Nottinghamshire Health & Wellbeing Board

NOTTINGHAMSHIRE JOINT STRATEGIC NEEDS ASSESSMENT

Nottingham and Nottinghamshire Integrated Care System: Autism

February 2025

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Executive summary

Introduction

Autism is a spectrum condition and affects people in different ways. Like anyone, autistic people have a range of strengths and challenges, and every autistic person will have their own unique experiences of being autistic. Autism is currently recognised as a lifelong disability which may affect how people communicate and interact with world, this can include:

- Differences in processing, understanding and interpreting social communication and interactions.
- Preference for routines.
- Repetitive behaviour which may serve a variety of purposes known as “stimming”.
- Differences in sensory processing.
- Highly focused interests.

These differences can offer many benefits but for some autistic people it can be challenging to adapt to a world that is too often centred around neurotypical people’s needs. For some autistic people, who may live with other co-occurring conditions, having the right adjustments or support to live well is essential, particularly in relation to accessing education, employment, social, and health services. Some autistic people may have little or no need for additional support to live their lives. Needs may also fluctuate over the course of a person’s life depending on the context and therefore it can be difficult to predict who may need additional support and when this support will be needed. Understanding a current medicalised approach and model to autism, needs to sit within a context of understanding neuro-affirmative practice, the philosophy and social movement, recognising the need to work towards ‘neurotype’ and respecting ‘autistic culture’ and the value of diversity[1].

Differences in sensory processing is one area where an autistic person may experience the world very differently to someone who is neurotypical. It is well understood that we all have 5 external senses (smell, taste, sound, sight and touch) but we also have 3 internal senses that affect how we feel, processing what our bodies are telling us, our position, movement and balance. Some autistic people may experience external and internal senses more strongly which can lead to a sensory overload, or some people may be under sensitive in processing sensory information. People who experience sensory differences may therefore need more support to manage their day-to-day life and could benefit from adjustments to the environment to reduce stressors. Some autistic people may only be able to process one sensory experience at a time and therefore when sensory overload occurs it can cause headaches, nausea, or a fight or flight response. It can also lead to some people shutting down completely. Some autistic people may struggle to filter information and so communicating information clearly or in a way the person prefers can increase accessibility for the person to crucial information.

[1] Hartman et al 2024 What does it mean to be neurodiversity affirmative? | BPS

Sometimes autistic people both consciously and unconsciously try to mask their differences. This has been particularly observed in autistic girls and women.[2] Masking or camouflaging autistic traits can be exhausting and is likely to have a negative impact on a person's health and wellbeing and therefore there is a need to accept differences and embrace neurodiversity.

There are many ways that communities and services can adjust and personalise their approach to be more inclusive to every autistic student, patient, and person. The NHS Long Term Plan » Learning disability and autism 2019 recommends that a 'digital flag' in the patient record will ensure that professionals in health services will know a patient has a learning disability or autism. The Equality Act 2010 sets out the legal obligation to make reasonable adjustments for people with disabilities. A failure to do so is not only unlawful but can represent a poverty of ambition for autistic people, and lead some to conclude that services are designed around the needs of the people who work in them, rather than the needs of the people who access them. Whilst there is a role for specialists and professionals, the person, their friends and family are the experts, and can reasonably expect that all services across education, social care, employers and health services will make adjustments to increase accessibility and positive outcomes to enable autistic people to thrive.

This chapter outlines the evidence that autistic people experience inequalities across health, education, employment and social opportunities. There has been a focus on building awareness of autism locally and nationally, however there is a need to move into a phase where services that support autistic people make adjustments and adaptations and seek to eliminate stigma, embracing the strengths of autistic people in order to reduce inequalities. This chapter will be used to support the Nottingham and Nottinghamshire Integrated Care System Autism Strategy to seek to improve the lives of autistic people locally. This chapter will use the term 'autism' as an umbrella term for all such conditions, in line with the terminology adopted by NHS England and will refer to "autistic people", using identify first language principles.

[2] Hull, L, Petrides, K.V, Mandy, W.(2020). The Female Autism Phenotype and Camouflaging: a Narrative Review. Springer Link. Volume 7, pages 306–317, (2020)

Unmet need and gaps

Access to Preventative Mental Health Provision: There remains a national and local programme to reduce the number of hospital admissions under the Mental Health Act for people with a learning disability and/or autism. Despite this, the evidence locally and nationally is that the numbers of people admitted into hospital is increasing and autistic people continue to be identified as at increased risk of suicide. Access to preventative mental health support that can make adjustments to support autistic people is required to prevent avoidable admissions into Hospital. The development of existing community-based mental health services to enable people to be supported before reaching the point of crisis is a key priority.

Reasonable adjustments across Health, Social Care, and Education services: There are identified inequalities in health, social and educational outcomes for autistic people. There are a range of barriers to accessing services for autistic people. Whilst significant activity has been undertaken to increase awareness of autism locally, there is a need for services to move to acceptance and adjustment. This will involve delivering services that take the time to understand what a person needs which will benefit everybody in the community, including autistic people and those without a formal diagnosis and improve access to meaningful support to prevent needs escalating.

Accommodation and Social Support: Some autistic people will require support to access good housing, that can meet their needs, in a place where they feel safe and may require support to live independently. There is evidence that autistic people do not feel they are able to access meaningful support and therefore working with people to understand how services can improve for autistic people is a key priority.

Employment: There is a need to ensure that autistic people have opportunities to gain skills and support to access paid employment and remain employed.

Assessment and Waiting Well: There is an increasing and high demand for autism assessments in Nottingham and Nottinghamshire and there are long waiting lists to receive a diagnosis. There is need to ensure that people receive regular communication whilst they are waiting and that they are able to access the right advice and support both before and after a diagnosis. There is also a need to ensure that opportunities for assessment are available to those where there are lower rates of prevalence such as women, older people and those from ethnic minority communities.

Planning services: Further work is required to understand the local population and identify needs, and priorities across health and social care services. Every autistic person is different and not everyone with a diagnosis will need support, and not everyone who needs support will have a diagnosis. Identifying where a person has autism can help services to consider current and future demand for services and working together with people with lived experience and their families to design services will lead to improved outcomes.

Recommendations for consideration

	Recommendation	Outcome	Lead
1	**Strategy** Refresh the Nottingham and Nottinghamshire Integrated Care Board All Age Autism Strategy with autistic people and their families to include key priorities to reduce inequalities and embed neuro - affirmative practice.	Agreed priorities for improving the experience of autistic people locally and reduced inequalities through the reasonable adjustment.	Nottingham and Nottinghamshire Integrated Care System – Learning Disability and Autism Programme
2	**Co-produce** Led by the expertise and experience of autistic people and their families and carers, strengthen the system approach to co-production and co-design with experts by experience in relation to the All-Age Autism strategy and subsequent implementation planning. Consider co-producing a needs-led toolkit for implementing adjustments for autistic people across Health, Social Care, Education and Employment services to reduce inequalities across all services.	System wide co- produced and co-designed refreshed All Age Autism strategy and Implementation Plan using the expertise and experience of autistic people and their families and carers.	Nottingham and Nottinghamshire Integrated Care System – Learning Disability and Autism Programme
3	**Governance** Strengthen existing governance structures, inclusive of but broader than the Learning Disability and Autism Board for implementing recommendations of this JSNA and the refreshed All Age Autism Strategy. Consider separate governance arrangements for the Autism Strategy with a focus on reducing inequalities.	Improved accountability to deliver change.	Learning Disability and Autism Programme Executive Board
4	**Understand** Nottingham and Nottinghamshire Integrated Care System to complete a review of data collected and data gaps with a view to improving quality of data, to have a better understanding of inequalities to assessment and support that exceeds national requirements via Assuring Transformation reporting in assessment.	Improved understanding of population and support development of future services	Nottingham and Nottinghamshire Integrated Care System – Learning Disability and Autism Programme
5	**Prioritise** Working with people with lived experience, to review local suicide prevention plans to include a focus on autism as a key at risk group.	Reduced prevalence of suicide in	Public Health and Nottingham and Nottinghamshire Integrated Care

		autistic people locally	System – Learning Disability and Autism Programme
6	**Mental Health** Review the experiences of autistic people when accessing community and inpatient Mental Health Services with a view to co-producing an implementation plan for making needs led adjustments to include a focus on communication and sensory differences and accelerate wraparound model learning.	Reduced inequalities and Improved mental health services for autistic people	Nottinghamshire NHS Foundation Trust and Nottingham and Nottinghamshire Integrated Care Board– Learning Disability and Autism Programme engaged with community and voluntary sector organisations.
7	**Implement** recommendations in relation to the review of the neurodevelopmental pathway for children and young people, working with families and autistic children and young people and the Special Educational Needs and Disabilities Improvement Plan	Supported waiting well principles and improving education	Nottingham and Nottinghamshire Integrated Care Board and Nottinghamshire NHS Foundation Trust
8	**Transition** Review the experiences of autistic children and young people who are transitioning to adult services and consider the opportunities for improving experiences through learning with people with lived experience.	Improved transitions into adulthood	Nottingham and Nottinghamshire Integrated Care System – Learning Disability and Autism Programme
9	**Employment** Consider the need for a separate strategy for improving employment opportunities for autistic people across Nottingham and Nottinghamshire Integrated Care System which seeks to better understand the opportunities to influence improved outcomes for local people.	Reduced inequalities and improved access to employment and improved adjustments	Nottingham and Nottinghamshire Integrated Care System
10	**Workforce Development** Continue to implement and evaluate Oliver McGowan training across the system and continue to develop infrastructure to roll out programme of National Autistic Society SPELL Framework training and pilot the Anna Freud National Autism Training Programme with a view to supporting staff to adapt approaches.	Delivered better autism informed services	Nottingham and Nottinghamshire Integrated Care System – Learning Disability and Autism Programme

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Full JSNA report

Notable changes from previous JSNA

Since the publication of the Autism JSNA 2019, economic, political, and social changes have influenced health and social care services being provided for neurodivergent children, young people, and adults both locally and nationally. The COVID-19 pandemic was an unprecedented challenge which had an impact on individuals, communities and governments across the world. Autistic people were significantly impacted by the pandemic, both directly, and indirectly due to severe service disruptions, social restrictions, and were suggested to be seven times more likely to be chronically lonely that the general population and six times more likely to have low life satisfaction.[3]

This chapter provides:

- An insight into the prevalence of autistic people living in Nottingham and Nottinghamshire.
- Exploration of several interconnected areas, using a range of data sources, to enhance understanding of health needs, inequalities, and aligned aspects of wellbeing such as social needs and employment.
- An overview of current service provision and assets.
- An exploration of policy guidance, literature and population data, national context and local context, current service provision and unmet needs in Nottingham and Nottinghamshire.
- Identified recommendations to support future planning in relation to local need and reducing inequalities for autistic people and their families to inform the All-Age Autism Strategy refresh.

[3] National Autistic Society. LeftStranded Report.indd (thirdlight.com)

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What do we know?

1. Who is at risk and why?

1.1 Premature Mortality and Suicide Prevention

Autistica's Happier, Healthier, Longer Lives report demonstrated 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.[4] Important factors include:

- Approximately 1 in 5 women with an eating disorder were autistic. Anorexia has the highest mortality rate of any mental illness.[5] [6] [7]
- A disproportionate number of people who die by suicide are autistic. Ongoing research suggests up to 11% of people who die by suicide have autism.[8] Autistic women are significantly more likely to due by suicide than neurotypical women.[9]
- Between 15% and 40% of people with epilepsy are autistic. Epilepsy is the leading cause of death for autistic people with a learning disability. [10]

The Learning from Lives and Deaths - people with a learning disability and autistic people report, published in November 2023, found the median age at death for people with a learning disability was 62.9 years and 55 years for autistic people with a learning disability compared to 86.1 years for women in the general population and 82.6 years for men.

The national LeDeR programme began reviewing the deaths of autistic adults without a learning disability in 2022 and found that within 36 reviews the most common causes of death were suicide, drug and alcohol related deaths and accidental deaths, such as falls. The review noted that ethnicity was strongly associated with age at death, and that people from an ethnic minority background with a learning disability (black, black British, Caribbean or African and Asian British) were more likely to die younger than those who were white.

[4] Hirvikoski T, et al. (2016). Premature mortality in autism spectrum disorder. The British Journal of Psychiatry, 207(5), 232-8. ncbi.nlm.nih.gov/pubmed/26541693
[5] Mandy W & Tchanturia K (2015) Do women with eating disorders who have social and flexibility difficulties really have autism? A case series. Molecular Autism 6:6. molecularautism.biomedcentral.com/articles/10.1186/2040-2392-6-6
[6] Westwood H, et al. (2017) Clinical evaluation of autistic symptoms in women with anorexia nervosa. Molecular Autism 8:12. ncbi.nlm.nih.gov/pubmed/28331571
[7] Koch S, et al. (2015). Autism spectrum disorder in individuals with anorexia nervosa and in their first- and second-degree relatives: Danish nationwide register-based cohort-study. Br J Psychiatry 206(5), 401-7 ncbi.nlm.nih.gov/pubmed/25657359
[8] Autistica (2017). Current research project – understanding suicide in autism. autistica.org.uk/our-research/research-projects/understanding-suicide-in-autism
[9] Cassidy S, et al. (2014). Suicidal ideation and suicide plans or attempts in adults with Asperger's syndrome attending a specialist diagnostic clinic: a clinical cohort study. Lancet Psychiatry 1, 2, 142-7. docs.autismresearchcentre.com/papers/2014_Cassidy_et_al_Suicidality_LancetPsychiatry.pdf
[10] Robertson J, et al. (2015) Prevalence of epilepsy among people with intellectual disabilities: A systematic review. Seizure – Eur J Epilep 29, 46-62. <ncbi.nlm.nih.gov/pubmed/26076844

In a recent study, Cassidy et al 2022 found through analysis of 372 coroners' inquest records in two regions of England, there was evidence of autism and elevated autistic traits in 10.7% of those who died by suicide – 11 times higher than prevalence of autism in the UK general population similarly including previously unknown diagnoses of autism (1.1%). Given that coroners' records do not systematically gather evidence of autism and autistic traits, this is likely an underestimate of the true rate.[11]

Reducing the prevalence of suicide for autistic people is a key priority. A new Nottingham and Nottinghamshire Self-Harm and Suicide Prevention Strategy was developed and includes an ambition to reduce suicide in at-risk groups[12] however does not specifically examine the experience of autistic people. A closer examination of how we can work with autistic people to reduce the risks of suicide is recommended as part of this chapter. The Integrated Care System continues to commission free suicide prevention, self-harm awareness, mental health awareness and suicide bereavement training (provided by Harmless). This is free to access for people working and volunteering across Nottingham and Nottinghamshire. In 2021 the International Society of Autism Research recommended autism adapted Safety planning has been recommended and feasibility trials suggest further research in autism adapted safety planning in their recent policy briefing.[13]

1.2 Pattern of Health Needs

National strategy for autistic children, young people and adults: 2021 to 2026 - GOV.UK (www.gov.uk) sets out that there is poor understanding of autism amongst health care professionals and symptoms can be overlooked by professionals. Autistic people may not get the right support when accessing health services, with the right reasonable adjustments and therefore may have traumatic experiences and avoid seeking help. Autistic people are found to have poorer health outcomes than the neurotypical population. Research has found that autistic people are more likely to develop health needs which include heart disease, diabetes, stroke, Parkinson's disease, allergies, gastro-intestinal disorders and autoimmune conditions.[14] Whilst the reasons for this are not fully understood, the correlation is well established. There is some evidence that autistic people are more likely to be obese[15] and experience issues with sleeping[16]. Research describes that these factors can lead to increased prevalence of comorbidities, and poorer physical health outcomes.

Studies have demonstrated that, mental health services do not adequately support autistic adults, and can even cause additional harm.[17] In addition, the prescription of psychotropic medications could

[11] Cassidy et al.(2022). Autism and autistic traits in those who died by suicide in England. docs.autismresearchcentre.com/papers/2022_Cassidy_Autism-and-autistic-traits-in-those-who-died-by-suicide-in-england.pdf
[12] Nottinghamshire Self Harm and Suicide Prevention Strategy 2024 selfharmsuicidepreventionstrategy.pdf
[13] International Society of Autism Research (2021). Autism Community Priorities for Suicide Prevention Policy Briefing. cdn.ymaws.com/www.autism-insar.org/resource/resmgr/files/policybriefs/2021-insar_policy_brief.pdf
[14] Croen L, et al. (2015) The health status of adults on the autism spectrum. Autism 19(7), 814-123. <ncbi.nlm.nih.gov/pubmed/25911091>
[15] Broder-Fingert S, et al. (2014). Prevalence of Overweight and Obesity in a Large Clinical Sample of Children With Autism. Academic Pediatrics 14(4), 408-414. <ncbi.nlm.nih.gov/pubmed/24976353>
[16] Ballester P, et al. (2018) Sleep problems in adults with autism spectrum disorder and intellectual disability. Autism Research 12(1). onlinelibrary.wiley.com/doi/full/10.1002/aur.2000>
[17] Brede J, Cage E, Trott J, Palmer L, Smith A, Serpell L, Mandy W, Russell A. (2022) We Have to Try to Find a Way, a Clinical Bridge" - autistic adults' experience of accessing and receiving support for mental health difficulties: A systematic review and thematic meta-synthesis. Clin Psychol Rev. 2022 Apr;93:102131. doi: 10.1016/j.cpr.2022.102131. Epub 2022 Feb 9. PMID: 35180632.



also be a contributory factor as the long- term use of medications of this type can cause other health problems.[18] Health behaviours of autistic people could be better understood however improving access to services through neuro-affirmative practice is likely to lead to better health outcomes for autistic people.

Some research suggests that autistic people are more likely to have treatment resistant epilepsies[19] and that epilepsy can sometimes presently differently in autistic people.[20]

The King's Fund vision for population health sets out a framework for population health, that focuses activity across four pillars.

- The wider determinants of health: these are the most important driver of health. In addition to income and wealth, these determinants include education, housing, transport and leisure.
- Health behaviours and lifestyle: are the second most important driver of health. They include smoking, alcohol consumption, diet and exercise. For example, while reductions in smoking have been a key factor in rising life expectancy since the 1950s, obesity rates have increased and now pose a significant threat to health outcomes.
- Places and communities: our local environment is an important influence on our health behaviours, and there is strong evidence of the impact of social relationships and community networks, including on mental health.
- Integrated health and care systems: this reflects the growing number of patients with multiple long-term conditions and the need to integrate health and care services around their needs rather than within organisational silos.

Improving population health requires action on all four of the pillars and, crucially, the interfaces and overlaps between them.[21] In order to tackle health inequalities for autistic people, action will be required across all four of these pillars.

1.3 Cancer screening

Cancer Screening - NHS England Digital introduced a new indicator for Breast Cancer screening for autistic females aged 50 to 69. The percentage of patients who were female, aged 50 to 69 with autism and a learning disability who were screened for breast cancer was 38.5% compared to 53.8% of female patients aged 50 to 69 who have autism but do not have a learning disability. In colorectal cancer screening there is a 4.3% increase in diagnosis between autistic patients who have a learning disability (53.2%) and those without (57.5%).

1.4 Access to Health and Social Care

The majority of autistic people will access generic health and social care services. Whilst in some ways this may be appropriate because of the presenting need, a lack of understanding and adjustment for autistic people by generic services can sometimes prove problematic and traumatic

[18] Public Health England (2019) Psychotropic drugs and people with learning disabilities or autism. <bit.ly/2Uti4GY>
[19] Bolton PF, et al. (2011). Epilepsy in autism: features and correlates. British Journal of Psychiatry, 198, 289-294. ncbi.nlm.nih.gov/pmc/articles/PMC3065774/>
[20] 1 Sansa G, et al. (2011) Medically refractory epilepsy in autism. Epilepsia 52(6). <onlinelibrary.wiley.com/doi/full/10.1111/j.1528-1167.2011.03069.x>
[21] The Kings Fund (2023). A vision for population health: towards a healthier future. www.kingsfund.org.uk/insight-and-analysis/reports/vision-population-health

for the person. The national strategy for autistic children, young people and adults: 2021 to 2026 is committed to delivering, "significant improvements to the provision and quality of community support, including social care, mental health and housing support. This will prevent more autistic people from reaching crisis point. For autistic people who require care within inpatient settings, we want to show this is of high quality, therapeutic and tailored to their needs, and as close to home as possible." [22]

The NHS Long Term Plan details a commitment to trialling a specific Health Check for autistic people. There is a need for better recording and improved data to identify autistic people and invite them to Health Checks in order to implement this more widely. A trial is currently being undertaken with Newcastle University and feedback from this is due in 2025. Initial feedback is that to implement this more widely, there will need to be a creation of a Quality Outcomes Framework (QoF) autism register with funded support from NHS England. Whilst primary care reporting of autism is good locally, wider health and social care systems in Nottingham and Nottinghamshire do not reliably record where a person has a confirmed assessment of autism nor is there a record where people self-identify as being autistic. Some clinical systems do not allow healthcare providers to report more than one diagnosis and often a person's autism is not the primary healthcare need for that provision.

There is also the need to make health and social care services more accessible to autistic people. Autistica outlined the following ways that services could be adjusted improve accessibility for autistic people[23]:

- Autistic people's communication and sensory needs vary and will therefore require different adaptations.
- For planned appointments, services should try to identify a person's needs before the visit or where this isn't possible, try to be flexible.
- Allowing autistic people more time to process questions, providing clear explanations and avoiding metaphorical language may be helpful.
- Where possible, services should provide information in advance about what to expect during or before a medical appointment. Uncertainty is a known cause for anxiety amongst autistic people and can exacerbate sensory difficulties.
- Providing information and pictures in advance can help autistic people prepare themselves for challenging physical environments and social interactions.
- Giving patients a choice about how they make an appointment (e.g. online instead of over the phone) and when that appointment could be (e.g. at a quieter time of day or during a specific time in a routine).

A Department for Health and Social Care study published in 2021 spoke to study participants about their experiences in accessing social care services.[24] Key recommendations from this study included:

- The importance of social workers in promoting key values in relation to personalisation and enabling choice and autonomy of the autistic person.
- The importance of maintaining contact with autistic people regardless of their current setting, and that they build strong relationships across agencies.

[22] National strategy for autistic children, young people and adults: 2021 to 2026 - GOV.UK (www.gov.uk)
[23] Building-Happier-Healthier-Longer-Lives-The-Autistica-Action-Briefings-2019.pdf
[24] https://www.gov.uk/government/publications/social-work-and-autistic-young-people-an-exploratory-study/a-spectrum-of-opportunity-an-exploratory-study-of-social-work-practice-with-autistic-young-adults-and-their-families#recommendations

- Ensuring autistic people have access to a qualified social worker with specialist knowledge and skills to work with autistic people, and across the full spectrum of health and care. This is supported by the NICE quality statements which set out that autistic people should be offered a named key worker to coordinate care and support.
- Ensuring that local Integrated Care Boards share a dynamic risk support register in the local area, jointly owned by health social care and education, which identifies children and autistic people at risk of admission to an institutional setting.

In a large survey of autistic people over 60% of adults said that they do not have enough support to meet their needs for social support; and of these, 70% said that with more support they would be less isolated, and over 60% said they would be more independent, and their general health would improve (Bancroft et al. 2012).[25]

Autistic people may be more likely to experience loneliness and feel socially isolated than non-autistic people. This can be due to a lack of acceptance and adjustment which leads people to feel excluded from social networks. Environments for socialising may not be suitable sensory experiences for some autistic people and some autistic people will have experienced bullying and trauma from social interactions in the past. This can lead to a deterioration in a person's mental health, stress, social withdrawal, feelings of anger, and can lead people to be more vulnerable to abusive relationships, and increased masking of autistic traits. Ensuring there are local opportunities for autistic people to socialise and that networks are adapted to meet the needs of autistic people is necessary to reduce social isolation as a means of preventing deterioration in people's wellbeing and physical and mental health.

Findings from research conducted in 2020 indicated that there is a lack of services and support available for autistic people and the area is under researched. The review found no research relating to interventions to improve physical health and wellbeing. In both physical and mental health services adaptations required from within services are cited as: communication needs, sensory needs and support reporting executive functioning and the service context[2627].

Due to limitations in reporting, it is not known how many autistic people in Nottingham and Nottinghamshire currently receive support from social care services. The Adult Social Care Outcomes Framework (ASCOF) measures how well care and support services achieve the outcomes that matter most to people. The measures are grouped into four domains which are typically reviewed in terms of movement over time. Data is provided at council, regional and national level. There are no specific measures in relation to autistic populations.

Using limited data, Nottinghamshire County Council are supporting at least 600 people with autism although the figure is likely to be higher as it is not always recorded where people have co-occurring conditions. There has been an increase in demand for social care services, although figures are not fully understood.

[25] Bancroft et al. (2012) The way we are: autism in 2012. National Autistic Society
[26] Mason D, Ingham B, Urbanowicz A, Michael C, Birtles H, Woodbury-Smith M, Brown T, James I, Scarlett C, Nicolaidis C, Parr JR. (2019). A Systematic Review of What Barriers and Facilitators Prevent and Enable Physical Healthcare Services Access for Autistic Adults. J Autism Dev Disord. 2019 Aug;49(8):3387-3400. doi: 10.1007/s10803-019-04049-2. PMID: 31124030; PMCID: PMC6647496
[27] Brice S, Rodgers J, Ingham B, Mason D, Wilson C, Freeston M, Le Couteur A, Parr JR. (2020). The importance and availability of adjustments to improve access for autistic adults who need mental and physical healthcare: findings from UK surveys. BMJ Open. 2021 Mar 18;11(3):e043336. doi: 10.1136/bmjopen-2020-043336. PMID: 33737429; PMCID: PMC7978247.

Innovation networks across health and social care have invited Commissioners to adapt their approach from conventional commissioning practices to "asset based" approaches which seeks to take a strengths-based approach to consider what people and their families can achieve with the right support. A key principle of this approach is to co-produce services with the people that will use them where people work together to design and prioritise service provision. This increases the opportunity to ensure services are fit for purpose, meet the needs of the people accessing them and prevents the need for crisis interventions. There is also evidence that when people are involved in co-production it increases their health and wellbeing. In order to improve services for autistic people, it is essential that they are involved in the planning, prioritising and design of local service provision.

1.5 Children and Young People

There continues to be high levels of demand for children and young people to be assessed for autism and there are likely to be more children and young people who are not diagnosed. National prevalence of autism in children and young people has increased from 1% to 2.78%[28]. Using Census 2021 population information this broadly projects that there were 1,834 autistic children between the ages of 0-18 in Nottingham city and 4684 autistic children living in the Nottinghamshire County.

Many children and young people may not have a formal diagnosis or may be waiting for an assessment. Nottingham and Nottinghamshire Integrated Care System have reviewed the diagnostic pathway for children and young people and published their report in April 2024.[29] 248 individuals were surveyed about their experience of the local assessment pathway. The primary concerns voiced by parents were about communication and support. While the extended waiting times were acknowledged as a barrier, many parents expressed a desire for more consistent communication and support during the waiting period, particularly in relation to education and mental wellbeing. Steps are being taken for Nottingham and Nottinghamshire integrated Care System to put in place action plans and implement changes to improve the local offer.

The National Autistic Society have undertaken research in relation to how autistic children, young people and their families experience education and published a report with their findings in 2023 .[30] The report found that there are over 180,000 autistic children and young people living in England and 73% attend mainstream schools and three out of four of the families of these autistic children felt the schools were not able to meet the needs of the young person. The research found that schools were not routinely putting in place adjustments to reduce sensory overload, improved training was needed for teachers and more support was needed to help children and young people with transitions. Separate Joint Strategic Needs Assessments for Special Educational Needs and Disabilities are available from Nottingham and Nottinghamshire that outline local plans for education.

The transition between childhood and adulthood is often a time of enormous change. Different legal frameworks are applied in health and care settings and very often there are different services available, with different pathways. This can give children, young people and their families the impression that becoming an adult is a "cliff edge". Both Nottingham City Council and Nottinghamshire County Council have social care teams that work with young people and their families to prepare for transitions into adulthood. Both authorities also have access to Key Working

[28] https://www.cdc.gov/autism/data-research/?CDC_AAref_Val=https://www.cdc.gov/ncbddd/autism/data.html
[29] Final-Neurodevelopmental-Assessment-CYP-Pathway-Review-.pdf (rainbowpcf.org.uk)
[30] https://www.autism.org.uk/what-we-do/news/education-report-2023

Services for autistic children and young people who are at risk of going into hospital or other care settings to offer support during these key transition phases. Nottingham and Nottinghamshire Key-working service provides support to children and young people with autism and/or a learning disability who are deemed at risk of hospital admission or placement breakdown due to mental health struggles. The service works with children and young people (CYP) up to the age of 25 years old and referrals can be made for a child or young person who is on the Dynamic Support Register (DSR). The keyworker will manage a caseload with focus on providing therapeutic intervention that is strengths-focused, evidence-based and tailored to meet the needs of the child/young person and their family/carer

1.6 Gender, and Identity

Five times as many autistic males receive a diagnosis than females. Research suggests that autism spectrum disorders are under-diagnosed in females, and therefore the male to female ratio of those who are on the autism spectrum may be closer than the 5:1 ratio. Research suggests it is much more difficult for females to gain a diagnosis of autism and that they are more likely to be misdiagnosed. Gould et al (2017)[31] recommended that because women and girls present differently from men and boys, diagnostic questions should be altered to identify women and girls and non-binary autistic people with who might otherwise be missed or diagnosed later in life linked to treatment for a co-occurring condition such as a mental health condition or eating disorder.

Table 1: Number of autistic children, young people and adults in Nottingham & Nottinghamshire with a confirmed diagnosis by gender as of September 2024.

	Children and Young People		Adults	
	Female	**Male**	**Female**	**Male**
Nottingham City	860	2,501	963	2,010
Nottinghamshire County	2,345	5,865	2,006	4,715
Total	3,205	8,366	2,969	6,725

Source: E-Healthscope Nottingham and Nottinghamshire Integrated Care System (September 2024)

Autistic women and girls face serious health inequalities. Autistic women with a learning disability are among those at highest risk of early death in the autistic community.[32] Autistic women are also markedly more likely to die by suicide than non-autistic women, and report lower quality of life than their male peers.[33] Initial evidence suggests that autistic women are at greater risk of abuse.[34] Data on non-binary people is not recorded consistently within health and social care services. Professionals supporting people with identity differences need to be suitably skilled to work with autistic people around this area of need. Likewise, there is a requirement for autistic adults to be able to access appropriate sexual health services, advice and education delivered by suitably qualified staff with experience of working with autistic adults and young people. Exploring autism and

[31] Gould, J et al (2017). Towards understanding the under-recognition of girls and women on the autism spectrum. Sage Journals Volume 21, Issue 6
https://doi.org/10.1177/13623613177061
[32] Hirvikoski T, et al. (2016). Premature mortality in autism spectrum disorder. The British Journal of Psychiatry, 207(5), 232-8.
<ncbi.nlm.nih.gov/pubmed/26541693>
[33] Mason D, et al. (2018) Predictors of Quality of Life for Autistic Adults. Autism Res 11(8), 1138-1147.
<ncbi.nlm.nih.gov/pmc/articles/PMC6220831/>
[34] Griffiths S, et al. (manuscript in preparation) Social vulnerability and mental health in adults with autism spectrum conditions. <autistica.org.uk/our-research/research-projects/why-are-autistic-people-more-vulnerable>

identity involves understanding the resources, support systems, and community initiatives available to autistic people and their families.

1.7 Ageing

English primary care data for 2020–2021 indicate that 0.1% or fewer of adults in the 50+ age-bands had a diagnosis, despite the evidence from community case-finding studies that autism prevalence is similar across different ages.[35] It is estimated that in 2025 there will be 2,222 autistic people aged over 65 in Nottinghamshire however there fewer than 180 adults over the age of 65 with a confirmed assessment of autism. Given there is an ageing population in Nottinghamshire and increasing demand for autism assessments, it is important to investigate the outcomes and experiences of older autistic adults. It is important to improve recording in relation to autism and ageing locally to help ensure autistic adults are able to access adjustments in older adult services across health and social care.

A study found that higher autistic traits were associated with poorer reports of physical health and a faster pace of ageing in midlife[36]. As autistic people age, they may develop additional needs and encounter additional problems. Dementia symptoms may be masked in the early stages or the person may develop further difficulties, e.g. sensory, as a result of dementia. Additionally, as people age, they are likely to experience additional physical health needs and it is important that any new symptoms are identified as early as possible to ensure treatment.

1.8 Autism and Ethnic Minorities

There is limited research which focusses on the experience of Black, Asian and Minority Ethnic communities around autism. The National Autistic Society report "Diverse Perspectives" published in 2014 found that some communities lacked an understanding of autism which could lead to stigma and shame around someone being autistic which resulted in families not seeking support and social isolation. In addition to this there was a lack of confidence in and mistrust of professionals and other barriers in terms of accessing services.

A more recent survey[37] outlines further evidence that the stance a family or community take about a condition such as autism is influenced by their cultural background and identified the need for collaboration to improve autism awareness within the community and understanding by professionals of the intersectionality between autism and identity in families across different communities was prioritised. Issues around feelings of stigma were common, but delegates felt that these were not well understood beyond people identifying as Black, Asian and Minority Ethnic.

In Nottingham and Nottinghamshire, 87% of people who have an autism diagnosis are white and 13% are from Black, Asian or Minority Ethnic communities. There is an ethnically diverse white non-

[35] O'Nions et al (2023) Autism in England: assessing underdiagnosis in a population-based cohort study of prospectively collected primary care data - ScienceDirect. The Lancet. Science Direct. Vol 23.

[36] Mason, D et al (2021) Autistic traits are associated with faster pace of aging: Evidence from the Dunedin study at age 45. Autism Research https://onlinelibrary.wiley.com/doi/10.1002/aur.2534

[37] Kandeh, M (2020) Autism in black, Asian and minority ethnic communities: a report on the first Autism Voice UK Symposium. https://ndconnection.co.uk/resources/p/autism-in-black-asian-and-minority-ethnic-communities-a-report-on-the-first-autism-voice-uk-symposium

British population in Nottingham and Nottinghamshire with 9% of the general population identifying as non-white non-British, including 6.1% in Nottingham City.

Table 2: Ethnicity of people assessed as autistic in Nottingham and Nottinghamshire, May 2024

Category	Number of people assessed as autistic where ethnicity is recorded	Percentage of autistic people in each Ethnicity category (2021 Census Data)
White Ethnic Group	17390	1.8%
Mixed Ethnic Group	985	3.3%
Asian Ethnic Group	755	1.1%
Black Ethnic Group	545	1.4%
Other Ethnic Group	195	1.5%
White Gypsy or Irish Traveller ethnicity group	15	Data not available

Source: E-Healthscope Nottingham and Nottinghamshire Integrated Care Board. May 2024

1.9 Autism and Learning Disabilities

It is recorded that 10.3% of autistic adults in Nottingham and Nottinghamshire have a co-occurring learning disability. Autism - NHS England Digital indicates that 3 in 10 people with a learning disability also have an autism diagnosis however it also notes people with a learning disability are 26 more times likely to receive an autism diagnosis than people without a learning disability.[38] Public Health England's data indicates that individuals with autism and learning disabilities have poorer health outcomes compared to the general population. This includes higher rates of mental health issues and lower life expectancy. This is particularly the case for autistic people with a learning disability and epilepsy. Nottingham and Nottinghamshire Integrated Care Board report that there are 2115 autistic people with a co-occurring learning disability, however this figure will not reflect the population that has not been assessed.

Nottingham and Nottinghamshire is an established Integrated Care System, within which Learning Disabilities and Autism Transformation is overseen by the Learning Disability and Autism Programme Executive Board. The Executive Board has strategic oversight of the transformation programme. The operational detail of which is overseen by the Operational Delivery Group. The Integrated Care System maintain a dynamic risk register for children, young people and adults with learning disabilities and autistic adults who are at risk of admission into hospital under the Mental Health Act. The aim is to report concerns early enough that actions are taken to reduce the risk of people going into hospital. Autistic people are more likely to receive support if they also have a co-occurring condition such as a learning disability which has been identified in childhood or a mental

[38] Health and Care of People with Learning Disabilities Experimental Statistics 2020 – 2021. NHS Digital Data – Autism. (2021) https://digital.nhs.uk/data-and-information/publications/statistical/health-and-care-of-people-with-learning-disabilities/experimental-statistics-2020-to-2021/autism#:~:text=The%20percentage%20of%20patients%20with,rise%20of%208.8%20percentage%20points

health problem. If an adult with autism does not receive the support they need for this condition they are more likely to develop a mental health problem.

1.10 Mental Health

Autistic children and adults are more likely to have a mental health condition. It is understood that 7 in 10 children with autism have a mental health condition and 4 in 10 have more than one.[39] 8 in 10 adults with autism have a mental health condition and up to 10% of adults in mental health inpatient settings are autistic[40] and 11% of people who die by suicide are autistic and that Nice Guidelines recognise that autistic people are among those who are at highest risk of suicide.[41]

It is recorded by Nottingham and Nottinghamshire Integrated Care Board that 2% of the autistic population in Nottingham and Nottinghamshire have a co-occurring serious mental illness. Autistic people can experience social isolation, which can contribute to feelings of loneliness, anxiety, and depression. Sensory sensitivities common in autism can also lead to heightened stress and anxiety, particularly in overwhelming environments. Higher rates of bullying and social discrimination faced by autistic people can also exacerbate mental health issues. Mental health conditions in autistic people are sometimes overlooked or misdiagnosed, as symptoms which may be attributed solely to autism, this is particularly reported in children and young people experiencing mental health issues.

Factors known to increase people's risk of suicide are more common in the autistic community, including social isolation, unemployment, trauma, abuse and other social and biological factors that increase the likelihood of mental health problems. A recent study showed that whilst autistic people were less likely to engage in substance misuse, those that did engage in substance misuse, tended to do so to reduce sensory overload, mask their autism or manage their mental health as a form of self-medicating. This study found that autistic people were four times more likely to report vulnerability associated with substance use compared to their non-autistic peers, including dependence/addiction, using drugs to deal with past trauma, and substance use associated with suicide.[42]

1.11 Treatment and Support for Mental Health

In 2019, the NHS Long Term Plan » Learning disability and autism pledged to halve the number of autistic people in mental health inpatient care by March 2024 compared to 2015 levels. The Government also promised to reform the Mental Health Act 1983 to reduce the inappropriate detention of people with a learning disability and autistic people in mental health hospitals in the long-term. Government figures published in May 2024 show that since March 2015 the number of autistic people in mental health settings has increased from 1,115 to 1,380. This includes an increase in the number of autistic women from 390 to approximately 500 over the last five years. Autistic

[39] Autistica Action Briefing: Children and Young People's Mental Health (2019) https://www.autistica.org.uk/downloads/files/Autistica-Action-Briefing-Children-and-Young-Peoples-Mental-Health.pdf

[40] Autistica Action Briefing: Adult Mental Health (2019) https://www.autistica.org.uk/downloads/files/Autistica-Action-Briefing-Adult-Mental-Health.pdf

[41] Cassidy, Understanding Suicide in Autism, Autistica (2017) https://www.autistica.org.uk/our-research/research-projects/understanding-suicide-in-autism#:~:text=The%20research%20findings,autistic%20or%20have%20autistic%20traits.

[42] Weir, E, Allison, C, & Baron-Cohen, S (2021). Understanding the substance use of autistic adolescents and adults: a mixed methods approach. The Lancet Psychiatry

people are also more likely to stay in hospital longer with 53% of autistic people staying in hospital for over 2 years. [43]

NHS England » Meeting the needs of autistic adults in mental health services (2023) recommends that there are 4 levels of access to mental health support for autistic people and recommend that good mental health care for autistic adults can be provided by all mental health services; not just those commissioned specifically for autistic people.
The four levels are:

- Level 1: Staying well in the community
- Level 2: Planned mental health care
- Level 3: Crisis care
- Level 4: Inpatient care

Early and preventative support for autistic people struggling with their mental health is essential in order to reduce admissions into mental health wards. It is essential that where possible autistic people are supported to access the right support in the community, which includes adjustments in therapeutic approaches and communication methods. There is growing evidence around the need to adapt therapies such as Cognitive Behavioural Therapy and the increased effectiveness of these therapies when adaptations are made.[44] Early identification of mental health conditions can help mitigate the severity of symptoms and improve long term outcomes.

In Nottingham and Nottinghamshire, autistic people access mental health support via the Local Community Mental Health Teams. These are stretched services with limited expertise in autism. Nottinghamshire NHS Foundation Trust has supported additional roles, including one full time equivalent Speech and Language Therapist to support the Local Mental Health teams to implement reasonable adjustments for autistic people but demand for input is high and waiting lists for specialist input can be over 12 months.

Nottingham and Nottinghamshire Integrated Care System share a register of autistic people who are at risk of admission into Hospital due to their mental health. In January 2024 there were 58 autistic adults listed on this register with no learning disability and 43 autistic children. It is not fully understood how many autistic people have been detained under the Mental Health Act in Hospital in Nottingham and Nottinghamshire however it is known that 70-80% of autistic adults will experience mental illness during their lifetime, which is considerably higher than the general population rate of 25%. According to data available from Nottinghamshire Healthcare Trust 48% of patients who were reported as having autism within primary care services have been referred to local mental health services and from 2020 to 2022 an average of 8.33% of people accessing Local Mental Health Teams were autistic. It is important to note that this data is likely to underrepresent the true picture, as recording of people with an autism diagnosis is limited and does not take into account the undiagnosed population. In April 2024 the Integrated Care Board reported that there were 30 autistic people in mental health settings across Nottingham and Nottinghamshire, however this figure is likely to be higher and only includes those with a formal confirmed assessment.

In adulthood should secondary mental healthcare be required whether through local mental health teams, specialist community pathways, urgent care pathways or inpatient care, there are no clear recommendations on adaptations or accessibility to services. A process of adaptation should be

[43] https://publications.parliament.uk/pa/cm5804/cmselect/cmwomeq/134/report.html#heading-1

[44] Nicolaidis C, et al. (2015) “Respect the way I need to communicate with you”: Healthcare experiences of adults on the autism spectrum. Autism 19(7), 824-831. ncbi.nlm.nih.gov/pmc/articles/PMC4841263

individualised and recognise the impact on a person's autism, and the limited resources available and an 'inflexible system' (Moore et al 2023)[45]. Locally during SPELL training (NAS) 75 staff completed a baseline survey highlighting low confidence ratings in awareness of autism and personalised care. In other Integrated Care Systems responses to evidence and local need have seen developments of a more diverse outreach support system e.g. Lancs & South Cumbria Autism Outreach Team. There is the opportunity to learn from successful models such as ECHO Autism » Bringing the Best Autism Care to Local Communities which includes knowledge sharing networks and mentoring to ensure good quality services are available locally.

Hospital environments are often busy places, with lots of sensory information to process which can have a significant and negative impact on some autistic people. Reasonable adjustments can be made to improve patients' experience. Nottinghamshire Healthcare NHS Foundation Trust have published their approach to reasonable adjustments that can be made in hospital for autistic people to Environmental considerations and adjustments for autistic people | Nottinghamshire Healthcare NHS Foundation Trust.

The Mental Health Act reforms highlight that Mental health hospital settings can often be unsuitable for people with a learning disability and autistic people, and risk worsening health outcomes due to inappropriate care and lack of therapeutic value, sensory overload, communication problems and staff training; restrictive intervention and delays to discharge. The government briefing highlights that Stakeholders agree that ideal care for people with a learning disability and autistic people is community-based, with an emphasis on quality of life and social inclusion to reduce the risk of crisis and that Community-based care for people with a learning disability and autistic people includes appropriate housing and care and support services, alongside specialist community teams. Baroness Hollins (2021) concluded a review of autistic people and people with a learning disability in long term segregation with significant recommendations. These included:

- Commissioners and the organisations they work for should be held accountable for poor use of public money - especially where their spending decisions result in human rights abuses and other unlawful actions by public bodies, such as failing to uphold the Care Act 2014
- Staff working with people with a learning disability and/or autistic people should be delivering therapeutic and human rights-based care culture and infrastructure in the community enables positive risk taking to help people to develop and grow.
- All staff that use any restrictive practice need to be trained in specialist interventions including the HOPES model
- An improvement in practice leadership is seen through specialist training
- Access to advocacy is available and prevents admission or readmission into hospital at times of acute distress where the community support services do not meet a person's immediate needs.

The recommendations include:

- Alternative accommodation to hospital should be available within each ICS area in times of acute distress, or emotional and behavioural crisis, and to facilitate earlier discharge.
- Commissioners should undertake pilots and evaluate the effectiveness of 'intensive recovery pods' (homely places of safety in the community) which are autism friendly, trauma informed and where the person and those supporting them feel safe.

[45]Moore, L., Larkin, F. & Foley, S. Mental Health Professionals' Experiences of Adapting Mental Health Interventions for Autistic Adults: A Systematic Review and Thematic Synthesis.(2023). J Autism Dev Disord 54, 2484–2501 (2024). https://doi.org/10.1007/s10803-023-06006-6

Alternative crisis responses and intensive support teams in learning disability and autism services are being developed in some places but are not universally available. Consistent, more reliable, robust and familiar multi-disciplinary community mental health support involving teamwork between the person themselves, their family and/or advocate is required. Integrated support from specialist practitioners in occupational therapy, speech and language therapy, specialist nurses, psychology, psychiatry and psychotherapy are essential.

1.12 Mental Health and Medication

NHS England » Stopping over medication of people with a learning disability and autistic people (STOMP) and supporting treatment and appropriate medication in paediatrics (STAMP) is national NHS England work programme to stop the inappropriate prescribing of psychotropic medications. Autistic people are 7 times more likely to be prescribed anti-psychotic medications than the general population. Oliver McGowan's tragic death was independently reviewed as part of NHS England » Learning from lives and deaths – People with a learning disability and autistic people (LeDeR) which unanimously concluded that Oliver's death was potentially avoidable. The review made 31 recommendations and concluded that Oliver was given excessive drugs due to medical staff not understanding learning disability and autism and that Clinicians involved in his care were not aware of the STOMP agenda. Paula McGowan, Oliver's mother campaigned for mandatory training for all health and social care staff in relation to learning disabilities and autism. In 2022 the government mandated the Oliver McGowan Training for all health and social care staff. More information about the campaign for improved training in relation to learning disabilities and autism is available Oliver McGowan | Oliver's Campaign |

1.13 Autism and Attention Deficit/Hyperactivity Disorder (ADHD)

NHS England define ADHD as a condition that affects people's behaviour. People with ADHD can seem restless, may have trouble concentrating and may act on impulse. It is frequently diagnosed in childhood before the ages of 12 but can be diagnosed in adulthood. Signs that a person may have ADHD include hyperactivity, impulsivity, difficulties with focus, and trouble following conversations. ADHD can impact how a person lives their daily life and some people with ADHD can struggle at school or work, however many people embrace the positives of ADHD. A recent study found that many people with ADHD reported that they are more creative and dynamic, high energy, passionate and open-minded.[46]

Autism and ADHD frequently co-occur. 21% of children with an ADHD diagnosis will also be autistic and approximately 3% of adults. In Nottingham and Nottinghamshire 23% of autistic people have a co-occurring ADHD. Common experiences for ADHD and autism include sensory differences, intense focus on specific interests, rejection sensitivity, executive dysfunction, sleep issues and emotional dysregulation. If someone is autistic and has ADHD, known as AuDHD, they may experience an internal struggle between their competing autistic and ADHD traits and a heightened experience of shared traits.

There has also been increased demand in people waiting for assessments for ADHD. The rapidly growing waiting lists for autism and ADHD assessments | Nuffield Trust explores some of the

[46] Schippers et al (2022) Front. Psychiatry, 12 October 2022 Sec. Autism Volume 13 - 2022 | https://doi.org/10.3389/fpsyt.2022.922788

potential reasons for this and notes that there is not enough data in relation to ADHD assessments but that the government is setting up a taskforce to better understand the condition.[47]

1.14 Demand Avoidance

Demand avoidance is widely understood to be a cluster of traits on the autism spectrum. Everyone experiences demand avoidance at times but in the context of an autism assessment it is referred to as a persistent resistance the demands of everyday life. Demand avoidance is considered to be a characteristic of autism and is the key characteristic of a proposed condition or profile of autism called Pathological Demand Avoidance (PDA), which has been criticised for pathologising differences in autistic people. In 2018 the PDA Society published Being Misunderstood – 2018 Survey | PDA Society Resources which found that many autistic young people with a PDA profile found school environments very difficult and how these issues can persist into adulthood. 70% of the parents surveyed reported that their child was not currently enrolled in school or was struggling to get into school.

1.15 Autism and Eating

Some autistic people may have issues with eating and drinking that may have an impact on their health. This can range from eating very little to eating excessively. Sensory differences, environmental factors, sensitivities, how food is presented, and the social aspect of mealtimes could all be factors in why an autistic person may have specific issues with maintaining a healthy diet. A study published in 2019 also suggested that autistic adults are more likely to be in non-healthy weight categories including obesity or underweight.[48] Avoidant or Restrictive Food Intake (ARFID), conditions such as PICA (eating non-food items) or Anorexia can be co-occurring conditions with autism and can impact on the overall health outcomes of the person.

1.16 Inequalities in Health

The Government published their final Committee Report in relation to Inequalities in healthcare and employment for people with a learning disability and autistic people in May 2024[49]. The report referenced a range of health, social and economic inequalities for autistic people including an unacceptable level of premature and avoidable deaths compared to the neurotypical population. The report notes the long waiting times for autism assessments and that services are not able to implement best practice as outlined by NICE. Reasons such as backlogs from covid-19 pandemic have been cited, however services were missing recommended timescales before the pandemic. The report also highlights the difference in spending within Integrated Care Boards between Learning Disability provision and Autism Services and the funding made available to Integrated Care Boards for autism assessments.

[47] Nuffield Trust. (2024) The rapidly growing waiting lists for autism and ADHD assessments. https://www.nuffieldtrust.org.uk/news-item/the-rapidly-growing-waiting-lists-for-autism-and-adhd-assessments

[48] Sedgewick, F et al (2019). Autistic adult outcomes on weight and body mass index: a large-scale online study. Springer. doi: 10.1007/s40519-019-00695-8

[49] https://publications.parliament.uk/pa/cm5804/cmselect/cmwomeq/134/report.html#footnote-047

Table 3: Total baseline expenditure in ICBs for learning disability and autism services; 2021-2024

	Learning disability services	Autism services	Unseparated learning disability and autism services	Total
21-22	£85.8m	£3.7m	£2,268.3m	£2,357.9m
22-23	£625.8m	£27.1m	£1,928.8m	£2,581.7m
23-24	£926m	£47.1m	£1,928.8m	£2,904.6m

Source: PQ 23733, 1 May 2024

It is estimated that approximately 2.18% of the population have a learning disability and 1% of the population are autistic.

Table 4: Additional national funding allocated to ICBs by NHS England, over each of the last five years, to improve autism assessment waiting lists and pathways, 2021-2025

	Service Development Funding via the NHS Long Term Plan Transformation Funding	Spending Review 2021 via the COVID-19 Recovery Fund	Total funding for autism assessment pathways
2021-22	£2.5m	£14.5m	£17m
2022-23	£5m	n/a	£5m
2023-24	£4.2m	n/a	£4.2m
2024-25	£4.3m	n/a	£4.3m

Source: PQ 23733, 1 May 2024

The report also notes the lack of understanding around the differences in the way autistic women and girls may present and that there is a need to improve diagnostic pathways and early identification of autism in females and there continued to be an over reliance on inpatient hospital stays, particularly for autistic people, despite the commitment to halve inpatient figures. Underfunded social care sectors and a lack of early intervention support for mental health are cited as reasons for the failure to meet ambitions in relation to hospital stays for autistic people.

1.17 Inequalities in Employment

Data published in Inequalities in healthcare and employment for people with a learning disability and autistic people 2022-2023 details 30.6% of autistic people were in employment, with the pay gap for disabled people continuing to widen with 69% of disabled people that were employed are paid less than £15 per hour[50]. In Nottingham City over half of autistic people are living in the most deprived areas of the city whilst less than 5% are living in the most affluent areas of the city.

The Buckland Review of Autism Employment (2024) made a series of recommendations to improve access to employment for autistic people.[51] Autistic adults have a wide range of skills, interests, and

[50] https://publications.parliament.uk/pa/cm5804/cmselect/cmwomeq/134/report.html#footnote-027

[51] https://www.gov.uk/government/publications/the-buckland-review-of-autism-employment-report-and-recommendations/the-buckland-review-of-autism-employment-report-and-recommendations

experience, in which the different approaches to cognition and communication can be key strengths, and a diverse workforce that includes autistic people generate new ways of thinking at work, and new ideas. The report details opportunities to significantly increase employment levels.

The autism employment gap is also detrimental to the UK economy, estimated at costing approximately £14.5 billion every year.[52] The benefits of employment are well documented which include the development of social networks and friendships, improved independence, economic mobility and social status. These factors contribute to an overall sense of life satisfaction and wellbeing. In 2013 The Office of National Statistics published their analysis of data in relation to the correlation between Wellbeing and employment. This data illustrated that people in full time employment had greater life satisfaction than people who were unemployed or identifying as having a disability and not working. The people identifying as disabled or unemployed also reported higher levels of anxiety.[53] Unemployment is also a risk factor cited in higher rates of suicide.[54]

There are a range of potential barriers to employment for autistic people, including inaccessible recruitment practices. Autistic people can have negative experiences of interviews, group tasks and psychometric tests. Some autistic people may experience difficulties in interpreting generic job descriptions, or open interview questions, sometime in challenging sensory environments, often with an emphasis on social skills rather than job skills. Autistic people who are looking for paid work in Nottinghamshire can access support from Nottinghamshire County Council, i-work Team.

Maintaining long-term employment can also be a challenge for autistic people. Many do not receive the necessary support or adjustments to enable them to fulfil their role in the face of inaccessible sensory and social environments and may feel that they need to mask their autism to get on at work. 35% of autistic employees are open about being autistic, with 1 in 10 not disclosing to anyone at work. Autistic people who did disclose their autism did so after they had started work and did not always have a positive experience after disclosing.[55]

Research has found that access to adjustments in the workplace for autistic people is variable, with the onus on the employee to identify and advocate for what they require. Around one third of autistic employees surveyed felt unable to discuss adjustments with their employer. Those who did request adjustments, over a quarter were refused and more than 1 in 10 found the adjustment was poorly implemented and employers did not have the knowledge or understanding to support autistic employees well.[56]

Nottinghamshire published a Health and Employment Strategy 2020-2030[57] however this does not make reference to autistic people's experience locally and does not set clear outcomes for promoting employment opportunities for autistic people by making adjustments and adaptations. This chapter will make recommendations to address this gap.

[52] Jacob A, et al. (2015). The Costs and Benefits of Employing an Adult with Autism Spectrum Disorder: A Systematic Review. PloS One 10(1), e0139896.
[53] https://www.gov.uk/government/publications/wellbeing-and-employment
[54] Van Orden K, et al. (2010) The Interpersonal Theory of Suicide. Psychol Rev 117(2), 575-600. ncbi.nlm.nih.gov/pmc/articles/PMC3130348/
[55] Romualdez A.M., et al. (2021). "People Might Understand Me Better": Diagnostic Disclosure Experiences of Autistic Individuals in the Workplace. Autism in Adulthood 3(2), 157-167.
[56] Davies J, et al. (2022). Autistic adults' views and experiences of requesting and receiving workplace adjustments in the UK. PLoS ONE 17(8): e0272420. ↩
[57] Notttinghamshire County Council. employment-and-health-strategy-2020-30.pdf

1.18 Housing

Housing is an important factor in wellbeing and living a healthy life. The Health Foundation outlines that the condition, nature, security and location of our housing has a big impact on our lives and a healthy home is affordable, warm and stable: somewhere safe that meets the diverse needs of the people living there, and helps them connect to community, work and services. [58]

The 2021 Census Outcomes for disabled people in the UK found that autistic people were more likely to live with their parents (76%) and less likely to own their own home (3.8%).

Building the Right Support (2015), highlights the rights of autistic people to have "the same opportunities as anyone else to live satisfying and valued lives, and to be treated with dignity and respect" and at the heart of this is ensuring that people have a choice about where they live and who they live with and that "people can be effectively supported to live as independently as possible in ordinary housing in the community, without creating institutional models of housing and care". [59]

Housing needs to be tailored to meet the individual needs of autistic people. In 2020 NDTi published Supporting autistic people flourishing at home and beyond: considering and meeting the sensory needs of autistic people in housing - NDTi is an important fully co-produced document that offers advice and guidance in relation to factors to consider when commissioning housing for autistic people.[60]

Many autistic people will be able to live independently without access to support however some people may require housing with support services or supported living. Local Authorities in Nottingham and Nottinghamshire do not currently collect data in relation to how many autistic people are living in supported living or residential care and better data is needed to understand this to map future demand for the local autistic population. Demand for supported living currently outweighs the supply of accommodation in Nottinghamshire and work is being undertaken to build additional capacity. The County Council are also working with District Councils to better understand housing needs across the county and work together to ensure the housing offer to ensure that disabled people have a place they can call home.

1.19 Criminal Justice System

Autistic people are more likely to be a victim or witness to a crime than a perpetrator however those that do come into contact with the criminal justice system report negative experiences with the criminal justice system and current practices are not well-adapted to support them in these settings. In 2022 the National Autistic Society published their Youth Justice Report (autism.org.uk) which found that there was a lack of support for young autistic people, both before entering and within the system, can have profoundly negative consequences on future life chances. The research found that 75% of autistic adults and 86% of their parents and carers had been visited at least once by the police.[61]

Crane et al (2016) found in an online survey of 394 police officers that just 42% of the officers contacted were satisfied with how they had worked with autistic people. Although officers acknowledged the need for adjustments, organisational and time constraints were cited as barriers.

[58] Health Foundation, https://www.health.org.uk/evidence-hub/housing
[59] NHS England. https://www.england.nhs.uk/learning-disabilities/natplan/
[60] NDti. https://www.ndti.org.uk/resources/publication/supporting-autistic-people-flourishing-at-home-and-beyond-considering-and-meeting-the-sensory-needs-of-autistic-people-in-housing
[61] https://www.autism.org.uk/what-we-do/news/youth-justice-report

Whilst 37% of officers had received training on autism, a need for training tailored to policing roles (e.g. frontline officers, detectives) was identified.[62]

The Ministry of Justice published a neurodiversity action plan (PDF) in June 2022. Neurodiversity support managers have been introduced in prisons and the Government planned to have one in every prison across England and Wales by 2024. It also notes that autism accreditation is being promoted across the prison estate.

In Nottinghamshire, efforts to improve the experiences of autistic people within the criminal justice system are in line with national strategies and initiatives aimed at supporting neurodivergent people with a key focus in improved engagement and training within Youth Justice services and the violence reduction partnership. Data is not collected locally in relation to how many autistic children and young people are engaged with Youth Justice services. The Integrated Care Board commission Community Forensic Services and a Community Forensic Intellectual Disability Service to provide support for people with offending risks or behaviours across adult services to support recovery, rehabilitation and give people the tools to build successful lives in the community.

1.20 Families

Being the parent of an autistic child can be emotionally demanding at times, leading to increased levels of stress and anxiety among family members. Autism may also occur within the same family and differences in communication, behaviours and sensory sensitivities can be challenging. Siblings of autistic children may also experience feelings of neglect, guilt, or resentment due to the additional attention and resources required for the autistic sibling. They may also take on caregiving responsibilities, affecting their own development and wellbeing. This can extend into adulthood, particularly where autistic adults have co-occurring conditions and more complex support needs.

The stress families and carer's face can be further compounded when navigating complex systems of education, healthcare and social care services and battling to get the support needed in a system that can be inflexible and not always have the right understanding of autism to adequately help in meaningful ways. A combination of these factors can lead to family members experiencing trauma and distress. Trauma informed approaches should be considered when supporting families.

Like any other Carer, there may be challenges associated with financial pressures in relation to balancing caring responsibilities with career progression and there are also additional costs associated with accessing support and specialist education and therapies. In 2023 Nottingham and Nottinghamshire Integrated Care System published Joint Carers Strategy 2023-28 | Nottinghamshire County Council which outlines how the local system will work with Carers to offer the right support.[63]

[62] Crane, L. et al(2016) Experiences of ASD and policing in England and Wales, Journal of Autism and Developmental Disorders 2016, Vol. 46 (6)
[63] https://www.nottinghamshire.gov.uk/policy-library/60887/joint-carers-strategy-2023-28

2. Population

2.1 Diagnosis and Prevalence

It is broadly estimated that 1% of the population are autistic and that there are 700,000 autistic adults and children in the UK, and a further 3 million family and carers however autism is often under-diagnosed, and under-reported. Using POPPI and PANSI data, it is estimated that there are 7,250 autistic adults living in Nottingham and Nottinghamshire and this will increase by 4.7% to 7,593 adults by 2040.[64] However, there are over 20,000 people in Nottingham and Nottinghamshire with a confirmed assessment of autism.

The below table shows the number of people diagnosed with autism across different areas of Nottingham and Nottinghamshire which demonstrates local prevalence between 1.10 and 2.20%.

Table 5: Number of people diagnosed with autism across regions of Nottingham and Nottinghamshire and percentage prevalence, May 2024

	Mid Nottinghamshire (Ashfield, Mansfield Newark and Sherwood)	Nottingham City	South Notts (Gedling, Broxtowe and Rushcliffe)	Bassetlaw
Population with confirmed autism assessment	6950	6140	5970	1375
Prevalence of autism as a percentage of the estimated population	2.20%	1.80%	1.70%	1.10%

Source: E-Healthscope. Nottingham and Nottinghamshire Integrated Care Board. May 2024.

There is no definitive test for autism. Assessments are based on the range of features evaluated by a combination of specialists who work together. Many autistic people face long waits for their assessment – and do not always receive support that is tailored to their needs at an early enough stage. More adults are undergoing an autism assessment due to changes in awareness, diagnostic criteria and professional practices. Receiving a confirmed assessment has a number of benefits; enabling access to services, support and adjustments, where required but it can also be validating for the person and help foster a positive autistic identity and facilitate connection within the autistic community. Despite the benefits of assessment there are many people without a formal diagnosis or who are waiting a long time for an assessment, who would benefit from support. There is growing

[64]PANSI and POPPI Projecting Adult Needs and Service Information System

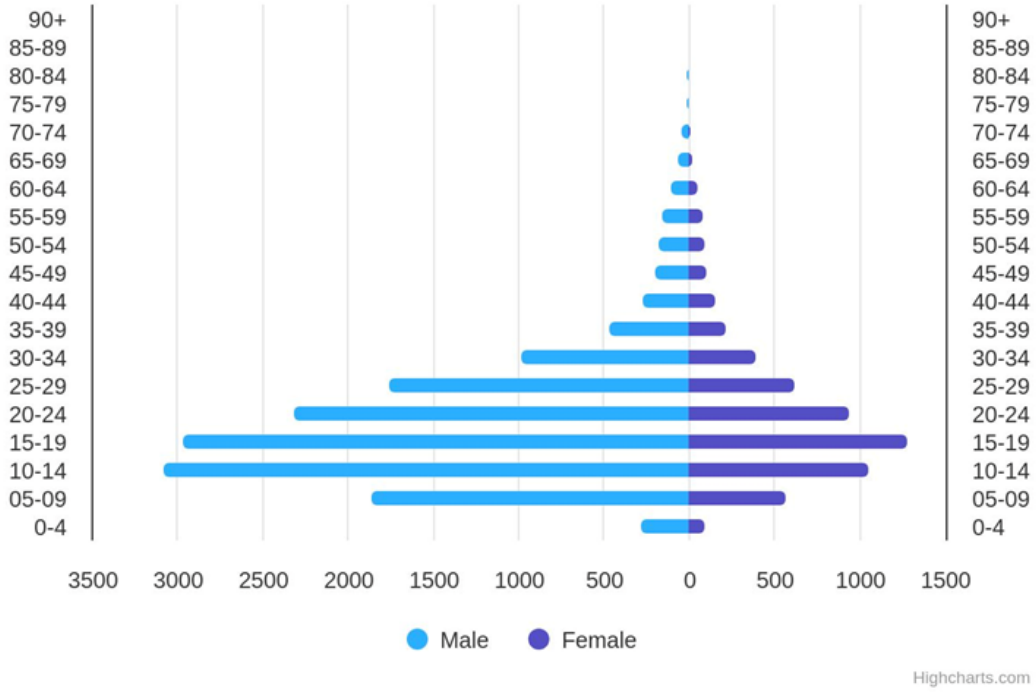
recognition of the need to focus on needs led, coordinated neurodevelopmental support. A consequence of this development in diagnostic criteria, is that it supports the shift in clinical practice, away from a "single condition" focus.

NICE (National Institute for Health and Care Excellence) guidance states that no-one should wait longer than three months between being referred and first being seen. NHS Digital provides data in relation to autism waiting times at a national level. In March 2024 only 5.6% of the patients with an open referral had a first appointment within the recommended 13 weeks. This represents a health inequality in relation to access for assessment.

In Nottingham and Nottinghamshire, the Neurodevelopmental Specialist Service (NESS) supports people seeking an autism and/or ADHD assessment. There is currently an average waiting time of 80 weeks for a completed assessment. As of June 2024, just under 2500 people in Nottingham and Nottinghamshire were waiting for an autism diagnostic assessment with NESS. On average NESS receives 144 Autism Diagnostic Referrals per month. Demand for assessments locally has nearly doubled and investment has been made locally to increase capacity for assessments.

Locally and nationally, there is a trend of increased rates of autism assessments in younger people compared with those aged over 55, where prevalence is likely to still occur, but assessments are less likely to occur. This is also the case for women, where there are fewer confirmed assessments.

Figure 1: Number of people with autism diagnosis across Nottingham and Nottinghamshire according to gender and age, May 2024



Source: E-Healthscope Nottingham and Nottinghamshire Integrated Care Board. May 2024

Nationally there has been an 787% increase in recorded incidents of autism over a 20 year period attributed to a potential growth in prevalence, but more likely increased awareness, reporting and

application of diagnosis[65]. Evidence shows that rates of diagnosis is much higher in children than it is in adults and many autistic adults have reached adulthood without a confirmed assessment, despite some people experiencing significant challenges in their daily lives.[66] Research from O'Nions et al (2021) identified 2.94% of 10-14 year olds had a diagnosis of autism in 2018 compared to 0.02% of people aged over 70, and estimated that one in 36 children are autistic, with prevalence likely to increase. The prevalence of autistic in children and young people has increased nationally from 1% to 2.78%. Locally, prevalence rates are 18% higher than the rate for England and 27% higher than the rate for the Midlands.

Research also highlighted under and misdiagnosis in females[67] and regional variation in diagnostic rates, potentially reflecting local variation in services.[68] The co-occurrence of a learning disability is suggested to be one in three, although data varies significantly by age groups. In autistic people under the age of 19 only 12% have a co-occurring learning disability.[69] In Nottingham and Nottinghamshire, according to locally recorded data in January 2022, 13% of the autistic population have a learning disability, 19% have anxiety, 25% have ADHD, 37% have language disorders and 37% have one or more long term condition including severe mental illness and depression.

Recording of people with autism across Health and Social Care services is limited. A key recommendation of the National strategy for autistic children, young people and adults: 2021 to 2026 is to improve reporting on a national and local level.

2.2 Population Projections

It is broadly estimated that 1% of the population are autistic. Consistent with national evidence, only a proportion of this group will be known to health and social care services. As per table 6, locally, there is an anticipated 7.96% increase in the number of adults predicated to have autism contrasted between 2025 and 2040. It is important to recognise the current autistic population, is much higher than forecasted with over 20,000 people with a confirmed assessment.

[65] Russell G, Stapley S, Newlove-Delgado T, Salmon A, White R, Warren F, Pearson A, Ford T. Time trends in autism diagnosis over 20 years: a UK population-based cohort study. J Child Psychol Psychiatry. 2022 Jun;63(6):674-682. doi: 10.1111/jcpp.13505. Epub 2021 Aug 19. PMID: 34414570.
[66] O'Nions, E, Petersen, I, Buckman, JEJ, Charlton, R, Cooper, C, Corbett, A et al (2023). Autism in England: assessing underdiagnosis in a population-based cohort study of prospectively collected primary care data. The Lancet. Vol 29, 100626, June 2023.
[67] Lockwood Estrin G., Milner V., Spain D., Happé F., Colvert E. Barriers to autism spectrum disorder diagnosis for young women and girls: a systematic review. Rev J Autism Dev Disord. 2021;8:454–470
[68] Roman-Urrestarazu A., Yang J.C., van Kessel R., et al. Autism incidence and spatial analysis in more than 7 million pupils in english schools: a retrospective, longitudinal, school registry study. Lancet Child Adolesc Health. 2022;6:857–868
[69] Autisitica. Learning Disbility and autism www.autistica.org.uk/what-is-autism/learning-disability-and-autism#:~:text=However%2C%20learning%20disabilities%20are%20more%20common%20in%20autistic%20people%20compared,this%20varies%20between%20age%20groups.

Table 6: Number of people in Nottingham and Nottinghamshire aged 18+ predicted to have autism, by age group

Age Group	2025	2030	2035	2040
18-24	1270	1430	1468	1388
25-34	1619	1526	1587	1719
35-44	1479	1594	1590	1509
45-54	1403	1400	1494	1480
55-64	1532	1480	1373	1379
66-74	1160	1301	1403	1366
75 and Over	1062	1169	1284	1443
Totals	**9525**	**9900**	**10199**	**10284**

Source: POPPI and PANSI. The prevalence rates have been applied to ONS population projections of the 18+ population to give estimated numbers predicted to have autistic spectrum disorder to 2040.

There has been an observed increase demand in autism assessments for children and young people however there are not forecasting tools available to predict how many of the children and young people waiting for assessments are likely to receive a confirmed diagnosis. It is estimated that 1 in 100 children are autistic and there are currently 184,600 children and young people living in Nottingham City and a further 168,500 living in the county and therefore there could be 3531 children and young people who are autistic, and only 2720 have a confirmed diagnosis. This picture will change over time depending on birth rates locally however we know demand for assessments is higher than current capacity and that there are likely to be many people living in Nottingham and Nottinghamshire that have not been assessed. To reduce wait times in accordance with national policy commitments, a minimum capacity is needed for at least 1.5 – 2.6% of the population to be referred to an autism assessment service and for at least 1.3 – 2.3% of the population to be assessed for autism.[70]

Table 7: Estimated Population with a Confirmed Diagnosis of Autism by 2025 in Nottingham and Nottinghamshire

	Nottingham City	Nottinghamshire County	Total Population
Number of **Children and Young People** Predicted to have Confirmed Assessment by 2025	810	1910	2720
Number of **Adults** Predicted to have Confirmed Assessment by 2025	2930	7480	10410

Source: Nottingham and Nottinghamshire ICS All Age Autism Strategy

[70] NHS England » A national framework to deliver improved outcomes in all-age autism assessment pathways: guidance for integrated care boards 2023

3. Targets and performance

3.1 National Strategic Drivers

National strategy for autistic children, young people and adults: 2021 to 2026 - GOV.UK (www.gov.uk) sets out the government's national strategy for improving the lives of autistic people and their families and carers in England, and implementation plan for 2021 to 2022.

NHS England » A national framework to deliver improved outcomes in all-age autism assessment pathways: guidance for integrated care boards sets out a framework for improving assessment pathways for autism.

Care Act 2014 (legislation.gov.uk) sets out the provision of social care services for people with disabilities and confirms the equal right to an assessment for the person and their carer, and the right to advocacy where appropriate. The Act also sets out a clear legal framework for how local authorities and other parts of the system should protect adults at risk of abuse or neglect.

NHS Long Term Plan » Learning disability and autism aims to improve people's health by making sure they receive timely and appropriate health checks, while improving the level of awareness and understanding across the NHS of how best to support them as patients.

NHS England » National plan – Building the right support The guidance supports NHS and local authority commissioners to reduce the number of people with a learning disability and autistic people in a mental health inpatient setting and to develop community alternatives to inpatient care in line with the National Service Model.

Health and Care Act 2022 (legislation.gov.uk) introduced a new legal requirement for all health and social care service providers registered with the Care Quality Commission to provide employees with training on autism and learning disabilities (called Oliver McGowan Training).

Equality Act 2010 (legislation.gov.uk) sets out legislation to protect people from discrimination in the workplace and in wider society. It replaced previous anti-discrimination laws with a single Act, making the law easier to understand and strengthening protection in some situations. It sets out the different ways in which it's unlawful to treat someone.

Mental Capacity Act 2005 (legislation.gov.uk) safeguards decision-making within a legal framework by empowering people to make decisions for themselves and allowing people to plan ahead for a time in the future when they might lack capacity.

Mental Health Act 1983 (legislation.gov.uk) legislation that covers the assessment, treatment and rights of people with a mental health disorder.

Children and Families Act 2014 (legislation.gov.uk) sets out the legal provisions for children, families and those with special educational needs.

Special Educational Needs and Disabilities (SEND) and Alternative Provision (AP) Improvement Plan (publishing.service.gov.uk)
Sets out plans to improve Special Educational Needs and Disability services.

Education Report 2023 (autism.org.uk) National Autistic Society have undertaken research on how autistic children and young people experience their education and sets out recommendations for improvement to enhance the experience of autistic children and young people.

Building-Happier-Healthier-Longer-Lives-The-Autistica-Action-Briefings-2019.pdf based on a range of research Autistica set out key recommendations for supporting autistic people to live happier lives.

Overview | Autism spectrum disorder in adults: diagnosis and management | Guidance | NICE outlines best practice guidance for diagnosis and management of needs for autistic people.

Recommendations | Autism spectrum disorder in under 19s: support and management | Guidance | NICE outlines best practice guidance to support children and young people with a diagnosis of autism.

NHS England » Dynamic support register and Care (Education) and Treatment Review policy and guide sets out how autistic people should be supported to prevent avoidable hospital admissions.

3.2 Local Strategic Drivers

Nottingham and Nottinghamshire Integrated Care System All Age Autism Strategy icsallageautismstrategy.pdf (nottinghamshire.gov.uk) sets out how partners will work together with people with lived experience to improve the lives of autistic people living in Nottingham and Nottinghamshire.

The Joint Health and Wellbeing Strategy for 2022 - 2026 | Nottinghamshire County Council sets out how partners across the Nottingham and Nottinghamshire ICS will work together to improve the health and wellbeing of people who live in the area and reduce health inequalities.

Adult Social Care Local Account | Nottinghamshire County Council sets out how Nottinghamshire County Council will work together with people with lived experience to live in the place they call home with the people and things that they love, in communities where they look out for one another, doing things that matter to them.

Joint Carers Strategy 2023-28 | Nottinghamshire County Council outlines how Integrated Care System partners will work with carers and partner agencies to provide the right care and support to carers living in Nottingham and Nottinghamshire.

Nottingham and Nottinghamshire JOINT LOCAL TRANSFORMATION PLAN for ChilDREN AND YOUNG People's EMOTIONAL WELL-BEING AND MENTAL HEALTH 2016 -2023

(healthandcarenotts.co.uk) sets out how partners across the Integrated Care System will work together to support children and young people.

Nottinghamshire Special Educational Needs and Disabilities Joint Strategic Needs Assessment - Nottinghamshire Insight

Nottinghamshire local area SEND strategy (2024-2027) | Nottinghamshire County Council sets out how partners will work together to implement the support for children and young people with special educational needs and disabilities.

Nottinghamshire SEND improvement plan (priority action plan) | Nottinghamshire County Council sets out the improvement plan for supporting children and young people with special educational needs and disabilities in Nottinghamshire.

Neurodevelopmental Assessment CYP Pathway Review - Report April 24.pdf sets out the review of the neurodevelopmental assessment pathway for children and young people.

3.3 Performance

Nottingham and Nottinghamshire Integrated Care System have made some progress in making changes to support autistic people to live healthy lives however performance is difficult to measure when there are gaps in understanding and identifying autistic people who require or even receive support.

Nottingham and Nottinghamshire Integrated Care System have achieved the following in meeting local and national targets:

- Published an All Age Autism Strategy.
- Established a Learning Disability and Autism Executive Board with people with lived experience as key members.
- Established a Key Working service for autistic children and young people.
- Established an active programme to plan and support autistic people living in Hospital settings to be supported in the community.
- Established a system wide Dynamic Support Risk Register to identify autistic people living in the community and at risk of hospital admission.
- Completed a review of assessment pathways for children and young people.
- Established a Nottinghamshire Special Educational Needs Improvement Plan.

Key strategic targets that have not been achieved include:

- Reducing avoidable admissions into hospital although it is noted admission performance for 2024 and 2025 does indicate a downward trajectory.
- Establishing affective and impactful community mental health support.
- Improving the quality of data in relation to understanding and identifying the local autistic population across health and social care services.

- Some people wait beyond the recommended 13 weeks for a first appointment when being assessed for autism.
- Working with people with lived experience and local community and voluntary services to design and implement strategies.
- Women, older people and ethnic minority communities continue to have lower than expected rates of autism assessments.

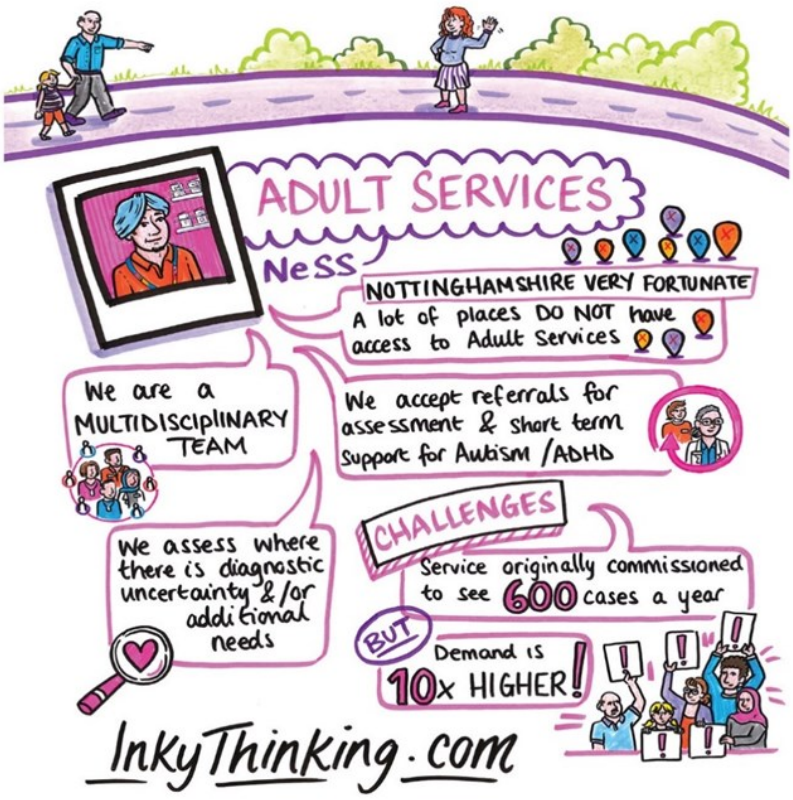
The recommendations of this chapter will seek to consider how the Integrated Care System can address and improve in these areas.

4. Current activity, service provision and assets

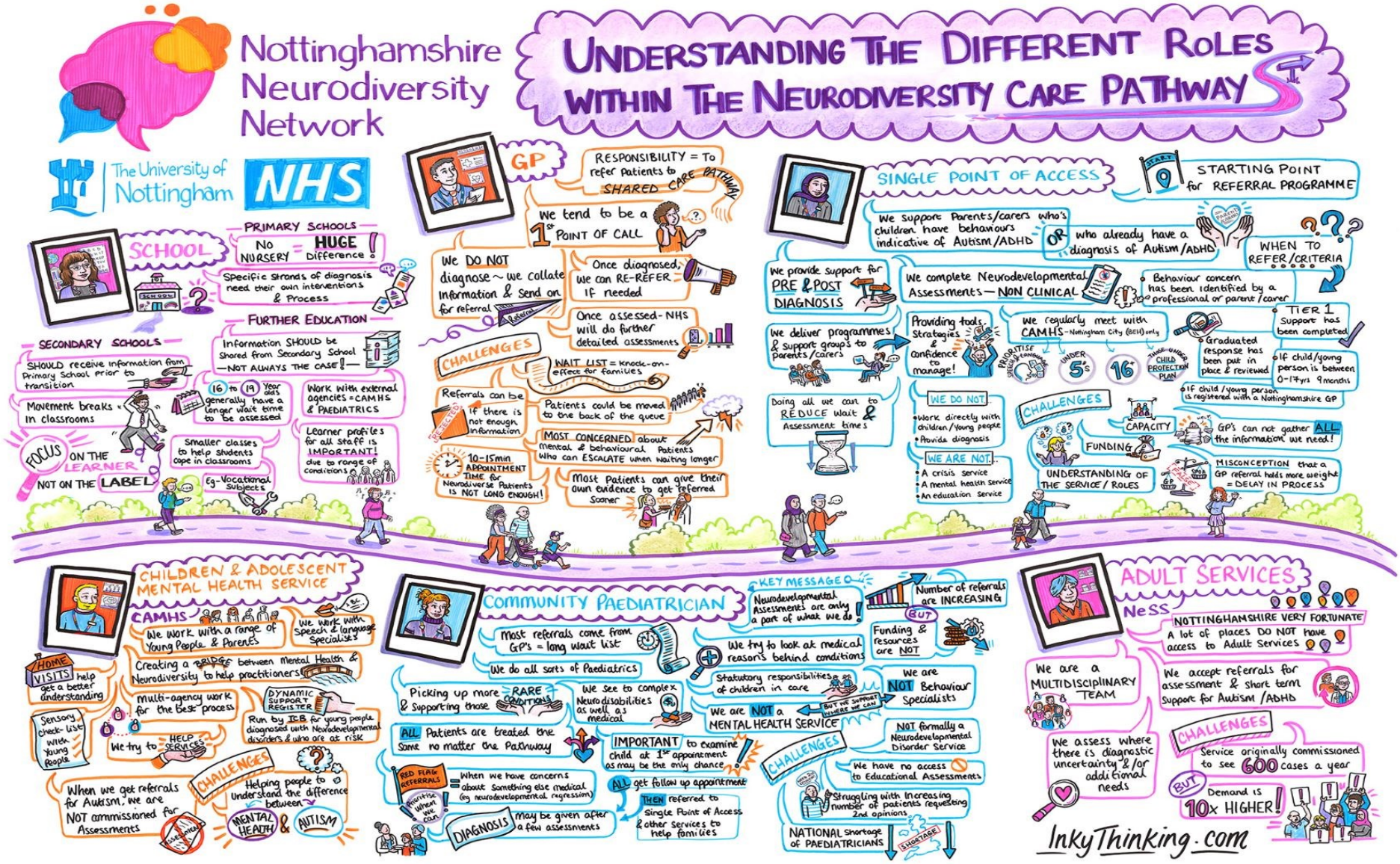
4.1 Local Pathways

The below infographic drawings from the recent Nottingham(shire) Neurodevelopment Network (NNN) workshop, created from conversations held with stakeholders from across our local health, education, and social care and third sector system, demonstrate the complexities and gaps in the neurodevelopmental care pathways for children, young people, and adults. Committed to collaboration and eager for change and improvement, the network strives to address the needs of our local neurodivergent population.

Figure 2: Summary of conversations at Nottingham(shire) Neurodevelopment Network workshop about neurodevelopmental care pathways for children, young people, and adults



Nottinghamshire Health & Wellbeing Board



Nottinghamshire Health & Wellbeing Board

University of Nottingham UK | CHINA | MALAYSIA

Nottingham and Nottinghamshire ADHD/Autism Assessment Pathways

Nottingham Neurodiversity Network

ICS Integrated Care System Nottingham & Nottinghamshire

	Children and Young People Pathway			Adult Pathway
1st step: Graduated Response	Discuss your concerns/child's needs with your child's health visitor or education setting to agree a support plan that can be regularly reviewed and adapted. Also, speak to the Healthy Family Team or 0-19 Early Support Services for further help and advice. This process is often referred to as the graduated response. More information can be found here: Graduated Response			Not applicable
2nd step: Referral (based on location of GP practice)	Nottinghamshire County	Nottingham City	Bassetlaw	Any
	Education, Health Professional/GP	Self-referral, Education, Health Professional/GP	Education, Healthy Family Team	GP
3rd step: Screening	Neuro-developmental Support Team (NST)*	Behavioural & Emotional Health Team (BEH)*	General Developmental Assessment (GDA)*	↓
4th step: Specialist Assessment Services (subject to screening outcome)	Community Paediatrics* AND /OR other specialist services depending on needs*			Neuro-development Specialist Service (NeSS)*

*While these pathways reflect the majority of referrals, some cases may be referred to other Nottingham(shire) based services. This is an overview of the pathway and does not include details of support services that are offered along the way. For more detailed information, please scan the QR code at the top of the page.

4.2 Adult Services

Local statutory social care and health services are commissioned across the Nottingham and Nottinghamshire Integrated Care System. These services offer primary and secondary healthcare and social care support, however there are no specialist teams that only support autistic people. There are also advocacy services available for autistic people, including those in Hospital. It is important that there is a programme of building awareness of the barriers some autistic people may face in accessing services and support and crucially making adaptations and adjustments to how services are delivered. There is coordination between services for autistic people who are at risk of hospital admission through the Dynamic Risk Register however there are still indications that people are not getting the right support and that many people wait too long for support. Nottingham and Nottinghamshire are seeking to work with support providers who can demonstrate they are able to embed Supporting autistic people and/or people with a learning disability | Skills for Health Core Competency Frameworks.

Nottingham and Nottinghamshire benefit from having access to services within the community and voluntary sector that support autistic people. This includes but is not limited to organisations such as Autistic Nottingham and Autism East Midlands which provide a range of services for autistic people and their families. There are also Local Carers Hubs to support family members and an Autism Alliance has been established for autistic people to come together. There is an opportunity to co-produce and co-design services with people with lived experiences through these forums.

4.2 Children and Young People

Nottingham and Nottinghamshire Integrated Care System offers a range of support to children and young people including Special Educational Needs Services and Children Disability Services along with health services. There are also social care services that support children who are transitioning into adult services. Nottingham and Nottinghamshire have established Key Working services for autistic children and young people in line with national guidance. There are a range of services to support children with their mental health including Children and Adolescents Mental Health Services (CAMHS) and services across the community and voluntary sector such as Notts Be U Support and A Place to Call Our Own although these services do not only support autistic children and young people.

4.3 Governance

Nottingham and Nottinghamshire have established a Learning Disability and Autism Executive Board which meet quarterly and oversee the governance of services for autistic people in Nottingham and Nottinghamshire. The Board is made up of a range of representatives including Experts by Experience and representatives from Nottingham and Nottinghamshire Integrated Care Board, Nottinghamshire County Council and Nottingham City Council and representatives from Nottinghamshire NHS Healthcare Foundation Trust. There are four workstreams that report to the Executive Board and an Expert by Experience Group that are

consulted with on a regular basis. The primary focus of the workstreams is the number of people in hospital or at risk of a hospital admission under the Mental Health Act and performance in relation to autism assessments. There is an opportunity to enhance the governance and oversight across this structure to ensure that broader concerns for autistic people and their families are prioritised which consider opportunities for promoting health and wellbeing to prevent autistic people from requiring admission in the first place.

5. Local Views

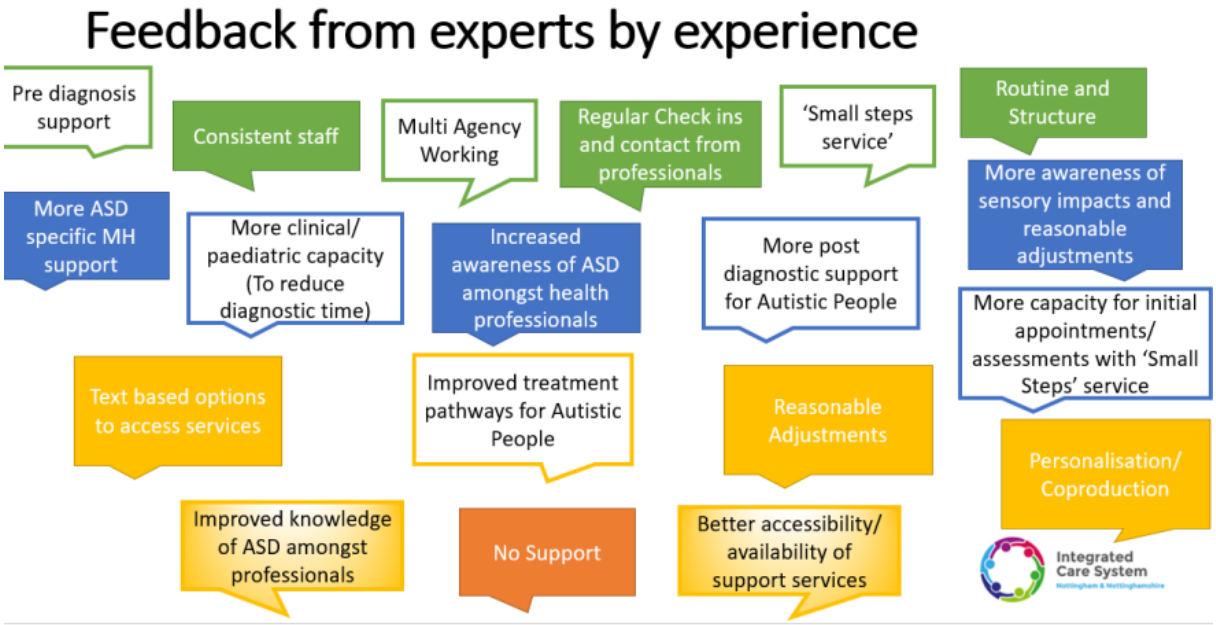
A survey for autistic people with lived experience was circulated to inform the Joint Strategic Needs Assessment. The majority of participants expressed that they have not always received autism informed care or support from local services across health and social care and that they have not always received support to understand their autism assessment. People with lived experience have also shared their experiences in relation to accessing mental health support and shared that they did not always feel respected by professionals, services being unresponsive and that there was sometimes a lack of understanding from professionals in relation to autism informed practice and autistic burnout.

The Midlands Autism Expert by Experience Focus Group shared themes in 2021 which set out priorities for autistic people across the Midlands. Key themes were that autistic people wanted to be involved in the planning and design of local services and that opportunities to be involved should be accessible and widely publicised and autistic people and their experiences should be respected. That there should be equity across the area and that support should be personalised and person centred, and support should be offered at the right time. Other priorities including developing services that seek to support people with a smooth journey, not requiring to tell their story over and over again. Autistic people wanted services that include diagnosis, advocacy, social networks, psychoeducation, mental health care and physical healthcare and support available to their families and that there was opportunity to learn from what is working well in services delivered by community and voluntary organisations.

In developing the Nottingham and Nottinghamshire All Age Autism Strategy in 2022 a range of consultation activities were undertaken with people with lived experience which included surveys, virtual group discussions and consultation events. Key messages from this work included:

- Systems don’t appear to be suitable for autistic people
- No wrong door – people felt passed from place to get the right support
- Diagnosis took too long
- There were barriers to accessing support from professionals and families and people with lived experience described this as an ongoing battle and struggle
- Employers didn’t have good understanding of autism
- Services there to provide support were not able or willing to make adjustments for autistic people.

Figure 3: Key messages from Nottingham and Nottinghamshire ICS All Age Autism Strategy consultation



Source: Nottingham and Nottinghamshire Integrated Care System All Age Autism Strategy

Whilst people with lived experience were consulted with in the design of the Nottingham and Nottinghamshire All Age Autism Strategy, it was acknowledged that the Strategy was not fully coproduced, and it will be important to address this in the planned strategy refresh and ensure that experts by experience are part of decision making on improvements to services and resource allocation. There are now two experts by experience on the Learning Disability and Autism Executive Board who spend time talking to other people with lived experience, to ensure local views of people with lived experience are represented.

Since the publication of the Nottingham and Nottinghamshire All Age Autism Strategy the Integrated Care Board have collaborated with the University of Nottingham School of Psychology & Institute of Mental Health Research Team to create the "Nottinghamshire Neurodiversity Network" (NNN). This group is instrumental in shaping the development of the ideal neurodevelopmental pathway for children, young people, and adults. Comprising of health, educational, and social care professionals, the group also includes stakeholders such as parents and carers with lived experiences. The collaborative effort involves proactive engagement through online review group meetings and in person workshops and has inputted in the recent review of the Nottingham and Nottinghamshire Children & Young People Neurodevelopmental Pathway Review. In addition, there was an extensive survey across carers and people with lived experience in relation to the current diagnostic pathway, where people asked for improved communication and regular information sharing with services.

6. Evidence of what works

6.1 Growing Awareness and Understanding

There is evidence that professionals working with autistic people across the Integrated Care System are still reporting that they do not have sufficient understanding of autism. The Oliver McGowan training programme will seek to develop awareness and understanding across the local system. Nottingham and Nottinghamshire have also started to roll out a programme of The SPELL framework. SPELL is the National Autistic Society's framework for understanding and responding to the needs of autistic children and adults. It focuses on five principles that have been identified as vital elements of good practice when working with autistic people, and emphasises ways to change the environment and our approaches to meet the specific needs of each person. A comprehensive programme of training across services should be developed with a focus on building on from the Oliver McGowan training and complementing it.

A focus on growing understanding of autism across mental health services is fundamental, given the evidence in this chapter of the co-occurrence of serious mental health conditions and autism. National Autism Trainer Programme (NATP) | Anna Freud is specifically targeted for professionals working across mental health services. Considering the introduction of this type of training. The model seeks to move beyond transfer of knowledge and offer opportunities for professionals to consider the impact of their own behaviour in how they respond to autistic people.

Part of growing local understanding includes a need to improve how we record that people are either assessed as autistic or that people self-identify as autistic. Improving how this information is recorded across health and social care services will help us to better understand patterns of accessing services and build a better picture of what is working and not working.

6.2 Adjust and Adapt

There are a number of ways services can adapt and change their approach to improve the experience of autistic people and there are a number of resources to help services get started. The National Autistic Society have published a range of articles and guides to support Professional practice. There is also a guide to Understanding and developing communication with autistic children and a guide to Asking for reasonable adjustments in mental health services and good practice guides in relation to delivering them. In Autistica's Building-Happier-Healthier-Longer-Lives-The-Autistica-Action-Briefings-2019.pdf there is a wealth of suggestions in relation to how services can make themselves more accessible to autistic people.

Different people will benefit from different adjustments however simple measures that could be put into place that may well benefit everyone could include:

- Asking people what would help them to improve their experiences of accessing health and care services.

- Offer flexible and reliable ways for autistic people to contact the service including via email or text.
- Offering flexible appointment times and lengths that best suit the person. Some people may prefer shorter appointments and some people may benefit from more time to process information.
- Helping autistic people understand what their experience will be like and give clear instructions about access. This could include pictures.
- Offering appointments online where appropriate.
- Considering how environments could be made more accessible by reducing risks of sensory overload. This could include facilitating quiet spaces, reducing brights lights and managing the temperature to ensure it is not too hot or cold.
- Adapting communication with the person to best suit their needs.

Planning how these approaches can be embedded across services will need to be explored in the All Age Autism Strategy.

6.3 Co-production and Co-design

Too often services don't take the time to work with people with lived experiences to co-design changes to services and co-produce strategic approaches. This can lead to services solving the wrong problem and mean that ultimately people's experience of services does not improve. There are a range of opportunities in Nottingham and Nottinghamshire to co-produce and co-design service changes and a willingness across the autistic community to engage in meaningful co-production. The Asset-Based Area - TLAP sets out the approach to asset-based commissioning and working with communities to co-produce and co-design local services and outlines the evidence base for taking this approach. In order to plan how we can adapt and adjust services to support autistic people there must be a focus on working with communities to agree how to prioritise the work needed to improve services in Nottingham and Nottinghamshire, to celebrate and embrace diversity and support everyone to thrive.

6.4 Accountability

Assuring Transformation Reporting collects data about how Integrated Care Systems are supporting transformation across services for adults with a learning disability and autistic people. This has supported a culture of accountability across services in relation to the number of people in hospital under the Mental Health Act and those who are at risk of admission. There is a need to ensure that there is accountability across the Integrated Care System beyond Assuring Transformation reporting to ensure that local strategies are implemented across all partner agencies, and services to bring about meaningful change for autistic people that does not just focus on those in hospital or at risk of admission. This may include broadening the focus of workstreams reporting to the Learning Disability and Autism Executive Board or may mean a separate governance structure is needed to ensure the priorities of autistic people are addressed and that there is more focus in how we can support autistic people to reduce health inequalities and promote good health and wellbeing to prevent people reaching mental health crisis.

7. What is on the horizon?

7.1 Increases in population

Nottingham and Nottinghamshire are experiencing increased demand in assessments for autism, especially across children and young people. There is a need to plan for this increase, particularly across adult services to ensure that autistic people can access the right support at the right time before and after they turn 18. There will be an increase in people over the age of 55 who have confirmed autism assessments and therefore services for older people will need to consider how they adapt to this change. There continues to be increases in demand across mental health services for children, young people and adults across all populations including those autistic people and therefore supporting these services will be key in managing demand.

7.2 All Age Autism Strategy Refresh

Nottingham and Nottinghamshire Integrated Care System are planning to refresh the current All Age Autism Strategy which will be a key vehicle for change following the recommendations of this chapter.

7.3 Joint Strategic Needs Assessment Learning Disabilities

Nottingham and Nottinghamshire Integrated Care System is planning to produce a Joint Strategic Needs Assessment for Learning Disabilities which will need to include a focus on autistic people.

What does this tell us?

8. Unmet needs and service gaps

Access to Preventative Mental Health Provision: There remains a national and local programme to reduce the number of hospital admissions under the Mental Health Act for people with a learning disability and/or autism. Despite this, the evidence locally and nationally is that the numbers of people admitted into hospital is increasing and autistic people continue to be identified as at increased risk of suicide. Access to preventative mental health support that can make adjustments to support autistic people is required to prevent avoidable admissions into Hospital. The development of existing community-based mental health services to enable people to be supported before reaching the point of crisis is a key priority.

Reasonable adjustments across Health, Social Care, and Education services: There are identified inequalities in health, social and educational outcomes for autistic people. There are a range of barriers to accessing services for autistic people. Whilst significant activity has been undertaken to increase awareness of autism locally, there is a need for services to move to acceptance and adjustment. This will involve delivering services that take the time to understand what a person needs which will benefit everybody in the community, including autistic people and those without a formal diagnosis and improve access to meaningful support to prevent needs escalating.

Accommodation and Social Support: Some autistic people will require support to access good housing, that can meet their needs, in a place where they feel safe and may require support to live independently. There is evidence that autistic people do not feel they are able to access meaningful support and therefore working with people to understand how services can improve for autistic people is a key priority.

Employment: There is a need to ensure that autistic people have opportunities to gain skills and support to access paid employment and remain employed.

Assessment and Waiting Well: There is an increasing and high demand for autism assessments in Nottingham and Nottinghamshire and there are long waiting lists to receive a diagnosis. There is need to ensure that people receive regular communication whilst they are waiting and that they are able to access the right advice and support both before and after a diagnosis. There is also a need to ensure that opportunities for assessment are available to those where there are lower rates of prevalence such as women, older people and those from ethnic minority communities.

Planning services: Further work is required to understand the local population and identify needs, and priorities across health and social care services. Every autistic person is different and not everyone with a diagnosis will need support, and not everyone who needs support will have a diagnosis. Identifying where a person has autism can help services to consider current and future demand for services and working together with people with lived experience and their families to design services will lead to improved outcomes.

9. Knowledge gaps

Recording and Reporting: There is a lack of local systematic recording of autistic people known to services across both Health and Social Care and significant population data gaps around intersectionality, ethnicity. There is insufficient analysis and data in relation to diagnostic trends for girls and women and older people and how to improve access to assessment and or adjustment for these populations.

Mental Health: There are known risks in relation to the prevalence of suicide in autistic adults and substantial evidence that co-occurring mental health conditions are impacting the lives of autistic people however data and recording of autistic people accessing mental health services is not fully understood. The trauma of accessing mental health services for autistic people is not known or measured locally. It is also not understood how local services perform in preventing crisis for autistic people.

Criminal Justice: There is a lack of data in relation to autistic people who come into contact with the criminal justice system to help shape preventative service provision.

Social Support: There is insufficient data available across social care services to identify the number of autistic children, young people and adults known to services, which identifies and separates those with co-occurring learning disabilities and those without a learning disability.

Assessment: There is understanding that demand for autism assessments exceeds local and national comparators in Nottingham and Nottinghamshire, however it is not understood what is driving this increase.

Employment: There is insufficient information in relation to employment of autistic people locally.

What should we do next?

10. Recommendations for consideration

	Recommendation	Outcome	Lead
1	**Strategy** Refresh the Nottingham and Nottinghamshire Integrated Care Board All Age Autism Strategy with autistic people and their families to include key priorities to reduce inequalities and embed neuro - affirmative practice.	Agreed priorities for improving the experience of autistic people locally and reduced inequalities through the reasonable adjustment.	Nottingham and Nottinghamshire Integrated Care System – Learning Disability and Autism Programme
2	**Co-produce** Led by the expertise and experience of autistic people and their families and carers, strengthen the system approach to co-production and co-design	System wide co- produced and co-designed	Nottingham and Nottinghamshire Integrated Care System – Learning

	with experts by experience in relation to the All-Age Autism strategy and subsequent implementation planning. Consider co-producing a needs-led toolkit for implementing adjustments for autistic people across Health, Social Care, Education and Employment services to reduce inequalities across all services.	refreshed All Age Autism strategy and Implementation Plan using the expertise and experience of autistic people and their families and carers.	Disability and Autism Programme
3	**Governance** Strengthen existing governance structures, inclusive of but broader than the Learning Disability and Autism Board for implementing recommendations of this JSNA and the refreshed All Age Autism Strategy. Consider separate governance arrangements for the Autism Strategy with a focus on reducing inequalities.	Improved accountability to deliver change.	Learning Disability and Autism Programme Executive Board
4	**Understand** Nottingham and Nottinghamshire Integrated Care System to complete a review of data collected and data gaps with a view to improving quality of data, to have a better understanding of inequalities to assessment and support that exceeds national requirements via Assuring Transformation reporting in assessment.	Improved understanding of population and support development of future services	Nottingham and Nottinghamshire Integrated Care System – Learning Disability and Autism Programme
5	**Prioritise** Working with people with lived experience, to review local suicide prevention plans to include a focus on autism as a key at risk group.	Reduced prevalence of suicide in autistic people locally	Public Health and Nottingham and Nottinghamshire Integrated Care System – Learning Disability and Autism Programme
6	**Mental Health** Review the experiences of autistic people when accessing community and inpatient Mental Health Services with a view to co-producing an implementation plan for making needs led adjustments to include a focus on communication and sensory differences and accelerate wraparound model learning.	Reduced inequalities and Improved mental health services for autistic people	Nottinghamshire NHS Foundation Trust and Nottingham and Nottinghamshire Integrated Care Board– Learning Disability and Autism Programme engaged with community and voluntary sector organisations.

7	**Implement** recommendations in relation to the review of the neurodevelopmental pathway for children and young people, working with families and autistic children and young people and the Special Educational Needs and Disabilities Improvement Plan	Supported waiting well principles and improving education	Nottingham and Nottinghamshire Integrated Care Board and Nottinghamshire NHS Foundation Trust
8	**Transition** Review the experiences of autistic children and young people who are transitioning to adult services and consider the opportunities for improving experiences through learning with people with lived experience.	Improved transitions into adulthood	Nottingham and Nottinghamshire Integrated Care System – Learning Disability and Autism Programme
9	**Employment** Consider the need for a separate strategy for improving employment opportunities for autistic people across Nottingham and Nottinghamshire Integrated Care System which seeks to better understand the opportunities to influence improved outcomes for local people.	Reduced inequalities and improved access to employment and improved adjustments	Nottingham and Nottinghamshire Integrated Care System
10	**Workforce Development** Continue to implement and evaluate Oliver McGowan training across the system and continue to develop infrastructure to roll out programme of National Autistic Society SPELL Framework training and pilot the Anna Freud National Autism Training Programme with a view to supporting staff to adapt approaches.	Delivered better autism informed services	Nottingham and Nottinghamshire Integrated Care System – Learning Disability and Autism Programme

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