



Birmingham and Solihull  
Integrated Care System  
Caring about healthier lives

## Strategic Vision

Autism  
2022-27



**Solihull**  
METROPOLITAN  
BOROUGH COUNCIL



**Birmingham**  
City Council

DRAFT  
SEPTEMBER 2022

## Our Vision

Enable all autistic individuals in Birmingham and Solihull, ***throughout their life*** to maintain their ***independence***, lead ***fulfilling, healthy, socially*** and ***economically active lives***. Autistic individuals have told us they want to enjoy life in Birmingham and Solihull, to feel welcome and have the same chances of achieving their full potential as other residents. This means tackling the inequalities and social injustice faced by autistic individuals and delivering outcome focused support based on need and not labels.

## Who is included in this strategy?

- Children and adults with a diagnosis of autism (all acuity, neuro-diverse conditions) and those with autistic traits who have not sought or are currently seeking a diagnosis.

## Language

There are diverse views held with the autism community about whether they prefer to be referred to as individuals with autism or autistic individuals. The later is more commonly preferred amongst adults, as autism is seen by many as a key part of who they are<sup>1</sup>. This strategic vision used “autistic individuals / people”, however we acknowledge for consistency throughout.

## What do we mean by autism?

Defining autism is challenging as there are various definitions and perspectives. Our purpose is to embrace an inclusive definition of autism as a lifelong developmental condition which affects how individuals communicate and interact with the world. We recognise that every individuals’ experience of autism will be unique but there are some common challenges.

Autistic individuals see, hear and feel the world differently to other people. Autism varies widely and is often referred to as a spectrum condition, because of the range of ways it can impact on people and the different level of support individuals may need across their lives.

**National Autistic Society** ‘Autism is a lifelong developmental disability that affects how people perceive, communicate and interact with others, although it is important to recognise that there are differing opinions on this and not all autistic people see themselves as disabled. Autism is a spectrum condition and affects people in different ways. Like all people, autistic people have their own strengths and weaknesses, gifts, and skills’.

## What do we know about our population in Birmingham and Solihull?

There is a lack of reliable data on the number of autistic adults, children and young people in the UK because of gaps in data collection and reporting. Therefore, it is

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<sup>1</sup> [NHS England » Making information and the words we use accessible](#)

only possible to provide estimates of these numbers. The estimates are usually based on the autistic population being around 1.1% of the total population (Used by *Skills for Care Calculator* and in Iris Fermin et al *Birmingham JSNA Autism Spectrum 2012*). However, it is acknowledged that this is likely to be an under-estimate of the true picture, especially for adults as some research places the rate as much higher. There are a number of factors which are thought to influence diagnosis rates, including available services in a locality and people's socio-economic conditions.

There are an estimated 700,000 autistic adults and children in the UK and, in addition, an estimated 3 million family members and unpaid carers of autistic individuals (The National Strategy for Autistic Children, Young People and Adults: 2021 to 2026).

There are approximately 16,020 people across Birmingham and Solihull who have been diagnosed with autism by the NHS, just over half of these are under 18 years old<sup>2</sup>. There will be others who have received a private diagnosis or have not sought a diagnosis. This suggests that the 1.1% estimate for population prevalence is a significant under-estimate.

## Waiting list time for assessment and diagnosis

Data also demonstrates that individuals, families and carers are waiting too long for assessment and diagnosis. Currently:

- Children being assessed now were referred for assessment in January 2021.
- There are currently 630 children awaiting assessment
- For adults the waiting list is approximately 12 months from referral to diagnosis<sup>3</sup>

## Who has been involved in creating this vision?

This vision has been co-produced with our experts by experience with feedback from the Midlands Autism Workstream Experts by Experience focus group, Birmingham and Solihull CCG, Birmingham City Council, Solihull Metropolitan Borough Council, Solihull Parent Carer Voice, and others.

## What do we mean by full potential?

Autistic individuals have told us that they want a life in which they are included and have equitable access to all aspects of life, not simply to health and social care support. They want to fulfil their dreams and aspirations. Autistic individuals have told us that access to diagnosis and access to person centred support from services that are coproduced is important. But that support should be based on need, choice and not constrained by diagnosis and labels.

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<sup>2</sup> ICB data – October 2021

<sup>3</sup> ICB data – September 2022

## How we will work as a Health and Care System

We know that the support people want and need changes across their lifetime, especially during major transitions and so our support offer will need to be flexible and responsive to those changes.

We recognise that to achieve this collective vision we will need to work with all our system partners to build resilience in our system, in our local communities and for individuals.



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From our engagement on this and linked strategies (e.g. the Additional Needs Strategy) we have developed a set of 'I' statements which sit under these groupings.

Personal Resilience	Community Resilience	System Resilience
<b>I know what I need and how to look after myself</b>	<b>I get the support I need to maintain my independence</b>	<b>I can get the right support I need at the right time for me</b>
<p>I have access to support early, including diagnosis.</p> <p>I have a voice that will be listened to, and my voice makes a difference.</p>	<p>I know what community support is available and how to access it.</p>	<p>I tell my story once and there is a single record of my support.</p> <p>I have access to the right support as I get older.</p>

<sup>4</sup> From East Riding of Yorkshire – BSOL version to be developed

<b>Personal Resilience</b>	<b>Community Resilience</b>	<b>System Resilience</b>
<b>I know what I need and how to look after myself</b>	<b>I get the support I need to maintain my independence</b>	<b>I can get the right support I need at the right time for me</b>
<p>I feel I have choice and control about my support.</p> <p>I have people around me who I like – family / friends.</p> <p>I have support available for my family and carer.</p> <p>I have access to employment opportunities and activities that will benefit me.</p> <p>I have access to education and learning.</p> <p>I have access to support for my sensory needs.</p> <p>I am involved in all the decisions about my life.</p>	<p>I feel safe, welcome, included and valued in my community.</p> <p>I am able to access housing appropriate to my needs.</p> <p>I get support to keep me well such as health checks</p> <p>I can access physical and mental health services when I need them.</p> <p>I am able to access good support.</p> <p>I am supported to do the things that interest me.</p>	<p>I am able to communicate my needs in an emergency.</p> <p>I have support which is coordinated, cooperative and works well together.</p> <p>I know who to contact to get things changed. It is right first time</p> <p>I have support that is flexible and personalised.</p>

## Priorities

### How we decide our priorities

A combination of factors has determined our local priorities, including:

- Feedback and engagement with autistic individuals, parents, carers and local residents that have identified gaps or services which are not working as well as they should
- Feedback from our own staff across the Birmingham and Solihull health and social care organisations
- National and local policies
- Recommendations from safeguarding reviews
- Building on good practice, learning and evaluation here or in other areas
- Building on the recent priorities from the All-Age Autism National Strategy 2021

We have grouped the priorities into these themes:

## **PRIORITY AREA 1: Access and Inclusion**

What we want to achieve:

- Increased awareness of autism, creating a safer and more inclusive community environment
- Earlier access to diagnosis and support
- Digital accessibility
- Increased access to employment

## **PRIORITY AREA 2: Quality and Choice**

- Health and social care provide consistent support and share records
- There is good choice of good quality support providers who have knowledge and expertise in Autism
- People who have Autism or care for a person with Autism are involved in service planning and recruitment

## **PRIORITY AREA 3: Holistic Support**

- Considering the whole family and community network, not just the presenting need
- Person centred support
- Building social networks/drop in support

## **PRIORITY AREA 4: Reducing Inequalities**

- Annual health checks
- Delivering recommendations from LeDeR
- Access to services is available at the right time and it is easy to find support

## **What will success look like?**

Measurable outcomes are co-produced with our experts as they know what good looks like and that these are constantly monitored and reviewed.

## **How we will deliver this:**

- Birmingham Delivery Plan – created, developed and discussed with all key stakeholders, experts by experience and with the Birmingham Autism and ADHD partnership board.
- Solihull Delivery Plan – to be created, developed and discussed with all key stakeholders, experts by experience and with the Solihull Autism partnership board.

## **Interdependencies**

**Birmingham All Age Autism Position Statement 2020**

# **Solihull Additional Needs Strategy 2022-25**