

# **Autism Strategy**

**2014-2017**

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## Document control

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# Partners

We are working together to improve the services and support available for people with autism, their carers and their families across Bolton.

Bolton Council

Bolton Clinical Commissioning Group

Greater Manchester West Mental Health Trust

Greater Manchester Police

Bolton Probation Service

Bolton Courts

Bolton College

Bolton Libraries

Job Centre Plus

Local employment support providers

Housing Associations



# 1. Our Vision

In Bolton we support the Government's vision for 2013 and beyond, which states that:

**“all adults with autism are able to live fulfilling and rewarding lives within a society that accepts and understands them. They can get a diagnosis and access support if they need it, and they can depend on mainstream public services to treat them fairly as individuals, helping them make the most of their talents”**

*(Department of Health (DH), 2010, Fulfilling & rewarding lives: the strategy for adults with autism in England).*

Our local strategy sets out how we will work with our partners to set the direction for services for adults with autism in Bolton in order to achieve this vision.

# 2. Background and Key Strategic Drivers

## The Autism Act 2009

The Autism Act 2009 underlined the Government's commitment to achieving the aforementioned vision. It was the first ever piece of legislation designed to address the needs of one specific group of people with impairments, adults with autism.

Prior to the publication of the Act, a number of high profile reports such as “Think differently - act positively: public perceptions of autism” and “I Exist: the message from adults with autism in England” (National Autistic Society, 2008), highlighted the difficulties experienced by adults with autism in England, including higher than average unemployment rates, a higher prevalence of mental health difficulties and the added burden borne by carers of caring for their sons and daughters into their old age.

The Act placed two key duties on the Government. The first was to produce a national strategy on services for adults with autism. The second was that statutory guidance for local authorities and local health bodies had to be published by the Secretary of State for Health by the end of 2010.

## Fulfilling & rewarding lives: the national strategy for adults with autism in England

The strategy for adults with autism in England, published by the Department of Health in March 2010, set out a direction for long term change for adults with autism. It called for a societal culture shift so that equality and human rights for people with autism are respected. To help improve the quality of life for people with autism, it sets out the need for better:

- Autism awareness
- Training for those working with people with autism
- Access to a diagnosis
- Assessments of people with autism
- Service and support
- Local leadership and planning

The strategy also outlines the negative impacts for people with autism if we do not change and improve services:

- Continued poor physical and mental health
- Continued involvement in crime and substance misuse
- Continued dependency on state benefits
- Continued economic and social costs for their carers and families

## **Statutory Guidance: Implementing “Fulfilling and rewarding lives”**

The ensuing statutory guidance for health and social care, *Implementing ‘Fulfilling and rewarding lives’* followed in December 2010, published with the purpose of securing the implementation of the strategy, by helping local areas to develop services that support and meet the locally identified needs of people with autism and their families and carers..

The guidance allows for some local discretion in how the strategy is implemented, but a lack of associated funds nationally may impede some of the key aims from being implemented. However, the national strategy recommends that the key to successful implementation is to make existing policies and public services work better for adults with autism.

The guidance requires local authorities and NHS bodies to improve their:

- Levels of autism awareness
- Diagnosis and assessment pathways
- Transition arrangements for young people with autism
- Local planning and service delivery

## **Think Autism – 2014 update**

The Government has recently published an update to the 2010 national autism strategy, entitled *Think Autism*. The document recognises the progress that has been made in improving support for adults with autism in England since 2010, and confirms its support for the vision and direction of travel that the original strategy set in train.

Think Autism identifies fifteen ‘Priority Challenges for Action’, which have been developed by people with autism, carers, professionals, and others who work with people with autism as part of the consultation carried out for the update to the strategy. These are split under three headings as follows:

An equal part of my community:

1. I want to be accepted as who I am within my local community. I want people and organisations in my community to have opportunities to raise their awareness and acceptance of autism.
2. I want my views and aspirations to be taken into account when decisions are made in my local area. I want to know whether my local area is doing as well as others.
3. I want to know how to connect with other people. I want to be able to find local autism peer groups, family groups and low level support.
4. I want the everyday services that I come into contact with to know how to make reasonable adjustments to include me and accept me as I am. I want the staff who work in them to be aware and accepting of autism.
5. I want to be safe in my community and free from the risk of discrimination, hate crime and abuse.
6. I want to be seen as me and for my gender, sexual orientation and race to be taken into account.

The right support at the right time during my lifetime:

7. I want a timely diagnosis from a trained professional. I want relevant information and support throughout the diagnostic process.
8. I want autism to be included in local strategic needs assessments so that person centred local health, care and support services, based on good information about local needs, is available for people with autism.
9. I want staff in health and social care services to understand that I have autism and how this affects me.
10. I want to know that my family can get help and support when they need it.

11. I want services and commissioners to understand how my autism affects me differently through my life. I want to be supported through big life changes such as transition from school, getting older or when a person close to me dies.
12. I want people to recognise my autism and adapt the support they give me if I have additional needs such as a mental health problem, a learning disability or if I sometimes communicate through behaviours which others may find challenging.
13. If I break the law, I want the criminal justice system to think about autism and to know how to work well with other services.

Developing my skills and independence and working to the best of my ability:

14. I want the same opportunities as everyone else to enhance my skills, to be empowered by services and to be as independent as possible.
15. I want support to get a job and support from my employer to help me keep it.

The document introduces some other significant developments, including the announcement of the Autism Innovation Fund, supported by £4.5 million revenue and capital funding to support some of the key themes set out in the update; a forthcoming national Autism Awareness and Champions programme; and confirmation that the third Autism Self-Assessment will be issued later in 2014, along with statutory guidance for the strategy.

### **National Institute for Health and Care Excellence (NICE) Quality Standard**

In January 2014 NICE announced a new 'quality standard' on autism, which is intended to address the current variation in diagnosis and treatment of the condition. NICE quality standards describe high-priority areas for quality improvement in a defined care or service area, consisting of a prioritised set of specific, concise and measurable statements. They draw on existing guidance, which provides an underpinning, comprehensive set of recommendations, and are designed to support the measurement of improvement.

The Autism quality standard contains eight measurable statements which have the overall aim of improving the quality and consistency of care for people with the condition. These statements cover autism in children, young people and adults, including both health and social care services:

1. Diagnostic assessment by an autism team
2. Assessment and diagnosis
3. Personalised plan
4. Coordination of care and support
5. Treating the core features of autism: psychosocial interventions
6. Treating the core features of autism: medication
7. Assessing possible triggers for behaviour that challenges
8. Interventions for behaviour that challenges

NICE state that the clinical picture of autism is variable because of differences in the severity of autism itself, the presence of coexisting conditions and the differing levels of cognitive ability, which can range from profound intellectual disability in some people to average or above average intellectual ability in others.

The NICE guidelines on autism (and the NICE pathway on autism) make similar recommendations to that of the Autism Act 2009, and they recommend that their quality standard should be used alongside the NICE guidelines and local strategies as a tool to inform the commissioning of autism services for children, young people and adults focusing on the key areas for improving the quality of existing services.

### 3. Scope of the strategy

In Bolton there are a range of adult social care services such as supported housing, specialist day services, respite care, and direct payments which may be accessed by people with autism who meet the Fair Access to Care Services (FACS) eligibility criteria for those services.

In addition to improving diagnosis and assessment for these people we are committed to improving services and support to people who have 'high-functioning' Autism or Asperger syndrome, who we know are most likely to fall through the gaps in current service provision as they may not be eligible for social care services.

#### Terminology

We recognise that there are a number of terms that individuals and groups prefer to use including **autistic spectrum disorder**, **autistic spectrum condition** and **autistic spectrum difference**. In this strategy we use the term **autism** as an umbrella term for all such conditions, including **Asperger syndrome**. This is in line with the approach to terminology adopted by key autism representative organisations, including National Autistic Society (NAS).

#### Definition of autism

For the purposes of this strategy, autism is defined as a lifelong condition that affects how a person communicates with, and relates to, other people. It also affects how a person makes sense of the world around them. The three main areas of difficulty, which all people with autism share, are known as the 'triad of impairments'. They are difficulties with:

- Social communication (e.g. problems using and understanding verbal and non-verbal language, such as gestures, facial expressions and tone of voice)
- Social interaction (e.g. problems in recognising and understanding other people's feelings and managing their own)
- Social imagination (e.g. problems in understanding and predicting other people's intentions and behaviour and imagining situations outside their own routine).

Many people with autism may experience some form of sensory sensitivity or under-sensitivity, for example to sounds, touch, tastes, smells, light or colours. People with autism often prefer to have a fixed routine and can find change incredibly difficult to cope with.

Many people with autism may also have other conditions such as attention deficit hyperactivity disorder (ADHD), a learning disability or dyspraxia. Autism is known as a spectrum condition, both because of the range of difficulties that affect adults with autism, and the way that these present in different people. For example, Asperger syndrome is a form of autism.

People with Asperger syndrome typically have fewer problems with speaking than others on the autism spectrum, but they do still have significant difficulties with communication that can be masked by their ability to speak fluently. They are also often of average or above average intelligence.

#### Partnership approach

This strategy is concerned with all public services for adults with autism in Bolton and it has been developed by and in partnership with a number of local organisations as listed on page 3.

Although adult social care has the lead responsibility for this strategy, we aim to ensure that all our local partners are signed up to the strategy. Through our engagement with them we can ensure they play a key role in successfully delivering the Implementation Plan.

As stated above, the national strategy particularly emphasises the importance of making changes to benefit people who may predominantly be ineligible for adult social care services, i.e. people with Asperger syndrome. This highlights the importance of involving local organisations from across the board, and we are clear that a multi-agency approach is key to the success of the strategy.

### Local reporting framework

Bolton's Disability Partnership Board will oversee the progress of the strategy's implementation, by incorporating the priority outcomes for the strategy into its established workstreams;

- A good experience of Health services
- A good experience of Social Care
- Active & Fulfilling Lives
- A Disability Friendly Bolton

Progress will be reported to Bolton's Health and Wellbeing Board, who will be ultimately accountable for the strategy, including an annual refresh of the Implementation Plan.

Partners are fully engaged in our local Autism Implementation Task Group which has helped us to drive forward the development of the strategy. More detail about our aims and priority outcomes is detailed in section 6, *What are we going to do?*

## 4. Evidence Base

The first local Autism-specific needs analysis was published in 2013 by [Bolton's Health Matters](#), home of the Joint Strategic Needs Assessment (JSNA) in Bolton. Bolton's JSNA describes the health and wellbeing needs of local people and provides the key evidence for the commissioning of services to address and improve the populations' health. Previously, the needs of people with autism had been analysed within the established Learning Disability JSNA chapter.

### Joint Strategic Needs Assessment (JSNA)

The autism JSNA chapter gives a summary of the level of need in the population, based on available evidence and data on people with autism in Bolton. The following sections on level of need, prevalence and further needs assessment work have been based on this chapter.

#### Level of need

The National Autistic Society uses a prevalence rate of 1 in 100 (1%) people to estimate the number of people with a condition somewhere along the autistic spectrum. The rate among men (1.8%) was higher than that among women (0.2%). Using these prevalence rates, as at 2012, there were an estimated 1,653 adults aged 18 -64 years with autism in Bolton with the following demographic profile. These are taken from the Institute of Public Care's PANSI (Projecting Adult Needs and Service Information) tool; PANSI does not provide any data on the prevalence of autism in the 65+ population.

Age Group	Males	Females	Total
18-24 years	227	24	251
25-34 years	326	36	361
35-44 years	328	37	365
45-54 years	333	39	372
55-64 years	274	31	305
<b>Total 18-64 years</b>	<b>1487</b>	<b>167</b>	<b>1653</b>

A more recent study published by the Health and Social Care Information Centre in 2012 combined the existing data with a new study of the prevalence of autism among adults with learning disabilities living in private households and communal care establishments. Based on this study the overall prevalence of autism was 1.1% and was higher in men (2.0%) than women (0.3%). This revised prevalence rate has not yet been incorporated into the PANSI tool but is actually closer to the alternative estimates provided by Planning4care, which also includes those aged 14-17 and 65+ years. Unlike PANSI, the Planning4care estimate is also based on population data adjusted for the 2011 Census which is likely to account for some of the difference in estimated numbers.

Total numbers of people estimated with autism, by age in Bolton 2011 (from Planning4care):

- Aged 14-17 = 170;
- Aged 18-64 = 1,950;
- Aged 65+ = 460;
- Total = 2,580.

## **Prevalence**

A recent study by the Department of Health's Learning Disabilities Observatory carried out a systematic review to estimate the prevalence of autism amongst adults with Learning Disabilities. The review led to the conclusion that the prevalence of autism amongst adults with learning disabilities was likely to lie somewhere between 20% and 33%. In 2012 the estimated number of adults aged 18 and over with a learning disability thought to be living in Bolton was 4,962. Of these at least 992 (20%), and at most 1,638 (33%), are likely to have autism. The most recent study indicated that the prevalence of autism increased with greater severity of learning disability/lower verbal IQ. Also, sex differences are less marked in adults with learning disabilities compared with the rest of the general population.

It has also been estimated that around half of people with autism fall into the category of 'High Functioning Autism' – i.e. they actually have an IQ greater than 70; indeed many have well above average IQ26. Planning4care estimates that in 2011 there were 1,090 adults aged 18 and over with Asperger Syndrome/High Functioning Autism in Bolton.

It is clear that the estimated prevalence rates for adults with autism can only be a very approximate guide to the actual numbers of people living with this condition in Bolton. However, there are currently no local sources of information on the number of adults with autism, even for those with a diagnosis.

## **Further needs assessment work**

There is currently very little local data on the number of adults with autism accessing specific services. Although the low levels of diagnosis among adults do make this challenging there are examples of good practice from other areas where services (e.g. social care, housing, health) are recording and sharing data about people with autism. This will help partners understand the scale of need for particular services currently, to consider service costs and to improve commissioning and monitoring of services.

A recent review of social care data requirements carried out by the NHS Health and Social Care Information Centre (HSCIC) has introduced a requirement on Local Authorities to begin recording 'Primary Support Reasons' and 'Health Conditions' within electronic social care record systems from April 2014, including Autism and Aspergers Syndrome as mandatory fields. This information will be reported from April 2015 and it is anticipated that this will lead to significant improvements the availability and robustness of local data on levels of need and autism prevalence in the future.

The full Autism JSNA chapter is available via the following link:

<http://boltonshealthmatters.org/content/autism-jsna>

## **Feedback from consultation and engagement**

Adults with autism, their families and the general public have been engaged with in a number of ways over recent years as part of the development of this strategy.

Two locally established support groups, the Aspergers Parent and Carer Support Group and Adult Bolton Asperger's Group (ABAG), have played a key role in helping to shape the Priority Outcomes for the strategy, and have shared their valuable experiences and views of services in Bolton.

Two Autism Self-Assessment exercises have taken place, in 2012 and 2013, enabling Bolton to assess its progress in implementing the 2010 national strategy, also incorporating the views of adults with autism and their families.

A number of listening and consultation events have taken place locally, including events held to celebrate Autism Awareness Day, inviting the general public to explore the key themes from the national strategy and to talk about living with autism in Bolton.

Below is a summary of the key issues and concerns raised from the various consultation and engagement exercises held:

### **Improving autism awareness:**

- Lack of information and understanding of the condition led some people to feel isolated, alone, bullied and harassed.
- Actual or perceived bullying, harassment and hate crime were major issues for many of the people consulted with.
- These negative experiences had occurred in childhood as well as in adulthood; in schools, in the work place, in the town centre, and in people's localities where they live.
- All the aforementioned have resulted in some people feeling anxious and scared of being in the community as well as in their own homes.

### **Perceived positive impacts of raising awareness:**

- People felt that raising awareness of autism would better prepare people to accept difference, be more supportive and understanding, as well as helping reduce the negative stigmas people felt were often associated with autism.
- More awareness raising events, information workshops and support groups which provide emotional support for people in similar situations, and easier access into health and well-being centres, could help to increase understanding and reduce isolation.
- Target groups for autism awareness raising included professional staff in health and social care including GPs and social workers, the police and probation, staff in Job Centre Plus and the employment sector in general, as well as staff in all mainstream services such as libraries and leisure centres.

### **Possible consequences of not raising awareness of autism:**

- Continued lack of awareness and understanding
- Continued negative stigmatisation of people with autism
- Continued perceived and actual bullying, harassment and hate crime

### **Getting a diagnosis of autism:**

- A major theme for adults who may be on the autistic spectrum and their families.
- Some adults had been diagnosed in adult life but had found it hard to attain this diagnosis.
- For some people having a diagnosis of autism helped them better understand themselves as individuals and their own characteristics.

- For other people, attaining a diagnosis validated their issues and allowed them additional resources, and/or support under the Disability Discrimination Act 1995.
- This included employers, Colleges and Universities making reasonable adjustments for people with autism.

**The negative impacts of autism on people's lives:**

- People indicated the significant impact autism has on their day to day life.
- Some of these impacts includes difficulty socialising with others, severe depression and anxiety, irregular sleep patterns, increased anxiety when in the company of strangers, misreading people and situations, difficulty appreciating other people's perspective, being easily misled or being made a fool of.

**Priorities for individuals:**

- Getting a diagnosis, receiving good support.
- Gaining employment.
- Going to places where they felt safe such, as a support group.
- Managing their own anxiety and stress and gaining more confidence.

**Concerns for carers and families:**

- Some carers and families of people with autism feared what would happen once their children left the structure of school.
- They worried whether they would be able to get the right support access Further and Higher Education, whether they would be able to get a job and get the right support in the workplace to be able to sustain their job, and whether the benefit system would give people the means necessary to live independently.
- The type of accommodation on offer and where the accommodation is situated was also an issue for carers, fearing that living in certain 'hotspots' known for anti-social behaviour would only exacerbate the difficulties their siblings faced.
- A further major cause of concern was how their siblings would cope if they as carers were no longer there. It was recognised that many carers spend a great deal of time in an informal caring capacity, spending hours on the end of the phone or with the person offering verbal and low level support and encouragement.
- However, it was acknowledged that without this hidden support, their siblings are likely to require much greater and more formal means of support to survive the everyday challenges of life.

**Ways to alleviate their concerns:**

- Parents and carers felt that autism awareness raising was an absolute necessity across all walks of life.
- They felt the need was particularly great with health and social care professionals, the police and probation, employers and employment agencies, within further education establishments, staff within the benefits agencies, and with housing officers.
- Carers were also happy that the Government has started to recognize the difficulties faced by people with autism, in particular Asperger's syndrome and are putting things in place to start to improve the issues.

## 5. What have we already done?

Much has already been achieved in the run up to the development of this strategy; in summary:

Commissioning of a diagnostic care pathway for adults with autism with referrals via GP's. The service is provided by Greater Manchester West Mental Health NHS Trust and includes diagnostic assessments, post-diagnostic support and on-going care co-ordination. The pathway has been in place since April 2013.

The establishment of a specialist supported housing service for adults with autism, learning disability, and complex needs, with 12 places across 3 purpose-built properties. This service has enabled some people to move back to their local community from expensive placements at a distance from Bolton, and others to stay near their homes in Bolton when they would otherwise have had to move out of the area.

Reconstruction of a building at Thicketford to accommodate a specialist day service base for adults with learning disability, autism and complex needs, who live with their families. The building is being constructed in line with best practice design principles to provide an appropriate environment for people with autism, and will replace the existing autism day service base that has been provided at Falcon View Centre.

A programme of training and awareness-raising across agencies, covering front-line staff in mainstream agencies as well as more highly specialised training for staff providing assessments and specialist services.

Support for the establishment of local support groups for adults with Aspergers, and for carers of adults with Aspergers.

Community care assessments available for adults with Aspergers who may be eligible for community care services.

An autism strategy implementation group with broad membership has guided the local strategy development and reports through local partnership structures to the Health and Wellbeing Board.

The inclusion within Bolton's Joint Strategic Needs Assessment of a specific chapter that covers autism.

The provision of a helpline for people with autism of all ages, and their carers providing support and advice on an open access basis, and signposts to relevant local, regional and national services.

## 6. What are we going to do?

### Our Priority Outcomes

We have developed seven priority outcomes which will help us to achieve our vision for adults and young people with autism, as follows:

**1. Local organisations and services have a better awareness and understanding of autism and make reasonable adjustments so that their services are more accessible to, and respond more appropriately to, adults with autism**

The more people know about autism, the more support can be targeted more promptly and effectively, with the possibility of better outcomes for individuals, carers and their families. A multi-agency training plan will be rolled out across services and agree which staff will be trained and at what level; ranging from basic awareness raising to secondary training for professionals requiring more in-depth knowledge. Health and social care commissioners will ensure that good autism awareness training is built into the services they purchase.

**2. A clear and consistent diagnostic pathway exists for adults with autism with post-diagnostic support where appropriate/needed**

A diagnosis can help explain to the individual and their family what had previously been unknown or misunderstood. It also avoids the problem of misdiagnosis and helps people access relevant services and benefits. Health and social care professionals working with people with autism need to know how to make a referral for a diagnosis. Staff involved in diagnosis and assessment will not only receiving training about autism, but also have an in-depth understanding of how the care pathway works.

**3. All adults with autism are able to access appropriate information and advice about services available to them**

Clear and appropriate information about local services for people with autism needs to be made available. Following diagnosis, people need good, prompt information about autism and where to get support. People with autism can find assessments perplexing. Assessing the social care needs of someone with autism should be done by a professional with sufficient training and experience, and reasonable adjustments may need to be made to ensure the assessment is as productive as possible.

**4. Transitional support is improved for young people with autism as they move into adulthood**

Through school, young people with autism and their families will usually have had access to support that helps them achieve and be included. Without effective transition planning, this support could disappear once people with autism reach adulthood, leaving them isolated at this critical point. Organisations and services need to work collaboratively to ensure that young people with autism are given the right start in their adult life.

**5. Adults with autism in Bolton are able to access employment opportunities**

The ability to get and keep, a job and then to progress in work is a central part of social inclusion. We know that adults with autism are significantly underrepresented in the labour market and we are committed to doing more to help adults with autism into work. This will include new developing approaches that will better support adults with autism and making sure that they benefit from wider employment initiatives.

**6. Local planning and leadership is in place in relation to the provision of services for adults with autism**

Through the Joint Strategic Needs Assessment (JSNA), there will be enhanced data available around adults and young people with autism in Bolton, leading to a better understanding of need. There will be local options for people with autism about where to live, how to spend their time and by whom they are supported. Specialist services are available for those who need them, offering structure routine and continuity. Mainstream services will be competent to support people with autism, with trained staff, low arousal areas and flexible processes.

## **7. Adequate specialist support services are commissioned to respond to the needs of adults with autism**

To ensure a clear response to Bolton's Joint Strategic Needs Assessment and [Market Position Statement](#); links need to be made with local housing and independent sector agencies to ensure there are agencies working locally that can provide skilled social care support to adults with autism.

# **7. Implementation Plan**

The strategy will be supported by the development of an ongoing Implementation Plan to be structured around our Priority Outcomes and will keep us on track throughout the delivery of the strategy and allow us to evaluate our progress as we go forward.

For each of our Priority Outcomes, 'Key Aims' have been identified for the whole 3 year life of the strategy, and have been cross-referenced with the recently published 'Priority Challenges for Action' as identified in *Think Autism*, the update to the 2010 national strategy.

We are also committed to working towards the seven quality outcomes as outlined by central government. These measures will also help us to evaluate our progress throughout the life of this strategy.

We want to make sure that adults with autism in Bolton will:

- ✓ Be included and economically active
- ✓ Achieve better health outcomes
- ✓ Live in accommodation that meets their needs
- ✓ Benefit from the personalisation agenda in health and social care, and access personal budgets
- ✓ No longer be managed inappropriately in the criminal justice system
- ✓ Be satisfied with local services, as well as their families and carers
- ✓ Be involved in service planning

The Implementation Plan will be reviewed on an annual basis by the Disability Partnership Board and User reference group and amendments or additional actions will be proposed at these times.

The strategy will be fully reviewed on a three-year cycle, next in 2017. Updates on progress will be reported to Bolton's Disability Partnership and the Health and Wellbeing Board annually.

# Appendix A – Bolton’s Diagnostic Care Pathway

