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Supporting the development of an All Age Autism Strategy for Oxfordshire

An evidence piece from SCIE for Oxfordshire County Council

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About SCIE

The Social Care Institute for Excellence improves the lives of people of all ages by co-producing, sharing, and supporting the use of the best available knowledge and evidence about what works in practice. We are a leading improvement support agency and an independent charity working with organisations that support adults, families and children across the UK. We also work closely with related services such as health care and housing.

We improve the quality of care and support services for adults and children by:

- identifying and sharing knowledge about what works and what's new
- supporting people who plan, commission, deliver and use services to put that knowledge into practice
- informing, influencing and inspiring the direction of future practice and policy.

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Introduction - why develop an all age autism strategy?

The Government states in their ministerial foreword for their National Autism Strategy that “The introduction of the Autism Act 2009 was ground-breaking because it was the first disability-specific piece of legislation in England. Over the decade since its inception, it has resulted in improvements in support for autistic adults across the country, and greater awareness of autism in society. However, we know that more still needs to be done to improve autistic people’s lives.” The Government therefore proposed **The national strategy for autistic children, young people and adults: 2021 to 2026 - GOV.UK**

Oxfordshire County Council is developing its own autism strategy in line with the National Autism Strategy, to improve the lives of autistic people living in the county across all aspects of their lives. This reports sets out the evidence base to underpin any new strategy which should be developed with key local partners especially autistic people, their families, parents, and carers. The new strategy needs to align with the existing statutory guidance on implementing the Autism Act for local authorities and NHS organisations to support implementation of the Adult Autism Strategy (2015). This sets out local authorities’ and NHS organisations’ duties to support autistic adults and remains in force, which means that local systems should continue to deliver on existing requirements, including having active Autism Partnership Boards in local areas. **The national strategy for autistic children, young people and adults: 2021 to 2026 - GOV.UK**

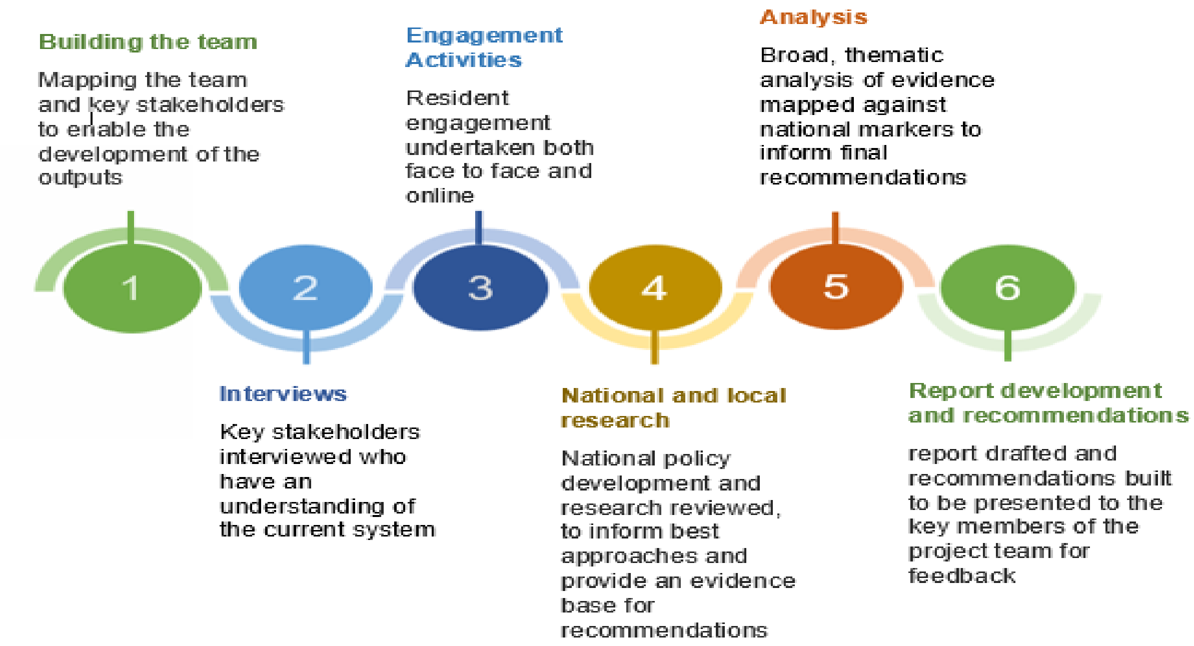
This paper sets out evidence against the key areas outlined in the national strategy alongside information gathered from residents and stakeholders. The strategy needs to be shaped by the clear and consistent messages we heard from Oxfordshire residents which were:

- for both young people and older adults to be heard,
- for autistic people to feel that they are being heard and for them to experience a system that communicates better with each other and better with them.

This strategy should forge a clear pathway between children’s and adults’ services and across health, social care, education and housing.

We would suggest that the final strategy also references and links to other strategies in Oxfordshire County Council including (but not limited to) the Oxfordshire Way Strategic Vision, the All Age Care’s Strategy, SEND strategy, Learning Disability Strategy and Oxford Health’s Autism Strategy.

Methodology



Building the team

Mapping the team and key stakeholders to enable the development of the outputs

Interviews

Key stakeholders interviewed who have an understanding of the current system

Engagement Activities

Resident engagement undertaken both face to face and online

National and local research

National policy development and research reviewed, to inform best approaches and provide an evidence base for recommendations

Analysis

Broad, thematic analysis of evidence mapped against national markers to inform final recommendations

Report development and recommendations

report drafted and recommendations built to be presented to the key members of the project team for feedback

How to use this report

This paper sets out evidence against the key areas outlined in the national strategy alongside information gathered from residents and stakeholders.

For each area we have tried to set out the following (where available):

- Data and evidence from the national context
- Data and evidence from the local context
- Views from autistic residents of Oxfordshire and their families, and stakeholders.

We have also based on the information and knowledge in some areas made:

- Recommendations for the development of the relevant section of the strategy
- Identified additional areas to consider that are not covered by national strategy headings.

*data used throughout this report was the most up to date available at time this report was written and research undertaken, some areas of research and data may be a few years old but still relevant.

*We also acknowledge that some language in this report is not necessarily what the autistic community would use, for example, recent national discussion has centred on the person first language and no longer referring to the ‘spectrum’ but referring to autistic people, generally. Some research refers to ‘Autism Spectrum Disorder’. We would always recommend checking language, with the communities you engage with, before using.

Creating an autism strategy

In SCIE's work and research nationally, and work with residents in Oxfordshire, a number of themes were consistently mentioned when discussing the creation of a strategy, and these are set out in the word cloud. A key test for the council and its partners would be to evaluate evidence against these, in both in the development of the strategy and how they are implemented, as part of the strategy.

Communication and engagement

A consistent theme in our engagement with young people, parents and adults was the need to communicate clearly and consistently. Any document created with and for communities, should be accessible and useable for communities. We would therefore recommend the adoption of:

Gloriously Ordinary Language - "We think too much of the language people use in and about social care reveals and shapes attitudes and ways of working that prevent people from living gloriously ordinary lives. We believe that the language of social care should be ordinary. Everyday words about everyday life. And we think our language should be glorious. Wonderful words about flourishing lives." **Gloriously Ordinary Language — Gloriously Ordinary Lives**

Oxfordshire County Council have already started this programme and so would recommend using the learning from this programme to shape the strategy.

SCIE recommends using language that is identified by your local autistic community and working with them to design topic headings and language, to use. It should be noted that while there are general headings that are indicated in the national strategy, there is no statutory requirement to use these headings, so you are able to coproduce a strategy in a language that works for the autistic community in Oxfordshire.

In the interest of good communication, accessibility and transparency, we have (throughout the project) recommended a dedicated web page be created to connect the strategy to, and to link other strategies to. During our research for this report, one area's strategy web page was cited as a good example:

LSC Integrated Care Board: Learning disabilities and autism

This would facilitate clear and timely communication and enable all those with an interest to know what is happening and how they can engage with the development of the strategy.

Co-production

Throughout this project, residents and stakeholders raised concerns about the involvement of autistic people in the development of the final strategy. It was acknowledged that the initial stages would involve a level of engagement only due to timescales but assurances give about further opportunities to get involved, in the development of the strategy and the action plan that arises from the strategy.

Evaluation

Within the principles of co-production, communication and transparency, we would recommend the development of an evaluation framework, with autistic people and their families.

A consideration for a framework to utilise for this evaluation would be Think Local Act Personal's (TLAP)'s **'Making it real' Statements** (**Making-It-Real.pdf**). These are a set of co-produced statements that describe what good care and support looks like. They are aligned to the Care Act, and built into the CQC Single Assessment Framework. The statements are written from two different perspectives:

The 'I statements' describe what good looks like from the perspective of someone who draws upon care and support.

The 'We statements' describe what people who work in care and support should do to make the 'I statements' real.

All of the statements were co-produced by people who draw upon care and support and people who work in it, so they are rooted in real life experience

They can be used to help evaluate the implementation of various aspects of the strategy.

We would also recommend an ongoing feedback loop for the strategy, for residents, when it is live.

What is autism?

National context: wording from national research

“Autism is a lifelong developmental disability that affects how people perceive, communicate and interact with others, although it is important to recognise that there are differing opinions on this and not all autistic people see themselves as disabled. With an estimated 700,000 autistic adults and children in the UK – approximately 1% of the population – most people probably know someone who is autistic. In addition, there are an estimated 3 million family members and carers of autistic people in the UK (**National Autistic Society**).

Autistic people see, hear and feel the world differently to other people. Autism varies widely and is often referred to as a spectrum condition, because of the range of ways it can impact on people and the different level of support they may need across their lives. While autism is not a learning disability, **around 4 in 10 autistic people have a learning disability (Autistica)**.

Some autistic people will need very little or no support in their everyday lives while others may need high levels of care, such as 24-hour support in residential care. People may need help with a range of things, from forming friendships, coping at school, managing at work, or being able to get out and about in the community. In this strategy, we also talk about neurodiversity, which refers to the different ways the brain can work and interpret information. It is estimated that around 1 in 10 people across the UK are neurodivergent, meaning that the brain functions, learns and processes information differently (**Embracing Complexity Coalition, 2019**).”

Views of residents

Autistic people, carers and their families, in Oxfordshire also said the following, when asked about their strengths:

Autism in Oxfordshire

Local context

According to local GP registers, the current Oxfordshire population is 827,848

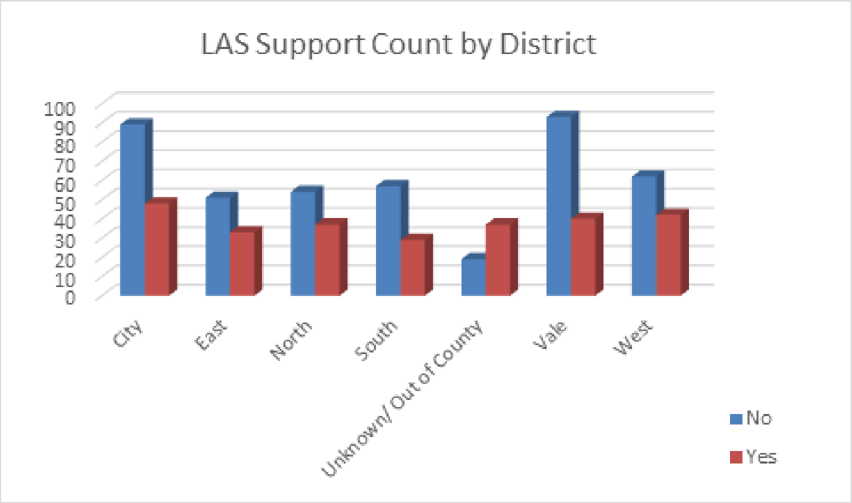
ONS Census Data 2021 shows the population of people with a disability was 165,482 in Oxfordshire, approximately 1 in 5 residents.

Adults (aged 16+) National Autism Prevalence 2020 Autism prevalence, UK, 2020 - Office for National Statistics (ons.gov.uk):

NHS Digital has indicated that up to 5% of the overall population will be impacted by Autism, as a diagnosed individual, carer or family member. Based on the ONS mid-year population data estimates, this would equate to 41,392people in Oxfordshire.

A revised estimate is that 1.7% of population autistic which is likely to be an underestimate, 2.9% prevalence rate in CYP (improving recognition and identification), 90% of autistic adults aged 50 or over undiagnosed - Petersen I, Buckman JEJ, Charlton R, Cooper C, Corbett A, et al. Autism in England: assessing underdiagnosis in a population-based cohort study of prospectively collected primary care data. Lancet Reg Health Eur [Internet]. 2023;29(100626):100626. Available from: **https://linkinghub.elsevier.com/retrieve/pii/S2666776223000455**

Data provided by the Council's performance team in December 2023 showed that the number of people with an autism diagnosis with a record on Liquid Logic Adults LAS is 691, of which 266 receive support provided by Oxfordshire County Council.



Autistic children and young people in Oxfordshire

The Joint Strategic Needs Assessment (JSNA) for 2023 showed there were 2,600 pupils in Oxfordshire registered with their primary/main type of need as "Autism Spectrum Disorder" This is 2.6% of all pupils. Of these, 995 were in state-funded primary schools, 1,151 were in state-funded secondary schools and 454 were in special schools. This is a 9% increase in the number of registrations in previous years, with 2,600 in 2022/23 compared with 2,385 in 2021/22.

*Autism Spectrum Disorder is a clinical term used in the medical manuals such as the DSM-5. While acknowledged this will be used in data collection and recording in the health system, the language recommended currently in communications, is to use person first - autistic people.

Ethnicity in Oxfordshire

According to the Office for National Statistics (ONS) Census 2021 survey, 13% of the total resident population of Oxfordshire was from an ethnic minority background, compared with 18% across England. According to the January 2021 Schools Census, 29% of pupils in state primary schools (in years 1 to 6) and 27% of pupils (years 7-11) in state secondary schools in Oxfordshire were from ethnic minority backgrounds.

Across Oxfordshire's districts, Oxford has the highest proportion of ethnic minority pupils and pupils whose first language isn't English. All districts aside from West

Oxfordshire have a higher proportion of ethnic minority pupils and pupils whose first language isn't English in Primary year groups (years 1-6) than in Secondary year groups (years 7-11).

National research on impact of Autism in communities would suggest, from a statistical viewpoint, that these groups are also likely be impacted. Conversations have also mentioned traveler community engagement needs.

Recommendations

It would be recommended to review co-production opportunities with wider ethnic communities.

Recommendation from Simon Tarrant to engage with Clitherow Trust **Margaret Clitherow Trust**.

It would also be recommended to work closely with public health and housing in the development of this strategy to review how to address the additional inequalities that are often faced by other ethnic groups in communities.

Diagnosing autism

There is both a national and local issue in relation to the time it can take to be assessed for autism across all age groups.

National context

The National Institute for Health and Care Excellence (NICE) has said people referred for an autism assessment should be seen within three months. The median waiting time ranged between 218 and 306 days (roughly seven to 10 months) in the months from April to December 2023.

The National Institute of Health and Care Excellence has set a target time of 13 weeks for those with suspected autism to be assessed.

Local context

BBC Local press (20/12/24) wrote "The Oxfordshire Adult Autism Diagnostic and Support Service (OAADSS) stopped taking on new patients at the end of November due to the size of its current waiting list.

In documents seen by the BBC, the OAADSS has told patients that those referred after July of this year will not be assessed until 2041 at the earliest.

Buckinghamshire, Oxfordshire, Berkshire West Integrated Care Board (BOB ICB), who oversee adult autism diagnoses in the county, said it was working to 'find a solution' to the delays."

Referral data for adults (Kingswood/Oxfordshire Adult Autism Diagnostic Support Service): Number of referrals in the last 12 months - 1026

Data from March 2024 covering the previous 3 months, states:

Number of people currently on the waiting list for a diagnosis	1308
Awaiting assessment	169
Awaiting screening	147
Awaiting return of screening forms	
Current wait time for seeking a diagnosis - pre-screening	10 years 6 months
Current wait time for seeking a diagnosis - post screening	8 years, 9 months
Number of people assessed in the last 12 months	176
% of the people referred to the service, that were formally diagnosed in the last 12 months	87%
% of the people referred to the service, that were signposted due to not meeting screening criteria in the last 12 months	25%

% of people in the last 12 months that have ‘dropped out’ of having a diagnosis, either in favour of Right To Choose or private assessment?	Less than 1.2%[1]
% of people that didn’t return the screening forms /disengaged / moved out of area/diagnosis sought elsewhere	17%

Children’s service data

“The request for Neuro Developmental Assessments continues to be high, the service is commissioned to provide 50 assessments per month and currently receiving 150 referrals per month. However we have implemented a living well programme for all families so they can learn about the conditions and adapt the way they respond to their child if they believe they have a neurodiversity. Initially this wasn’t taken up a lot by families, but we have since been offering webinars jointly with the Parent Carer Forum (PCF) which have been more popular.” **Oxfordshire Child and Adolescent Mental Health Service HOSC report.pdf**

Resident and stakeholder feedback

“I mean so many times I've been diagnosed with depression, anxiety post Natal depression, blah, blah, blah. All of these things with the root cause in the anxiety caused by social situations, which is the root causes of autism”

“I'm worried about with this project, it says it's about autism, but I think it should be about neuro neurodiverse children, because a lot of young people don't get that full diagnosis they present with autism, but they're eight. They've got ADHD. My young person has got autism, ADHD, and processing disorder”.

“often a problem really to get the diagnosis in the 1st place, which and there are huge waiting lists which we will be aware of both for children and for adults. I was quite lucky. I think I waited for my assessment for 10 months, but someone told me that it's now like closer to five years or something like that. It's like crazy.”

This is a key area of concern for residents especially for parents as significant delays have a cumulative impact on their child and their subsequent challenges in being able to secure a EHCP plan. Some who had experienced input from professionals (teachers / SENCOs) especially in primary schools stated that had they been better trained and supported in terms of autism, then the experiences for their child and themselves may have been less antagonist.

Some also asked about the disparity with other local authorities such as West Berkshire who were identified as having a much better approach and resources.

Gaps

Notwithstanding the issue of lack of diagnostic provision in Oxfordshire, the local statistics available at the time of this report relate to the adult diagnostic waiting list

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[1] This figure may be higher; however, patients do not always inform the provider when they choose an alternate provision or move out of county

and therefore could be a much bigger picture when reviewing waiting times (if they exist) for autism diagnosis in children.

People we spoke to while had some stories around issues waiting for diagnosis, or mis diagnosis until later life, discussed the need to speak to someone when querying a diagnosis, to seek advice, guidance and usually support.

The majority of people we spoke to alluded to not necessarily seeing the diagnosis as providing any further help with their issues, but was part of their identify and understanding themselves, but they felt that if services were able to identify how to support them without diagnosis, this would have provided benefits to their overall wellbeing and experience.

Recommendations

Specifically address the issue of diagnostic waiting times in the strategy, with key achievable actions these could include, but not limited to:

- Providing training to education staff on how to provide support/adjustments before and after a person receives a diagnosis.
- Create a system that will support without diagnosis, and are needs lead rather than diagnosis lead.
- Providing training and information to GP services about available support and signposting when a person seeks further support.
- Providing training and information to children’s and adults mental health teams on supporting a person in the absence of diagnosis.
- Setting up or signposting to peer support groups for families and individual to meet with others awaiting or confirmed diagnosis.
- Provide a directory of services available to support people without diagnosis
- Provide support to people who are waiting for a diagnosis, such as information and advice, peer support and existing community groups.
- **Westminster commission on autism also proposed acceptance of self-identification.** **support-surrounding-diagnosis.pdf**

Improving understanding and acceptance of autism within society

National context

Public campaigns play a key role in raising awareness and reducing the stigma surrounding autism. While professional knowledge of autism has improved, public understanding remains limited. Despite 99.5% of people being aware of autism, misconceptions are widespread: over one-third of UK residents still mistakenly believe autism is a learning disability, and 30% are unsure whether it can be cured **(Autism Alliance, 2024)**. These gaps in understanding perpetuate negative stereotypes, highlighting the need for targeted education to foster a more accurate and empathetic perspective on autism.

There are a number of potential actions that could be considered. The actions below have been listed from work underway at national, regional or local level.

National level:

- At a national level this has led to a range of actions focusing on staff training across a range of sectors some of which are listed below Encouraging more autism-friendly programmes in the cultural and heritage sectors
- Providing funding (£600,000) for autism training and professional development in schools and colleges
- Carrying out a new anti-bullying programme in schools, to improve the wellbeing of children and young people in schools, including those who are autistic
- Engaging with potential providers of training as part of our commitment to recruit and train Designated Mental Health leads in schools
- Continuing to trial and develop the Oliver McGowan Mandatory training on learning disability and autism for all health and adult social care staff
- Reviewing the call for evidence on neurodiversity, and developing a toolkit to educate frontline staff about neurodiversity, and the additional support they might need
- Providing training for healthcare, social care, and education professionals can lead to earlier identification of autism and better immediate responses to the needs of autistic individuals (N8 Research Partnership, 2024; Autism Alliance, 2024).
- Autism training for transport staff, businesses, and community services to make public spaces more accessible. See initiatives including:
    - Nexus (2023): Trained over 100 staff (Metro, ferry, and bus stations) in autism awareness. The programme included communication techniques, recognising hidden disabilities, and creating sensory guides to make services autism-friendly.

  - NAS Pilot with DfT (2022a): Collaborated with the Department for Transport to develop a programme reducing barriers for autistic passengers, aiming to decrease social isolation.

Regional actions

Some regional information (particularly in West Berkshire) provided as part of this project included:

- Training and development – support co-ordinated training offers to reduce the burden on systems to develop individual packages locally. This will include training on autism awareness and reasonable adjustments for staff both in inpatient units and in the community.
- Provision of central communication and campaign resource to pro-actively promote and deliver autism campaigns, share good practice, and support engagement with the autistic community.
- Support staff to participate in autism related training and development. This will include Oliver McGowan mandatory training and any other core or advanced training once available. Ensure locally procured training is co-produced and co-delivered by autistic people.
- Improve the level of information available to autistic people and their families through better guidance and signposting, and greater support for self-help, self-management, and parent/carer groups locally.
- Develop an autism service directory/ booklet that gives information about autism and lists local services for autistic people
- Set up an autism web page
- Work with the local autism diagnostic service to ensure everyone who receives a diagnosis has more information about existing groups/services post diagnosis
- Raise awareness of the Autism Alert Card
- Identify a single identifiable contact point where autistic adults (whether or not in receipt of a statutory service) can get information, signposting and autism-friendly entry points for a wide range of local services
- Raising awareness of initiatives undertaken elsewhere and encouraging them locally: Find good practice about slower lanes / quieter hours, changing lighting, turning down volume of music etc. and present to Newbury Bid at a themed Autism Partnership Board
- Encourage organisations to make autism friendly adjustments to the physical environment and practice, provide autism friendly specific sessions/days where possible
- Develop a range of information stands/roll up banners and coordinate where they will be displayed

- Support autism training that enables delegates to understand autistic behaviours and how to deal effectively with them
- Hold an annual event to celebrate national autism day (2nd April each year)
- Ensure local residents, professionals, and employers have access to autism awareness training to learn more about autism.
- Work in partnership with the West Berkshire libraries service to develop and promote a list of books about autism.

Improving autistic children and young people’s access to education, and supporting positive transitions into adulthood

National context

For the purposes of an all age autism strategy in Oxfordshire, depending on the particular circumstances of the individual, different legislation may be in operation. Therefore, it is SCIE's recommendation that the All Age Autism Strategy will need to recognise overarching legislation including but not limited to: The National Health Service Act, 1946, Health and Social Care Act, 2012. The Mental Health Act, 1983, The Mental Capacity Act, 2005, The Care Act, 2014, The Human Rights Act, 1998, The Children Act, 1989 and 2004, The Education Act, 1988, The Data Protection Act, 2018, and General Data Protection Regulation (GDPR). However, for individuals where different legislation, regulations and statutory guidance are relevant these will need to be taken into account as well.

There is a legal duty on local authorities under section 19 of the Education Act 1996 to make arrangements for the provision of suitable education (in school or out) for children of compulsory school age who, for whatever reason, may not receive suitable education unless such arrangements are made for them.

Supporting autistic children and young people in education requires targeted interventions to address the challenges they face. Key priorities include:

- Improving the Special Educational Needs and Disabilities (SEND) system to better meet the needs of autistic students
- Implementing anti-bullying campaigns
- providing teacher training to foster inclusive learning environments
- Additionally, supporting transitions to adulthood—such as access to higher education and employment opportunities.

Evidence highlights significant gaps in support. Delays in diagnosis and inadequate school interventions negatively affect the emotional and physical health of autistic children and their caregivers. Training is needed to clarify thresholds for education, health, and care needs assessments while promoting evidence-based approaches (Martin-Denham, 2022). Funding constraints further compound these issues: only 2% of school leaders in England report having sufficient funding for Educational, Health, and Care Plans (EHCPs), and 94% face challenges in supporting disabled students (King et al., 2018).

Bullying is another critical concern. In the UK, research from NAS (2022b) indicates that 34% of autistic children report experiencing bullying at school. International evidence suggests even broader challenges: pooled prevalence rates show 47% of autistic individuals experience bullying, 16% face child abuse, 40% endure sexual victimisation, 13% experience cyberbullying, and 84% report multiple forms of victimisation (Trundle et al., 2023).

Promoting acceptance within school pupils: **Learning About Neurodiversity at School (LEANS) | Salvesen Mindroom Research Centre** this point also links to promoting acceptance.

Despite only 32% of pupils with EHCPs having autism, almost half (45%) of appeals were related to autistic children and young people – suggesting that autistic children may find accessing support particularly challenging. **New statistics on Education, Health and Care Plans (EHCP) for children with special educational needs | Children's Commissioner for England**

Special Educational Needs and Disabilities (SEND) has been a recent, (and continuous) topic area for discussion and national focus:

Ofsted says special educational needs 'biggest issue' for schools - BBC News

from 2018-2023, there has been an 81% increase in EHCPs

• There are many professionals and agencies involved and often they are not joined up around cohorts of need –

these are defined in the Code of Practice as:

(1) Communication & interaction;

(2) Cognition & learning;

(3) Social, emotional & mental health, and;

(4) Sensory &/or physical needs.

There are often conflicting demands on different parts of the system resulting in different prioritisation of delivering services for children with SEND. Examples include:

- Current behaviors/practice direct demand to specialist support – impacting spend allocations.
- Lack of focus on effective early intervention
- Ineffective and weak joint commissioning
- Parents and professionals not having confidence in the local offer
- Not having a consistent and strategic ownership and oversight of area system
- Workforce vacancies.

In December 2024, the Department for Education (DfE) announced £740m of funding to increase the number of places available for Send pupils in mainstream schools.

Human rights approach to preparing for adulthood

NHS guidance states the need to “think about how to best involve the young person so that they are involved in these significant decisions about their lives” (NHSE guidance for meeting the needs of autistic adults in mental health services).

This is supported by a variety of legislation (The Human Rights Act Mental Health Act 1983, The Mental Capacity Act 2005 and the Care Act 2014).

“Each autistic person should be at the centre of their own transition and be supported to participate from the outset”.

Human rights for young autistic people and young people with a learning disability aged 14 – 25 (guide) | Local Government Association

Notwithstanding requirements under various legislation, there are recommended requirements also, under the United Nations Convention on the Right of The Child, as well as the Convention of the Rights of Persons with Disabilities (both signed up for by the UK).

The relevant conventions state:

The following rights are of equal importance to every child. Every child has the right to:

- Relax and play (Article 31)
- Freedom of expression (Article 13)
- Be safe from violence (Article 19)
- An education (Article 28)
- Protection of identity (Article 8)
- Sufficient standard of living (Article 27)
- Know their rights (Article 42)
- Health and health services (Article 24).

UN Convention on Rights of a Child (UNCRC) - UNICEF UK

And

“The purpose of the present Convention is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity.

Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.”

Convention on the Rights of Persons with Disabilities | OHCHR

Autism and parent blame

The report ‘Autism and Parental Blame: Blamed Instead of Helped’, is intended for professionals, policymakers, researchers, and anyone who is interested in improving the lives of autistic children, young people, and their families.

It presents key findings from all three phases of the project and sets out eight areas that we believe are worthy of further consideration. These are:

- Autism is widely misunderstood by professionals
- Accusations of blame result in trauma, long term damage and increased risk of suicide
- Autistic parents may be at higher risk of parental blame as they face additional discrimination when seeking help for their child
- Parents of autistic children have a high level of mistrust in services and professionals.
- Parents of autistic children may be at higher risk of child protection proceedings as parents were frequently accused of neglect or harm
- Parental knowledge is not recognised or valued,
- Parental blame is more likely before a child is diagnosed as autistic
- Current support offered to parents is often unhelpful and sometimes reported as doing more harm than good.

Autism and parental blame research | WMADASS

***To be linked to** SEND strategy, policies and improvement | Oxfordshire County Council)*

Autism and ethnicity in education

National context

A study undertaken in 2020 found:

- Chinese and Black pupils were 38% and 26% more likely to be recorded with an Autism Spectrum Disorder (ASD) in the English educational system than White pupils.
- Pupils from a Roma/Irish Traveler background were almost 60% less likely to be recorded with ASD compared with White pupils.
- Pupils whose first language was not English were less likely to have an ASD diagnosis in the English education system.

They also noted that racial/ethnic differences in ASD were mediated through socioeconomic disadvantage. The greatest effect was found among Black pupils (with 12.41% of the increased prevalence of ASD among Black pupils being explained by social disadvantage).

Association of Race/Ethnicity and Social Disadvantage With Autism Prevalence in 7 Million School Children in England | Population Health | JAMA Pediatrics | JAMA Network

Autism and socio-economic disadvantage in education

When comparing socioeconomic disadvantages in the school population, we found that pupils with ASD (35.23%), pupils with ASD and a learning difficulty (37.93%), and pupils with other types of SEND (44.61%) all had higher proportions of socioeconomic disadvantage than pupils with no SEND (24.47%).

Our findings show that pupils facing social disadvantage were more likely to have ASD (aPR, 1.61 [95% CI, 1.59-1.63]).

Comments from Simon Tarrant: “There will be an additional impact on parents capacity for holding down a job plus SEND caring responsibilities, exacerbated if child not in school or frequently excluded - something to be considered in action planning.”

Association of Race/Ethnicity and Social Disadvantage With Autism Prevalence in 7 Million School Children in England | Population Health | JAMA Pediatrics | JAMA Network

The conversations with residents identified this as a theme. Residents that we were able to speak to, commented that they were confident in navigating and negotiating education systems. They also noted in most cases they had the resources, knowledge and confidence to do so, but they were worried for those families who did not have resources or confidence to advocate and not take “No” for an answer.

Resident and stakeholder feedback

- Poor communication in SEND services
- Trauma in education
- Mainstream education not suitable.

“Mainstream schools rough for neurodiverse people”

“Cliff edge at 18, mental health services said couldn’t support because he had autism.”

“We have a neurodiverse child with complex needs. We have been trying to access support for years and have been constantly ignored by services. We should have a Child in Need Assessment in place again this has been ignored despite assessment stating we need support.”

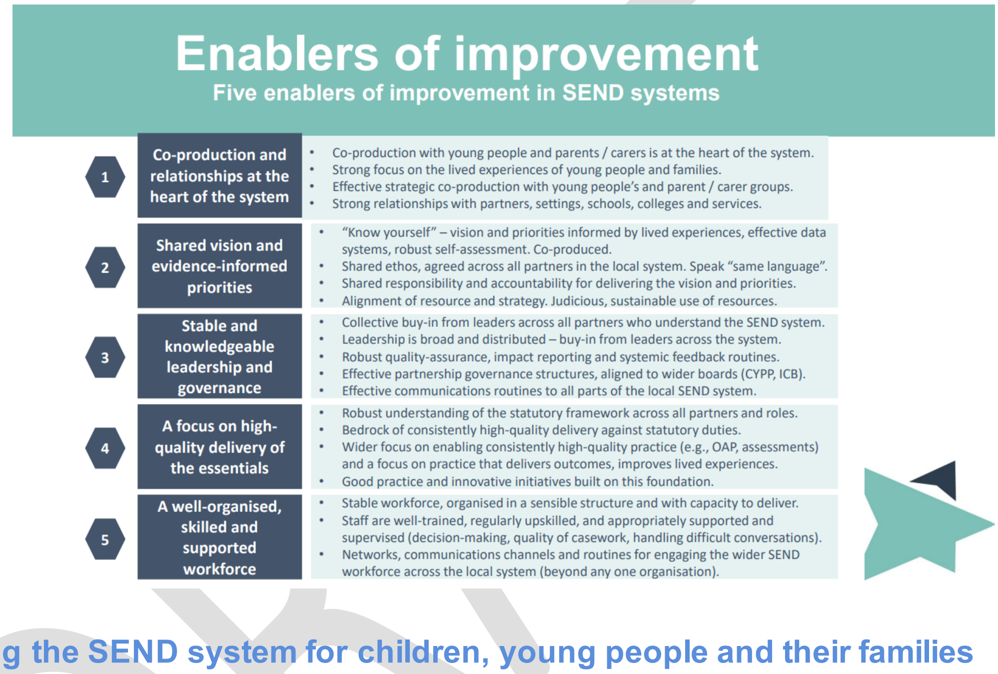
Gaps

- Support in mainstream education
- A clear and transparent pathway between children’s and adults services
- Training for all mainstream schools on support autistic young people.
- A whole family approach to support pre and post diagnosis
- Communication and transparency with families about SEND, EHCP, children’s social care pathways (which are often diagnostic rather than needs driven).

Recommendations

National research recommendations include, developing a continuum of local high-quality provision and enable all services to be inclusive and deliver excellent outcomes for children with SEND, including building on existing good practice.

- Enable children and young people with SEND to access opportunities that are important to them and for them.
- To provide timely and equitable access to high quality services before, during and beyond statutory school age including education, health and social care.
- To ensure that there is seamless and effective transition at all points for young people with SEND to access opportunities that are important to them and for them.



Enablers of improvement

Five enablers of improvement in SEND systems

1	**Co-production and relationships at the heart of the system**	• Co-production with young people and parents / carers is at the heart of the system. • Strong focus on the lived experiences of young people and families. • Effective strategic co-production with young people's and parent / carer groups. • Strong relationships with partners, settings, schools, colleges and services.
2	**Shared vision and evidence-informed priorities**	• "Know yourself" – vision and priorities informed by lived experiences, effective data systems, robust self-assessment. Co-produced. • Shared ethos, agreed across all partners in the local system. Speak "same language". • Shared responsibility and accountability for delivering the vision and priorities. • Alignment of resource and strategy. Judicious, sustainable use of resources.
3	**Stable and knowledgeable leadership and governance**	• Collective buy-in from leaders across all partners who understand the SEND system. • Leadership is broad and distributed – buy-in from leaders across the system. • Robust quality-assurance, impact reporting and systemic feedback routines. • Effective partnership governance structures, aligned to wider boards (CYPP, ICB). • Effective communications routines to all parts of the local SEND system.
4	**A focus on high-quality delivery of the essentials**	• Robust understanding of the statutory framework across all partners and roles. • Bedrock of consistently high-quality delivery against statutory duties. • Wider focus on enabling consistently high-quality practice (e.g., OAP, assessments) and a focus on practice that delivers outcomes, improves lived experiences. • Good practice and innovative initiatives built on this foundation.
5	**A well-organised, skilled and supported workforce**	• Stable workforce, organised in a sensible structure and with capacity to deliver. • Staff are well-trained, regularly upskilled, and appropriately supported and supervised (decision-making, quality of casework, handling difficult conversations). • Networks, communications channels and routines for engaging the wider SEND workforce across the local system (beyond any one organisation).

Improving the SEND system for children, young people and their families

Supporting more autistic people into employment

The Buckland Review of Autism Employment: report and recommendations, Published 28 February 2024 The review sought views from autistic people, employers, employer organisations, and specialist support groups. It explored how employers recruit, retain and develop autistic people, identifying barriers to this happening and developing effective ways to overcome those barriers, with the aim of significantly improving the autism employment rate over the next 5 years.

It states that despite their wish to work, only around 3 in 10 working age autistic people are in employment, compared with around 5 in 10 for all disabled people and 8 in 10 for non-disabled people.

Resident and stakeholder feedback

“Some simple (Needed) mentoring help, with CV writing, interviews.
You know, help with raising awareness to employers, there are fantastic people out there. The actual interview process, I don't know how many interviews I've kind of, you know, messed up because I'm too direct and don't play the game.”

Gaps

Local autism employment data

Information on how to access support for the autistic people, to apply for and maintain, employment.

Recommendations

Recommendations

1. Use of an Employment toolkit such as **Supporting neurodivergent people at work :: Workforce Transformation**.
2. Link to **Oxfordshire Employment | Oxfordshire County Council**.
3. Review Oxfordshire County Council’s recruitment process to ensure it is accessible for neurodivergent people.
4. Set up a task group for autistic/neurodivergent employees to review recruitment and retention needs.

Tackling health and care inequalities for autistic people

*Link to Oxfordshire Health Autism Strategy

National context

Tackling inequalities for adults with learning disabilities – SCIE guidance

Autistic adults are more likely than non-autistic adults to report poorer adult life outcomes (**37**), lower quality of life (**38**), symptoms of mental ill health and to be diagnosed with a mental health condition (**39** – **41**).

Many autistic people have at least one co-occurring condition, including mental and physical health conditions, other neurodevelopmental conditions, learning difficulties or a learning disability (**20**,**39**,**42**). For instance, an estimated 12-30% of autistic people have a co-occurring learning disability (**42**,**43**) and approximately a third report a diagnosed mental health condition (**44**,**45**).

Lever and Guerts estimate this higher at 78%: Lever AG, Geurts HM. Psychiatric co-occurring symptoms and disorders in young, middle-aged, and older adults with autism spectrum disorder. J Autism Dev Disord [Internet]. 2016;46(6):1916–30. Available from: **http://dx.doi.org/10.1007/s10803-016-2722-8**

Additionally, other neurodevelopmental conditions often co-occur with autism, for example, attention deficit/hyperactivity disorder (ADHD) has been found to have a lifetime prevalence of 40.2% in autistic people (**46**). NHS England » Meeting the needs of autistic adults in mental health services

The **NHS Long Term Plan** (2019) includes objectives for improving access to autism diagnosis and post-diagnostic support, as well as improving autistic people's mental and physical health.

Autistic traits, alongside many wider determinants of health, place autistic people at a higher likelihood than non-autistic people of needing mental health services during their lifetime, with approximately a third of autistic people reporting a diagnosed mental health condition. This increased need is often compounded by autistic people facing more barriers to good mental health care than non-autistic people; barriers such as inaccessible services, treatment which is less effective for autistic people than non-autistic people, and services with insufficient capacity to meet demand.

It is noted that also staff may also lack the knowledge and skills to change approaches to supporting autistic people, and people suspected to be autistic. A systematic review and thematic meta-synthesis. Clin Psychol Rev [Internet]. 2022;93(102131):102131. Available from: **https://linkinghub.elsevier.com/retrieve/pii/S0272735822000162**

Autism or learning disabilities aren't a mental health problem, but research suggests that autistic people, and people with learning disabilities are more likely to experience mental illness.

Autistic people also often face significant healthcare disparities – for example, more than 5 in 10 autistic adults have had depression, and autistic adults (without an intellectual disability) are more than 9 times more likely to consider suicide than the general population."

The latest National LeDeR report which reported on Autistic people for the first time, detailed suicide, misadventure* or accidental death** as the highest cause of death for this cohort of people, accounted for in 11 cases. Master LeDeR 2023 (2022 report) (kcl.ac.uk)

Autistica's **Happier, Healthier, Longer Lives** briefings have identified that autistic people have poorer physical health outcomes and a lower life expectancy than the general population. The available evidence indicates that autistic people die on average 16 years earlier than the general population (Premature Mortality in Autism Spectrum Disorder, The British Journal of Psychiatry, 2016) (Latest research indicates this gap is 6-7 years, this is because previous research has combined autism with LD: **Premature death of autistic people in the UK investigated for the first time | UCL News - UCL – University College London**).There are many possible reasons for this gap, including poor professional understanding of autism among health and care staff, which can result in autistic people having signs of illness or their needs overlooked. Without the right understanding, autistic people can miss out on adjustments needed for them to engage in medical appointments, which often leads to distressing experiences, avoiding seeking medical attention or losing out on support.

Mental Health 360 | Access | The King's Fund - also references poor access and poor outcomes.

We note that as well as healthcare, there continues to be poor access to social care for autistic people:

- SDS report 2022 Report highlights barriers to social care support for Autistic people - Self Directed Support Scotland
- Autism: Improving access to social care support (Sheffield Autism Society) 2017 Autism: Improving access to social care for adults
- Barriers to healthcare and their relationship to well-being and social support for autistic adults during COVID-19, Featherstone et al 2022 (Barriers to healthcare and their relationship to well-being and social support for autistic adults during COVID-19 – PMC)
- Healthwatch 2018Six ways we can improve services for people with autism | Healthwatch.

Autism and drugs and alcohol

Research shows that 45% of autistic adults would not seek help if they were experiencing problematic drinking. Reasons for this include concerns about challenging, unfamiliar environments and being judged and misunderstood by a therapist. Drug and alcohol service providers have reported that they have received no specific training or support focusing on autism and they thought that treatment outcomes of autistic clients were likely to be worse than non-autistic clients.

There is a potential gap in local data on autistic people drawing on support for drug and alcohol addiction.

Autism, human growth and development

"Menopause was a nightmare"

"Some autistic people report that menopause played a role in discovering that they are autistic, as their autistic traits became more apparent during menopause or perimenopause.

Menopause can affect autistic people in a number of ways and their autistic characteristics may become more apparent including:

- Intensified sensory sensitivities
- Difficulty with emotional regulation
- Difficulty with executive function, for example planning, and focusing
- Increased difficulty with social interaction and communication
- Some autistic people with ADHD found their ADHD traits became more prominent. " **NAS_MenopauseGuide.pdf**

Another area to consider for autistic people is the experience of puberty. While research is available on Menopause, there is limited research on puberty and autism. Due to the physiological changes experienced, it would be beneficial to explore the impact of the physical and emotional changes on autistic people, to provide the most appropriate support at certain stages of their life.

Local context

Oxfordshire CAMHS data:

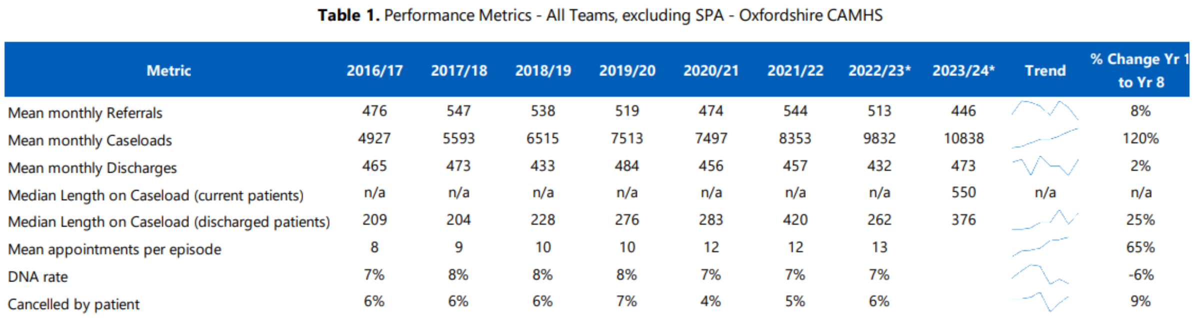


Table 1. Performance Metrics - All Teams, excluding SPA - Oxfordshire CAMHS

Metric	2016/17	2017/18	2018/19	2019/20	2020/21	2021/22	2022/23*	2023/24*	Trend	% Change Yr 1 to Yr 8
Mean monthly Referrals	476	547	538	519	474	544	513	446		8%
Mean monthly Caseloads	4927	5593	6515	7513	7497	8353	9832	10838		120%
Mean monthly Discharges	465	473	433	484	456	457	432	473		2%
Median Length on Caseload (current patients)	n/a	n/a	n/a	n/a	n/a	n/a	n/a	550	n/a	n/a
Median Length on Caseload (discharged patients)	209	204	228	276	283	420	262	376		25%
Mean appointments per episode	8	9	10	10	12	12	13			65%
DNA rate	7%	8%	8%	8%	7%	7%	7%			-6%
Cancelled by patient	6%	6%	6%	7%	4%	5%	6%			9%

Resident and stakeholder feedback

"Online GP form took me 1.5 hours to complete because it asked me if there was anything else I would like to add, and then the GP didn't even refer to it"

"Needed help with a mental health collapse for my teenage autistic child. A year and a half wait for first appointment. Initial online appointment by someone who tried to tell me .. wasn't depressed, and this was normal for autistic people and to do some activity days. Ill-informed and failing. Offered completely inappropriate CBT type thing or social prescriber neither of which my child could access (because depressed) also because not autism friendly. The social prescriber however has been supportive and managed to get us (with a fight) an appointment with a psychiatrist 6 months after my initial complaint and in the meantime my child's mental health has got worse. Mine has been affected as well."

"My child has ADHD and CAMHS refused to see them, they said he did not meet their threshold for an assessment."

Gaps

A new commissioning strategy that looks at the needs of the Oxfordshire Autistic population.

Link to and collaboration with Oxford health and public health to develop and evaluate actions to address health inequalities for autistic people in Oxfordshire.

Recommendations

National recommendations:

improve health and social care staff understanding of autism

Social prescribing has shown positive effects on mental health, subjective well-being, self-esteem, and social isolation in general population groups (Boyce et al., 2018; Foster et al., 2020; Kimberlee, 2016).

Build the strategy with commissioning teams, to embed recommendations around housing, care, education and co-production into commissioning strategies and approaches to commissioning support for Autistic people in Oxfordshire, using guidance such as the following:

- **https://www.skillsforcare.org.uk/resources/documents/Developing-your-workforce/Care-topics/Autism/Commissioning-autism-services**
- **NHS England » National framework and operational guidance for autism assessment services**

School-based identification programme - based on a pilot in Bradford This involves health and education staff working together in schools to assess children suspected to be autistic. Early findings from the pilot are positive, with children being identified and getting support earlier. **The national strategy for autistic children, young people and adults: 2021 to 2026 - GOV.UK**

Building the right support in the community and supporting people in inpatient care

This section sets out some areas where there is limited local data, but these are areas which need consideration.

National context

"The numbers of people diagnosed as autistic in mental health inpatient settings is increasing; data collected by NHS England tells us that there was an increase of 7.3% in the numbers of autistic inpatients (both with and without a learning disability) in mental health hospitals between March 2017 and August 2023 and an increase of 51.3% in the numbers of autistic inpatients without a learning disability in the same timeframe. More work is needed to ensure all mental health services are accessible to autistic adults and have capacity to meet their mental health needs, which can range from mild to severe."

Mental ill health is a significant aspect of increased mortality for autistic adults. Autistic adults are up to nine times more likely than non-autistic adults to experience suicidal ideation (**47**,**48**). Overall, autistic adults are up to seven times more likely to die by suicide than non-autistic adults (**21**,**49**). The relative risk may be greater for autistic people with co-occurring ADHD (**50**) and for autistic women, who have been found to be 13 times more likely than non-autistic women to die by suicide (**21**). Prevalence of non-suicidal self-injury in autistic people is also high, with a recent meta-analysis suggesting this may be around 42% (**51**).

Autism in a mental health inpatient setting: Alexis' story: **Rarely an hour goes by that I don't think about what happened in hospital.**

"People in hospital report widespread frustration, feel that hospital environments are not conducive to getting/staying well, and face multiple barriers to leaving hospital. Without someone to fight for them, people struggle to overcome the inertia built into our current systems and processes."

"Hospital staff from different professional backgrounds do not have a shared sense of how many people really need to be in hospital or how many people could be cared for in different settings – suggesting that different definitions, world views and professional judgements might be at play."

Why are we stuck in hospital? - University of Birmingham

The research proposed actions that local authorities should take including:

- Agree as a local system that delayed discharges are a potential harm event,
- Use the existing tools and frameworks (including the 12-point discharge plan, the clinically ready for discharge definition, the joint guiding principles, and Care (Education) and Treatment Reviews (C(E)TR) and the C(E)TR toolkit discharge standards)

- Identify and engage at the earliest opportunity with all relevant partners, including (where appropriate) the Care Quality Commission, and the Ministry of Justice where there are restrictions relating to a person's care and discharge.

Throughout a person's inpatient stay:

- ensure that the clinical care and treatment plans are based on a holistic assessment of need, and have a plan for discharge from the point of admission
- have a continued focus on the person's mental, physical and emotional wellbeing
- ensure that discharge planning properly considers any support needed through the transition from hospital to life in their local community.

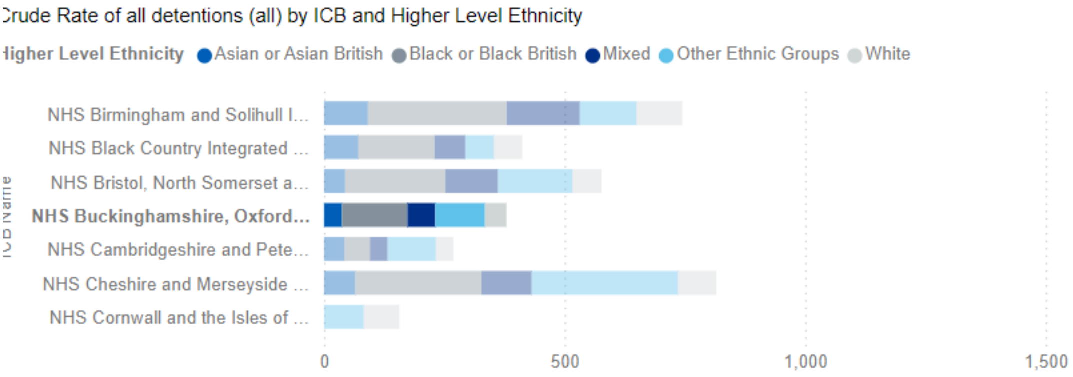
NHS England » Five key elements for discharge – supporting people with a learning disability and autistic people to leave hospital

- The Dynamic Support Register (ensuring autistic people at risk of inpatient admission are identified and receiving the correct multi-agency support and interventions **NHS England » Dynamic support registers and Care (Education) and Treatment Review code of practice**
- Ensuring CeTR is in place and providing the correct support functions, once admitted into hospital ensuing the Commissioner Oversight Visits are of good quality and happening: **NHS England » Monitoring the quality of care and safety for people with a learning disability and/or people who are autistic in inpatient care**

Racial disparities in Mental Health

Local data and information:

At the end of November 2024, similar to most ICB areas, the majority of people detained under The Mental Health Act are recorded as Black or Black British, in the Buckinghamshire, Oxfordshire ICB footprint (likely to need to include Berkshire also).



In November 2024, there were 30 inpatients recorded with an autism diagnosis and a further 15 autistic people also with a learning disability diagnosis, in the NHS Buckinghamshire, Oxfordshire and Berkshire West ICB area (NHS England's Learning disability services monthly statistics from the Assuring Transformation (AT) dataset reports).

Autism and housing options

National context

The autistic experience of homelessness: Implications from a narrative enquiry - Beth Stone, Ailsa Cameron, Sandra Dowling, 2023

"Emerging research suggests autistic people are disproportionately represented in homeless populations (**Churchard et al., 2019**; **Kargas et al., 2019**; **Pritchard, 2010**). Less is known about how autistic people experience homelessness and what prevents them from exiting homelessness

After becoming homeless, a clinical diagnosis is more difficult to obtain due to the lack of regular service access and requirement of additional information, such as developmental history (Nishio et al., 2015). In a recent screening study of 106 adult people in London, 12.3% of the sample met Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5) autism criteria, but only one had a pre-existing diagnosis (Churchard et al., 2019). In consideration of service eligibility, the lack of clinical diagnosis could constitute a significant barrier to exiting homelessness for autistic people."

Local data on homelessness

There was a 39% increase in households assessed as owed a homelessness duty (prevention or relief) in Oxfordshire in 2023. It had risen from from1906 in 2022 to 2655 in 2023.

Resident and stakeholder feedback

“Quite a big problem in Oxfordshire is housing”

Gaps

Considering and meeting the sensory needs of autistic people in housing | Local Government Association

Local homelessness data on autism.

Recommendations

Review homelessness data for disability type and break down to include autism, or neurodiversity (likely to be undiagnosed).

Consider or review current screening mechanisms to identify additional support needs associated with autism, particularly if undiagnosed.

Additional support for identified autistic people to transition to accommodation due to potential challenges of change in environment and routine and sensory needs.

Improving support within the criminal and youth justice systems

Autistic people, like anyone else, can sometimes come into contact with the criminal justice system

Average age range for early concerns for both autistic adults and parent/carers is 13-15 years

Many autistic respondents had not had their autism diagnosis until adulthood, whereas most relatives of parent/carers were diagnosed at primary school age

75% of autistic adults and 86% of parent/carers reported that they had been visited at least once by the police

In most cases both autistic adults and parent/carers received no reasonable adjustments from all sections of the criminal justice system.

When they were put in place, adjustments that were common when being interviewed by police were use of an appropriate adult and clear language when questioning. In court the most common adjustments were assessment by a psychologist or psychiatrist and being told in advance what to expect.

Higher rates of female autism in prisons: **Short report: Prison-reported rates of autism in female prisons in England - Katy-Louise Payne, Emma Gooding, 2025** higher rates of autism in prisons **Characterization of autism spectrum disorder inside prison - PMC**:

We do not have access to local data on autism presentation in the Oxfordshire Criminal and Youth Justice Systems.

Additional areas for consideration

Keeping autistic people safe from abuse

There are currently limited resources available on how to approach safeguarding of children and adults, who are autistic. Safeguarding requirements will follow statutory requirements in Safeguarding, generally – however there are questions around known inequalities for autistic people, that may increase their risk of harm and abuse, and have been subject of some serious cases such as that of Winterbourne View and Cawston Park.

LeDeR data has also only recently started to include autistic people.

We would recommend working with Oxfordshire Safeguarding Adults Board and The Oxfordshire Safeguarding Children's Partnership to review information and guidance on the specific needs of autistic people, in Safeguarding process and procedures, as part of the strategy development.

This should include, (not limited to):

1. Supporting autistic parents through child protection proceedings
2. Tailoring safeguarding awareness for children, for autistic children, where they may communicate in different ways
3. Supporting autistic adults to understand indicators of abuse and support available, and various ways to raise a concern.
4. Supporting professionals to recognise that changes in behaviour, rather than verbal disclosure could indicate potential abuse and trauma.

Autism and intimate lives

"Intimate relationships are an important, yet ordinary, part of many people's lives. However, autistic people experience greater challenges around sex and intimate relationships and more loneliness and isolation. As diagnostic rates for autism in the United Kingdom increase, international research shows that support around sexuality and gender diversity is imperative to promote autistic people's well-being. Health and social care policies should guide social care systems to address inequalities that autistic people face. However, our recent policy analysis shows that national health and social care policies in England tend to overlook support for intimate relationships" **A Critical Analysis of How Local Autism Strategies Represent Autistic Adults' Intimate Lives | Autism in Adulthood**

Supported Loving have tailored, accessible resources to inform, and promote healthy and informed relationships. **Choice Support | Supported Loving**

While there is no local information or indeed feedback in relation to this area, it was clear from conversations with residents that 'ordinary lives', relationships and self-awareness was an important part of their experience as young people and adults.

We would recommend linking with public health to ensure that any agenda relating to sexual health, and healthy relationships takes into account the needs of autistic people.

Autism and aging

Some residents that we spoke to, discussed their experience of being diagnosed in later life.

One resident said that she had gone through life diagnosed with everything else including post-natal depression and anxiety and found Menopause a ‘nightmare’, before she eventually considered being screened for autism. The resident went onto explain how it has helped in the workplace, to be able to identify when she needs additional support in her workplace to reduce ‘burnout’.

Another resident discussed her experience as an adult carer for her parents, one of whom has cancer and is end of life. She stated that she would like to see support for autistic carers and specific support to prepare for and after the death of a person in their family.

Looking to the future

1. Incorporating **Mental Health Act** reforms that relate to autistic people.
2. Link to findings of Social Care Commission review due 2028 (initial findings to be shared 2026).
3. Review implications of '**Get Britain Working**' white paper – only 30% of autistic people nationally, are in work. Including review of the impact on Promoting Independent Payments,

.

Final summary

While there are a number of areas to consider, as included in this document, there are a few areas which we feel outweigh some, due to the consistency in feedback from residents and stakeholders that we spoke to, and the detail within that feedback.

These areas are:

1. Special Education Needs and Disabilities (SEND) support, pathways, information and services
2. Moving between childrens and adults services (often referred to as ‘transitions’) and preparing for adulthood, support, pathways, information and services.
3. Mainstream education support for autistic people.

We would suggest these as the top three areas to review and determine short and long-term actions against based on current work taking place across children and SEND and would highly recommend identifying real opportunities for co-producing this part of the strategy based on feedback from residents

In addition to these, and the overview contained in this report of recommendations, we would highlight again, the importance of intersectionality and not considering the needs of autistic people in isolation of multifaceted areas of identity and need that lead to multiple inequalities faced by individuals drawing on health and social care support, and reasonable adjustments and better knowledge and skills in health and social care services including (but not limited to):

- Perinatal and postnatal services
- Children’s and adults social care workforce
- Drug and alcohol services
- Housing services.

Good communication with Oxfordshire residents has been a key message given to us, by residents and would therefore advise that co-production and involvement become an integral party to the development of this strategy and accompanying evaluation framework.

References

Youth Justice Report

Oxfordshire Joint Health Scrutiny Committee (HOSC) Annual Report 2022/23

The Oxfordshire Way in Adult Social Care

Making-It-Real.pdf

Autism and addiction | Autistica

PowerPoint Presentation 16.9

Preparation for adulthood arrangements in local areas: a thematic review - GOV.UK

BOB ICB LEDER 2023

Autism-Strategy-Final-draft-290622.pdf

Autism and the Law — Autism Alliance UK

Appendices

social care
institute for excellence

Literature review: Key messages to support the building of an All-age Autism Strategy

To support the work, a short literature view was undertaken to consider the research question , “What factors contribute to good lives for autistic people?”

This document has been organised based on the six key areas outlined in the **National Autism Strategy (2021–2026)** to enhance the lives of autistic individuals across the country.

Area 1: Raising Awareness and Understanding of Autism

Public campaigns play a key role in raising awareness and reducing the stigma surrounding autism. While professional knowledge of autism has improved, public understanding remains limited. Despite 99.5% of people being aware of autism, misconceptions are widespread: over one-third of UK residents still mistakenly believe autism is a learning disability, and 30% are unsure whether it can be cured (Autism Alliance, 2024). These gaps in understanding perpetuate negative stereotypes, highlighting the need for targeted education to foster a more accurate and empathetic perspective on autism.

Evidence:

Short-term outcomes:

- **Improved Public Knowledge**: Campaigns and education initiatives can help dispel stereotypes and increase understanding of autism to promote more inclusive attitudes in communities, schools, and workplaces (Autism Alliance, 2024).
- **Professional Training:** Providing training for healthcare, social care, and education professionals can lead to earlier identification of autism and better immediate responses to the needs of autistic individuals (N8 Research Partnership, 2024; Autism Alliance, 2024).
- **Autism training** for transport staff, businesses, and community services to make public spaces more accessible. See initiatives including:
    - *Nexus (2023)*: Trained over 100 staff (Metro, ferry, and bus stations) in autism awareness. The programme included communication techniques, recognising hidden disabilities, and creating sensory guides to make services autism-friendly.
    - *NAS Pilot with DfT (2022a)*: Collaborated with the Department for Transport to develop a programme reducing barriers for autistic passengers, aiming to decrease social isolation.

Long-term outcomes:

- **Enhanced Data Collection:** Improved mechanisms for gathering data to better understand the needs and experiences of autistic individuals (Heyl et al., 2023).
- **Creation of Autism-Friendly Spaces:** Development of environments that accommodate sensory and accessibility needs, promoting greater inclusion in public spaces (Rees and Tissot, 2023; Milton et al., 2016).
- **Expanded Professional Understanding:** Increased awareness among professionals in public services, enabling earlier recognition and identification of autism in children and adults (Crane et al., 2018; Rogers et al., 2016).

Area 2: Support for Autistic Children and Young People in Education

Supporting autistic children and young people in education requires targeted interventions to address the challenges they face. Key priorities include improving the Special Educational Needs and Disabilities (SEND) system to better meet the needs of autistic students, implementing anti-bullying campaigns, and providing teacher training to foster inclusive learning environments. Additionally, supporting transitions to adulthood—such as access to higher education and employment opportunities—remains essential for long-term success.

Evidence highlights significant gaps in support. Delays in diagnosis and inadequate school interventions negatively affect the emotional and physical health of autistic children and their caregivers. Training is needed to clarify thresholds for education, health, and care needs assessments while promoting evidence-based approaches (Martin-Denham, 2022). Funding constraints further compound these issues: only 2% of school leaders in England report having sufficient funding for Educational, Health, and Care Plans (EHCPs), and 94% face challenges in supporting disabled students (King et al., 2018).

Bullying is another critical concern. In the UK, research from NAS (2022b) indicates that 34% of autistic children report experiencing bullying at school. International evidence suggests even broader challenges: pooled prevalence rates show 47% of autistic individuals experience bullying, 16% face child abuse, 40% endure sexual victimisation, 13% experience cyberbullying, and 84% report multiple forms of victimisation (Trundle et al., 2023).

Short-term outcomes:

- Ensure Autistic Children and Young People feel supported in schools
- **Clear and easy access to support** for families and young people where the autistic young person is experiencing difficulties accessing school based learning, including through non-attendance (Rees and Tissot, 2023)

Area 3: Improving Employment Opportunities

Employment opportunities for autistic individuals remain significantly limited, with systemic barriers and societal biases contributing to high unemployment rates. In the UK, only 29% of autistic people aged 16–64 are in employment, with just 16% in full-time work (ONS, 2021; Autism.org, 2024). This contrasts starkly with the willingness and capability of many autistic individuals to work. Globally, the unemployment rate for autistic people is estimated at 80% (Ki-moon, 2015).

Challenges in accessing employment are multifaceted. Hiring processes, such as job applications and interviews, often fail to accommodate neurodiverse candidates, leading to exclusion (Davies et al., 2023). Moreover, social networks—frequently critical for job opportunities—tend to be smaller for autistic individuals, reducing their access to suitable roles (Markel and Elia, 2016; Orsmond et al., 2013). Autistic people also face barriers in securing work experience and tailoring their skills to job requirements, further reducing their employability (Baldwin et al., 2014; Vincent, 2020).

Many autistic individuals report that employers focus on their diagnosis rather than their abilities, reflecting a pervasive culture of ableism in employment systems (Martin, 2020). This issue is compounded by misconceptions, as behavioural and social challenges are more likely to lead to job loss than the inability to perform assigned tasks. These systemic issues underline the need for targeted interventions to promote inclusivity and address biases in employment practices.

Efforts to improve employment opportunities must address these barriers through initiatives such as autism-inclusive hiring practices, tailored support for job retention, and education campaigns to challenge ableism and shift societal perceptions of autism in the workplace.

Short-term outcomes:

- **Support autistic residents** who want to work to have better access to employment opportunities (Mavranezouli et al., 2014), prepare individuals for employment by developing or improving their employability skills using a customised approach (specialist employment services) (Lynas, 2014).
- **Support employers** to understand the needs of autistic people in the workplace and provide practical examples of how reasonable adjustments can be applied prior to application, at interview and after recruitment. (Romualdez et al., 2021)

Preventing instances where employers don't see their ability, but rather their autism.

- **Training** for job centre staff to better assist autistic job seekers (UK Government, 2021)
- **Tackling challenges in retirement planning** and adjustment for autistic adults and awareness of avenues for improved support during and after the retirement transition (Davies et al., 2024)

Long-term outcomes:

- Recognising and leveraging the strengths of autistic individuals enriches society and contributes to economic productivity (Autism Alliance, 2024; Mavranezouli, 2014)
- Accessible support and advice around welfare benefits system
- Working with employers to create autism-friendly workplaces (Remington and Pellicano, 2019).
- Enhanced support through the Access to Work scheme or work internship programs (Romualdez et al., 2020)

Area 4: Equal Access to Health and Social Care Services

Autistic individuals face significant barriers when accessing health and social care, contributing to stark disparities. Although autism is not a degenerative condition or illness, its characteristics—including differences in communication, social interaction, and sensory processing—can be disabling in many contexts (Barber, 2017; World Health Organisation, 2018). These factors, combined with systemic issues, result in a higher prevalence of preventable physical and mental health concerns, as well as increased mortality and shorter life expectancy compared to the general population (Hirvikoski et al., 2016; Hudson et al., 2019; Kinnear et al., 2019; Woolfenden et al., 2012).

Autistic individuals are significantly more likely to have co-occurring conditions. For instance, 70% have a mental health condition, and 40% live with two or more (UK Parliament, 2020). Anxiety, depression, and a lower quality of life are more common in this population, with suicide being a leading cause of early mortality (Autistica, 2024). Research shows that up to 66% of autistic adults have considered suicide, and 35% have attempted it. While autistic individuals make up 1% of the UK population, they account for as much as 15% of those hospitalised after a suicide attempt (Autistica, 2024).

Research highlights stigma, communication challenges, and anxiety as common experiences for autistic people in health and social care settings (Grant et al., 2024). These barriers often lead to unmet needs and significant health inequalities. Autism Health Passports (AHPs) offer a potential solution by providing standardised information about care needs, yet a recent study found that only 4% of autistic participants were familiar with them, and 73% had never encountered one. Barriers to using AHPs include fears of discrimination, staff unfamiliarity, and negative responses from professionals (Grant et al., 2024).

Despite the urgent need for tailored support, adjustments in health and social care remain inadequate. Services must adopt meaningful changes, including improved sensory environments, clinician training, and more accessible services. Bridging gaps in diagnosis, particularly for females, and creating policies that reflect the lifelong needs of autistic individuals are essential to reducing inequalities and improving outcomes.

Focus:

- Reducing diagnosis waiting times with significant funding.
- Improving adult diagnostic pathways and post-diagnostic support.
- Expanding community mental health services to prevent crises.

Short-term outcomes:

- Ensuring that need/support is evaluated on an individual basis, rather than being prescribed homogenously (Spain et al., 2021)
- Assessing the suitability of residential care for older autistic adults (Davies et al., 2024)

Long-term outcomes:

- Actively challenge mainstream services where autism diagnosis (or lack of diagnosis) is perceived as a barrier to access to prevent discriminatory practice (Wilson et al., 2023; Radev, 2023)

Area 5: Community-Based Support

Community-based support is vital in addressing the unique needs of autistic individuals by promoting social inclusion, improving well-being, and reducing health inequalities. In the UK, an autism diagnosis alone does not grant access to mental health or learning disabilities (LD) services (Barber, 2017; Department of Health, 2014). The UK Government's Autism Strategy (Department of Health, 2014) emphasises the need for community-based, low-level services for autistic adults. These services aim to reduce inpatient admissions, promote social inclusion, and support individuals who are ineligible for or not engaged with other services, ultimately improving outcomes for this group.

Social prescribing, a key component of this support model, links individuals to community-based activities such as art groups, exercise clubs, and outdoor events, through referrals from GPs or link workers (Chatterjee et al., 2018; Kimberlee, 2015). This holistic approach offers an alternative to traditional healthcare by focusing on long-term well-being and addressing the social determinants of health. It is increasingly prioritised and funded within primary care networks in the UK (NHS, 2019; Polley et al., 2017). Social prescribing has shown positive effects on mental health, subjective well-being, self-esteem, and social isolation in general population groups (Boyce et al., 2018; Foster et al., 2020; Kimberlee, 2016).

Autistic individuals, who often face significant disadvantages such as lower educational attainment, high rates of unemployment, housing disparities, and social isolation (Brugha et al., 2011; National Autistic Society, 2016; Orsmond et al., 2013), could greatly benefit from these initiatives. By addressing social factors like financial difficulties, skill development for employment, and opportunities for social participation, social prescribing can reduce stress, enhance emotional well-being, and improve relationships (Jani et al., 2020; Parkinson et al., 2015; South et al., 2008).

Autistic people experience greater challenges around sex and intimate relationships and more loneliness and isolation (Jay et al, 2024). Intimate relationships are a common part of life for many adults but are less accessible to autistic people, who face stigma and significant barriers in this area (Botha et al., 2022). These challenges stem largely from navigating a neuro-normative, heteronormative society with dating norms that exclude or even harm autistic individuals. Harmful stereotypes, including the infantilisation of disabled people, frame relationships as inappropriate or risky for autistic individuals, further marginalising them and limiting their access to support (Botha et al., 2022; Huysamen et al., 2023; Jay et al, 2024). This lack of support contributes to greater loneliness, social isolation, and mental health issues for autistic people, who are at higher risk of suicide compared to non-autistic individuals. Positive relationships can reduce loneliness, improve mental health, and enhance well-being (Cassidy and Rodgers, 2017; Hedley et al, 2019). Despite many autistic people wanting and valuing support around sex and relationships, it is rarely provided (Bates and Matthews, 2024)

Gaps in current health and social care provision often leave autistic individuals without adequate support. There is also an increasing call for greater funding to help local authorities support autistic individuals in integrating into their communities. Increased investment is needed to provide services that focus on daily living skills, such as cooking, budgeting, and personal care, which can enhance independence and quality of life. Expanding services that promote social inclusion, like community groups, work placements, and volunteering opportunities, is equally crucial. These services would help autistic individuals build relationships, gain confidence, and actively participate in their communities.

Integrating social prescribing into community-based support systems, combined with increased funding and expanded services, can address these gaps in support. By providing tailored, accessible, and holistic care, this approach would not only improve health outcomes for autistic individuals but also empower them to lead fulfilling lives within their communities.

Short-term outcomes:

- Importance of understanding cultural views of autism and the need to raise awareness, reduce stigma and provide support to encourage families not to delay seeking help for their children (Fox et al., 2017)

Long-term outcomes:

- Integrating social prescribing into community-based support systems
- Increasing funding for local authorities to help autistic people integrate into their communities.
- Expanding services for daily living skills and social inclusion.

Area 6: Addressing the Needs of Autistic People in the Justice System

Autistic individuals face significant challenges within the criminal justice system (CJS), often due to misidentification or lack of recognition of their condition. The condition affects various stages of their journey through the CJS, from police questioning to court proceedings and long-term legal outcomes. However, prevalence estimates within the CJS remain unclear (Robinson et al., 2012), and autism is frequently overlooked or misunderstood (Woodhouse et al., 2024). Research indicates that the lack of autism-specific screening tools and insufficient awareness among police, courts, and prison staff exacerbate these issues, leaving many autistic individuals disadvantaged and vulnerable (Chaplin and McCarthy, 2014).

For example, police officers report dissatisfaction in handling interactions with autistic individuals, with many feeling inadequately trained to manage such situations. Crane et al. (2024) surveyed 394 police officers, and 52% reported feeling unknowledgeable about autism, with 29% feeling poorly equipped to manage autistic individuals effectively. The Criminal Justice Joint Inspection (2014; 2015) identified that insufficient support and awareness within the police, courts, and prisons contribute to a lack of appropriate accommodation for autistic people, affecting their experiences and treatment.

Furthermore, autistic individuals may face heightened distress when navigating environments like police stations or prisons, where their communication and social interaction challenges are not adequately addressed. Adaptations such as noise-cancelling headphones or designated retreat spaces could help mitigate some of these difficulties, improving their overall wellbeing (Vinter, 2020).

The lack of specialised, autism-sensitive assessment tools and policy reforms in this area suggests that improvements in training, screening, and institutional adaptations are necessary to reduce the risk of distress and miscarriages of justice for autistic individuals within the CJS.

Evidence:

Short-term outcomes:

- Training frontline justice staff to improve understanding of autism.

Long-term outcomes:

- Ensuring better treatment and accommodations within the system.
- Improved data collection on autistic individuals in contact with the justice system

Key legislation, strategies and guidance

- NHS Long Term Plan (2019)
- The National Strategy for Autistic Children, Young People and Adults: 2021 to 2026
- Department of Health in 2010 (Fulfilling and Rewarding Lives; the strategy for
- adults with autism in England)
- National Institute Of Health & Care Excellence (NICE) Guidelines
- Special Educational Needs and Disability and Childrens and Families Act 2014
- The Autism Act (2009)
- Strategy for Adults with Autism 2010
- Learning Disability Mortality Review (LeDeR/ learning from lives and deaths)
- Think Autism 2014 and Statutory Guidance 2015
- Care Act 2014
- Equality Act 2010
- The Health and Care Act 2022
- Core Capabilities Framework for Supporting Autistic People 2019. The Department of Health and Social Care

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Resident conversations

Transcript

December 18, 2024, 12:36PM

DV 0:52

Not not not at this point. Really. I it's good to to know that you said there might be later conversations because when I so when I heard about this about the strategy and that there will be appointments I thought oh, that's amazing. That's really great that that you seek like feedback from all different.

DV 1:10

Groups like yeah, parents.

Autistic grown grown-ups or adults? And then I thought 15 minutes. I don't think that there is anything in the world which I managed to explain in 15 minutes.

DV 1:25

Because I'm not sure, it might not be all autistic persons, but the ones I know usually quite detail oriented.

DV 1:34

And I also I should probably mention I'm not only autistic, but I also have ADHD, which can make me quite an entertaining storyteller, but it can also mean I start at some point and end somewhere completely different. And then I don't remember what the start was so that that that would have been actually my question like, is this like because we only have 15 minutes, do you have specific questions which you are asking me or is it like free text?

DV 2:52

Yes, and and I also had a look at it yesterday. So I didn't receive it right in the beginning. So when I received the consent form and the the first question referred to the briefing Pack, I thought I haven't received any. And then I sent an e-mail asking and then I received it three times. So Derek sent it. Ruby send it, you send it. So I thought, OK, now I really have it. And and and I was quite glad about that because that's that's another thing which might not be much of a problem for other people. I wouldn't be.

DV 4:01

Not in the school or education system, because I'm an adult who was diagnosed only three years ago.

DV 4:11

So both, yes. So my ADHD diagnosis back in Germany in 2014 and autism in 2021 here in Oxfordshire.

DV 4:22

I have experienced quite quite a few barriers, but not not referring to to schools or education system. I do. I do think though what I hear from from friends.

DV 4:35

That it's often a problem really to get the diagnosis in the 1st place, which and there are huge waiting lists which we will be aware of both for children and for adults. I was quite lucky. I think I waited for my assessment for 10 months, but someone told me that it's now like closer to five years or something like that. It's like crazy.

DV 4:56

And it might be difficult depending on where you go to and in schools. Apparently to receive the proper support. Although I think technically it shouldn't be based on the diagnosis, it should be possible to get support without a proper diagnosis, but sometimes it seems to be a barrier.

Don't have the official diagnosis, but this is not like my personal experience now because I just yeah.

DV 5:35

Yeah.

So I think what is quite a big problem in Oxfordshire is housing. So I I lived in chat accommodation for quite a long time, which is not ideal for someone with my conditions because also I am I am working full time which I have to to pay my rent etcetera, because living in Oxford is expensive.

In a career which is not the perfect one for someone with my condition, so I'm working in an administrative role which for someone with ADHD can be challenging.

DV 6:11

And probably I would have chosen a different career if I had been diagnosed like in childhood. I mean, I'm I'm doing the best I can and I'm I think I'm doing quite well because I you also learn. I have been like in this path now for, for, in, in, in this profession for about 20 years or now for, for, for over almost 25 years. But so yes. So the need to work full time because housing is very expensive.

The problem to find appropriate housing. So I had to share because nothing else was.

Was affordable and I do think so in in theory or not in theory. There there is something like supported accommodation for people.

Who are autistic? However, I think this would usually be for people who might not be able to work full time, etcetera.

Whose support needs are deemed higher?

I tried at some point. Actually this applies to when when you want to access any service I.

I was off sick for a longer time this year, which was, yeah.

Basically a burnout.

Dealing. Yeah, I mean, stress and anxiety would be something which very commonly happens in in autistic people.

Especially the ones maybe which which might deem and I don't like the term very much. High functioning. I really don't like these terms because for one it also implies that there was.

Something which is called low functioning, but also because just because I appear like I I I do manage. I I I I work, I pay my rent, but this doesn't mean that life is easy. It's not nothing. Nothing feels easy. And so yes. So I I find it quite difficult.

DV 8:08

To to access services I did when I was.

Unwell. I did talking therapy, but again, this is usually not.

For new divergent people and there are not necessarily experts for working with new divergent people, I still found it helpful, but it would be good if there was something like me because it's very much focused then on like depression and anxiety and.

DV 8:38

And you, you, you then have to complete this questionnaire every every week where you are asked, like how much your conditions or no where it's more or less measured. If you're getting better, but it's not. I mean, I'm not. I'm not. I'll as such.

DV 8:52

I'm differently wired, and yes, depending on how wested I am or how stressed I am, I might feel better or worse, but it's not something it. It would be good to have like more like a long term support, which which also can help people with, I don't know, like yeah, excess housing or for me it can be a difficulty already to make an appointment with the GP because.

DV 9:19

You.

In the past, I was encouraged to complete an equan site form and I was told this takes like 10 minutes for me because they ask is there anything else you need to mention or you want to mention? It took 1 1/2 hours to complete this form and I put like everything in and then I'm going to the appointment very nervous already and the GP asked me what can I do for you today and they said I've wrote it all in there.

DV 9:42

And they even made notes on my phone and showed it to her. And then you're told, OK, so we will do like another appointment then, but you will only be able to book that appointment two weeks before. So please call then and these things to remember these things because I can do these things for my job. I need to be very organised in my job. But in my personal life, things like, I don't know, keeping my household in order.

DV 10:08

Organise these doctor's appointment, then constantly feeling misunderstood or not being taken seriously. So maybe I know from a previous role that there is something in Oxfordshire for people with mental health issues like floating support.

DV 10:24

Which used to be offered by connection support and Elmore if there was something like that in place for autistic people or for new divergent people, that would be amazing.

Just really to and and I know this would probably be very expensive.

Yes, some kind of network or some something where where people also can contact them if they need in a specific situation for a specific discussion with an authority with the GP, whatever. If they need kind of an advocate and there might be something in place like that which I'm just not aware of.

But yes, so.

Because that's the other thing. Very often you are depending on on searching for, for, for office yourself proactively, which not everyone might have the possibility to do. Because I mean, many of us are like very good in researching information and once you find like your special interest.

You, you, uh, you will be really good at that. And we'll spend a lot of time on that, but you don't always necessarily have the energy to do so because I spent a lot of energy on functioning at work as well as I possibly can.

Yeah, I hope I didn't jump too, too, too, too, too, too much back and forth now. But it gave gave you, like, kind kind of an idea. So I know that when I applied for the talking therapy and had like the the assessments.

DV 11:52

With Oxfordshire talking therapy that I also had phone calls and at some point autism at Kingwood was mentioned, which I know of a supported housing and I do think they also offer some other kind of support and they got in touch with them at that point. But.

To to inquire with them if they might actually be the better place for me or the the well, not the better place. But if if the support they offer might be more suitable for me.

And they were told Pexen. I think that they don't take any any referrals right now because they would just be, you know, swarmed with, with referral, with referral. And again, I think and I can fully understand that I I know from from a previous role which I had as referred coordinator in a mental health charity, I wouldn't be in the top priority of list because I am yeah. So.

I I am in a situation that I can.

Well, I.

I can live independently. I can manage my finances more or less. I can. Yeah, I can work full time. Although I probably shouldn't. So if I really would be focusing on what would be good for my well-being and what would enable me to also have have energy for, for a social life, I probably would work maybe three days per week. Because when, when, when I go out on a Friday, when I'm meeting friends on a Friday, I struggle to be.

DV 13:25

To go to work. But yes, so there there are always people, of course, who really have higher support needs and I think they need to be prioritised. So if there it might be maybe there that there would even be kind of a peer system or something like that which which which could be set up. It doesn't need to be like as an expensive experts but but if there was something like a hub like where where where people really can go. So I know for example for ADHD.

DV 13:55

There, there, there is like a support group in Oxfordshire, ldhd, Oxfordshire, which I used to visit, but I'm not aware of something like that for autistic people.

I mean, maybe also because we might not be the most social or or because it it costs so much energy for many, but I still think that that many of us would also find a type. And I mean one can still create it in a way then that it that it is at least stressful as as possible.

So it's usually less stressful for me to to speak to other new divergent people because they they understanding and also the the the tolerance for maybe not staring into someone's eyes.

Is is is higher.

DV 14:45

But housing is, so I managed in the end because I I really I I got very angry in, in, in, in the end. And I thought yeah, it doesn't I I would spend all of my spare time in my room would not dare.

Down into the kitchen because I just didn't manage to have any conversations, I got the most twist. I got the most sensitive. I got to to to the smells and and sounds in the house. So yeah, in the end, I was lucky enough to to find like, like a little apartment. Like a tiny apartment. And like a family home. But I have my own kitchen. I have my own bathroom, still noisy. But I have noise cancelling headphones but it.

Like it costs an arm and a leg so it's so I I wouldn't be able. So if I was somebody who wasn't able to work full time.

DV 15:35

I I wouldn't be able to afford that because it's almost like 1000 lbs per month, which is, which is for Oxford. Actually not that bad for self-contained, but yeah, but just just a lot of money so.

Yeah, some some advice around these things, because that's the other thing. Maybe they would. Technically, I don't know if I would have had any prior if I could have gotten in any priority group, if I had applied for the housing register, maybe.

But I don't really know and I didn't I I wasn't in the place to spend like time going into these things and going through the process because that again is like quite difficult. I think that they're they're quite a few obstacles to apply for these things and to advocate for yourself. So yeah, sorry, I think I I almost exceeded our 50 minutes already.

DV 17:13

Thank you. Thank you very much. Lovely to to, to meet you too. And yes, I I'd love to to to be kept in the loop on like any further development. And if you would like any further input, please please get in touch because I I think it's an amazing opportunity.

DV 17:31

To to to to ask the people who are affected, and I thought that probably there will be quite a lot of parents because obviously I I think the the the easier of the earlier diagnosis takes place.

DV 17:44

Or support needs amid the easier it might be later in life. So I mean that that, that that is obviously very important to focus on, but I've had there were also quite a lot of people like me because when I grew up I I was born in 78, not many people my age will have been diagnosed in early childhood until they they were like really disruptive or like really you know, so they I think there was quite a huge group out there.

Transcript

December 18, 2024, 1:52PM

LM 0:29

Either the parent or the carer, in order to enable and be the voice for the child.

By understanding loads of different things, which is amazing. So we know that it's all evidence based and we're where where it's on our plan and we're moving forward with that, which is amazing. So we're training and those families and parents and carers as NT as one to ones teachers and senkos that we are attempting to get trained up and understand it's been very successful. And So what happens is the parent or the OR the carer and that other people.

LM 1:01

They become the advocates, and then they're like, I don't need you anymore.

Speech and language therapist. Thanks very much. I can do this on my own, which is fantastic. So that's really good. So that's perfect. I also do something called Maya. Join you where we packed is. So I mean, it costs, I think it's around 5 to 10 grand per person to train. So it's very expensive. And so we've we've just my amazing managers done that really well to do that and so.

LM 1:31

That couldn't be the only thing that we did because it's too much. So we've create, there's a lady has created another package called mayor join you.

You can just Google. May I join you? YouTube is a 40 minute thing that the.

LM 1:48

This is also in Welsh, which is really helpful, so it just gives you strategies and there's a lovely print that does the strategies in the middle and then as in like the they bubble out on the outside and I use that quite a lot in my hold on one SEC, if I can just get it up, that'd be really helpful for you to get snapshot. And so we use that quite a lot and we empower families in order to again using similar.

LM 2:21

To sort of aid those families, which is great. So that's kind of the thing that we want to do and what it does is we use because mostly professionals know how to do most things, which is great. And so we're just enhancing them with a mayor, drawing you principles and being more reflective. And so we're asking, you know, what is he saying by doing this, what what is his action?

LM 3:06

So and a lot of these are packed principles as well.

And which is great. And so it was just like, how can we get families on this? So then I'm going to share one other thing.

So that was that. And then we do a reflections log.

Which I'll just give you sort of some of the reflective bits of it, because obviously I need to be really careful.

With what I'm doing as well, but the strategies are all in line, so that's easy, but this isn't, but it's kind of a reflection of like using those strategies which were just there. How? How do I watch and learn? How do I what? How did my play help them to achieve that? How you know that kind of it, you know, self leading questions that you know which.

LM 3:55

Most early years professionals are doing anyway.

LM 3:58

As somebody who is early years trained at Mvq Level 3 done a degree, but in exercise science I have underpinned a lot of my.

Understanding from somebody called Kathy Stevenson, she is AOT. Sorry, I'm going really fast just to try and get all this stuff in. Yeah, I don't. I've got 4 minutes left and basically there is a book called Ready Steady Connect by a lady called Jesse Aaron's Insbourg. And it's amazing because it basically says that the foundation of any learning is sensory regulation.

LM 4:32

And unless that happens in our 1970s legislated school buildings.

LM 4:40

It's 50 years out of date, folks.

LM 4:43

We there's a lot that needs to be changed. I spoke to a lecturer yesterday here at Brooks University. Just so happened to create a networking connection and he happens to also have a child who is on the autistic spectrum is accessing things, but he can see that that's not the access that others have had. The same access that his child who is now in secondary has.

Which is difficult. I'm come from background of working in children's centres where I was a room lead and I was very, very fortunate to have children centre workers around me. If somebody needed support I could say, hey, can you just come in at the end of the session, I'm going to introduce you to this parent. You can then support them. We'll do the childcare. You can help them through life. And so it that is now missing. That is now no longer available as a parent. I was really able to access that when my child was, you know, 10 years ago.

LM 5:36

But it very quickly with my other two children, came along. There was no children, centres to access.

So they were the ones that were catching it quickly. They were the ones that we were doing ehcps with and EHCN as so then there's that.

LM 5:51

As a as a professional going into schools absolute nightmare, I find it really difficult because a nobody knows anything about sensory processing in any way. Nobody knows about the fact that schools hoard like.

LM 6:06

And they got so much stuff, they don't know what to do with the stuff. And actually the stuff is not the thing. It is us as the people who are the ones that are using whatever that child touches to create a learning development opportunity. And that's not happening at all. So that's really tricky. And so they and they feel alone, one to ones haven't got a clue. They haven't got any support to their sencos, they're useless. I'm really sorry. As somebody who was one to one, I have no one to talk to. Ever.

LM 6:35

You know, I'm running around 17,000 steps a day after a child. I'm exhausted, you know? And I don't have the support. The fact that I might actually be near a typical as well. I mean, so neurodiverse as well, because I have such great skills that you guys need, because I that's the only thing I could do. I couldn't go on to university. Couldn't do all these things. But I've got an NVQ Level 3 in childcare because I'm great with kids, but nobody is saying these really basic things to these people.

And it's really unfair.

LM 7:05

I've never been able to progress from my career because that's the only thing I was good at.

And I, you know, haven't been able to lead, haven't been able to do these things. I mean, that's my own professional frustration. But also, I am neurodiverse. I'm not diagnosed. I've probably got ADHD, which you're finding with the fact that I'm talking so fast and I keep missing opportunities to do things. But I know that I know all these things. So I'm living like I am and knowing and accepting that there will be a marvellous mistakes that come along the road because that's the only way I'm learning. But it's not fair. We've got a culture here.

LM 7:37

That is really damning.

And we're not celebrating anybody. Like, there's so much to celebrate. Yeah, so.

LM 8:33

So the only thing that the NHS delivers is if you are on a communication pathway as as in a social comms pathway social communication pathway, do you get access to and depending on your age will depend on whether you get packed and then it will be the school that might be delivered. May I join you, the sensory processing, Sally, the lady called Kathy Stevenson from the NHS.

LM 9:00

Sadly, she was not commissioned to do her thing.

Even though Jessica and her book ready, so to connect, says the fundamental thing that we need in order to do anything is regulation. And if we can't, we can't even learn. We can't even engage none of it. And so if we. Yeah. And so the fundamental thing and as a parent, I asked my husband to go on the pilot that she commissioned, that she was commissioned because I know what I know from my work. But as a couple.

LM 9:33

We didn't know. I was saying all this stuff and my husband's like, yeah, you know.

How do you cook eggs? You know? But he's like, oh, this is the thing. It's transformed our lives. Our children are accessing school. But in a Independent School because we chose that because we did. We couldn't access things as a couple when we were younger. So our children couldn't either. So yeah, there's a lot. Yeah, to access. Sorry.

Claire Webster (SCIE) 10:04

This is absolutely brilliant and I will e-mail you to arrange another catch up so we can talk about this more and if there is anything you want to send me in advance of that. So all of that stuff that you've been talking about, just send it to me. That'd be brilliant. And I'll make sure it's all included. So that's great. Thank you so much, Liz, for your time.

Transcript

December 18, 2024, 2:08PM

DR 0:14

The kind of the leverage and the bridge to kind of get across irrespective of my.

For diversity.

DR 0:22

Kind of in terms of kind of any barriers and kind of the the more juicy bits of kind of what we're looking at today. For me, it's the writing aspect now. I appreciate there are many different things in Neuro. Diversity covers a whole spectrum of things, but that's kind of where I struggle a bit. I mean thankfully we've got Co pilot now, which is especially with the roles I do, I'm sure you'll speak to a variety of people and but what I do writing is quite essential. And and Oxford, you have been very good at providing that tool.

DR 0:49

Kind of impasse instances, though. There have been things where it's like, maybe it's just the unfortunate reality of working in children's and in education there's this kind of innate presumption that you work in children's and you can just write and it's. And I'm. I don't. And I'm not calling people out because this is not the place to do that, but it's there is a special it's getting better. I want to say that I want to put that in there, but there used to be a presumption that.

DR 1:15

You know, we're senior people with degrees, and I think it happens because it's a professional local authority where there are people with degrees like.

DR 1:21

Innate presumption that you can just write and that being semi bad at maths is understandable.

Not saying that is the case, but I'm saying there you can. From my perspective, there is a can be a culture of that. I think that's Day's getting better as time goes on, especially in reverse groups. But that's kind of where there's been a main barrier in terms of my work. But I've been working on tools of that. But to say that it hasn't been a challenge in the in the past we'll be lying.

Yeah, absolutely. It's good to know that they're using technology to make some of those bits of work that you find most difficult, easier, which is.

DR 1:55

Of course. Oh, it's it's definitely. It's definitely improving. It's just about how we go about it, because I think it's thing is, I don't know, you don't always know whether it's an individual case by case. Someone's being a bit ignorant, put it politely or whether it's actually a system thing. And I don't have the expertise or knowledge to evidence that correctly and appropriately so. But I mean from my understanding is it it wouldn't surprise me if it was, you know, very educated people and children's and maybe some in adults that are just so used to being around people.

DR 2:24

That are highly educated.

DR 2:26

And not saying I'm not intelligent because everyone's intelligent in their own way. That's why we've got these jobs and what not. But I think occasionally there is kind of this blind laugh of why can't this minutes just be good and, you know, it's like you can't. This is a bit of a dig, but it's not a dig at the same time, it's actually useful.

DR 2:43

You have if you want to have neurodiversity and you want to provide an environment where people prosper, you, you have to accept there's going to be a variety of results.

Arjuna, there's a there's a variety of ways of achieving results. That is what I'm trying to say. I've proven not explained it very well. But yeah, that's kind of more past. But yeah, that's kind of.

DR 3:21

So yeah, so in terms of oxfordoverall, I've been around. So in terms of I've, I mean, I've been diagnosed since I was born practically, so they not practically essentially so into I used to be on the old statement system as well as being on the well. I think I was on the HCP system for a year or two. I mean this was I finished secondary school in 2018, so that would have been that that period. Then in terms of kind of my experiences, it's been pretty good. I mean, I was very lucky. I was at the Warriner school, we had a senco called Rachel Cosgrove.

DR 3:49

And some sencos are literally lifesavers, because without their support, you know.

DR 4:17

I say that that was a hardship, but just be one look is he can be hardships, but it's yeah, it's how is that it's it's a normal teenage thing that you are going to find school a bit stressful basically and whether that's due to the neurodiversity not too sure but I think that definitely didn't help but that's kind of that'll be where my thoughts are with that question.

DR 4:47

Yeah, I mean, I definitely try and do my best with it. I mean, I'm very lucky. I am quite a sociable person. It's definitely a skill that I've developed. I've been very lucky with some of the relationships I've made at work. I mean, I didn't. I have either reasonably good network of people who I meet and whatnot. I'm part of APA Private PA network outside of work, so I don't struggle on that front compared to a lot of neurodiverse people. I think kind of the things that I would struggle with is just kind of as you know, always knowing other people how people view things like the, the writing and kind of there are bits of perspective things. And I'm just like, well.

DR 5:17

No, The thing is, you've got to give yourself that because no one is perfect, so you can't. It's just not realistic to be everyone's cup of tea. But I think that's I think that's a gradual young person's think because I'm 23. I'm imagining you're going to be interviewing the people of a variety of ages. So you're going to get interesting. Well, not interesting. You're going to get a variety of different responses about that question, but that'll be where my thought process is on that.

DR 5:50

So during before Occi sadly got kicked out of a classic car apprenticeship, which was not a good time and I used the the neat set well, the things called the E service or the NEAT service and they were OCC and I think every council has one. It's a not employment education training and they were fantastic and they and I was going for a really tough period then I don't because it wasn't clinical depression, but it definitely was this is not the right thing going on.

DR 6:15

And people were concerned about me. But I mean, I'm very thankful. I've managed to sort my life out, but I'm not from an Uber privileged background, but I was very lucky to have that support, and I don't think people always have that support. So, and I'm aware of that so.

DR 6:35

I think it was. I think the, I mean I was about 17 at the time. Yeah, 1617 and especially as a young bloke it's very difficult. You've got this is going down a long path. I can't go on forever and ever in terms of when you're a young bloke you want to especially during that period of time you want to be in college or training or you want to be doing something in your life and there's this kind of not pressure but there's this kind of idea in the back of your mind you want to move out you want to get your first car you want to you know.

DR 7:11

It's and it's it and it's very difficult if you're if you're employed and it's very difficult for people that get that all their full a stars at GCSE. But you know, if you've got no opportunity, no opportunities, you know you're not getting interviews for employment, you know, and X the list goes on and on and on it you, you'd be surprised by how much people struggle. It's, yeah. When when people are struggling with employment, it's not a joke. It's.

DR 7:43

The difference between you and someone like is luck. Like I look. Yeah. So that that's kind of I think that's kind of how it manifests itself and how it that's how it affected me and that's kind of how I think it affects most people. But I know depression comes in a variety of forms. So yeah.

DR 8:04

So in terms of in terms of sensory things, I kinda I well, I have a chair that I like. I was a big gaming chair that I like. I changed that over 'cause. I found it too too much.

DR 8:13

I I mean, I don't know whether it's just because I like it or I sometimes when I'm in meetings, I just turn my camera off and I'll start typing away in one minutes. But admittedly, that's more of a practical thing because it lets the higher priority people go on camera and be on the screen. And also it means that I don't have to worry about what people are looking at me. I can type all on pace. Don't think that's really a sensory thing. I think that's just me being courteous and just common sense in terms of a sensory thing.

DR 8:35

I don't really. I mean, I get chill blains a lot, so I try and keep myself warm and especially this time of year, it's not been too bad actually. But yeah, not the funnest. As you can imagine. Yeah, I don't. Yeah. I mean, for me, it's more about the Co pilot and recordings in AI. That's kind of where I'm where I'm at. And I occasionally I use earplugs occasionally, but it's mostly because I don't want to burst my eardrums, which I think is a semi reasonable.

important or you know that kind of thing so.

DR 9:41

OK, OK.

Yeah. So in so in terms of in terms of the one, the kind of thing we'll not think as you mentioned about the kind of supporting people and what you know the thing about cost really, really and I'm not going to go down too much. The rabbit hole is, I'll tell you a story. I have two people I work with who are definitely paid more than me. That is, you don't even need to look at their salaries, but you know a Co pilot licence is two £300 a year. I think I roughly worked out how.

Claire Webster (SCIE) 9:58

Yeah, yeah.

DR 10:14

Hours that need to use to cover the cost in terms of efficiencies and at the moment we're not producing any more copilot licences and I'm just thinking how many things are going that's not really that important. It's important, but it's like, imagine how many things like that are going on in regards to things that people need for sensory and so and so forth, just for the sake of cost and imagine how much savings that they need basically needs to be. I don't know what the word is, but there needs to be a kind of a thought process around if we do give this person what they need.

Yes, it will cost us £200. Let's say let's think about how much better there'll be, how much more efficient it'll be over a course of a year. And I know that's easier said than done and we're not here to change Council viewpoints because, believe it or not, they're bigger than me. But that's kind of that's one thing I think about because I mean, I on my stepmum, she's a Sen consultant, so, so I so she gives me a lot of insight to things. So that's kind of where my a lot of my education needs come from. So.

Of course.

Absolutely.

Transcript

December 18, 2024, 3:47PM

ON 0:20

But I suppose I'll start with him first, so.

I think some of the barriers have been within.

Education. Getting access to educational, health and care plan was a challenge.

We came from overseas here from Australia back about 10 years ago and at that time we'd gotten wealth of reports on his disabilities, including, you know, everything and but they wouldn't recognise them, which was a bit ridiculous because we're, you know, we even have cams in Australia. So it didn't make sense. Yeah.

ON 1:00

Yeah, it it was. Yeah. So it wasn't a third world country. It was a, you know.

On par with here, really. But anyway, so we had a challenge there. We ended up having to involve the MP and all the challenges to get that educational, healthcare and plan.

ON 1:17

In place, then accessing special education need education was challenging because he was that he had a breakdown and was quite poorly. And I'm getting that access was difficult.

I think then once we got into an SEM school, it went really well. So there was a period, I mean other than the lack of mental health support, which is been a concern all the way along. He coped quite well. He was underpinned by the adoption support team, which gave us some of that mental health that we couldn't get him anywhere else.

But I know he's got peers that weren't so fortunate, and then when he came to.

18 at that time he was had a consultant with CAMS, a consultant with the.

Adoption support team. He had a consultant with the Tavistock because he was being seen by them as well. All three of those and but at 18 it all the Cliff edge happened because he didn't meet the threshold initially for adult mental health. They all challenged it. They were really good progressive team and they challenged it and eventually got got some got some support but.

ON 2:34

What their excuse? Eventually you got to not support him was the fact they said he had autism and we don't support autism, which so and there is nothing else within.

The county he was referred to the reasonable adjustment team for autism, but at that time they only did the a report which allowed profession to give a communication plan for other professionals to work with them, which was useless because then adult mental health team weren't involved, with no professionals involved.

ON 3:06

Social care. He was lucky. He had initially had a really poor social worker that didn't understand the concept of masking, and he, you know, he's a quite an intelligent young man and he just to get her out of the room. He'll just said he did it. You could do everything. When he can't do anything.

ON 3:25

Fortunately, we had to challenge that, got it redone, and we've got a great social worker now. She does understand she was able to drill through that and understand that when he said he could cook.

He meant he could look on Google when we drilled down. Oh, I could look on Google. Maybe I could do it from that.

ON 3:44

Yeah, but I've never done it and he still doesn't 23 because he doesn't like hot things or. Yeah, so there's barriers still, but yes, we got over that. But mental health is still an ongoing problem. And I recently raised a complaint to the CQC about it and it's now being dealt with by the NHS. That's a separate thing.

ON 4:08

As a as a professional working with those young people moving into adulthood team.

I think the biggest gap for us is the mental health support, the lack of.

Support for young people who don't have a learning disability but present with autism in the county, from meeting friends to, you know, get get meeting up with like minded people through to respite.

ON 4:42

Out, out, out, outreach services, they're just not channelled or or very rarely suited for that cohort of people.

ON 4:52

Commissioning. Don't and brokerage don't seem to have a specialised support team for that.

And they do get missed out on the thing I'm worried about with this project, it says it's about autism, but I think it should be about neuro neurodiverse children, because a lot of young people don't get that full diagnosis they present with autism, but they're eight. They've got ADHD. My my young person has got autism, ADHD, central, autistic processing disorder.

ON 5:21

Also associated with autism, but you know or on that strength, but.

ON 5:28

I think that some people aren't so fortunate if they just got ADHD this this this might miss and a lot of the people we worked with that came out of leaving care could be within the moving into adult team had diagnosis for ADHD but not autism and yet they presented with very similar traits.

ON 5:51

Yeah. So I think that's that's so I think this project should be wider.

Yeah, I think that's the basic things I've tried to think of.

Wanted to say.

ON 6:25

I'm saying, yeah, specialised housing, there's going to be able to live on its own. So specialised housing, he's very intelligent, got up to Level 3 in advanced Level 3 at college with a lot of with one to one support, which was, you know, that was great that we got that. But he's now at home and has nothing to do. So yeah, some some help more help on that. I think we've got the Oxygen employment service great and.

ON 6:53

But I still think there's that missing link for those young people that are stuck in their room and can't engage with those services.

There needs to be more hands on approach, somebody that's willing to, you know, meet them online. Do you know other other methods of communication?

ON 7:11

Yeah, much more in the way of reasonable adjustments.

It's all in the reasonable adjustment team for autism report, but people don't read it or use it. So.

ON 7:26

So when you get referred to the reasonable adjustment T for autism in Oxfordshire, they can do a communication plan. It's brilliant. It tells them what they really do get to know the person they get to write, how to communicate with them, what works best, what doesn't, very informative but sadly not used, no.

ON 7:49

Yeah, I think that's really important. It's such a it's such a shame because it's such a, you know, it took weeks of.

Hard work from the person to write it and do it and to because they managed. They got the skills to do to communicate with that with him. You know, it's brilliant.

ON 8:22

And other parents get those reports and share them with us in in the moving into adulthood team.

Yeah, OK. All right. No, that's worth noting. OK, because I think there is, there's always something about that even when you have got these really good pockets of resource, how are they making sure that that information is shared with all the other relevant organisations?

It would be. It would be really good from day one. The educational health and care plan was always the concept that it would include education, health and care, social care.

ON 9:13

Throughout my whole time of using it, it was all focused on education.

ON 9:18

It was very difficult to get anything added to that.

And.

They and education really are quite strong ownerships of that report and.

And don't necessarily work well with social care and health to keep to maintain that report, there needs to be a report out or something that captures that young person that's updated on a regular basis and follows them through health, education and social care. As a parent, the worst nightmare is having to repeat yourself over and over again every year. And.

ON 9:57

And more frequently, and also the fact that you know, it's quite emotional having to go through all those negatives that you live every day.

And put it down on paper again. It's quite soul destroying and I think that would be good. Yeah. And we and we do get traumatised as parents I think from the process.

ON 10:18

I think one of the biggest things that my young person needs to lead a good life and the people I was born is that ability to access social care, social skilling or social groups.

ON 10:32

Some more focus on finding some meaningful activities.

Work and or work experience that's that can be adjusted to their needs.

ON 10:44

And yeah, I think those are the biggest things. And also I'm social care, recognising that the Sen Act covers 18 to 25 and yeah, we have a children's provision that provides a local OfferUp to 18 and then we have adults provid a low cost from 818 onwards.

ON 11:06

But the adults offer is very much focused on older adults, not younger people. So we have this little missing cohort of 18 to 25 year olds that they totally miss out.

ON 11:22

Yeah. And it and I think it's more about our systems are wrong. You know we need to, we need to embrace the fact that if we're looking at a local offer, it should be from 18 to 25 for that you know or 16, sorry 25. Yeah across the pitch. And one more thing. Last thing is that we've.

ON 11:43

It the global authorities really addressing everything through online services. But I worked with a lot of young people and their families.

ON 11:53

Who were not it literate and I had three sets of parents that couldn't do anything online. Two of them couldn't read or write, and we are discriminating against them by not having accessible system. So I used the only way I could do it was literally to visit them for everything and to do it manually because our systems don't allow it to do it otherwise they couldn't even make GP appointments. So I had to help them with that because the GP said no, they have to do it online. And I said but.

Claire Webster (SCIE) 12:28

And it's interesting because I just had a conversation with somebody, even when they can get online, the process of going through that form isn't straightforward for people. I've heard people spending hours just thinking about what to complete on it because it just doesn't. It's not reasonably adjusted to think about that. So.

ON 12:50

For mine and I found it so not strength based, it was all about the negatives. There was nothing about, you know, all the in the things you might enjoy with your own person or, you know, to celebrate. It was all it was, always. It drove you always in the way of saying what was wrong. And that's not how, as a social worker, we would do those.

ON 13:12

Those those assessments, we would, we would take a lot more focus on the strengths first and then look at the things that they can't do.

Claire Webster (SCIE) 13:28

Yeah, I'm saying that's definitely something to report in in terms of a strategy and approach. If people are going to be sported to do, say, their own assessments.

Or contributing to their assessments is actually how well that reflects how you would have a conversation with people about it so.

ON 13:44

And also to reflect the local authorities ethos, which is about strength based and the what they call the Oxfordshire Way, which is about finding.

ON 13:55

Solutions within the their local area and not not locally. Oh yeah, and the language we need to keep the language better. Things like not using community like notice I said local area, not using community, you know not using all those buzzwords. We want to talk about them as individuals. Yeah.

Transcript

December 18, 2024, 5:05PM

Yeah. OK.

Sure, it has been absolutely awful experience. My daughter has very light autism. I'd say she's mainstream. She will remain mainstream. She does have combined ADHD. So those things work.

WS 1:18

In contrast to each other, which has made it complex, she's 8 1/2, but just the parental experience.

Has been horrendous because I think.

Actually, they're blind side of us.

And I think the main thing that was difficult is.

There's no guidance.

WS 1:43

There's, it just feels like you are just thrown into the abyss and you're told.

Oh, look at this website and and navigate it. Navigate this **** show that you found yourself in.

That's fine going to do every single page of an ****** website to and just summarise and distil and work out what you're supposed to be doing. But we were.

WS 2:15

She had really bad sleep, so we were utterly broken, human beings told to just.

Squeeze.

Pulling through websites into our day jobs and our free time that wasn't free.

And you know, it's actually I'm getting upset. I'm actually getting trauma therapy. I've just started to get trauma therapy because the whole thing. And I had a whole issues postpartum. So that was just, you know, an explosion decimated things. But.

WS 2:55

Just the that experience was really, really, really unnecessarily awful and there's.

Central Guidance, central signposting. There's so much out there, but again, you you your brain is pulverised.

WS 3:16

Anyway, as a as a working parent of a with a young child, your brain is pulverised. Aden Sen issues and it's just, you know, you neurologically toast. You're absolute toast.

WS 3:29

And you know, it's sort of your responsibility to have the wherewithal to make it happen. And I think, you know, I would pass myself as one of the lucky ones. Like, I am intelligent, educated.

You know, determined so out of lots of people, I would be the one who would be trawling the websites and I couldn't and I literally didn't have the emotional energy to.

I've been upset here. I didn't have the emotional energy.

To just.

Do any more work and and use my brain any further and and you know. You know what it's like when you're like, if your brain is mashed and someone says solve this really big problem. Well, how on Earth are you meant to do that?

WS 4:21

And it's all these different agents, all these websites and you know I have I if you told me now who I spoke to about what and when and what I did, I say I haven't a bloody clue.

WS 4:34

Not a clue. I couldn't recount any of it. Sorry. So you are bad to ask a question there.

WS 5:30

That's OK. Yeah, I would. I would also say actually one of the things that makes it quite difficult is.

The the the spectrum is so broad you have other Sen issues that overlap and the information is like, you know, if your child's autistic do this, but it's like well, my autistic child has farly different to every other autistic child I know with all that. But I mean it's and it's in a different even just different levels of severity it's and there's no real help for it didn't seem like.

.

WS 6:02

There was help for daughter of at my level at her level, which is.

Reasonably, you know mainstream.

We went to send gymnastics and all the parents there said they'd have to take their children out of mainstream school and into special school because they got zero help from their school. So this was the everybody but me had had an awful experience with their primary school.

And we just were very lucky. We had an incredible primary school.

WS 7:10

So I think that the general experience is that schools haven't clear what's what they're doing.

WS 7:17

Just adds to the pain, frankly.

WS 7:30

Yes.

Well, they just, they sort of, they're just they put lots of interventions in place, there's loads of send kids there because they are attracted to the school. So you don't feel like your child's weird. They have lots of interventions in place and they're doing the eacp and yeah, you feel like.

As much as they can do to be with the funding they have that they have, you know it's a safe hands situation which is great, but obviously they can do a lot more funding as could everybody. And obviously I think you'll have heard this about 11 billion times a day. Cans is on its knees.

WS 8:12

I can say what you're doing is you're having parents, sort of.

You know, back borrowing and stealing to go private and then that's not a sort of that does not dovetail back into the GP system.

WS 8:26

And again, it says more. It's more like, you know, you have to go looking under every single rock of the Internet to find out what the Hell's going on.

WS 8:41

It's been awful. It's underfunded.

Yeah, I think so. I think I think it. Yes. For me the key message is those that the information is so confusing, it's it's almost inhumane.

WS 10:34

Well, we're doing a teacher. We're we're all trying to teach her integral life skills. We're getting the trying to get an ehcp with her. Secondary schooling would be very closely monitored as to where we send her.

WS 10:51

Regards what we think between handle and yeah, it will all be focused on just getting her safely into adulthood and beyond.

WS 11:23

I mean, I think it's it's no understatement to say that it can destroy marriages.

WS 11:30

The the experience in its entirety, and it could that just be really could be avoided.

it and it's also like, you know what support genuinely could be offered. You know, there's a lot of, oh, go and find time to go and meet other parents in the same or a similar ish phone. It's like that's not helpful.

WS 13:08

Really, in advancement, yeah.

So yeah.

Yes. And it's just, it's just not ultimately not going to change what's going on at home, so.

Transcript

December 18, 2024, 5:56PM

R 0:34

I would say the main thing for me is that I'm so I was diagnosed in January this year, so I'm 60.

R 0:43

So 1259. So I was 59 3/4.

R 0:47

So to me the main thing is that it's it's it's we're invisible people. Older people are invisible and.

I had no idea. I only know I only got diagnosed because one of my sons and my adult sons, who's also counts as late diagnosed.

Has got had a diagnosis last year, so one of the things is it's it's we're invisible. Everything is a gut geared around younger people, but there are lots of older people like me who struggle through life with mental health issues and particularly, I mean so many times I've been diagnosed with depression, anxiety post Natal depression, blah, blah, blah. All of these things with the root cause in the anxiety caused by social situations, which is the root causes of autism. So that's the first thing in terms of the visibility.

R 1:31

And it's quite difficult because lots of people, obviously of my age and older have no idea because it wasn't a thing, so.

R 1:38

But that is a barrier that I feel like I have to explain every time. I'm very lucky that I'm a teacher, so I work in a school where they're very supportive and one of my fellow faculty members is there, you know, key stage four and five senko. So I'm very lucky.

But it's it's a funny situation to be in that you're trying to like you're invisible. You have needs that are invisible. And there are things which are not necessarily huge things to.

Address. They're just and you know, things like little tiny adjustments that I've got small adjustments in my routine. What I do that make my life manageable and mean that I'm still almost full time as a teacher.

Rather than a few years ago thinking that I would just, you know, Chuck it all in, because I couldn't cope.

So I think that's that's the first thing.

Other than that, generally it said, I think a lot of education is needed to people I've I spend a lot of my time, I mean.

Both in the in the sense that what I know about autism is mainly from stuff I've taught myself, so it's become one of my special interests.

Partly because of me and my friends, and partly because I'm a teacher and I want to know, I'm desperate to know more, so I can help my students. So I'm firing on all cylinders. You know, young, you know, teenagers. I teach teenagers so teenagers and older people. I'm interested. I'm just interested in the whole thing. So it's very difficult for. I've spent a lot of time trying to explain to people.

R 3:07

You know what it is. So one of my friends when I was diagnosed, you know, he's known me since I was a teenager.

You know well, that can't be true because you know, because you've had all these traumatic things happen to you in your life, and that's why you're depressed and.

It's very, very hard to actually convince her that there's something else going on.

R 3:25

So yeah, so there's two things is we're invisible. Older people are invisible. Things are no one twigs that if there's all these youngsters being diagnosed with autism, then their parents are, you know, their parents doesn't come out of thin air genetic.

R 3:40

That's something. And the other thing is just, yeah, awareness, really.

R 4:21

No, no, I mean it's it's almost I think anybody who's who's older and has diagnosed as basically self diagnosed first.

R 4:30

Because no one's going to say to you. Oh, do you think you might be autistic? You know, several of my friends afterwards said, oh, I thought you might be, but why didn't say anything?

R 4:39

But.

No, and I and I did it through. So, Dylan, my son, last year I had he he's was I paid for it as a private diagnosis and then mine. I got through right to choose. So I went to London ultimately and have face to face the face to face session because it's just I want and it was quite good it was pretty good. It was pretty quick. So I was very lucky to get that get that slot in there.

R 5:06

I've lost the thread of what we're going to say now.

No, I mean you, you wouldn't. Nobody would know what you would particularly with older, you know particularly with older people. The other thing I have done is I have tapped into the Oxford into the adult Autism Service, which is available through the NHS in Oxford, which is I have been, I've done there.

Post diagnosis course, which sort of already knew it, but I went anyway. I went to see what was available, so I think in terms of, I mean, I'm fine. Obviously I've managed to get through my whole life, you know, and I'm still working. And you know, I'm still here despite everything. But for other people like my son, who's much, he's much more badly affected, sort of mental health side of things than I am. I just think in terms of the for me, the small adjustments have meant that I can carry on working.

R 5:49

So there must be lots and lots of people who want to be employed or who, you know, that employment support.

For adults, it doesn't seem to be. I mean, I say I've I've because I'm on it like as as research. One of the things that that's just as an autistic person. I'm just like that because I'm on it. I've burrowed away and found anything that I can find out. But there are lots of things I was completely hopeless, you know, doesn't have a clue without me helping him. There must be other, you know, it's an area that if you want more people working, if we're all supposed to be, you know, more people in the workplace then.

Claire Webster (SCIE) 5:56

Yeah.

Yeah.

Yeah, absolutely.

R 6:22

Some simple things to sort of mentoring help with CB writing interviews.

You know, help with raising awareness of employers, that they're fantastic people out there. But for them, the actual interview process, I don't know how many interviews I've kind of, you know, messed up because I'm too direct and and don't play the game, can't play games.

R 6:42

So those those kinds of things, that awareness would be good.

Claire Webster (SCIE) 6:58

Is thinking about the female experience of autism, and there's been a lot of discussion which I think is really important about, for example, menopause and how menopause effects autistic women even more differently than the rest of the population. And we're not talking about it enough. And I wondered.

R 7:28

I had the menopause from hell. I mean, it may be almost suicidal. I used to drive to work and think I have to crash the car and die.

R 7:36

Because it was so bad at that time, it was before the the recent awareness as well. So I was sort of under almost, you know, threatened with disciplinary action for having time off.

Because I was a previous employer, previous school.

And but because I'm very persistent, I kind of tried every kind of hrti think until I found something that worked, but it was it was really, really bad. And and friends who just like had a few nights where, you know, oh few flutters and off you go. I had no idea it was it was very, very bad. Now I don't know whether that's me or.

R 8:09

Whether that's I wouldn't know whether that's, you know, unfortunately, I'm still over the age where most women my age, we didn't talk about it.

R 9:13

Basically, you know, The thing is well, the sleep, the sleep, the disturbed sleep and menopause. If you already have poor sleep. So my sleep is very odd, you know.

I've got Bing me. I've got, like, 10 years of data from sleep cycle.

R 9:29

You won't be surprised to know Mrs Data collection, so I know that my cycle of my sleep, I don't sleep like a good night. I'd go through this. I cycle through the different parts of the rhythm of sleep. And there are other nights where sleep cycle tells me that I've sat really, really well. But I know I've gone straight down into a deep sleep. I'm virtually dead. And then I wake up again. I feel terrible. So all sorts of weird things are happening as well already. And then on top of that, you pile on the fact that you can't sleep because you keep waking up every 5 minutes and going sort of meerkat mode like this. You know, you can't go back to sleep again.

I probably have ADHD as well, which doesn't help but.

Claire Webster (SCIE) 10:02

But it's again something that's usually quite expected as well, so.

So.

R 10:06

So.

So yeah, there are there are lots of interesting. It's very, very interesting. The whole research, you know, in the whole kind of what's going on is so interesting with it. But anyway, yes, there are lots of. Yeah, I do. I wouldn't. I wouldn't wish that experience on anybody.

R 10:59

And obviously then it's it's communicating, you know, so I'm chatting to you. It's fine. But I I do. I do get to sit when I'm tired or stressed. I find it very difficult to communicate. And if I you know I do. I have to make it my To Do List is like you know to actually communicate with my children my grown up children it's effort it's kind of hard.

R 11:19

It's so stupid. My eldest, my eldest son and I run a business together for a while and he was constantly you don't communicate, mum. You don't communicate.

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