
Leeds Adult Autism Strategy 2017-2022

Introduction

Autistic people share many of the same aspirations and have similar needs to any other people, and may wish to use the same resources and services. As well as this they may have additional needs, and strengths, which arise from their autism. We now know that autistic people can really benefit from the work that we can do locally to improve options for them.

This is our second strategy, over the past 5 years we have achieved substantial improvements for and with autistic people in Leeds. There is still work to do though in a wide range of different areas; this work will need input from many different organisations and people.

One of our main achievements is to have developed a wide network of autistic people and carers who can really inform our work. With their help we made some significant progress, however, we recognise that there is still work to do.

Leeds autistic people say:



Thanks to the strategy, autism services in Leeds have really raised their game.

Leeds Autistic Citizen

Overview



The draft plan targets all the most important areas for us but agencies drafting plans have to show they are serious about tackling the issues identified so far.

Leeds Autistic Citizen

Priorities

The broad task described nationally and which we are describing locally is:

- to continue to make services that everyone can use more accessible to autistic people
- to continue to maintain or increase (if necessary) a minimum necessary level of specialist resources
- to work towards the needs of autistic people being considered within all other relevant planning and oversight bodies.
- To work in partnership. It is very common for autistic people to have more than one condition - so partnerships between different agencies become even more important.

Underlying practice commitments:

- To maximise co-production with autistic people, carers and providers. This approach has already shown strengths and we have every expectation that it will continue to do so.
- To ensure that we maintain a regular planning process attended by senior people. Its job is to make sure we keep up with our work and to make sure that autistic people and carers can contribute genuinely.
- To monitor the effectiveness of our work and of wider research and use this to inform future work plans and activities.

- To work alongside any people or organisations which aim to destigmatise autism and educate the public.
- To make sure that all relevant staff in the city have access to good quality autism training, and that all specialist staff can get specialist training.
- To continue to collect and update the information we have on prevalence and demand in Leeds.
- To ensure that our work meets the needs of all different people - whatever their age, gender, ethnicity and LGBT (sexuality).

Areas for action

We will work, over time, towards improving all the following areas. The partnership board will produce and oversee an annual action plan to help us prioritise what is a very big task.

Services anyone can use

The well-being of autistic people depends on:

- Good quality health services (including mental health) which know how to make reasonable adjustments for people with autism.
- Public health resources which are reasonably adjusted for autistic people.
- Good quality employment services which are able to help autistic people get and keep fulfilling work.
- Housing services which know how to support people with autism and how to make adjustments to help them get good quality housing.
- Criminal justice services (police, probation, courts, prison) which are all able to communicate well with people with autism.
- Education including schools, colleges and universities.
- Services which help young people as they move from children's to adults services.
- Easily accessible welfare benefits advice.
- Public transport which is able to meet the needs of autistic people.



We want support for people to get to new places to broaden our horizons and help get jobs.

Leeds Autistic Citizen

Non autistic Specialist Services

- Trained and experienced social work staff to assess people for social care funded services and to support them after assessment.
- Carers support services which are sufficiently well informed about autism.
- Commissioned services which are properly able to support people with autism as well as other needs.

Autism specialist services/resources

- A specialist diagnostic team and an appropriate amount of access to specialist health treatment.
- Post diagnostic support and information - this may include support for people to identify their individual autistic needs and be able to communicate these to other people or agencies.
- The right sort of support and advice for young autistic people as they grow up from 14 to 25.
- Advice, information and social support for people who aren't eligible for social care support.

How will we do this:

We will maintain an autism partnership board with relevant reference groups.

Terms of reference, membership and meeting structure will be reviewed every 2 years or as the board, or external changes require.

The board will be responsible for the annual national self-assessment form (SAF), data collection, liaison and partnership. It will undertake to produce an annual action plan and be responsible for monitoring this.

We will report this strategy and annual action plan to the adult social care directorate leadership team, the health and wellbeing board, health commissioners, the LCC Executive committee and any other relevant body as requested, or as planning and oversight systems develop.

The board will also undertake to see that information on recent research and training information resources is available within the city.

Background information

1. What is autism?

Throughout the strategy, the term 'autism' is used to refer to all diagnoses on the autism spectrum, including Asperger syndrome, high functioning autism, Kanner or classic autism. 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.

Autism is a lifelong condition, people with autism are very different from one another and it is important not to generalise. Someone with autism can show marked difficulties with social communication, social interaction and social imagination. They may be preoccupied with a particular subject or interest. Autism is a neurological difference and is not a mental illness in itself. However, people with autism may have additional or related problems, which frequently include anxiety. These may be related to social factors associated with frustration or communication problems or to patterns of thought and behaviour that are focussed or literal in nature.

A person with autism may also have sensory and motor difficulties that make them behave in an unusual manner, which is likely to be a coping mechanism. Autism is independent of IQ ie a person with autism may or may not have learning disabilities as well as their autism. 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.

Adults with autism 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 got their diagnosis.

2. Demographics

We do not have a register of autistic people but recent research suggests that approximately 1.1% of the population is on the autistic spectrum¹, which means for Leeds there are approximately 7,500 autistic people, 5,700 of whom will be over 18. Autism affects people in different ways - some can live relatively independently, in some cases without

any additional support, while others require a lifetime of specialist care.

Up to 30%² of the learning disabled population is likely to be autistic (approximately 630 people in Leeds). Therefore, it's likely that there are approximately 5,000 adults in Leeds on the autistic spectrum without additional learning disabilities most of whom do not receive social care or specialist health support.

In Leeds we have an autism section to our joint strategic needs assessment. This will be updated at regular intervals as we gain more information about autistic people in Leeds. <http://observatory.leeds.gov.uk/resource/view?resourceId=4701>

3. Consultation summary

We have recently consulted members of the public for priorities for a renewed Leeds Autism Strategy.

60 people filled in the electronic survey and there was a high level of agreement that most issues were very important. These issues included:

- A partnership board that includes autistic people and carers.
- Good quality health services, including mental health services.
- Good quality employment services.
- Good quality staff training.
- Housing services which are able to support people with autism.
- Criminal justice services which are able to communicate well with people with autism.
- Good quality, and linked up, diagnosis and social care assessment services.
- Post diagnostic support.
- The right sort of support for young people from 14-25.
- Advice and information for people who are not in receipt of social care support.
- Accessible welfare benefits advice.
- Provider services that are able to properly support people with autism.

¹ <http://content.digital.nhs.uk/catalogue/PUB21748/apms-2014-autism.pdf> (accessed 27-1-17)

² http://www.improvinghealthandlives.org.uk/uploads/doc/vid_8731_IHAL2010-05Autism.pdf (Accessed 27-1-17)

These consultation results indicate that this Leeds autism strategy should, (like the last Leeds strategy and the current national strategy “Think Autism”) cover the need to improve a wide range of services and systems.

Feedback from carers in particular has indicated that, although they are supportive of a broad strategy, they would also like to see a detailed action plan which focuses down on specific areas at specific times and where individual agencies are encouraged to take full responsibility for improvement in their areas of work.

4. National policy and guidance

There have been two national strategies and statutory guidance since The Autism Act was passed in 2009.

The current statutory guidance expects Local Authorities and the NHS to work in collaboration with local partners to take forward the key priorities in Think Autism.

This document can be found at <https://www.gov.uk/government/publications/think-autism-an-update-to-the-government-adult-autism-strategy>

Think Autism updated the 2010 Cross Government Autism Strategy in April 2014. The progress report has now been issued setting out what has been achieved since then and setting 31 new actions to continue to help local areas implement the autism strategy.

5. Challenges

Finance:

Current financial uncertainties mean that commitment to extra resources or indeed retention of existing resources will remain a challenging task. Whilst we will commit ourselves to maximising opportunities much of our work will need to (as it has been to date) be focused on helping other funded organisations to maximise their offer for autistic people and to seize funding options when they present themselves. Our annual action plan - guided by these agreed objectives- will maintain our readiness to use these opportunities.

6. Cost benefit

We are not as yet able to provide detailed cost benefit information but there is now some research based information on the lifetime costs of autism:

“The cost of supporting an individual with an ASD and intellectual disability during his or her lifespan was £1.5 million in the United Kingdom. The cost of supporting an individual with an ASD without intellectual disability was £0.92 million in the United Kingdom. The largest cost components for children were special education services and parental productivity loss. During adulthood, residential care or supportive living accommodation and individual productivity loss contributed the highest costs. Medical costs were much higher for adults than for children.”³

Local knowledge and case studies give an early indication that timely low level support is able to deliver on reducing overall system costs.

7. Overlaps with different tasks.

In order to meet the aims of this autism strategy it will be necessary to work with a wide range of different systems and services. Many of these are undergoing change - often driven by financial, political and demographic pressures.

Both because of the nature of autism and for the same historical reasons that autism has been left out of existing service provisions one of our tasks will be to influence these areas of development to make sure that in future the needs of autistic people and their families are fully and appropriately taken into account.

This will be a long and slow process and will require a degree of prioritisation (in line with annual action plans). Some current (as at autumn 2016) key developments are in mental health, transforming care, Department of work and pensions redesign, and changes within housing services. The partnership board will update this list when necessary to inform the annual action plans.

³ *Costs of Autism Spectrum Disorders in the United Kingdom and the United States*

¹Ariane V. S. Buescher, MSc; ^{2,3}Zuleyha Cidav, PhD; ¹Martin Knapp, PhD; et al ^{2,3}David S. Mandell, ScD
JAMA Pediatr. 2014;168(8):721-728. doi:10.1001/jamapediatrics.2014.210

8. Current research

There is increasing amounts of research on the needs of autistic adults, and on what approaches are helpful, but the evidence base is incomplete. At the time of writing “The Autism Dividend” is a comprehensive review of the state of autism research as it relates to the effectiveness of interventions: <http://nationalautismproject.org.uk/the-report>

There is also some recent research which gives stronger evidence for substantial health and wellbeing issues for autistic people. A large scale Swedish study indicates that life expectancy for autistic people can be between 10 and 2 years lower than that of a matched control group. Suicide rates for autistic people without learning disabilities were found to be ten times those of the wider population. There is also some evidence that autistic people will have a higher level of mental health issues. <http://www.nhs.uk/news/2016/03March/Pages/People-with-autism-are-dying-younger-warns-study.aspx>

9. Thank yous

This strategy has been influenced and approved by a wide range of different people - I would like to thank all those who contributed directly and indirectly both to this strategy and to the developments in Leeds over the past 5 years.

We look forward to continuing to work together to improve the options in Leeds over the next 5 years.



For further information please visit:

<http://www.leeds.gov.uk/residents/Pages/Autism.aspx>

Or you can contact:

Helen.Gee@leeds.gov.uk

This publication can also be made available in plain English.

