Autism Spectrum Disorders in Swindon
Joint Strategic Needs Assessment

Public Health/Swindon Borough Council, ASD Partnership Board, Swindon CCG, Avon & Wilts Partnership (MH NHS Trust)

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Glossary of Key Abbreviations

AADS	Adult Autism Diagnostic Service (part of AWP)
APMS	Adult Psychiatric Morbidity Survey
ASD	Autism Spectrum Disorders
AWP	Avon and Wilts Partnership (Mental Health NHS Trust)
CAMHS	Child and Adolescent Mental Health Services
DASH	Discovering Autistic Spectrum Happiness (Local support Group)
EHCP	Education, Health and Care Plan
PCLS	Primary Care Liaison Service (part of AWP)
SASS	Swindon Autism Support Service
SEN	Special Educational Needs
SEND	Special Educational Needs & Disability
TaMHS	Targeted Mental Health Services

Executive Summary

Introduction

- This JSNA Report gives an overview of the prevalence of Autism Spectrum Disorders (ASD) in Swindon UA, the services available, the experiences of people with ASD and their carers, together with progress on previous re-commendations, and refreshed recommendations for the future.
- Autism Spectrum Disorders (ASD), 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.
- Swindon has a multi-agency ASD Partnership Board. The Board has produced the Swindon Adult Autism Strategy for 2015-2018. This is due to be revised and extended in 2020 to include children and young people, and accordingly the scope of this present JSNA 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 5-19 year olds, 1.9% among boys and 0.4% among girls.
- Data from the 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 school-based prevalence from the school census for all-England also appears to be higher than the national survey would predict. 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.
- The proportion of SEN pupils in Swindon with ASD as a primary or secondary need, has been growing since 2016.
- Just over a half of pupils with ASD as a primary SEN in Swindon have an Education, Health and Care Plan (EHCP), which delivers 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.
- 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 longer.
- Work was underway in 2019 to re-design the ASD assessment and diagnostic pathway for children in Swindon. Existing support includes a range of services from Swindon Borough Council, such as Swindon Autism Support Service

(SASS), Early Bird, Cygnet Group, and Aiming High, as well as the Child and Adolescent Mental Health Services (CAMHS) provided by the NHS.

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 & Wilts Partnership NHS Mental Health Trust) is commissioned to carry out autism assessments for adults aged 18+ who live in Swindon. The Adult Autism Diagnostic Service experiences high demand and lack of resources to meet it.
- In 2018/19 the service received 182 referrals (15 a month), a rise from 135 in 2017/18. In late 2019 waiting times were averaging 97 weeks and 176 people were waiting. The rate of positive diagnoses is higher for people from more deprived areas.
- The LIFT Psychology service, part of AWP, provides more general support to adults experiencing mental health difficulties such as anxiety, low mood and stress. The LIFT service frequently sees people with ASD, but the number of people with ASD is not recorded systematically because of workload issues.
- 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 the Wiltshire Autism Alert Card Scheme.
- Mental health services for adults with ASD who also have co-morbidities, (i.e. additional mental health conditions) are provided by AWP; current wait times are reported to be very low.

Views of local people on services and support available for people with ASD

- Parents with children with ASD have raised issues concerning: long wait times before and after diagnosis, coping while waiting for a diagnosis, the clarity of information given to them at various points, the gap while waiting for a diagnosis, transitions between services, obtaining help for problems such as anxiety in their children; once a child was ‘in the system’, support given was generally deemed to be of good quality.
- Parents and carers for children with SEND (Special Educational Needs and Disabilities) have emphasised problems with: long wait times for neuro-developmental assessments and for mental health support from CAMHS, a gap between Targeted Mental Health Services (TaMHS) and CAMHS resulting in children falling between these two services; the national shortage of Speech

and Language therapists, occupational therapists and Educational Psychologists was also felt to be having an impact on children with ASD.

- Adults with ASD have also stressed issues concerning: accessing mental health services, the long wait times for assessment and diagnosis that have been experienced, use by professionals of excessively technical language in oral and written communications; however, once a diagnosis had been made, adults with ASD said it became easier to access services.

Updated Recommendations

Recommendations for further action as updated in this JSNA include:

- Ensuring that the present needs assessment is used to inform the planned refresh of the Autism Strategy…
- Ensuring that there is greater representation of people with ASD, including young people and their carers on the ASD Partnership Board…
- Continuing to work with GPs as gatekeepers to diagnostic services for adults,and sometimes for children, to ensure they have adequate training and information available to understand the whole autistic spectrum and the new local diagnostic pathway…
- Continuing to work towards achieving the NICE best practice standard for access to diagnostic services, with both adults and children seeking an autism diagnosis having a first appointment within three months of their referral…
- Commissioning services as appropriate and developing specific pathways for children and adults with ASD in order that they might more easily access mental health support from CAMHS and AWP respectively.

1. Introduction

Background

Health needs assessment is a systematic method of identifying unmet health needs of a population, with the goal of informing the planning and commissioning of health, well-being and social care services within the local authority area. The overall goals of health needs assessments are to improve health and reduce health inequalities.

A Joint Strategic Needs Assessment (JSNA) is a type of health needs assessment that is commonly co-produced by a number of partners with a focus on longer-term strategic issues. The local Health and Wellbeing Board has a statutory obligation to produce regular JSNAs which must describe the current and future health, well-being and social care needs of the local population.

Autism spectrum disorders (ASD), also sometimes referred to as autism, are developmental disorders characterised by impaired social interaction and communication, severely restricted interests, and highly repetitive behaviours (NHS Digital, 2016). Autism is neither a learning disability nor a mental health problem, although both of these are more common among people with autism. Autism occurs early in a person's development and is a lifelong condition. People with autism may also experience some form of hypersensitivity or lack of sensitivity. For example, different sounds, smells, lights or colours or other sense impressions can have an impact on how people experience, and cope with, different environments. Autism is regarded as an impairment for children and adults under the Equality Act 2010 and the legislation stipulates that reasonable adjustments must be made for them.

Autism affects people in different ways. Some can live independently without any additional support, while others require a lifetime of specialist care. However, the outlook need not be a negative one. With appropriate and timely support, people with ASD can be helped to enjoy safer, healthier, more sociable, more creative and happier lives. These are the objectives of organisations such as DASH (Discovering Autistic Spectrum Happiness) Swindon, for example, an independent local charity whose mission is to improve the quality of life of adults of working age with high-functioning ASD. The clubs and social and events organised by DASH play an active role in contributing to the well-being of people with ASD (https://www.dashswindon.com). It is also worth noting that some people with ASD regard their autistic traits as a valuable part of their personality, something that contributes to their creativity and gives them a unique perspective on the world.

Policy context

Autism is a national priority. In 2009 the Autism Act was passed to make provision for meeting the needs of adults with autistic spectrum conditions, and the publication of a national autism strategy followed in 2010, 'Fulfilling and rewarding lives: the strategy for adults with autism in England'. An update to this strategy, namely 'Think Autism', was published in 2014 (HM Government, 2014). In 2019, the Department of Health and Social Care and the Department for Education has again been reviewing the 'Think Autism' strategy and intends to extend it to cover children as well as adults.

The vision of the national autism strategy is that:

'All adults with autism are able to live fulfilling and rewarding lives within a society that accepts and understands them. They can get a diagnosis and access support if they need it, and they can depend on mainstream public services to treat them fairly as individuals, helping them make the most of their talents.'

Swindon has a multi-agency ASD Partnership Board as recommended by the national strategy. The Board has produced the Swindon Adult Autism Strategy 2015-2018, which is due to be refreshed and expanded in 2020 to include children and young people. The local strategy sets out seven key priorities to improve the health and wellbeing of adults with ASD living in Swindon, which are based on national policy priorities and also local needs as identified by the 2015 Adult Autism Needs Assessment. The seven priorities are:

- Evidence-led planning, commissioning and service provision
- Training and awareness-raising to improve understanding of autism amongst professionals and the public
- Ensuring that the right support for people with autism in Swindon is available at the right time during their life-course
- Transition planning and support for young people with autism as they prepare for adulthood
- Employment and learning opportunities for adults with autism
- Working with the criminal justice system so that it takes account of the needs of people with autism
- Housing and support for people with autism so they can live independently

Aims and structure of the 2020 ASD Joint Strategic Needs Assessment

As mentioned above, in 2015, an Adults Autism Needs Assessment was published in Swindon, which informed the Adult Autism Strategy for 2015-18.

Periodically, local autism strategy groups are required to carry out an Autism Self-Assessment to monitor their progress in implementing the government's 'Think Autism' strategy, in partnership with local residents with autism and their family and carers. One of the actions arising from the 2018 self-assessment in Swindon was a decision to refresh the previous needs assessment.

Hence, the main aims of this present Joint Strategic Needs Assessment are to update the 2015 Adult Autism Needs Assessment for Swindon, and additionally to assess the needs of children and young people with ASD.

The specific objectives of the 2020 ASD Joint Strategic Needs Assessment are as follows:

- To provide an up-to-date overview of the prevalence of autism among children and adults in the population of Swindon Unitary Authority (UA)
- To assess current service provision for children and adults with autism and identify gaps in provision
- To present information gained through consultations with parents of children with ASD in February and June 2019 and through consultation carried out by Healthwatch in April 2019 with adults with ASD on services and support available in Swindon
- To provide a progress update on the recommendations of the 2015 Adult Autism Needs Assessment
- To set forth revised or new recommendations for future work to improve the lives of children and adults with ASD in Swindon

Accordingly, the 2020 JSNA is divided into six main sections:

1. Introduction
2. Children and Young People with ASD in Swindon
3. Adults with ASD in Swindon
4. Views of local people on services and support available for ASD in Swindon
5. Recommendations, with progress on previous recommendations, and revised or new recommendations
6. Concluding Remarks

The respective chapters on adults and children both review prevalence estimates as well as service provision. In relation to the latter, information is presented on the assessment and diagnostic pathway, on ASD-specific services available from Swindon Borough Council (SBC), the NHS children's services, the third sector, and on NHS mental health services. Apart from assessment and diagnostic services, there are no ASD-specific services provided by the NHS.

Mental health service use is the focus of this present needs assessment, however, because of the greater burden of mental ill-health among adults and children with ASD. For instance, about 40% of people with ASD have symptoms of at least one anxiety disorder at any time, compared with about 15% of the general population (National Autistic Society, 2019). Similarly, more than 7 out of every 10 children with ASD are thought to have a co-occurring mental health problem (South West Children and Young People's Mental Health Strategic Clinical Network, 2018).

2. Children and Young People with ASD in Swindon

Prevalence of ASD among Children and Young People in Swindon: National prevalence estimates

Autism or ASD is diagnosed by a clinical assessment, usually involving a team of professionals. For children the team will include an educational specialist and a psychologist, for example. ASD is not routinely screened for in any way or diagnosed by genetic testing.

The NHS Mental Health of Children and Young People survey is the most reliable national profile of child mental health available; it is an epidemiological, population-based survey which identifies both diagnosed and undiagnosed mental health disorders (NHS Digital, 2018). The most recent survey, conducted in 2017, had a representative sample of over 18,000 children and young people, drawn from the NHS Patient Register for England.

The results indicate that the prevalence of ASD is 1.2% among 5-19 year olds (with a 95% confidence interval (CI) of 0.9%-1.4%), with the prevalence among boys (1.9%) over 4 times higher than that among girls (0.4%). The survey was first carried out in 2004. Comparing the results of the 2004 and 2017 surveys suggests that the prevalence of ASD in 5-15 year olds has remained fairly stable (1.0% in 2004 versus 1.3% in 2017). Table 1 below shows the prevalence estimates from the 2017 epidemiological survey and gives the expected counts for Swindon, calculated by applying the national prevalence estimates to our local population figures.

Table 1. National prevalence estimates of ASD among 5-19 year olds from the 2017 Mental Health of Children and Young People survey and expected counts for Swindon

Group	Estimated prevalence of ASD	Expected count for Swindon
Boys aged 5-19 years	1.9%	387
Girls aged 5-19 years	0.4%	78
Population of 5-19 year Olds	1.2%	465 (sum of above)

Sources: NHS Digital, 2018, ONS 2017 mid-year population estimates

The gender gap in prevalence of ASD has long been recognised; however, recently, questions have been raised about whether ASD may be under-diagnosed among females (NHS Digital, 2018). This could be the case for a number of reasons, including biased assessments by clinicians and other professionals due to a male 'stereotype', or it could be that girls with autism present differently to boys. In relation to the latter point, girls typically have higher levels of social skills and it may be that thresholds for social skills deficits applied for recognition of autism may be appropriate for boys, but too low to identify girls with ASD, who are functioning far below their female 'neurotypical' peers (NHS Digital, 2018).

Prevalence of ASD among Children and Young People in Swindon: estimates based on School and Special Educational Needs (SEN) data

ASD is known to be strongly associated with the presence of learning disabilities; research suggests that 60-70% of people with ASD will also have a learning disability (Mental Health Foundation, 2019). Linked with this, the majority of children with ASD have special educational needs (SEN). The 2017 Mental Health of Children and Young People survey found that, although the prevalence of ASD is 1.2% among the general population aged 5-19 years, only 0.1% of children without SEN have ASD. Thus SEN data from local authorities is a key source of data for the local prevalence of ASD in Children and Young People, although care must be taken in making comparisons.

Local data from the school census of January 2019 suggests that 2.4% of school pupils[1] (of statutory school-age) in Swindon have ASD as a primary or secondary SEN; this is almost double the national epidemiological prevalence rate of 1.2% observed in children aged 5-19 years.

However, the school-based prevalence in England as a whole also appears to be notably higher than the national epidemiological survey would predict. If we focus on ASD as a primary need only, data from the school census indicates that in 2019, the proportion of pupils recorded as having ASD as a primary SEN in state-funded primary, secondary and special schools in Swindon was 1.99%, compared to 1.62% for England as a whole (Dept for Education, Special Educational Needs tables, January 2019.) The same source also suggests that the England level comes even closer to the Swindon levels, if ASD as a secondary need is taken into account.

To summarise, then, the school-based prevalence of ASD in Swindon is much higher than the national epidemiological survey predicts, but the same is true of the school-based prevalence of ASD in England as a whole. In other words, Swindon's school-based prevalence is higher than we might anticipate, but the true disparity with England as a whole is not nearly as great as it might seem at first glance.

With regard to the higher rate in Swindon, it is conceivable that local specialists may be more inclusive when diagnosing ASD in children in a 'real-life' service than were

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[1] This Swindon school census prevalence is based on children from reception year to year 11 only, as this is the most robust measure. School census data for Swindon includes children attending a Swindon school, irrespective of whether they are Swindon residents; Swindon resident children who go to school outside of Swindon are not included.

the researchers who conducted the national survey in a more academic context. The same might also apply to specialists in services in England as a whole.

Table 2 gives the number of pupils and the proportion of SEN pupils with ASD as a primary SEN in state funded schools in Swindon in 2018. In all, 622 children were recognised as having ASD as a primary SEN in state-funded schools in Swindon.

Some of these children actually came from outside the resident Swindon population, that is, from local authority areas that are neighbouring to Swindon and their parents might have been attracted by the educational facilities in Swindon. Yet even if so, this would in itself make only a small contribution to the higher than anticipated figures. The rate of any SEN and the rate of ASD (as a primary need) were only slightly higher in children who came across the border into Swindon than in children resident in Swindon; local data based on postcodes suggest that there were probably only about 11 more children with any SEN and only about 5 more children with ASD (as a primary need) coming in from neighbouring areas than we might have anticipated by making a statistical prediction.

Table 2 Number and proportion of SEN pupils in state funded schools in Swindon in 2018 with ASD as a primary SEN

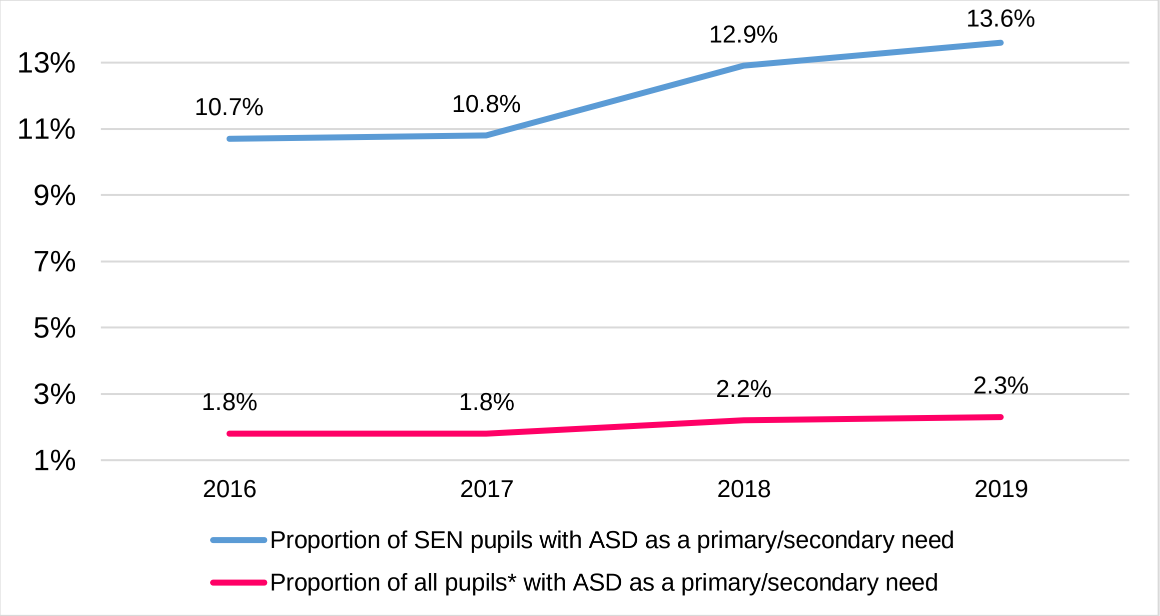
Type of school (all state-funded)	Number of pupils with ASD as a primary SEN	Proportion of all SEN pupils with ASD as a primary need
Primary	238	7.4%
Secondary	191	10.6%
Special	193	32.1%
Total across all types of schools	**622**	**11%**

Source: Department for Education, 2018

Just over a half of pupils with ASD as a primary SEN have an Education, Health and Care Plan (EHCP); this is a legal document for those children and young people aged up to 25 years who need more intensive SEN support than is typically available through mainstream educational settings. An EHCP identifies the child or young person's special educational, health and social care needs and the support needed to meet those needs. Local data for 2019 shows that nearly 30% of children and young people with EHCPs in Swindon have ASD recorded as a primary need.

The proportion of all school pupils in Swindon with ASD as a primary or secondary SEN, and the proportion of SEN pupils with ASD as a primary or secondary need, has been growing since 2016, as illustrated in Figure 1 below.

Figure 1 Proportion of pupils with SEN, and proportion of all pupils, with ASD as a primary/secondary SEN respectively, from 2016-2019 in Swindon



*all pupils refers to all children attending Swindon schools, including nurseries and sixth forms that are part of schools and Education other than at school, but does not include Further Education colleges

Characteristics associated with ASD

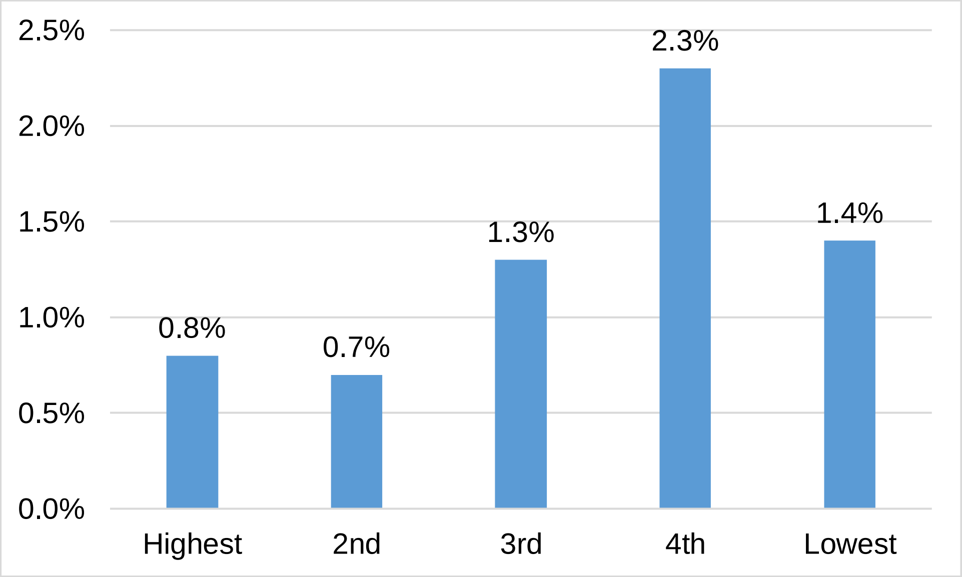
The 2017 Mental Health of Children and Young People survey indicated that certain characteristics are associated with ASD; children and young people with these characteristics are more likely to have ASD, although people without these features may also have ASD. The characteristics are: male gender, White British ethnicity, having special education needs, fair, bad or very bad self-reported general health (physical and mental health), parental psychological distress, 'Unhealthy' family functioning (assessed with the McMaster Family Activity Device), low-income households or parental receipt of low income or disability benefits.

ASD is known to be strongly associated with the presence of learning disabilities. Research suggests that 60-70% of people with ASD will also have a learning disability (Mental Health Foundation, 2019). Linked with this, the vast majority of children with ASD, as implied above, have special educational needs (SEN); the 2017 Mental Health of Children and Young People survey found that, although the prevalence of ASD is 1.2% among the general population of those aged 5-19 years, only 0.1% of children without SEN have ASD.

ASD and socio-economic deprivation

The 2017 Mental Health of Children and Young People Survey highlighted an association between ASD in children and living in a low-income household, as illustrated in Figure 2 below. However, no association was found with neighbourhood deprivation.

Figure 2 Prevalence of ASD among 5-19 year olds by equivalised household income quintile



Source: NHS Digital, 2018

If we situate these findings in the broader research literature, however, the relationship between ASD and socioeconomic status becomes less clear. Some studies, many of which were carried out in USA and Australia, have found an association between ASD and higher socioeconomic status, probably due to a bias in case detection. In line with these findings, a UK study using data from the ‘Born in Bradford cohort’, comprising of 13,857 children born between 2007 and 2011, found a higher rate of ASD diagnosis among children of mothers with a higher level of education. Specifically, the study showed that children of mothers educated to A-level standard or above had twice the rate of autism diagnosis (1.5%, 95% CI 1.1%-1.9%) compared to children of mothers with lower levels of education (0.7%, 95% CI 0.5%-0.9%) (Kelly, Williams, Collins et al., 2019). After taking into account maternal education level, no significant relationships were found between ASD prevalence and income or neighbourhood deprivation level. These findings corroborate those of an earlier study of over 50,000 children aged 9-10 years in the South Thames region which found a lower rate of ASD diagnosis among children of lower socioeconomic status (Baird, Simonoff, Pickles et al., 2006). This study also found no association between ASD prevalence and income or neighbourhood deprivation, after taking account of parental education status. These findings suggest that ASD may be under-diagnosed among children of parents with a lower education level.

However, other studies, many of which have been carried out in Europe, have found an association between ASD prevalence and lower socioeconomic status (Delobel-Ayoub, Ehlinger, Klapouszczak et al., 2015). This association is not easily explained, and if valid, the underlying mechanisms are likely to be complex.

In summary, there is no clear consensus in the literature regarding the relationship between ASD and socioeconomic status, but there is some evidence that there may be a detection bias in relation to socioeconomic status, with children of parents with a lower level of education less likely to be diagnosed.

Community Paediatrics ASD Assessment Clinic in Swindon

The current assessment and diagnostic pathway for ASD in children aged 0-18 years in Swindon is outlined in Figure 3 below. Referrals from health or education professionals are made to the consultant-led Paediatric ASD Assessment Clinic (run by the Community Paediatrics team) at Great Western Hospital (GWH). In 2017-18, the main referral sources (for all referrals to Community Paediatrics, not just those relating to ASD) were GPs, Swindon Borough Council and Targeted Mental Health Services (TaMHS, which are delivered by SBC). Cases in which a diagnosis cannot be made by one clinician are discussed at the monthly multi-agency Complex Cases meeting; approximately 25% of children referred to the ASD service are discussed at these meetings.

Figure 3 Current assessment and diagnostic pathway for ASD in children in Swindon

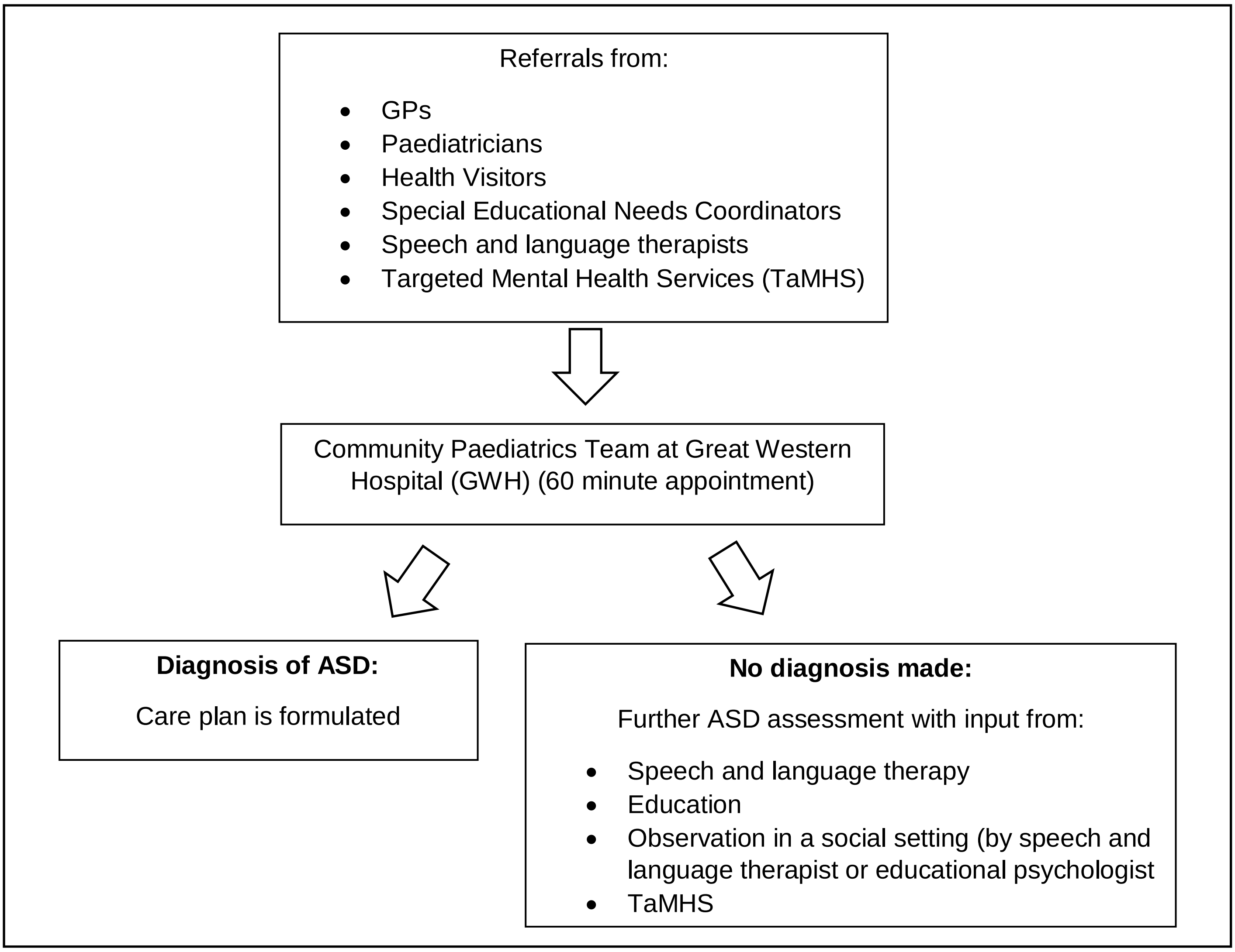


Table 3 below shows the current make-up of the Community Paediatrics team at GWH (as of October 2019). Swindon CCG has allocated funding for the purposes of employing another community paediatrician, but an appointment has not yet been made.

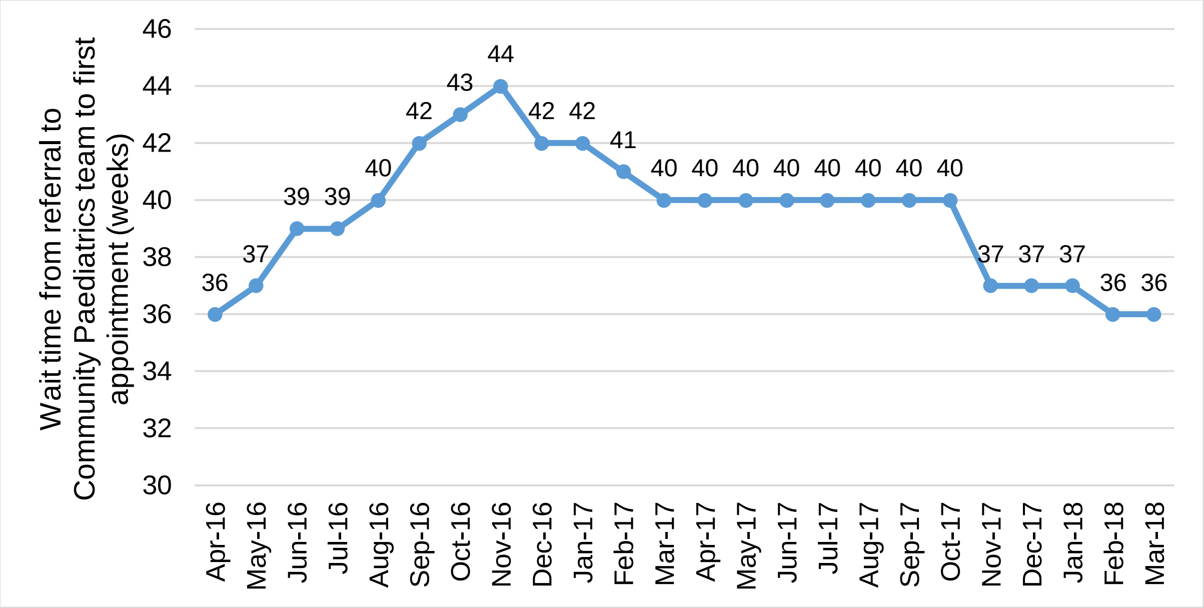
Table 3 Staff make-up of the Community Paediatrics team at GWH (as of October 2019)

Staff Group	Whole Time Equivalent (WTE)
Consultant	4
Associate Specialist	0
Specialty Doctor	0.8
Registrar	0.1
Specialist Nurse	1
Total WTE staff members	**5.9**

The ASD Assessment Clinic run by the Community Paediatrics team experiences high demand; it receives 150% of the expected referrals for Swindon's size, and wait times for assessments far exceed the three month guideline from the National Institute of Health and Care Excellence (NICE, 2011).

Figure 4 below shows that average wait times from referral to the Community Paediatrics team to first appointment (for all types of referrals, not just those for ASD) peaked at 44 weeks in November 2016 for the period April 2016 to March 2018. Average wait times have been dropping gradually since then, to 36 weeks as of March 2018, and 35 weeks as of May 2019.

Figure 4 Monthly reported wait times (in weeks) from referral to Community Paediatrics team to first appointment from April 2016 to March 2018 (across all referrals; not just ASD referrals)



More detailed data for referrals between 1st April 2018 and March 31st 2019 received from the Community Paediatrics team shows that the overall picture in terms of time to an assessment is a complex one, as children are seen according to perceived clinical need and risk, and the age of the child is also an important factor.

This review of data for the year in question took place at 30th September 2019: for children aged under 5 years, 236 referrals were made and 209 children were seen, with 27 still waiting to be seen; the average wait time of those actually seen was 19 weeks, with a range of wait times from 1.5 weeks to 74 weeks.

For children aged 5 years and over the total referrals were 469, the number seen was 171, with 298 still waiting to be seen. The average wait was 21 weeks with a range from 2 weeks to 62 weeks. Yet it must be observed that these wait times do not include the numerous children who had not actually reached assessment. The team reports that wait times for some of the older children can eventually be as long as two years when they finally reach the assessment stage. Thus, it is clear that the average wait time is not a particularly informative measure of how long children experience a delay for their assessment. The Community Paediatrics team reports that 38% of these referrals were for possible ASD.

Children and Adolescent Mental Health Services (CAMHS) Neurodevelopmental Assessment Clinic in Swindon

Outside of the main ASD diagnostic pathway outlined in Figure 3, children and young people who are open cases to CAMHS or the CAMHS-LD (Learning Disability) services in Swindon may be referred internally to the Neurodevelopmental Assessment Clinics if there are concerns that they may be presenting with an underlying neurodevelopmental difficulty in addition to the mental health need for which they are being seen by CAMHS.

For the period April 2017 to March 2018, 69 CAMHS patients and 12 CAMHS-LD patients were referred to the Swindon CAMHS Neurodevelopmental Assessment Clinic. For the former group, 26 assessments were completed, and for the latter all 12 referrals were assessed. In 2018, the average wait time for assessment of CAMHS referrals was 11 months, and the wait time for CAMHS-LD referrals was 18 months.

Re-design of ASD assessment and diagnostic pathway for children

Work has been underway throughout 2019 to re-design the ASD assessment and diagnostic pathway for children in Swindon with the following aims:

- To reduce waiting times for assessment and diagnosis
- To provide a single point of access for all neurodevelopmental conditions
- To provide an approach which is embedded in the communities, families and social networks of service-users
- To maintain a focus on helping individuals to manage their condition, and on helping their families to support them to do this
- To deliver a model that is outcomes-led, delivered by an experienced multi-agency team in partnership with parents and individuals living with ASD and/or Attention Deficit-Hyperactivity Disorder.

This work is being led by Swindon CCG’s Autistic Spectrum Conditions Strategy Group and Project Group, and has been informed by engagement workshops carried out with parents/carers and other stakeholders on their experiences of the current diagnostic pathway in summer 2018. These workshops highlighted a current lack of support:

- For families whilst waiting for assessment
- For older children
- For children who do not exhibit specific manifestations of ASD, and are higher functioning

Suggestions made at the workshops for the new pathway included:

- Having an information hub available to families to answer questions and find out what services Swindon has on offer
- Having a single point of contact for triage of referrals
- Offering alternative provision/support for those who do not receive a diagnosis as part of the pathway.

Services and support available from SBC

Table 4 below outlines the key ASD-specific services and support provided by SBC for children who have been diagnosed with ASD and their families in Swindon.

Table 4 Outline and description of services and support provided by SBC for children with ASD and their families

Name of service	Brief description of service
Swindon Autism Support Service (SASS)	SASS is commissioned by SBC to provide an advisory and outreach service that supports the inclusion of pupils with ASD or social communication and interaction difficulty (SCID). This service is known to schools as the Swindon ASC School Response Team. It The responds to individual pupil referrals and provides advice, training and support to enable schools to meet the needs of ASD/SCID affected pupils and enable them to engage more fully and access learning. The service works with a wide range of ASD/SCID pupils, school/settings staff, parents and multi-agency professionals. As well as the advisory and outreach service commissioned by SBC, SASS offers an enhanced level of support and intervention for pupils with ASD/SCID as a traded service called the 'Autism Resource Centre' (ARC). ARC offers educational programmes of social communication and therapeutic learning activity, which can be commissioned by schools, other educational settings or social services.
Early Bird and Early Bird Plus	The Early Bird programme is a three-month parenting support and training programme for parents of pre-school children who have a diagnosis of ASD. The programme consists of eight group training sessions with five individual home visits, where video feedback is available. The aim of the programme is to empower parents/carers and support families in the period between the diagnosis of ASD and school placement. The Early Bird Plus programme is a three-month training programme for parents/carers of children aged 4-8 years with a diagnosis of ASD, and childcare professionals. The programme aims to encourage a consistent approach between home and school by training parents and childcare professionals who work with the child in school together.
Cygnet Group	Cygnet is a parenting support programme for parents/carers of children/young people aged 7-18 years who have a diagnosis of ASD. The course was developed by Barnardo's and its effectiveness has been supported by a number of studies. It consists of 10 sessions, each lasting 2.5 hours. The programme gives parents and carers an opportunity to better understand ASD. It offers practical strategies that can be implemented at home, and gives attendees the chance to meet with others in a similar position and hear about their experiences.

Aiming High	Aiming High provides short breaks and positive activities for families of children and young people with disabilities aged 0-18 years. The service allows parents and carers to have a break from their caring responsibilities, and enables their children to take part in social and leisure activities. Short breaks can include day, evening, overnight, weekend or holiday activities. Among the services offered by Aiming High are social activity groups for children aged 5-18 years with a diagnosis of ASD; these groups run after school during term-time and during the holidays. There is also a monthly Saturday group. There is a charge of £6.25 per session for the after school groups, and £10 per session for the Saturday and holiday groups. Aiming High also offers social activity groups for children attending specialist education provision who have a possible diagnosis of ASD and/or communication difficulties. These groups run bi-monthly on a Saturday, and during holiday periods. There is a charge of £10.00 per session. The types of activities that children participate in include cookery, play, outdoor play (bikes, scooters, ball games etc.), arts and crafts, social games, sensory play, swimming and walks to the local park.
Sunflower lanyard scheme	Not a full service as such but a scheme at Great Western Hospital that allows children with hidden disabilities such as ASD to be visible.

Services and support available from third sector organisations in Swindon

There are a range of charities, community groups and parents' support groups in Swindon that offer services and support for children with ASD and their families. Many of these groups and organisations are listed on the Council's Local Offer page for ASD: https://localoffer.swindon.gov.uk/content/send-local-offer/landing-pages/swindon-send-local-offer/

Mental health service use by children with ASD in Swindon

Child and Adolescent Mental Health Services (CAMHS) in Swindon are provided by Oxford Health NHS Foundation Trust and Targeted Mental Health Services (TaMHS) by Swindon Borough Council. There is a single point of access and needs are assessed and a decision taken about what support is necessary and which team will provide it depending on the needs of the young person. TaMHS generally offers short term interventions, whereas CAMHS provides more intensive support.

Within Oxford Health, although diagnoses of ASD can be recorded on the electronic clinical record, the service has identified that these are currently being under-reported by staff. Therefore, the decision has been taken not to include any CAMHS data on ASD in this section for data quality reasons. The CAMHS service has undertaken to improve the recording of ASD in the future.

All young people referred to Oxford Health in Swindon are offered a mental health assessment which identifies their individual needs. Children with an ASD diagnosis have access to the full range of interventions, as other children entering CAMHS, and are seen by a range of clinical staff. These interventions are adapted to meet the young person's needs. Those with a diagnosis of ASD and who have a learning disability will generally be offered support through specialist LD clinical staff. CAMHS follows the NICE guidance around working with children and young people with ASD.

Oxford Health employs a wide range of professionals from varied backgrounds. All staff at CAMHS will be supported to have a basic level of understanding of the needs of young people with a diagnosis of ASD and what adjustments may be required to adapt interventions. Specific staff groups, e.g. LD nurses, Occupational Therapists, psychologist and doctors will have more comprehensive ASD training. There is a clinical lead for neurodevelopmental CAMHS who, as part of their role, provides direction and leadership around ASD diagnosis and intervention. All staff can access consultation and joint working from more experienced staff when required to adapt their practice. CAMHS is undertaking more work to equip all staff to a higher basic standard on ASD and are planning to bring the LD staff group and core CAMHS clinicians together to increase skills.

3. Adults with ASD in Swindon

Prevalence of ASD among adults in Swindon

Until recently, there have been no reliable estimates of the true prevalence of diagnosed and undiagnosed ASD among adults in England. This is because ASDs are more apparent and easier to study in children, in part because the diagnosis of autism should include presence of symptoms during childhood; parent and teacher observations of this are more likely to be accurate and available for this group. (NHS Digital, 2016, Chap. 6).

In 2007, the Adult Psychiatric Morbidity Survey (APMS) became the first ever general population survey in any country to assess ASD in adults, and the survey was then repeated in 2014. The APMS is carried out every seven years and provides an assessment of mental health in England. It is the most reliable profile of adult mental health available, taking a representative sample of over 7,500 adults from across the country and identifying both diagnosed and undiagnosed disorders (NHS Digital, 2016).

The APMS has used a two-phase process to identify potential cases of ASD; the Autism Quotient instrument was used to screen for ASD in the phase one interview. Participants with a score of 4 or more went on to have a fuller assessment in phase two by clinically trained interviewers using the Autism Diagnostic Observation Schedule. As only 31 potential cases were identified across both the 2007 and 2014 APMS combined, the data should be interpreted with caution.

National prevalence estimates based on combined data from the 2007 and 2014 surveys are outlined in Table 5 below for the population overall (aged 16 and over), by gender, along with the corresponding expected counts for Swindon. These are the best available guideline we have to the number of adults with ASD in Swindon. This is because not all adults with ASD will be in contact with public services at the same time, and the times between contacts may vary greatly; as all children should be within the purview of the education services at the same time, the task of estimating the true local prevalence of ASD for them is much more straightforward.

Table 5 National prevalence estimates of ASD among adults aged 16+ from the 2007 and 2014 APMS and expected counts for Swindon

Group	Estimated prevalence of ASD (95% CI)	Expected count for Swindon
Men	1.5% (0.8%-2.6%)	1,303
Women	0.2% (0.1%-0.6%)	177
Population overall	0.8% (0.5%-1.3%)	1,480 (sum of above)

Sources: NHS Digital, 2016, ONS 2017 mid-year population estimates

Estimates from the APMS highlight an even more pronounced gender gap in the prevalence of ASD in adults compared with the prevalence estimates for children; Table 5 shows that prevalence among men (1.5%) is estimated to be nearly eight times as high as among women (0.2%), whereas estimates from the 2017 Mental Health of Children and Young People Survey suggest that prevalence among boys (1.9%) is about four times higher than among girls (0.4%) (NHS Digital, 2018). However, as the two surveys use different methodologies and investigate different age-groups, their results are not strictly comparable.

As discussed in the section above on children and young people, questions have been raised about whether ASD may be under-diagnosed among females, and whether females with ASD may present differently to males (NHS Digital, 2018). If assessments for autism are based more on how the condition manifests in men, this may contribute to under-identification of ASD in women (NHS Digital, 2016).

Characteristics associated with ASD in adults

Data from the 2007 and 2014 APMS indicate that ASD is associated with male gender, and with a lack of educational qualifications. In terms of level of educational qualification, prevalence of ASD was highest among those with no qualifications (1.5% overall, but 3.2% among men in this sub-group) and lowest among those with a degree level qualification (0.2%). The surveys may have failed to identify other characteristics associated with ASD due to the relatively small number of cases that could be detected using this sample size.

The assessment and diagnostic pathway for adults with ASD in Swindon

Swindon Adult Autism Diagnostic Service (which is part of Avon and Wilts Partnership (Mental Health NHS Trust), often referred to as AWP), is commissioned to carry out autism assessments for adults aged 18 years and over who live in Swindon. This is a diagnostic service only. Referrals are made by GPs but may be instigated by LIFT psychology or the AWP Primary Care Liaison Service (PCLS). There are three or four appointments in the process:

- Clinical interview – 2 to 2.5 hours with 2 assessors
- Clinical assessment – 1 to 1.5 hours with 1 or 2 assessors
- Feedback appointment – 1 hour, applicant informed of decision
- Follow up appointment (if necessary)

A decision is made as to whether the individual meets the clinical criteria for ASD or does not meet (or cannot supply enough evidence to meet) the clinical criteria for a diagnosis of ASD.

Table 6 Staff make-up of the Adult Autism Diagnostic Service at AWP

Staff Group	Staff numbers
Diagnostic lead and assessor	1
Assessor	4
Support worker	1
Team admin	1
Total staff members	**7**

The Adult Autism Diagnostic Service is experiencing high demand. The service is commissioned to provide 8 assessments a month, and would not be able to increase this with current funding whilst preserving its service quality. In 2018-19 the service received 182 referrals (15 a month) up from 136 in 2016-17 and 135 in 2017-18. The 8 assessments are performed each month, although the need is actually for twice that number. This has created a considerable waiting list, with 176 people waiting at the end of November 2019. Average waiting times (from initial referral) have risen from 39 weeks in 2016-17 to 97 weeks in late 2019, and some people may be waiting longer than this. In 2018-19, in one quarter of the assessments the person was not diagnosed with ASD at the end of the process. As waiting times for an initial assessment by Adult Autism Diagnostic Service for adults with possible ASD is now averaging 97 weeks, this means that some people will wait longer than that. As of November 2019, 176 people are waiting. In 2018-19, in one quarter of the assessments the person was not diagnosed with ASD at the end of the process. Over the last year, the commissioners have been proactive in offering funding for a pilot project with a partner organisation, and the service has been able to offer a number of diagnostic assessments via a web-based platform, which is available outside standard office hours.

Despite the prevalence of ASD in men being several times higher than in women according to the APMS survey, the Adult Autism Diagnostic Service has been receiving similar numbers of referrals for men and women in recent years. Women made up 41% of referrals in 2017-18 and 40% in 2018-19. The women referred are equally likely to receive a diagnosis of ASD from the service (78% in 2018-19 compared to 76% of men). The average age of referrals has increased from 28 in 2016-17 to 34 in 2017-18 and 48 in 2018-19.

Post-diagnostic support is provided at feedback and follow-up appointments. These are used to make sure that people are signposted to DASH or LIFT so that they can have access to support to enable them to understand their diagnosis. Onward referrals will also be considered, e.g. to Therapeutic Work In Gardening Swindon (TWIGS) or Building Bridges for employment support, and a disclosure document or employment support plan will be developed if this is needed. If there is no further multi-disciplinary work required, the person is discharged.

The Adult Autism Diagnostic Service also runs a rolling programme of training workshops with an 'expert by experience', a person with autism diagnosed within the service. There are three half-day sessions looking at autism, differences for women, and ways to support effective communication. They are free for people with autism with one supporter, but the sessions also function as a form of Continual Professional Development for local staff.

People diagnosed with ASD between 2016-17 and 2018-19 were not evenly distributed across the population of Swindon. Overall in Swindon, 10.4 people per 10,000 adults were newly diagnosed with ASD by the Adult Autism Diagnosis Service during this time. However, in Liden, Eldene and Park South ward the rate was almost double this, 18.3 per 10,000. This was the highest rate for any ward, followed by 16.9 per 10,000 for Walcot and Park North. The rate of positive diagnoses was higher in more deprived areas. In the most deprived quintile (most deprived fifth) of areas in Swindon (according to the Index of Multiple Deprivation 2015), 19.2 per 10,000 adults were newly diagnosed with ASD compared to less than 10 per 10,000 in each of the other four quintiles. The least deprived quintile had the lowest diagnosis rate (7.8 per 10,000).

It should be note that an additional problem with gaining accurate figures about adults with ASD in Swindon is that local clinicians prefer not to diagnose using ICD 10 (International Classification of Diseases, Revision 10), criteria which have limitations when working with able adults on the autism spectrum. As a result, the DSM 5 (Diagnostic and Statistical Manual of Mental Disorders Edition 5) criteria are used in the Swindon Adult Autism Diagnostic Service, while NHS data systems tend to record using ICD-10 codes. The situation might improve when the revised ICD-11 codes become the norm, but this will not happen in the NHS as a whole for number of years. These difficulties have been highlighted within AWP and it is hoped a solution will be reached.

Services and support available from SBC

SBC does not provide or commission 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 (particularly for young people looking to move out of home), domiciliary care, residential care, supported living and support to manage health and wellbeing needs from Community Navigators and Community Support workers.

Up until 2019, data collection on adult social care service users with ASD was not robust because it was not mandatory to record information on medical diagnoses on the case management system. However, recording is now required and thus, in future, more robust data will be available to examine service use by adults with ASD.

Bearing in mind significant problems with data quality, adult social care data for 2018-19 indicates that 207 service users with ASD were supported. The vast majority had a dual diagnosis of ASD with a learning disability, and hence were supported by the Learning Disability team. The most common services accessed by people with ASD in 2018-19 included:

- Residential care
- Direct payments
- Day care
- Domiciliary care
- Supported living
- Education

Services and support available from third sector organisations

There are a number of voluntary sector-led services that support people with autism and their carers in Swindon, including;

- **DASH (Discovering Autistic Spectrum Happiness)**, which is an independent local charity with a mission to improve the quality of life of adults of working age with high functioning Autistic Spectrum Conditions living in Swindon. DASH organises social groups for people with ASD to reduce social isolation, enable people to meet other people with the same condition in a safe and supportive environment, and increase skills and confidence in social and work based interactions. Representatives of DASH have expressed concern about the amount of support DASH and other agencies are able to give people with ASD, particularly with the amount of time that can be spent with any one individual.

- **Swindon Advocacy Movement (SAM)** is a user-led independent advocacy service. There is a dedicated staff member who supports people with ASD to understand their condition better, to communicate needs and wishes to family members, carers and professionals, to access the adult diagnostic service, and access other services for advocacy and support

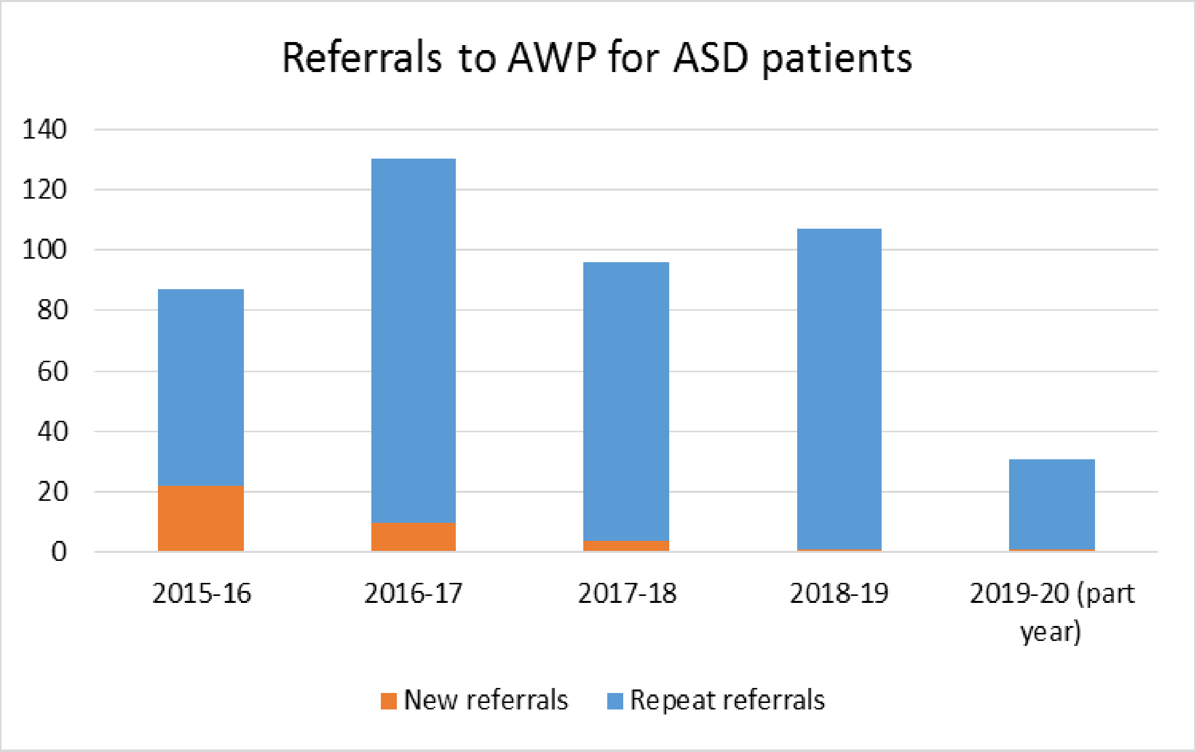
- **Wiltshire Autism Alert Card Scheme**, which aims to help those with ASD who come into contact with the criminal justice system and emergency services to receive appropriate support in difficult situations, and to raise of awareness autism and understanding amongst professionals working in these services. The scheme provides a card designed to be carried in a wallet or purse at all times

- **The National Autistic Society**, offers information, support and signposting services for children and adults with autism and their carers, but this is only through a website for people in Swindon, as there is not a currently an active local branch

Mental health service use by adults with ASD

Mental health services for adults in Swindon are provided by AWP. The number of referrals over the past five years has remained broadly stable at around 100 each year. The majority of these are repeat referrals. The majority of those who are diagnosed with ASD are recorded as having Asperger syndrome (ICD10 code F845) and also co-morbidities related to mental health issues such as behavioural disorders or substance misuse.

Figure 5 Annual referrals of ASD patients to AWP



Almost half of referrals were seen by the Primary Care Liaison Service (PCLS) and this was fairly constant over the approximately four year period of the analysis. A further 12% were seen by Intensive Teams, 8% by an Approved Mental Health Practitioner and 7% by the criminal justice liaison team (CARS). The number of referrals accessing each different service or team has changed little over the last five years.

The average waiting time to be seen by AWP has fallen from 15 days in 2017-18 to seven days in 2018-19 and to four days in 2019-20 to date. However, the average waiting time to be taken on by the service has historically been much longer, although this too has reduced from 74 days in 2017-18 to 29 days in 2018-19 and is currently being reported by AWP as only three days for 2019-20 to date.

The LIFT Psychology service, part of AWP, provides support to adults experiencing mental health difficulties and offers a range of courses that teach people how to manage conditions such as anxiety, low mood and stress. Staff from LIFT Psychology are based at each GP practice across Swindon and Shrivenham. People do not need a GP referral to use LIFT Psychology and can book a course by telephone or online.

The LIFT service reports that LIFT frequently sees people with ASD, but the number of people with ASD is not recorded systematically because of workload issues. At any one time a high number of people with ASD are waiting for low and high intensity Improving Access to Psychological Therapies (IAPT) referrals from LIFT (internal referrals for one-to-one Cognitive-Behavioural Therapy) with ASD. LIFT also signposts a number of people towards support at DASH and refers a small number of people for assessment in PCLS (Primary Care Liaison Service, the access service into secondary mental health services) each year. The majority of these people are directed back to LIFT after assessment in PCLS. LIFT would not generally direct people with ASD towards services other than these (*Personal Communication from LIFT staff.*)

Costs and Impact of Autism Spectrum Disorders

The costs associated with an Autism Spectrum Disorder can include direct medical costs, non-medical costs (for example, special education, day care and after-school care), accommodation costs (private, supported living, residential or hospital) and out-of-pocket payments by families (such as travel to medical appointments and home modifications). In addition, additional costs may arise as a result of unemployment in people with ASD and their families. NICE (2015) has cited evidence of the costs of ASD, principally based on work by Buescher et al. (2014). Buescher and colleagues have used existing data to estimate the annual and lifetime costs associated with people with ASD in the UK and in the USA in 2013. The costs in this particular analysis were accommodation, medical services, non-medical services, special education, employment support, and out-of-pocket payments by families. Additional costs were calculated as lost productivity as a result of lost or disrupted employment for people with ASD and their families. Lifetime costs assumed a life expectancy of 67 years for people with ASD.

The annual cost to the UK of children under the age of 18 years with ASD was estimated as £3.1 billion a year, assuming a 40% prevalence of intellectual disability. The annual cost was estimated at £3.4 billion when the prevalence of intellectual disability was assumed to be 60%. These costs were largely driven by direct non-medical costs, such as special education, and indirect non-medical costs, such as loss of parental productivity.

The annual cost of adults with an ASD was estimated as £29 billion a year in the UK, assuming a 40% prevalence of intellectual disability and £31 billion a year assuming a 60% prevalence. The largest contributing factors to these costs were accommodation, direct medical costs, and productivity loss for the person with autism. The cost of ASD throughout a person's life in the UK was estimated as £1.5 million per person for those with intellectual disability and £0.92 million per person for those without intellectual disability. This analysis has a number of limitations; for example, some costs had to be estimated by imputation, the authors did not take account of the possible benefits of interventions and support, and they may have over-estimated the proportion of ASD people with an intellectual disability. Therefore the costs calculated may be over-estimates. That said, these are accepted by NICE as the most accurate figures available. The conclusion is that autism is costly for families and society, and that the direct and indirect economic effect is greater for people with ASD who also have intellectual disability, particularly when this involves impaired development of life skills.

The length of the average life-span has been increasing over the past decades and this means that people with ASD will be living to a greater age. An important ramification of this is that people with ASD may require services that relate to their age as well as to their autism. A full discussion of this issue lies beyond the scope of this present JSNA report.

4. Views of local people on services and support available for people with ASD

Part One: 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 asked were drawn mainly from those used by Healthwatch Swindon in their 2019 public engagement programme to inform implementation of the NHS Long Term Plan; they focused on experiences of the assessment and diagnostic process, and of accessing health and care support (see Appendix 1 for the specific questions asked).

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 6-8 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 0-5 years with special needs) helped to put speech and language support in place for her child while she was waiting for an assessment.
- Following 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 on the list actually do, and the reasons for which parents should contact them. 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 will depend 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 12-18 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:

    - 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 and council tax relief), and providing access useful information such as this in one place
    - Providing more support for mental health problems, especially anxiety in children and young people with ASD, as outlined below.

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 CAMHS for anxiety alone. One participant’s son is receiving support from CAMHS-LD for ‘violence’; the underlying issue is in fact anxiety, but he would not be given support if the referral was 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.

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

The Director of Children Services at SBC held two sessions in February 2019 for parents and carers to provide feedback on their experiences in 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, crisis.

- 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 that the national shortage of speech & language therapists, occupational therapists and educational psychologists is having an impact on children.

Part Three: 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 highlighted below. Since the survey was about the health service in general, was not primarily for people with ASD and involved a small number of people, the results must be treated with some circumspection and a larger sample size might be sought in the future:

- 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.

- Long waiting times for assessment and diagnosis have been experienced and can be detrimental to mental health.

- 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.

- Respondents found it was easier to access ongoing support after a diagnosis was made; in fact all respondents selected, ‘Very Easy’, ‘Easy’ or ‘Okay’ when asked to rate how easy it was to access ongoing 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.

5. Recommendations: Progress Reports on previous recommendations and Updated recommendations (with SEND recommendations also shown).

Background to the Recommendations

The 2015 Adult Autism Needs Assessment made ten key recommendations. Each of the recommendations from the 2015 needs assessment is listed in the following section with a progress update. Then in the succeeding section, the updated recommendations based on this current 2020 report are set out. Recommendations are intended for the Health Community of Swindon as a whole, but in particular the Health and Well-being Board and Autism Partnership Board with their facilitating roles.

2015 Recommendations (1 to 10) with Progress Reports

1. *Develop an Adult Autism Strategy for Swindon to include action on these recommendations as well as national strategy and statutory guidance.*

Progress report:
The Swindon Adult Autism Strategy 2015-2018 was jointly developed by SBC and Swindon CCG. It is due to be refreshed and expanded to include children and young people in 2020 by the ASD Partnership Board as part of the SAF 2018 Improvement Plan.

2. *Ensure that the Swindon Autism Partnership Board has clear Terms of Reference and a work plan informed by Swindon's Adult Autism Strategy and local priorities identified by this JSNA. The Board should include people from across the autism spectrum and their carers, as well as partners from all agencies in Swindon required to deliver the work plan.*

Progress report:
Terms of Reference for the ASD Partnership Board were developed and included in the Adult Autism Strategy 2015-2018. The Self-Assessment Framework 2018 Improvement Plan constitutes the Board's work plan. There is some, albeit limited, representation of people with ASD and their carers on the Board; more work is needed to ensure greater representation and more consistent attendance from these groups. There is a need for younger people with ASD to be represented at Board meetings; New College could be a potential partner to work with on this.

3. *Ensure that the right support for people with autism is available at the right time during their life time. This should include good transition support for young people with autism moving to adult services, and that the changing needs of people with autism are planned for as they grow older.*

Progress report:
Improving transition support and communication between Children's and Adult Services is a focus in the SAF 2018 Improvement Plan.

4. *Work with community and voluntary sector partners to promote access to 'lower level' local preventative support and activities that enable people with autism to be connected with peers and local community groups.*

Progress report:
No voluntary sector services are currently commissioned by Swindon CCG or SBC to support people with ASD specifically. There is a need for more partnership working with key organisations in the voluntary sector to promote and maximise the impact of community-based support, including DASH and the National Autistic Society (though the latter does not have an active local branch).

5. *Ensure that the information about support services in Swindon available to people with autism is up-to-date and accessible in a way that is appropriate and identifiable. This includes maintaining the Autism Directory of Services and ensuring information is easily accessible on the Swindon My Care, My Support website.*

Progress report:
The Autism Directory of Services was maintained by SEQOL, the community services social enterprise which has now ceased to exist. SBC's MyCareMySupport site is was relaunched in 2019; the new site is called the 'Swindon Local Offer'. This represents a key opportunity to ensure that clear and up-to-date information on services and support for adults and children with ASD is provided on the new site. Engagement work with parents of children with ASD has been undertaken to support this aim. In the consultation carried out in June 2019 with parents of children with ASD as part of this needs assessment, parents emphasised how helpful it would be to be able to access information on services, support groups, and entitlements (e.g. Disability Living Allowance for children and council tax relief) in one place; the new Local Offer website will be able to fulfil this role.

6. *Ensure that autism awareness training is available to all frontline staff so that they are able to identify potential signs of autism and understand how to make reasonable adjustments in their behaviour and communication. This may be as part of equality and diversity training. In addition ensure plans are in place to provide specialist training for those in roles that have a direct impact on access to services for adults with autism.*

Progress report:
AWP provides basic ASD awareness training; however, there is no regular reporting on the delivery of training. This is an intelligence gap that must now be addressed

7. *Ensure that GPs, as the gatekeepers to diagnostic services, have adequate training and information available so that they have a good understanding of the whole autistic spectrum and the local diagnostic pathway and how to refer.*

Progress report:
As above, more information is needed from AWP on the ASD awareness training that they provide to assess how many GPs have received the training. The assessment and diagnostic pathway for children with ASD has been re-designed and the new Neurodevelopmental Conditions Pathway was due to be launched in 2019; information on the new pathway will be provided to GPs.

8. *Work towards achieving NICE best practice for access to diagnostic services; where people seeking an autism diagnosis have a first appointment within three months of their referral as set out in the NICE Quality Standard on autism [QS51].*

Progress report:
Waiting times for assessment for many adults and children in Swindon clearly remain above the three-month guideline from NICE. The re-design of the assessment and diagnostic pathway for children in Swindon was undertaken with the key aim of reducing wait times; the new Neurodevelopmental Conditions Pathway was due to be launched in 2019. Engagement work with parents of children with ASD highlighted that, currently, there is no signposting or support offered while parents are waiting for an assessment for their child. This is a potential 'quick win' in terms of improving support for parents, while longer-term work to reduce wait times is ongoing. The Council's new Local Offer website will be a key resource for providing information. Work is ongoing to reduce wait times for the adult diagnostic service at AWP. The CCG is funding the use of an online diagnostic tool to increase the service's capacity.

9. *Work with all local service providers to develop and improve methods of data collection to ensure that the numbers of people with autism in their area of responsibility are appropriately recorded and analysed, and information about need (health, social care, education, employment, housing) is captured. Commissioners and service providers should use this information to develop and improve services.*

Progress report:
Use of health and social care services by people with ASD is not routinely reported, and in general, data collection is not robust. Improving data collection and sharing on service use by people with ASD is an area of focus for the ASD Partnership Board in the SAF 2018 Improvement Plan. A multi-agency working group will take this forward during 2020.

10. *Work with local employers, colleges and support services to ensure that there are employment opportunities for people with autism in Swindon and that appropriate support is available to help people with autism to find and keep a job.*

Progress report:
SBC has produced a Supported Employment Strategy for Swindon for 2018-2022, which sets out a vision that all young people and adults with care and support needs in Swindon have the opportunity and support to gain sustained paid employment or a volunteering post. The needs of people with ASD need to be borne in mind in the implementation of the action plan for this strategy.

2020 Updated Recommendations (1 to 10, with 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 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 DASH and National Autistic Society) 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 as the gatekeepers to diagnostic services (for adults, sometimes for 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 NICE best practice 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 a means of signposting.*

Updated Recommendation 9:

> *In line with the objectives of the 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 service use by people with ASD.*

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 further new 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 needs assessment, 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 to use health services for a mental or emotional reason (NHS Digital, 2016). This is probably due to a lack of recognition of the mental health needs, such as anxiety and depression, of people with ASD (National Autistic Society, 2019).

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 post- diagnosis and have a clear pathway available.

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.*

Recommendations from the SEND JSNA Bulletin 2019

(Because ASD is a common form of SEND, the recommendations from SBC's SEND JSNA Bulletin 2019 are also set out below. Cross-references to the ASD JSNA Recommendations above have been added for the convenience of the reader where this seems to be applicable.)

Joint Commissioning Priorities

1. *Autistic Spectrum Disorder: 30.2% of students with an EHC plan had ASD as a primary need in 2019. Early identification, support and provision to meet the needs and improve the outcomes of children and young people with ASD should be a commissioning priority for the LA and CCG.*
(See ASD Recommendation 8).

2. *Speech, Language and Communication Difficulties: 11.9% of the Swindon school population have Speech, Language and Communication identified as their primary need. Demand for the Speech and Language Therapy Service remains high and the service receives around 900 referrals per year and an increased number of students have required therapeutic input in recent years. Early identification, support and provision to meet the needs and improve outcomes for children and young people with such difficulties should be a joint commissioning priority for SBC and the CCG.*

3. *Social, Emotional and Mental Health Difficulties: 17.1% of students have a primary need of Social, Emotional and Mental Health. The rate of hospital admissions for self-harm in young people aged 10 to 24 years is significantly higher in Swindon than in England as a whole. Early identification, support and provision to meet the needs and improve the outcomes of children and young people with such difficulties should be a joint commissioning priority for SBC and the CCG.*
(See ASD Recommendations 8 and 11).

4. *Specialist provision and services need to work alongside colleagues across SBC and the CCG when commissioning and/or decommissioning specialist provision and services in Swindon to meet the needs of children and young people with SEND and improve their outcomes.*
(Implied in ASD Recommendations but related to ASD Recommendations 2,4,9,11).

5. *Employment for SEND: Alongside colleagues from the employment and training workstream, review current provision and options and outcome measures for young people to increase the percentage of young people with SEND in sustainable paid employment. Identify support and provision options and pathways for future commissioning priorities for SBC and the CCG.*
(See ASD Recommendation 10).

Data Monitoring

6. *SEND Population and demographics: SBC should continue to closely monitor the overall SEND population to ensure that the percentage of the school population with an EHC plan continues to remain stable and that the proportion at each age group is stable and in line with national and comparable areas.*

(See ASD Recommendation 9).

7. *Requests for Statutory Assessment and EHC plans issued: Since 2012 the number of EHC plans (or previously statements) issued annually has been on an upward trajectory. SBC should continue to closely monitor by age range the proportion of requests per 10,000 of the population and against national and regional benchmarks to ensure that this remains stable and begins to reduce over time. The impact of early support and improved pathways to employment should be monitored for the impact on total numbers of EHCPs.*

(Partially related to ASD Recommendation 9).

Further Research and Analysis

8. *Children in Care with SEND: Children in Care in Swindon are more likely to have SEND. Further research and analysis is required of the SEND cohort of children in care to identify why there is a disproportionate number of children in care with SEND and their outcomes. Once this is better understood, the findings should inform a joint commissioning priority for SBC and the CCG to ensure there is early identification, support and provision in place to meet the needs and improve the outcomes of children in care with SEND.*

9. *The participation of children and young people with SEND as indicated by attendance, absence and exclusion figures should be a commissioning priority in Swindon within the context of national developments and local developments such as the mental health trailblazer programme.*

(See ASD Recommendations 8 and 11).

6. Concluding Remarks

This JSNA Report gives an overview of the prevalence of Autism Spectrum Disorders (ASD) in Swindon UA, the services available, the experiences of people with ASD and their carers, together with progress on previous recommendations and meanwhile presenting refreshed recommendations for the future. The JSNA has noted that the schools-based prevalence of children with ASD in Swindon is higher than we would anticipate, but the disparity between this and the schools-based prevalence in England as a whole is not large. That said, the challenge for services has continued to grow locally. Adults with ASD and the parents of children with ASD have expressed concerns about wait times for diagnosis and support, as well as about achieving access to mental health services. Data emanating from local diagnostic services confirms that their capacity is not on a par with the local need; the situation is also made more complex, since the numbers of people with ASD or possible ASD who make contact with services locally are not always routinely recorded by those services.

The updated recommendations of the JSNA include: ensuring that there is greater representation of people with ASD, including young people and their carers on the ASD Partnership Board; continuing to work with GPs who act as gatekeepers to adult diagnostic services, (and sometimes for 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; continuing to work towards achieving the NICE best practice standard for access to diagnostic services, with both adults and children seeking an autism diagnosis having a first appointment within three months of their referral; commissioning services as appropriate and developing specific pathways for children and adults with ASD in order that they might more easily access mental health support from CAMHS and AWP respectively.

A number of issues were beyond the scope of this JSNA and so could not be addressed. These include the fuller social implications of ASD including participation in society and school exclusion, the possible effects on health and life-span of ASD, the ramifications for services of ageing in people with ASD, some of the complex educational needs of young people with ASD, especially those in young people beyond statutory school age. The new Bath Swindon Wiltshire CCG (BSW CCG) comes into being on 1st April 2020 and could possibly lead to services being commissioned in forms that differ from current patterns. Swindon's multi-agency ASD Partnership Board should be supported so that it continues to contribute vital insights and have a pivotal role in the new situation.

Swindon's ASD Partnership Board is now due to revise and extend its existing ASD strategy to include children and young people, informed by the findings of this JSNA.

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Appendix 1: Consultation questions for parents of children with ASD

Assessment & diagnosis:

- How would you describe the time you had to wait for your child to receive their initial assessment or diagnosis? Please tell me more about the length of time you waited.
- Were you signposted to any support whilst you were awaiting the initial assessment? If so, what was offered and did you take up the offer?
- After your child was diagnosed or assessed, were you offered access to further health and care support for them?
- If so, did the support options you were offered meet your expectations? Please explain how they did or did not meet your expectations.

Experience of accessing support:

- How would you describe the time you had to wait between your child's initial assessment/diagnosis and receiving further health and care support?
- If you accessed support, what aspects worked well?
- If you accessed support, what could be improved?
- How would you describe your overall experience of getting help?
- If you needed it, how easy did you find it to access ongoing support after your child was diagnosed or assessed?

Final thoughts & comments:

- What could the Council and/or NHS do to help your child stay healthy and live well with ASD?
- Any further comments?

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