

Swindon Joint Strategic Needs Assessment Bulletin

Autism Spectrum Disorders (ASD) 2020



Key Points

- A national epidemiological survey suggests for England a prevalence of ASD of 1.2% in 5 to 19 year olds
- School-based figures (Jan 2019) indicates that 2.4% of school pupils in Swindon have ASD as a primary or secondary Special Educational Need (SEN)
- But our most reliable comparison, using school-based figures for England shows less disparity, 1.62% for England and 1.99% for Swindon for ASD as primary need (5 to 19 year olds, Jan 2019)
- In all 622 children were recognised as having ASD as a primary SEN in state-funded schools in Swindon in 2018, 11% of children with SEN
- We estimate that there are 1,480 adults with ASD in Swindon
- The Adult Autism Diagnostic Service in Swindon is experiencing high demand
- In 2018/19 the service received 182 referrals; wait times averaged 97 weeks
- Service-users and their carers have highlighted: long wait times before and after diagnosis, difficulties coping while waiting for a diagnosis, lack of clarity of information given by professionals, problems obtaining help for problems such as anxiety in children, a gap between CAMHS (NHS) and TaMHS (SBC)
- Recommendations include: a greater number of people with ASD including young people and their carers to be on the ASD Partnership Board; continuing to support GPs in understanding ASD and the new local pathway; aiming at maximum three month's waiting time to diagnostic decision for children and adults
- A new Recommendation is to commission pathways for both children and adults to make accessing mental health support from CAMHS and AWP more straightforward

What is JSNA?

JSNA helps us to understand: what we know about the current health of local people, how their needs are being met, what we think their future needs are likely to be, and how their needs can best be met. The JSNA process involves many different partners and is overseen by Swindon's Health and Well-Being Board. Understanding Swindon's changing population, the factors that affect health and well-being, the town's assets and the implications for future services are vital in setting priorities and planning future services. This JSNA Bulletin examines the topic of Autism Spectrum Disorders.

Introduction

Autism Spectrum Disorders also sometimes referred to as autism, are developmental disorders characterised by impaired social interaction and communication, severely restricted interests, and highly repetitive behaviours. However, people with ASD can be helped to enjoy safer, healthier, more sociable, more creative and happier lives.

This JSNA Bulletin gives an overview of the prevalence of Autism Spectrum Disorders (ASD) in Swindon UA, the services which are available, the experiences of local people with ASD and of their carers, together with refreshed recommendations for action in the future.

Introduction (Continued)

Swindon has a multi-agency ASD Partnership Board. The Board has produced the Swindon Adult Autism Strategy for 2015-2018. This will be revised and extended in 2020 to include children and young people. Accordingly the scope of the full JSNA and this more concise JSNA Bulletin includes children and young people, as well as adults.

Children and Young People

A key national epidemiological survey suggests that the prevalence of ASD is 1.2% among 5 to 19 year olds, that is 1.9% among boys and 0.4% among girls. Data from the local school census (January 2019) indicates that 2.4% of school pupils (of statutory school-age) in Swindon have ASD as a primary or secondary Special Educational Need (SEN), so nearly double the expected rate.

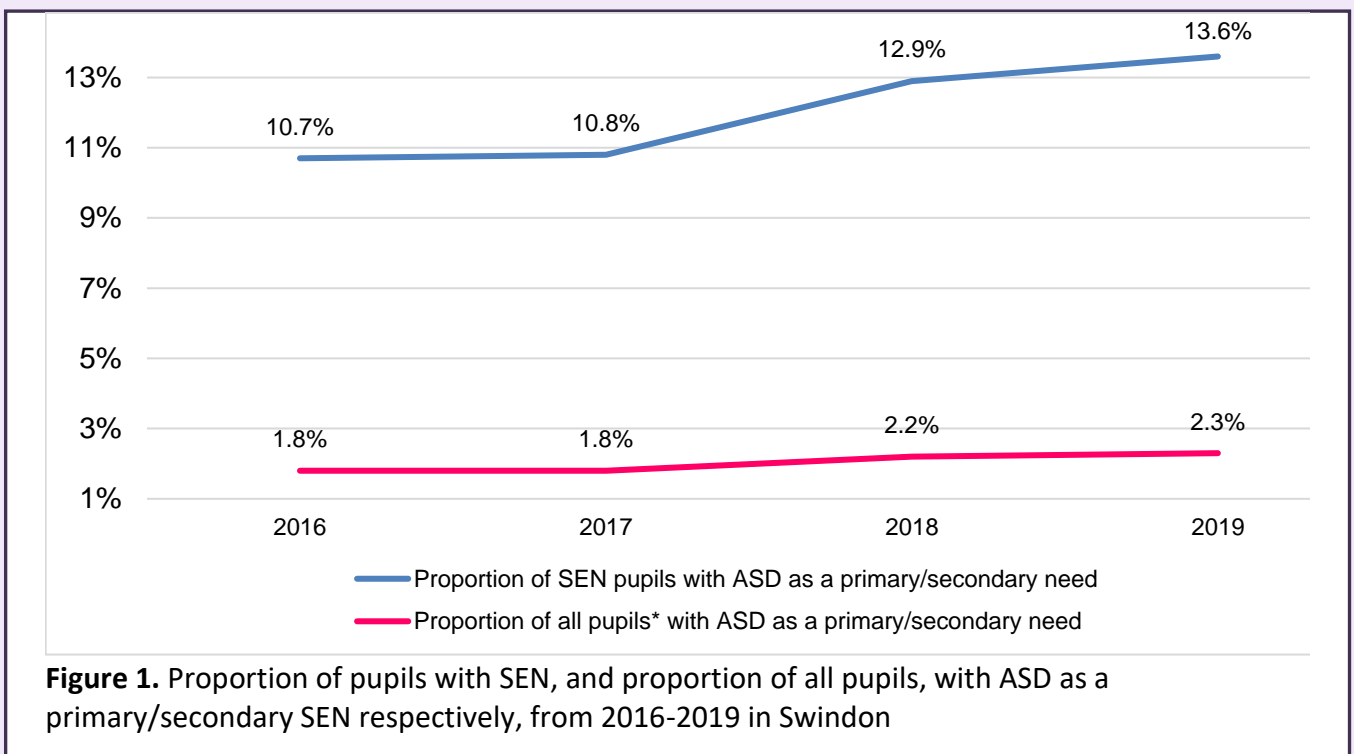
However, the prevalence from the school census for all-England also appears to be higher than the national survey would predict. In January 2019 1.62% of school-children in England had ASD recorded as a primary need compared with 1.99% in Swindon schools.

Thus, Swindon's school prevalence is higher than we might anticipate, but the disparity with the all-England situation is not as great as it might seem at first glance.

In all, 622 children were recognised as having ASD as a primary SEN in state-funded schools in Swindon in 2018, 11% of children with SEN. Just over a half of pupils with ASD as a primary SEN in Swindon have an Education, Health and Care Plan (EHCP), delivering intensive support. Some children with ASD come from outside the resident Swindon population, but this in itself makes only a small contribution to raising the Swindon rate.

As Figure 1 shows, the proportion of SEN pupils in Swindon with ASD as a primary or secondary need, has been rising since 2016.

Initial referrals from health/education professionals are made to the Community Paediatric ASD Assessment Clinic at Great Western Hospital. Wait times at mid-2019 averaged 21 weeks for children aged 5+ years. But some may have waited about three times as long as the average, and conceivably even longer.





Adults

At present we cannot directly record the number of adults with ASD in Swindon UA. However, the national Adult Psychiatric Morbidity Survey predicts a prevalence of 0.8% in people aged 16 years and over, 1.5% in males and 0.2% in females. Thus we would currently expect 1,303 males and 177 females to have ASD in Swindon, 1,480 adults in total.

Swindon Adult Autism Diagnostic Service (which is part of Avon and Wilts Partnership, NHS Mental Health Trust or AWP) is commissioned to carry out autism assessments for adults aged 18+ who live in Swindon. The Adult Autism Diagnostic Service is currently experiencing high demand. In 2018/19 the service received 182 referrals (15 a month), a rise from 135 in 2017/18, which means that the monthly demand is twice the capacity of the service.

Waiting times are currently averaging 97 weeks. The rate of positive diagnoses is higher for people from more deprived areas.

SBC does not provide any specialist services for adults with ASD, but adults with ASD can access a range of social care services, including direct payments, support to find appropriate housing, domiciliary care, residential care, supported living and support to manage health and wellbeing needs. Third sector organisations that provide support locally include DASH (Discovering Autistic Spectrum Happiness), Swindon Advocacy Movement (SAM), and Wiltshire Autism Alert Card Scheme. Mental health services for adults with ASD who also have mental health conditions are provided by AWP; current wait times are reported by AWP to be very low.

Local Views on services and support available for people with ASD

Consultation with parents of children with ASD in June 2019

In June 2019, SBC Public Health and Swindon CCG jointly ran a consultation with parents of children with ASD, which was attended by six mothers. The questions focused on experiences of the assessment and diagnostic process, and of accessing health and care support. The perspectives and experiences that emerged from the feedback gathered at this consultation are highlighted below as a series of main themes:

Assessment and diagnostic process

- Getting a diagnosis is crucial to accessing services and support.
- Wait times for assessment and diagnosis are long, and this can be detrimental to parents' physical and mental health (e.g. leading to anxiety, depression, high blood pressure). Participants reported variable wait times for assessment, ranging from 6 to 8 weeks, to 4 years at the extreme. For most, a range of one year to 18 months was reported.
- There is no signposting or support offered while parents are waiting for an assessment for their child. However, one participant mentioned that 'Koalas' (a nursery for children aged 0 to 5 years with special needs) helped to put speech and language support in place for her child while she was waiting for an assessment.
- Following an assessment, paediatricians give parents a sheet with a list of useful organisations and contacts. However, more information is needed about what the organisations and services actually do. Parents may find it difficult to absorb information at the initial assessment appointment and it would be beneficial to be able to contact someone after diagnosis for advice.

- The access offered to further health and care support depends on a number of factors such as the paediatrician undertaking the initial assessment, the child's more obvious needs, and how the child presents on the day of the assessment appointment.

Accessing health and care support

- After assessment and diagnosis, there are long waiting times (usually 12 to 18 months) to access health and care support.
- Participants said that once they received the support it worked well; they praised the Occupational Therapy (OT) service, the disability section of the speech and language therapy service, and the Early Bird, Early Bird Plus and Cygnet parenting courses. They said that these parenting courses are very valuable for families because they give parents strategies and tools to manage the child at home, and the opportunity to meet other parents and make friends.
- Participants with children in special schools and nurseries found it relatively easy to access support, as this can be done directly through the schools and nurseries. For participants whose children are not in special schools, it is not easy to access ongoing support; the best way to do so is through social services.
- In terms of improving the support that is currently available, participants emphasised the following:

Reducing wait times, providing more help with transitions (between schools and services), providing more signposting and information on services, support groups, and entitlements (e.g. Disability Living Allowance for children, council tax relief), providing access to useful information such as this in one place, providing more support for mental health problems, especially anxiety in children and young people with ASD.

More mental health support for anxiety needed

- Participants said that anxiety is a major issue for children with ASD and it is difficult to obtain support for this.
- They said that it is very difficult to access support from Child and Adolescent Mental Health Services (CAMHS) for anxiety alone. One participant's son was receiving support from CAMHS-Learning Disability for 'violence'; the underlying issue was in fact anxiety, but he would not be given support if the referral were for anxiety alone.
- The criteria used by CAMHS are considered problematic by some parents, because children with ASD do not necessarily fit in well with a set of criteria.

Special Educational Needs and Disabilities Parent/Carer Focus Groups in Feb. 2019

The Director of Children's Services at SBC held two sessions in February 2019 for parents and carers to provide feedback on their experiences with Special Educational Needs and Disability (SEND) services in the local area. The sessions were facilitated by the chair of Swindon SEND Families' Voice. Swindon SEND Families' Voice is the Council's strategic partner in consulting with parents and carers of children with SEND.

- Findings from these consultations also emphasised that wait times for neuro-developmental assessments and for mental health support from CAMHS are too long, leading to unmet needs and in some cases, to crises.
- It was also highlighted that the gap between Targeted Mental Health Services (TaMHS) and CAMHS is too large, resulting in children 'falling between the cracks' of these two services.

- Parents said the national shortage of Speech & Language therapists, occupational therapists and educational psychologists is having an impact.

Healthwatch Swindon survey results for adults with ASD in April 2019

Healthwatch Swindon conducted a number of focus groups and surveys in March and April 2019 to gather information on local people's experiences of NHS services and support; this was part of Healthwatch Swindon's engagement programme to inform implementation of the NHS Long Term Plan. As part of this programme, survey data were gathered from five Swindon residents with autism, both males and females, with ages ranging from 18 to 44 years. Some key themes that emerged from their responses are given below, though a future survey, devoted to ASD and with a larger sample, would be warranted:

- Long waiting times for assessment and diagnosis have been experienced and can be detrimental to mental health. More mental health support and easier access to such support is needed; one respondent said that it took a suicide attempt before they received the support they needed through CAMHS.
- When asked to rate their overall experience of receiving help, there was a wide range in responses from very positive to very negative, with two people saying it was average.
- Most respondents found it relatively easy to access support after diagnosis.
- Respondents said that care could be improved by ensuring that oral and written communications are easier to understand and avoiding the use of jargon.

Updated Recommendations for 2020 (Recommendations 1 to 10 from previous JSNA refreshed and updated, with addition of new Recommendation 11)

Updated Recommendation 1:

Ensure that the present needs assessment is used to inform the planned refresh of the Autism Strategy, and that people with ASD and their carers are consulted as part of the process of refreshing the strategy.

Updated Recommendation 2:

Ensure there is greater representation of people with ASD, including young people, and their carers on the ASD Partnership Board. Consider working with New College in Swindon to involve more young people with ASD in Board meetings.

Updated Recommendation 3:

In line with the objectives of the Self Assessment Framework (SAF) 2018 Improvement Plan, improve communication between Children's Services and Adult Social Care services and data collection concerning young people with ASD transitioning to adulthood.

Updated Recommendation 4:

Develop partnerships with key ASD organisations in the voluntary sector (e.g. the National Autistic Society, and DASH) to promote access to and maximise the impact of community-based support and activities for adults and children with ASD.

Updated Recommendation 5:

Ensure that comprehensive, up-to-date and accessible information about services and support for adults and children with ASD is continuously provided on SBC's new Local Offer website (launched in autumn 2019).

Updated Recommendation 6:

Put arrangements in place to ensure regular reporting from AWP on the delivery of ASD training. Once this intelligence gap has been addressed, identify training needs among agencies and health and social care professionals in Swindon.

Updated Recommendation 7:

Continue to work with GPs who are the gatekeepers to diagnostic services for adults and some children, to ensure they have adequate training and information available so that they have a good understanding of the whole autistic spectrum and the new local diagnostic pathway and how to refer.

Updated Recommendation 8:

Continue to work towards achieving best practice as recommended by NICE for access to diagnostic services, where both adults and children seeking an autism diagnosis have a first appointment within three months of their referral. Put arrangements in place to ensure that adults and parents of children seeking a diagnosis are signposted to services and support while they are waiting for an assessment. The Council's new Local Offer website is a key resource as an instrument for signposting.

Updated Recommendation 9:

In line with the objectives of the Self-Assessment Framework (SAF) 2018 Improvement Plan, form a multi-agency working group to drive forward improvements in data collection and data sharing on health and social care improvements in data collection and data sharing on health and social care.

Updated Recommendation 10:

Ensure that the needs of young people and adults with ASD are advocated in the implementation of the action plan associated with the Supported Employment Strategy for Swindon 2018-2022.

One new, additional recommendation regarding mental health support is made here based on the findings of the present needs assessment:

Engagement work with parents of children with ASD and with adults with ASD, presented earlier in this bulletin has highlighted the need for more mental health support, especially for anxiety, and easier access to such support for both children and adults with ASD. The most recent Adult Psychiatric Morbidity Survey showed that adults with ASD are less likely than those without ASD to use health services for a mental or emotional reason. This is probably due to a lack of recognition of the mental health needs, such as anxiety and depression, of people with ASD.

The ASD Partnership Board recognises the need for mental health support for people with ASD and has included the following objective in the Self-Assessment Framework (SAF) 2018 Improvement Plan: People with Autism need to be able to access local mental health services after they have been diagnosed and have a clear pathway made available to them.

In line with this objective, the new recommendation below is made as part of the present needs assessment:

New Recommendation 11:

Commission services as appropriate and develop specific pathways for children and adults with ASD in order that they might access mental health support from CAMHS and AWP respectively.





Concluding Remarks

A number of issues were beyond the scope of the JSNA Report and this bulletin and so could not be addressed. These include the fuller social implications of ASD including participation in society, school exclusion, the possible effects on health and life-span of ASD, some of the complex education needs of young people with ASD, especially those in young people beyond statutory school age, and the ramifications for services of ageing in people with ASD,

Swindon's multi-agency ASD Partnership Board contributes valuable insights and plays a pivotal role locally. It is now due to revise and extend its existing ASD strategy to include children and young people, informed by the findings of this 2020 JSNA Report and Bulletin.

Acknowledgements

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Where to find more information

More information about all Swindon's JSNAs can be found on the JSNA website, where the full JSNA for ASD can also be found: <http://www.swindonjsna.co.uk/>

If you have any queries (or would like to contribute to needs assessment activities in Swindon) please contact: JSNA@swindon.gov.uk

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