

5.1 Children and young people with Autistic Spectrum Conditions

Why is this issue important?

Autistic Spectrum Conditions (ASC) are developmental disorders causing differences in reciprocal social interaction and social communication, combined with restricted interests and rigid repetitive behaviours, often with lifelong impact. People with ASC also frequently experience a range of cognitive, learning, language, medical, emotional and behavioural problems. These problems can substantially affect a person's quality of life, and that of their families and carers, and lead to social vulnerability.¹ ASC is a spectrum which means that, although people with ASC share certain difficulties, their condition affects them in different ways.

People with ASC have high levels of additional needs with 70% having at least one other mental or behavioural disorder and 40% having at least two disorders, most commonly anxiety, Attention Deficit Disorder (ADHD) and Oppositional Defiant Disorder (ODD).²

Preliminary data from a surveillance study conducted in the UK and Republic of Ireland of children and adolescents attending gender identity services showed that 20% had been diagnosed with ASC.³

Children and young people with ASC may be diagnosed at various ages, and this process can be lengthy. Transitioning between primary and secondary school and between children and adults services can cause added worry and disjointed care, this is particularly the case in children without significant learning disabilities who may go from being supported to having nothing on transitioning to adult services.²

Key outcomes

None of the indicators in the Public Health, NHS or Adult Social Care Outcomes Frameworks are specifically focused on ASC.

Impact in Brighton & Hove

There are 59,000 children and young people aged 0-19 resident in Brighton & Hove,⁴ and around 31,550 children and young people attending schools in the city (excluding independent schools).⁵

Prevalence of ASC in the UK is estimated at between 0.2 and 1%,^{6,7} data from the UK General Practice Research Database showed diagnosed prevalence of ASC in 8 year olds of 3.8 per 1,000 boys and 0.8 per thousand girls.⁶ The Special Needs and Autism Project looking at children in South Thames found higher rates estimated at 1% prevalence in 9-10 year olds when children with SEN are screened for ASC.⁵

This means that we would estimate between 118 and 590 children and young people aged 0-19 in the city to have a diagnosis of an ASC at any time, and around 65 to 315 children and young people in Brighton & Hove schools.

Each local authority has a statutory responsibility to hold a register of disabled children. In Brighton & Hove this is The Compass database administered by Amaze, a local parent support CVS organisation. Registration on the Compass is voluntary and there has been a steady increase in the number of registered children with up-to-date records from 1,480 in 2008/09 to 1,908 in 2012/13 (29% increase). The associated incentive leisure/sporting card means the voluntary register has a much higher sign-up than most local authority registers.

⁴ ONS mid-year estimate 2013 aged 0-19 years in Brighton 59,009, rounded in text
<http://ons.gov.uk/ons/taxonomy/index.html?nscl=Population+Estimates#tab-data-tables> accessed 3/10/14

⁵ Schools, Pupils and their characteristics: January 2014. Office of National Statistics, Department for Education local authority and regional tables:SFR15/2014 <https://www.gov.uk/government/statistics/schools-pupils-and-their-characteristics-january-2014> accessed 3/10/14

⁶ Baird G, Simonoff E, Pickles A et al. Prevalence of disorders of the autism spectrum in a population cohort of children in South Thames: the Special Needs and Autism Project (SNAP). *Lancet* 2006 Jul 13;368(9531):201-5

⁷ Taylor B, Jick H, MacLaughlin D. Prevalence and incidence rates of autism in the UK: time trend from 2004-2010 in children aged 8 years. *BMJ Open* 2013;3:e003219 doi: 10.1136/bmjopen-2013-003219

¹ National Institute for Health and Care Excellence. Autism, January 2014. NICE Quality Standard 51 (QS51) <http://guidance.nice.org.uk/qs51>

² Brighton & Hove City Council, Services for Children with Autism Scrutiny Panel report, April 2014 [http://present.brighton-hove.gov.uk/Published/C00000728/M00004870/AI00039830/\\$FinalreportforServicesforchildrenwithautismfinalApril2014withoutDRAFTmarks.doc.pdf](http://present.brighton-hove.gov.uk/Published/C00000728/M00004870/AI00039830/$FinalreportforServicesforchildrenwithautismfinalApril2014withoutDRAFTmarks.doc.pdf) accessed 23/9/2014

³ SN Khadr, P Carmichael, V Holt, et al. Surveillance Study of Gender Identity Disorder in Children and Adolescents. *Arch Dis Child* 2013 98:A1

5.1 Children and young people with Autistic Spectrum Conditions

In July 2014 The Compass had 481 0-19 year olds registered with an ASC, this is the most common diagnosis accounting for 29% of all aged 0-19 registered on the database. Males were more heavily represented with 390 registrations compared to 91 female. Between April 2009 and April 2014 the number of children 0-19 registered on Compass with ASCs has risen by 24%,⁸ in line with the general rise of 0-19 year olds registered on the database. There has been substantial work increasing access to register on the database, which may explain this overall rise.

Nationally, 21% of statements of Special Educational Needs (SEN) are for autism.⁹ In Brighton & Hove there are 185 children with ASC with a statement, representing 18% of children with SEN statement.¹⁰

The Autistic Spectrum Condition Support Service (ASCSS) offers support for state schools with one or more pupils with a diagnosis of an ASC. There are currently 285 pupils with ASC on the diagnosed pupil database of the ASCSS: pupils included are in pre-school settings, and mainstream Primary and Secondary Schools, in Brighton & Hove.¹¹

For an ASC diagnosis in Brighton & Hove children and young people have to be referred by a professional to Seaside View Child Development Centre (Seaside View). The process for assessment has two stages: a general development assessment at stage 1 and a more detailed multi-disciplinary ASC specific clinic at Stage 2. An estimated 86 children were seen from July 2012 - July 2013 and around 64% of these received a diagnosis of an ASC.¹²

Around half (52%) of children with ASC on the Compass database have moderate to profound learning difficulties, the majority of these have

moderate difficulties, at 27.0%, or severe difficulties, at 22.5%.¹³

Where we are doing well

An ASC working group was established in the spring 2013, with representation from parents/carers, the voluntary sector and professionals from education, health (including the Child and Adolescent Mental Health Service (CAMHS)) and social work services. This group has been instrumental in taking forward a partnership approach to developing services for children and young people with ASC.

In April 2014 Brighton & Hove City Council published the Services for Children with Autism Scrutiny Panel report. This examined services for children and young people with autism within Brighton & Hove and included input from parents/carers and service providers. The report laid out 20 recommendations for action around home support, available information, pathways to diagnosis, training and awareness.¹⁴ Responses to the recommendations were accepted by the Health and Wellbeing Board in July 2014.^{15,16}

Local inequalities

Of the 421 children registered with ASC within Brighton & Hove, 390 were male compared to just 91 female, this equates to a ratio of approximately 4:1 male to female, which is what is seen nationally.¹⁷

The Compass database has lower rates of Black or Minority Ethnic Group (BME) represented in 0-19 year olds than seen in the population of Brighton & Hove as a whole, with 17% BME and 83 % White

⁸ Amaze Compass data 2014

⁹ Department for Education, Statistics Children with special educational needs: an analysis – 2013 <https://www.gov.uk/government/publications/children-with-special-educational-needs-an-analysis-2013> accessed 3/10/14

¹⁰ REF Alison's report

¹¹ Figure provided by ASC Support Service on 7/10/14

¹² Brighton & Hove City Council, Services for Children with Autism Scrutiny Panel report, April 2014 [http://present.brighton-hove.gov.uk/Published/C00000728/M00004870/AI00039830/\\$FinalreportforServicesforchildrenwithautismfinalApril2014withoutDRAFTmarks.doc.pdf](http://present.brighton-hove.gov.uk/Published/C00000728/M00004870/AI00039830/$FinalreportforServicesforchildrenwithautismfinalApril2014withoutDRAFTmarks.doc.pdf) accessed 23/9/2014

¹³ Amaze Compass data 2014

¹⁴ Brighton & Hove City Council, Services for Children with Autism Scrutiny Panel report, April 2014 [http://present.brighton-hove.gov.uk/Published/C00000728/M00004870/AI00039830/\\$FinalreportforServicesforchildrenwithautismfinalApril2014withoutDRAFTmarks.doc.pdf](http://present.brighton-hove.gov.uk/Published/C00000728/M00004870/AI00039830/$FinalreportforServicesforchildrenwithautismfinalApril2014withoutDRAFTmarks.doc.pdf) accessed 23/9/2014

¹⁵ Agenda item 16, Health and Wellbeing Board, Brighton & Hove City Council. 29 July 2014

[http://present.brighton-hove.gov.uk/Published/C00000826/M00005481/AI00041396/\\$Item16ResponsetotheScrutinyPanelresponsefinal16714v4GRedit.doc.pdf](http://present.brighton-hove.gov.uk/Published/C00000826/M00005481/AI00041396/$Item16ResponsetotheScrutinyPanelresponsefinal16714v4GRedit.doc.pdf) accessed 3/10/14

¹⁶ Minutes Agenda item 16 Health and Wellbeing Board 29 July 2014

<http://present.brighton-hove.gov.uk/ielssueDetails.aspx?Iid=43067&PlanId=0&Opt=3#AI41396> accessed 3/10/14

¹⁷ Taylor B, Jick H, MacLaughlin D. Prevalence and incidence rates of autism in the UK: time trend from 2004-2010 in children aged 8 years. *BMJ Open* 2013;3:e003219 doi:10.1135/bmjopen-2013-003219

5.1 Children and young people with Autistic Spectrum Conditions

British compared to 22% BME and 78% White British in 0-19 year olds across Brighton & Hove.¹⁸

Predicted future need

The number of children and young people living in Brighton & Hove is predicted to slowly increase and is projected at 62,000 persons aged 0-19 in 2024,¹⁹ compared with 59,000 in 2013. Although there has been a marked increase in diagnosis of ASC in the last 30 years, the numbers have plateaued since the early 2000s so we wouldn't expect much change in prevalence in the coming years.²⁰

Taking the higher estimate of 1% prevalence we would expect 620 people with ASC in this age group. This means there will be a moderate increase of 25 extra young people with ASC in Brighton & Hove in 10 years.

What we don't know

There is not a single definitive database of children and young people with a diagnosis of autism in the city, the reporting through Compass is voluntary, and so does not contain full information regarding local patterns of ASC.

Key evidence and policy

National Institute for Health and Care Excellence (NICE), Autism Quality Standard, Jan 2014 (QS51). This quality standard covers autism in children, young people and adults, including both health and social care services.

<http://guidance.nice.org.uk/qs51>

National Institute for Health and Care Excellence. Autism diagnosis in children and young people (CG128): Recognition, referral and diagnosis of children and young people on the autistic spectrum, September 2011

<http://www.nice.org.uk/guidance/CG128>

¹⁸ Office for National Statistics. Census 2011: Ethnic group by sex by age (Table DC2101EW). Available from <https://www.nomisweb.co.uk/census/2011/dc2101ew> [Accessed 16/09/2014]

¹⁹ ONS 2012 based Subnational Population Projections for Regions in England, 29-May 2014 <http://www.ons.gov.uk/ons/taxonomy/index.html?nscl=Sub-national+Population+Projections#tab-data-tables> accessed 18/9/2014

²⁰ Taylor B, Jick H, MacLaughlin D. Prevalence and incidence rates of autism in the UK: time trend from 2004-2010 in children aged 8 years. *BMJ Open* 2013;**3**:e003219 doi: 10.1136/bmjopen-2013-003219

The NICE pathway for Autism works in line with the guidance:

<http://pathways.nice.org.uk/pathways/autism>

Children and Families Act 2014. This bill aims to make life better for children and young people with SEN. The existing system for Educational Statements, School Action and School Action Plus, will be replaced by a single Education, Health and Care Plan (EHCP) that will remain in place until a young person is 25 years old (up from 18 years at the moment).

<http://www.legislation.gov.uk/ukpga/2014/6/contents/enacted>

There is no national policy specifically in relation to children and young people with ASC. However, The Autism Act (2009) requires each local authority to develop a local autism strategy for the provision of health and social care services for people with autism (aged 14 years and older).

<http://www.legislation.gov.uk/ukpga/2009/15/introduction>

Recommended future local priorities

Summary of Scrutiny Report Recommendations:

- Nominated key workers for all children with ASC
- A pathway for children with autism but neither learning difficulties nor mental health Issues
- Improved home support for families
- CAMHS and Seaside View services to put parents at the heart of their provision
- CAMHS and Seaside View to have open and accountable monitoring frameworks
- Clearer accountability lines for all tiers of CAMHS
- Improve links between Health Visitors and GPs
- All schools take up training to become 'autism aware'
- All Governing Bodies to undergo SEN training and be given copies of Scrutiny Report
- Consideration to be given to increasing funding of ASC support service

5.1 Children and young people with Autistic Spectrum Conditions

- Monitoring of all relevant plans and strategies including those for transition to adulthood
- Appoint an Autism Champion
- ASC working group to oversee Scrutiny Panel recommendations
- Joint Strategic Needs Assessment (JSNA) to include a section on children with autism
- Creation of a youth club for young people with autism

Key links to other sections

- Children and young people with disabilities
- Adults with Autistic Spectrum Conditions
- Education

Further information

Services for Children with Autism Scrutiny Panel report, April 2014:

[http://present.brighton-hove.gov.uk/Published/C00000728/M00004870/AI00039830/\\$FinalreportforServicesforchildrenwithautismfinalApril2014withoutDRAFTmarks.doc.pdf](http://present.brighton-hove.gov.uk/Published/C00000728/M00004870/AI00039830/$FinalreportforServicesforchildrenwithautismfinalApril2014withoutDRAFTmarks.doc.pdf)

Draft Plan for families and children with ASC. Working in Partnership to meet the needs of children and Young People with Autism in Brighton & Hove 2013-2017. 'Better outcomes, better lives' Response to the scrutiny panel report: Services for Children with Autism, this was the report taken to the Health and Wellbeing Board:

[http://present.brighton-hove.gov.uk/Published/C00000826/M00005481/AI00041396/\\$Item16ResponsetotheScrutinyPanelresponsefinal16714v4GRedit.doc.pdf](http://present.brighton-hove.gov.uk/Published/C00000826/M00005481/AI00041396/$Item16ResponsetotheScrutinyPanelresponsefinal16714v4GRedit.doc.pdf)

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