A country that works for all children and young people

An evidence-based plan for addressing the autism assessment and support crisis

Child of the North
N8 Research Partnership
Health Equity North
Centre for Young Lives

Contents

Foreword by Anne Longfield and Camilla Kingdon

A growing number of children and young people (CYP) are being diagnosed as autistic. The most recent government estimate is that almost 2% of pupils in England now have an autism diagnosis, a number that has risen over recent years as awareness about autism has increased. Autistic CYP experience the world in a different way which can have an impact on social communication and interaction, interests, and can be characterised by restricted or repetitive behaviours. Autistic CYP may also have different ways of learning, moving, or paying attention.

These factors can have a profound impact on the daily life of autistic CYP and their families, and most will face some challenges as they grow up. The education system can be difficult for some autistic CYP, particularly those at schools with very rigid policies. Only a quarter of autistic CYP say they feel happy at school – and it is perhaps unsurprising that an autistic CYP is twice as likely to be excluded from school as a child without Special Educational Needs or Disabilities (SEND).

Most autistic CYP – and their families – need some health service and other support as they grow up. Too often the gateway to receiving that support is complex. It requires an assessment to take place, yet as this report sets out, the UK has an autism assessment crisis. Thousands of CYP who need an autism assessment and support are not receiving timely help. As one parent seeking an assessment for her child told the report authors, “it was an absolute nightmare”.

Many thousands of families feel the same way, and they are being left to navigate a support system that is hampered by processing delays and long waiting lists. On average, only one in 10 CYP are receiving an appointment within 13 weeks of being referred, and as the statistics in this report show, girls and children from ethnic minority groups are even less likely to receive the support they need.

This failure to provide the right autism support can lead to poor long-term outcomes for autistic CYP, including an increased prevalence of connected conditions such as mental ill health.

As anyone who has worked with CYP in an education or secure setting knows, there can be huge costs and consequences of failing to support autistic CYP – reduced life chances, a higher risk of school exclusion or not attending school, and in the very worst cases a greater risk of harm, exploitation, or criminalisation.

The systems for those autistic CYP who do need health service support need to be transformed, and the way assessments are delivered and how information is shared needs urgent reform. As well as improving life chances, tackling this autism assessment crisis could have a beneficial knock-on effect to the wider education, health, criminal justice systems, and reduce some of the enormous current financial pressures on those services.

This report sets out how change can happen. It has been produced by eight research-intensive universities in the North of England – the N8 Research Partnership – combined with a wider academic community (the N8+) as part of the Child of the North initiative, and the new Centre for Young Lives thinktank. It is the first in a series of 12 Child of the North/Centre for Young Lives reports to be published during 2024, which together will look at how we can encourage government to reset its vision for CYP.

The series of reports will show how putting the interests and life chances of CYP at the heart of policymaking and delivery is crucial to Britain’s future. They will shine a light on some of the biggest challenges facing government, including reducing child poverty, and improving support for CYP with mental health conditions, while also providing rigorous research and pragmatic, evidence-based recommendations which acknowledge the ongoing financial limitations on government spending.

As we approach the next general election, there is no better time to make the case for changing the Government’s overall approach to improving the lives of CYP and families, whichever political party is in power.

Since the COVID-19 pandemic, there has been a **306%** increase in the number of children waiting for an autism assessment.

The series begins with this analysis of the current system of support for autistic CYP. It reveals that while we are spending large amounts on the system, and despite the publication of the Government's autism strategy in 2021, the autism assessment crisis is continuing to worsen. Waiting times for assessment have soared since the COVID-19 pandemic and the number of CYP accessing autism services is now at a record high. This is a system under unsustainable pressure.

In July 2022, more than 125,000 people were waiting for an autism assessment by mental health services, an increase of 34% since October 2021. By July 2023, this number had risen to more than 143,000. Figures published in September 2023 show there were 157,809 patients with an open referral for suspected autism.

On average, one out of 10 CYP are still to receive an appointment 13 weeks after their referral.

More than one in four parents have waited over three years to receive support for their child.

The evidence shows that early identification and support is crucial. CYP with autism and related issues, such as attention-deficit hyperactivity disorder (ADHD), can thrive in mainstream education if their needs are identified early. Instead, too many autistic CYP are being left without an assessment, and without early help, partly because the system places so much emphasis on assessment before support is provided. Too many CYP are not receiving the help needed in school without first receiving a medical diagnosis.

Yet autistic CYP are at significantly greater risk of both social and school exclusion, and the group at greatest risk are those with a referral who are awaiting assessment. As waiting times increase, so will the risk of increased exclusion and poorer educational outcomes for these children. Some will end up in Alternative Provision (AP) – with its associated higher costs and generally lower academic outcomes – because they haven't received support earlier in their school life. This is particularly frustrating given the evidence shows that when support is in place following a diagnosis, autistic CYP are less likely to be excluded.

We must move towards a needs-led approach, rather than just relying on a diagnosis-led system. Early identification and support, rather than waiting for a diagnosis, will lead to better long-term outcomes and reduce costs. As this report argues, improved information-sharing between the health and education systems and a more coordinated approach to support, including early help in nurseries and schools before formal diagnosis, is essential.

Education settings can play such a major role in identifying and supporting autistic CYP, flagging CYP with a high likelihood of undiagnosed autism, and providing an environment for autism assessment. Health services can help schools prioritise children with increased likelihood of needing additional support. Government should be helping health and education systems to share information by using the NHS number as a single unique numerical identifier across public service records.

As this report highlights with existing examples of good practice, the development of genuine formal partnerships at local authority level between health and school services and nurseries, and voluntary services, faith groups, universities, and businesses, is key to tackling the autism assessment crisis and creating autism-friendly environments. Government has a vital role to play in ensuring this coordination happens, although expecting Whitehall to solve this crisis will not be enough on its own.

Bradford has shown how creating its own database of primary and secondary healthcare records across the District that links with education, social care, and policing data produces a powerful research tool that reveals the social issues facing different services. So, we now know that 77% of CYP diagnosed with autism in Bradford are male, and that large numbers of girls in Bradford are not being identified (a nationwide problem, as this report also makes clear). This analysis also confirms there are significant and troubling ethnic inequalities in autism diagnosis.

The report makes a powerful case for how education data can identify autistic CYP "falling under the radar", how autism assessments can be conducted successfully in schools, and how better training of education and health professionals can improve the needs of autistic CYP. It also stresses the importance of national and local political leadership to drive coordinated, whole system public service delivery at a local level.

Too many autistic CYP are being held back because our institutions are failing to provide an autism-friendly environment, and the system to provide the support they need isn't working. One parent told our focus group that Children's Mental Health Services admitted to her that they were in crisis and letting her child down, urging her in desperation to write to her MP. This is no way to run a support system for some of our most vulnerable CYP. Without urgent reform, we cannot hope to improve the life chances of the next generation. As this report shows, change is possible – and it is happening in some schools and local areas already. What is needed now is the determination from government and others to make it happen everywhere.

Anne Longfield CBE,
Executive Chair of
the Centre for Young Lives

Dr Camilla Kingdon,
President of the Royal College
of Paediatrics and Child Health

This report is a collaborative programme of work between Child of the North and the Centre for Young Lives.

Cite as: N8 Research Partnership (2024). A country that works for all children and young people: An evidence-based plan for addressing the autism assessment and support crisis. doi.org/10.48785/100/195

A full list of authors and contributors can be found at the end of the report.

A note about language

"Autistic person" vs "person with autism"

Following extensive PPIE work, autism-first language is used throughout this document, i.e., "autistic person" rather than "person with autism", as this moves us toward understanding autism as an integral part of an individual's identity rather than an additional "condition". While further research is needed to understand how we should talk about autism in a way that reflects the preferences of all autistic people (e.g., speaking and non-speaking, with and without intellectual disability), current guidance from autistic advocates suggests a preference for autism-first language [1, 2].

Schools, nurseries, and educational settings

Please note that this report often uses "schools" as shorthand for "schools, nurseries, and other educational settings such as pupil referral units and special schools". One central message of this report is the need for a "whole system" approach that includes all relevant stakeholders, and this includes all parts of the education system. We highlight that special schools have limited spaces, meaning CYP who require the support of special schools are in mainstream education, where the current special educational needs support available cannot meet the growing demand.

About Child of the North

Child of the North is a partnership between the N8 Research Partnership and Health Equity North which aims to build a fairer future for children across the North of England by building a platform for collaboration, high quality research, and policy engagement. @ChildoftheNort1

About the N8 Research Partnership

The N8 Research Partnership is a collaboration of the eight most research-intensive Universities in the North of England: Durham, Lancaster, Leeds, Liverpool, Manchester, Newcastle, Sheffield, and York. Working with partner universities, industry, and society (N8+), the N8 aims to maximise the impact of this research base by promoting collaboration, establishing innovative research capabilities and programmes of national and international prominence, and driving economic growth. www.n8research.org.uk @N8research

About Health Equity North

Health Equity North is a virtual institute focused on place-based solutions to public health problems and health inequalities across the North of England. It brings together world-leading academic expertise, from the Northern Health Science Alliance's members of leading universities and hospitals, to fight health inequalities through research excellence and collaboration. www.healthequitynorth.co.uk @_HENorth

About the Centre for Young Lives

The Centre for Young Lives is a new, dynamic and highly experienced innovation organisation dedicated to improving the lives of children, young people, and families in the UK – particularly the most vulnerable. Led by former Children's Commissioner, Anne Longfield CBE, who has been at the forefront of children's issues for decades, the Centre's agile team is highly skilled, experienced, and regarded. It is already widely known and well respected across government departments, Parliament, local and regional government, academia, the voluntary sector, and national and local media. The Centre wants to see children and young people's futures placed at the heart of policy making, a high priority for Government and at the core of the drive for a future for our country which can be much stronger and more prosperous. www.centreforyounglives.org.uk

Quotations

The illustrative quotations throughout the report were taken from extensive qualitative work with children, families and professionals in the North of England conducted by Danielle Smith [3], Emily Chapman [4], and Leanne Rogan [5] as part of their Doctorate in Clinical Psychology.

Acknowledgements

We would like to thank colleagues from the Bradford Priority Education Investment Area and Educational Alliance for Life Chances (and associated DfE colleagues) for their amazing work on addressing inequity and for their support with getting this report off the ground: Elizabeth Anoliefo; Lauren Batty; Ruby Bhatti; Anne-Marie Canning; Eve Chambers; Verity Cook; Carol Dewhurst; Craig Dillon; Kersten England; Ellen Flint; Jimmy Hinton; Nick Ireland; Duncan Jacques; Alexandra Jessup; Maryam Kapree; John Leese; Kathryn Loftus; Sue Lowndes; Andrew Morley; Naveed Mushtaque; Richard Padwell; Katie Pritchard; Charlotte Ramsden; Will Richardson; Alex Spragg; Lisa Stead; Laura Thompson; Linda Wright. We would like to thank everyone who participated in the research that is described in this report and would like to particularly highlight the wonderful contributions made by the participants from the Born in Bradford programme, led by Professors Rosie McEachan and John Wright. This work would also not be possible without generous funding from our UK and EU research funding bodies who are an essential part of the system that needs to work together in the best interests of CYP. The report benefitted from a knowledge exchange session kindly hosted by the Department for Education's Science Team in general and Julia Erdlemann, Marium Orme, and Tony Carter in particular. The knowledge exchange session meant we benefitted immeasurably from the wisdom and insights of NHSE, DHSC and DfE colleagues – and special mention of Lorcan Kenny must be made in this regard. Finally, we would like to make special mention of Katie Pritchard and her colleagues from Liz Franey's Department for Education Opportunity Area team – Lee Turner, Theo Brady, Naz Khan, and many others - who supported much of the research reported in this report (providing a tantalising glimpse of how the whole system can work together in the best interests of children and young people).

Key insights

Prevalance and wait times

The number of children accessing autism services is at a record high.

As of September 2023...

↑46% Increase in closed autism referrals in the last year

↑27% Increase in new autism referrals in the last year

>93% Of children did not receive an appointment within 13 weeks of being referred

The number of children still yet to receive an appointment after 13 weeks has increased by...

↑36% Since COVID-19

↑21% In the last 12 months

Ethnicity

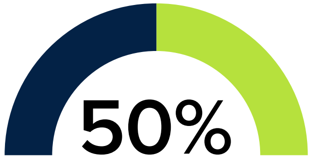
Structural inequalities in autism pathways hinder the chances of children from ethnic minority backgrounds accessing timely support.

GIRLS OF ASIAN HERITAGE HAVE:

3X Decreased odds of receiving an autism diagnosis compared to males

2X Decreased odds of receiving an autism diagnosis compared to children of white heritage

Children of white heritage are 50% more likely to receive an autism diagnosis compared to children of Asian heritages



306%

Increase in the amount of children waiting for an autism assessment since the COVID-19 pandemic

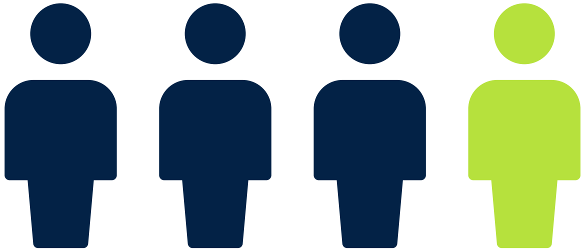
School

Autistic children face additional barriers in the school environment.

2X

Autistic children are **2X** as likely to be excluded from school compared to non-SEND children

ONLY 26% Of autistic children feel happy at school



3 in 4 parents said their autistic child's school did not fully meet their needs

Gender

Autism can present differently in girls, meaning many children's needs can go unnoticed.

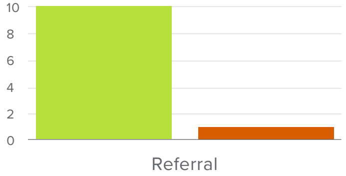
75%

Of autistic girls are estimated as being unidentified

Of the girls who are identified and assessed, a further **20%** are missed

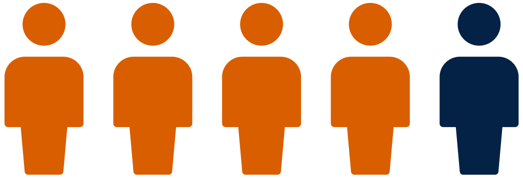
Boys are referred for a diagnostic assessment.

10X More frequently than girls



Physical & mental health

Autism is associated with poor mental and physical health.



4 IN 5 Young autistic people have co-occurring mental health conditions

Autistic people have a shorter life expectancy by up to...

30 YEARS

Defining autism and associated developmental differences

Autism is not an illness or disease – it is a term used to describe people with a specified collection of behavioural characteristics. The World Health Organization categorises autism as a “neurodevelopmental disorder” within its International Classification of Diseases (ICD-11) [6]. ICD-11 is the framework used within UK healthcare to diagnose autism. In the USA, the American Psychological Association’s Diagnostic and Statistical Manual of Mental Disorders (DSM-5) is used instead, but there are only minor differences between ICD-11 and DSM-5, with some UK services using DSM-5 criteria in practice.

Healthcare professionals diagnose autism using tools that standardise observations of how someone behaves in a particular situation. These behaviours relate to difficulties with communication or social interactions; repetitive or restrictive behaviours; sensory differences (e.g., sound, vision, touch, taste, smell, temperature); and highly focused interests. It is important to emphasise that the observed behaviours lie on a continuum, with large proportions of the population exhibiting such characteristics. The diagnosis is therefore based on a clinical threshold where the behaviours are deemed to be occurring to an extent that warrants specialist healthcare support.

National Health Service England (NHSE) outline four major advantages to this approach: (i) it enables clinicians to recommend interventions that have been tested for safety, acceptability, efficacy, and effectiveness with people who face similar challenges within society; (ii) it ensures reasonable adjustments are made in general physical or mental health services (given the association between autism and the increased risk of poor general health); (iii) it helps develop a positive autistic self-identity and foster connections with the autistic community; (iv) it facilitates access to some forms of statutory protection beyond the healthcare context [7]. There are three critical points to make in the context of the above. First, children are constantly developing, and upstream experiences will shape their behaviours at an older age. This means that a child provided with adequate support at an early age may not subsequently need specialist healthcare intervention. Second, many children will not reach the clinical threshold, but will still need support. Third, the need for specialist healthcare does not imply that the responsibility for support falls on healthcare alone. The goal must be for appropriate support to be provided within homes and educational settings.

There is a danger that children who have autistic traits but do not reach clinical diagnostic thresholds fall into the gaps between health and education [8]. The World Health Organization's (1980) International Classification of Functioning, Disability and Health (ICF) provides a useful framework for considering an individual's functional abilities within the context of their nursery or school environment. The ICF defines disability as the inability to participate and engage in activities of daily living (which for children includes educational activities). The ICF emphasises that neurodevelopmental differences (albeit unhelpfully described as "impairments") can cause disability if the environment (or activities) are not modified to accommodate these differences. This serves as a useful reminder that a child's "disability" can be removed or decreased by adjusting activities and the classroom environment, regardless of a formal diagnosis.

There is a need for a shared understanding of the intersections between the ICD-11 and the ICF and how they can be better used to identify the specific role of health (ICD-11) and schools (ICF) in supporting autistic CYP.

The terminology for autism has evolved. Currently, some of the language adopted in international and national legislation is unhelpful and does not reflect the language preferred by those with lived experience [9]. Nevertheless, it is **necessary to recognise the existing legislative terminology when discussing system reform to avoid confusion** (noting that this does not preclude a change in terminology in the longer term).

Autism policy recommendations

The evidence is clear: human society can meet complex challenges through a concerted, collaborative effort to address a well-specified problem (from splitting the atom to the COVID-19 vaccine) [10]. To facilitate the UK in its mission to improve autism health service support in a systematic and scientific manner, we make three evidence-based recommendations.

> “You’re blocked from accessing services until you get that [diagnosis]... **parents are forced down this route.”**
>
> - Parent of an autistic young person

1

Build effective partnerships between education and health professionals for assessing and supporting autistic children. This should include delivering assessments in education settings and making a holistic offer of support in schools and nurseries before and after a formal diagnosis is made.

The evidence is clear – educational settings can play a major role in identifying and supporting autistic CYP. Education data, specifically data routinely collected through the Early Year Foundation Stage Profile (EYFSP), can flag children with a high likelihood of undiagnosed autism, often at an earlier age than is possible via health routes [11]. Autism assessments can be conducted efficiently in education settings [3, 12]. Meanwhile, health information can help schools and other educational settings prioritise children with increased likelihood of needing additional support. The exchange of information and genuine partnerships between health and education services can offer a more effective and efficient approach to assessment than the current model. Adopting this approach could begin to reverse the autism assessment crisis and reduce the structural inequities revealed by the research. A coordinated approach could allow children’s needs to be supported before a formal diagnosis has been made.

2

Provide and extend access to mandatory Continuing Professional Development (CPD) courses for health, education, and social care professionals that improve understanding and awareness of autism (and related issues). These courses should include information on how to create “neurodiverse friendly” environments, and particularly raise awareness of autism in girls and ethnic minority groups. Additional training should be co-produced by individuals with lived experience, delivered to professionals, and integrated into undergraduate health and education professional training, to improve the identification of autistic girls.

The evidence is clear – structural inequity can be seen in autism assessment so girls, ethnic minorities, and lower socioeconomic groups receive support later than their peers (see “Inequity must be addressed in autism pathways” section) [13]. The evidence suggests that improving awareness across professionals could address some of these issues and accelerate the creation of autistic led and coproduced health and education provision [3, 14]. Inclusive spaces are characterised by flexibility, whereby reasonable adjustments are made with the potential to benefit everyone [15]. Schools and colleges should measure success in this area by reporting on attainment, attendance, elective home education rates, exclusion, and suspension for autistic CYP.

3

Create formal partnerships at a local authority level comprising sector leaders (including schools, health, voluntary services, faith, universities, educational psychologists, and businesses) to oversee a prioritised governmental ward-level approach to addressing the autism crisis. The partnership should focus on its most disadvantaged wards and provide leadership in trialling data-driven, community and family co-produced, “whole system” approaches to improve autism support with and through education settings.

The evidence is clear – the complex needs of autistic CYP and their families need public services, businesses, and the voluntary sector to collaborate and create “autism-friendly” places [16]. The creation of autism-friendly places, such as sensory rooms, must be tailored to the cultural backdrop of an area. The evidence suggests this is best achieved at the ward-level and this, in turn, allows a strategic approach to addressing inequity [17]. The “Integrated Care Systems” (42 systems across England responsible for delivering health and social care services) provide an outstanding opportunity to implement such approaches supported by the Core20PLUS5 NHS inequality initiative [18].

These recommendations have resource implications but offer immense potential for decreasing the long-term costs associated with not acting early (i.e., the health, social care and criminal justice bill that results from not supporting children’s needs); they will help the UK benefit from the economic growth available if the autistic population’s talents were deployed within the workforce.

Principles

The evidence on current autism support across the UK paints a compelling and worrying picture: there is an urgent need for the UK to transform its support systems for autistic CYP and their families. We cannot keep doing more of the same (e.g., throw some additional resource at conducting a few more assessments in hospitals to reduce autism waiting list times – a costly approach tried many times, in many places, with no lasting impact). We need a radical overhaul of our approach to supporting autistic CYP and – most critically – to trial new approaches that better connect health and education.

Overview

The recommendations within this report relate to the population of autistic CYP who have needs that require specialist medical support. A future report will address the wider population who require additional special education support but do not meet the clinical threshold for specialist healthcare intervention.

The evidence shows that the problems affecting autism healthcare pathways are complex – where complexity is defined as an inability to address the problem through action in a single component part of the system [19]. It follows that successful solutions will transcend the NHS and involve multiple stakeholders working in partnership with affected CYP and their families. Central and local government have a necessary role to play in connecting, coordinating, supporting, and challenging systems, but government action alone is insufficient. The time has come for everyone to cross organisational and geographical boundaries and commit to working together in the best interests of autistic CYP and their families.

Our recommendations are based on seven principles and the evidence that underpins the recommendations is laid out within this report. The recommendations are pragmatic in nature and recognise that the UK will be in a perilous financial state in 2024, meaning that solutions must make best use of existing capacity and not simply involve cash injections (which we would argue are anyway insufficient). What is needed is a change in mindset, rather than changes to funding allocations per se. We note that the autism assessment and support crisis worsens each year despite decades of attempts to reverse the problems [20]. Thus, we argue that there is a need for the next UK government to act at pace.

These recommendations do not pretend there is a magic wand. Rather, they avoid the trap where the impossibility of perfection is a barrier to improvement (so nothing changes). They do provide a platform that would allow the UK to harness the scientific method to learn what works best for which community – noting that science is society's most powerful tool for improving health and wellbeing.

> "It's not just CAMHS. I'm talking health visitors, probably midwives, school nurses, social workers, across the board... we're assigned these workers who **do not understand what our children need and what we need."**
>
> - Parent of an autistic young person

Our seven principles

1 **Putting our children first** – The future of a country depends on a healthy workforce, equipped with the skills needed by the economy and society. Childhood determines long-term health and is *the* critically important period for developing the core skills needed to function within society [3]. Logic thus dictates that the UK must prioritise children if we want to enjoy a healthy future. A more proactive and timely approach to meeting the needs of autistic CYP will ensure that they are able to reach their potential, and reduce the longer-term demand for health, social care, and other services.

2 **Addressing inequity** – This will reduce the financial burden of poor population health on public services. Concurrently, *economic stagnation must be reversed* to generate wealth and ensure the UK makes the best use of all its assets (i.e., the brilliant young minds located across all our communities). The UK's structural inequity is laid bare within the autism assessment pathways and a failure to support this population will starve the UK of talented individuals within the future workforce.

3 **Adopting place-based approaches** – Geography, culture, economic activity, and other factors vary between localities, changing the way that support needs manifest, and the way communities prefer to engage with services. New approaches to reaching and helping families must be planned and aligned to the needs and preferences of the locality and its communities. There are many cultural factors that impact autism assessment, including stigma and reduced autism awareness, and these local contexts must be addressed for efficient service delivery.

4 **Working together effectively across our public services** – The needs of children and families cannot be neatly divided into silos such as "health", "education", "social care", "criminal justice" etc. We must recognise that our current organisational arrangements are not fit for purpose and find new ways of delivering connected public services so that the necessary holistic ("whole system") solutions to complex problems can be implemented. We recommend in this report how such connected service delivery can be operationalised from the perspective of autism.

5 **Putting education at the heart of public service delivery** – Schools and other educational settings need to be at the epicentre of support. For example, typical "outside support" from specialist services (e.g., child and adolescent mental health services (CAMHS)) needs to be delivered within the school gates. In doing so, we start to remove the additional barriers encountered by the most disadvantaged children, reduce the burden placed on families, and destigmatise autism support. A genuine attempt to improve autism healthcare delivery will involve closer working between health services and education settings.

6 **Establishing Universities as the "Research and Development" departments for local public services** – Universities can bring together insights from across multiple disciplines, ensure decisions are based on the best possible evidence, oversee evaluation of service delivery and train future health, social care, and education professionals. There is a wide scientific literature that captures international approaches to improved autism care and universities must draw on existing evidence, as well as researching specific inequalities, to support public service colleagues [21].

7 **Using and sharing information across public service providers effectively** – Data are currently collected within organisational silos, which fails to reflect the reality of how families interact with services. Only by connecting our public service data (i.e., education, healthcare, social care etc.), can we: (i) begin to understand how services intersect and interact within families; (ii) allow the essential information sharing that will safeguard children. The information held within education systems can help clinicians (and services such as social care) to make more accurate decisions, faster. Information held within health systems could help schools and other educational settings identify children with a greater likelihood of having autism and thereby decrease the time for children to enter the autism pathway.

> **"It just makes me so angry** that we're all going through the same thing. It's like we're rewriting it over and over again, aren't we, for each child and the amount of time that it's taken."
>
> - Parent of an autistic young person

The evidence

A failure to provide appropriate autism support results in poor long-term outcomes in social and individual functioning, high rates of associated health problems, and an increased prevalence of connected conditions (such as sleep difficulties and mental ill health) [22]. The recommendations within this report are based upon consideration of the following evidence and our seven principles previously outlined.

The UK government must prioritise support for autistic CYP

£1.5M to support an autistic person over their lifetime [12]

The evidence is clear: CYP with autism and common, co-occurring conditions such as ADHD, and/or anxiety, can thrive in mainstream education if their needs are adequately supported in a timely manner.

It is estimated that it currently costs £1.5 million to support an autistic person over their lifetime due to the complexity of their needs and the greater need for specialised help [16]. Autism and other commonly co-occurring neurodevelopmental disorders increase the risks of physical health morbidity and multimorbidity in later life [23]. Early identification and support can mitigate the negative effects on an individual's physical health and the associated costs.

The evidence is equally clear that CYP often do not receive the support they need for many years, exacerbating their needs and causing stress and frustration to the family (often creating associated mental health problems which generates yet further pressure on our systems) [24].

> "Professionals are becoming resentful of parents because **they think we're obsessed by getting a diagnosis** and it's not that at all, it's that we can't get [support] without it… so it's just this silly catch-22."
>
> - Parent of an autistic young person

A major barrier in our existing systems is the perceived need for a medical diagnosis of autism before any child can receive support. In many cases, there is no legal need for a diagnosis but the perception among schools and the wider community that this is a requirement prevents children from accessing support [25]. This relates to another problem within our current system around the "medicalisation" of developmental difference. This often means that a child needs (or is perceived to need) a medical diagnosis to access support, but the health system simply cannot meet the demand for all such assessments [5]. In turn, this can prevent timely access to the essential help a child needs in school. Autistic CYP who have newly immigrated to the UK also need a formal diagnosis in the UK before they can access service support, despite having a diagnosis in their home country; a simpler process is desperately needed. From an educational perspective, this lack of equitable provision can result in children "failing while waiting" because of system failures. As a society, we cannot afford the costs associated with young people leaving school without core skills (e.g., literacy which relates closely to health literacy and, in turn, long term health prospects in adulthood).

Some children who show developmental differences require specialist healthcare assessment and support – and, indeed, have a statutory right to access such healthcare. One major difficulty in debates around improved autism support is a tension between groups who understandably wish to avoid the perils of "medicalisation" and groups who wish to ensure that children obtain the healthcare support they need. While these groups may differ in their views on autism identity, all these groups are notably motivated by a common desire to support children, and debates are often the result of miscommunication on both sides. Thus, there is a need for precision in language, and rigorous frameworks that provide a structure for considering the pathways of developmental difference. Page 9 details two World Health Organization frameworks that provide a useful structure for approaching debates around support for autism and related developmental differences.

The evidence suggests we need to further promote, refine, and define a "needs-led" approach instead of relying on a "diagnosis-led" system [3]. Early identification is the norm in a "needs-led" approach and faster, effective support can be offered, without relying on a diagnosis. The sooner individual needs are identified, the sooner they can be supported, leading to better long-term outcomes (and reducing the long-term costs on public services). Future reports will highlight evidence-based suggestions for creating "needs-led" approaches across a range of issues.

> **"Giving support regardless,** even if they don't have a diagnosis of autism."
>
> - Autistic young person

> "Unless [you've] got a physical diagnosis, **schools won't support, which I completely disagree with,** because if you're on the waiting list or you're trying to get that diagnosis, you're going years without support."
>
> - Autistic young person

Inequity must be addressed in autism pathways

The UK is struggling with problems associated with inequity. Inequity can be illustrated vividly through a comparison between the North and South of England. Children in the North of England are more likely to live in poverty than their Southern peers – and increasingly so [26]. Poverty leads to worse physical and mental health outcomes, lower educational attainment, and lower lifelong economic productivity [26]. Poverty also maps onto healthcare inequity (i.e., access to the appropriate health systems) and this can be seen clearly via the prism of autism [3].

The evidence shows that children born to mothers without educational qualifications will receive an autism diagnosis two years later than their peers and are two times less likely to receive the diagnosis compared to children born to mothers with A-level qualifications or above [27, 27].

The issues around timely identification and support are exacerbated for girls, who are more likely to be misdiagnosed and diagnosed later than boys, or not at all [5]. These differences are likely to be due to diagnostic criteria, assessment tools, professional training, and general awareness of autism being based on male presentation and the ability of girls to mask their autistic traits.

Bradford has created a first-of-its-kind connected database that contains the primary- and secondary-care health records of citizens across the Bradford district that are linked with education records, social care, policing data, etc. [28]. The database is an incredibly powerful research tool that allows scientists, working with policymakers, to undertake holistic data science that can shine a light onto critical social issues that span disparate services.

Evidence from the Connected Bradford database showed that 77% of CYP diagnosed with autism were male, indicating large numbers of autistic girls in the district who had not been identified (given national norms) [5]. These quantitative insights were explored further through interviews with people who have lived experiences of the autism pathways.

Parents reported waiting over four years for an autism assessment for their daughters, which is in stark contrast to the recommended three months [29]. Although males also face long wait times, figures suggest that males were on average more likely to be diagnosed younger than females [3]. Therefore, many girls are being failed by not receiving a timely assessment and related support. This research demonstrates the power of connected datasets coupled with qualitative investigation in identifying and understanding problems.

The Bradford district provides a devastating illustration of the continuously increasing wait times for autism assessments. Bradford autism services have the capacity to conduct 90 assessments a month but receive over 200 referrals every month on average. In the 2022/23 academic year, there were 926 dual assessment referrals for autism and ADHD, which has increased by 575% since 2019/20. In June 2023, 2579 CYP were waiting to be seen by autism services (1285 waiting for an autism assessment and another 1294 waiting for an autism and ADHD assessment), with waiting times up to 110 weeks (over 2 years). After waiting for an assessment, most of these children will receive a diagnosis of autism (in Bradford the "conversion rate" is 86%). This highlights the importance of needs-led approaches, to prevent CYP going for years without the support they need.

> "Girls have been diagnosed later because of **failings in people's training and responsibility.**"
>
> \- Autistic young person

Moreover, these systems show structural inequalities as can be seen clearly in Figure 1, showing the percentage of CYP diagnosed in a particular demographic for autism or ADHD from newly analysed Connected Bradford data. For example, around 0.7% of Asian females were diagnosed with autism, around 1% of "Other" females, and around 2% of White females. White individuals are far more likely to have a diagnosis across the board for both autism (2.63x) and ADHD (5.32x) when compared to Asian individuals. Furthermore, males are, on average, far more likely to have a diagnosis than females (Autism: 2.70x, ADHD: 3.32x). While this research included males and females, it is worth noting that people of non-binary genders often face additional barriers to accessing autism pathways [30]. Autism pathways are reported as being the most difficult chronic health condition for transgender and non-binary people to navigate [31].

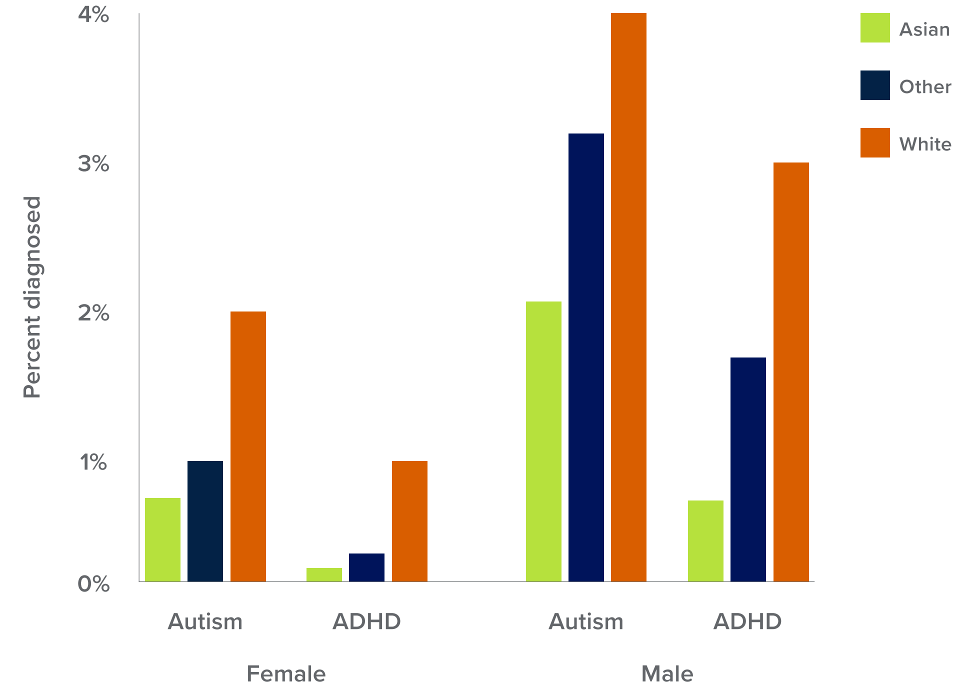


Figure 1: Percentage of individuals diagnosed with autism or ADHD by sex and ethnicity. Note that analyses use demographic data from the Department for Education school census. The category of ethnicity is therefore Asian, in alignment with census categories, but the sample is predominantly South Asian – and primarily Pakistani – in heritage.

Continued...

Qualitative work also highlighted several issues raised by autistic females [5]. Females consistently reported “masking” (a coping mechanism in which individuals minimise autistic characteristics to fit into the social environment) as a deliberate decision that became an unconscious activity with time and practice, although some girls may never be aware of their masking behaviours [5, 32]. CYP described the fear of negative social evaluation if they did not mask and said that disguising their social interaction difficulties resulted in internalised mental ill health symptoms (such as anxiety and depression) [33].

The ability to “mask” their difficulties hindered the recognition and support of the autistic girls, with education professionals dismissing parents’ concerns if behaviours were not observed within the school environment. Furthermore, participants felt that schools did not recognise or support their needs until academic attainment was directly impacted by their difficulties [34].

The evidence suggests that improving awareness and education about sociodemographic differences in autism presentation could accelerate the process of identification and support [3]. However, the evidence also suggests that this would require a multifaceted approach, with a concerted effort across education and health services, with families involved in the planning process [17].

> “The person I was at school and the person I was automatically at home were **two completely different people.**”
>
> - Autistic young person

> “I was holding up to the standards they had... **it was never a concern to them** to look into maybe the weird things that I did do, because **the only thing they were looking at was if I could get the grades.**”
>
> - Autistic young person

Place-based approaches must be adopted when addressing the autism crisis

Evidence from across the UK shows that CYP from ethnic minority backgrounds experience lower rates of identification of autism and often experience more severe difficulties [35]. There is compelling evidence of underdiagnosis among bilingual CYP and ethnic minority CYP in comparison to White British CYP (see Figure 1) [36].

Clinician bias, discrepancies in diagnostic measures, reduced awareness, masking, cultural beliefs, biological reasons, and access to services across ethnic groups all contribute to ethnic inequalities [35]. The geographical concentration of ethnic groups can help explain why a place-based approach is so important when addressing structural inequity in autism assessment.

These issues are further compounded by intersecting factors such as gender and socioeconomic disadvantage [3]. The current fragmented system and lack of data linkage between health and education sectors also contribute to challenges in accessing timely support.

Analysis of the Connected Bradford dataset confirmed previous reports of ethnic inequalities in autism diagnosis and revealed similar patterns across the Bradford District [3]. These quantitative insights were explored further through interviewing people with lived experiences of the autism pathways. The evidence showed that stigma, lack of understanding, and cultural beliefs about autism were major barriers in acquiring a diagnosis and receiving support, with parents facing blame, privacy concerns, and a lack of awareness. Parents with autistic CYP report not raising concerns about their child's unmet needs to schools out of fear that their parenting would be judged [37]. Language barriers also posed challenges, especially for those less proficient in English [3].

The evidence from Bradford has emphasised the need for culturally competent practice; information on autism should be made available in community languages, and for interventions to be culturally sensitive. Evidence suggests that the most promising interventions for autistic children up to eight years old are naturalistic developmental behavioural interventions, these take place in natural settings and involve the child and professional taking equal roles when using behavioural strategies to learn skills [38, 39].

Many of those interviewed suggested that raising awareness of autism and the support that is available in South Asian (and other ethnic minority) communities was key, as well as ensuring any intervention or support is culturally sensitive [3]. In addition, it is vital that the pathways to receiving support are made much easier to navigate. As well as pathways differing across regions, services are continuously changing criteria to access support, adding to the complexities of navigating the pathway. By connecting services (i.e., schools, healthcare, and specialist services) and working as one, children and families can be better supported and, ultimately, autistic CYP will be able to thrive.

> "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?"**
>
> - Parent of an autistic young person

> "Kids that are higher functioning from a South Asian background are then even **more disadvantaged."**
>
> - Focus group participant

Universities must become the “Research and Development” departments for local public services

Through community engagement, universities (in partnership with hyperlocal charities, schools and other institutions) can play a key role in ensuring that research is relevant and useful. The Lancet Commission brought together leading clinicians and other healthcare professionals, researchers, and autism community representatives (autistic people, their parents, carers, teachers, and allied professionals) from six continents to identify strategies to improve the future of care and clinical research in autism [40]. The Commission called for coordination and collaboration between healthcare, education, finance, and social sectors across the lifespan, and the active inclusion and participation of autistic people and their families in the decisions made about them. This responds to an increasing demand from autistic people for opportunities to be involved in the research- and practice-based decisions that impact on their lives, as exemplified by “nothing about us without us”.

There is under-investment in autism research in the UK compared to the US and Australia. In addition, autism research efforts do not always reflect the views and priorities of the autistic community or involve the community in shaping the research agenda, its implementation, and the dissemination of its findings [41, 42]. We need more inclusive research involving partnership and collaboration with community members; citizen science where researchers partner with community-led projects (e.g., looking at what can be developed and changed in schools to mitigate the challenges autistic students may experience, such as anxiety around transitions, or problems with social interaction [43]).

Participatory approaches can contribute to practical knowledge by valuing the perspectives of the autistic community on the strengths, skills, needs, and support priorities of autistic CYP, to optimise learning and wellbeing [44]. Participatory approaches challenge the “traditional, unidirectional research pipeline from basic science to intervention development” which is evident in much of the autism research, or the use of measures and interventions that do not always make sense to autistic people, or are inconsistent with their views and experiences [45, 46].

Collaboration between community and academic partners can build capacity for effective services and improving clinical outcomes [45]. These collaborations can build local capacity and contribute to the development of culturally and contextually appropriate interventions that address locally perceived needs [47].

University education departments can also play an important role in supporting schools to become more autism-friendly. Australia is far ahead of the UK in this respect with the world’s first national, cooperative research effort focused on autism under the Australian Government’s Cooperative Research Centres (CRC) [48].

Autism CRC provides independent, national capacity to develop and deliver evidence-based outcomes through a unique collaboration with the autistic community, research organisations, education and health professionals, industry, and government. A similar collaborative partnership between universities, schools, other educational settings, and health professionals would be greatly beneficial within the UK.

> “I think the **training would be really helpful** if it was put together [by] **people with lived experience.**”
>
> - Parent of an autistic young person

Supporting schools, parents, and carers and professional development for teachers

Researchers argue that planning and resourcing for diverse needs should be "baked into our school systems, rather than overlaid as optional extras" [15]. This requires schools to be shaped by a neurodiversity affirmative model, to inform thinking about classroom adjustments that could be made to support autistic CYP.

Creating a visually accessible environment by reducing "visual clutter" and providing materials against a plain or dark background to minimise visual effort and maximise visual attention - including teacher clothing and wall/floor coverings.

Delivering low arousal teaching, with short, clear instructions delivered in a calm and even tone. Multiple methods of communication should be used by staff, including both written and verbal communication.

Relaxing school uniform policies – this supports pupils with sensory issues who cannot tolerate wearing the uniform.

Maintaining a consistently structured school day, and structured and calm transitions and lunch times.

Removing the sounding of a bell between classes, which generates a calmer atmosphere for all.

Providing absolute clarity of expectations for all students and staff, regularly communicated.

On page 35, autistic young people share their 12 top tips for supporting the autistic community.

These adjustments would likely also help both other neurodivergent and neurotypical pupils.

There is also a need for improved teacher education – both initial teacher education and ongoing professional development, to enhance understanding of autism and support schools to consider, implement, and evaluate changes to the learning environment.

In Australia and the US, there are online resources to support teacher awareness (e.g., inclusionED which is an online professional learning community, co-designed with educators, for educators). It provides evidence-based teaching practices and tools to support diverse learners in inclusive classrooms. https://www.inclusioned.edu.au/

Additionally, the Autism Education Trust developed an extensive collection of resources which have been co-produced with the autistic community. https://www.autismeducationtrust.org.uk/resources

Health and education must work together for autistic CYP

Research suggests that autistic CYP are at an increased risk of being excluded from school. Using data from the Connected Bradford database, analyses found that children who had been referred, but were still awaiting an assessment, were at greatest risk of being excluded from secondary school [4]. Autistic CYP who had a diagnosis were less likely to be excluded from school, compared to those awaiting an assessment, suggesting a diagnosis, and subsequent support, has a protective effect [4]. With waiting times increasing nationally, this represents a growing risk to education outcomes, as well as individual and societal costs. The evidence suggests that many autistic CYP end up in Alternative Provision (AP) with much higher associated costs than education [49].

School exclusion has profound negative implications, affecting children's academic performance and overall well-being [50]. According to studies, only 7% of permanently excluded or frequently suspended students pass crucial exams, demonstrating the negative impact of exclusions and insufficient AP [4]. The parents of autistic CYP are often unable to engage in the economic workforce because of their child's exclusion. Exclusion also has long-term effects on a child's psychological well-being, contributing to higher risks of crime involvement, anti-social behaviour, social isolation, and limited social capital [49]. Schools are often unable to explore drivers of behaviour and instead rely on a clinical diagnosis and other services for assistance.

These findings demonstrate the issues around "diagnostic-led" systems, whereby children identified as having difficulties and referred for further assessment but still waiting for that clinical diagnosis do not receive the necessary support. This lack of support causes a myriad of difficulties within the classroom and means existing problems escalate.

Notably, the evidence shows that once appropriate support is in place (following diagnosis), autistic CYP are less likely to be excluded [49]. These findings emphasise the need for an integrated approach to the implementation of autism across health and education settings.

ONLY 7% of permanently excluded or frequently suspended students pass crucial exams, demonstrating the negative impact of exclusions and insufficient Alternative Provision [4].

> **"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."
>
> - Focus group participant

Schools, nurseries and other educational settings must be at the heart of autism service delivery

The evidence is clear: the divide between health and education service delivery means that autistic CYP frequently fall in the gaps between schools and health services. Thus, many CYP experience health barriers to education that could and should be supported, but their needs are not being met due to siloed working.

An example of a national programme linking health and education is the Special School Eye Care Service, launched in 2021 [51]. Fewer than 7% of CYP with special educational needs have had an eye check, yet those with special educational needs are 28 times more likely to have a vision problem. Providing in-school assessments has allowed children requiring help to access vision support more effectively. Special School Eye Care Services allow strategies that improve visual learning to be given directly from health to education professionals in real time [52].

The long-term consequences of not supporting autism are devastating, with evidence showing that such health needs increase the risk of CYP being absent from school and ultimately becoming NEET (Not in Education, Employment or Training) [53]. Moreover, the evidence shows that improving the educational attainment of CYP decreases the risk of long-term physical and mental health problems.

There is accumulating evidence that health and education can work together effectively to ensure that CYP's health, education and social needs are met in a timely fashion [3]. Autistic CYP frequently possess a plethora of strengths, such as attention to detail, and have the potential to thrive in education if appropriately supported. The SEND crisis and the waiting list problems associated with autism (and other developmental differences) is just one example of the need for health settings to work in partnership with educational settings to effectively tackle problems that affect both services.

The evidence suggests that multidisciplinary clinical teams can work effectively in school settings, and this opens the possibility of new ways of working (especially in our most disadvantaged communities). In the next section ("innovative approaches trialled in real world settings"), we highlight an innovative approach (SUCCESS) where autism assessments were conducted in partnership with schools [54].

Integrated care systems provide an outstanding opportunity for such integration, but schools and nurseries must be properly represented within these groups.

> "CAMHS said to me, **'we're in crisis. We're letting children down.** Please, can you write to your MP' And I was like, if I had time, I would do that."
>
> - Parent of an autistic young person

Fewer than 7% of CYP with special educational needs have had an eye check, yet those with special educational needs are **28 times more likely to have a vision problem.**

Information must be shared across health and education when identifying autistic CYP

The evidence is clear: the inability of public service organisations to share information acts as a major barrier to planning and delivering integrated care [3].

Public services are organised and delivered within specialist organisations (e.g., education, health, social care, and policing). Policies are developed within political structures that map to these organisations both centrally (e.g., Department for Education, Department for Health and Social Care, Ministry of Justice, etc.) and at a local level (e.g., multi-academy trusts, hospital trusts, local authorities, and regional policing authorities).

As already discussed, the fundamental problem with this structure is that the lives of families and individuals do not fall neatly within these organisational silos. This underpins the drive to move towards "integrated care systems" where organisations are better connected. Unfortunately, the planning of integrated care is prevented through a lack of knowledge about how services intersect and interact within the lives of families. The delivery of integrated care is hindered because practitioners cannot share information across organisations.

For example, health services are often aware of children with rare chromosomal conditions known as "neurodevelopmental copy number variants" (ND-CNVs). ND-CNVs are minor genetic rearrangements where a small segment of a chromosome is missing or duplicated. Cardiff University research has found that a range of ND-CNVs have been robustly associated with autism [55].

It has been found that 1.99% of children in the Born in Bradford cohort have at least one of these ND-CNVs, highlighting that, although each of these conditions is individually rare, they are collectively common within the population [56, 57]. Upon examination of the Early Years Foundation Stage Profile scores, children with ND-CNVs exhibited early indications of language and communication challenges, as well as physical development concerns and autistic traits in comparison to their peers [57]. Given the significant impact ND-CNVs can have on many functional domains, children with these conditions often require specialist care. Yet, recent research into the school experiences of this group reports the "fight" parents have with public services to secure SEND support for their child. Almost a quarter (23.1%) of parents of children with a ND-CNV are dissatisfied with their educational support [58].

The challenges experienced by parents of children with a ND-CNV when trying to access support are reflective of the SEND review findings – with parents struggling to navigate a complex, underfunded, and structurally unequal system, which is more accessible to individuals of higher socioeconomic status and riddled with processing delays [59]. Under these difficult circumstances, parents of CYP with a rare chromosomal condition face additional challenges in proving need due to limited awareness of these conditions. In some cases, parents seek additional and more known neurodevelopmental diagnoses (such as autism) to secure support, even when the needs of their CYP are already apparent, contributing to even longer waiting lists for autism diagnostic services and inefficient use of resources.

The number of children diagnosed with a ND-CNV early in life is increasing as diagnostic technologies improve, and this can be expected to continue considering the ambitions of the UK regarding the future of genomic medicine [60]. The opportunity for early intervention for children diagnosed with a ND-CNV is great but will require information sharing across health and education if we are to provide comprehensive support to these children.

The evidence shows that it is possible to integrate information across health and education and understand the intersections and interactions between services to ensure early school support is in place for vulnerable children, such as those with a ND-CNV. Bradford has proved the principle with Connected Bradford and provided a methodology that should be scaled up across the UK to inform a national approach [28].

HOW GOVERNMENT CAN HELP HEALTH AND EDUCATION SYSTEMS SHARE INFORMATION TO CREATE THE BEST OUTCOMES FOR CYP

Education systems record children's Unique Pupil Number (UPN), while health systems record NHS numbers. The lack of a common denominator currently hinders data linkage. To facilitate cross-sector data sharing, the UK government must take the following action:

Use an individual's NHS number as a single unique identifier across public service records.

This government action will enable information sharing and allow our public sector organisations to work together more effectively to meet the needs of the autistic population.

> **"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."
>
> - Focus group participant

Innovative approaches trialled in the real world

The recommendations made within this report are based on innovative ways of working that have been trialled in real-world settings.

We highlight five evidence-based approaches – new tools and ways of working – designed in alignment to the principles set out in this report. We also highlight the incredible work undertaken in Limpsfield Grange school which shows there are solutions to the challenges. These approaches demonstrate the capacity of our schools, universities, and health institutes to innovate through applied research. They represent and show what can be achieved by combining academic expertise with the skills and knowledge of front-line professionals and the insights of children and families with lived experience.

These approaches show that it is possible to take different approaches to the identification and support of autism that do not follow the traditional models of service delivery. We show that education data can identify autistic CYP falling “under the radar” (underpinning our first recommendation around information sharing). We show that autism assessments can be conducted successfully in schools (hence our second recommendation for “whole system” partnership working). We highlight how these innovations have been developed in other areas (supporting our recommendation for place-based working). We showcase an oral health intervention that illustrates the usefulness of providing training around the needs of the autistic population (our third recommendation). Finally, we draw attention to the availability of psychoeducation tools.

1

Using education data to identify autistic CYP

> **“If it was easier [to access help],** I think more people would pick up on the signs a bit earlier.”
>
> - Focus group participant

The Early Years Foundation Stage Profile (EYFSP) is a universal teacher-reported assessment completed for all children in Reception classes across England.

Evidence suggests that the EYFSP could act as a “red flag” for identifying unmet needs within the population [61]. This could then trigger a process of assessment and support provision. Such practice could be particularly useful in addressing structural inequalities (i.e., identifying the CYP who are more likely to slip under the radar because of ethnicity, gender, or socioeconomic inequalities). This highlights the need for tailored support-led tools which can identify children with difficulties in communication and social skills throughout their time at school.

The evidence also shows that the education system has information that could be useful to clinicians when assessing a child for autism [7]. Autism assessments are lengthy processes typically conducted in environments unfamiliar to the child (i.e., clinics). The ability to efficiently share information on how a child behaves in the classroom could speed up the autism assessment process and help reduce waiting list times.

In many geographical areas, CYP sit on a waiting list for several years before being assessed for autism. The inherent difficulties in navigating the autism pathways mean that most children on the waiting list will be diagnosed with autism (e.g., in Bradford the “conversion rate” is 86%) [17]. This observation suggests that it would be reasonable to assume an autism diagnosis and provide support to all children currently on the waiting list in many locations. It further suggests that examining the EYFSP for children on the waiting list could provide a rapid indication of the likelihood of a child being autistic with good sensitivity and specificity. We recommend that such approaches are explored to address the unacceptable waiting times that currently plague the system and fail to serve CYP and their families.

The EYFSP covers a range of academic (e.g., mathematics and literacy) and non-academic (e.g., socioemotional development, language) elements. Teachers report on many of the behaviours that form the basis of standardised clinical autism assessments, raising the prospect that the EYFSP could flag unidentified autistic CYP, with a low score indicating that the expected progress in a domain has not been met. This hypothesis was tested using data from the Born in Bradford longitudinal birth cohort study through the ‘Digitally Acting Together As One’ (DATA1) project.

The evidence showed that children with low total scores on the EYFSP were over 25 times more likely to receive a diagnosis of autism [61]. Similarly, children who failed to reach a good level of development were 4.8 times more likely to have an autism diagnosis than those who did; similar findings have also replicated in a larger population-based cohort (the Connected Bradford database) [5].

The research further mapped some EYFSP elements onto four aspects of autism (social skills; language and communication; imagination; and repetitive behaviour) to create an “autism-specific weighted sub-score” [61]. Analyses revealed that children who scored poorly on the autism-specific score were approximately 50 times more likely to receive a confirmed autism diagnosis, compared to children who did not receive a low score [61].

These results show that teachers are well-positioned to identify developmental differences. This is intuitive, as teachers can often draw on years of experience about the behaviours expected of a child at a given age. In contrast to a snap-shot assessment by a health professional, teachers observe children throughout the year, enabling a fuller picture of the child’s global functioning, and facilitating the identification of the children who show different behaviours. We acknowledge the growing pressure placed on teaching staff to take on additional responsibilities on top of their already overstretched workload. Therefore, our recommendations focus on reasonable adjustments that can be easily implemented within the classroom as part of inclusive high quality teaching.

2

Autism assessments in schools

> "Even if we ignore diagnosis and focus on the needs... **the relationship between the school and the parents** is so important."
>
> - Focus group participant

The SUCCESS (Supporting Understanding of Children's Communication, Emotional and Social Skills) project was trialled in 10 Bradford primary schools through the Department for Education's Opportunity Area programme [13].

SUCCESS involved the deployment of multi-disciplinary teams **within the school gates** to conduct autism assessments for children identified as being at risk of undiagnosed autism (and other neurodevelopmental disorders) [54]. The evidence showed that clinicians were able to combine their clinical observations with those of teachers, who observe the child working, learning, and playing in a familiar environment every day. Many of the additional barriers that families often face, such as hesitancy about mental health services due to cultural beliefs, were overcome due to the trust families placed in the school. The SUCCESS approach allowed more children to access autism services and thereby reduce the likelihood of missed appointments and the resultant costs [54]. The evidence from the SUCCESS trial suggests this approach could provide major long-term savings and reduce waiting times for autism assessment and support [54].

> "...to be able to participate in that piece of work was fabulous... [it's] **enabled us to facilitate work between services** that would normally only be available post-diagnosis."
>
> - Educational psychologist

3

Tailoring promising approaches to place

> **“We’re not having a universal offer.** It’s a bit of a postcode lottery really.”
>
> - Parent of an autistic young person

Innovative approaches should not be “dragged and dropped” from one locality to another. Instead, they should come with guidance and methodologies to help local leaders create something tailored with and for their communities.

DATA1 and SUCCESS were implemented in Bradford and found to be useful approaches. However, these approaches need to be tailored to the needs and priorities of an area, given the differences in autism pathways and cultural milieu across different regions.

In line with this “place-based” principle, DATA1 and SUCCESS have been trialled successfully in different areas across England (Cambridgeshire, East Sussex, Barnsley, and Manchester) using a “test and learn” methodology through the Department for Education’s Opportunity Area initiative [61].

In Cambridgeshire, for example, the approach was adopted to focus mainly on girls in Years 5 and 6 (9-11 year olds), who, according to previous research, were less likely to be identified due to the masking of their difficulties in the classroom [34]. It was also noticed locally that autistic girls showed behaviours that were missed by traditional methods of diagnosis, (e.g., the Autism Diagnostic Observation Schedule; ADOS) [5, 37], with additional investigation often needed to uncover behavioural issues.

The team in Cambridgeshire further found that specialist teachers could observe girls skilfully masking their autism behaviours, but this required experience. The evidence suggested that subtle behavioural markers (e.g., discrete stimming in the form of small finger movements) would go unnoticed in a busy classroom if teachers were not trained to recognise these characteristics.

The Cambridgeshire project highlighted the need for more specialist training around the presentation of autism across different demographic groups [37]. The project also showed the value of listening to voices from different disciplines and viewpoints (including pupils, families, schools, health, and specialist teachers). This multifaceted approach enabled rich discussions on the appropriate support for a child, support that was based on true triangulation of need.

In East Sussex, the **Early Identification of Autism and Teacher Training in Primary School Settings Project** provided autism training to teachers, teaching assistants and SENCOs to promote identification and needs-led support for potentially autistic pupils.

Teachers and parents were actively involved in the screening process for autism and the diagnosis process was conducted in schools by assessors with relevant training and background on autism. Clinicians supervised the diagnostic process via video recordings. This was proved to be a successful pathway to autism diagnosis and early identification of the pupils needs, significantly reducing clinician’s time spent on each diagnosis.

In Mansfield and Ashfield, the **Young Wellbeing Hub: Early Identification Project** implemented SUCCESS [62]. They found that by outsourcing caseloads to a “Young Wellbeing Hub”, it was possible to provide more efficient support than available through overstretched services (such as CAMHS). The evidence showed a reduction in waiting times, waiting lists, and patient numbers – meaning more CYP received the support they needed to thrive.

In Nottinghamshire, the **Early Identification of Autism** project aimed to identify communication and interaction needs in 7–11-year-olds to reduce assessment waiting lists and promote early intervention. The project brought together health and education colleagues to undertake assessments so that timely, appropriate support could be identified and delivered to CYP, families, and schools at a much earlier stage in a child’s educational journey. The evidence showed that training allowed school staff to gain a unique insight into the diagnostic process and improve knowledge about autism. In turn, this led to children’s needs being identified and tailored support offered at an earlier stage.

> **“I think schools need a lot more training on autism in girls.** I think when you get autism training, it’s mainly looking at kind of how boys portray it and girls can be completely different to that.”
>
> - Autistic young person

4

Oral health approaches for autistic CYP

> “I just feel for some of these parents that probably don’t know how to find this information and **they’re struggling.”**
>
> - Parent of an autistic young person

The toothPASTE project works with autistic children, their families, and healthcare professionals to co-design an oral health support package. toothPASTE aims to help prevent tooth decay, a significant public health concern [63]. Around one in four five-year-olds in England have tooth decay and is the primary reason for hospital admissions, incurring over £50 million annually in NHS costs [64, 65] Tooth decay leads to a domino effect of significant consequences, such as pain, problems with speech, sleep disruption, altered eating habits, and financial impact on families (including time off work) [66]. The evidence is clear: poor oral health has a direct impact on school attendance, potentially widening educational inequalities [67].

Tooth decay is largely preventable, however, twice-daily brushing with fluoride toothpaste and reducing sugary foods and drinks, can be challenging. Communication and sensory differences and rigid behaviour patterns can make oral health routines more complex for autistic children [68]. For example, toothpaste can be felt as an “explosion in the mouth” [69]. Research demonstrates that autistic children are less likely to visit the dentist [70]. When attending, they’re less likely to receive preventative treatments. This disparity is alarming, particularly as autistic CYP are twice as likely to need their dental treatment provided under a general anaesthetic – with each operation costing the NHS around £1,000 per child.

Parents of autistic CYP commonly report feelings of isolation and confusion, frequently describing tooth brushing as a “battle” [69]. The advice that parents receive around oral health is often generic and does not address specific autism challenges. This leaves these parents to seek guidance from professionals they encounter across early-year health, education, and the third sectors. Yet, evidence indicates that these professionals have limited training in oral health and are often unsure about what advice they should offer [71].

The experiences of parents and children within dental environments identify a crucial, yet often overlooked need – the necessity for “autism-friendly” places and mandatory training for health and educational professionals, aligned to an NHS clinical standard [72]. Parents reported feeling judged or dismissed by their dentist. Moreover, research shows sensory challenges are not only limited to inside the mouth, they also include the harsh glare of bright lights, the loud sounds of drills and electric toothbrushes, and overpowering smells in the bathroom and clinic [73]. This not only highlights the necessity for training professionals but also the importance of empowering and supporting parents in their homes. In response to these challenges, the toothPASTE project has worked with autistic CYP, their families, and early years professionals to develop a detailed prototype that aligns with their preferences and needs. The toothPASTE research identified what oral health support families need (including a website and resources) and a training package for early years professionals [69]. The training package, ready for September 2024, will allow early years professionals to feel confident that the oral health support they provide is correct and sensitive to the family’s needs.

The toothPASTE support package will aim to break the cycle of siloed working. This involves making the programme freely accessible to families (without the need for a formal diagnosis), while the training package will be simultaneously available across early years professionals, not just within healthcare. This whole-system implementation plan will be continuously refined in collaboration with local authorities and key stakeholders in West Yorkshire to ensure local relevance and effectiveness. This will learn from, and collaborate with, other programmes such as Healthier Together and Autism Central [74, 75].

5

Psychoeducation for autistic CYP

> “The training needs to be wider, not just the teachers. **I’m talking about the caretaker. I’m talking about the lunchtime supervisors...** everybody should have all that same understanding.”
>
> - Parent of an autistic young person

Researchers from the University of Sheffield have collaborated with the University of Derby, NIHR’s Children and Young People Medtech Cooperative (CYPTECH) and Sheffield Hallam University’s Lab4Living to co-design psychoeducational resources that help primary-aged children with autism or ADHD. Psychoeducational resources are those that teach an individual about their condition by providing support, information, and management skills [76]. Whilst psychoeducation interventions are recognised as being beneficial for these groups [77, 78] and recommended by UK clinical guidelines, there is little age-appropriate material currently available for CYP attending mainstream schools.

The resources developed within this project include workbooks for the CYP to complete themselves and help lay the foundations for the development of self-advocacy. Providing accessible self-advocacy training for CYP with autism and ADHD is fundamental for individuals’ success in the long term [78] but particularly important for girls [79] due to the additional barriers they often face within educational settings [80, 81]. CYP, their families, clinicians, educational professionals, charities, and academics, have been central to the project throughout all stages of developing these resources; from identifying unmet need, to co-designing the content of the resource, to testing and developing initial prototypes. The resources have now been adopted by several schools and NHS Trusts and Councils across the UK [82].

> “I think there’s something about that **accessibility of information...** it’s that real self-help element.”
>
> - Focus group participant

What “good” looks like in autism education

Limpsfield Grange, in Surrey, is the UK’s only special school solely for autistic girls aged 11-16 years. Their work shows that there are solutions to the challenges CYP face, that need to be adapted into neurodiversity affirmative mainstream school environments. Many of the students have additional needs including ADHD; speech, language, and communication needs; medical needs; and emotional difficulties associated with their autism. All the students have an Education, Health and Care Plan (EHCP) that outlines their needs. Many Limpsfield Grange students have had an incomplete experience of primary school, often with very poor attendance due to their previously undiagnosed autism, which led to persistent levels of anxiety that affected their wellbeing.

Limpsfield Grange offers a broad and balanced, challenging, and relevant curriculum, delivered by experienced and dedicated staff. Staff build relationships with students based on a deep understanding of their needs, and these relationships are key in supporting students to fulfil their potential. The aim of the school is to fully prepare autistic girls for successful lives in wider society, so that they can work and make their contribution to the world.

Limpsfield Grange believe that their students should be just as successful in their wellbeing, communication, and independence, as they are academically. This gives them the greatest possible chance of success as learners and in the wider world. This unique school teaches these skills as a unique subject area known as WACI (Wellbeing; Academic Achievement; Communication; and Independence). WACI underpins the curriculum and is credited as the reason Limpsfield Grange students are successful.

Wellbeing - promoting the importance of self-awareness and self-care that enhances both physical, and mental wellbeing so that each student develops the resilience to cope with the ups and downs of everyday life. Students develop their understanding of healthy and unhealthy relationships so that they are able to recognise any red flags and understand how to respond in a range of situations, with friends, family, online and in the wider community. They learn a range of tools for living safely online and develop the ability to recognise and manage the risks they may encounter online and offline.

Achievement - developing skills and knowledge, validated through externally recognised qualifications such as GCSEs, BTECs and Functional Skills that enable each student to successfully transition to their next education placement.

Communication - good communication skills are important for enabling our students to understand and be understood by others. We teach students how to interact with their peers and with both familiar and unfamiliar adults. Students develop social communication and interaction skills so they can engage confidently and meaningfully in a range of scenarios.

Independence - developing independence skills enables our students to manage their own lives and make their own decisions. Most functional life-skills can be learnt at home, so our focus is on developing skills for the workplace, managing money and understanding how to be a responsible and active citizen.

The holistic approach to educating the whole person within Limpsfield Grange leads to great outcomes for their students who make excellent progress in their academic studies, with **100% of students each year successfully transitioning to and sustaining a post-16 placement.**

Limpsfield Grange alumni attend universities across the country; have jobs and apprenticeships; they pay taxes; have friends; and lead **rewarding and fulfilling lives.** Limpsfield Grange aims for all autistic girls to have the support and opportunities offered to them to enable them to thrive.

Limpsfield Grange experiences

Some of the wonderful students at Limpsfield Grange reflect on their experiences.

This is what Connie, Sally, Darya, D'Arcy, Elizabeth, Rose, Baylei, Beth, Ellie, and Georgia had to say about life before Limpsfield:

> When I was in primary school, I couldn't keep up with the work and was made fun of – people called me "dumb" and "stupid". People always left me out of things including games at breaktime. I felt like an outsider and got cross. It's not nice to be in that position.

> I don't remember a lot from primary school, but I struggled with being with other people and got left out a lot of the time. With learning, I was put in a group with three boys away from the classroom. I didn't like that.

> I wasn't allowed to sit my SATs at primary school. I felt left out. I wasn't allowed to do them because I was dyslexic.

> I always felt in primary school that people never got me. I had one TA who was really nice to me. In maths I was only taught the basic things so I was never able to catch up with everyone.

> My experience of getting diagnosed was a rollercoaster. I was diagnosed with ADHD before autism, my autism diagnosis was a bit of a shock.

> My diagnosis took a while. The doctors thought I was hard of hearing then I was diagnosed with autism at around 8 years old. ADHD diagnosis was really weird – I didn't want to sit through the assessment and I remember them chasing me round and round trying to do the assessment. It was really stressful.

> My parents told my primary school about my diagnosis and the primary school kicked me out because they didn't believe me.

> They need to realise that girls can have autism too. It's not fair that they only diagnose boys. There needs to be more ways to help, not just CAMHS, but doctors should have an autistic department as well.

> They said I shouldn't have emotions. If I'm stressed out, I should be allowed to feel that way but staff at primary school didn't understand and would just say "stop it".

This is what Connie, Sally, Darya, D'Arcy, Elizabeth, Rose, Baylei, Beth, Ellie, and Georgia had to say about how health and education systems should change:

> People should all get what they need to be successful, not just autistic people. Everyone should have the tools to be a success.

> They need to stop separating neurotypicals and autistic people. There should be a fair and understanding system. People never understand us. It's really selective and there should be something different done. If they need help someone should be there to help them. People who can't get a diagnosis and haven't got a special school place should be offered help in the classroom rather than be taken out.

> Try not to have as much discrimination. I was called so many names in primary school because I was different.

> Sometimes schools can have stereotypical views. They just think it's a characteristic, not that it's a symptom of having autism.

> Teachers and TAs in all schools should get a better understanding of autism.

> We should be taught about autism, neurodiversity, and mental illness. This could help students more because lots of teachers don't understand their students' needs.

> Autism is different in everyone so they should know that, and also that you can have more conditions than just autism.

And here are their 12 top tips for supporting autistic CYP:

1. Movement breaks could really make a difference to autistic CYP in mainstream schools.
2. Primary schools could add an area where people can have a break if they're feeling stressed.
3. A changes board (where changes in routine are recorded) can really help so changes aren't a surprise.
4. Schools could have swings to help if someone is feeling really stressed.
5. Make teaching more specific – things are better when everything is clear and easy to understand.
6. Regular check-ins with a teacher or staff member are important for autistic people. Everyone should be offered check-ins if they need them.
7. Offer a counsellor to help people talk about their experiences. It would help with diagnoses.
8. More explanations on social rules that must be obeyed, to help autistic people to understand. People shouldn't get in trouble for reacting in a non-neurotypical way.
9. It's important for students in mainstream to be taught that autistic people might not understand things that they find straightforward.
10. Provide allowances for sensory needs (e.g., allow "fidgets" or students to undertake activities like crochet and doodling).
11. Schools should allow autistic CYP the option to choose their own timetable or provide more flexibility about the timetable.
12. If a student is feeling stressed, they should be able to ask for help and know that someone will speak to them.

Implementation

NHSE have provided two important and useful documents that could and should guide the implementation of the recommendations made within this report:

National framework to deliver improved outcomes in all-age autism assessment pathways

Operational Guidance to deliver improved outcomes in all-age autism assessment pathways

The “Framework” and “Operational Guidance” documents were co-produced with a wide range of stakeholders including people with lived experience (autistic people, their families, and carers). The documents identify barriers to the autism assessment pathway and provide evidence of good practice.

The societal challenge is twofold. First, we must determine how these guidelines can move from abstract (and easily ignored) aspirations to concrete and measurable actions across the UK. Second, we need to transform our systems so that the responsibility for implementing autism support does not lie solely with the health system.

The first challenge can be operationalised via existing NHS structures and frameworks. The 2022 Integrated Care Boards (Establishment) Order legally established 42 Integrated Care Systems (ICS) across England, with each ICS comprising an Integrated Care Board (ICB), an Integrated Care Partnership, local authorities, place-based partnerships, and provider collaboratives. ICBs provide a useful organisational structure through which autism services can be transformed [83].

> **“I wish that there were just more services available for them…** in all honesty, **there’s hardly anything…** our kids are the ones that struggle the most, but they get the least services offered to them.”
>
> - Parent of an autistic young person

We recommend that ICBs work together to create a single regional “point of truth” where families, expectant families, practitioners, and educational providers can obtain evidence-based health advice on autism. The advice can be hosted on NHS webpages and capture core principles whilst ensuring the messages are tailored for the region. The Healthier Together programme shows the effectiveness of such an approach [74].

Likewise, an existing NHSE framework for addressing health inequalities can be utilised to create change at pace. **Core20PLUS5** advocates a system level approach to inequity that targets the most deprived 20% of the national population (‘Core20’) [18]. Core20PLUS5 encourages use of the national Index of Multiple Deprivation (IMD) to identify where efforts must be concentrated. The IMD is the official measure of relative deprivation in England (with similar measures available across the devolved nations). IMD2019 combines and weights 39 factors across seven domains of deprivation (income; employment; education; health; crime; housing and services; living environment) [84]. IMD2019 allows geographical “hotspots” of deprivation to be identified and serves as a useful geographical guide to target health interventions.

Thus, Core20PLUS5 identifies where actions should be prioritised within an ICB area. Importantly, it recognises that the system cannot simply throw a switch and transition to new ways of working in every area across the UK. Pragmatically, we recommend that around three of the most disadvantaged wards are selected within each local authority area and new approaches to supporting autistic CYP are developed in each of these wards. We recommend working at a ward-level to reflect the existence of a democratic elected councillor who can provide local political support for the work.

The implementation of innovative approaches to the transformation of autism pathways within a small number of wards will allow an area to “test and learn” what works best and scale up a system level transformation in a manageable fashion.

> “I think services need to try and engage with the children as well, rather than just **completely ignoring them and going to the parents.”**
>
> - Autistic young person

Core20PLUS5 suggests that specific populations should be prioritised at a local level (the “PLUS” part of its name) [18]. Examples include ethnic minority communities, people with a learning disability, and autistic people. **We strongly advocate an approach where ICBs prioritise improvement of their autism pathways.**

We note that the evidence presented in this report also applies to other developmental differences (e.g., ADHD). Importantly, a sustained focus on one condition (autism) would allow the issues associated with system transformation to be trialled in a manageable fashion. This approach will yield the wider changes required in a shorter time frame than an approach that tries to achieve everything at once.

To ensure that addressing the autism support and assessment crisis remains a priority, we recommend that “Futures Groups” be established to support ICBs. Humber and North Yorkshire ICB have established such a group, and the Futures Group provides advice on how the ICB can effectively implement a prevention strategy. These groups could utilise academic capacity within regional universities with experts who have the bandwidth necessary to help ICBs focus on the long-term agenda. The immediate demands on ICBs (from doctor strikes to A&E waiting times) otherwise hinder a sustained focus on inequity prevention. The evidence from Humber and North Yorkshire ICB is that there is an academic community willing and able to advise and support the ICB on such matters.

In summary, we need political leadership to drive coordinated public service delivery at a local level. This would ensure autistic CYP and their families receive the holistic care they need. The delivery of coordinated services requires the creation of formal partnerships at local authority area level. These partnerships can then enable services such as schools, health services, local authorities, voluntary services, faith leaders, and businesses to propel data driven, “whole system” approaches to improving outcomes for autistic CYP through schools and nurseries [24].

There is a role for central and local government to mandate and oversee such pragmatic approaches, providing challenge and support.

> **“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 neurodiversity.”
>
> - Focus group participant

The role of educational psychology

Workforce issues will need to be addressed as part of the solution to the problems affecting autism assessment and support services.

Educational Psychologists (EPs), along with other professionals such as speech therapists and occupational therapists, play an important role in the support available to schools.

EPs can cotribute to supporting autistic CYP and their schools and families. They work with the 0-25 age range and support pre-schools, schools, and post-16 settings at the organisational level (e.g., providing training and helping with developing general systems of support), as well as working with individual children with and without a medical diagnosis. EPs work across settings providing transition support, including support with the transition to adulthood [85].

Autism-focused activities can form a large part of an EP's workload. They can work with schools to assess autistic CYP's needs; advise on or provide interventions and therapeutic work; provide training for staff and parents; work collaboratively with families, school staff and other services; support the development of the local autism strategy, such as autism assessment pathways; and some have specialist roles as part of autism diagnostic teams [86, 87].

Through their knowledge of individual schools and communities, EPs' school-based work can assist in developing staff knowledge of autism, for instance by helping staff to understand different presentations of autism such as autism in girls or co-occurring difficulties such as selective mutism, anxiety or emotionally based school avoidance [88, 89]. However, as young people have emphasised, this needs to be sustained support as an afternoon's training is not enough. EPs can help schools increase their capacity to meet needs through regular training and support with implementation of evidence-based approaches such as visual supports or social stories and by collaborating with school staff and families to develop individualised plans for pupils.

Increasing the number of EPs may potentially increase capacity for them to be able to focus on this important area of work, although there are concerns about continuing shortages. It is promising that since 2020 the Department for Education has increased the number of educational psychology training places available from 160 to 204 per year [90]. Nevertheless, EPs are leaving the service at a greater rate than they are being replaced and there are geographical inequalities impacting the availability of EPs in parts of the UK. For instance, there is no EP training provision within West Yorkshire, and this means that local authorities such as Leeds and Bradford struggle to recruit. Innovative approaches are required within the profession of educational psychology – such as the development of Masters level apprenticeship grades which enable graduates to apply their skills within schools under the supervision of a Doctorate level qualified EP.

Educational psychologists can help schools **increase their capacity** to meet needs through regular training and support.

End word

Evie
Shore

Jennifer
Shaw

Megan
Roker

Nat
Merrick

END WORD: Evie Shore, Jennifer Shaw, Megan Roker and Nat Merrick (The Research and Implementation Fellow Team from Born in Bradford's Centre for Applied Education Research)

As young people from the North of England, we are grateful that attention is finally being paid to the struggles and inequalities impacting CYP, with an immediate call for action. We are excited to have had the opportunity to contribute to this report and highlight the perspectives of young people, including those with autism.

One of the struggles which resonates with us most is the impact of the COVID-19 lockdowns and the effect they had on young people's educational experience. During this period, we experienced struggles with isolation, where we felt a lack of support and an absence of social interaction. CYP with autism and/or additional needs have been disproportionately affected by the COVID-19 pandemic and have faced additional barriers to accessing support during this time. Post-pandemic, the burden on health services because of this global crisis means CYP are unable to access support for many years, suffering with subsequent mental and physical ill health. The inherent inequalities and complexities of navigating autism pathways are leaving CYP and their families without the resources they need.

Having only recently exited the school system we can testify to the major role that school plays in a young person's daily life. We completely agree with this report's conclusion that the school system should be utilised to identify and support autistic CYP. Additionally, as teachers observe the behaviour displayed by CYP daily, their insights are invaluable when identifying individuals with unmet needs, as well as advising clinicians during autism assessments. Through working with the Centre for Applied Education Research (CAER) in Bradford, we have witnessed the need for place-based approaches, the importance of which is highlighted by the socioeconomic and cultural differences seen across the District. We also recognise that these developments must be evidence-based, using research and high-quality data. We have observed the success of using this approach in creating appropriate interventions that have real world benefits.

We wholeheartedly agree that working alongside autistic CYP is vital to ensure services are equipped to best support their needs. People with autism are best equipped to identify the challenges they face and propose efficient approaches. This can be seen in the toothPASTE project, helping support oral health through working with autistic CYP and their families. Psychoeducational resources produced with autistic CYP also highlight the importance of co-production; autistic CYP have often been wrongfully excluded from decisions about autism service provision, despite their expertise and insight.

Evie Shore: As part of the CAER team, and as a female autistic young person who has navigated the education system without additional support, I feel that the challenges I have personally experienced have been recognised by this report. It is refreshing to see so many practical recommendations be made, with the offer of an accessible needs-led approach. In the same breath, it is disheartening to discover the numbers of CYP who are being continuously failed by the system. The lack of awareness among healthcare professionals regarding how autism presents in girls is hindering CYP's chances of excelling in the classroom and beyond. Going for years unnoticed and without support can have profound negative effects on CYP's mental health considering the challenges of school transitions, and the complexities of secondary school social life. It is crucial to provide thorough training co-produced by CYP with lived experience, regarding the presentation of autism in girls, including what adjustments can be put in place to meet the needs of autistic girls earlier and more effectively.

> One of the struggles which resonates with us most is the impact of the **COVID-19 lockdowns** and the **effect they had on young people's educational experience.**
>
> We need a government who will put **CYP at the forefront of their decision making** and deliver the recommendations given by this report. **We need system-wide change, and we need it now.**

References and author list

Infographic references

Ambitious About Autism. (2023). Position statements. Ambitious about Autism. https://www.ambitiousaboutautism.org.uk/what-we-do/policy-and-campaigns/position-statements

Aylward, B. S., Gal-Szabo, D. E., & Taraman, S. (2021). Racial, Ethnic, and Sociodemographic Disparities in Diagnosis of Children with Autism Spectrum Disorder. Journal of Developmental & Behavioral Pediatrics, 42(8). https://doi.org/10.1097/dbp.0000000000000996

Care Quality Commission. (2023, October 20). Inequalities - Care Quality Commission. Www.cqc.org.uk. https://www.cqc.org.uk/publications/major-report/state-care/2022-2023/inequalities

Constantino, J. N., Abbacchi, A. M., Saulnier, C., Klaiman, C., Mandell, D. S., Zhang, Y., Hawks, Z., Bates, J., Klin, A., Shattuck, P., Molholm, S., Fitzgerald, R., Roux, A., Lowe, J. K., & Geschwind, D. H. (2020). Timing of the Diagnosis of Autism in African American Children. Pediatrics, 146(3), e20193629. https://doi.org/10.1542/peds.2019-3629

Crane, L., Pellicano, L., Adams, F., Harper, G., & Welch, J. (2017). Ambitious about Autism. https://rb.gy/k1roit

Department for Education. (2023). Special Educational Needs in England. Explore-Education-Statistics.service.gov.uk. https://explore-education-statistics.service.gov.uk/find-statistics/special-educational-needs-in-england

Department of Education. (2019). The unequal representation of ethnic minorities in special education in England: Extent, causes and consequences. University of Oxford.

Johnson, M., Doherty, M., & Shaw, S. C. (2022). Overcoming barriers to autistic health care: Towards autism-friendly practices. British Journal of General Practice, 72(719), 255–256. https://doi.org/10.3399/bjgp22x719513

McCrossin, R. (2022). Finding the true number of females with autistic spectrum disorder by estimating the biases in initial recognition and clinical diagnosis. Children, 9(2), 272. https://doi.org/10.3390/children9020272

National Autistic Society. (2023a). Autism assessment waiting times. Www.autism.org.uk. https://www.autism.org.uk/what-we-do/news/autism-assessment-waiting-times-3

National Autistic Society. (2023b). Education Report 2023. Education Report Series. https://www.autism.org.uk/what-we-do/news/education-report-2023#:~:text=It

NHS Digital. (2023a). Autism Statistics, October 2022 to September 2023. Autism Waiting Time Statistics. NHS Digital. https://digital.nhs.uk/data-and-information/publications/statistical/autism-statistics/october-2022-to-september-2023

NHS Digital. (2023b). Learning Disability Services Monthly Statistics, AT: November 2023, MHSDS: September 2023 & October 2023. NHS Digital. https://rb.gy/8cfkqk

NHS Digital. (2023c). Mental Health Services Monthly Statistics, Performance October 2023. NHS Digital. https://digital.nhs.uk/data-and-information/publications/statistical/mental-health-services-monthly-statistics/performance-october-2023

North Yorkshire Council, North Yorkshire Autism Group, Humber and North Yorkshire Integrated Care Board, Community First Yorkshire, Inclusion North, & Tees Esk and Wear Valley NHS Foundation Trust. (2023). North Yorkshire All-age Autism Strategy. Health and Wellbeing Board North Yorkshire.

O'Nions, E., Petersen, I., Joshua E.J. Buckman, Charlton, R. A., Cooper, C., Corbett, A., Happé, F., Manthorpe, J., Richards, M., Saunders, R., Zanker, C., Mandy, W., & Stott, J. (2023). Autism in England: assessing underdiagnosis in a population-based cohort study of prospectively collected primary care data. The Lancet Regional Health, 29, 100626–100626. https://doi.org/10.1016/j.lanepe.2023.100626

Smith, D. L. (2023). A District Level Population-Based Study of Structural Inequalities in Autism Pathways. DClin Psycology Thesis. The University of Leeds, School of Medicine, 2023.

Report references

[1] Autistic Self Advocacy Network, “Identity First Language,” 2021. [Online]. Available: https://autisticadvocacy.org/about-asan/identity-first-language/.

[2] National Autistic Society, “How to talk and write about autism,” 2021. [Online]. Available: https://www.autism.org.uk/contact-us/media-enquiries/how-to-talk-and-write-about-autism.

[3] D. A. Smith, “A district level population-based study of structural inequalities in autism pathways,” DClin Psycology Thesis. The University of Leeds, School of Medicine, 2023.

[4] E. Chapman, “Preventing Unmet Need Leading to School Exclusion: Empowering Schools to Identify Neurodiversity Earlier,” DClin Psycology Thesis. The University of Leeds, School of Medicine, 2023.

[5] L. Rogan, “Exploring factors related to delayed diagnosis for autistic girls through the Connected Bradford Cohort Daatabase,” DClin Psycology Thesis. The University of Leeds, School of Medicine, 2023.

[6] M. Jit, A. Ananthakrishnan, M. McKee, O. Wouters and P. Beutels, “Multi-country collaboration in responding to global infectious disease threats: lessons for Europe from the COVID-19 pandemic,” The Lancet Regional Health, vol. 9, 2021.

[7] A. Likhar, P. Baghel and M. Patil, “Early Childhood Development and Social Determinants,” Cureus, vol. 14, no. 9, 2022.

[8] Qualter, Bond, Jefferson, Verity and Farzinnia, “Evaluation of the Early Identification of Autism,” Department for Education, 2023.

[9] P. Geelhand, P. Bernard, O. Klein, B. van Tiel and M. Kissine, “The role of gener in the perception of autism severity and future behavioural development,” Mol Autism, vol. 10, no. 16, 2019.

[10] Department for Education and The Department of Health and Social Care, “The national strategy for autistic children, young people and adults: 2021 to 2026,” 2021.

[11] A. Buescher, Z. Cidav, M. Knapp and D. Mandell, “Costs of autism spectrum disorders in the United Kingdom and the United States,” JAMA Pediatrics, 2014.

[12] NHS England, “Operational guidance to deliver improved outcomes in all-age autism assessment pathways: Guidance for integrated care boards,” 2023.

[13] NHS England, “Core20PLUS5 (Adults) - an aproach to reducing healthcare inequalities,” 2021. [Online]. Available: https://rb.gy/vcepz1.

[14] C. Featherstone, R. Sharpe, N. Axford, S. Asthana and K. Husk, “Health and wellbeing outcomes and social pescribing pathways in community-based support for autistic adults: A systematic mapping review of reviews,” Health and Social Care in the Community, vol. 30, no. 3, pp. e621-e635, 2022.

[15] National Autistic Society, “Autism Assessment Waiting Times,” 2023.

[16] World Health Organisation, 15 September 2023. [Online]. Available: https://www.who.int/publications/i/item/9789240080232.

[17] L. Kenny, C. Hattersley, B. Molins, C. Buckley, C. Povey and E. Pellicano, “Which terms should be used to describe autism? Perspectives from the UK autism community,” Autism, vol. 20, no. 4, 2015.

[18] World Health Organisation, “International Statistical Classification of Diseases and Related Health Problems, Eleventh Revision (ICD-11),” 2021.

[19] NHS England, “A national framework to deliver improved outcomes in all-age autism assessment pathways: guidance for integrated care boards,” 2023.

[20] S. Chawner, J. Doherty and et al., “A Genetics-First Approach to Dissecting the Heterogeneity of Autism: Phenotypic Comparison of Autism Risk Copy Number Variants,” The American Journal of Psychiatry, vol. 178, no. 1, 1 1 2021.

[21] H. Steinhausen, C. Mohr Jenson and M. Lauritsen, “A systematic review and meta-analysis of the long-term overall outcome of autism spectrum disorders in adolescence and adulthood,” Acta Psychiatr Scand., 2016.

[22] M. Micai, L. Fatta, L. Gila and et al., “Prevalence of co-occurring conditions in children and adults with autism spectrum disorder: A systematic review and meta-analysis,” Neuroscience and biobehavioural reviews, vol. 155, 2023.

[23] M. Menezes, M. Robinson, C. Harkins, E. Sadikova and M. Mazurek, “Unmet health care needs and health care quality in youth with autism spectrum disorder with and without intellectual disability,” Autism, vol. 25, no. 8, 2021.

[24] C. Wallace-Watkin, J. Sigafoos and H. Waddington, “Barriers and facilitators for obtaining support services among underserved families with an autistic child: A systematic qualitative review,” National Autistic Society, vol. 27, no. 3, 2022.

[25] M. Mon-Williams and M. Wood, “Addressing Education and Health Inequity: Perspectives from the North of England. A report prepared for the Child of the North APPG,” Health Equity North, 2023.

[26] B. Kelly, S. Williams, S. Collins, F. Mushtaq, M. Mon-Williams, B. Wright, D. Mason and J. Wright, “The association between socioeconomic status and autism diagnosis in the United Kingdom for children aged 5–8years of age: Findings from the Born in Bradford cohort,” Autism, vol. 23, no. 1, pp. 131-140, 2019.

[27] K. Sohal, D. Mason, J. Birkinshaw, J. West, R. McEachan, M. Elshehaly, D. Cooper, R. Shore, M. McCooe, T. Lawton and M. Mon-Williams, “Connected Bradford: a whole system data linkage accelerator.,” Wellcome Open Research, vol. 7, 2022.

[28] National Institute of Health and Care Excellence, “Autism spectrum disorder in under 19s: recognition, referral and diagnosis. Clinical guideline [CG128],” National Institute of Health and Care Excellence, London, 2017.

[29] J. Hall, Batza, K, C. Streed and et al., “Health Disparities Among Sexual and Gender Minorities with Autism Spectrum Disorder,” Autism Dev Disord, vol. 50, pp. 3071-3077, 2020.

[30] C. Saunders, A. Berner, J. Lund and et al., “Demographic characteristics, long-term health conditions and healthcare experiences of 6333 trans and non-binary adults in England: nationally representative evidence from the 2021 GP Patient Survey,” BMJ Open, vol. 13, no. 2, 2023.

[31] M. Tubio-Fungueirino, S. Cruz, A. Sampaio, A. Carracedo and M. Fernandez-Prieto, “Social camouflaging in females with autism spectrum disorder: A systematic review,” J Autism Developmental Disorders, 14 09 2020.

[32] J. Beck, R. Lundwall, T. Gabrielsen, J. Cox and M. South, “Looking good but feeling bad: “Camouflaging” behaviors and mental health in women with autistic traits,” Autism, vol. 24, no. 4, pp. 809-821, 2020.

[33] A. Cook, J. Ogden and N. Winstone, “Friendship Motivations, Challenges and the Role of Masking for Girls with Autism in Contrasting School Settings,” European Journal of Special Needs Education, vol. 33, no. 3, pp. 302-315, 2017.

[34] S. Tromans, V. Chester, E. Gemegah, K. Roberts, Z. Morgan, G. Yao and T. Brugha, “Autism identification across ethnic groups: A narrative review,” Advances in Autism, vol. 7, no. 3, pp. 241-255, 2021.

[35] S. Beeger, S. Bouk, W. Boussaid, M. Terwogt and H. Koot, "Underdiagnosis and referral bias of autism in ethnic minorities. Journal of autism and developmental disorders," Journal of Autism and Developmental Disorders, vol. 39, pp. 142-148, 2009.

[36] PinPoint Cambridgeshire, "Early Identification of Autism Project (EIA)," 03 2023. [Online]. Available: https://pinpoint-cambs.org.uk/early-identification-of-autism-project-eia/.

[37] L. Schreibman, G. Dawson, A. Stahmer and et al., "Naturalistic Developmental Behavioral Interventions: Empirically Validated Treatments for Autism Spectrum Disorder," J Autism Dev Disord., vol. 45, no. 8, pp. 2411-2428, 2015.

[38] C. Lord, T. Charman, A. Havdahl, P. Carbone, E. Anagnostou, B. Boyd, T. Carr, P. Vries, C. Dissanayake, G. Divan, C. Freitag, M. Gotelli, C. Kasari, M. Knapp, P. Mundy, A. Plank, L. Scahill, C. Servili, P. Shattuck, E. Simonoff, A. Singer, V. Slonims, P. Wang, M. Ysrraelit, R. Jellett , A. Pickles, J. Cusack, P. Howlin, P. Szatmari, A. Holdbrook, C. Toolan and J. McCauley, "The Lancet Commission on the future of care and clinical research in autism," The Lancet, vol. 399, pp. 271-334, 12 2021.

[39] E. Pellicano, A. Dinsmore and T. Charman, "Community views and piorities from the United Kingdom," Autism, vol. 18, no. 7, 2014.

[40] S. Fletcher-Watson, K. Brook, S. Hallett, F. Murray and C. Crompton, "Inclusive practices for neurodevelopmental research.," Curr Developmental Disorders Rep, vol. 8, pp. 88-97, 2021.

[41] A. Stahmer, A. Aranbarri, A. Drahota and S. Rieth, "Extending translational science from research to community and back again," Autism, vol. 21, no. 3, pp. 259-261, 2017.

[42] S. Jones, "Measuring the wrong thing the right way? Time to rethink autism research tools," Autism Adulthood, vol. 4, no. 2, pp. 104-109, 2022.

[43] Cooperative Research Australia, "About the Cooperative Research Centres Programme," 2021. [Online]. Available: https://cooperativeresearch.org.au/cooperative-research/crc-program-australian-government/.

[44] L. Robinson, C. Bond and J. Oldfield, "A UK and Ireland survey of Educational Psychologists' intervention practices for students with Autism Spectrum Disorder," Educational Psychology in Practice, vol. 34, no. 1, pp. 58-72, 2018.

[45] S. Saddrendini, C. Bond and J. Oldfield, " How do educational psychologists in the UK and Ireland assess the needs of autistic children and young people?," Good Autism Practice, vol. 20, no. 1, pp. 41-49, 2019.

[46] C. Neilson and C. Bond, "After a long period of being in hibernation – these little green shoots were growing." Lived experiences of effective support for autistic young people who have experienced extended school nonattendance.," Journal of Research in Special Educational Needs, 2023.

[47] S. O'Hagan and C. Bond, "The role of Educational Psychologists in supporting autistic girls in education.," Hebron J & Bond, C (Eds) Education and girls on the autism spectrum: developing an integrated approach, 2019.

[48] J. White, C. Bond and C. Carroll, "An exploration of how selective mutism training informs teachers' understanding and practice," Support for Learning, vol. 37, no. 1, pp. 3-20, 2022.

[49] Department for Education, "Educational psychology services: workforce insights and school perspectives on impact.," Research Report RR1354 DfE, 2023.

[50] B. Graham, C. White, A. Edwards, S. Potter and C. Street, "School exclusion: a literature review on the continued disproportionate exclusion of certain children," 2019.

[51] T. Ford, Parker, C, J. Salim, R. Goodman, S. Logan and W. Henley, "The relationship between exclusion from school and mental health: a secondary analysis of the British Child and Adolescent Mental Health Surveys 2004 and 2007," Psychological Medicine, vol. 48, no. 4, pp. 629-641, 2018.

[52] NHS England, "Engagement – in school eye testing for pupils in special schools in England," 2023. [Online]. Available: https://rb.gy/x9d7pq.

[53] NHS England, "Special schools eye care – proof of concept evaluation report," 2023. [Online]. Available: https://www.england.nhs.uk/publication/special-schools-eye-care-proof-of-concept-evaluation-report/.

[54] I. Ringbom, J. Suvisaari, A. Kääriälä, A. Sourander, M. Gissler, T. Ristikari and D. Gyllenberg, "Psychiatric Disorders Diagnosed in Adolescence and Subsequent Long-Term Exclusion from Education, Employment or Training: Longitudinal National Birth Cohort Study," BR J Psychiatry, 2022.

[55] B. Wright, K. Konstantopoulou, K. Sohal, B. Kelly, G. Morgan, C. Hulin, S. Mansoor and M. Mon-Williams, "Systematic approach to school-based assessments for autism spectrum disorders to reduce inequalities: A feasibility study in 10 primary schools," BMJ Open, vol. 11, 2021.

[56] S. Chawner, M. Owen, P. Holmans, F. Raymond, D. Skuse, J. Hall and M. van den Bree, "Genotype–phenotype associations in children with copy number variants associated with high neuropsychiatric risk in the UK (IMAGINE-ID): a case-control cohort study," The Lancet Psychiatry, vol. 6, no. 6, pp. 493-505, 2019.

[57] R. Birnbaum, B. Mahjani, R. Loos and A. Sharp, "Clinical Characterization of Copy Number Variants Associated With Neurodevelopmental Disorders in a Large-scale Multiancestry Biobank," JAMA Psychiatry, vol. 79, no. 3, pp. 250-259, 2022.

[58] N. Ali, "Neurodevelopmental and neuropsychiatric disorders in individuals with rare pathogenic genetic variants: Analysis in clinical and population-based cohorts.," Cardiff University, 2023.

[59] L. O'Dononan, "School experiences of children with rare genetic conditions associated with high risk for neurodevelopmental difficulties.," 2023.

[60] Department for Education; Department of Health and Social Care, "SEND Review: Right support, right place, right time. Government consultation on the SEND and alternative provision system in England.," 2022.

[61] HM Government, "Genome UK: the future of healthcare.," 2020.

[62] B. Wright, M. Mon-Williams, B. Kelly, S. Williams, D. Slims, F. Mushtaq, K. Sohal, J. Blackwell and J. Wright, "Investigating the association between early years foundation stage profile scores and subsequent diagnosis of an autism spectrum disorder: a retrospective study of linked healthcare and education data," BMJ Paediatritcs Open, vol. 3, no. 1, 2019.

[63] Care Quality Comission, "Young Wellbeing Hub," [Online]. Available: https://youngwellbeinghub.co.uk/autism/.

[64] The Centre for Applied Education Research, "Supporting Parents of Children with Autism with Oral Health (ToothPASTE)," [Online]. Available: https://t.ly/U71cu.

[65] National Dental Epidemiology, "National Dental Epidemiology Programme (NDEP) for England: Oral Health Survey of 5 Year Old Children," 2022. [Online]. Available: https://shorturl.at/einzA.

[66] Office for Health Improvement and Disparities, "Hospital tooth extractions in 0 to 19 year olds 2022," 2023. [Online]. Available: https://www.gov.uk/government/statistics/hospital-tooth-extractions-in-0-to-19-year-olds-2022/hospital-tooth-extractions-in-0-to-19-year-olds-2022.

[67] Public Health England, “Health matters: child dental health,” 2017. [Online]. Available: https://www.gov.uk/government/publications/health-matters-child-dental-health/health-matters-child-dental-health.

[68] M. Rebelo, J. Vieira, J. Pereira, L. Quadros and M. Vettore, “Does oral health influence school performance and school attendance? A systematic review and meta-analysis,” International Journal of Peadeatric Dentistry, vol. 29, no. 2, pp. 138-148, 2019.

[69] J. Parry, S. Brosnan, T. Newton, C. Linehan and C. Ryan, “Brief Report: Analysis of Dental Treatment Provided Under General Anaesthesia for Children and Young Adults with Autistic Spectrum Disorder and Identification of Challenges for Dental Services,” Autism Developmental Disorders, vol. 51, no. 12, 12 2021.

[70] Linktree, “toothPASTE,” [Online]. Available: https://linktr.ee/toothpastestudy.

[71] A. Sherriff, R. Stewart, L. Macpherson, J. Kidd, A. Henderson, D. Cairns and D. Conway, “Child oral health and preventive dental service access among children with intellectual disabilities, autism and other educational additional support needs: A population- based record linkage cohort study. ,” Community Dentistry and Oral Epidemiology, vol. 51, no. 3, pp. 494-502, 2023.

[72] Public Health England, “Local authorities improving oral health: commissioning better oral health for children and young people,” 2014.

[73] NHS England, “Clinical standard - oral healthcare for autistic children and young people and/or those with a learning disability in special educational settings,” 2023.

[74] National Autistic Society, “Dental care and autism – a guide for dentists,” 2020. [Online]. Available: https://rb.gy/3izfiv.

[75] Healthier Together, “Healthier Together- A National Programme,” [Online]. Available: https://rb.gy/j0p336.

[76] Autism Central, “Autism Central,” [Online]. Available: https://www.autismcentral.org.uk/.

[77] G. N. Bai, Y. F. Wang, L. Yang and W. Y. Niu, “Effectiveness of a Focused, Brief Psychoeducation Program for Parents of ADHD Children: Improvement of Medication Adherence and Symptoms,” Neuropsychiatric Disease and Treatment,, pp. 2721-2735, 2015.

[78] L. A. Powell, J. Parker, A. Weighall and V. Harpin, “Powell, L. A., Parker, J., Weighall, A., & Harpin, V. Psychoeducation intervention effectiveness to improve social skills in young people with ADHD: A meta-analysis,” Journal of Attention Disorders, vol. 26, no. 3, pp. 340-357, 2022.

[79] B. Doran and H. J. Kang, “Autonomy, Self-Realization, and Self-Advocacy and the School- and Career-Related Adjustment of Adolescent Girls With Disabilities,” Career Development and Transition for Exceptional Individuals, vol. 39, no. 3, pp. 132-143, 2016.

[80] L. Lindstrom, R. M. Harwick, M. Poppen and B. Doren, “Gender gaps: Career development for young women with disabilities Lindstrom, L., Harwick, R. M., Poppen, M., & Doren, B. (2012).,” Career development and transition for exceptional individuals, vol. 35, no. 2, pp. 108-117, 2012.

[81] B. Doren and M. R. Benz, “Gender equity issues in vocational and transition services and employment outcomes experienced by young women with disabilities,” in Double Jeopardy: Addressing gender equity in special education, Albany, State University of New York Press, 2001, p. 289–312.

[82] K. Powers, J. Hogansen, S. Geenen, L. E. Powers and E. Gil- Kashiwabara, “Gender matters in transition to adulthood: A survey study of adolescents with disabilities and their families,” Psychology in the Schools, vol. 35, no. 4, pp. 349-364, 2008.

[83] U. o. Sheffield, “Learning About Autism: Activites for children, young people and their families,” 2023. [Online]. Available: https://www.adhdfoundation.org.uk/wp-content/uploads/2023/10/Learning-About-Autism_web.pdf.

[84] NHS England, “The Integrated Care Boards (Establishment) Order,” 2022. [Online]. Available: https://rb.gy/pgrc67.

[85] Ministry of Housing, Communities and Local Government, “The English Indices of Deprivation,” 2019. [Online]. Available: https://rb.gy/4bjvme.

[86] D. Aitken and S. Fletcher-Watson, “Neurodiversity affirmative education: why and how?,” The Psychologist, 15 12 2022.

[87] M. Sandbank, K. Bottema-Beutel, S. Crowley, M. Cassidy, K. Dunham, J. Feldman and T. Woynaroski, “Project AIM: Autism intervention meta-analysis for studies of young children,” Psychological Bulletin, vol. 146, no. 1, pp. 1-29, 2020.

[88] S. Fletcher-Watson, J. Adams, K. Brook, T. Charman, L. Crane, C. James, S. Leekam, D. Milton, J. Parr and E. Pellicano, “Making the future together: Shaping autism research through meaningful participation,” Autism, vol. 23, no. 4, 05 2019.

[89] R. Poulsen, P. Dwyer, D. Gassner, M. Heyworth and Z. Williams, “The INSAR Community Collaborator Request: Using community-academic partnerships to enhance outcomes of participatory autism research,” Autism Research, pp. 1-6, 2023.

Author list

Core writing team

Nabila Ali	Cardiff University
Anna Purna Basu	Newcastle University; Great North Children's Hospital
Sara Basuc	Fenland and East Cambridgeshire Priority Area
Caroline Bond	University of Manchester
Eleanor J. Bryant	University of Bradford
Emily Chapman	University of Leeds
Amrit Chauhan	University of Leeds
Samuel J.R.A Chawner	Cardiff University
Peter Day	University of Leeds; Bradford Community Dental Service
Emily Douse	Healthwatch York
Lucy Eddy	University of Bradford
Mai Elshehaly	City, University of London
Rai Fayette	University of Manchester
Melissa Gladstone	University of Liverpool
Kara Gray-Burrows	University of Leeds
Karen Guldberg	University of Birmingham
Sean Harris	Tees Valley Education
Calum Hartley	Lancaster University
Judith Lunn	Lancaster University
Prithvi Perepa	University of Birmingham
Rachel Pilling	University of Bradford
Lauren Powell	University of Sheffield
Pamela Qualter	University of Manchester
Judith Rankin	NIHR Applied Research Collaboration North East and North Cumbria; Newcastle University
Sue Robson	Newcastle University
Leanne Rogan	University of Leeds
Fiona Routh	University of Central Lancashire
Nikki Rutter	Durham University
Rebecca Salmon	Cambridgeshire County Council
Danielle Smith	University of Leeds
Kuldeep Sohal	Bradford Institute for Health Research
Lydia Gabriela Speyer	Lancaster University
Paul Sullivan	University of Bradford
Jacqueline Taylor	Cambridgeshire Community Services
Paraskevi Triantafyllopoulou	University of Kent
Marianne B.M. van den Bree	Cardiff University
Matthew Warburton	University of Leeds
Nicole Webb	Young Wellbeing Hub
Harriet Whitaker	Young Wellbeing Hub
Sarah Wild	Limpsfield Grange School

Editors

Mark Mon-Williams	Born in Bradford's Centre for Applied Education Research; University of Leeds
Evie Shore	Born in Bradford's Centre for Applied Education Research; University of Leeds
Megan L. Wood	Born in Bradford's Centre for Applied Education Research; University of Leeds

Core editorial team

Lydia Gunning	Born in Bradford's Centre for Applied Education Research; University of Leeds
Nat Merrick	Born in Bradford's Centre for Applied Education Research; University of Leeds
Mallory Morehead	Born in Bradford's Centre for Applied Education Research; University of Leeds
Lowri O'Donovan	Cardiff University
Alistair Quaile	University of Leeds
Megan Roker	Born in Bradford's Centre for Applied Education Research; University of Leeds
Jennifer Shaw	Born in Bradford's Centre for Applied Education Research; University of Leeds

Contributing experts

Christian Bunting	St Edmund's Nursery School; Bradford Birth to 19
Diane Daley	Bradford Teaching Hospitals NHS Foundation Trust
Nicole Dempsey	Dixons Academies Trust
Ava Green	Bradford District Care Trust
Jo Green	Centre for Young Lives
Margriet A. Groen	Lancaster University
James Lauder	Dixons Academies Trust
Margaret Nash	AWARE

Child of the North

N8 RESEARCH PARTNERSHIP

HEALTH EQUITY NORTH

CENTRE FOR YOUNG LIVES