

Nottingham & Nottinghamshire Integrated Care System

All Age Autism Strategy (April 2022-March 2025)



**Integrated
Care System**
Nottingham & Nottinghamshire

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EXECUTIVE SUMMARY

As an ICS partnership we would like to extend our thanks to all those who have contributed to the development of the strategy. This strategy would not have been possible without the valuable input of our partners, stakeholders and in particular our Experts-by-Experience (EbE) who gave their time freely.

The Integrated Care System (ICS) strategy is based upon the National Strategy for autistic children, young people and adults 2021-2026: [The national strategy for autistic children, young people and adults: 2021 to 2026 - GOV.UK \(www.gov.uk\)](https://www.gov.uk/government/consultations/the-national-strategy-for-autistic-children-young-people-and-adults-2021-to-2026) which built on [Think Autism](#), the preceding adult strategy published in April 2014. This Strategy replaces existing draft (Nottinghamshire County Council) and published strategies developed locally from both Nottingham City Council (2018-2022) and Bassetlaw Clinical Commissioning Group.

Our vision is that across our ICS we will 'develop services to improve the health (both physical and mental health) and wellbeing of autistic Children and Young People (CYP) and adults to ensure that they can live happier, healthier and longer lives.'

Consultation In developing the ICS Strategy, we have undertaken consultation with a range of key stakeholders in particular EbE, carers and families.

Prevalence - Estimates show approximately 1.1% of the population of UK are autistic, equating to approximately 700,000 people. In Nottingham and Nottinghamshire there are approximately 16,500 autistic CYP and adults with a confirmed autism diagnosis. Some autistic CYP and adults also have learning disabilities, mental health issues or other conditions.

National Context - The National Strategy sets out six themes that would have an impact on significantly improving the lives of autistic CYP and adults. This Strategy also takes account of other national reports **Baroness Hollins Report** and **Mental Health Act Reforms**.

Local Context – Locally we have a total of 9,545 CYP and 7,135 Adults who are diagnosed and registered on our GP database (eHealthscope) as having autism. This shows there is a growing autistic population within our ICS area. This strategy makes the commitment that as ICS partners we will continue to learn from autistic CYP and adults and we recognise the need to see them as individuals with differing intersectional identities and lived experience.

We recognise the impact COVID-19 pandemic has had on autistic CYP and adults. For example, loss of services, lack of routine structure and lack of support for carers have led to increase mental health problems and anxieties. However, we have also learnt the benefits for some individuals engaging in services remotely. We will take this learning to inform the delivery of the strategy.

Strategic Priorities - Our priorities will focus on the following key areas:

- Improving the diagnostic pathway and post diagnostic support
- Improving autistic children and young people's access to education and supporting positive transitions into adulthood
- Supporting people in the community and avoiding inpatient care
- Improving access to and the quality of inpatient services for autistic people
- Autism and Suicide Prevention

- Tackling health and care inequalities for autistic people
- Meeting the needs of autistic people from ethnic minority groups
- Gender, sexuality and identity
- Community inclusion
- Supporting more autistic adults into employment
- Improving support within the criminal and youth justice systems
- Ageing with autism

There are several themes that cut across our strategic priorities which are ***improving mental health support for autistic people, recognising, and supporting the families of autistic people and better understanding and supporting autistic females.***

Enablers - In year one of this strategy, we will focus on putting in place the enablers required to deliver on the strategy and demonstrate that we are making progress on actions, which are as follows:

- Improving data collection and reporting to monitor implementation of the strategy and drive system improvement
- Strengthening and developing the workforce
- Strengthening governance, leadership, and accountability

Next Steps:

- Development of implementation plan with key stakeholders
- Coproduction – we will work with our virtual EbE to ensure that our implementation plan is coproduced.
- Look at ways of effectively engaging with underrepresented groups

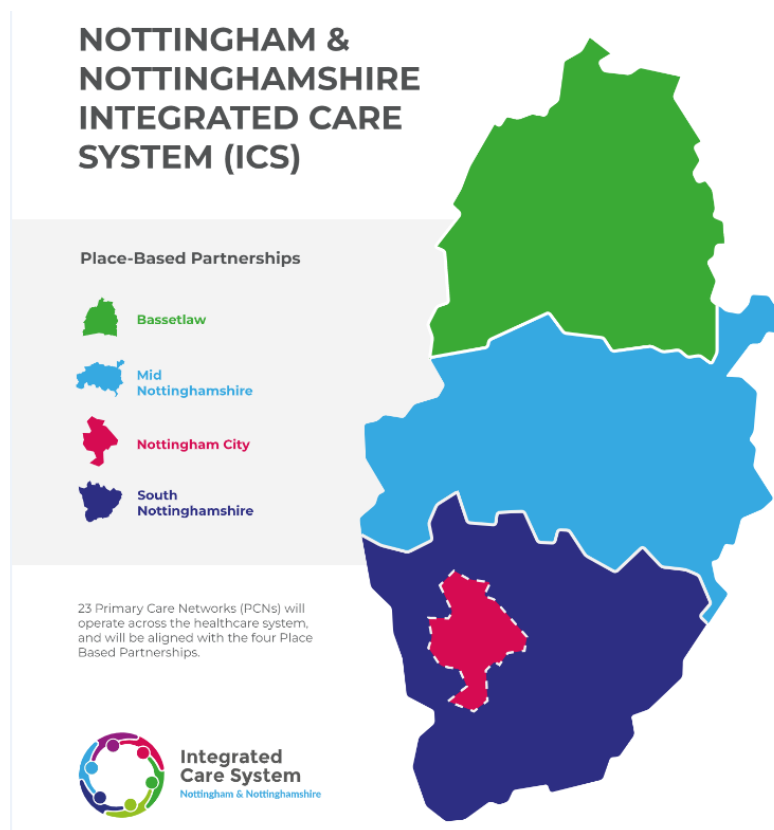
Nottingham And Nottinghamshire Integrated Care System All Age Autism Strategy (April 2022-March 2025)

1 INTRODUCTION

Our vision is that across our ICS we will 'develop services to improve the health (both physical and mental health) and wellbeing of autistic Children and Young People (CYP) and adults to ensure that they can live happier, healthier and longer lives'.

The Strategy will be underpinned by local communication and marketing plans to raise awareness and understanding of autistic CYP and adults within our communities, services, and businesses. This will support and enable autistic CYP and adults to have equal access to services, supporting them to be full participants within our communities.

The Autism Strategy will encompass autistic CYP and adults and their families and carers who live in the Nottingham and Nottinghamshire ICS area, as outlined in the map below.



Overarching Principles

The Strategy recognises the broad spectrum of autism, recognising how the needs of autistic CYP and adults differ across the life course. Nottingham and Nottinghamshire ICS is committed to delivering change that better enables autistic CYP and adults to fulfil their potential.

The ICS Autism Strategy has been developed within the social model of disability. It recognises that disability is caused by the way society is organised, rather than by autism itself and considers ways of removing barriers that restrict life choices for autistic CYP and adults. Evidence highlights that key

barriers to accessing support for autistic people include communication needs, sensory differences, and planning/coordination of accessing support (Brice et al 2021, Mason et al 2019). The Strategy identifies opportunities to remove barriers, so autistic CYP and adults living in Nottingham and Nottinghamshire ICS can be independent and equal, with greater choice and control over their own lives.

Autism is a spectrum condition. All autistic CYP and adults share certain differences in social understanding, communication, flexibility, information processing and understanding, and sensory processing and integration, but being autistic will affect people in different ways. These differences, along with differences in diagnostic approach, have resulted in a variety of terms being used to categorise autistic people. The Strategy uses the term 'autistic' throughout the document. In keeping with the preferences of most autistic people, we will be using identity-first language to include all autistic CYP and adults, and not use harmful functioning labels. When working with an individual their own preference for the terminology they use to identify should of course be used.

Our approach to coproduction

In developing the ICS Strategy, we undertook the following consultation activities:

- Consultation event with the Expert by Experience (EbE) Learning Disability and Autism Virtual group
- Online questionnaire with patients/service users/carers/frontline staff.

The key messages from the consultation were:



- Systems that work – Systems don't appear to be suitable for autistic people.
- No wrong door – People felt passed from place to place to get the right support or referrals were turned down as didn't meet criteria.
- Timely diagnosis – People felt as though diagnosis took too long for CYP and adults.
- Information sharing and not questioning – People felt information sharing between professionals was acceptable at some points and not others. But also felt that when information was shared, it was then questioned by professionals opposed to moving ahead with offering support.

- Employer understanding of autistic employees – Conversations around employers having a better understanding of autistic employees, particularly managers understanding how best to manage/ lead autistic employees. Conversations about voluntary versus paid hours for the same work, sending mixed/ unclear messages.
- Paid employment of autistic people – Autistic people were often utilised for voluntary work which did not progress into paid work or who were doing the work of paid employees without being paid for unacceptable periods of time.
- Not questioning of diagnoses. Forward planning – similar point to above, there was a clear theme that a diagnosis felt like a relief initially, and that they could then get support. However, when attempting to access support, they felt stuck in a battle of professionals questioning diagnoses opposed to offering support/ forward planning.
- Blame culture within services – Some felt that there was a blame culture within services, particularly towards parents. Some parents spoke of services suggesting that if CYP were removed from the environment, it would reduce the risk of crisis intervention. However, this proved to only exacerbate the risk of crisis and need for intervention. There was a suggestion parents should be included in the decision-making process and listened to/ valued.
- Transition year to year - Clear communication and the right support is needed (particularly for CYP transitions). The sensory processing offer progress (delivered by Occupational Therapists) is missing from schools.
- Struggle and fight – A strong theme was the struggle families and service users felt in finding the right support through existing services.

Whilst we have undertaken some engagement with EbE, we recognise that locally we have not coproduced the Strategy. The aim is that the implementation of the Strategy will be to provide more opportunity for us to co-produce with EbE. Coproduction will include EbE being directly involved, as equal partners, in the design, planning and implementation of the Strategy.

The partnership is committed to producing a fully co-produced implementation plan, which will embed the voices of autistic CYP and adults in service delivery. Additionally, we will ensure that our experts by experience will be part of our decision making on improvements to services and resource allocation. To show our commitment to this have appointed an autistic expert by experience on our Learning Disability and Autism Executive Board. They will be supported by our expert by experience virtual Board to ensure a wide range of experiences is heard, shared, and understood across the ICS partnership.

Our Commitments

The Nottingham and Nottinghamshire Autism Strategy outlines how, as a system, we will deliver against our statutory requirements outlined in the Autism Act (2009). To support this, we undertake the following commitments:

- To summarise and coordinate existing activity on autism across the Nottingham and Nottinghamshire ICS
- To increase the profile of Nottingham and Nottinghamshire's ICS work on autism and the needs of autistic people
- To improve the ICS data about our local population needs to support resource allocation
- Influence decision-making including commissioning decisions
- Inform the delivery of our Learning Disability and Autism Transformation Programme.

2 CONTEXT

2.1 Prevalence

It is estimated that approximately 1.1% of the population of UK are autistic, this equates to approximately 700,000 people¹. Skills for Care have developed a tool to estimate the local autistic population in 2020 and beyond² which estimates there will be 13,140 autistic CYP and adults in Nottingham and Nottinghamshire by 2025. However not all CYP and adults receive a diagnosis and some may never be diagnosed.

In Nottingham and Nottinghamshire there are approximately 16,500 autistic CYP and adults with a confirmed autism diagnosis³. Table 1 below shows the breakdown of our current local autistic population taken from e-Healthscope (an information system used by General Practice) against the national estimate for 2025 using the Skills for Care tool.

Table 1: The projected number of Children and Young People (CYP) and adults diagnosed with autism in the Nottingham and Nottinghamshire ICS.

Year	Children & Young People (CYP)		Difference	Adults		Difference
	2022	2025		2022	2025	
Nottingham City	2,650	810	1840	2,265	2,930	-665
Nottinghamshire County	6,715	1,910	4805	4,870	7,480	-2610
Total	9,365	2,720	6645	7,135	10,410	-3275

The Adult Psychiatric Morbidity Survey (APMS) (2014) found the overall prevalence of autism to be 0.7 % and was higher in men (1.1%) than in women (0.2%).⁴ The Loomes 2017 data would suggest that though the prevalence of autism in females is now higher the diagnosis still shows more men with autism (3:1 male: female).

Whilst there are more males than females diagnosed as autistic, this is not necessarily because there are more autistic males than females but rather that the diagnostic process is still designed and weighted towards a certain presentation of autism. As such female and non-binary people are generally diagnosed later in life than their male counterparts, if at all. Women may instead often be diagnosed as needing support around their mental health and the late diagnosis may mean that a failure to provide support at an early stage may also lead to a greater degree of mental ill health and

¹ [The National Autistic Society](#)

² [Understanding-the-local-population-of-autistic-people-v2-x.xlsx \(live.com\)](#)

³ e-Healthscope data (correct on 31 January 2022). Figures are approximate and rounded to the nearest five.

⁴ -Brugha et al (2012) Estimating the Prevalence of Autism Spectrum Conditions in Adults: Data quality and methodology document, NHS Information Centre

crises developing. Additionally, there is a significant increase in young women and non-binary people being treated for eating disorders who are ultimately diagnosed as autistic.

Table 2 below shows the number of autistic CYP and adults in Nottingham & Nottinghamshire with a confirmed diagnosis by gender. The figures show females make up a quarter of the local autistic population (4,075).

Table 2: The number of autistic CYP and adults in Nottingham and Nottinghamshire with a confirmed diagnosis, by gender.

	CYP		Adults	
	Female	Male	Female	Male
Nottingham City	570	2,080	615	1,650
Nottinghamshire County	1,665	5,050	1,225	3,645
Total	2235	7,130	1840	5,295

Some autistic CYP and adults also have learning disabilities, mental health issues or other conditions, meaning people need different levels of support. In Nottingham and Nottinghamshire, according to locally recorded data, 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.⁵

The needs of autistic CYP and adults is varied and can change for the individual in different contexts. Some autistic people have a life-long need for care whilst other autistic people live and work independently. All autistic CYP and adults should be helped to live more fulfilling lives of their own choosing.

This Strategy commits the ICS partners to continued learning from autistic CYP and adults and recognises the need to see them as individuals with differing intersectional identities and lived experiences. Autism affects people across all ages, genders, sexual orientations, classes, races, ethnicities, religions, and beliefs, as well as people with co-occurring disabilities. We acknowledge the current national disparities in recognition, diagnosis rates and specialised support and understanding of, for example, women, girls, trans and non-binary people, and those from many ethnic minority groups. We recognise that autistic CYP and adults who experience an overlap in various intersectional identities can be impacted by higher levels of mental ill health and occurrences of bullying, systemic oppression, and discrimination. We commit to engaging with individuals and communities across the City and County to better understand and meet the needs of all autistic CYP and adults.

2.2. National Context

In July 2021 the Government published the National Strategy for autistic children, young people and adults 2021-2026: [The national strategy for autistic children, young people and adults: 2021 to 2026 - GOV.UK \(www.gov.uk\)](https://www.gov.uk/government/consultations/the-national-strategy-for-autistic-children-young-people-and-adults-2021-to-2026). Easy read version [The national strategy for autistic children, young people and adults: 2021 to 2026 \(Easy Read\) \(publishing.service.gov.uk\)](https://publishing.service.gov.uk/government/consultations/the-national-strategy-for-autistic-children-young-people-and-adults-2021-to-2026-easy-read). This new Strategy aligns with the Adult Autism Strategy 2015 and the Special Educational Needs and Disability (SEND) Code of Practice (2015) for Children. Both these documents set out the duties of local authorities and NHS organisations to support autistic adults, children, and young people.

⁵ e-Healthscope data (correct on 31 January 2022)

The National Strategy sets out six themes that would have an impact on significantly improving the lives of autistic CYP and adults. These themes have been adopted by this Strategy and are:

- Improving understanding and acceptance of autism within society
- Improving autistic children and young people's access to education, and Supporting positive transitions into adulthood
- Supporting more autistic young people and adults into employment
- Tackling health and care inequalities for autistic CYP and adults
- Building the right support in the community and supporting people in inpatient care
- Improving support within the criminal and youth justice systems

This Strategy also takes account of other national reports:

Baroness Hollins Report ([Independent Care \(Education\) and Treatment Reviews - GOV.UK \(www.gov.uk\)](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/681147/Independent_Care_Education_and_Treatment_Reviews_-_GOV.UK.pdf)): This report highlighted inappropriate use of long-term segregation to manage challenging behaviour in the absence of the right therapeutic care and environment.

Mental Health Act Reforms: (*Source and full report:* [Reforming the Mental Health Act: summary - GOV.UK \(www.gov.uk\)](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/681147/Independent_Care_Education_and_Treatment_Reviews_-_GOV.UK.pdf))

The government and NHS England and Improvement (NHSEI) are delivering the most ambitious programme to transform mental health care that England has ever known, with substantial changes to the Mental Health Act to give those who require care under the Act to have greater control over their treatment and receive the dignity and respect they deserve.

2.3. Local Context

This Strategy replaces existing draft (Nottinghamshire County Council) and published strategies developed locally:

- Nottingham City Council (2018-2022):
(<https://www.nottinghaminsight.org.uk/themes/health-and-wellbeing/key-strategies-and-research-reports/key-health-strategies/>).
- Bassetlaw Clinical Commissioning Group: [Bassetlaw \(bassetlawccg.nhs.uk\)](https://www.bassetlawccg.nhs.uk/).

Nottingham and Nottinghamshire have a mature Learning Disability and Autism Transformation Programme which commenced in April 2016. A key part of this programme is to resolve the issues identified in the aforementioned Hollins report as well as those outlined in the National Strategy. Transformational projects are in place to improve our diagnostic pathways for autistic children, young people and adults, improve community provision and develop skills and understanding within the health and social care workforce.

The delivery of this programme will be aligned to support the implementation of our local ICS Autism Strategy. This programme is managed by the Learning Disability and Autism Executive Board who take a leadership role in implementing improvements within health and social care pathways to improve outcomes for autistic CYP and adults and those with learning disabilities. The Executive Board will oversee the development and delivery of the implementation plan.

3 IMPACT OF COVID

The COVID-19 pandemic has been an unprecedented challenge which had had an impact on individuals, communities and governments across the world. A number of reports have been published, highlighting the specific challenges faced by autistic people:

- [‘Left stranded: The impact on autistic people and their families in the UK’](#) (National Autistic Society, 2020)
- [impact of the COVID-19 pandemic on autistic children](#)
<https://pubmed.ncbi.nlm.nih.gov/32986631/>
- [The Impact of COVID-19 on Autistic People in the United Kingdom: Final Report \(piru.ac.uk\)](#)
(Department for Health and Social Care, 2020)

These studies have highlighted several adverse consequences such as:

- Lack of routine and predictability due to school closures and reduced access to services
- Lack of or reduced support due to restricted access to support and therapy services
- Postponed or cancelled appointments which has led to increased waiting times for diagnostic assessments and/or appointments
- Overwhelming responsibility on care givers
- An exacerbation of mental health problems
- Increased anxieties around health

However, for other autistic people, it has taken away some of the societal pressures around joining groups and interacting at work. From a society perspective there has also been a lack of understanding around mask exemptions for those with hidden disabilities.

We will take action to support autistic children and young people and all those with SEND as we move out of COVID-19 restrictions over the academic year 2022 to 2023. So far, we have published a range of guidance to support remote education, including specific support for children and young people with SEND. We recognise that some autistic children and young people have benefitted from access to remote learning which can be personalised and accessed flexibly, including outside of the school environment, and we will continue to personalise support for individuals as we move into recovery.

4 STRATEGIC PRIORITIES

Our priorities will focus on better understanding and meeting the needs of autistic CYP and adults with a focus on the following key areas, which relate to the 6 key themes outlined in the national strategy:

- Improving the diagnostic pathway and post diagnostic support
- Improving autistic children and young people’s access to education and supporting positive transitions into adulthood
- Supporting people in the community and avoiding inpatient care
- Improving access to and the quality of inpatient services for autistic people
- Autism and Suicide Prevention
- Tackling health and care inequalities for autistic people
- Meeting the needs of autistic people from ethnic minority groups
- Gender, sexuality and identity
- Community inclusion
- Supporting more autistic adults into employment
- Improving support within the criminal and youth justice systems
- Ageing with autism

There are a number of themes that cut across the strategic priorities above, which are ***improving mental health support for autistic people, recognising, and supporting the families of autistic people and better understanding and supporting autistic females.***

4.1. Improving the diagnostic pathway and post-diagnostic support

Why is this a priority?

One of the primary issues reported by autistic people and their families is around timely access to diagnostic services and tailored support once a diagnosis has been received. Autistic people tell us that once a diagnosis has been given there should be some continuation of support to assist them with coming to terms with their diagnosis and to support them with their additional needs or support with any co-existing conditions. Co-existing conditions range from mental health issues such as depression and anxiety to physical health conditions. Increasingly autistic CYP and adults are being diagnosed with an eating disorder, including Avoidant Restrictive Food Intake Disorder (ARFID) or disordered eating.

What is happening locally?

Children and Young People

In Nottingham and Nottinghamshire, services are commissioned in the City and County to deliver pre-diagnostic support and diagnostic assessments are carried out predominantly by Community Paediatrics and Child and Adolescent Mental Health Services (CAMHS), where the CYP is receiving support from their service. In Bassetlaw, diagnostic assessments are carried out by Community Paediatrics, Speech and Language Therapists and Clinical Psychologists. CAMHS also carry out some diagnostic assessments. We know that CYP are waiting too long for a diagnosis and CYP and their families tell us that support is not available early enough. There are some post diagnostic support groups for parents and access to 1:1 interventions. There is limited support for some eating disorders such as ARFID and those with disordered eating.

Adults

In Nottingham and Nottinghamshire, Nottinghamshire Healthcare NHS Foundation Trust are commissioned to provide the Neurodevelopmental Specialist Service (NeSS) which offers multi-disciplinary assessment, diagnosis and post-diagnostic support to adults with suspected/confirmed autism and/or ADHD, in line with NICE guidance and the Autism Act. We know that adults are waiting too long to receive a diagnosis. A pre-diagnostic support service has also recently been commissioned to support people with their primary presenting needs throughout their diagnostic journey and to ensure that adults can receive support whilst awaiting a diagnosis. Post diagnostic support is limited due to capacity within services that are having to prioritise diagnostic assessments. There is limited support for some eating disorders such as ARFID and those with disordered eating.

What are our priorities for 2022-2025?

- Ensure there is timely access to pre-diagnostic and diagnostic services for CYP, with the inclusion of psychology and increased speech and language therapy in diagnostic assessments
- Develop and maintain a website for CYP and their families in order for them to navigate through the pathway and obtain support and information around service provision
- Work with our Neurodevelopment Specialist Service (NeSS) to continue to provide a clear diagnostic pathway for adults, and ensure timely access to diagnostic services and post-diagnostic support
- Develop a clearly written diagnostic pathway for children and adults with visual diagrams
- Evaluate our local pre-diagnostic support offer for adults

- Ensure a clear pathway into social care for autistic adults and their carers
- Ensure information and support plans are clear and understood by those receiving a diagnosis to support them post diagnosis
- Ensure all staff involved in the pathway and providing services to autistic people are appropriately trained in autism awareness as a minimum.
- Ensure local pathways and services meet the needs of autistic people throughout their lives and during challenging times including change in life circumstances (such as the death of a parent or partner) and at points of contact with the Criminal Justice System.
- Ensure mental health services are able to meet the needs of autistic people
- Develop an all-age pathway for autistic CYP and adults who have ARFID

4.2. Improving autistic children and young people's access to education and supporting positive transitions into adulthood

Why is this a priority?

A growing number of children and young people are being diagnosed as autistic, with special educational needs data suggesting that 1.8% of all pupils in England now have an autism diagnosis. We also know there are many more autistic pupils in our schools without a diagnosis. It is unacceptable that many autistic children and young people are still having poor experiences within school, are not reaching their potential and are struggling in their transition to adult life. The All Party Parliamentary Group on Autism's (APPGA) report on the Autism Act, 10 Years On showed that autistic children and young people often find it difficult to get the help they need at school due to poor understanding of autism among education staff, highlighting that fewer than 5 in 10 education staff reported being confident in supporting autistic children and young people. This can inevitably result in missed opportunities to enable pupils to reach their potential, and in minimising the risks of children and young people experiencing mental ill-health and escalating anxiety levels and resulting distress behaviours, due to unmet needs.

Many autistic children find school environments overwhelming and evidence from the APPGA shows they often feel misunderstood or judged by their peers, which can impact on their ability to engage and succeed in education. In addition, the research highlighted that autistic children and young people often struggle to get the support they need through the SEND system more generally, including being unable to access support early enough from health and social care, as well as education. We also know that many autistic young people find transitions into adulthood difficult because this is a period of heightened uncertainty and can result in changing access to services and support.

We want the SEND system to enable autistic children and young people to access the right support, within and outside of educational settings. We want schools to provide better support to autistic children and young people, so they can reach their potential. We are committed to ensuring that fewer autistic children are permanently excluded or suspended from school due to their differences, needs and resulting distress behaviours not being understood. We will make improvements to the support autistic people get when transitioning into adulthood, so that more autistic people can live well in their chosen communities, and successfully access work, training, higher education, or other meaningful opportunities they seek that enable them to feel fulfilled and thrive. We will ensure that support is proactive and person-centred, to minimise the risks of young people avoidably experiencing crisis, and where mental health services or crisis support is needed, that this is provided in a timely manner in a way that is understanding and respectful of autistic differences.

We want more teachers and educational staff to understand the specific individual needs of their autistic pupils, ensuring that more school placements can be sustained where appropriate, or person-centred solutions sought, so that pupils have positive educational experiences in the provision or

setting right for them. We want to demonstrate that more autistic children have had their differences identified and shared with them from the earliest possible age, so that they can grow up with a positive understanding of their strengths and needs, and celebrate being authentically and uniquely them, without learning to mask who they are.

To improve transitions into adulthood, we will continue to ensure education, health and social care professionals work in partnership and have the skills required to support the specific needs of autistic young people during what can be an anxious and challenging time. As part of this focused work with educational settings, we expect that building independence and preparing for adulthood is a key theme right through a young person's education, and that transitions are introduced to the individual and supported at a time and in a way that is right for them to minimise anxiety. We support educational settings to give appropriate and person-centred information, advice, and guidance, that is led by a young person's choices and preferences, and that is clearly communicated in a way that they understand.

We are committed to supporting more autistic young people to access further education, employment, or training. We are strengthening and promoting pathways to employment, such as through supported internships, traineeships, and apprenticeships. ICS partners recognise the barriers created by many current recruitment systems and support a review of existing application and interview processes across organisations.

What is happening locally?

There are Autism Teams in both the City and County that provide training and information to schools across Nottingham and Nottinghamshire. This includes access to the Autism Education Trust (AET) training, specific to the three phases of education: Early years, school and post 16. Nottinghamshire offer free Making Sense of Autism training on a 2-year rolling programme for everyone working in schools, inclusive of e.g. admin, catering, sites staff and governors, as well as classroom staff and Speech and Language Therapists, acknowledging that every member of the school community will be working with autistic pupils. The Communication and Interaction Team support schools to strategically develop their good autism practice through use of the AET Standards, Competencies and Progression Framework, and deliver internally developed training specific to pupil needs and the needs of their school.

The CYP steering group have secured funding to pilot the Autism in Schools Project and four schools have been identified to develop and support their understanding of autism. The Autism in schools project aims to improve the school experience for autistic CYP, their families and the school staff. The project is comprised of 3 key areas to influence reasonable adjustments of school policies and procedures.

- Support of autistic CYP in understanding their diagnosis
- Upskilling of school staff in working with autistic CYP
- Improving communication between families and schools

Nottinghamshire County Council have a Preparing for Adulthood Team which works with autistic young people to consider their future aspirations and social care needs to support them as they transition into adulthood.

The CCG have secured monies to facilitate the development of a website for CYP and their families in Nottingham and Nottinghamshire. Once developed, the website will provide a dedicated online

resource which clearly outlines what to expect in terms of patient experience and journey within the autism pathway. The website will include information about support available, useful self-help tools and pathway resources. It will also link to the respective Local Offer websites and the Nott Alone website.

What are our priorities for 2022-2025?

- We will develop training materials and resources through which we learn from and amplify autistic voices inclusive of their intersectional identities and experiences.
- We will commit to improving early identification of children and young people's needs, and making sure that the health, social care and education systems work together to support children holistically before their needs escalate.
- We will ensure, in line with the Nottinghamshire SEND Policy that there is a broad range of local SEND provision and educational settings, so that more children and young people's needs are met closer to home. Children and young people in Nottingham and Nottinghamshire do not need to have an Education, Health and Care Plan to access resources. Support and provision are needs led.
- We will embed autism as a priority for educational leadership, recognising this as vital in developing autism-inclusive cultures, and we will share good autism practice within all education settings. We will also work with professionals and schools to sign-post them to good quality resources.
- We want the right community services to be available for autistic children and young people and those with other special educational needs and their families, based on what they say they need.
- There will be a focus on our SEND system to support CYP to access the right support within and outside of school. We will review the Autism in Schools pilot and consider its expansion across all our schools as system partners.
- Pre-planning for transitions and discussions with young people will take place at a time and in a way that is right for them to minimise anxiety.
- Work across partner organisations to develop a clear pathway for transitions across all service areas with the promotion of employment as part of options post-learning

4.3. Supporting autistic people in the community and avoiding inpatient care

Why is this a priority?

Nationally and locally, efforts to ensure people with learning disabilities and/or autism can live in their community, close to home, with the right support is led by the 'Transforming Care' agenda. Building the Right Support (2015) and Building the Right Home (2016) focus on the community support and housing plans elements of the Transforming Care agenda.

The Learning Disabilities and Autism (LDA) Transformation Programme aims to prevent unnecessary hospital admissions for people with a learning disability or autism. Many autistic people can experience severe difficulties with 'unfriendly' environments. This can mean that a person may have problems with sensory input from the world around them. This may affect them in a variety of different ways, from being distracted, unable to concentrate and having mild discomfort, to symptoms of acute 'pain' and deterioration in functioning. This can be particularly problematic when someone is living in an inpatient facility.

What is happening locally?

The ICS have commissioned a pre diagnostic information, advice and guidance service to support people waiting for a diagnosis. This service will include peer mentoring to support people who are waiting for a diagnosis or who have a diagnosis of autism to access services to help improve their health and wellbeing. Nottinghamshire County Council are also writing a prevention strategy which will seek to consider opportunities to support people to promote their wellbeing. Nottinghamshire County Council are also updating their strategy around day opportunities for people with disabilities and this will include a focus around increased opportunities to access employment and day opportunities that support people to build on their strengths.

To support this ambition the LD&A Transformation Programme has funded two specialist commissioners to work across our ICS. Their focus will be to develop strong market management plans that sets out clearly to potential providers the ask in terms of the types of provision we require across our ICS and grow the specialist provision for autistic people with complex needs including those that pose a forensic risk, disordered eating or those that display behaviours that may challenge services. The LD&A Transformation Programme is also undertaking a review of the community wraparound services available to autistic people to prevent admissions into Hospital.

As a local system we have commissioned four unplanned care beds as a short-term accommodation where adults whose mental health is deteriorating and/or behaviours are escalating to the point where they can no longer receive support safely within their home can go and safely receive support from community services, enabling recovery and avoiding an unnecessary hospital admission for a short period of time. The Intensive Community Assessment and Treatment Team (ICATT) has been expanded to provide wraparound support to the Unplanned Care Beds and support autistic adults not currently under Mental Health Services, within their home to avoid continued escalation of behaviours resulting in a crisis and an hospital admission. In addition, a Behaviour Intensive Community Service (BICS) is being piloted during 2021-22 to provide intensive support to autistic CYP or those with a learning disability and their families with the aim of avoiding family breakdown and school absences.

Our LA partners on behalf of the ICS partnership will drive the housing agenda in ensuring adults and young people have a variety of housing options available to them.

What are our priorities for 2022-2025?

- Evaluate the BICS pilot and extend the service if it demonstrates positive outcomes
- Develop short term accommodation for CYP to prevent hospital admission
- Ensure specialist placement/short breaks/day services for autistic people are in place. This is key to enable carers to have a break. There will be a review to consider whether the needs of autistic CYP and adults are being met adequately
- Transitional accommodation which promotes independence where people may find transition from long term hospital to supported living too big a step in one go and the opportunity for compatibility assessment where people are preparing to live in shared accommodation. Bespoke robust housing options for people who may experience or present risks in unsuitable physical environments. Access to general needs housing for people whose needs are not best served by access to specialist or clustered housing
- Review Shared Lives placements, for both long and short term
- Review and develop move on options for people whose support needs have reduced over time and who no longer need specialist accommodation
- Ensure there is appropriate housing and support for those whose primary needs are due to their autism rather than any associated learning disability and/or behaviour that challenges.

- Develop a housing market that supports greater independence and quality of life for autistic CYP and adults who may or may not have a learning disability but have complex needs

4.4. Improving access to and the quality of inpatient services for autistic people

Why is this a priority?

As a Partnership we recognise the need to make adjustments within our inpatient mental and physical healthcare to improve access. Brice et al (2021) highlights that three key areas impact on successful outcomes for autistic people: the sensory environment, clinical and service context, and clinician knowledge and communication.

When autistic people do require a hospital admission, we know that we need to be ambitious about the quality of support provided. It is nationally recognised that an inpatient admission can lead to additional distress for an autistic person. The national strategy for autistic people is ambitious about health pathways and takes learning from the Out of Sight (2020) report where hospital wards were frequently cited as not being therapeutic environments for this population; low quality care was also associated with a lack of care planning and staffing.

Our aim will be to ensure high-quality, specialist care for people who are in hospital for short periods. The focus will be on improving their health and supporting them to be discharged safely within the community with the right support and care in place. The specialist community teams will have assessed the reasonable adjustments required in the hospital setting and come with clear and measurable objectives set for their admission to hospital. Discharge planning will commence before admission.

Within a hospital environment, further assessments including autism diagnostic, sensory, mental health, physical health, trauma, learning disability must take place. We will work towards the environment being therapeutic and autistic people will be cared for in small person-centred units with the right sensory environment, as recommended by the National Institute for Health and Care Excellence (NICE).

What is happening locally?

Locally we will raise awareness, build up skill level across the inpatient workforce and social care workforce (whose focus is discharge planning into the community) in understanding the sensory needs for autistic adults. Developing skills across the workforce will support a cultural shift in the way care is delivered within inpatient and community settings. Our focus will be to drive the following activities:

- Delivery of training by a practitioner trained in sensory integration
- Post graduate opportunities in sensory integration for staff in adult mental health and secure care services. These staff will be sensory champions within their service taking environmental assessment of their inpatient services
- Sensory staff champions will engage with local EbE to ensure that the learning is embedded within work practices.
- Set up established network staff groups to support future learning.

What are our priorities for 2022-2025?

- Developing specialist posts within our CAMHS and Adult Mental Health Services to ensure that reasonable adjustments are recognised for autistic people

- Consider how our inpatient environments can be more 'sensory friendly' for autistic people, embedding the learning from the Sensory inpatient pilot

4.5. Autism and Suicide Prevention

Why is this a priority?

There is some evidence^{6 7 8} that autistic people and those with other neurodevelopmental conditions are at increased risk of suicide when compared with the general population. This evidence is sparse and highlights gaps in understanding but provides a basis on which strategy and provision can be formed.

What is happening locally?

Nottingham and Nottinghamshire have a Suicide Prevention Strategy and Action Plan for the period 2019-2023, developed and overseen by a well-established Suicide Prevention Strategic Steering Group reporting into the Nottingham and Nottinghamshire ICS Mental Health and Care Board. The overall aim of the strategy is to 'reduce the rate of suicide and self-harm in the Nottingham City and Nottinghamshire population, by proactively improving the population mental health and wellbeing, and by responding to known risks for suicide in the population' [Mental health - Nottinghamshire Insight](#)

Nottingham and Nottinghamshire ICS has been successful in obtaining new Wave 4 Suicide Prevention funding from NHS England over a three-year period. Local delivery of the Wave 4 Suicide Prevention Programme will consider the needs of autistic people including:

- The inclusion of services working with autistic people in a training needs assessment that will make recommendations in relation to suicide prevention, self-harm and mental health training
- The consideration of how best to communicate suicide prevention messages to autistic people and those with learning disabilities and other neurodevelopmental conditions
- Consideration of the needs of autistic people in the development of any targeted support for suicide prevention/crisis and self-harm

The Suicide Prevention Strategic Steering Group is contributing to a study being led by the University of Nottingham and University of Newcastle to find out how useful adapted safety plans are for autistic adults experiencing self-harm or suicidal thoughts.

What are our priorities for 2022-25?

The Suicide Prevention Action Plan was refreshed by the Suicide Prevention Strategic Steering Group (SPSG) in October 2021, and now includes additional actions relating to suicide prevention for autistic people and those with other neurodevelopmental conditions:

- Establish links between the SPSG and the Autism Strategy Group and the Learning Disability/Autism three-year transformation programme

⁶ Hirvikoski, Tatja, et al. "Premature mortality in autism spectrum disorder." *The British Journal of Psychiatry* 208.3 (2016):

⁷ Cassidy, Sarah, et al. "Suicidal ideation and suicide plans or attempts in adults with Asperger's syndrome attending a specialist diagnostic clinic: a clinical cohort study." *The Lancet Psychiatry* 1.2 (2014): 142-147

⁸ Suicide in Children and Young People, National Child Mortality Database Thematic Report, Oct 2021

- Undertake an evidence review in relation to autism/learning disabilities/neurodiversity and suicide prevention and consider recommendations within the SPSG, Autism Strategy Group and Autism transformation programme
- Support organisations to develop guidance and training relating to autism and suicide prevention with training focussed initially on urgent care within Nottinghamshire Healthcare Foundation Trust

4.6. Tackling health and care inequalities for autistic people

Why is this a priority?

Autistic people (particularly those with an associated learning disability) are often at a disadvantage compared to the wider population in terms of health inequalities. One of the reasons for this has been noted to be the accessibility to statutory services and the understanding of staff within those services once contact has been made. Autistic people tell us that there is a lack of knowledge and understanding by a range of professionals with regards to their presenting needs including psychological and maternity services. To ensure parity of health with the general population it is important that autistic people are supported to maintain their own health and wellbeing including access to universal (or specialist) health services including screening programmes. We have also highlighted in Section 3 how Covid had a particularly negative impact on autistic people.

What is happening locally?

We know that the needs of autistic people in Nottingham are diverse and that support is required to address physical and mental health conditions and social problems.

Nottingham and Nottinghamshire has a well-established process for implementing the Learning Disabilities mortality reviews (LeDeR) and is embedding themes from LeDeR reviews into service improvements. From January 2022 there was a requirement to undertake reviews for autistic people and work has commenced around embedding these into services. This includes the development of review pathways, specific autism review training for reviewers. There are mechanisms in place to encourage collaboration with partners to improve care provision across the ICS through a LeDeR steering group and a wider physical health steering group.

What are our priorities for 2022-2025?

- The NHS Long Term Plan (2019) gave a commitment to implement a digital flag for autism in the patient's clinical record and pilot the introduction of a specific Annual Health Check for autistic people by 2023/24⁹. Nottingham and Nottinghamshire ICS will work with key partners to implement this commitment in line with national timescales and guidance.
- From January 2022, Learning Disabilities Mortality Reviews (LeDeR) in respect of autistic people are being undertaken. We will utilise the learning from these reviews to identify themes and inform service developments and improvements
- Develop a local LeDeR review team to ensure timely completion of quality reviews, including autism reviews
- Nottingham City and Nottinghamshire County Council will make reasonable adjustments to general council services to improve access and support for autistic people

⁹ [NHS Long Term Plan » Learning disability and autism](#)

- Promote reasonable adjustments to enable autistic people to access health and social care information, support, and advice
- Work with local health services/providers to reduce the barriers to care including those to preventative medicine and screening programmes
- Work with public health to develop targeted programmes around healthy lifestyles

4.7. Meeting the needs of autistic people from ethnic minority groups

Why is this a priority?

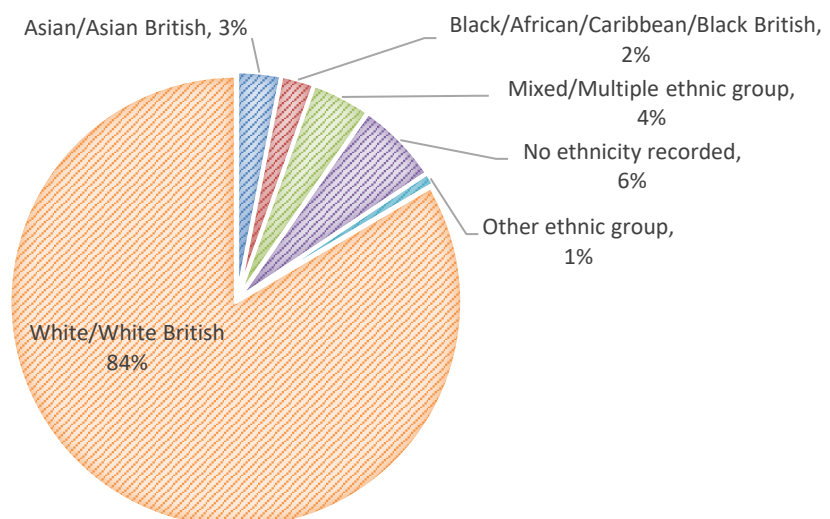
The [National Autistic Society 2014](#) states that all families affected by autism experience a struggle when trying to get a diagnosis, access the services they need and integrate their child with their local community. However, they also found that certain additional challenges are more prevalent within ethnic minority groups including understanding of autism, issues around accessibility such as information not being available in the first language of the family needing it and understanding by staff and services of the cultural needs of the autistic person. As a result, families have had poor experiences of services which discourage them from accessing them leading to further isolation.

What do we know locally?

In Nottingham and Nottinghamshire 10% of the autistic population are from an ethnic minority group, this increases to 23% in Nottingham City.

We also have an ethnically diverse white non-British population in Nottingham and Nottinghamshire with 9% of the general population identifying as white non-British, including 6.1% in Nottingham City because of international migration to the area from Eastern Europe.¹⁰

Figure 1: Ethnicity of autistic people in Nottingham and Nottinghamshire (e-Healthscope 31 January 2022)



What are our priorities for 2022-2025?

¹⁰ [Demography chapter: the people of Nottingham \(2021\) - Nottingham Insight](#)

- Consult families, carers and autistic people from ethnic minority groups about their needs
- Gain an understanding on whether ethnic minority groups are seeking diagnosis in the first instance.
- Improve recording of the number of diagnoses of autism in people from ethnic minority groups and whether people from ethnic minority groups are using local autism services
- Raise awareness and understanding of autism in local ethnic minority groups, where needed
- Ensure that services are inclusive and culturally competent, providing tailored information on autism and their services in appropriate languages and that this is promoted to ethnic minority groups
- Ensure that services that are accessible for local ethnic minority groups, including in appropriate locations and at appropriate times
- Enable peer support forums for parents and carers from local ethnic minority groups and, where appropriate, tailored support services
- Provide advocacy, translation, and interpretation services for families from ethnic minority groups who require support during and following diagnosis of autism.

4.8. Gender, sexuality, and identity

Why is this a priority?

As outlined in Section 2, there can be differences in presentation between autistic males and females and there are often misconceptions for females due to a greater awareness of stereotypical male presentations of autism. We need to increase our understanding of the different ways autism presents so that women, girls and non-binary people in particular are no longer missed. There is some evidence to show a higher prevalence of autistic people identify as LGBTQ+. In particular, autistic people may experience gender identity differences, where someone's gender identity does not match the sex they were assigned at birth. There is developing research Warrier et al. (2020)¹¹ but more is needed to ensure that autistic people's experiences of gender are better understood and their needs met. 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.

What do we know locally?

Section 2 outlines our autistic male and female populations in Nottingham and Nottinghamshire. This shows that there are more males with a diagnosis of autism than females. Data on non-binary people is not recorded consistently within health and social care services and we need to improve on this.

What are our priorities for 2022-2025?

- Increase awareness around the needs of autistic females
- Improve the recording and reporting of non-binary autistic people.
- Work with autistic people to determine what type of support is required

¹¹ [Elevated rates of autism, other neurodevelopmental and psychiatric diagnoses, and autistic traits in transgender and gender-diverse individuals | Nature Communications](#)

- Ensure staff and professionals have the appropriate skills to support autistic people around gender, sexuality, and identity
- Ensure that support is firmly embedded in the diagnostic pathway including any wrap around provision
- Make support available across the lifespan, appropriate to the age and stage of the individual
- Ensure appropriate provision is available as early as possible to prevent crises occurring
- Ensure autistic people are able to access inclusive *Personal, social, health and economic (PSHE) education* and *Relationships and Sex Education (RSE) and Health Education* in school.

4.9. Community inclusion

To enable autistic children and young people and adults to access a wider variety of community opportunities it is necessary to make communities more “autism friendly”¹². ‘Autism Friendly’ is challenging to define and therefore this strategy adopts a broader concept of ‘Autism Friendly’ that includes:

- Increased understanding of autism including through the support of Autism Champions.
- Considering the needs of autistic CYP and adults in new and remodelled buildings and environments.
- Encouraging and supporting public facing organisations and businesses to make small adaptations such as having an ‘autism hour’ where music is off, lights are dimmed, a quiet space is available and staff are aware of the needs of, and welcoming to, autistic people.
- Recognising the challenges some autistic CYP and adults have in accessing public transport and the support they may need to access public transport including an ‘accompanier’.

What is happening Locally?

Nottingham and Nottinghamshire have delivered autism awareness training across Health and Social Care. There has also been some work undertaken with transport providers so that autistic people can access services. It is recognised that there is more work to do in communities to ensure autistic people can access community services.

¹² **Autism Friendly**

Is about making spaces that meet the sensory needs of individuals and allowing people the time and space they need to process information and communicate in the best way for them.

[Autism Friendly Award](#) – This is an award that businesses can register for to show they have completed a certain level of training, made adaptations, etc. There is a recognition that the cost of this award may be a barrier particularly for small voluntary and community organisations.

According to the National Autistic Society there are lots of small changes you can make that make a big difference to autistic people – from customer information to staff awareness. Each venue that achieves the Autism Friendly Award will be helping to make the UK a more autism-friendly place by opening their doors to autistic people and their families whose lives are affected daily by businesses that do not understand their needs.

What are our priorities for 2022-2025?

- Increase understanding of autism throughout Nottingham and Nottinghamshire ICS through the provision of autism awareness training across communities including service providers, community, and voluntary organisations.
- Encourage groups, individuals, and organisations to make small changes to their environments that can make a big difference to autistic CYP and adults such as having a quiet space for those feeling overwhelmed and reducing ambiguity in correspondence
- Continue to work with transport providers to develop autism friendly access to services
- Use local networks, social media etc. to promote autism friendly communities and understanding of the needs of autistic people
- Continue to develop the market locally to meet the needs of autistic CYP and adults (e.g., there is a defined need for appropriate housing, supported living, local befriending services and around key life events)
- Ensure the needs of autistic CYP and adults and their families are incorporated into wider commissioning plans including the auditing of existing contracted services to ensure compliance with the equality act in terms of autism
- Ensure availability of appropriate information and advice to support autistic CYP and adults and their families to access available services, support, and community assets
- Ensure that Nottingham and Nottinghamshire ICS are an Autism Friendly Local Partnership through commissioned services, service provision and autism aware staff

4.10. Supporting more autistic adults into employment

Why is this a priority?

This strategy aims to influence employers and businesses to remove barriers that restrict community presence, supporting and enabling autistic CYP and adults to fully contribute to Nottinghamshire's communities.

Supporting more autistic young people and adults into employment requires a partnership approach including work with schools and colleges. There are approximately 489,800 adults of working age (18-64) in Nottinghamshire¹³ with an estimated 5615 of these people being on the autistic spectrum. Whilst in Nottingham City there are approximately 235,400 people of working age population aged between 16-64 years old¹⁴

What is happening locally?

Currently autistic people and people with Learning Disabilities who are looking for paid work in Nottinghamshire are supported by the Nottinghamshire County Council, i-work Team. To date 793 autistic people and/or those with a learning disability have been supported by the i-work Team. Overall, 676 autistic people and/or those with a learning disability have been in paid work at some time with i-work support. There are 275 autistic people or those with a Learning disability being supported in work at this time.

¹³ Nottinghamshire: <https://www.nottinghamshireinsight.org.uk/people/key-population-facts/>

¹⁴ <https://www.nottinghaminsight.org.uk/population/>

For those people with a sole autistic diagnosis, 234 have been in paid employment at some time. Currently the i-work Team are supporting 71 autistic people in Nottinghamshire who are in paid employment.

i-work offers a person-centred employment service to promote independence both in and outside of work by:

- Enabling autistic individuals or those with a learning disability to undertake paid work
- Supporting individuals with job searches, interviews, applications and settling into work
- Supporting individuals within work to maintain or progress their work pathways
- Supporting travelling to and from work
- Providing support, advice and training for employers including bespoke training packages.
- Providing information, advice, and guidance to support job coaching and job retention.
- Helping individuals to become independent at work, using the place, train, and fade supported employment model.
- Supporting employers to improve their recruitment processes to make it more accessible for autistic individuals and/or those with a learning disability – e.g., work trials, working interviews and work experience.
- Supporting employers with reasonable adjustments in the workplace to enable autistic individuals and/or those with a learning disability to attain, perform, achieve, and retain their jobs.
- Supporting with disciplinary processes and representation at tribunals.
- Liaising with the DWP around specific health benefits including: Access to Work, Personal Independence Payments (PIP) and Permitted Work.

What are our priorities for 2022-25?

- Support the implementation of the Nottinghamshire Day Opportunities Strategy which aims to support people to access appropriate employment, training opportunities and employment support
- Work with a range of potential employers to ensure workplaces are autism friendly and have the appropriate recruitment processes in place to enable autistic people to successfully apply for jobs
- Encourage employers to recognise the huge benefits that many autistic people will be able to bring to their organisation and the mechanisms which could support them to be successful in their chosen career (e.g. job carving, the ability to work flexibly and from home etc.)
- Work with schools, colleges and other establishments to support young people throughout their career journey

4.11. Improving support within the criminal and youth justice systems

Why is this a priority?

Autistic people may have vulnerabilities around being victims and perpetrators of crime based on their presenting, and sometimes misinterpreted, needs and actions, especially around intent. It is therefore important that people are supported in the correct way to prevent unnecessary contacts with the criminal justice system and to ensure people remain safe living in community settings and family homes.

What do we have locally?

In Nottingham and Nottinghamshire we are improving how we identify and meet the needs of CYP with SEND within our youth justice teams. There is access to speech and language therapists within the teams, who support with ensuring communication needs are met.

The Youth justice services regularly benchmark and assess their practice to ensure good practice is embedded to meet the needs of children and young people within the youth justice service. All staff receive training for SEN and additional training on specific conditions such as Neurodevelopmental Conditions, and speech, language and communication needs assessments are undertaken, recognising the impact these can have on communication.

Currently there is not a data system in place to identify the number of children within the Youth Justice service with SEND. However, data is captured on the number of young people receiving court orders or out of court disposals (OOCD) and the number and percentage of those recorded with EHCP and also those without EHCP but with SEN.

Work is underway with the violence reduction unit to embed speech and language therapy within the Youth Justice services, recognising the important role communication has in understanding a young person's needs. In addition to this, the CAMHS Head 2 Head team and Youth Justice Nursing Team support the Youth Justice Services in order to ensure the health needs of this cohort are understood and met.

As part of our LD&A Transformation Programme we have funded a Community Forensic Intellectual and Developmental Disabilities (CFIDD) team to support adults who are or have previously been in contact with the criminal justice system. The team provides in-reach support to those in inpatient settings and supports successful discharge to the community. The focus of the work of this team is to support individuals to recovery and to support them to lead successful lives out of the criminal justice system.

What are our priorities for 2022-25?

- Improve data recording so that we know how many autistic CYP are accessing our youth justice services
- Work with the Violence Reduction Unit to embed speech and language therapy within youth justice services
- Continue to ensure that people working in youth justice services have access to training around autism and other neurodevelopmental conditions
- Review and evaluate the CFIDD team

4.12. Ageing with autism

Why is this a priority?

As autistic people age, they may develop additional needs and encounter additional problems. For example, some individuals may develop dementia. In the early stages the dementia symptoms may be masked by autism or the individual 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 can be initiated in a timely manner. It is important to be able to be mindful of the need to be able to

explain changes in health and any treatment to the autistic person in a way that is understandable to them.

What do we know locally?

There are approximately 170 autistic people aged 65 and over in Nottingham and Nottinghamshire, which represents 1% of the local autistic population.

Of our total autistic population, 0.1% also have a recorded diagnosis of dementia. Looking at the autistic population by age, we can see 2.5% of those aged 65 and over have dementia. Of those aged 40-64, 0.3% have a dementia diagnosis.¹⁵

What are our priorities for 2022-2025?

- Ensure there is specific training available for health and social care professionals in the presentation of older autistic people and the need to combat social isolation
- Ensure autism awareness training forms part of the Dementia Quality Mark (DQM) for care homes
- Ensure autism awareness training (levels 1 and 2 where appropriate) form part of commissioned service contracts e.g., home care, care homes, reablement etc.
- Work with providers of services for younger autistic adults to ensure staff are suitably trained to recognise the signs of age-related illness in autistic people
- Ensure appropriate post-diagnostic support and wrap-around services are available for those ageing with autism to support them with their changing needs
- Ensure the needs of families are met as those who care for autistic people also age

5 ENABLERS FOR THIS STRATEGY

In year one of this strategy, we will focus on putting in place the enablers required to deliver on the strategy and demonstrate that we are making progress on actions, which are as follows:

- Improving data collection and reporting to monitor implementation of the strategy and drive system improvement
- Strengthening and developing the workforce
- Strengthening governance, leadership, and accountability

5.1. Data Collection & Analysis of data

As autism is not consistently recorded by services, as it tends not to be the primary presenting need or condition for treatment/support, it is challenging to assess whether autistic CYP and adults have equality of access to, and equality of outcomes from, health and other services.

It is also difficult to identify and understand the intersectional identities of autistic people and their unique needs or barriers to accessing services e.g., autistic people from different ethnic minority groups or autistic trans or non-binary people for example.

¹⁵ Figures taken from E-Healthscope as at 22 March 2022

Without data that establishes how many autistic people are using which services, specifically when compared to the neuro-typical population, commissioners are limited in their ability to review services to ensuring their meeting the needs of autistic people.

As part of the NHS Long Term Plan (2019), the ICS will be working towards the establishment of a digital autism flag in the patient's clinical record, which will ensure staff know they are autistic and support improvements in data recording.

5.2. Workforce Development

5.2.1. Training

Increasing understanding of autism, including through formal training, underpins every area of focus in this strategic framework as without adequate understanding of autism all other actions to improve the lives of autistic CYP and adults in Nottingham and Nottinghamshire ICS is limited. Arguably, increasing understanding of autism is particularly important for those working on the frontline.

Increasing understanding of autism has both an internal and external focus. Within organisations, the internal focus is on recruitment, retention, and reasonable adaptations. To do this, it is important that organisations understand how many autistic people are in their employment. In the future, this could be expanded to how many people apply for jobs but are unsuccessful in their application.

5.2.2. Skilling Up the Health and Social Care Workforce

Nottingham and Nottinghamshire Learning Disability and Autism (LD&A) Transformation Programme includes training programmes with the health and care workforce and families, parents, and carers. Co-production events, engagement, Care and Education Treatment Reviews (C(E)TR's) and LeDeR reviews have continued to identify the need for further training amongst the workforces. The LD&A Transformation Programme will continue to fund learning and development opportunities, complimenting what is already being delivered by local system partners. System partners have considered how this training can complement their internal training programmes. It has been identified that the following stakeholders should be targeted for specific training under the programme to support building up an effective system of support for autistic CYP and adults:

- Mental health teams (health and social care). A gap has been identified that mental health staff teams are not as well equipped as they need to be to effectively support autistic people. We have secured funding to target specialist autism training and development within our inpatient mental health staff teams.
- Registered managers need support and training on resilience and leadership as this has been an on-going issue within our system which in turn impact on workforce retention.
- All direct care staff (social and health) to have access to training to develop greater expertise across the whole system of health and care provision. From primary and secondary care staff.
- Families and Carers supporting autistic people and/or those with complex learning disabilities to have access to training to up skill them and develop greater resilience.
- Skilling up the school workforce to support autistic CYP effectively for them to participate fully and successfully in school life as well as reducing the number of autistic CYP being temporarily or permanently excluded from school.
- Partners committing to ensuring that their staff are trained in the Oliver McGowan training.

The TCP have considered what training would benefit the system in developing expertise in providing effective care and support to autistic CYP and adults. To understand this, it has considered previous training sessions and learning, learning from the third sector (Autism East Midlands and Mencap), considered the challenges within our system and learning from other regional partners. We have therefore prioritised the following training modules under the programme for the ICS workforce as priorities:

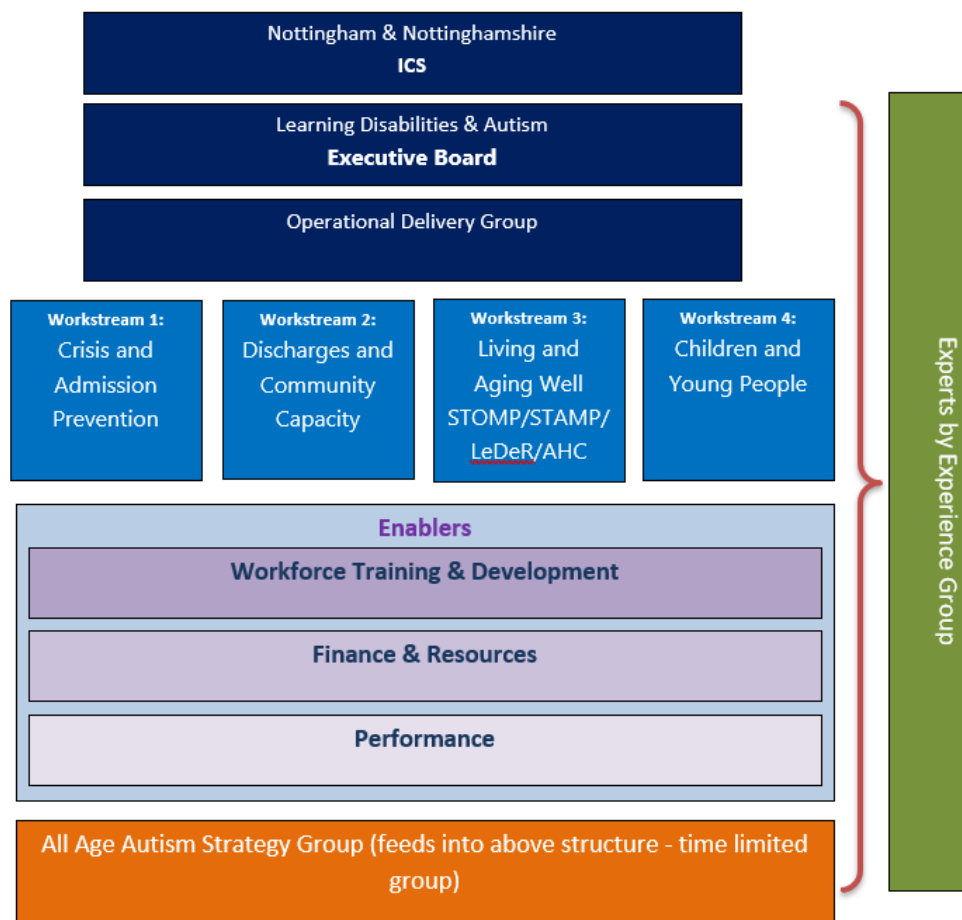
- Autism training Attachment and personality disorder
- Understanding behaviour and positive approaches supporting people
- Eating disorder conditions.

The TCP workforce action plan will support the partnership to drive improvement in the above areas.

5.3. Governance and accountability

Our existing governance structure will ensure there is effective governance and accountability to drive forward the Strategy and implementation plan. Workplans for each workstream will be strengthened, with risks and mitigations developed to provide assurance.

Figure 2: Nottingham and Nottinghamshire ICS LDA Strategy governance overview.



In addition, autism needs to be regarded as everybody's business and considered within other ICS agendas and strategies to ensure that the needs of autistic CYP and adults are addressed. It will be important for interdependencies and relationships between the current LDA programme and other ICS groups to be established and strengthened in order to implement the strategy effectively.

6 NEXT STEPS

We will be developing an ICS wide Implementation plan, with clear timescales and outcomes, from July 2022 to ensure our commitments within our Strategy are delivered. This will be coproduced with our EbE and partners and overseen by our Learning Disability and Autism Executive Board.

The Autism Strategy group will drive forward the implementation plan and will provide regular progress updates to the LDA Executive Board.