



ST HELENS
BOROUGH COUNCIL

ALL AGE AUTISM STRATEGY

SEPTEMBER 2023



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FOREWORD

I AM DELIGHTED TO DELIVER OUR NEW ST HELENS ALL-AGE AUTISM STRATEGY FOR 2023–2026, WHICH AIMS TO ENSURE THE NEEDS OF AUTISTIC PEOPLE LIVING IN OUR REGION ARE RECOGNISED AND MET.

Significant progress has been made in strengthening services and raising awareness of the needs of autistic people since the Autism Act was passed into law in 2009 and the national policy “Think Autism” was released in 2014. However, there are still a lot of gaps in the local support system for autistic people and their families, and it is very evident that the Covid-19 pandemic has exacerbated matters.

To ensure that both specialised and mainstream mental and physical health services more effectively meet the needs of autistic people and their families, it is our intention that the St Helens All-age Autism Strategy will outline the expectations on local services across the region.

WE MUST “DO MORE TO ENSURE THAT ALL PEOPLE WITH A LEARNING DISABILITY, AUTISM, OR BOTH CAN ENJOY HAPPIER, HEALTHIER, LONGER LIVES,” AS STATED EXPLICITLY IN THE NHS LONG TERM PLAN. AS SUCH, WE WILL FOLLOW A RANGE OF GUIDELINES TO ENSURE THAT WE ACHIEVE THIS:

- All age approach - Promoting an age-inclusive approach for people with autism that focuses on advancement along a person’s entire life pathway and makes sure that all the typical life transitions are successfully handled and seamless.

- Person-centred - Putting autistic people, their families, and carers at the centre of everything we do while providing services and support for autistic people that highlight their strengths.
- Right support, right time, right place - By collaborating with important partners, we can improve access to and experiences with education, health, training, and employment by delivering the appropriate support at the appropriate time and location.
- Early intervention - Giving young people early access to high-quality, timely, and pertinent information, advice, and intervention in line with statutory guidance and the preventative agenda across children’s and adult services, supporting and enabling those on the road to diagnosis
- Outcomes focused - To enhance outcomes for autistic people and their families, public and voluntary services are using their resources in the most effective ways possible.
- Right to respect - Defending the right of all people - children, adolescents, and adults - to a life free from abuse while upholding the values of respect for their equality, autonomy, dignity, and privacy.
- Integration - Whenever possible, commissioning services that support integration with health and social care will help everyone understand the requirements of those who have autism.
- Co-production - Including individuals with autism and their families in strategic and tactical planning and decision-making ; regularly gathering input from individuals’ experiences to inform how services are provided.

- Shared responsibility - Accepting joint accountability for achieving desirable, mutually agreed-upon results and effectively communicating information to guide service delivery strategy (in accordance with relevant guidance & legislation).

Our Strategy has been guided by our Autism Needs Assessment which has meant that we have set a range of priorities based on the needs and wants of our population. We will not deliver this in isolation; our partners and communities have helped to shape exactly what it is that we need to focus our efforts on. This includes:

- Having well-defined routes for children and adults based on a needs-led approach, along with strong pre- and post-diagnosis care, is important.
- Training and awareness-building efforts are being made in every sector to enable professionals and services better understand the requirements of those with autism in our local communities and services and to acknowledge the fact that autism affects individuals differently.
- Services that support people with autism throughout their lives and help them in school, in colleges, and in universities so they can live independently and have meaningful work prospects.

- Collaboration between the fields of health, education, and social care to provide integrated services that make the most of the available resources.
- In order for people with autism to have pleasant experiences when they enter healthcare, educational, and social care settings like primary care and hospitals, it is important for services to understand what acceptable adaptations are and how they might enhance environments.

TOGETHER WITH OUR PARTNERS, WE CAN ENSURE THAT ALL PEOPLE, REGARDLESS OF THEIR PERSONAL NEEDS, CAN LIVE LONGER, HAPPIER AND HEALTHIER LIVES.



M. M. Quinn

Councillor Marlene Quinn
Cabinet Member - Integrated Health & Care

1. INTRODUCTION AND CONTEXT

1.1. AUTISM AND OUR COMMUNITIES

Although it is important to acknowledge that there are different perspectives on this and not all autistic people consider themselves as impaired, autism is a lifelong developmental impairment that impacts how people perceive, communicate, and connect with others. There are an estimated 700,000 autistic adults and children in the UK, or about 1% of the total population. Additionally, it is projected that 3 million family members and carers of autistic individuals reside in the UK.

Individuals with autism experience the world in a unique way from other people. Due to the vast range of effects it can have on individuals and the varying levels of support they may

require over the course of their lives, autism is frequently referred to as a spectrum condition. Approximately 4 in 10 autistic individuals have a learning disability, even though autism is not a learning condition.

Some autistic people will require little to no assistance in their daily life, but others may require intensive care, such as round-the-clock assistance in a residential facility. People may require assistance with a variety of issues, such as making friends, managing their time at school or job, or having the mobility to move around their communities.

1.2. AUTISM IN ST HELENS

Approximately 1,046 people between the ages of 18 and 64 in St Helens have been diagnosed with autism spectrum disorder, with 90% of them being men. Even while all newly diagnosed individuals are eligible for a social care

assessment under the Autism Statutory Guidance, not all people request one. The following table shows the how this number is expected to change over time:

| Age | 2017 | | 2020 | | 2025 | | 2030 | | 2035 | |
|-----------------|--------------|--------|--------------|--------|--------------|--------|--------------|--------|--------------|--------|
| | Male | Female | Male | Female | Male | Female | Male | Female | Male | Female |
| 18-24 | 124 | 13 | 115 | 12 | 110 | 12 | 121 | 13 | 122 | 13 |
| 25-34 | 202 | 23 | 207 | 23 | 203 | 22 | 184 | 20 | 185 | 21 |
| 35-44 | 185 | 21 | 184 | 21 | 200 | 23 | 212 | 24 | 207 | 23 |
| 45-54 | 230 | 26 | 218 | 25 | 193 | 22 | 185 | 21 | 202 | 23 |
| 55-64 | 202 | 23 | 216 | 24 | 223 | 26 | 211 | 25 | 187 | 22 |
| Total by gender | 943 | 107 | 940 | 106 | 929 | 105 | 913 | 103 | 904 | 102 |
| Total | 1,050 | | 1,046 | | 1,034 | | 1,016 | | 1,006 | |

Source: PANSI 2018

1.3. AUTISM AND MENTAL HEALTH

According to the autism research charity Autistica, seven out of ten autistic people have a mental health condition such as anxiety, depression, attention deficit hyperactivity disorder (ADHD) or obsessive-compulsive disorder (OCD).

There is little research into why this is, but it may be because autistic people:

- Can struggle to try to fit into or make sense of the world, which can lead to feelings of depression and anxiety
- May face delays in getting their mental health problems diagnosed
- Are more likely to face stigma and discrimination

- Are less likely to have appropriate support available. For example, group therapy might not be suitable for some autistic people, or therapists might not know how to adapt their approach to helping an autistic person.

Inpatient mental health hospitals supported 2,075 autistic and learning-disabled people as of June 2021; 1,200 (58%) of these patients are autistic. This is particularly pertinent given the current Government's vow to change mental health laws in England and Wales. This will include:

- Determining the best method to amend the Mental Health Act's definition of "mental disorder" so as to exclude autism
- Establishing a responsibility to offer adequate community services
- Making decisions from the Care and Treatment Review enforceable

1.4. OUR COMMITMENT

St Helens resolves to radically improve life for people with autism, their families, and carers in accordance with the National Strategy. Our commitment, therefore, is to show how our work has improved the lives of autistic people and their families by:

- Increasing societal awareness of and acceptance of autism
- Enhancing the educational opportunities available to autistic adolescents and teenagers and fostering successful adult transitions

1.5. WORKING TOGETHER

How we deliver the above commitments, will be contained within the action plan associated with this document. However, this is not a singular Strategy and is created, influenced, and delivered through our numerous partnerships, service providers and communities which includes:

- Services for healthcare, social care, education, housing, and criminal justice
- Leaders of Integrated Care Boards and local authorities

- Assisting more autistic individuals to find employment
- Addressing disparities in health and treatment for those with autism
- Fostering community support and helping those receiving inpatient treatment
- Enhancing support within the youth and criminal justice systems.

- Service providers for social services, health care, and education
- Health, social, and education service commissioners
- The community and voluntary sector

The delivery of coordinated and seamless services to help people, including those with learning disabilities and autistic people, live healthy, independent, and dignified lives increases with the integration of health and social care, which also improves results for the population as a whole.



2. VISION AND PRIORITIES

2.1. WHAT WE ARE TRYING TO ACHIEVE

The following diagram provides a summary of our vision and includes a clear set of statements as to what we are trying to achieve. At the base of the diagram are the six priorities that we will focus on; each will be described in further detail:



2.2. OUR PRIORITIES

WE HAVE IDENTIFIED SIX PRIORITIES TO DELIVER OUR OVERALL VISION. THESE HAVE BEEN DEVELOPED THROUGH OUR ONGOING WORK WITH OUR PARTNERS AND COMMUNITIES AND REFLECT THE NEEDS AND WANTS OF PEOPLE WITH AUTISM IN OUR BOROUGH.

PRIORITY 1: INCREASING SOCIETAL AWARENESS OF AND ACCEPTANCE OF AUTISM

By demonstrating that autistic people feel more included and accepted in their communities, we will increase the general public's understanding of and acceptance of autism. To modify people's attitudes toward autistic people and their families, we also want the general public to understand how autism can affect people differently, especially the differences in how autistic women and girls present. To ensure that autistic people may access these areas and services on an equal basis with everyone else, we want many companies, public sector agencies, and various transportation systems to become more autism inclusive.

PRIORITY 2: ENHANCING THE EDUCATIONAL OPPORTUNITIES AVAILABLE TO AUTISTIC ADOLESCENTS AND TEENAGERS AND FOSTERING SUCCESSFUL ADULT TRANSITIONS

We want autistic children and young people to have access to the appropriate help both within and outside of the classroom through the special educational needs or disability (SEND) system.

To ensure that autistic children and young adults to reach their full potential and to demonstrate that fewer autistic children are permanently excluded from or suspended from school owing to their behaviour, we want schools to better support them. To increase the number of autistic people who can live happily in their own communities, obtain employment, pursue higher education, or take advantage of other opportunities, we will improve the support that autistic people receive as they transition into adulthood. This is crucial in avoiding the crisis point or admission into inpatient mental health services for more young people.

PRIORITY 3: ASSISTING MORE AUTISTIC INDIVIDUALS TO FIND EMPLOYMENT

By enabling more people who are capable and want to work to do so and making sure those who have found employment are less likely to lose it, we will make progress in reducing the employment gap for autistic people. As well as enhancing autistic workers' experiences at work, we want more companies to feel comfortable hiring and supporting autistic people.

PRIORITY 4: ADDRESSING DISPARITIES IN HEALTH AND TREATMENT FOR THOSE WITH AUTISM

As well as demonstrating that autistic people are living better and longer lives, our goal is to lessen the health and care disparities that autistic people experience throughout their lives. To ensure that autistic people have access to a quick diagnosis and any necessary care throughout their life, we also want to have achieved considerable progress on enhancing early identification, lowering diagnosis waiting times, and improving diagnostic pathways for children and adults.

PRIORITY 5: FOSTERING COMMUNITY SUPPORT AND HELPING THOSE RECEIVING INPATIENT TREATMENT

We will meet the goals outlined in the NHS Long Term Plan to cut down on the admission of persons with learning disabilities and autism to inpatient mental health facilities. To decrease avoidable admissions to inpatient care, we will improve the treatment of autistic people in mental health legislation in addition to enhancing the availability of crisis support and community

mental health services. Additionally, we will increase the availability and suitability of social care and housing support. Additionally, for those who do require inpatient mental health facilities, the care quality will be better and more individualised to their requirements, and they will be discharged as soon as possible back into their communities.

PRIORITY 6: ENHANCING SUPPORT WITHIN THE YOUTH AND CRIMINAL JUSTICE SYSTEMS

We will enhance our knowledge of how autistic people interact with the juvenile and criminal justice systems, as well as the kind of help they might require in court, in prison, and while on probation. To ensure that autistic people receive the proper support that is tailored to their needs, we will increase the understanding of autism among police officers and other criminal justice system personnel. We will also work to make sure that all areas of the justice system, from prisons to courts, are more autism inclusive.

2.3. WHAT SUCCESS LOOKS LIKE

As shown in the diagram (section 2.1), the above priorities feed into three clear objectives that set out what we want to achieve and determine whether our overall vision is being met. We can therefore reference each of these objectives to determine whether we are being successful or not:

OBJECTIVE 1: IMPROVE EQUALITY AND ADAPTABILITY

This means that:

- We will prioritise each individual and focus on each person's own unique entire life journey
- We will develop joint care plans for those who would most benefit, focusing on happier, healthier, and longer life (rather than cause and condition)

OBJECTIVE 2: IMPROVE HEALTHCARE EXPERIENCE AND OUTCOMES

This means that:

- We will make sure that individuals with learning disabilities and autistic people of all ages receive excellent, timely help that honors their unique needs and preferences and upholds their human rights.
- To establish the assistance that prevents crises and admittance, we will work with our communities and our numerous partners
- When someone would benefit from being admitted to a mental health hospital, we'll make sure they get therapeutic, high-quality care and that they are discharged as soon as possible
- When a person is ready to leave a mental health hospital, any obstacles will be eliminated through our joint efforts

OBJECTIVES 3: INCREASE INDEPENDENCE WHERE APPROPRIATE

This means that:

- We recognise that every person has the right to lead a regular, independent life in society
- We will work alongside people with autism, their families and carers to continue to design our services and ensure that we are doing the right things.



3. HEALTH, WELLBEING AND AUTISM

3.1. INTERDEPENDENCIES

The delivery of this all-age autism strategy will not be achieved in isolation. If we want to ensure that autistic people of all ages in St Helens can live happier, healthier, longer lives we must align everything we do, as a local authority and community partner, to achieve better health and

wellbeing for all our residents. As such, we are committed to enhancing a wide range of services including social care, housing, employment, education, and leisure services. The following sections provide an overview of how everything we do links together and enables future success.

3.2. LIVING WELL

The St Helens People’s Plan 2020-2024 on Living Well states:

OUR RESIDENTS WILL ACHIEVE AND MAINTAIN A SENSE OF WELLBEING BY LEADING A HEALTHY LIFESTYLE SUPPORTED BY RESILIENT COMMUNITIES, AND EXCELLENT SERVICES WHEN NEEDED.

This priority includes several areas of focus for Learning Disability and Autism:

| Areas of Focus | 2019-20 | 2020-22 | 2022-24 |
|---|--|--|--|
| Increase the number of annual physical health checks for Adults with LD | Physical Health Nurse in place to progress this work within Primary Care | Establish the Cancer Hub from April 2020 Treatment for all first appointments commence and complex follow ups | Established a radiotherapy service subject to demand and business case |
| Community provision - intensive, crisis support (IST) 7 day specialist MDT services | IST service in place and funded until December 2020 | Secure funding from the decommissioning of ATU beds to recurrently fund the IST service | |
| Provide accommodation for people with complex LD | Design a service that will meet the identified needs locally based on evidence to plan accommodation needs | Implement new service specifications | |
| Review the Assessment and Treatment inpatient provision for people with LD | Protocols for in place for personalising/stratifying the follow up of prostate and | Personalised care for cancer patients will be available | |
| Enhance the existing Autism and Spectrum Disorder service | Funding secured to deal with waiting lists and a further successful bid made to enhance the service | Commission a new ADHD service | |

3.3. CRISIS CARE

The St Helens Demand Strategy 2022-2025 for Crisis recognises that there is currently no in-Borough care able to support individuals with complex behaviours arising from Autism or Learning Disability. Coupled with this, the updated Mental Health Act will largely remove the possibility of a person with Learning Disability in crisis being admitted into hospital. Therefore, a jointly commissioned Learning Disability crisis resource is an imperative for the Council. We will seek to develop a joint commissioning strategy with NHS Cheshire and Merseyside and wider partners.

3.4. INTEGRATED COMMISSIONING

St Helens Adult Social care integrated commissioning strategy 2022-2024 highlights that there is a need for increased services for people on the autistic spectrum, for people with more complex needs who need highly skilled staff to ensure they remain independent at home. We will seek to develop a joint commissioning strategy with NHS Cheshire and Merseyside and wider partners.

3.5. SPECIAL EDUCATIONAL NEEDS AND DISABILITIES (SEND)

Any transition from children's services to adult social care can be an extremely daunting process for young people with SEND and their families. Indeed, parents and carers in St Helens tell us that the transition to adulthood as one of the greatest challenges. Transitions from childhood into adulthood involves supporting people to be autonomous individuals with rights and responsibilities; supporting choice and control over how people live their lives. Employment is fundamental in this to reduce welfare dependency and improve health and happiness.

The following actions are included in our SEND Strategy:

Outcome: Children with SEND experience smooth transitions and are successfully prepared for adulthood.



What we will do:

- Review and improve the information, guidance, and support at points of transition to support proactive planning and better co-ordination.
- Young people, parents, carers, and professionals will have accessible and up to date information via the St Helens Local Offer website about the range of opportunities available and how to access them.
- Work with children, young people and families using a person-centered approach which enables choice and control at each transition point
- Have a clear health pathway/ offer post 19 which builds on the strengths of the support for children of school age

What success will look like:

- More children are ready for school with good social and emotional development
- All EHCPs from year 9 and beyond will reflect aspirations for future training or employment
- Young people and their families report that their transition is well- coordinated at all key points through to adulthood.
- Children with continuing care needs will have future support and transitions to adult continuing health care, where they meet the criteria, mapped into EHCPs.



3.6. HOUSING

The St Helens Borough Housing Strategy 2022-2027 includes proposals in relation to 'housing mix'. This would deliver 25 or more new dwellings where at least 20% of these must be designed to an 'adaptable' standard and at least 5% of these must be designed to a 'wheelchair user' adaptable standard. The council will therefore work with partners to facilitate the provision of bungalows, and specialist and supported

housing for elderly and vulnerable people. To ensure that there are sufficient accommodation options for residents with learning disabilities and autism, Housing Services will engage via the Transforming Care agenda to maximize any opportunities for the development of new services and align joint projects together with the Cheshire and Mersey Health & Care Partnership.

3.7. LEARNING DISABILITIES

As stated within our Learning Disability Strategy;

WE WILL MAKE CERTAIN THAT EFFECTIVE PATHWAYS FOR CHILDREN AND YOUNG PEOPLE WITH AUTISM ARE IN PLACE, AND THAT UNJUSTIFIED WAITING TIMES ARE ADDRESSED. WE WILL ALSO UPDATE OUR JOINT STRATEGIC NEEDS ASSESSMENT (JSNA) TO HELP INFLUENCE ST HELENS' FUTURE COMMISSIONING PLANS

Children and young adults with a learning disability, autism, or both should, if possible, receive the support and resources they require to remain with their families, in their own homes or near to home. According to NHS England, placements outside of the area should be avoided wherever possible.

IN ADDITION, BETWEEN 25% AND 40% OF PEOPLE WITH LEARNING DISABILITIES STRUGGLE WITH MENTAL HEALTH ISSUES.

The prevalence rate of a diagnosable psychiatric disease among children and adolescents with learning disabilities is 36%, compared to 8% in children and adolescents without a learning disability. In addition, these young people are 33 times more likely to be on the autism spectrum. As a result, as a Local Authority, we will ensure that support pathways for dual diagnosis are in place, as well as early intervention for those with mental health difficulties, to avoid a crisis.



4. MONITORING, REVIEW AND CONTINUOUS IMPROVEMENT

Monitoring and evaluating the impacts of this Strategy, the six priorities contained within, and all the interdependent components is vital in ensuring that our efforts continue to be focused on the cared-for and carer experiences. This, in turn, needs to feed into every commissioning decision that we take.

As such, we are developing an action plan for the whole of Adult Social Care to ensure that we understand progress, tackle any issues that arise and focus on continually improving the services we commission and provide. There are two levels of effectiveness for monitoring this:

LEVEL ONE - GUIDING PRINCIPLES

These principles work to prioritise the needs of the people we support and ensure that the assistance they get will both achieve the desired outcomes and manage any risks:

- **The right people:** those who require assistance are identified and given top priority
- **The right time:** to prevent things from getting worse, to increase resilience, and to encourage independence
- **The best location:** Depending on the need and the most cost-efficient solution, at home, in the community, or in a specialised environment
- **The correct support:** Just enough to keep everyone safe while also preventing, minimising, or delaying the need for long-term support, supplied by the appropriate individuals with the appropriate skills
- **Improved coordination and cost-effective support:** May be provided through working more effectively with individuals, their friends and families, as well as in partnership with other organisations.

LEVEL TWO - PERFORMANCE REPORTING

To determine whether services for those with learning disabilities are achieving the necessary strategic results, the overall organisation and coherence of those services will be tracked and evaluated. Performance indicators (PIs), regular critical appraisals, satisfaction surveys, and the departmental index of complaints will all serve as guidelines for the reporting structure.

To support the above, we will routinely gather and compile data from a range of sources which will include:

- Employing regional and national performance metrics to compare our performance to that of other local authorities and assess the development of certain goals
- Continually evaluating our actions in light of past, present, and projected requirements in strategic and performance management frameworks to ensure that we have enough capacity to meet any changes in service user demand
- In order to accelerate the implementation of innovative thinking that support the essential elements of the vision, we modified our strategy to take advantage of the most recent best practice.



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