

What is autism?



Autism is a developmental condition, it affects people's communication and people may have sensory difficulties

Autism occurs early in a person's development. It 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. The spectrum includes Asperger syndrome and high-functioning autism.

People with autism may also have learning disabilities or mental health problems. Whether or not they do, autistic people are likely to find aspects of their lives challenging, although they may have much to offer if supported properly in the right role.

Someone with autism may have difficulties with social communication, interaction and imagination. They may be preoccupied with a particular subject or interest. They may also have sensory and motor difficulties, including sensitivity to light, sound, touch and balance.

The population

We do not have a register of autistic people but know that at least 1.1% of the population is on the autistic spectrum, which means for Leeds there are approximately 7,500 autistic people, 5,700 of whom will be over 18.

Up to 30% 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.



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There are substantial health and wellbeing issues for this group of people. There is now evidence, from a large scale study, that life expectancy for autistic people, is between 2 and 10 years lower than that of a matched control group. Suicide rates for autistic people without learning disabilities were found to be up to ten times those of the wider population. There is also some evidence that autistic people will have a higher level of mental health issues. More information can be found in the [autism section of the Leeds JSNA](#). This is currently being updated, the most current information is found in appendix 2.

Since the autism partnership board has been in operation (we began in 2011) we have a much better understanding of the importance of the wider public health agenda for the wellbeing of autistic people. Some of this is driven by recent research, the substantial impact of autism on life expectancy is referenced above (1). Recently more specific (peer reviewed) research indicates the overrepresentation of autistic people (relative to a demographic baseline of 1.1%) in other service areas. 8-12% of service users in a homeless service were or might be autistic (2) and a review of substance misuse which indicates a doubled risk of substance misuse problems for individuals with autism diagnoses, higher if they had a comorbidity with ADHD (3). Evidence of and concern

about suicide and suicidality is also growing (4). (Links and references at the end of the document)

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>

Nationally concern around new research has been reflected in the recent refresh of the National autism strategy. This effectively rearranges the existing priorities and introduces two new overarching objectives:

1: Reducing the gap in life expectancy for autistic people

2: Autistic people are able to play a full role in society

<https://www.gov.uk/government/publications/think-autism-strategy-governance-refresh-2018>

The NHS long term plan now indicates an intention to improve access to and quality of treatment for autistic people.

Leeds strategy

Leeds consulted on and adopted a new adult autism strategy in 2017. This was reported to the Health and Wellbeing board on 20th July 2018.

The focus of the strategy is broad reflecting the wishes of local stakeholders. There is an annual action plan which identifies priority areas for the partnership board's work. Currently these priorities are health, particularly mental health; criminal justice system, training and travel training.

Local processes and reporting

We have an Autism partnership board, which is responsible for influencing and guiding partner bodies and evaluating the progress of the Strategy. People with autism and carers are an important part of the partnership board through a reference group for people with autism and a carers' reference group. A separate group for providers also meets.

As well as the stakeholder representatives membership of the board includes operational and commissioning staff from health and social care, representatives from children's service, further education; housing, and the Department of work and pensions.

The board meets quarterly as do the reference groups.

Leeds completes an autism self-assessment (SAF) annually to report to Central Government, which also goes to the Health and Wellbeing Board. The most recent version was submitted in 2018.

Progress in Leeds

Current developments in health and social care services

There are a number of interesting pieces of work underway in Leeds at the moment to improve the wellbeing of autistic people, both by providing support to them as individuals and/or by organisational changes to facilitate reasonable adjustments.

The list below indicates some of the local work underway, all of which represents a positive change. It is very useful that this work continues within its separate organisations. It is now becoming clearer that the next most useful step would be to revisit the question of a system overview enabling a continuity of support between within organisations, some of the current work underway to assist individual autistic people to understand and communicate their own needs will complement and be essential to the wider picture.

This section highlights some areas of work:

- Physical health
 - LTHT are working to extend their programme of reasonable adjustments for people with learning disability to autistic people. They are supported in this by a group of autistic self advocates.

- Mental health developments
 - A range of mental health services including IAPT and the new 3 third sector service Livewell Leeds, are undertaking additional autism training and examining the best ways to adapt their services to meet autistic needs. The continuing need for autism specific psychological therapy, currently met by the individual funding request process is being reviewed. The diagnostic service suits within LYPFT and works with their staff on a consultancy basis as well as offering training and consultancy to GP services.

- Social world
 - Most autistic people are not eligible for adults social care services, for many their priorities are e.g. housing or employment. . For those that are social workers have had additional training and there is a small range of specialist provider services on offer., some more generic services are beginning to build a cohort of support workers with autism experience.
 - The CCG has recently awarded longer term funding to Leeds autism aim. This is for those people who are not eligible for social care, it is a preventative service which as part of its range of options helps to provide guidance to other organisations as they seek to make reasonable adjustments.

Other Current Challenges and Opportunities

Although Leeds has made substantial advances since 2010 there are some issues which remain significantly challenging. The current financial pressures on all areas add to these challenges but the cross cutting nature of autism is also a contributory factor.

Preparing for adulthood/transitions:	The numerous boundaries between childhood and adulthood can present challenges to people on the autistic spectrum. There is a particular gap in transition supports for people at the higher IQ end of the autistic spectrum, which may present later than usual.
Reasonable adjustments in both physical and mental health services:	The current challenge here is to look at methods for “joining up” the good work which is underway.
Transforming care:	This big national project may result in better outcomes for the small number of autistic people who sit in this cohort.
Training:	Much autism training takes place but keeping this updated, and appropriate is a continuing challenge.
Employment:	This is of key importance to many autistic people, who can offer much to employers if supported appropriately in the right role. Although the DWP has the lead responsibility in this area health and well-being board members will be providing employment support. As big employers, they also have an opportunity to improve both recruitment and retention of autistic employees. We have recently held our 3 rd Hidden talents event – a job fair for autistic people which also offers training for employers.
Housing:	Access to appropriate housing is essential to enable people on the autistic spectrum to lead a good life. New national guidance for housing services for autistic people has just been issued.

Conclusion

The work to improve the wellbeing and opportunities for adults with autism and their families and friends is continues to have an impact. National developments and increasing public awareness give us a climate of high expectation and increasing demand for those limited resources we have. At the same time we have a level of interest and engagement from wider service and areas which supports us in a gradual improvement. Our local progress is such that we now are at a stage where a review of the links between services would be valuable

Recent research on autism: references and links

1: Premature mortality

Premature mortality in autism spectrum disorder.

Hirvikoski T. *et al.* *Br. J. Psychiatry* Epub ahead of print (2015)

2: Homelessness

The prevalence of autistic traits in a homeless population

Alasdair Churchard, Morag Ryder, Andrew Greenhill, and William Mandy (Apr 10, 2018)

<http://journals.sagepub.com/stoken/default+domain/IAmuFddNNmeCRNV5RWXY/full>

Blog

<https://connection.sagepub.com/blog/psychology/2018/04/17/on-sage-insight-the-prevalence-of-autistic-traits-in-a-homeless-population/>

3: Substance misuse:

Increased Risk for Substance Use-Related Problems in Autism Spectrum Disorders: A Population-Based Cohort Study

Butwicka, A., Långström, N., Larsson, H. *et al.* *J Autism Dev Disord* (2017) 47: 80.

<https://doi.org/10.1007/s10803-016-2914-2>

<https://spectrumnews.org/features/deep-dive/autisms-hidden-habit/>

4: Suicide/Suicidality

This link takes you to a presentation which contains an overview and links to various pieces of research <http://www.nspa.org.uk/wp-content/uploads/2017/02/1b.-Suicide-in-autism.pdf>

5. National strategy refresh

<https://www.gov.uk/government/publications/think-autism-strategy-governance-refresh-2018>