

Swindon's Joint Strategic Needs Assessment

JSNA Bulletin: Adult Autism

Key Points

- The JSNA provides evidence to help us understand the current picture regarding adult autism in Swindon and make recommendations for work to improve lives of people with autism.
- Autism is neither a learning disability nor a mental health problem, although mental health problems are more common among people with autism and it is estimated that one in three of adults with a learning disability also have autism.
- Autism affects the way a person communicates with and relates to other people. It also affects how they make sense of the world around them. It is known as a spectrum condition because it affects people in many different ways.
- Gathering data on the numbers and needs of people with autism at a local level is challenging. Health and adult social care services are likely to know only a small number of all local people with autism and many people are undiagnosed.
- It is estimated that around 1% of the population in England have autism. This is equivalent to approximately 2,300 adults and children in Swindon.
- There is a range of services and sources of support available to people with autism and their carers in Swindon. Whilst some of these are health and social care services, the community and voluntary sector play an important role. Local survey responses also highlight the hugely important role parents and carers have in supporting people with autism of all ages.
- Consultation with service users in Swindon highlighted significant unmet need for support; just 34% of survey respondents felt they had enough support to meet their needs.
- Improving access to local support and services is important to develop the skills and independence of adults with autism in Swindon and prevent, delay or reduce the care needs of them and their carers.
- The JSNA makes 10 recommendations for future work to improve lives of people with autism in Swindon – these are set out on page 8.

What is Joint Strategic Needs Assessment?

Joint Strategic Needs Assessment (JSNA) helps us to understand:

- what we know about the current health and wellbeing needs of local people;
- how their needs are being met;
- what we think their future needs are likely to be; and
- how their needs can be best met.

The JSNA process involves many different partners and is overseen by Swindon's [Health and Wellbeing Board](#). Understanding Swindon's changing population, the factors that affect health and wellbeing, the town's assets and the implications for future services are vital in setting priorities and planning future services.

The Adult Autism JSNA

The aim of this bulletin is to describe the current picture with regard to adult autism (age 18 and over) in Swindon. It provides a summary of the estimated number of people with autism in Swindon; information about support and services available; and findings from consultation undertaken to learn about the experiences of people with autism living in Swindon.

Recommendations are made to inform an Adult Autism Strategy for Swindon in line with national policy, statutory guidance and local need identified through this JSNA.

Information about autism in Swindon is also included in both the [Adult Mental Health and Wellbeing](#) and [Learning Disability](#) Joint Strategic Needs Assessments.

About autism

Autism is known as a spectrum condition, both because of the range of difficulties that affect adults with autism, and the way that these present in different people. Throughout this bulletin, unless otherwise specified, the term 'autism' is used to refer to all diagnoses on the autism spectrum, including Asperger syndrome, high functioning autism, Kanner or classic autism.

Autism occurs early in a person's development. Autism affects the way a person communicates with, and relates to, other people. It also affects how they make sense of the world around them. It affects people in different ways; some can live independently without any additional support, while others require a lifetime of specialist care.

Autism is neither a learning disability nor a mental health problem, although mental health problems are more common among people with autism and it is estimated that one in three of adults with a learning disability also have autism.

Autism is a relatively 'modern' diagnosis; the term 'autism' only came into common clinical use in the 1960s and whilst most diagnosis now occurs in childhood many adults remain undiagnosed. Getting a diagnosis can be a crucial milestone for people with autism; many have felt different and unable to "fit in" for all of their lives.

Those with the condition share three main areas of difficulty, which are sometimes called the triad of impairments.

Difficulty with social communication

People with autism have difficulty using and understanding verbal and non-verbal language, such as gestures, facial expressions and tone of voice. Some might not speak, or have fairly limited speech. They may understand what people say to them but prefer to use alternative forms of communication, such as sign language.

Difficulty with social interaction

Those with the condition have difficulty recognising and understanding people's feelings and managing their own. This can make it hard for those with the condition to make friends and can lead to social isolation.

Difficulty with social imagination

People with autism have difficulty understanding and predicting other people's intentions and behaviour, and imagining situations that are outside their own routine. A lack of social

imagination should not be confused with lack of imagination. Many people with autism are very creative.

People with autism may also experience some form of hypersensitivity or lack of sensitivity. For example to sound, touch, taste, smell, lights or colours can have an impact on how people experience, and cope with, different environments.

Autism is a lifelong condition and people may need to use services at any time in their life. However, every day we hear stories of people with autism who are living successful and rewarding lives: achieving at college, working in fulfilling jobs, and contributing to their local community.

What do local people think?

Understanding what local people with autism and family members and carers think about living with autism in Swindon is essential for developing and improving local services.

A number of methods were used to find out about local people's views and get their feedback on services they use. These included a service user survey which was completed by 91 respondents; and face-to-face consultation at the Swindon Autism Network Event in November 2014. Members of the Autism Partnership Board who work with and support people with autism through their roles in health and social care services and the community and voluntary sector have been involved throughout the development of this JSNA. Information has been gathered from them and other local stakeholders through a series of meetings and network events.

How many people are affected by autism?

Gathering data on the numbers and needs of people with autism at a local level is challenging as historically services have not collected comprehensive data about this population.

Health and adult social care services are likely to know only a small number of all local people with autism because many people are undiagnosed and not all people with autism will come into contact with health and social care services.

The latest prevalence studies of autism indicate that 1.1% of the population in the UK may have autism. When applied to Swindon Borough Council's current estimated population (214,000)

this equates to just over 2,300 people (adults and children) in Swindon.

The Adult Psychiatric Morbidity Survey suggests that autism is more common in males (1.8%) than females (0.2%). Applying these prevalence estimates to the adult population suggests that there are 1,481 men over the age of 18 years with autism in Swindon and 173 women. However, other research suggests that autism is under-diagnosed in females, and therefore the male to female ratio of those who have autism may be closer.

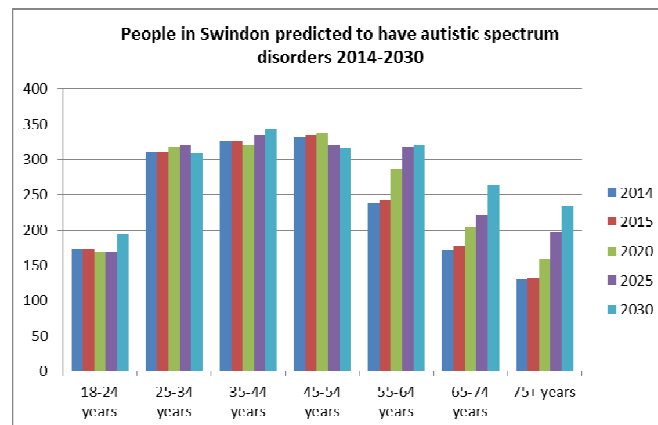
The majority of epidemiological studies on autism do not report or analyse data regarding ethnic background, and those that do produce an inconsistent picture of prevalence amongst different ethnic groups

It is estimated that there are 3,600 to 3,800 adults with learning disabilities in Swindon ranging from mild to severe disability. Around a third of people with a learning disability may also have autism; approximately 1,200 people in Swindon. Only a proportion need support from social care services. The Swindon Learning Disabilities JSNA found that 213 adults with Autistic Spectrum Disorder were known to social care services in Swindon in 2012. Of these 128 (60%) also had a learning disability. This is 22% of the adults with learning disabilities known to social care during. This fits with national estimates that between 20% and 33% of people with learning disabilities known to local authorities also have an autistic spectrum disorder.

Service users were asked through the Swindon survey if they had been diagnosed with any other conditions or disabilities. 52 people responded to this question, of whom 44% said they had a mental health condition; 19% a learning disability; 12% a physical disability and 12% a physical long term condition.

What does the future look like?

Although the prevalence of autism is not expected to change, as the number of people living in Swindon increases, so too will the number of adults with autism from around 1,700 in 2014 to 1,975 in 2030. This is particularly true for older people; the number of people over the age of 65 with autism is expected to grow by 65% from 300 to 500 in 2030.



Source: POPPI and PANSI

There appears to be under-diagnosis of autism in older people and little is known about the experience of ageing in this group. What is known is that people typically experience increased health problems in older age and this may pose particular difficulties for people with autism because of difficulties in recognising and communicating ill health, and in accessing treatments. At the same time as people with autism move into older age their needs and support networks may change. A key challenge for many older adults with autism is that they will have had significant support from their families, but as families age, this becomes less possible and they are a group particularly at risk of loneliness and social isolation.

National policy context

Autism is a national priority. In 2009 the [Autism Act](#) to make provision about meeting the needs of adults with autistic spectrum conditions was published, and the publication of a national autism strategy [Fulfilling and rewarding lives: the strategy for adults with autism in England](#) followed in 2010 together with [statutory guidance](#) for local authorities and NHS organisations to support implementation of the autism strategy.

An update to the strategy [Think Autism Fulfilling and Rewarding Lives, the strategy for adults with autism in England](#) was published in April 2014 and will be supported by new [statutory guidance](#). These updates build on rather than replace the themes of the 2010 strategy.

The clear vision 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 makes the most of their talents.”

The building blocks of the Autism Strategy 2010 are crucial foundations to future work and are expected to be in place in every local area. They are:

Increasing awareness and understanding of autism among frontline professionals

Autism awareness training should be available to all staff working in health and social care and local areas should develop or provide specialist training for those in key roles in order to increase the recognition of autism and enable staff to be better equipped to meet people's needs.

Developing a clear, consistent pathway for diagnosis in every area, which is followed by the offer of a personalised needs assessment

There should be a clear pathway to diagnosis in every area from initial referral through to assessment of needs. Diagnosis should lead to a person centred assessment of need and should be recognised as a catalyst for a carer's assessment.

Improving access for adults with autism to the services and support they need to live independently within the community and helping adults with autism into work.

Ensure that a range of services and support can be accessed by people with autism and that most importantly; opportunities for employment and housing are expanded, challenging the current high levels of social exclusion.

Improving information about the population of adults with autism and enabling local partners to plan and develop appropriate services for adults with autism to meet identified needs and priorities.

The 2014 review highlights fifteen priority challenges for action which have been identified by people with autism, carers, professionals and others who work with people with autism as shown at the end of this bulletin.

Local policy context

The [One Swindon](#) partnership has four key outcomes that underpin all the planning and commissioning that takes place by Swindon Borough Council and Swindon Clinical Commissioning Group. All are relevant to the *Think Autism* vision.

They are:

- We can all benefit from a growing economy and a better town centre.
- I like where I live.
- Everyone is enjoying sports, leisure and cultural opportunities.
- Living independently, protected from harm, leading healthy lives and making a positive contribution

The Joint [Health and Wellbeing Strategy](#) focusses more specifically on health and wellbeing outcomes. Its priorities are also very relevant to the *Think Autism* vision.

They are:

- Every child and young person in Swindon has a healthy start in life
- Adults and older people in Swindon are living healthier and more independent lives
- Improved health outcomes for disadvantaged and vulnerable communities (including adults with long term conditions, learning disabilities, physical disabilities or mental health problems, offenders)
- Improved mental health, wellbeing and resilience for all
- Creation of sustainable environments in which communities can flourish

Swindon has no current local autism strategy. One of the aims of this JSNA is to provide evidence and make recommendations to inform an Autism Strategy for Swindon in line with national policy and statutory guidance.

Swindon does have an Autism Partnership Board as recommended by the national strategy. This includes some dedicated members who have worked hard over the last few years to improve services for people with autism in Swindon. However, consultation with stakeholders and service users identified opportunities for improved communication between agencies and more joint working and information sharing which could be achieved through a strengthened Autism Partnership Board and local Autism Strategy.

What services do people use?

In Swindon there is a range of services and sources of support available to people with autism. Whilst some of these services are health and social care services, the community and voluntary sector play an important role in providing interventions such as information & advice, advocacy, outreach, social groups, and occupational opportunities.

Survey responses also highlighted the hugely important role parents and carers play in supporting people of all ages with autism. A number of respondents expressed concerns about what would happen to them and how they would cope as their parents grew older.

Responses to the service user survey provide some information about the types of services people with autism in Swindon use. 39% reported currently receiving help from health or social care services. For those receiving support the most frequently reported services accessed were GP Practices (30%), mental health support (24%) and counselling and talking therapy (19%).

Some respondents also provided information about other services they are currently using for help and support. These included social groups (68%), information and advice services (32%) and advocacy (24%). Many also commented on the support they received from their family.

Consultation with service users highlighted significant unmet need for support; just 34% of respondents felt they had enough support to meet their needs.

Frequently reported unmet needs included more social activities; relationship advice and counselling; employment support; information and advice about issues such as benefits; and better support and information for carers. Respondents also felt that health and social care staff understanding of autism could be improved.

"Groups where we can learn to understand more about autism."

"Someone to talk to about my problems."

This section describes some of the services available in Swindon that are specifically provided for people with autism. However, those with autism also access a range of universal services. A key challenge is to ensure that these are accessible and staff have the knowledge and training to be able to confidently meet the needs of people with autism.

The Swindon Adults with Autism Spectrum Conditions (ASC) [Directory of Services](#) provides further information about local services.

Assessment and diagnosis

There is a clear assessment and diagnosis pathway for adult autism in Swindon based on

[Adult Autism Diagnostic Assessment NICE guidelines](#). Access is via GP referral.

Swindon's health and social care provider [SEQOL](#) provides assessment, diagnosis and focused post-diagnostic support for adults (those aged 18 and over) who suspect they may have an autism spectrum condition, including Asperger Syndrome. Following diagnosis the service offers signposting towards relevant support agencies, and a follow up session which is primarily "Solution Focussed" in terms of where to go next, how to disclose the diagnosis and provide a Self-Advocacy book.

6 people a month are currently being diagnosed by the SEQOL Swindon autism diagnostic service. Demand is high and there is an 8 month waiting list for the service.

86% of service user survey respondents who provided information about where they had been diagnosed said this had been in Swindon. Just over half (57%) had been diagnosed in adulthood (over 18 years).

Respondents were asked about how they found the process of being diagnosed and if they felt there was anything that could have made it better. Those with a recent diagnosis generally reported a positive experience. However, whilst many said they found receiving a diagnosis helpful many also felt that it came too late.

"It helped explain a lot getting the diagnosis. Still learning what it means as I go forward."

"I was very upset as I realised the past negative experiences were not all my own fault...I know I can't go back to being in my teens and then being diagnosed"

Of those who commented on what they felt would have made the diagnosis process better, 18% said that they felt that more support was needed after diagnosis, and another 15% felt that the time it took from initial discussions with a GP to referral and formal diagnosis was too long. Many felt that GP awareness of autism and the diagnostic pathway should be improved to ensure timely and appropriate referral.

The comments about post-diagnostic support were mixed and many felt that they needed more support than they received.

"Did not have any support after diagnosis - no difference in your life after diagnosis - labelled and left."

“Just got handed leaflets, lists of books to read - one quick follow up appointment.”

“I am still muddling through myself to learn about Aspergers and how I can manage life around me to reduce anxiety impacts etc. I had developed amazing coping strategies myself apparently but help and advice with someone just to understand my triggers better would be amazing.”

Mental health support

People with autism are particularly vulnerable to mental health problems such as anxiety and depression. 44% of Swindon service user survey respondents said they had a mental health condition; this is much higher than the estimated 25% of people in the general population who will experience some kind of mental health problem in the course of a year. Comments provided in the survey highlighted the high burden of mental health problems such as depression and anxiety and obsessive compulsive disorders (OCD) amongst people with autism in Swindon.

SEQOL reports that for many adults autism diagnosis follows contact with a service for support for a primary mental health problem such as anxiety or depression, often following a significant event in their lives, such as the breakdown of a relationship, bereavement, loss of a job or change within their family which they find they are struggling to cope with.

SEQOL works closely with [LIFT Psychology](#), which is the main provider of one-to-one post-diagnostic psychological support for people with autism in Swindon. LIFT Psychology also provides ongoing mental health support for those with autism both through targeted and universal services.

Between November 2013 and 2014 40 patients attended the autism stress and mood management course provided by LIFT; 32 patients and carers attended the Autism Skills workshop and 70 adults with autism were referred for one-to-one therapy.

The service is currently working with SEQOL to pilot a package of Cognitive Behavioural Therapy (CBT) for those with autism. Psychology practitioners at LIFT have become aware of the high prevalence of deliberate self-harm linked to autism and are also developing new ‘Managing Difficult Emotions’ courses tailored for people with autism, which explore

the nature of self-harming behaviours, and introduces skillsets that reduce these.

Information, Advice and Advocacy

There are a number of voluntary sector led services that also support people with autism and their carers in Swindon.

The National Autistic Society Swindon & District Branch provides social events and offers information, support and signposting services for children and adults with autism and their carers. They work closely with other local autism-related groups including SCAAS (Support for Carers of Adults with Asperger’s in Swindon) and [DASH](#) (Discovering Autistic Spectrum Happiness).

DASH is an independent local charity whose mission is to improve the quality of life of adults of working age with Asperger’s and other high functioning Autistic Spectrum Conditions living in Swindon. DASH current activities encompass 6 social groups with the common purpose of reducing social isolation, enabling people to meet other people with the same condition in a safe and supportive environment, to increase skills and confidence in social and work based interactions; providing the Swindon Autism Information & Advice Service; as well as partnership projects with other local services such as [LIFT Psychology](#). Between April 2013 and March 2014 the DASH Information service responded to 180 requests. The social groups have a weekly attendance of between 25 and 35 people.

[Swindon Advocacy Movement](#) is a user led independent advocacy service for people with a learning disability and High Functioning Autism and Asperger’s in Swindon. It provides a specialist advocacy service which supports those with autism to understand their condition better; communicate needs and wishes to family members, carers and professionals; access the Adult Autism Diagnostic Service; and access other services for advocacy and support.

The [Wiltshire Autism Alert Card](#) scheme aims to help those with an autistic spectrum condition who come into contact with the criminal justice system and emergency services to receive appropriate support in difficult situations, and to raise awareness of 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.

Consultation with service users shows that the card has been used by holders with a wide range of services including the Job Centre, GP surgeries, shops and at interviews and when applying for college and has proved a useful tool in providing an explanation for unusual behaviours and raising awareness about autism.

Developing the skills and independence of adults with autism

Swindon service user survey respondents were asked what they felt would help develop their skills and independence.

Increased awareness and acceptance of autism in my community and in local services	74%
More opportunities to connect with other people e.g. social groups, autism peer groups	56%
More help and support for my family, carers and people who support me	42%
More opportunities for education and learning	36%
Support to get a job	39%
Support for employers to help me and others with autism to keep their jobs	53%
Better housing	30%

A large proportion of respondents (74%) commented that improved awareness and understanding amongst health and social care professionals and the public would help them the most.

"I think general awareness and acceptance from the community towards people with disabilities is a good first step."

"Because there is not yet enough awareness of autism in wider society and the particular challenges we face. I think because we look OK people simply do not understand."

Over half (56%) felt they would benefit from more opportunities to connect with other people and 42% identified a need for more help and support for family and carers. There is good evidence that this kind of "lower level" local preventative support can prevent, delay or reduce the care needs of adults with autism and their carers.

30% identified the need for better housing. The JSNA process has highlighted a gap in knowledge about the housing needs of people with autism. Experience of those working with this group is that many have on-going problems with finding suitable accommodation and that those currently living with their parents will have

housing needs in the future when parents are no longer able to manage. It would be helpful to explore this further to help inform housing plans.

The service user survey identified the need for more opportunities for education and learning and support to gain and maintain employment.

For children with autism in Swindon there is a clear transition process in place from children's to adult services which include a strong education and employment focus. However, this hasn't always been the case; only 5 survey respondents said that they had a transition plan for moving in to adult services when they were at school. From the comments made it seems this reflects the age of the respondents and the number diagnosed in adulthood rather than current services.

Education and employment can improve the long-term opportunities of all people with autism. Gathering and interpreting data on education and employment status is difficult because autism affects people in so many different ways and their needs vary widely.

Whilst some with autism also have a learning disability those with Asperger's and high functioning autism are likely to be of average or above average intelligence. Data from the service user survey showed that a larger proportion of respondents had at least 1-4 GCSEs or equivalent than the general UK population. 66% had spent time in college since the age of 19; however fewer had a degree level qualification than the general UK population.

30% of respondents were in paid employment (14% full-time, 16% part time) and 14% volunteered in unpaid work. A very small proportion (4%) said they were currently looking for work.

Demand for further courses or education opportunities focussed mostly on social skills (55%) and practical skills (47%) rather than further or higher education courses.

Many of the comments given about employment highlighted difficulties in maintaining relationships at work and therefore sustainable employment.

"Easy to find - difficult to keep."

"Easy to find but could not succeed in keeping jobs - too hard to socialise with people lack of understanding."

Consultation highlighted some good sources of support in Swindon from local colleges and education and employment services such as DASH. However it was felt that more could be done to improve employer understanding of autism and help those with autism manage relationships in the workplace.

Recommendations

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

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.
8. Work towards achieving [NICE best practice for access to diagnostic services](#); where people seeking an autism diagnosis have a first appointment within 3 months of their referral as set out in the NICE Quality Standard on autism [QS51].
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.
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.

Acknowledgements

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Where to find more information

Background documents and other Swindon JSNA Briefings can be found on Swindon's [JSNA website](#).

Further information about the 'Think Autism' government adult autism strategy can be found [here](#).

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

The 15 Priority Challenges for Action – *Think Autism* National Strategy

An equal part of my local community

1. I want to be accepted as who I am within my local community. I want people and organisations in my community to have opportunities to raise their awareness and acceptance of autism.
2. I want my views and aspirations to be taken into account when decisions are made in my local area. I want to know whether my local area is doing as well as others.
3. I want to know how to connect with other people. I want to be able to find local autism peer groups, family groups and low level support.
4. I want the everyday services that I come into contact with to know how to make reasonable adjustments to include me and accept me as I am. I want the staff who work in them to be aware and accepting of autism.
5. I want to be safe in my community and free from the risk of discrimination, hate crime and abuse.
6. I want to be seen as me and for my gender, sexual orientation and race to be taken into account.

The right support at the right time during my lifetime

7. I want a timely diagnosis from a trained professional. I want relevant information and support throughout the diagnostic process.
8. I want autism to be included in local strategic needs assessments so that person centred local health, care and support services, based on good information about local needs, is available for people with autism.
9. I want staff in health and social care services to understand that I have autism and how this affects me.
10. I want to know that my family can get help and support when they need it.
11. I want services and commissioners to understand how my autism affects me differently through my life. I want to be supported through big life changes such as transition from school, getting older or when a person close to me dies.
12. I want people to recognise my autism and adapt the support they give me if I have additional needs such as a mental health problem, a learning disability or if I sometimes communicate through behaviours which others may find challenging.
13. If I break the law, I want the criminal justice system to think about autism and to know how to work well with other services.

Developing my skills and independence and working to the best of my ability

14. I want the same opportunities as everyone else to enhance my skills, to be empowered by services and to be as independent as possible.
15. I want support to get a job and support from my employer to help me keep it.