

## **Autistic Spectrum Conditions: access to support in Bradford and District**



**September 2018**

## Foreword

In January 2017 we published a report on people's experiences of seeking diagnosis for autistic spectrum conditions (ASC). This found that people struggled to get a referral for assessment, and were often waiting a very long time to receive their diagnosis.

The report can be found here:

<http://www.healthwatchbradford.co.uk/news/people%E2%80%99s-experiences-autism>

Both during and after this work, we also heard from people who wanted to share their experiences of trying to get support. The National Autistic Society notes the importance of support to living well: 'All autistic people share certain difficulties, but being autistic will affect them in different ways.'

Some autistic people also have learning disabilities, mental health issues or other conditions, meaning people need different levels of support. All people on the autism spectrum learn and develop. With the right sort of support, all can be helped to live a more fulfilling life of their own choosing.'

Support for autism includes a wide range of activities, tailored to the particular needs of autistic people. This includes needs assessments, housing and supported living, support to find employment, leisure activities, skills workshops, peer support, specialist counselling, support to access mainstream health services, education support, and benefits including Personal Independence Payments, Employment Support Allowance, and Universal Credit (as well as help to apply for these).

This report explores access to support in depth, and sets out a number of recommendations to providers and commissioners.

## Healthwatch Bradford and District

On the 1<sup>st</sup> April 2013 under the provisions of the Health and Social Care Act 2012, 152 Local Healthwatch organisations were established throughout England.

The aim of local Healthwatch is to:

- Strengthen the collective voice of citizens and communities in influencing local health and social care services to better meet their needs.
- Support people to find the right health and social care services for them by providing appropriate information and signposting.
- Encourage and support people and groups to share their views about services; listen to people's needs and experiences of services.

We achieve this by:

- Listening to people, especially the most vulnerable, to understand their experiences and what matters most to them.
- Influencing those who have the power to change services so that they better meet people's needs now and in the future.
- Empowering and informing people to get the most from their health and social care services and encouraging other organisations to do the same.



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## Background to this report

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<sup>1</sup> <https://www.autism.org.uk/about/what-is/asd.aspx>

## What we heard: Summary

This report is based on conversations with, and stories from, people with lived experience of ASC, their families and carers. In developing this work we also had useful background conversations with those working with people with autistic spectrum conditions.

We heard:

- People struggle to find out information about the pathway for diagnosis, the support available, and about their condition.
- While increased resources have been made available for diagnosis, demand still far outstrips capacity, as the diagnosis service for adults, Bradford and Airedale Neurodevelopment Service (BANDS), remains closed to new referrals.
- To access a diagnosis now people either have to make an Independent Funding Request through their GP for diagnostic assessment out of area, pay for private assessment which many can not afford. Otherwise they have to wait for BANDS to reopen.
- Specialist support for autism is vital to people's wellbeing, helping them socialise, learn skills, stay in education and employment, and manage their mental health. Despite this, we heard that people struggle to access the support they need.
  - Without a diagnosis, people are unable to access services.
  - There is limited support available for people even with a diagnosis, meaning people are forced to use support that is not designed for autistic people, or is insufficient to meet their needs.

- The support that is offered can be short-term or inconsistent, and people can find the help they are getting is reduced after a while.
- There is a lack of understanding about ASC among GPs and other professionals including dentists, those working in schools, and social workers, which can make it difficult for people to access diagnosis and support, but can also leave them shut out of other support such as primary care.
- Because services do not understand their communication needs, autistic people often struggle to understand the information provided to them, or to engage effectively with healthcare professionals.
- The cumulative impact of these issues can have a devastating effect on the mental health of autistic people and their families.

The effect of these issues is severe, both for those on the autistic spectrum and their families and carers. We heard again and again about the impact that not being able to get a diagnosis, not having the information they need, and not being able to access effective and appropriate support has on every aspect of their lives.

The impact on mental health was stark; so too the impact on people's education, their life chances, and their ability to live a life that they find fulfilling.

## National Policy

In 2014, the government launched a new autism strategy, *Think Autism*<sup>2</sup>. This builds on, rather than replaces, the previous strategy *Fulfilling and Rewarding Lives*<sup>3</sup>, published in 2010.

The new strategy sets out three key proposals:

- Autism Aware Communities - local awareness projects to be established with pledges for local organisations to work towards.
- Autism Innovation Fund - for projects that promote innovative local services, particularly those providing support for preventing crises.
- Better data collection and more joined up advice and information service.

In 2015, the government published new statutory regulations<sup>4</sup> to support the implementation of the Adult Autism Strategy. This sets out the legal requirement and expectations of both local authorities and NHS commissioners and providers.

Key expectations within the statutory requirements include:

### Local authorities, NHS bodies, and NHS Foundation Trusts should:

- Ensure autism awareness training is included within general equality and diversity training programmes for all staff working in health and care.

2

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

<sup>3</sup> <https://www.gov.uk/government/news/fulfilling-and-rewarding-lives-the-strategy-for-adults-with-autism-in-england>

- Use appropriate communication skills when supporting a person with autism.
- Ensure those in posts who make decisions about the lives of adults with autism, including psychiatrists and those conducting needs assessments have a demonstrable knowledge of autism, including how it presents across the lifespan, levels of ability, communication needs, relevant pathways and screening tools, and the common difficulties faced by autistic people and their families.

### Local Authorities must:

- Ensure that any person carrying out a Care Act 2014 assessment has the skills, knowledge and competence to carry this out. If the assessor does not have experience of autism, the local authority must ensure that a person with that expertise is consulted.
- Under the Care Act 2014, assess people who may be in need of community care services. This duty applies to people with autism, and is not dependent on them having been formally diagnosed as having autism.

### NHS England should:

- Ensure that GPs have adequate training in autism beyond general awareness training and a good understanding of the local diagnostic pathway.

4

<https://www.gov.uk/government/publications/adult-autism-strategy-statutory-guidance>



### **Local Authorities should:**

- Ensure that autistic people are aware of the right to access a needs assessment (for the adult) and a carer's assessment (for the carer).
- Ensure there is a meaningful local autism partnership arrangement that brings together different organisations, services and stakeholders locally, including the CCG, and people with autism, and sets a clear direction for improved services.
- Allocate responsibility to a named joint commissioner/senior manager to lead commissioning of care and support services for adults with autism in the area.
- Ensure that they include in local autism plans how people can access local autism advice and information easily in a way that is appropriate and identifiable for people with autism.

### **Local Authorities, NHS bodies with commissioning responsibility should jointly:**

- Consider and include the number of people with autism in their area as part of the Joint Strategic Needs Assessment (JSNA). It will typically be necessary (as a minimum) to gather information about the number of adults known to have autism, the range of need for support to live independently, and the age profile of autistic people in the area.

### **NHS bodies and NHS Foundation Trusts should:**

- Provide access to services that can diagnose autism, and its frequently associated medical and mental health conditions.
- Ensure that people with autism have equal access to local psychological therapy services, e.g. IAPT. If IAPT cannot help an autistic person directly, arrangements should be made so that other appropriate local services can provide support.

### **Clinical Commissioning Groups should:**

- Designate a health lead responsible for developing, maintaining and promoting a diagnostic treatment pathway (Local Authorities should work with the CCG to help ensure this).

### **Local Authorities and NHS bodies should jointly:**

- Ensure the provision of an autism diagnostic pathway for adults including those who do not have a learning disability and the existence of a clear trigger from diagnostic to local authority adult services to notify individuals of their entitlement to an assessment of needs.

NICE guidelines state that people should wait no more than three months for a diagnosis assessment. In September 2017 the government committed to collecting data on the length of time people wait for diagnosis.



# Autism spectrum conditions in Bradford and District: diagnosis and support

## Children and Young People

There are a number of different options for seeking a diagnosis of autism for children and young people. They, or their parents, can contact their GP to ask for a referral. For children who are pre-school age, midwives or health visitors may be the first contact for a parent who may be concerned. For children of nursery or school age, parents can to speak to the Special Educational Needs (SEN) co-ordinator in the nursery or school. Bradford Child and Adolescent Mental Health Services (CAMHS) currently provides assessment and diagnosis for children over 12 in Bradford, and over 7 in Airedale.

The SEN co-ordinator may be able to help in obtaining an individual Education, Health, and Care Plan (EHCP), a plan of care for children and young people aged up to 25 years who have more complex needs. Parents can also independently request an SEN assessment (EHCP), with or without a diagnosis. A referral might be made to the Child Development Team which could involve a range of specialist clinicians. The Bradford Portage service offers a home visiting and an early education support group service for pre-school children.<sup>5</sup>

Further information relating to children can be found via the Bradford Local Offer:

<https://localoffer.bradford.gov.uk/>

Support for autistic children and young people is provided by:

- AWARE - Airedale and Wharfedale Autism Response. A parent-run group supporting families with children and young adults on the autistic spectrum (formal diagnosis not required): <http://awareuk.homestead.com/>
- Aspire - supporting the autism community. A parent-run support group for families who have children on the Autistic spectrum aged 0-25 years. Their child does not need a diagnosis to access the group: [https://www.facebook.com/ASpire-supporting-the-autism-community-815882405173641/?ref=page\\_internal](https://www.facebook.com/ASpire-supporting-the-autism-community-815882405173641/?ref=page_internal)
- Barnardo's Cygnet Service, a parenting support programme available to parents of autistic children aged 5-15: [http://www.barnardos.org.uk/cygnet/yk\\_cygnet-bradford\\_district\\_services.htm](http://www.barnardos.org.uk/cygnet/yk_cygnet-bradford_district_services.htm)

Some support is available through these organisations to children without a formal diagnosis.

National autism charities also provide vital information and support to parents, including the National Autistic Society (NAS)<sup>6</sup> and the Autism Alliance<sup>7</sup>. There are a number of local branches of NAS operating, including in Keighley<sup>8</sup>.

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<sup>5</sup> <https://www.portage.org.uk/bradford-portage-service>

<sup>6</sup> <https://www.autism.org.uk/>

<sup>7</sup> <https://www.autism-alliance.org.uk/>

<sup>8</sup> <https://www.autism.org.uk/directory/resources/16909.aspx>

## Adults

For adults seeking a diagnosis, the first point of call should be the GP. If appropriate, they would then make a referral for assessment by Bradford and Airedale Neurodevelopment Service (BANDS). However, this has been closed to new referrals since April 2016, and is currently working through a backlog of referrals. Following feedback received via Healthwatch, the Clinical Commissioning Groups, which commission this service, are currently looking at the level of provision for diagnosis with additional funding to be provided to tackle the waiting list.

The alternative for diagnosis is to pay for one privately, or for the GP to make an Individual Funding Request (IFR) for diagnosis outside the area. However, this process has strict criteria that people would need to meet to obtain this funding. Information about making an Individual Funding Request in Bradford is available on the Bradford District CCG website.<sup>9</sup>

Following diagnosis, a social worker will take a case for funding for support to a Funding Panel. This will consider any contribution the individual will need to make towards the services they receive. Support for adults with autism in Bradford is provided by Specialist Autism Services<sup>10</sup>. This is paid for either through a Personal Budget or commissioned by the Local Authority. It is only available to people who have a formal diagnosis. HFT also provides some support for adults with autism, commissioned by the local authority.



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<sup>9</sup> <http://www.bradforddistrictscg.nhs.uk/about-us/what-we-do/individual-funding-requests/>

<sup>10</sup> <http://www.specialistautismservices.org/>

## **Bradford District and Craven Autism and other Neuro-diversity Strategy**

The Bradford Autism Partnership Board was established to help improve local support. It included representatives of organisations working with people with autism, commissioners and providers, and Healthwatch.

In 2017, the Board developed a Bradford District and Craven 'Autism including other Neuro-Diversity Strategy'. The strategy was discussed by the Transforming Care Partnership in spring 2018, and the CCG and Bradford Council are now discussing, with the voluntary sector, how to put this into practice. The final strategy has not yet been published.

Funding for support from the council for the Bradford Autism Partnership Board has been cut, and council officers are currently looking at how the engagement that the board offered can be continued.

## **West Yorkshire and Harrogate Health and Care Partnership**

The West Yorkshire and Harrogate Health and Care Partnership brings together health and care services across the area to work together and provide more integrated services. The partners have a commitment to work collaboratively on autism, to drive forward improvement. The focus is on assessment and diagnosis, as well as looking at provider and market development around autism specialist housing.

The partnership is hosting an initial adult autism workshop in September. This will bring together the providers of autism assessment and diagnosis to share learning, good practice, look at variance and determine what could be worked on collectively to improve waiting times.

## Methods

This report takes an all-age approach. It draws on the stories and experiences of children, young people, and adults.

Our findings are based upon what we heard from people with autism, and their families, through a variety of methods and sources. We carried out face-to-face interviews with people with autism, and their carers, with assistance from their support workers. We also received stories from people with lived experience who contacted Healthwatch directly, by phone, email and through social media. In some cases we followed this contact up to ask for clarification or more detail. We also heard from people who we met at our regular outreach sessions.

Overall 21 people contacted us or spoke to us directly and 10 were interviewed face to face. The information was then analysed and the main themes identified. These are set out below.

We have also met with those working for the CCG, the council and local providers to gain an understanding of the current situation in terms of diagnosis, specialist support, and the progress of the strategy and partnership board.





## Access to diagnosis

Unsurprisingly, given that BANDS remains closed to new referrals, we continued hear from people who had experienced substantial waits for a diagnosis.

*“My son would believe his diagnosis is helpful. It’s an explanation for why he has the difficulties he does.”*

*I was referred to the service by my GP in [late] 2015. At the time I was told that the waiting time was approximately 6 months, which is twice the maximum length stipulated by NICE. By May 2016 I had heard nothing so went back to my GP...I was told that the waiting list had increased to about...12 months. In [late] 2016 I enquired again and was told that it could be up to 2 years wait. In [summer] 2017 I...was told that I was 72<sup>nd</sup> on the waiting list and that it would likely be [spring] 2018 when I would be seen...I was also offered a screening assessment the following week, which I accepted. [They] recommended that I remain on the waiting list for a full assessment since I show many autistic traits. She estimated it would be potentially another 12 months before would be able to be seen however. This would take my total wait to nearly three years, instead of the three months stipulated by NICE. Three years waiting time is wholly unacceptable.”*



These delays leave people in limbo, meaning that they cannot get an explanation of the difficulties they are facing, but also, crucially, leaving adults in particular unable to access care. We heard that this could have a deleterious impact on people’s lives, including their access to education and employment, and on their mental health.

## Specialist support for autism

We heard from a number of people about how vital specialist autism support is to helping people live well, with one person describing it as a ‘lifeline’.

People told us that they enjoy the support they receive, and that they gained confidence and independence from either the one-to-one or group support they accessed.

*“I am very grateful for the specialist service. I would say it’s been a lifeline. People with autism are such one-offs. They all function very differently. Their needs don’t fit with a time-limited way of working. Their lives are difficult.”*

*“The support is “awesome, very helpful. I learn a lot of new things”*

*“Gives me a chance to socialise with people and get away from the house. I get to go to places I wouldn’t expect to go.”*

*“We look after each other really. I like to see my friends. I’ve got friends here.”*

However, we heard many stories about how difficult people found it to access specialist support for their autism, either because they cannot access a diagnosis, or because of the capacity within the service.

Those who had been unable to access a diagnosis found themselves being referred to inappropriate services, in particular mental health services, in the meantime. These services were not equipped to help them with their autism-specific needs; nor were staff in those services trained to understand the needs of people with autism.

Several people told us that they were passed from service to service without finding the support they needed. This could last for years, creating confusion and anxiety.

We also heard that people felt they were not always accessing the type or level of support they felt they needed. One issue that was raised was that people felt the social workers charged with carrying out needs assessments did not have the necessary experience or expertise.

*“Untrained social workers doing needs assessments- may be able to tick box that they’ve had 2 hours autism training.”*

*“Some social worker comments on assessments weren’t accurate, are misleading.”*

*“Adults with ASC will always have ASC and this will impact on them differently at different stages of their lives, access to support should be made available at a point when they need it.” (Parent of autistic person)*

## Accessing funding for specialist support

Accessing funding for specialist support involves a social worker putting forward a funding package/plan to the council's Funding Panel. We heard that this was a difficult process, and that people felt that the outcome was a lottery. Access to a social worker is limited and can take a long time to secure, and success in applying for funding can depend on the skills of the individual social worker.

People told us that that some social workers had a good understanding of autism, and were willing to “fight” to get the funding they need. However, others were described as having little understanding of autism or how to approach someone with autism.

*“It was hard to get the funding and his social worker had to fight hard for him to receive funding to go four days a week. He was ‘excited’ when he found out the news.”*

*“My child has support from two services now but only one is Autism specific, would have liked 5 days with them, but there is not enough funding.”*

*“You have to find the right service for Autism, but social services won’t fund it.”*

People also raised concerns that members of the Funding Panel itself do not have the specialist understanding of Autism needed to understand people’s level of need: one

person told us that the panel is “Learning Disability specialists with no understanding of Autism”.

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## Transition from child to adult services

Most of the people we spoke to who had moved from child to adult services found the transition difficult. In particular, we heard that information was difficult to access and hard to understand:

One person told us they received no information about transition, *“all was word of mouth - someone told me about a specialist service but I had to seek it out.”*

It is essential that this transition, whether in support for autism, mental health or other needs, is managed in an autism-aware way, as periods of change can be particularly

unsettling for a person with autism. However, we did hear a positive experience from one parent, who told us:

*“Transition workers were helpful, and there were helpful services that communicated with me about my child.”*

Peer support workshops are currently being rolled out across the Yorkshire and Humber region to enable more shared good practice and work including on transitions.



## Access to primary care

Primary care, particularly GPs, can be vital in helping people to access diagnosis and support, but also to help them live well with ASCs. We heard that people have mixed experiences at their GP surgery, and that a lack of understanding of the condition among GPs and other practice staff can make it difficult to access health care.

We also heard that it can be particularly important to autistic people be able to see the same GP, both because they would know the individual's condition, but also because this offers people the reassurance of seeing someone they already know.

People reported mixed experiences with their GP. Communication with GPs was a common concern, which seems to reflect a lack of understanding of the needs of people with ASC.



*“We had difficulties with our GP wanting to reduce medication, who didn’t want to listen to history of behaviour, and communication unclear.”*

*“Doctors are all as bad as each other - I don’t feel they understand the condition. Receptionist could have been more helpful when moving to another GP practice. They could make it clearer what needs to be done for appointments.”*

*“I don’t think my autism is flagged when I sometimes have to see other GPs. It’s better if they do know, but it’s not essential.”*

A better understanding of the autistic spectrum conditions could make a difference in how people are able to access primary care. One person told us:

*“I don’t like visiting the GP...getting up early to phone for triage. It’s a wheel of fortune regarding which doctor you get. We’ve had so many doctor changes, we never see the same person twice.”*

Other practices seemed better prepared to adapt how they work with autistic people.

*“[Our] family GP is very good, surgery know to book late appointments when surgery is quiet. GP knows my son and understands his condition.”*

*“Now he sees the same GP each time, which is much better, but she [the GP] thinks he’s only flagged as having a learning disability, no Asperger’s. I feel they’ve been quite sympathetic and understanding and helpful within the limitations they have themselves. I always have to accompany my son.”*

These challenges were also experienced by people trying to access other types of primary care, such as dentistry - one person told us that he feels his new dentist does not understand his needs, but that because the appointments are only every six months, they cannot get to know them.

We also heard some examples of how a lack of understanding of autism spectrum conditions can affect access to secondary care:

*“BRI turned us away when using X ray, it was too distressing and they didn’t understand the condition.”*

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## Accessing mental health services

We heard that mental health providers often do not have a good understanding of autism, which affects people’s ability to access appropriate treatment.

*“Trying to access mental health services has been a long process, getting my son to go to appointments takes a lot of preparation - it would help if home visits were possible.”*

*“My son was diagnosed at 7 years old privately, through a GP referral, this was a thorough assessment which was managed well. However, adult access to mental health services has been difficult.”*

People also found that mental health services are not sympathetic towards people who struggle with appointments, or who need support to attend. This can lead to a merry-go-round of re-referrals, long waits, and no support in the meantime.

*“Professionals encountered in mental health services and general health services had little to no understanding of ASCs, they tried to understand but didn’t use correct approaches which often led to distress of [my] son following appointments. Time frame was also short for ASC’s needs, e.g. counselling sessions [NHS standard] were 6 weeks but didn’t give enough time for my son to become comfortable.”*

*“[Our daughter] has had a 12 months stay as an inpatient [at a mental health service]...It’s been a horrible experience - she was taken straight from day service to being admitted as an inpatient because of violent behaviour - no one understood.”*

This lack of understanding can mean people are penalised for not attending appointments:

*“I couldn’t go to all my appointments at a [mental health service] because of my anxiety. I tried ringing but they told me I had lost my CPN because of it. I am now in trouble and I need housing.*

*I don’t know where to go or what to do. I had CBT but it didn’t help because I couldn’t understand what she was talking about and came away in a worst state, she didn’t understand me or Aspergers.*

*People need to know I didn’t not attend on purpose, I needed support to attend the appointments. I have now been told I need to go back to my GP and go on the waiting list for another CPN but that could take weeks.”*

We also heard that people may be offered forms of support that are inappropriate given their needs, such as group therapy they cannot cope with, to then be labelled as ‘not participating’.

Mental health services should be autism friendly, particularly given the impact that autism can have on people’s mental wellbeing where they do not have access to appropriate levels of support. Staff in these services should be offered training to understand not only the impact that autism can have on people’s mental health, particularly if they are unsupported, but also how ASCs can affect their communication and other needs.



*“We need more autism specific counselling services since, as a parent I don’t feel understood by services.”*

## Impact on education

Although Healthwatch does not report on educational services, for many people we spoke to, difficulties getting the support they needed at school was an important part of their story. We heard that when children

and young people struggled to get a formal diagnosis, or the support they needed, it could have an ongoing effect on their education and their ability to socialise at school.



*“Secondary school never gave me the social and emotional support. The SEN worker refused to contact CAMHS because the school I went to didn’t recognise autism as existing.”*

*“When I went to school I was bullied and people picked on me and laughed...I had a really bad stutter and was teased. The SEN teachers at school didn’t know anything and didn’t offer any support. A few years ago I went for therapy for my stutter and it is now much better. I had no support in any school - primary, middle or secondary schools offered no support. I was frustrated and had anger issues, but I kept everything inside for 20 years.”*

The school environment can be challenging for a young person with autism, meaning that a good understanding of the condition, and appropriate support can be vital to enable people to be able to engage fully in their education.

Some schools were seen as offering important support. One parent told us how she felt lucky that her daughter’s diagnosis had only taken 18 months:

*“One school I was only at for a few months because it was too crowded and stressful. The younger I was, the harder my autism was to manage.”*

*“Those on the spectrum can lead perfectly fulfilled lives if only the support is put in place early enough. I’m now struggling with obtaining an Education, Health and Care Plan as this has been difficult but my child needed additional support in school and the school fought hard to get it.”*

*“I’m someone who likes a really settled routine. It was all over the place. Sometimes it [college] finished at 5. Sometimes it finished at 12.”*

## Information and communication

Since August 2016, all organisations that provide NHS care or publically funded adult social care are legally required to follow the Accessible Information Standard.<sup>11</sup> This sets out a specific, consistent approach to identifying, recording, flagging, sharing and meeting the information and communication support needs of patients, service users, carers and parents with a disability, impairment, or sensory loss.

Despite this, we heard that people with autistic spectrum conditions are often provided with information they cannot understand or process, and are asked to respond using methods they find difficult, for example by telephone rather than face-to-face.

*“I would need to know where to get the information from and couldn’t understand it without support.”*

*“I need support to do all written things, and I struggle to read and process information.”*

*“Professionals need to take more time to explain things.”*

*“The information and support from GP have been good, but follow on services have not been so good.”*

*“My experience was not good at all, there have been regular appointments but feel that communication is very poor, when asking questions services take the first answer but Autism is not taken into account. There are very few strategies to deal with Autism.”*

*“It’s not easy to understand the terminology used unless you are really familiar with the condition, or a clinician.”*

*“I didn’t get any information, and they never send anything except appointment letters.”*

*“I feel that information is not easily available for adults who have a learning disability and mental health, I have to read and explain what doctors or psychiatrists are saying and spell it out easier.”*

Health, social care and other services should ensure that information is clear and accessible to autistic people, and staff should be trained to understand how autism can affect how people communicate and to tailor their interactions with autistic people accordingly.

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<https://www.england.nhs.uk/ourwork/accessibleinfo/>

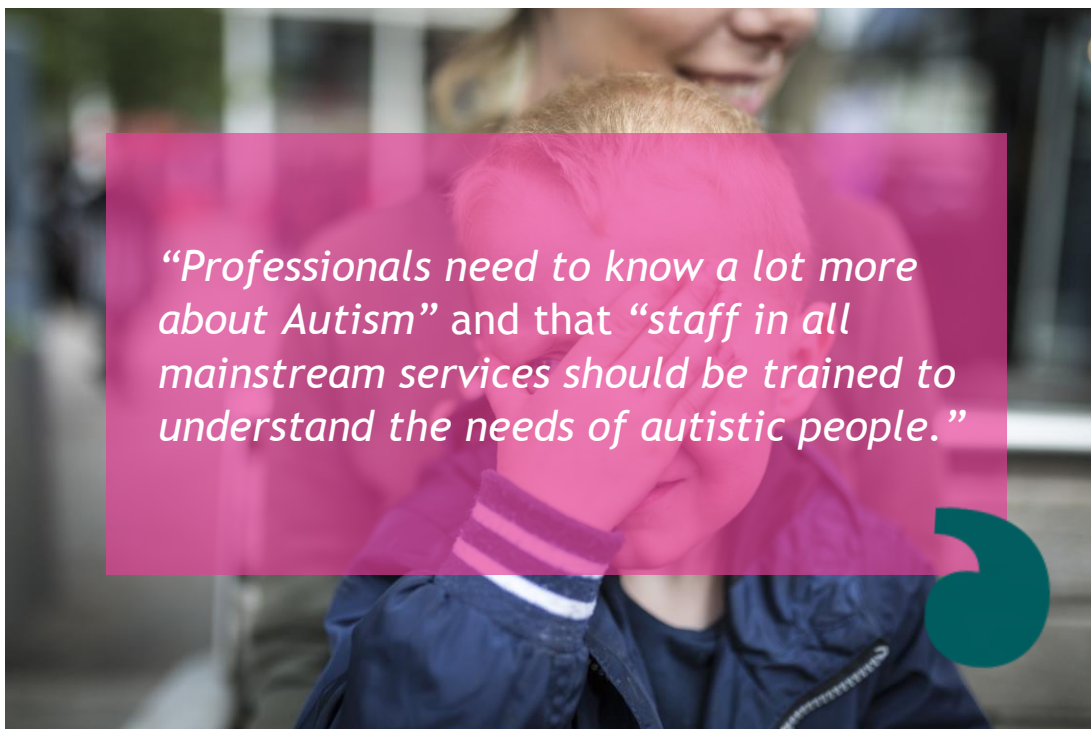


## Accessing other support

The need for a proper understanding of autism, and for clear and accessible information and communication, goes beyond autism-specific support. We heard that information and forms are not always easy for people with autism to understand - letters setting out what the individual needs to contribute towards their support were not user-friendly, creating anxiety and stress. Any professionals interacting with autistic people need to be aware of their needs and able to tailor information accordingly.

We heard from support workers that people with autism often experience difficulties when accessing assessments under the Care Act 2014, for personal budgets, for financial contributions, and when trying to access benefits and support such as Personal Independence Payments. Staff carrying out assessments often lack any understanding of the way in which autistic people may interpret what is being asked of them, or how autism can affect their day to day lives.

### We heard that:



## The effect on autistic people and their carer

We heard powerful testimonies setting out the devastating impact a lack of support can have on people. Several people told us that

they had felt desperate, vulnerable, and suicidal at times, or had self-harmed because support has not been in place, or had been reduced or withdrawn.

*“The lack of emotional and psychological support has led to having poor mental health - the first time I wanted to kill myself was in year 8. When it really kicked in I was about 15.”*

*“I was funded through Bradford and went for an assessment [for being on the spectrum] but it was not successful. I had been to-ing and fro-ing between my social worker and [a mental health service] but nothing happened. I was angry and frustrated. I couldn't sleep and was panicky and worried. I got desperate and self-harmed and [attempted suicide] - I was in A&E nearly every week. I was head-banging and very angry. Funding in Bradford was poor. I was diagnosed a few years ago in my late 20s.”*

One parent we met had taken her adult son to the GP after he had made a threat to take his own life. She was concerned about his mental health and also how his behaviour exacerbated his isolation. He had already been diagnosed with neurological conditions but she wanted an ‘assessment of his functioning’. The GP was sympathetic and discovered BANDS.

However, at that time, there was a two-year waiting list, and they were not accepting new referrals. Instead, her son was referred onto a [mental health service] but when they went there they were told that ‘just because they [BANDS] don't have a service you can't just come here.’ They assessed his mental health but it was not what she had set out to find.



We also heard about how parents and families can struggle because of the lack of support available to them, and to autistic people.

*“As a carer I didn’t know who to turn to when my son’s mental health dipped with OCD and depression, I felt out of my depth e.g. a chat with a professional for mental health advice, CBT wasn’t suitable for my son, filling in diaries wasn’t helpful.”*

*“There are no information leaflets so you can take in info at your own pace.”*

*“Parents are afraid of cuts to individuals’ funding that they don’t ask for support themselves.”*

Parents told us what would help them support their children and manage better:

- Help to manage challenging behaviours.
- Respite services specifically for autism.
- Would like things explained better.
- Seems like there’s a lot of support in child services but not adults, adults’ needs are complex.
- Old system was good, a named social worker for my daughter who knew my daughter and family history - one named social worker for life. This no longer happens and there is no personal touch any more.
- More awareness of the condition itself.
- To be in a service that just deals with Autism and nothing else.
- More support for them, help around the house, respite time etc.



## Conclusion

Autistic people in Bradford are currently struggling to get the help that they need to live a fulfilling, happy, and independent life. The ongoing problems with access to diagnostic assessment have left people in limbo, in some cases for several years. Without a diagnosis, adults in particular are unable to access support, which can make it difficult to live well, stay in education or employment. It can also have a negative effect on people's mental health.

However, even where people are able to secure a diagnosis and access specialist support, they often still struggle. While the support available is welcomed, people often feel that they are not offered enough. The process of accessing funding can be challenging, and professionals do not always have sufficient understanding of autism to help them.

A lack of autism awareness was reported across a wide range of professionals, including GPs, mental health workers, social workers, and those carrying out Care Act 2014 and other assessments. This can leave people without the support they need, and can be upsetting and frustrating.

There is limited information available about diagnosis pathways and support in Bradford, which can make it more difficult still to get support. Health and other information is often not tailored to the particular needs of people with autism which can affect their access to healthcare as well as other services.

It is vital that these issues are addressed. We welcome additional funding to address the waiting list for BANDS, but believe more needs to be done to ensure that people with autism can leave happy, healthy and independent lives - and to fully meet the statutory regulations relating to autism. People need to be able to access support before receiving a formal diagnosis, and better information is urgently required to help people understand the pathway, and where to turn for help.

Greater awareness and understanding of autism is needed to ensure that people can live well and access the services to which they are entitled. All staff across the local authority and NHS who are likely to work with autistic people should be trained to have a proper understanding of how this affects people, and how to best support them.

We hope that the Council, NHS, voluntary sector and wider autism community can come together to work in partnership to improve support available to people with autism.

## Recommendations

Given the stories that have been shared with us by autistic people and their families across Bradford and District, we recommend:

1. The implementation of the Autism Strategy and other Neurodiversity including the Implementation Plan and Training Strategy, and the appointment of a named local lead for the local authority and CCG.
2. Provision of a service for diagnosing Autism and other Neurodiversity either by re-opening or re-organising BANDS so it is fit for purpose, or commissioning a new service to facilitate undertaking diagnoses of Autism to include those on the current waiting list and those waiting to be referred onto it.
3. Collection and publication of length of time to diagnosis for people with autism in Bradford.
4. Bradford should become an *Autism Friendly City*, with health services and the Council aiming for the National Autism Society's Autism Friendly Business accreditation.<sup>12</sup> GP practices and other organisations who will support people with autism should be encouraged to apply for this.
5. Continuous professional development training should be made available, ideally compulsorily for NHS and council staff, to improve understanding of autism and how to ensure services are fully accessible to people with autism and other neuro-diversity. This should be made available to all staff who may come into contact with autistic people, including those performing financial and Care Act assessments, mental health services, learning disabilities services, and Bradford's First Response service.
6. Access to autism-specific services should be improved, and made available while waiting for a diagnosis. This is particularly urgent while significant delays to diagnosis remain.
7. Clear and accessible information on Autistic Spectrum Conditions and other Neurodiversity, and on accessing diagnosis and support, including support for carers, in Bradford and District, should be easily available in one place. This should be co-designed with people with lived experience to ensure it meets their needs.
8. Support for parents, families, and carers should be expanded. This should include clear information about autism, diagnosis and support.
  - A clear pathway should be set out that enables parent/carers and autistic people themselves to identify where they are, and what help is available at any point. This should include a pathway for transition from child to adult services.
  - The Barnardo's Cygnet programme should be opened up to parents/carers who are waiting for diagnosis.
  - Peer support should be easily available.
  - Online 'good practice' examples of other families' experiences, aspirations, and practical ways forward should be made available.

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<sup>12</sup> <https://www.autism.org.uk/professionals/autism-friendly-award.aspx>

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To find out more about Healthwatch, or to discuss this report please get in touch.

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