

7.5.3 Adults with Autistic Spectrum Conditions

Why is this issue important?

Autistic Spectrum Conditions (ASC) are developmental disorders and not mental health problems. If they are not identified and diagnosed in childhood, adults with Asperger Syndrome and High Functioning Autism, in particular, can struggle to receive the support they need to lead fulfilling and rewarding lives.¹

Nationally it is estimated that there is a prevalence of 1% amongst adults, with 700,000 adults in the UK having an Autistic Spectrum Condition.²

One of the key issues for adults with Autistic Spectrum Conditions is that without a clear pathway to services they risk falling into the gap between services for people with learning disabilities and services for people with mental health conditions.

The number of people with Autistic Spectrum Conditions in full-time employment is very low, with research suggesting 6% of all people with Autistic Spectrum Conditions are in full-time employment and 12% of those with Asperger Syndrome or High Functioning Autism. At the lower functioning end of the spectrum this falls to an estimated 2% rate of employment.³ This compares with 46% of working age people with disabilities and 76% of working age people with no disability in 2012.⁴

Key outcomes

- **Adults with a learning disability who live in stable and appropriate accommodation (Public Health Outcomes Framework)***
- **Gap in the employment rate between those with a learning disability and the overall employment rate (Public Health Outcomes Framework)***

- **Adults with learning disabilities in stable accommodation (Adult Social Care Outcomes Framework)***
- **Adults with learning disabilities in employment (Adult Social Care Outcomes Framework)***
- **Social care related quality of life (Adult Social Care Outcomes Framework)**
- **Client satisfaction with care and support (Adult Social Care Outcomes Framework)**
- **Enhancing the quality of life for people with long-term conditions (NHS Outcomes Framework)**

**These outcomes will only apply to people with Autistic Spectrum Conditions and a learning disability*

Impact in Brighton & Hove

In 2015 there were an estimated 1,960 adults aged 18-64 years with Autistic Spectrum Conditions in Brighton & Hove.⁵

A third of adults with a learning disability also have an Autistic Spectrum Condition.⁶ In 2015 the estimated number of adults with a learning disability thought to be living in Brighton & Hove was 5,532.⁵ Of these, between 1,106 (20%) and 1,844 (33%) are likely to have Autistic Spectrum Conditions. These figures may be underestimates in view of the large proportion of young people within the city.⁷

In 2014/15 there were 725 people with a learning disability receiving long term support from Brighton & Hove City Council. Applying the estimated rates of adults with a learning disability who also have an Autistic Spectrum Condition to this figure gives an estimate of between 145 and 242 adults with a learning disability receiving long term support from the council who also have an Autistic Spectrum Condition.⁸

¹ Brighton & Hove City Council. Scrutiny panel on services for adults with autistic spectrum conditions. Report of the Adult Social Care and Housing Overview and Scrutiny Panel. March 2011.

² The National Autistic Society, Autism facts and history. Available at: <http://www.autism.org.uk/about/what-is/myths-facts-stats.aspx> [Accessed 20/07/16]

³ Barnard J. Harvey V. Prior A. et al. Ignored or Ineligible: the Reality for Adults with Autistic Spectrum Disorders. The National Autistic Society. 2001.

⁴ Department for Work & Pensions, Disability facts and figures. Available at: <https://www.gov.uk/government/publications/disability-facts-and-figures/disability-facts-and-figures#employment> [Accessed: 20/07/2016]

⁵ Institute of Public Care. Projecting Adult Needs Information System. Available at www.pansi.org.uk and Projecting Older People Population Information System available at www.poppi.org.uk [Accessed: 20/07/2016]

⁶ Emerson E, and Baines S. The Estimated Prevalence of Autism among Adults with Learning Disabilities in England. Department of Health. 2010.

⁷ NHS Brighton and Hove and Brighton & Hove City Council. Adults with Autistic Spectrum Conditions Needs Assessment. 2011.

⁸ NHS Digital, Community Care Statistics, Social Services Activity, England - 2014-15. <http://digital.nhs.uk/catalogue/PUB18663>

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In July 2016, Assert, a local voluntary organisation for people with Asperger Syndrome, were supporting approximately 650 people both with and without formal diagnoses of Asperger Syndrome and High Functioning Autism.⁹ This increased from 300 people in 2010.

Some of the expressed needs identified by the Brighton & Hove Adults with Autistic Spectrum Conditions Survey 2011 included:

- Few respondents felt their GP understood their condition or medication requirements
- They felt less safe during the day or after dark than the general adult population and two-thirds said they had been attacked, intimidated, harassed or robbed and over half of these on more than one occasion
- Concern that they did not meet the eligibility criteria for Adult Social Care and so could not access support. Half of respondents felt they did not receive support to live as independently as they would like.

The Adult Autism Strategy for England (2010) and the Brighton & Hove Adults with Autistic Spectrum Conditions needs assessment (2011), identified needs for improvement in the following areas.¹⁰

- Reviewing the care pathway to speed up the diagnostic process and take account of the needs of people with Asperger Syndrome or High Functioning Autism.
- Opportunities for further education.
- Information and support for adults with autism and their carers.
- Training of mental health, primary care and reception staff in identification and support needs of people with autism.
- Improved transition planning.
- Increased autism awareness amongst employers, police and the criminal justice system.

- Housing provision to reflect the individual needs of people with Autistic Spectrum Conditions.
- Data sharing across appropriate agencies to aid strategic planning.

The ASpire survey of people with Asperger's Syndrome and High Functioning Autism in 2016 identified the need for:¹¹

- Improved support after diagnosis, including accessing health and social care
- Training health and social care staff in understanding reasonable adjustments
- Specialist groups for adults with Asperger's Syndrome and Autistic Spectrum Conditions
- Regular reviews of wellbeing and quality of life
- Accessible online information on autism services.

In addition, whilst we have insufficient data on how people with Autistic Spectrum Conditions access social housing, some feedback from stakeholders suggests there may be potential barriers caused by eligibility criteria.

Where we are doing well

A neuro behavioural service was commissioned and has been in operation since 2013. This service provides assessment and diagnosis for people who may have an Autistic Spectrum Condition.

The Brighton & Hove NHS Clinical Commissioning Group (CCG) is undertaking a psychology led review in 2016 of the support offered by this service post diagnosis.

A Joint Children's and Adults' Autism Strategy is being developed. To support this work a joint stakeholders' group has been established from former separate children's and adults' groups. A work plan is being developed and a report will be taken to the City Council Scrutiny Panel in February 2017 to update on progress.

⁹ Email communication with ASSERT. July 2016.

¹⁰ Department of Health. Fulfilling and rewarding lives. The strategy for adults with autism in England. 2010.

¹¹ Asperger's Impetus Healthwatch full report. Access to Health and Social Care Services March 2016

Conditions

Local inequalities

Autistic Spectrum Conditions are likely to be more prevalent in younger age groups as they were only formally recognised as a group of conditions in the late 1960s.¹² There may be older people who were never diagnosed. The numbers of people estimated to have Autistic Spectrum Conditions are greatest in the 25-44 year old age group (Table 1).

Age Group	Number of people
18-24 years	390
25-34 years	487
35-44 years	421
45-54 years	403
55-64 years	260
Total 18-64 years	1,960

Source: Institute of Public Care. Projecting Adult Needs and Service Information (PANSI) www.pansi.org.uk

*Figures may not sum to total due to rounding

Men are more at risk of developing Autistic Spectrum Conditions than women. Prevalence is estimated to be 1.8% in men and 0.2% in women.¹³ There were an estimated 1,771 men and 189 women with Autistic Spectrum Conditions in Brighton & Hove in 2015.⁶

Predicted future need

The number of people with Autistic Spectrum Conditions is projected to continue to increase and to exceed 2,000 by 2020 (Table 2).

Table 2: People aged 18-64 predicted to have Autistic Spectrum Conditions, by age and gender, projected to 2030, Brighton & Hove

	2015	2020	2025	2030
Males	1,711	1,845	1,899	1,944
Females	189	192	194	197
Total	1,960	2,037	2,093	2,141

Source: Projecting Adult Needs and Service Information (PANSI) www.pansi.org.uk

The number of people aged 25-34 years with an Autistic Spectrum Condition is likely to peak in 2020 and start to decrease thereafter. An increase in 35-44 year olds is expected from 2025.

It is not known how many adults with Autistic Spectrum Conditions currently managed by the mental health services will require on-going support.

It is also hard to predict the number of adults with Asperger Syndrome/High Functioning Autism who do not receive support from Adult Social Care, because they do not meet the existing eligibility criteria, but who still require ongoing support with their daily lives.

What we don't know

We don't have accurate figures for the number of people with Autistic Spectrum Conditions using local services because there has been no statutory requirement to code Autistic Spectrum Conditions on service databases.

Recording has however commenced within the Social Care information system, which will record all non mental health service users. A commitment has been reached to begin coding people on the housing register and for those accessing mental health services.

There is insufficient data available about disability, sexual orientation, ethnicity, gender reassignment or other protected characteristics groups.

Little is known about the prevalence or support needs of older adults with Autistic Spectrum Conditions.

¹² Emerson E, and Baines S. The Estimated Prevalence of Autism among Adults with Learning Disabilities in England. Department of Health. 2010.

¹³ Health and Social Care Information Centre. Autism Spectrum Disorders in adults living in households throughout England: Report from the Adult Psychiatric Morbidity Survey 2007. 2009

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Key evidence and policy

The most recent national policy guidance is the Department of Health: Think Autism: Fulfilling and Rewarding Lives, the strategy for adults with autism in England (2014)

<https://www.gov.uk/government/publications/think-autism-an-update-to-the-government-adult-autism-strategy>

Following the Winterbourne View Scandal, the national Transforming Care Agenda, led by NHS England has developed a new national plan for supporting people with learning disabilities and / or autism.

NHS England: Building the Right Support: A national plan to develop community services and close inpatient facilities for people with a learning disability and / or autism who display behaviour that challenges, including those with a mental health need. 2015

<https://www.england.nhs.uk/wp-content/uploads/2015/10/ld-nat-imp-plan-oct15.pdf>

National Institute for Health and Care Excellence. Autism in adults (CG142). Autism: recognition, referral, diagnosis and management of adults on the autism spectrum. 2012

<https://www.nice.org.uk/guidance/cg142>

Recommended future local priorities

The Joint Children's and Autism Stakeholder Group have identified the following shared priority areas which will inform the development of a future strategy:

1. Improving the experience of people moving through transitions from children's to adult's services.
2. Improving pathways and accessing services in health and social care.
3. Raising awareness and increasing staff training.
4. Improving Information, Advice and Signposting.
5. Supporting families and carers

Key links to other sections

- Education
- Employment and unemployment

- Health in the workplace
- Young offenders
- Crime, anti-social behaviour & safety
- Housing
- Noise pollution
- Emotional health and wellbeing
- Mental health
- Adults with learning disabilities
- Adults with physical disabilities
- Sensory impairments
- Primary care

Further information

Adults with Autistic Spectrum Conditions Needs Assessment. NHS Brighton & Hove and Brighton & Hove City Council. 2011.

<http://www.bhconnected.org.uk/content/needs-assessments>

Adults with Autistic Spectrum Conditions Strategy [http://present.brighton-hove.gov.uk/Published/C00000151/M00003308/AI00023534/\\$Item50AdultswithASCDRAFTvs8app1.doc.pdf](http://present.brighton-hove.gov.uk/Published/C00000151/M00003308/AI00023534/$Item50AdultswithASCDRAFTvs8app1.doc.pdf)

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