



Living my best life with Autism Stoke-on-Trent Strategy for Autistic Children, Young People and Adults 2023 - 2026



I would like a house that I could feel safe in where there is someone who can help me if I feel scared and security to move on trouble makers

It is struggle to connect with people and also when you have to explain that you are on the spectrum people and services do not understand the condition

I have a fantastic supportive family who help me if I need them to

I feel more should be done to provide mental health services to autistic people as I struggle to say what help I need as I feel I would be judged

Autistic people need more encouragement and support in education and career aspirations.

School should be a safe place.

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FOREWORD

The quotes at the start of this strategy are from autistic people living in Stoke-on-Trent.

Their words illustrate the challenge to improve health, wellbeing, community safety and to raise aspirations. This means receiving a timely diagnosis, being supported by professionals with a good understanding of autism, finding services, organisations and employers that make reasonable adjustments when required and being included in community life.

The strategy sets out the outcomes autistic people told us were important to them. Raising expectations and ambitions is key: autistic children, young people and adults need to be valued and feel valued. By delivering this strategy in partnership with autistic people and their families, we will rise to the challenge, making Stoke-on-Trent a place where autistic people can feel safe, be healthy, aspire, live independently, have control over and enjoy their life.

We welcome the National Strategy for Autistic Children, Young People and Adults 2021- 2026 and accompanying NHS investment to support improvement of provision for autistic people, this offers a real opportunity for us to make a difference.

We are, therefore, delighted to introduce "Living my best life with Autism", our joint life-course strategy for Stoke-on-Trent.

Acknowledgements

We want to say a big "thank you" to those who were able to help us shape this strategy, initially under the very unusual circumstances of Covid-19 pandemic and its accompanying restrictions. Thanks especially to our local third sector organisations; Reach, PEGIS, Caudwell Children and Lifeworks who were able to connect us to autistic people to ensure they were engaged from the very start of the development process for the strategy and in our more recent conversations to localise the national themes. Moving forward, we plan to strengthen co-production approaches to ensure autistic children, young people and adults are fully involved in developing, directing and overseeing our plans to make Stoke-on-Trent an autism friendly city.

Duncan Walker

Councillor Duncan Walker Cabinet Member for Adult Services



Councillor Sarah Hill Cabinet Member for Children's Services

Chris Bird Chief Transformation Officer Staffordshire & Stoke-on-Trent ICB

EXECUTIVE SUMMARY

Autistic people, like most, aspire **to have fun, make new friends, learn new skills and build their selfesteem, confidence and resilience**. By aligning with the aims of the government's National Strategy for improving the lives of autistic people, their families and carers in England, Stoke-on-Trent City Council, working in partnership with Staffordshire and Stoke Integrated Care Board (ICB) have developed a strategy that sets out the outcomes autistic people told us were important to them.

Access to mainstream public and community services can be hard for autistic people. We recognise the need for early help and support, particularly during childhood and early adulthood and then in later life. Whilst some services are improving data collection and analysis, we need better data so we can target support.

Autistic people in Stoke-on-Trent told us that inclusion in school life and educational achievement is very important to them. A majority of parents felt that mainstream schooling was the best way of educating their child. There were positive stories about nurseries and schools that have supported parents and children.

Young people need to be given employment opportunities as an alternative to staying on at college. Changes such as bereavement, moving home, getting married and divorced, having children or becoming unemployed can have a significant effect on an autistic person. It is important to support people to be as independent as possible at all times. Choice and control are particularly important, having a say, being able to choose the support needed and planning for the future.

When autistic people come into contact with the criminal justice system it is often up to them, or their carer, to explain what having autism means. Parents and carers are critical to the health and wellbeing of autistic people and want to ensure a positive future for their loved one and want support when they themselves are an autistic individual.

The seven themes, detailed on page 12 of the strategy, underpinned by the four key principles - community first, equality, strengths based, person centered and five outcomes – safe, healthy, achieve, live and enjoy – set out the commissioning and strategic intentions; a focus on achieving the right model of care for autistic people.

We also welcome the government's implementation plan for subsequent years of the National Strategy, setting out further actions. A detailed plan with resource allocation working in partnership with Local Authorities, the NHS and the voluntary sector, as well as autistic people, to move closer towards a united vision.

The next steps after the launch of this strategy, working with the ICB, is to develop an implementation and a delivery plan, develop an autism partnership board using person-centred, joined up approaches across multiple organisations to contribute to enabling autistic people to live within a community of their choice.

Living my best life with Autism in Stoke-on-Trent 2023 – 2026 Plan on a Page

In Stoke-on-Trent, autistic people thrive within the communities they live and when help, advice or support is needed, it is easily accessible and person centred.



Commissioners aim to move to a system that is focused on improving the outcomes that matter to autistic people. Commissioners will improve commissioning and market development to ensure good quality, cost efficient services that work together and find more innovative solutions to care that focus more on preventative services and self-management.

National Theme 1 : Improving understanding and acceptance of autism within society.	National Theme 2: Improving autistic children and young people's access to education and supporting positive transitions into adulthood.	National Theme 3: Supporting more autistic people into employment
National Theme 4: Tackling health and care inequalities for autistic people	National Theme 5: Building the right support in the community and supporting people in inpatient care	National Theme 6: Improving support within the criminal and youth justice systems
	Local theme 7: Supporting parents and carers	



INTRODUCTION

This strategy is about autistic people's lives – where they live, where they go to school or work and the communities they live within. Since the ground-breaking Autism Act 2009 and the new National strategy for autistic children, young people and adults 2021-2026¹, progress has been made in improving support for autistic people in Stoke-on-Trent. We now have dedicated assessment services for children, young people and adults, better data and a better understanding as to the hopes and aspirations of autistic children and adults. We acknowledge there is much more to do and we set out, in this local joint strategy, our intentions for making the required changes in Stoke-on-Trent.

The Autism Act 2009 and new National Strategy 2021-26 provides the strategic framework for improvement across all services to support autistic people. The related statutory guidance² sets out local authorities' and NHS organisations' duties to support autistic adults, so local areas must continue to deliver on existing requirements, including having autism partnership boards.

For public services, autism must not be seen as an add-on. Such services will already be in contact with, and providing support to, many autistic people. By encouraging more innovation in the way services are delivered and through services making more reasonable adjustments, individuals can experience good quality education, attend their local council office, GP or hospital feeling confident that these services are aware of their autism and know that adjustments can be made for them. The local outcomes in our strategy align to the approach and six key themes in the new National strategy for autistic children, young people and adults 2021-26:



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 people into employment



Tackling health and care inequalities for autistic people



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



Improving support within the criminal and youth justice systems

By taking an integrated and whole life approach, from childhood into adolescence, adulthood and older age, we can work better in ensuring support is person-focused, strengths based, equitable and available within local communities wherever possible.

In producing this strategy, we have engaged with local partners within health, the city council and police, with care and education and training providers and with autistic children, young people and adults as well as parents and carers and advocacy groups. We have used the stories autistic people and their carers shared with us and included findings from our surveys and workshops to demonstrate where we are in relation to the five outcomes and six national themes. We will publish this insight as a separate document.

This strategy links to the "Living my best life" strategy for those living with a learning disability. Deliberately, the outcomes are the same in both strategies to account for some autistic people having a learning disability. This approach means we have a better understanding of the specific needs, expectations and aspirations for autistic people and those who also have a learning disability. It is our intention that this strategy will inform local delivery plans and commissioning strategies (where applicable) so that the ambitions and outcomes are achieved.

This strategy links to and is informed by the following key strategies for Stoke-on-Trent:

- Local Policy and Guidance
- Joint Health & Wellbeing Strategy 2020 2023
- Stoke-on-Trent City Council Strategic Plan (Stronger Together)
- Sustainability and Transformation Plan (Together We're Better)
- Stoke-on-Trent Life Course Strategy for people with Learning Disability in Stoke-on-Trent 2021-26
- Stoke-on-Trent Room to Grow Children and Young People's Strategy 2020 24
- Stoke-on-Trent Inclusion Strategy 2021-24
- Stoke-on-Trent 14- 25 Learning and Skills Strategy 2022-2027
- Stoke-on-Trent Joint All Age Carers Strategy 2021 2023
- Place To Be Adult Services Strategy 2023-2026
- "Lets Talk" Adult Community Mental Health Strategy for Stoke-on-Trent 2022 2025
- Stoke-on -Trent Housing Strategy 2017 2022
- Stoke-on-Trent Community Safety Strategy 2020 2023 & Community Cohesion Strategy 2020 – 2024
- Staffordshire Police Early Intervention Strategy 2018 2021
- Office of the Police & Crime Commissioner (Safer, fairer, united communities for Staffordshire 2017-2020

The strategy is also guided and supported by wider national legislation and other local strategies and procedures³.

WHO IS THE STRATEGY FOR?

The strategy is for any autistic child, young person or adult.

Throughout the strategy, we use the term "autism" as an umbrella term for all autistic spectrum conditions. We use the term "autistic adult/child/person/people" in line with the terminology in the National strategy.

Nationally, as well as locally, there is limited data relating to autism. Recent estimates by NHS Digital suggest that around one in one hundred people in England (over 500,000 people in total) have autism. In Stoke-on-Trent, this equates to approximately 2564 people (based on ONS mid-year population estimates 2020).

What is Autism?

Autism is a lifelong developmental disability which affects how people communicate and interact with the world.

Autism is different for everyone

Autism is known as a spectrum condition, both because of the range of difficulties that affect autistic adults and the way in which these can present in different people. The definition of autism has changed over the decades and could change in future years as we understand more.

Available evidence suggests that more men and boys have a diagnosis of autism than women and girls, with estimates of male to female ratios varying from 2:1 to 16:1 as women and girls have been underdiagnosed compared to men and boys⁴.

Autistic children and young people may also have special educational needs and disabilities (SEND). A child or young person may be classed as having SEND if they require more help to learn and develop than children and young people of the same age⁵.

Autism is not a mental health condition or a learning disability, however, around half of autistic people have a learning disability and three quarters are likely to have a mental health condition at some point during their lives⁶. Neurodiversity is a term that includes a range of conditions that may co-occur with autism⁷. A relatively small number of such people will require additional care and support. This strategy applies to autistic people with these additional needs, so that meaningful and seamless pathways to care are available.

Autistic people will have had very different experiences, depending on factors such as their position on the autistic spectrum, the professionals they have come into contact with and even how and when they received their diagnosis. Autistic people may never come to the attention of services because they have developed strategies to overcome any difficulties with communication and social interaction, have supportive relationships, live in strong communities and have found fulfilling employment.

AUTISM IN STOKE-ON-TRENT



By **2035** it is estimated that there will be approximately

2,740 people in the city with autism (POPPI & PANSI predictions for autism in adults)

Health and social care services are currently likely to know only a small number of all local autistic people. There are many reasons for this, including:

- many autistic people are likely to be undiagnosed;
- not all autistic people will come into contact with social care services and so local authorities are unlikely to have information on them or their needs;
- many people, especially older adults or people from certain communities, have managed through the support of family and friends and are unknown to statutory services. This may be because they are not eligible for statutory services or because they do not know what help is available;
- the way local services are organised (e.g. learning disability and mental health teams may miss autistic people who don't also have these needs).

OUR VISION

In Stoke-on-Trent, autistic people thrive within the communities they live and when help, advice or support is needed, it is easily accessible and person centred.

OUR PRINCIPLES

We have developed four key principles that will underpin the delivery of both the Autism strategy and Learning Disability strategy for Stoke-on-Trent:

Community First

- Living within the community where appropriate.
- Access to community activities and community life.
- Support services easily available when help is needed.

Equality

- Needs are understood and reasonable adjustments made
- Equal opportunities e.g. access to health services, learning, employment, housing, social and leisure activities
- Equality and Diversity is respected and valued.

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Strengths based



- Focus on what people can do, not what they can't. Thinking what's strong, not what's wrong.
- Involvement of families and carers and prioritising carer's needs

Person Centred

- Everyone is treated as an individual with their own needs, ambitions and desires.
- Everyone is treated with dignity and respect and able to make their own choices.
- A flexible approach which means pathways and services are coordinated around the needs and wishes of the person

OUR OUTCOMES

Five outcomes emerged from the conversations with autistic people and their carers in Stoke-on-Trent.



A detailed breakdown of each outcome across the life course can be found in Appendix 1.



Development of the strategy

In developing this strategy, we revisited the engagement work undertaken prior to publication of the National strategy. This work was based on the six themes in the National strategy, our local commitments and how we could develop them within Stoke-on-Trent.

This involved extended engagement sessions during May and June 2022 with a diverse range of stakeholders including parents, carers, autistic children, young people and adults. This was achieved via virtual group and 1-1 sessions and written feedback.

In addition to this an on-line survey was published for members of the public to share their views on the national themes and local commitments.

NATIONAL STRATEGY THEMES

The outcomes in our strategy align to the six key themes in the new National strategy for autistic children, young people and adults 2021-26.



Theme 1:

Improving understanding and acceptance of autism within society

Theme 2:

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

Theme 3:

Supporting more autistic people into employment



Theme 4:

Tackling health and care inequalities for autistic people



Theme 5:

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



Theme 6:

Improving support within the criminal and youth justice systems

In our strategy, for each national theme, we:

- **Identify** current issues through data analysis and engagement feedback •
- **Commit** to actions •
- **Develop** measures that will evidence that change is happening

Additional Local Theme 7

Supporting parents and carers

During our conversations to develop the strategy, we heard about the importance of parents and carers to autistic people's lives and the value of their care, support and advocacy from childhood and into adulthood.

We also know there are autistic parents and carers who may sometimes need support with family life and navigating the structures in healthcare, education and the wider world, for themselves and their loved ones.

We have therefore created an additional local theme in recognition of the role of parents and carers.



As an autistic adult I find that unless you shout and scream that your (sic) autistic and wear a huge badge to say so noone understands your difficulties. It's like walking around in a costume 24/7. A fake smile, a well-planned reaction.

What are the issues?

Autistic adults want an everyday life, romantic relationships, family and meaningful employment. Autistic people told us that, on the whole, they enjoy their life and get along with people but for many autistic people, mainstream public and community services can be hard to access. Some of this is due to a lack of understanding of autism among staff but this is not the only factor. Many autistic people are hypersensitive to light and noise; they can have significant difficulties with communication and can struggle with the formats, language or instructions in written and verbal information.

Locally, this lack of understanding extends to parents and carers of autistic children. Such children, of school age often struggle to find a job to work around school hours. Additionally there are few before or after school club opportunities for these children.

For children, this means having more opportunities to socialise and mix with others and be safe from bullying.

We also heard about the lack of understanding regarding autistic people who are transgender and where autistic people do not necessarily recognise gender and identify in the way non-autistic people do. This can lead to misdiagnosis of mental health issues and mean autistic people do not have access to support.

What will the future look like?

We recognise the need for early help and support, particularly during childhood and early adulthood and then in later life to support autistic people to be healthy, happy and independent for as long as possible. We understand much of what is available from statutory services requires a diagnosis of autism and we will improve the assessment process and post-diagnosis support, regardless of the age of the person.

Whilst some services are improving data collection and analysis, we need better data so we can target support for autistic children, young people and adults, especially at key points in life – those who are moving from childhood to adulthood, those who are carers, getting older or when there is a life changing event.

Accessibility to community and leisure facilities across the city needs to improve, as well as access to public transport. Reasonable adjustments and increased awareness of autism, to include training for public transport driver's/staff and more accessible transport at all times of the day. Initiatives such as autism friendly drivers would help ensure confidence both in the client and the taxi driver.

Earlier support to autistic adults to navigate issues such as housing advice, advice on documentation, such as letters and bills, and opportunities to stay healthy. This type of support could prevent crisis situations from occurring by reducing anxiety and isolation and maintaining a level of independence.

Mandatory training to raise awareness of autism is being rolled out in health and social care⁸. Elsewhere, service providers, schools, businesses and community facilities should look at providing awareness training on autism and neurodiversity for all frontline staff to enable them to make reasonable adjustments to their services and staff behaviour. Training needs to focus on the reality of day to day life for an autistic person and needs to be designed and delivered with autistic people. This will increase the accessibility of mainstream and community services for autistic people and lead to a better understanding of autism.

Commitments	Measure of success
Improve data and reporting.	Data action plan developed.
Increase early support offer e.g. housing, employment, health advice.	New Prevention, Early Intervention and Enablement Service in place.
Support opportunities to make friends and have places to go.	Reported impact via monitoring and evaluation activity.
Roll out mandatory Oliver McGowan training to health and social care staff.	Numbers completing training.
Improve access to public transport.	Reported impact via monitoring and evaluation activity.

Theme 2: Improving autistic children and young people's access to education and supporting positive transitions into adulthood

I feel that for autistic children there are not as many opportunities for them to learn new skill join clubs because adults are not trained to deal with SEN behaviour.

What are the issues?

Autistic children and young people in Stoke-on-Trent told us that inclusion in school life and education achievement is very important to them. They identify life ambitions and report wanting to have a job with an understanding employer and gain the independence that this brings. They report feeling pressure to be the same as everyone else in school. To help them prepare for moving into adulthood and regardless of education setting, they request consistent support, more opportunities around work experience, the opportunity to gain qualifications and good quality careers advice.

The majority of parents felt that mainstream schooling within Stoke-on-Trent was the best way of educating their child and we heard many positive stories where nurseries and schools have supported parents and children. Parents felt that there should be more provision for autistic students particularly in support with promoting positive behaviour and that schools should be more autism aware. Some schools are more aware than others of autism and there is a growing movement to promote neurodiversity awareness in schools. Parents worry for their young person and are not always confident that their child will get the support they need as they move into adulthood.

Waiting times for specific assessment such as Autistic Spectrum Disorders (ASD) and Attention Deficit Hyperactivity Disorder (ADHD) assessments can have an impact on reasonable adjustments in schools and education opportunities. The impact of Covid on developmental assessments in pre-school age children is having an impact on preparation for school, education health care (EHC) planning and transition from nurseries to primary school.

Where EHC plans are in place, these are often generalised and are not specific to the needs of the autistic child. This has an impact for preparation for adulthood, which does not always happen at year 9.



What will the future look like?

Better transition planning and progress checks will enable autistic children to move from early years to school and for young people to move to further education and universities will help to support autistic people to lead independent lives and fulfil their potential.

Neurodivergence is the term for when someone's brain processes, learns, and/or behaves differently from what is considered "typical". If children have a diagnosis of a neurodivergence, it helps adults around them reframe "impulsivity", "not listening" and "meltdowns" as being part of a condition that requires support, rather than "bad behaviour" that requires sanctions. A better understanding of neurodivergence would potentially lead to a reduction in the number of exclusions in schools. We will explore opportunities to build on the "Autism in schools" pilot, currently running in three schools, which is aimed at improving links and training, leading to improved attendance and reduced exclusions.

We will limit the use of Out of Area residential education placements so that autistic children and young people remain in the city, able to make friends and linkages to their community. EHC plans need to strengthen considerations on housing, employment, health, independence and social inclusion.

The proposed Skills and Post-16 Education Bill will make provision for local skills improvement plans relating to further education⁹. Locally, the council is developing a strategy for 14-26 year olds to increase the opportunities available to young people with SEND in the city.

A Supported Work-Based Training Team (SWBT) based in Learning Services at the city council will bring together employers, education providers, the EHC team and careers specialists to create a highquality, city-wide service to support young people into sustainable paid employment. This includes supported internships which are now live, inclusive apprenticeships/traineeships and supported employment programmes that will offer individual tailored in-work support from a skilled and qualified job coach to help a young person learn a job and adapt to the workplace.

Commitments	Measure of success
Improve preparation and transition from early years to primary school.	 NHS autism assessments undertaken in a timely manner. EHC plans in place.
Improve preparation for adulthood.	 Improved pathways in education, health and care. Increased opportunities for training and employment. Autism training and professional development in schools and colleges. GCSE attainment
Evaluate the autism in schools' pilot and agree next steps.	The evaluation report is produced and agreed and next steps identified.
Strengthen and promote pathways to employment, such as Supported Internships, Traineeships and apprenticeships.	 Develop 14-25 year olds employment and skills offer. Number of Internships, Traineeships and apprenticeships. Training programme in place for employers.



Theme 3: Supporting more autistic people into employment I have a degree and am capable of teaching others, yet autism puts me at the bottom of the pile.

What are the issues?

Autistic adults are currently significantly underrepresented in the labour market and our local engagement found that they often report wanting to work and have skills and talents that would be useful in the workplace. However, autistic people report feeling they do not have choice over whether they have a job and also report feeling they are not able to achieve what they want from life.

Work environments are not accommodating nor accepting of those who do not conform to normal/ usual expectations of employees. This is a waste for the individual and for the economy and we need to remove the glass ceiling and lift the lid on expectations to ensure that autistic people have the opportunity to achieve their aspirations. This means support to apply for jobs, support with interview techniques and support within the work environment, including reasonable adjustments and training for employers and work colleagues.

Young people need to be given employment opportunities as an alternative to staying on at college.

What will the future look like?

For work experience and employment, the NHS will set an example locally, becoming an autism friendly place to work. Nationally, supported internship opportunities within the NHS targeted at people with a learning disability, autism or both will increase by 2023/24, with at least half converted to paid employment over the first five years of the Long Term Plan. The number of NHS internship and employment programmes/sites delivered through 'Project Search' and 'Project Choice' will increase. Work is ongoing with Department for Work and Pensions and their programme for "Disability Confident Employers". Part of the supported employment for vulnerable groups is about training and supporting employers to work with those groups, offering work experience, work placements and permanent employment. With support, autistic people can both get and keep a job.

Innovative opportunities for other work-based approaches such as self-employment should be offered.

We will redesign short breaks/day opportunity to develop age appropriate person-centred activities that provide opportunities for learning and skills. We will also explore suitable work or volunteering opportunities within these programmes.

Commitments	Measure of success	
Increase career, training, volunteering & work experience opportunities for those young people and adults who want them.	 Increase in number of autistic people in paid employment. Increase in number of apprenticeships. Increase in volunteering opportunities. 	
Redesign of short breaks and day opportunities.	New offer with a focus on learning and skills.	
Increase the availability of support roles (e.g. Occupational Therapy etc.)	Increased support for preparation for employment.	



Theme 4:

Tackling health and care inequalities for autistic people

My Dr. told me all my physical pain was in my head without ever examining me. I have since not wanted to see a Dr. for anything

I have been in hospital twice this year and they have no idea about autism

What are the issues?

Changes such as bereavement, moving home, getting married and divorced, having children or becoming unemployed can have a significant effect on an autistic person. Amongst those who support people at these critical points in life, such as psychiatrists, counsellors and psychiatric nurses, staff who are trained about autism should be available and counselling should be adapted as appropriate. When services such as these do not meet the needs of autistic people, the result can be that they can spiral into mental health crises with parents/carers left to pick up the pieces, or if they are not available, expensive and inappropriate inpatient admissions or to contact with the criminal justice system.

Our engagement found that significant numbers of autistic adults reported not feeling listened to at medical appointments They stated they do not feel mentally and emotionally well most of the time and they also do not expect to live a long and healthy life. Access to mental health support is a particular issue, autistic people reported feeling they would benefit more where mental health practitioners were suitably qualified and experienced in relation to autism. Access to social workers was also raised as an issue and where people do have a social worker, they do not report feeling joined up working across health and social care is always good.

Some autistic people and those that support them, continue to report gaps in provision or waits for diagnostic services. Diagnosis can be particularly important for adults who did not have their condition recognised as children. Their life to date may have been affected by a sense of not fitting in, of not understanding the way they respond to situations or why they find social settings difficult. They may also have been in learning disability or mental health services, where their autism was not recognised or supported. A diagnosis can be an important step in ensuring that support takes account of how a person's autism affects them and their whole family.

What will the future look like?

The NHS Long Term Plan identifies that the NHS has a crucial role to play in helping autistic people, a learning disability or both, lead longer, happier and healthier lives, and: **'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'**

Assessment and post diagnoses support

Additional capacity to undertake autism assessments in children and young people has been commissioned by the Integrated Care Board (ICB) and further expansion for capacity in the Discovery Group led by paediatrics is being explored to address the waiting times for assessment. Support post diagnostic interventions such as ARFID (avoidant restrictive food intake disorder) are being held by children and young people mental health services. Paediatrics are running sleep clinics to reduce dependency on drugs to help children sleep.

Mental health and suicide prevention

Autistic people are almost never mentioned in local suicide prevention plans. This lack of recorded diagnoses amongst autistic adults and the manner in which suicide datasets are currently collated means they are unlikely to reliably represent their deaths. The guidance informing local authorities about suicide prevention planning is currently being reviewed and The Health and Wellbeing Alliance are currently developing a pro-forma to support coroners in identifying relevant factors surrounding deaths by suicide.

Annual health checks

NHS England and NHS Improvement, in partnership with <u>Autistica.org.uk (external link)</u>, have supported the development and piloting of an autism-specific health check in primary care. Newcastle University are currently running this pilot in the North East to determine its effectiveness and ease of use by practitioners. Results from the study are expected late in 2024, with an economic evaluation.



The Learning Disability Mortality Review produced by LeDeR - (a service improvement programme for people with a learning disability and autism)

Review of the impact and planning to include our population with autism from January 2022. In Staffordshire and Stoke-on-Trent, we have worked collaboratively with our system partners, and through the use of the national platform, maintained a comprehensive monthly record of the deaths of people with learning disabilities which has helped us to support the identification of required service changes. This has also helped in the forecasting and planning of services for our patients with learning disabilities and autistic adults.

Digital flags

NHS England commissioned NHS Digital to create a Reasonable Adjustment Flag on the NHS Spine for the benefit of all relevant patients covered by the definition of impairment under the Equality Act with the requirement that by 2023/24, a 'digital flag' in the patient record will ensure staff know a patient has a learning disability or autism. All organisations are legally responsible for making reasonable adjustments to their services for relevant individuals. These adjustments may be recorded in some clinical systems but are not always recorded or shared consistently across health and care, or when the patient moves from one care setting to another. The Flag will provide an immediate visible alert, provide basic context, is a prompt for key adjustments and can signpost to further information in shared clinical records or from other organisations, other healthcare professionals, individuals' carers or individuals themselves.

Screening

Health facilitation nurses have been looking at making screening programmes more accessible locally.

STOMP / STAMP

We will ensure health care providers who prescribe psychotropic medicine to people with a learning disability, autism or both adopt these health care pledges:

- STOMP Stopping over medication of people with a learning disability and/or autism
- STAMP Supporting treatment and appropriate medication in paediatrics.

We will review the levels of prescribing especially for children and young people. We will develop a multi-agency steering group following that review to create an action plan with a focus on raising the awareness and training not only within the NHS but with schools, local authority staff and families in the issues of inappropriate prescribing. Our vision is to bring our prescribing levels down to the level of the best, with the first offer to people of talking therapies support for mental health issues rather than prescribing.

The Long-Term Plan promises the provision of specialist community teams to support autistic children and their families. This will improve assessment, diagnosis and post diagnosis support.

We will ensure whole system approaches that enable joined up responses across health, social care, housing, employment and beyond to tackle some of the wider determinants of poor health¹⁰. Reducing Out of Area residential placements for children, young people and adults will be a key objective for this strategy, as well as innovative alternatives to hospital placements.

We will continue to work towards having an integrated commissioning pooled budget for autistic people to develop appropriate and timely services. Personal Health Budgets (PHBs) are already available.

We have recently been accepted into the National Development Team for Inclusion (NDTi) "Small Supports" pilot which will enable individual tailored support to those autistic adults who are still living in hospital settings or who are at risk of hospital admission¹¹.

We need alternatives to inpatient admission for someone in crisis and better crisis plans to prevent escalation. This includes better trained care staff (e.g. in positive behaviours support) and a range of options that avoid hospital admission.

For those at risk of, or already admitted to, inpatient units, we will review and look to strengthen the quality assurance and representation for existing Care, Education and Treatment Review provision and Care and Treatment Review policies, in partnership with autistic people to assess such policies' effectiveness in preventing and supporting discharge planning.

The ICB will ensure that autistic children have their healthcare needs met and that the needs of children and young people are included in reviews as part of general screening services and are supported by easily accessible, ongoing care.

Stoke-on-Trent is an early adopter of the Keyworker programme for children and young people aged 0-25 with a learning disability and/or autism. It is time limited targeted support aimed at those children and young people on the Dynamic Support Register that are at risk of an inpatient admission or already in an inpatient bed. Keyworkers will work as part of a multi-agency approach to offer specific support and coordination above and beyond what may be provided by multi-disciplinary teams. They will develop an integrated multi-agency approach to working with children and young people at risk of admission or those in crisis and ultimately identify and support in a proactive manner to avoid escalation of needs. In addition, we will develop learning and development initiatives that define key competencies to enable people who have roles that include care coordination to improve support.

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Commitments	Measure of success
Review of the NHS autism diagnosis pathway (adults and children), to include post diagnosis support that links to increased support from voluntary organisations and peer support.	 By 2023/24 children and young people with learning disabilities, autism or both who are at risk of admission to hospital will have a designated key worker. Improved life expectancy and quality of life.
Address gaps in mental health services around supporting autistic children, young people and adults.	New offer with a focus on learning and skills. Mental health practitioners better able to support autistic people with mental health issues.
Support engagement in health and wellbeing processes.	 Increase in reasonable adjustments for access to health. Increase uptake of screening services.
Accelerate the roll out of Personal Health Budgets to give people greater choice and control over how care is planned and delivered.	 Increased uptake of Personal Budgets to give people greater choice and control over how care is planned and delivered. Increase uptake of screening services.

Theme 5:

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

The safe spaces programme around Hanley and Stoke is good and helpful to know where I could go if I needed a safe space.

What are the issues?

Autistic people told us it's important to support people to be as independent as possible at all times. This means there needs to be good information to help people choose the right care and support and having good accessible services and a good design for the people who use them so that things work well. Choice and control are particularly important, having a say, being able to choose the support needed and planning for the future.

For those children and young people who are living in Stoke, they are, on the whole, happy where they live and with their family. However, too many children and young people with SEND are placed in residential settings (including schools) that are outside of Stoke-on-Trent. As well as the high economic cost, this means local linkages, family relationships and the ability to form life-long friendships is limited. Older teenagers sometimes find family life difficult and this can lead to crisis and a breakdown in family relationships.

Autistic adults report feeling they have a choice over where they lived and felt safe and supported by care staff (where applicable), family and friends and within their home environment. Most reported feeling that they lived in a home of their choice, with whom they wish to live with, feeling safe and cared for and having as much independence as they chose. They did report feeling that there was insufficient access to personal assistants and personal budgets. Older carers reported worrying about where their loved one is going to live in the longer term and if they will be able to stay in the family home.

Our supported living offer is limited and we are too reliant on residential homes. As autistic people live longer, health needs are likely to increase as is the prevalence neurological conditions such as dementia¹².



Reported views on feeling part of the community are mixed, some autistic people felt safe, valued, respected and others do not feel safe, connected or cared for by their community. The feeling of safety comes from being with family, carers and friends. This links to low numbers of autistic adults feeling they have the opportunity to connect with other people.

When autistic people face barriers and when adjustments are not made, they can find themselves in crisis and this can lead to admission to inpatient hospital facilities, sometimes for significant periods of time.

What will the future look like?

Keeping autistic people safe in their homes and supporting communities to be strong and inclusive requires a joined-up response from key agencies such as schools, police, criminal justice and the city council as well as support from local communities.

Taking an asset-based approach, we need to understand what is available in our communities and develop/adapt where there are difficulties accessing community activities. We want to enable autistic people to be included as part of the community. This means looking at how we build communities that are more aware of, and accessible to, the needs of autistic people, bringing together champions for change.

Through the Inclusion Partnership Board, we will support autistic children to stay close to home for their education so they know and are known in their community.

Care providers of specific specialist services to autistic people should be exploring the use of assistive technologies with the people they support to help develop their confidence, sense of achievement and independence.

When autistic people find themselves in crisis, they should spend the minimal time possible in inpatient settings. Nationally, the number of beds is being reduced, with the focus on community-based support and, if someone is admitted to an inpatient bed, that the admission period is short, with a focus on recovery and using the Care Treatment Review (CTR) and Care Education Treatment Review (CETR)¹³ processes to address the issues that led to the crisis.

We know that autistic adults are more likely to be known to health and social care services if they also have a learning disability or mental health issue. Otherwise the offer for them is limited. Our engagement suggested people do not necessarily want more support from social care, rather they wanted a better understanding in other services as to reasonable adjustments to improve their daily lives. We wish to develop innovative local ideas, services or projects which can help people in their communities, particularly for early support for those not meeting eligibility criteria for statutory support. This includes models which will support early intervention or crisis prevention or which support people to gain and grow their independence, or to find employment, potentially delivered by peer support and "community of interest" voluntary groups.

For people with the most complex needs, we will continue to improve access to care in the community, so that more people can live in or near to their own homes and families and not in hospital settings.

Commitments	Measure of success
Support communities and local services including schools to be welcoming and accessible to autistic people.	 Reduced incidences of bullying in schools. Number of children in out of area school placements. Reporting of hate and mate crime. Number of Safe Places offering support
Improve digital connectivity and use of technology.	Increased independence.
Increase options for where individuals can choose to live, including supported living, across the life course.	 Local Authority care and support framework in place. Increase in choice and type of accommodation.
Review the use and impact of CTR/CETR.	Improved outcomes and reduced inpatient stay.



All the police and emergency services should have autism awareness training.

What are the issues?

Autistic adults want an everyday life, romantic relationships, family and meaningful employment. Autistic people can experience problems with understanding social interactions, having sensory acuity that can easily lead to overwhelming anxiety and reaction and other associated issues, which can mean that they become involved with criminal justice agencies because of their autism rather than through intention or be subject to bullying or harassment.

The lack of awareness from wider society, understanding in schools and impact on behaviours can lead to children and young people finding themselves excluded from school and coming to the attention of the youth justice system. The health team based in the youth offending team have identified that many children and young people are not being assessed, do not meet the criteria for formal diagnosis and are facing multiple disadvantages as a result.

At least 1 in 3 people moving through the justice system are thought to be neurodivergent; many will not have been diagnosed during school days¹⁴.

When autistic people come into contact with the criminal justice system it is often up to them, or their carer, to explain what having autism means.

We found there is strong partnership working between health agencies, the council and the police. This strategic partnership approach needs to translate into more joined up working on a day to day basis for front line staff.

What will the future look like?

The Early Intervention and Prevention unit within Staffordshire Police is analysing the prevalence of incidents whereby autism is noted to highlight and understand key themes. The police will also include autism in hate crime training and awareness packages and work alongside communities and partners to support earlier reporting of incidents and seek to remove any barriers that are preventing reporting.

Staffordshire Police have also:

- identified Autism Champions within the force who have had additional enhanced training. These champions offer support to their colleagues when dealing with a member of the public, either witness, victim or offender with autism and additional guidance is needed;
- introduced Autism Awareness Training into Officer Personal Safety Training sessions in order for officers to be cognisant of people who are neurodiverse;
- introduced Autism Alert Cards which is a small credit card style card helping autistic people disclose their autism to others when in difficult or emergency situations, and
- developed a Vulnerability Toolkit to support custody units and investigative services.

Our youth offending team are also working with custody suites to improve understanding of autistic/ neurodiverse children and young people and adults.

Prison healthcare services have an important role and opportunity in reducing the health inequalities experienced by autistic people. Services need to be fully accessible to all, with robust care pathways in place that form part of a whole-prison approach to meeting people's needs. NHS England and NHS Improvement will retain accountability for Health and Justice commissioned services which includes prison healthcare¹⁵. Regionally, a number of initiatives and pilots are planned to develop and improve pathways, NHSE/I led, these include:

- A scoping exercise regarding learning disabilities & autism (adult specific) looking at the identification and needs of those within our secure estates but also on their journey into the secure estate.
- A scoping exercise regarding children and young people with learning disabilities and/or autism in the criminal justice pathway (this includes those in the non-custodial pathway and those within Werrington Youth Offending Institute.
- The Staffordshire & Stoke-on-Trent Liaison & Diversion Service will be an all age, all vulnerability service which is part of a wider Integrated Offender Health Service. The new service will be in place by April 2023. The current service identifies those with autistic needs and helps individuals into support and/or treatment services to support with their vulnerabilities.
- A number of initiatives have been funded by NHSE/I for health and justice staff, including Children and Young People Learning Disability & Autism Train the Trainer.



Commitments	Measure of success
Training and awareness raising in criminal justice system.	 Fewer young people engaged in crime and anti-social behaviour. Rate of offending and reoffending
Services are in place to ensure there are timely interventions in place to support children and adults that may come into the criminal justice system, if needed.	Increased offer in relation to designated support around autism.
Range of initiatives and pilots to improve autistic people's experience of the criminal justice system.	 Pathways developed. New Liaison and Diversion service in place.

Theme 7:

Supporting parents and carers

Parents and carers are critical to the health and wellbeing of autistic people and want to ensure a positive future for their loved one and want support when they themselves are an autistic individual. Through our engagement, parents and carers said they want to be valued as advocates, many feel they have to fight to ensure their loved one gets the support they need at every age and stage in life. Being a parent or carer of an autistic person can require additional skills and knowledge that can be hard to find and we heard how much our local groups run by parents and carers and autistic people are valued.

We heard examples about the impact of slow transition in nursery on working parents and the lack of support in some cases around such things as toileting and eating issues, especially when a child is not diagnosed. We also heard positive stories about services that have gone the extra mile to help families and good quality day services and health services.

Older carers have told us they worry about what will happen when they are no longer able to care for their loved ones.

Autistic parents of children reported feeling there was too heavy a focus on safeguarding and parenting ability if they themselves needed help, when the focus should be on need and a whole family approach. In some cases, children were being removed from their parents. Support is needed so that autistic parents can parent, rather than being seen as abusive. Autistic parents felt a better multi-agency response is needed, taking a whole family approach, which may then prevent the need for court proceedings.

Autistic people may themselves be caring for parents informally as part of family life.

There is a need to expand support for parents and carers – with help to manage and understand and implement changes in approaches to management of their loved ones. The Carers Strategy and Carers Partnership Board will link closely with this strategy to deliver joint initiatives that benefit carers.

Commitments	Measure of success
Identify Autism Champions within relevant public sector organisations.	Number of Autism Champions in place.
Expand support for autistic individuals who are caring for children and young people and/or parents, if needed.	Improved outcomes for families.
Implement quality reviews using people with lived experience.	Complaints, comments and compliments.

STAFFORDSHIRE AND STOKE-ON-TRENT LDA 3 YEAR ROAD MAP

As part of a move towards an integrated care partnership for Staffordshire and Stoke-on-Trent, there is a focus on achieving the right model of care for autistic people. To make this a reality, we need to understand across the system where we are in relation to:

- A system-wide approach across specialised and ICB commissioning, health and social care and other services such as housing, for those in Staffordshire and Stoke-on-Trent with autism and challenging behaviours.
- Care and support services to minimise inpatient care such as crisis prevention, respite or assessment when community provision is not possible, or when it is mandated by the courts.
- A 'whole life' preventative approach for care and support with a much greater emphasis of addressing or reducing the impact of challenging behaviours from a young age.
- Market development and provider liaison to achieve the changes required by building the skills and capacity in the market, and to avoid destabilisation. There is a greater need to future-proof community solutions based on the needs of children and young people.
- Reducing the reliance on inpatient care through person-centred care.
- Transferring care into a community setting that offers high quality, safe, and wherever possible, local services.
- Developing and maintaining the right workforce who have the necessary skills and knowledge.
- Improving integration and communication across the system.



HOW WILL WE BE ACCOUNTABLE?

The engagement and consultation exercises provide the basis for the strategy and we recognise that there is much more to do to develop further our approach to co-production. We pledge to build on this work as we develop a new autism partnership board to lead the delivery of the strategy as we move forward. This board will include autistic people as experts by experience.

This Stoke-on-Trent focussed partnership will be part of a wider collaborative approach with Staffordshire partners to oversee the delivery of the NHS-led 3 year Road Map¹⁶ and is responsible for any funding allocations to support implementation of the Road Map.

At an individual level, accountability will be via client feedback and satisfaction surveys within services and via self and group advocacy so that autistic children, young people, adults and older people can tell us what is changing for them.

CONCLUSION

This strategy is in response to the National strategy, building on the engagement work with local autistic people who developed the outcomes framework for Stoke-on-Trent. It aims to maximise opportunities for autistic people to live fulfilling lives. The values and principles in this strategy are important to the outcomes. Autistic people, regardless of their age, want to enjoy the same opportunities as other people in education, employment and relationships, feeling part of their local community and wider society.

Autistic disorders exist on a wide spectrum – we need to look at needs as the label 'Autism' means different things to different people. For children, neurodiverse needs are not being supported because children don't 'fit the tick box' and this follows into adulthood. Autistic people and their families need support to understand options, navigate services and plan for the future.

It is difficult to determine how many autistic people will need care and support. Personal circumstances will have a bearing on specific requirements. We need to avoid, as much as possible, admissions to institutions and long stay hospitals.

Our engagement exercise showed that most autistic people report wanting to live an ordinary life, but are prevented by a society that does not understand or adjust. This can lead to them feeling isolated and misunderstood and increases the likelihood of ill health and other issues that will need support from services; yet when they do seek help, they often report finding that services are not autism friendly. We want to improve outcomes for autistic people, across the life course. We will utilise continuous steps to promote social inclusion and increase an individual's ability to become an active citizen within their local community, have a job and meaningful relationships. Person-centred, joined up approaches across multiple organisations will contribute to enabling people to live within a community of their choice.

We can't make all the changes needed all at once, but by fast tracking improvements in the assessment/diagnosis process and investing in staff training, we can begin to make Stoke-on-Trent much more autism friendly.

We recognise we need to strengthen linkages to autistic people and their representative organisations to improve their participation developing strong local partnerships that are based on trust and respect.

There are many elements of change needed and we need to present this in a tangible and simple way, so partners and stakeholders can understand how and when we will be focussing on key areas so autistic children, young people, adults and older people in Stoke-on-Trent can live a full life. In response to the National Autism strategy, Skills for Care¹⁷ have developed a comprehensive commissioning framework and the council and Staffordshire and Stoke-on-Trent ICB will explore adopting this.

Everyone, whatever their support needs, should be

"able to live fulfilling and rewarding lives within a society that accepts and understand them"¹⁸.

CONTACT US

If you want to tell us something about the strategy or you would like to get involved you can contact us: By email: **commissioningandpartnerships.sp@stoke.gov.uk**

APPENDIX 1

Life course outcomes matrix

Outcomes	Children & young people	Adults & older people
Outcomes Safe I feel safe within, and valued by, the community in which I live and the environments I am in	 Children & young people I am happy and safe at a school that is as close to home as possible. I feel valued as an individual, cared for and respected by the community. I am free from bullying and know how and who to ask for help if it happens. I feel understood by the police and justice system if I come into contact with them. 	Adults & older peopleI can get around freely and safely.I feel valued as an individual, respectedand cared for by the community.I am able to access community activitiesand facilities and connect with otherpeople.I am free from hate and mate crime andknow how and who to ask for help if ithappens.I feel understood by the police and
Healthy I have equal	I can use high quality health services that are co-ordinated in ways that meet	justice system if I come into contact with them. I can use high quality health services that are co-ordinated in ways that meet
opportunities to good health and wellbeing	my needs. I am happy and fulfilled, feeling physically, mentally and emotionally well.	my needs. I am happy and fulfilled, feeling physically, mentally and emotionally well.
	I am able to make informed choices about healthy and safe lifestyles as I get older and given lots of opportunities to be physically active.	I am socially connected. I expect to live as long as other people that don't have learning disabilities.
Achieve I am aspirational in my life goals which are purposeful and valued	I have opportunities to develop my education and skills and am encouraged to make the most of my abilities.	I can choose to have a job. I can volunteer and contribute to the community, if I choose.
	I have a past, present and future with people who are important to me. I get the right support to help me	I have opportunities to continue developing and using my skills and make the most of my abilities.
	influence and make choices about my life and the future.	I have a past, present and future with people who are important to me. I know where I can get help or support
		to make informed choices about my life I am supported to be financially independent
		Independent

Outcomes	Children & young people	Adults & older people
Live	I live with family/carers or in another	I have choice as to where and
I live in a home that	environment that meets my needs and	with whom I live, family/carers/
I choose, with who I choose, that meets	where I can thrive.	Independent/supported living.
my needs.	I am able to choose who and where I	I have as much independence as I
	live as I get older.	choose.
		I feel safe, cared for and I can thrive.
Enjoy	I have a wide range of social and leisure	I have a wide range of social and leisure
I have equal	opportunities and activities to choose	opportunities and activities to choose
opportunities to a	from.	from.
good quality life, to		
feel included in my	I have friendships and relationships that	I have friendships and relationships that
community and enjoy	are good for my wellbeing.	are good for my wellbeing.
my life.		
	I am able to connect with friends in	I am able to make my own decisions
	person and on line.	even if they are considered unwise or risky by others.



APPENDIX 1

¹gov.uk/national strategy for autistic children young people and adults 2021 to 2026 (external link) ²2015 Adult autism strategy: supporting its use - gov.uk/adult autism strategy statutory guidance (external link), gov.uk/Autism strategy implementation plan: 2021 to 2022 (Annex A) (external link)

³High impact actions for service improvement and delivery by Transforming Care Partnerships (published November 2016), Building the right support (published October 2015), Children's Commissioning Strategy, Transforming Care for People with Learning Disabilities – Next Steps; progress report (published July 2015), Special Educational Needs and Disability Code of Practice (2015) SEND 2018 Protocol, Winterbourne View – Time for Change 2014, The Housing Act 1996, 'Statutory Guidance for Local Authorities and NHS organisations' in March 2015 (updated 2018), Skills and Post-16 Education Bill

⁴women and girls have been underdiagnosed compared to men and boys,

women and girls with 'high-functioning' autism may be better at masking their difficulties than men and boys, women and girls may be less likely to develop autism, but are more severely impaired when they do

⁵mencap.org.uk/advice-and-support/children-and-young-people/send-system (external link)

⁶NICE has made recommendations about the delivery of care to children and young people on the autism spectrum. This includes a recommendation that local services should work with and support the families of children and young people on the autism spectrum. It also recommends that local services should be coordinated by a local autism multi-agency strategy group.

⁷neurodiversity : attention deficit hyperactivity disorder, dyspraxia, dyslexia, dyscalculia and language impairments

⁸The Oliver McGowan Mandatory Training in Learning Disability and Autism. | Health Education England - <u>hee.nhs.uk (external link)</u>

⁹Skills and Post-16 Education Bill [HL] - Parliamentary Bills - <u>bills.parliament.uk (external link)</u> ¹⁰Poverty, poor housing conditions and unemployment.

¹¹Small support organisations have a number of things in common including: planning and delivering in a truly person centred way; person led staff recruitment and training; structuring and using funding around the person; a separation of housing and support; strong partnerships between the individual and family, commissioners, and providers; and staying small.

¹²Considering and meeting the sensory needs of autistic people in housing | Local Government Association - <u>local.gov.uk (external link)</u>

¹³Care Treatment review NHS England » Care and Treatment Reviews Care, education, treatment review <u>england.nhs.uk/ctr (external link)</u>. NHS England » Care, Education and Treatment Reviews (CETRs) <u>england.nhs.uk/cetr (external link)</u>

¹⁴Neurodiversity in the criminal justice system: A review of evidence - HMICFRS **justiceinspectorates.gov.uk (external link)**

¹⁵B0707 meeting the healthcare needs of adults with a learning disability and autistic adults in prison **england.nhs.uk/B0707 (external link)**

¹⁶NHS Long Term Plan - longtermplan.nhs.uk/learning-disability-and-autism (external link)
 ¹⁷Commissioner framework - supplement FINAL 210621 - skillsforcare.org.uk (external link)
 ¹⁸Fulfilling and Rewarding Lives: The strategy for adults with autism in England 2010

