

Autistic Spectrum Conditions: What We've Heard So Far

January 2017





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Acknowledgements

Healthwatch Bradford and District would like to thank everyone who contacted us directly and those who have met with us to talk about their individual experiences at support groups in Bradford. We appreciate people taking the time to give us their feedback.

The word cloud on the title page gives a visual representation of the frequency of words used by people who have spoken to Healthwatch Bradford about Autistic Spectrum Conditions.



Healthwatch Bradford and District has heard from several members of the public about their experiences of Autistic Spectrum Conditions (ASC). We have heard how difficult it is to find information about the pathway for referral and to get a referral for diagnosis, how long people are waiting for assessment, and how there is lack of support for people with ASC and their families.

As a result of those concerns, Healthwatch decided to speak to more people with ASC, carers, family members and professionals working in this area to gain a fuller understanding of the issues. This report details the experiences of the people we spoke to. The common themes appear to be:

- no clear pathway to diagnosis of ASC for either children or adults
- concerns with the length of time it takes to get diagnosis
- insufficient support available for people with ASC in the area, especially if they don't also have a learning disability or mental ill health
- poor understanding of ASC within health services, particularly primary care
- significant variation in the level of knowledge and understanding of ASC in schools and nurseries
- difficulties in transition from children's services to adults'
- difficulties in obtaining employment as a result of poor understanding of ASC

Healthwatch was concerned that there was no current pathway or strategy in place for ASC, and that there were gaps in the system that were leading to poor experiences. We raised these issues with City of Bradford Metropolitan District Council (BMDC) and local health commissioners, who are jointly responsible for services relating to disabilities, mental health and autism.

People who talked to Healthwatch told us there was no clear referral pathway for referrals for assessment or diagnosis - this was the case across all ages spanning children to older adults.

Some people described a 'lottery' of response for children thought to be on the autistic spectrum - families' experiences varied and seemed to be dependent on individual staff and their receptiveness to or knowledge of the condition and willingness to refer. Some parents reported feeling 'demonised' by school staff and perceived their child being labelled as 'disruptive' or 'difficult'. In some instances, children have been excluded from school.

Across all age groups, some people have waited extraordinary lengths of time for a referral and/or diagnosis, with the whole process sometimes spanning many years. For example, Healthwatch has followed the progress of one man, who first sought a referral for autism assessment via his GP in July 2015, and in January 2017 is still waiting for a full assessment through Bradford and Airedale Neurological Development Service (BANDS). He was given an initial screening through the service

and he is now likely to wait a further 18 months for full assessment. His story is detailed in Case 1.

Healthwatch has learned that the BANDS service is over-subscribed and under-resourced with only one part-time worker undertaking assessments of four patients over two days per week, resulting in huge waiting lists. People talked to us about the impact of waiting times on them and their families resulting in anxiety issues and on occasion, mention of suicide attempts and thoughts, either of the cared-for or the carer.

The delays in diagnosis of ASC are very significant, because people are unable to access appropriate support services without a formal diagnosis.

Healthwatch understands that BANDS is currently closed to any new referrals, but that there are plans to review this service. This may result in additional resources for the service, but Healthwatch understands that this is still under discussion.

Healthwatch has continued to raise concerns about pathways and services for people with ASC through several channels, including the local Health and Wellbeing Board, directly with commissioners and through the local Autism Partnership Board.

Recently, in response to concerns raised and gaps identified in the pathway and services for ACS, commissioners have committed to creating an all-age strategy specifically related to ASC, including Asperger's Syndrome. This will take into account relevant legislation such as The Autism Act 2009, Think Autism 2014, Statutory Guidance of March 2015, Children & Families Act 2014, NICE Guidelines and The Care Act 2014 together with relevant guidance relating to learning disabilities and mental health. This is to be drafted by the Autism Partnership Board.

Some examples of what people have said to Healthwatch are detailed below, and although not exhaustive, they demonstrate the concern, distress and anxiety experienced by people with ASC and their families, who live in the Bradford area.

● No clear pathway to diagnosis of ASC for either children or adults

People who contacted Healthwatch told us they couldn't find up to date information about any Bradford care pathway or support, either online or through helplines. Information is offered by national organisations but people were frustrated as this didn't relate to Bradford, and they didn't know where to go for help.

Once families and individuals have raised concerns with either their GP or school, it is apparent that many of them feel 'stuck', having neither a clear idea of what progress is being made or when to expect it.

"My daughter is antisocial and has communication issues. She has been transferred from Paediatrics to CAMHS, however we have received nothing in the way of communication and know nothing about what we should expect, since March 2016. Every time we try to sort it out we have to go over the same thing again and give the same information as every time we speak to someone different - it's a nightmare trying to get anything done. Communication is shambolic. We have had no support." (Parent, September 2016)

The parent whose story is detailed in Case 2 said that one of her daughters

"has just been left hanging in the air - she was supposed to be referred to CAMHS but the worker is off sick and we have heard nothing."

The parent whose story is detailed in Case 3 said:

"My children are now adults, however when they were younger and came under Children's Services, I found that the pathways for seeking an assessment and a diagnosis were not clear at all."

● Concerns with the length of time it takes to get diagnosis

Several people who contacted Healthwatch were very unhappy with the length of time it took to get a referral for an assessment, or to obtain a subsequent diagnosis.

"I felt something was wrong and went to see my GP who eventually, after insisting, referred us onto a paediatrician but it took a year." (Parent)

"My child, A, was picked up in nursery school. Once the education system had identified concerns, it took around 11 months to get a diagnosis. My older child, B, displays issues with social interaction but I don't want B to go through the process of assessment, observations and such - I have no confidence in the process." (Parent)

The carer whose husband is awaiting screening at BANDS (see Case 2) said:

"My husband is number 97 on the list of those waiting. By my reckoning he will have to wait at least another 12 months or more. There is the mention of another OT being trained to help but this may not happen. He then would be referred for a full screening if felt necessary, which will be more waiting."

● Insufficient support available for people with ASC in the area, especially if they don't also have a learning disability or mental ill health

Many people have mentioned insufficient support for people on the autistic spectrum and their carers in the local area, and we have received several requests for information from people struggling to find appropriate services. Although some support does exist, this is often for a narrow age group or is geared towards people with learning disabilities or mental health conditions, which excludes people with ASC alone. Parents told us that support within education is inconsistent and on occasions has been withdrawn.

“His statement was taken away when his school became an Academy. CAMHS later confirmed that he was on the autistic spectrum but he still does not have a Health Education and Care Plan. He has 12.5 hours of support at school a week, but he has no care plan in place.” (Parent)

The parent whose story is detailed in Case 3 said:

“If someone attends a special school for learning disabilities, the system seems to be different and there is some kind of system in place to help them and refer to other services. If someone attends mainstream school, though, there seems to be no clear pathway for those leaving school with a diagnosis.”

The mother of 19 year old autistic man phoned Healthwatch to raise concerns about the lack of support and specialist services in Bradford for people with autism, unless they are in a crisis position. In this case they go through mental health teams but these have said they don't have the specialist knowledge or expertise on autism. She was concerned that the Autism Bill specifies that a specialist service should be available, but Bradford is not complying with this legislation.

A father at a Parent Carers Forum related the huge amount of stress that the family had experienced in trying to get appropriate services for their four year old daughter.

● Poor understanding of ASC within health services, particularly primary care

Several of those who have spoken to Healthwatch have reported poor understanding of the needs of people with ASC by staff and professionals within health services. Parents have also told us they felt dismissed by GPs when trying to get a referral for diagnosis. Others have told us that communication with adults needing referral and diagnosis isn't always suited to their needs.

“My daughter is ten years old. She is difficult to manage. Help from GPs is limited as they don't know what to do - it's hopeless.” (Parent)

The carer whose story is detailed in Case 2 said of her husband:

“He is expected to do so much like making phone calls and dealing with everything which he finds really difficult and he struggles with communication and sometimes

on the phone can't speak at all. Staff are dismissive and unhelpful about this and don't understand. It's heart-breaking and they are asking him to do the impossible, but don't understand."

Someone contacted us by telephone to tell us that a patient with autism and related mental health conditions was sectioned and treated as an inpatient at Lynfield Mount Hospital. After several months an Independent Manager's Hearing ruled that he should not be treated there. He was discharged to a relative but with no support. Because of this lack of support his condition deteriorated and he was readmitted. Hourly staff rotations, which are not conducive to a patient with autism, led to faster deterioration of the patient's condition.

A parent of a young child with autism who we spoke to during outreach work said she was treated poorly and disrespectfully by reception staff at her GP practice, after being assured that the child would receive a flu jab at nursery or home due to the child's phobia of doctors. The parent felt that doctors at the practice are unable to adequately treat a child with special needs, causing anxiety.

A father at Parent Carers Forum said that their GP was very dismissive of the family's concerns about their daughter and refused several times to make a referral, saying things like, "She looks fine to me" and "Very unlikely for a girl to be autistic".

Healthwatch has noted that several people have struggled to obtain recognition of autistic traits in their daughters, and is aware of research suggesting that there could be under-diagnosis of ASC in females.

● Significant variation in the level of knowledge and understanding of ASC in schools and nurseries

Healthwatch has heard how some schools and nurseries in the area have been supportive and understanding but that many others have left parents feeling dismissed, ignored and unsure of the next step to take in getting a diagnosis or support.

"My daughter is anti-social and has communication issues. The school nurse ignores the problem. I know my child and I know the difference between "naughty behaviour" and when something is wrong." (Parent)

"I have moved my daughter from one school, who were useless, to another, which is a little better and at least they try to help. They are the ones who referred us to this support group otherwise we would have no support at all. Schools don't know what to do and SENCOs are useless and don't know what to do." (Parent)

"Schools don't always see the symptoms as they only see half the story. My daughter can mimic the behaviour of others but then acts out at home and it is really difficult. I have taken in videos of what she is like at home behaviourally, but they are dismissive. One school was not responsive - this is now an academy and

once I complained about lack of support they withdrew all support. We have moved schools and it is better but we still can't get a referral or a diagnosis.” (Parent)

“Our son's behaviour was picked up at nursery, however the first nursery we took him to at our own expense just had him sitting in a high chair and left because they didn't know what to do. The second nursery were much better and he was diagnosed as being on the spectrum at 3 and a half years old. He is now 11 years old and goes to Beck Foot Special School and we feel we are doing ok.” (Parent)

“My child was picked up on in nursery school, and I had help and support from the head teacher and SEN coordinator.” (Parent)

The parent whose story is detailed in Case 3 said:

“If someone attends a special school for learning disabilities, the system seems to be different and there is some kind of system in place to help them and refer to other services. If someone attends mainstream school, though, there seems to be no clear pathway for those leaving school with a diagnosis.” (Parent)

● Difficulties in transition from children's services to adults

Some of those who contacted Healthwatch described their experiences of their child going through transition from Children's Services to Adults'.

The parent whose story is detailed in Case 3 said:

“When my children went through transition from Children's into Adult Services, I found that there is only one Transitions Team and it is for Learning Disabilities. My child, E, did not have LD, but I was insistent and they eventually took E on, otherwise there would have been nothing for E. Subsequently E was identified as having mental health needs and he was passed on to that service.” (Parent)

● Difficulties in obtaining employment due to poor understanding of ASC

Healthwatch heard from people who were worried about employment prospects for people with ASC, because of a lack of understanding amongst employers.

“My son is now aged 18 years and managed to do quite well at A level, and is therefore deemed “OK”. He has no diagnosis but I'm sure his is on the spectrum and we are trying to have him assessed. He is trying to sign on for benefit, but has been deemed “fit to work” by a GP who has only seen him twice in the last 4 years and doesn't know him. He can't manage work situations and finds it difficult to communicate, and has started to realise this himself. He has been offered an assessment but has turned this down. He is unable to cope with every day things and is struggling but can't get any support financially. We are stuck.” (Parent)

On the next pages are three case studies that touch upon many of the difficulties experienced by people with ASC and their families.

In September 2015, Healthwatch heard from someone concerned about their adult relative, H, who shows many signs of being on the autistic spectrum but who does not have a diagnosis or receive any support.

H and his family had been to their GP in summer 2015 and the GP decided that a proper assessment for ASD was needed but told H that this would need the agreement of the CCG. The GP told the family that if they heard nothing in a month they should get back to him. One month later they had indeed heard nothing and so reminded the GP, this time in writing. Another month later they were still waiting.

Shortly afterwards the GP referred H to BANDS for assessment. At the beginning of 2016 we were again contacted by the carer saying that the assessment had not happened because the assessment team said they did not have the right information from H's GP. We followed this up with the GP practice - the practice manager took up this case, demonstrated that all required information had been sent to the Bradford and Airedale Neuro Developmental Disorder Service (BANDS) and pushed hard to get an assessment.

In January 2016 the Practice Manager was told by BANDS that H's referral had been accepted but unfortunately there was now an 8 to 9 month waiting list. Healthwatch and Practice Manager challenged this as original referral from GP had been in October.

H had a screening interview at BANDS at the end of March and we were told he would go forward for a full assessment. In January 2017 he is still waiting for the full assessment through BANDS. He has been told that the wait is likely to be a further 18 months.

His family are not receiving any support to manage H's needs, and they are worried about the future as they are becoming elderly and have long term health conditions.

H himself is now facing physical health problems, and his anxiety makes each medical appointment very stressful. Because he does not have an ASC diagnosis, he cannot access specialist health services which would be better able to meet his needs.

His family have been advised that the only way to get diagnosis more quickly is to put forward an Individual Funding Request to ask the CCG to pay for an out of area assessment.

Email and face-to-face between September 2015 and January 2017

Healthwatch spoke to a woman who is the carer of her husband and two daughters. Her husband is aged 37 years and has a diagnosis of ADHD. He is awaiting screening at BANDS for diagnosis of ASC.

She said,

“My husband is number 97 on the list of those waiting. By my reckoning he will have to wait at least another 12 months or more. There is the mention of another OT (Occupational Therapist) being trained to help but this may not happen. He then would be referred for a full screening if felt necessary, which will be more waiting. He is expected to do so much like making phone calls and dealing with everything which he finds really difficult and he struggles with communication and sometimes on the phone can't speak at all. Staff are dismissive and unhelpful about this and don't understand. It's heart-breaking and they are asking him to do the impossible, but don't understand.

“Both my two daughters are awaiting diagnosis. One has been screened and is awaiting a panel decision. The other has just been left hanging in the air - she was supposed to be referred to CAMHS but the worker is off sick and we have heard nothing.

“I have tried to kill myself as I have depression and anxiety. The First Response - the system to respond in an emergency - say that I am not in crisis but I feel that I am. I stopped eating as I felt then I would be in control. We have made 60 calls to this service and they are useless.”

Autism Support Services Group September 2016

Healthwatch spoke to someone at a Parents Forum. They said:

“My children are now adults, however when they were younger and came under Children’s Services, I found that the pathways for seeking an assessment and a diagnosis were not clear at all. There was no information on the internet, and still isn’t much except for one document “Fulfilling and Rewarding Lives” for those in Bradford. This is dated 2011 and is out of date according to current legislation. It relates to adults.

“When my children went through transition from Children’s Services into Adult Services, I found that there is only one Transitions Team and it is for Learning Disabilities. My child, E, did not have LD, but I was insistent and they eventually took E on, otherwise there would have been nothing for E. Subsequently E was identified as having mental health needs and he was passed on to that service.

“If someone attends a special school for learning disabilities, the system seems to be different and there seems to be a kind of system in place to help them and refer to other services. If someone attends mainstream school, though, there seems to be no clear pathway and nothing for those leaving school with a diagnosis. There are few available options.

“Specialist Autism Services do help to support parents, but I think this organisation is at risk of losing funding and closing. There is Focus Autism but this is limited to those aged up to 25 years, and there is also Making Space, supporting those with a learning disability, but options are few at best.

“A Personal Health Budget (Continuing Care) is in place for one of my children and this helps in targeting support.

“One of the most debilitating symptoms for those on the spectrum is anxiety - it can be crippling and can lead to isolation. Little support is available and it can be extremely debilitating for those who suffer with it. It is not given the importance it deserves, and requires careful and exhaustive management, and often this is underestimated.

“Some of those with symptoms as children (diagnosed or not) are now being picked up by drug and alcohol services as adults, as they use drugs or alcohol as a means of dealing with their anxiety - this is having a knock-on effect on those services, particularly if the person was not diagnosed as a child and now has no diagnosis as an adult. I have first-hand experience as a parent as to how these services are impacted upon as a result of those on the spectrum suffering crippling anxiety and the input from services this needs in later life.”

Parents Forum August 2016

Healthwatch Bradford and District will continue to work with the Autism Partnership Board to ensure that the views and experiences of people living with Autistic Spectrum Conditions are at the heart of the district’s strategy for ASC and plans for services.

We look forward to supporting future engagement with those affected by ASC, as the council and health commissioners develop plans for the future of assessment, diagnosis, and ongoing support.

Since compiling this report “Autistic Spectrum Conditions: What we’ve heard so far”, Healthwatch is pleased to learn that there is to be additional funding made available for the Bradford & Airedale Neurodevelopment Service (BANDS) to increase professional capacity with a view to reducing the current waiting list.

Healthwatch would like to state that any information in the report is a replication of what people have said to us, and is not checked for factual accuracy.

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