excluding age 11, which given the effect size and confidence intervals is likely a statistical anomaly) were not significant predictors of autism diagnosis. Lastly, the interaction between sex and EYFS score was significant for both the Total score and the sub-score. Indeed, compared to the reference group, males with low EYFS sub-scores had approximately 36 times increased odds of being diagnosed with autism.

The lived experiences of South Asian parents (n=7) were collected through individual semi-structured interviews. Views and experiences of professionals working across Bradford autism services (n=19) and DfE place-based projects (n=9) were collected through two separate focus groups. Interviews and focus groups were analysed separately using Thematic Analysis, with overall identified themes combined.

Thematic analysis of parent interviews and focus groups identified three overarching themes of barriers and facilitators of identification and diagnosis, barriers and facilitators of support and provision, and suggestions for improving identification, diagnosis and support. Across these themes there was a total of 26 subthemes organised according to the settings of community, healthcare, education and the wider system.

## Discussion

The following section will discuss key points related the quantitative and qualitative work combined. It will then describe the strengths and limitations of the project, and end by discussing the clinical implications, areas for further research and recommendations.

The inequalities identified in the quantitative analyses can be explained to some extent by the findings of the qualitative work with parents and professionals. Parents and professionals discussed the cultural barriers of stigma, less awareness and understanding of autism, and having English as an additional language as impediments to identification of their child’s needs and accessing a diagnostic assessment. Whilst 6/7 of the parent participants had received a diagnosis for their children (one was awaiting an assessment), most of these parents acknowledged that they had achieved this due to their own resources (level of education, work experiences, confidence etc.), having support from a health /education professional (e.g. paediatrician/school staff), and/or being able to access social support from other parents who were willing to share their own experiences of navigating the pathways. Even with these resources, all parents described how difficult, lengthy, and complicated the process was, often feeling they had to convince professionals to take their concerns seriously. Despite their needs being apparent from a young age and concerns being shared with professionals in education and/or health, four of the participants’ children were only referred for a diagnostic assessment after the age of 6, and the majority waited around two years before receiving a diagnosis. Three of the seven participants waited at least 15 months and were then offered a private assessment to reduce the remaining wait time. This conflicts with evidence showing that:(i) signs of autism can be detected in the first two years of life (Zwaigenbaum et al., 2015), (ii) interventions are effective for autistic children before the age of three and promote parent wellbeing, and (iii) clinical recommendations that these interventions should be delivered as early as possible (Zwaigenbaum et al., 2015).

It is reasonable to assume that parents from a racially minoritized background who experience high levels of stigma and lack access to crucial personal and social resources are likely to raise concerns later, and have their child referred and diagnosed at a much older age (if at all). Indeed, research has identified an association between higher parental educational level and parental age at birth and earlier autism diagnosis (Hrdlicka et al., 2016) and highlighted maternal education level as being key to accessing an autism diagnosis (Kelly et. al, 2019). For example, analysis of the Born in Bradford data showed twice the rate of autism diagnosis in children of mothers educated to A-Level or above than children of mothers with lower levels of education (Kelly et. al., 2019). Furthermore, the finding that children from Pakistani heritage had the lowest odds of being diagnosed with autism after a Low EYFS score compared to all other ethnic groups is consistent with research showing higher levels of disadvantage in this population in accessing support for health needs (Kapadia et. al, 2022), special educational needs and disabilities (Akbar & Woods, 2019; Akbar & Woods, 2020; Fazil et. al., 2010) and autism (Crowther, 2019).

## Age of diagnosis

Quantitative findings demonstrated diagnosis rates peaked around the ages of 4 and 9 but when ethnicity was considered diagnosis rates in children from Asian backgrounds peaked at the age of 4 years and then sharply declined after this age in comparison to children of white heritage.

One of the explanations for this peak in diagnosis around age four and then sharp decline could be that there is an increase in identification and referrals for assessment when children start nursery, perhaps due to their delays in development and social communication needs becoming more apparent in an environment with other children of the same age. Nurseries and schools have the most frequent contact with children and parents, and because of this are uniquely positioned to observe and get to know children over a longer period and discuss observations directly with parents. For parents with less personal resources, lower levels of autism awareness and understanding, and no prior contact with health professionals, nurseries and schools may represent the first opportunity for their child to be observed by other adults with a greater knowledge of child development and signs of neurodevelopmental and special educational needs, and for them to talk to other adults about any concerns. Some of the parents interviewed talked about having a greater awareness of their child’s needs once they started nursery/school, and this being the first time they shared their concerns with someone outside of the family. Furthermore, professionals in the Department for Education focus group highlighted the importance of the relationships between parents and schools, and the effectiveness they had experienced of conducting autism assessments in schools and directly involving school staff with greater knowledge of the child, their behaviours and their family situation. This view was echoed by two SENCos who provided positive feedback on their regional autism in schools project, which involved working collaboratively with school staff to trial a new format for school-based diagnostic assessments.  The SENCos shared that they had learnt a lot about autism and the assessment process by being involved, and that the parents that had taken part had felt supported in the assessment and feedback process.

Another explanation described in the quantitative discussion section above is that only South Asian children with more complex needs are referred and diagnosed earlier, with those with less obvious needs being more likely to be under identified in schools. Multiple additional needs such as challenging behaviour, physical health conditions and ID may increase the likelihood of autism being diagnosed in children from ethnicity minority backgrounds, due perhaps to increasing contact prior to nursery/school age with health professionals able to support a referral, and/or having a great impact on behaviour and learning which are more noticeable and less easily masked in comparison to social communication difficulties. Indeed, children with higher intelligence quotient and greater cognitive functioning are more able to mask their needs in schools as a survival strategy (Hull et. al., 2021), a factor which can also contribute to under identification of possible autism. There are also gender differences in levels of masking/camouflaging, with these behaviours found to be more present in girls than in boys (Mcquaid et al., 2022; Moyse & Porter, 2015; Wood-Downie et. al., 2020). It is well documented that girls are less likely to be diagnosed with autism than boys (Fombonne, 2005, Loomes et. al., 2017), a fact which can be attributed to higher levels of masking (see Allely, 2019).

In the parent interviews, it was interesting to note that of the six children who had been diagnosed with autism all six were male (the one child who was waiting for an assessment was female). Furthermore, all three who were referred for an assessment before the age of five (and therefore diagnosed younger) showed lower levels of functioning, for example greater learning needs/possible ID, more challenging behaviour, and lack of speech. Other research supports the theory that greater complexity of needs increases likelihood of diagnosis in racially minoritized children (see introduction for discussion), but more large scale comparison research into the likelihood of diagnosis and age at diagnosis by ethnicity and co-existing difficulties is needed.

Conversely, some research has shown that increased complexity and additional diagnoses such as ADHD or ID may overshadow possible autism and be another factor resulting in delayed/missed diagnosis (Kentrou et al., 2019). This fits with one parent's experience whose child was assessed at preschool age but, despite showing high levels of complex needs which had been present from birth, did not receive a diagnosis.. The needs of this child continued to become more complex as he got older until he was finally diagnosed at 14 years after years of his parents advocating for more support. From another perspective, clinicians in the focus group highlighted how additional complexity makes the diagnostic assessment process longer and more difficult to conclude, as it can be challenging to disentangle co-occurring traits with several possible underlying explanations to identify the most useful and accurate way to understand a child's needs. In the assessment process clinicians have the complicated task of collating and weighing up multiple sources of information and often conflicting views about the child and must hold in mind the benefits of diagnosing (e.g., enabling access to provision) which can create pressure, along with the imperative to diagnose correctly and avoid misdiagnosing. Diagnostic labels hold a lot of power for individuals and the systems around them, with the positives potentially including increased understanding and access to support, and the negatives potentially being increasing stigma and bullying and limitations on future employment options. This is a complicated task for any clinician, but one which must be improved so that children facing multiple disadvantage can receive the support they need at the earliest possible opportunity.

## Gender and its interaction with ethnicity

In the whole cohort boys were diagnosed earlier than girls, but this only applied to boys from white and Other ethnic groups; in Asian ethnic groups, girls were shown to be diagnosed earlier than males. As the majority of the parent participant's children were male, gender differences in identification and diagnosis rates were not considered and discussed. However, professionals in the focus groups discussed gender and the issue of masking in girls evidenced in research mentioned above. It is possible that the earlier diagnosis of Asian girls compared to boys could be due to cultural factors such as traditional values and social expectations for girls around gender roles, behaviour, and communication (see Heer et. al., 2012; Hickman-Dunne et al., 2018; Shmengler et al., 2021). It may be more noticeable when girls deviate from these cultural expectations and developmental milestones in comparison to boys, whose behaviour may perhaps be more likely to be labelled as 'naughty' and attributed to poor parenting. This was the experience of many of the parents interviewed, the majority of whom had boys diagnosed with autism.

## Other identified inequalities

Further explanations of the inequalities highlighted through the qualitative work in this project include: (i) the wider system issues of reduced funding into services and provision, (ii) less public representation of South Asian autistic individuals (which could challenge stigma and misunderstandings), and (iii) language barriers. It is also important to acknowledge the biases in identification and assessment measure most of which were developed on white western children (see Harrison et al., 2017). This means they are likely to lack cultural validity and lean to a narrow view of autism presentations which could mean different indicators of autism in South Asian children may be missed due to not conforming to professionals' expectations of a 'typical' autism presentation. However, many 'typical' behaviours known to be early universal indicators of autism were noticed by parents (although not linked to autism at the time). These included delayed developmental milestones, speech and language difficulties, sensory needs (hyper- and hyposensitivity to specific sights and sounds), rigidity in play and lack of flexibility in adapting to changes, reduced social interaction etc. Many of these observations were shared with professionals, however parents reported many experiences of feeling dismissed by professionals and their concerns not being taken seriously or attributed to other explanations rather than autism. This would suggest that the inequalities in identification and diagnosis are not necessarily due to different presentations in racially minoritized children, but rather to racism, and racial stereotyping and assumptions made by professionals. This is consistent with research indicating that a passive or reassuring response to parents' early concerns by professionals is a contributor to diagnostic delays in autism, and that parents of autistic children are more likely to receive these types of responses from professionals than parents of children with other developmental difficulties (Zuckerman et al., 2015). It is probable that this increase in passive responses from professionals, together with an increased likelihood of racial assumptions, has a cumulative effect compounding the disadvantage faced by racially minoritized autistic children in accessing a diagnosis and support.

## Strengths and limitations

This project represents the first mixed methods, place-based approach to identifying and understanding the ethnic inequalities faced by South Asian families at a district wide level. Using routine connected data for a large sample and integrating these findings with the lived experiences of parents and professionals has enabled a detailed exploration of the issues unique to this specific population. A strength of the project was in the design and development process, which involved consultation with several members of the system across the sectors of health and education, including clinicians, managers, and district level NHS executives. This meant the research aims and questions were developed organically based on the views and insights shared by those working 'on the ground'. Another strength of the project is in how it captures the views of stakeholders from all levels of the system from the micro-level (parents) to the macro-level (clinicians, education and healthcare professionals), to the wider system (department for education). This is consistent with inequalities research which emphasises that for inequalities to be understood and addressed at multiple levels, research must involve gaining the views and insights of all relevant parties (McGibbon & McPherson, 2011, Attwood, 2003). As stated by McGibbon and McPherson (2011):

> Local, regional, national, and international systems of inequity are inextricably linked and cannot be ameliorated without an analytic focus on how these complex systems act together in a complex web of larger systems that coalesce to produce growing health and social inequities (p. 71-72).

A key limitation of the project centres around the use of a large data set involving missing and incomplete data. This can cause assumptions to be made that a lack of data means a negative observation (i.e., in this case a lack of recorded diagnosis means no diagnosis rather than that it has not be recorded in a child's records). The highest quantity of missing data related to recorded ethnicity, which is consistent with the reports of Bradford district clinicians who highlighted this is an issue across autism services in the region. It also can be explained by the lack of a robust, standardised autism data recording system relating to information about an individual's characteristics and autism referral and assessment across Bradford autism services. This was uncovered through the research process and efforts have since been put in place to develop this system as a result to enable more efficient capturing and analysis of routine data relating to the autism pathways and services in Bradford. Furthermore, the use of SNOMED codes as indicators of an autism diagnosis within the dataset represents a less than ideal way to determine presence of a diagnosis as it relies upon GP records, however it was the best available at the time. It is also important to highlight that one of the research areas this project planned to address (around additional diagnoses and timeliness of diagnosis) was not possible to explore due to a lack of knowledge about how this data is routinely recorded by different services.

Other limitations refer to the participant sample and researcher bias. The parent sample was obtained through volunteer sampling and all participants were fluent in English. The majority were from a middle-class background and in employment, and all but one were university degree educated. These attributes are likely to have made it more possible for them to put themselves forward to participate in the interview, and therefore their views cannot necessarily be said to represent the views of parents with different demographic characteristics. These attributes are also likely to have impacted the subtheme of parental agency which came through in the analysis. Less advantaged participants may have felt less able to ‘fill in the gaps’, find strategies to support their children, and persistently challenge powerful systems to gain an assessment of their children’s needs (consequently impacting on their eligibility to take part in this research). Furthermore, all participants were from a Pakistani background, meaning their views, especially around cultural barriers, may not apply to other South Asian groups. However, this specific ethnic group are the second largest in Bradford (8.3% of the population) according to the recent census figures (ONS, 2022). Therefore, it was important to prioritise capturing the views of this group in a project centred on the Bradford district.

Finally, it is important to acknowledge the impact of researcher bias in this project. The lead researcher, project supervisor and second coder are all from a White British background which is likely to have influenced the lens through which the research was designed and conducted, and it would have been preferable to have worked with a second coder from the ethnic group being researched to incorporate an ‘insider’ perspective. The ‘insider-outsider’ paradigm in qualitative research has been extensively discussed, with pros and cons highlighted with both positions. For example, an ‘outsider’ perspective has been argued to increase neutrality, enabling the researcher to use more clarifying to minimise the distortion of meaning that can come through overfamiliarity with a particular group or topic (Asselin, 2003, Dwyer & Buckle, 2009). Also, to address possible researcher bias throughout the study period, the project was designed in consultation with the wider research team and members of the target population, and a second coder (albeit someone sharing many of the characteristics of the lead researcher) was assigned to analysis the qualitative data from a more distanced perspective.

## Clinical implications

The findings of these analyses highlight the need for targeted interventions aimed at increasing the awareness of autism in racially minoritized communities to increase rates of identification across the age range. The role of schools is particularly apparent in the identification process due to daily contact with children and their parents over a long period of time. This means that there is a need to increase the education and training around autism awareness and how autism presents in different ethnic groups (particularly in those without additional difficulties such as ID) for all school staff. The findings also highlight the potential for using the EYFSP to identify autistic children earlier, especially those who may present with more subtle traits or who may be able to mask their difficulties.

This is consistent with the clinical practice recommendations made by Tromans et. al. (2021) which included: (i) creating and implementing training programs for healthcare professionals to increase understanding of autism presentation in racially minoritized groups, (ii) universal screening for all children (iii) the development of culturally sensitive interventions, and (iv) increasing the representation of individuals with autism from diverse ethnic groups in media and public health campaigns.

## Recommendations

The following recommendations have been developed based on the findings of this research and are organised according to the settings identified in the qualitative aspect of the project. It is recognised that while important, these are in many ways desirable, "ideal world" recommendations, and for this reason some arguably more achievable suggestions are highlighted below.

### 'Real world' recommendations

- Start routinely collecting and monitoring ethnicity data across all autism services
- Schools to put up autism signs posters/send out information to all parents in multiple languages
- Nursery and school staff to access online autism training/information to increase awareness of early signs
- Professionals to open up conversations with parents about autism and early signs observed

### Community

- Implementing culturally appropriate awareness raising programs in South Asian communities to tackle stigma and increase understanding and acceptance. Developing relationships and working with community leaders to do this, and using safe, accessible community spaces such as children's centres, libraries etc.

- Increasing the accessibility of information and guidance for SA families less fluent in English by providing this information in different formats (e.g. on social media and leaflets) and in relevant languages.
- Identifying and approaching positive autistic role models from the SA community through social media to help create and implement an awareness raising campaign.

## Healthcare

- Increase autism awareness and early identification training offer for all medical and allied health professionals working with children, especially Health visitors, Paediatricians, GPs, and Speech and Language Therapists.
- Train more allied health professionals such as Occupational Therapists to be able to conduct diagnostic assessments to reduce the waiting times
- Healthcare staff to work more closely with professionals in education and social care to support autistic children and their families, for example offering consultations, staff support, joint sessions with school staff and parents etc.
- Conduct diagnostic assessments in schools where possible, in collaboration with education staff.
- Professionals to offer more post diagnosis support to families from racially minoritized groups around understanding the diagnostic report and what the diagnosis means for them and their child, and guidance on how to manage their child's needs. Professionals to also offer support and signposting to parents on how to access educational support and specialist provision, making onward referrals for additional assessments where needed.

## Education

- Increase training offer for all education professionals on autism awareness: Nursery and school staff to be offered ongoing learning and development opportunities around understanding and identifying signs of autism and the spectrum of needs, and how these needs can present differently at different ages, across genders and in different ethnic groups.

- Improve the relationships between schools and parents - schools to prioritise building supportive relationships with parents whereby open communication is encouraged and maintained, and the needs of individual families are considered and provided for e.g., language barriers to communication, parent's learning needs etc. School staff to invest in developing and practising cultural humility in the relationships with parents from racially minoritized groups, seeking first to understand the challenges and recognising the role of possible cultural/community barriers to accessing and engaging with support.
- Schools to employ Neurodiversity family support keyworkers representative of the local community who can help build relationships and support parents. These keyworkers could help with identifying possible autism and other neurodevelopmental needs such as ADHD, referring for assessment, linking in relevant services and healthcare professionals with prior involvement, and educating and supporting parents on how to understand autism, manage needs, and navigate the pathways through services.
- Schools to provide autism information/consultation sessions for parents of children showing early signs of possible autism. Schools to personally invite appropriate parents to these sessions to address barriers to help seeking.

### System

- Addressing structural racism and racial stereotyping in the cross-sector autism workforce by investing in equality and diversity training on how autism can present in racially minoritized groups, and how to move towards racially equitable practice, and committing to regular collecting, monitoring and auditing of ethnicity data at all stages of the autism pathway.
- Recognising the impact of multiple areas of disadvantage on access to early identification and intervention and offering greater cross sector support to the families most in need
- Creating a single source of information about autism accessible to children and families from racially minoritized groups

- Improving cross sector working by establishing a centralised place-based system for recording and monitoring routine data on demographics, early signs of autism, referrals, assessments and involved services/professionals such as social care. Enable this system to be accessed by parents, the education system and diagnosing clinicians needing up to date information at the point of assessment.
- Reducing the burden of responsibility on parents by implementing the above recommendations and developing universal screening tools which can identify early signs of autism.
- Increasing government investment in services and changing the commissioning models to move towards a needs-led approach whereby services are funded to provide support based on presence of need rather than presence of an autism diagnosis.
- Local authorities to use population data to recognise future demand-capacity issues and act early to prevent escalating difficulties in the system around waiting times and availability of provision.
- Developing simplified place-based pathways to a referral, diagnosis and specialist support which are centred on joint working across services.

## Future directions for research

Research recommendations highlighted in recent studies have included recording ethnicity data in all prevalence studies (and using this for quantitative analysis) and conducting qualitative research exploring autism belief systems and diagnostic experiences for racially minoritized individuals and their families (Tromans et. al., 2021).

More research specific to UK South Asian populations is needed to further understand the findings of this research and more broadly the inequalities specific to these populations. To confirm the validity of the possible explanation that greater severity of difficulties increases overall likelihood of diagnosis and earlier diagnosis in South Asian and other racially minoritized groups, further quantitative and qualitative research is needed. Using the methodology followed in this project, quantitative research on this topic would involve firstly identifying a cohort within connected datasets with an autism diagnosis and a higher level of need (indicated by the presence in the data of additional diagnoses of ID, mental health need, and/or medical condition) and a comparison group with an autism diagnosis but no additional diagnoses. Secondly once identified, the data could be analysed to identify the differences between this cohort and the comparison group in age at diagnosis by ethnicity and severity of need. Following this, a qualitative approach could then be used to understand the data findings, exploring specifically with relevant stakeholders *how* autism traits commonly present in children from Asian backgrounds and how these might differ to those displayed by children from white backgrounds (especially in children who might be classed as having 'less severe' difficulties), and *how/why* having an additional diagnosis impacts on the timeliness of autism identification, diagnosis and support.

Finally future research using an intersectional framework to explore the impact and interactions between these multiple identities on navigating the autism pathways would be beneficial in increasing understanding of how to address the barriers underpinned by the structural inequalities (see Abrams et. al., 2020 for guidance on using intersectionality in qualitative health research).

## Conclusions

Consistent with previous evidence, these findings further highlight the significant structural inequalities continuing to impact the experience of South Asian families of navigating the pathways to a diagnosis and accessing crucial support and provision for their autistic children. Whilst these findings relate specifically to children and families from South Asian backgrounds living in the Bradford district, it is reasonable to assume that similar barriers are faced by these populations, and individuals from other ethnic groups across other areas of the UK. However, to accurately identify areas of similarity and difference between different ethnic groups in different geographical areas and understand the issues unique to specific ethnic groups in specific areas in the UK, further place-based studies with larger sample sizes are needed.

In this project we have used routine data to identify the inequalities in the autism pathways operating at a local level, and the CLEVER framework to integrate the data findings with the views and lived experiences of parents and autism service providers. This work has enabled several crucial recommendations for the changes needed to improve the pathways and overcome the identified inequalities in the Bradford district. The project highlights the power of this approach in unveiling issues at the core of systemic societal failures to meet the needs of children and families from racially minoritized communities, and the need for action to be taken urgently to achieve justice for these communities and ensure *all* children can access the support they need to thrive.

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# Appendix A – Link to Supplementary Materials

Below is the link to access the supplementary materials (including parent interview and focus group topic guides, parent information sheet and consent form and additional quotes for identified subthemes) not included in this report:

https://www.dropbox.com/scl/fo/ggamykxozbpg6pyhvbr21/h?dl=0&rlkey=nai8k1ufs7ordylmmo4xghu1w