

Report of Healthwatch Bradford and District to the meeting of the Health and Social Care Overview & Scrutiny Committee to be held on September 6 2018

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Subject:

Autistic Spectrum Conditions: access to support in Bradford and District

A report by Healthwatch Bradford and District

Summary statement:

This report sets out the findings from a new report by Healthwatch Bradford and District on the experiences of autistic people across the area. It sets out the challenges that people face accessing both diagnosis and support, and the impact that these have on them, and their families and carers. The report makes a number of recommendations to the Council and NHS.

Portfolio: Healthy People and Places

**Overview & Scrutiny Area
Health and Social Care**

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1. Summary

Healthwatch Bradford and District

This report sets out the findings of a project on autistic spectrum conditions carried out by Healthwatch Bradford and District. The data set out here will shortly be published in a report. This builds on a report published in 2017 which set out the difficulties people faced in accessing a diagnosis of autism. Following publication of this report, we continued to hear from people with autism and their families, in particular about the limited support available to them, and the impact this has on their lives and wellbeing.

The forthcoming report focuses on autistic people's experiences of accessing support. We heard:

- People struggle to find 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, Bradford and Airedale Neurodevelopment Service (BANDS), remains closed to new referrals.
- People therefore continue to wait a long time for an assessment. Their choices are therefore to attempt an Independent Funding Request through their GP for assessment out of area, pay for private assessment – which many cannot afford to do - or wait for it to reopen to new referrals.
- 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 not entitled to specialist support, which means they can be waiting for help for years.
 - People are therefore referred to alternative forms of support, e.g. mental health or learning disability services which are not equipped 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 has an often devastating effect on the mental health of autistic people and their families.

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 effect 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.

2. Background

Based on prevalence in the 2011 Census, it is estimated that 1.1 per cent of the UK's population is autistic.¹ This would mean that there are 5,877 autistic people in Bradford Metropolitan District.²

The report brings together autistic people's experiences of accessing both a diagnosis, and support for their autism. A number of people contacted us directly to share their experiences, and we also carried out 10 interviews with people currently receiving support services. Information was collected between February 2017 and February 2018.

In common with the people who have spoken to us, Healthwatch Bradford and District has found it difficult to find clear information about the pathway for diagnosis and support in the area. However, our understanding is as follows:

Children and young people

There are a number of different points of access for an autism diagnosis for children and young people, including midwives and health visitors, GPs, and SEN co-ordinators in schools or nurseries. SEN co-ordinators can help parents access an Education, Health and Care Plan, or parents can ask for an independent assessment for this, with or without a diagnosis. The Bradford Portage Service provides home visiting and an early education support group for pre-age children.

There are some services providing support to children and young people (and their families) locally, including AWARE and ASPIRE. Information about support available can be obtained through the Local Offer webpage.

Adults

To seek a diagnosis, an adult should be referred to Bradford and Airedale Neurodevelopment Service (BANDS). However, this service has been closed to new referrals since April 2016. The reasons behind this do not appear to have been clearly communicated to people trying to access a diagnosis. Alternatives to diagnosis through BANDS are paying for a private diagnosis, or applying for an Individual Funding Request through their GP for an out-of-area diagnosis.

To access specialist autism support, adults require a formal diagnosis. Once they have this, a social worker will apply on their behalf to the Funding Panel to determine the level of support they are entitled to, and any contribution the individual needs to make to the costs of support services.

Bradford District and Craven Autism and other Neuro-diversity Strategy

This was developed by the Autism Partnership Board, which brought together organisations working with autistic people, commissioners and providers, and

¹ <https://www.autism.org.uk/about/what-is/myths-facts-stats.aspx>

² Based on ONS statistics about the population Bradford <https://www.bradford.gov.uk/open-data/our-datasets/population/>

Healthwatch. The strategy has recently been approved by the Transforming Care Partnership, and discussions are taking place about how to implement this.

Funding for the Autism Partnership Board, along with other partnership boards, has been reduced, and council officers are looking at how the involvement the Board offered can be continued.

West Yorkshire and Harrogate Health and Care Partnership

The Partnership has a commitment to collaborate across the area on autism, to drive improvement in provision. It is focusing on diagnosis, along with market and provider development.

National policy

National policy on autism is set out in two autism strategies: *Fulfilling and Rewarding Lives* from 2010, and *Think Autism*, published in 2014. In 2015, the government published Statutory Regulations on autism. These set out requirements and expectations for local authorities and NHS commissioners and providers.

These 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.
- Local authorities must, 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.
- Local authorities should allocate responsibility to a named joint commissioner/senior manager to lead commissioning of care and support services for adults with autism in the area
- 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 diagnostic assessment for autism.

In September 2017, the government announced that data on the length of time people wait for a diagnosis should be measured from April 2018, to be published in 2019.

3. Report issues

Access to diagnosis

Unsurprisingly, given that BANDS remains closed to new referrals, we have continued to hear from people who have experienced long waits for assessments. One person who contacted us, for example, had been waiting for three years. People told us how important accessing a diagnosis can be. In part, this is because it helps them understand themselves and their lives better; it is also vital as without one, people are left in limbo,

unable to access tailored supports to meet their needs. This has a significant impact on people's lives, affecting their access to education and employment, and their mental health and wellbeing.

Specialist support for autism

People told us that specialist autism support can be a 'lifeline':

"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 how people struggle either because they cannot access support while they are waiting for assessment, or because the support they are offered is insufficient to meet their needs. Where people do not yet have a formal diagnosis, we heard that people are often referred instead to mental health and other non-autism services that cannot help them with their autism. A lack of understanding of autism and how it affects people means that people can struggle to make use of mental health services.

We also heard that people felt that the social workers supporting them to access specialist services did not necessarily have the understanding of autism needed to fully understand their needs:

"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 any point when they need it." (Parent of child with autism)

Accessing funding for specialist support

Similarly, people found the process of securing funding for specialist support difficult. Access to a social worker is limited and can take a long time, and people feel the outcome can depend on the autism awareness and skills of the social worker. Some social workers were praised, but people felt that others were not equipped to support them.

"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."

We also heard concerns that members of the Funding Panel may not have sufficient understanding of autism and how it affects people's lives.

Transition from child to adult services

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

Access to primary care

Primary care, particularly GPs, can be vital in helping people to access diagnosis and support, but also to help people live well with ASCs, and manage their health. 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.

People had mixed experiences with their GPs. While some GPs show a good understanding of the needs of autistic people, others appeared to lack awareness.

We heard of good practice from some GPs (and other primary care providers including dentists) including ensuring autistic people see the same doctor, and offering early or late appointments when the waiting room is quieter.

Accessing mental health services

We heard that mental health professionals often don't have a good understanding of autism, which affects people's ability to access appropriate treatment. Communication is not always tailored to the needs of autistic people, meaning people can struggle to understand what's being said.

"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."

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.

"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."

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, 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.”

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.

“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.”

“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.”

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: *“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”*

Information and communication

We heard throughout that people struggle to access information about autism, and the pathways for diagnosis and support. This was reflected in the challenges we experienced trying to find information to share with people who contact us.

Where people do receive information, they told us this is often difficult to understand, and professionals do not have sufficient understanding of the communication needs of autistic people.

Since August 2016, all organisations that provide NHS care or publically funded adult social care are legally required to follow the Accessible Information Standard.³ 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 need support to do all written things, and I struggle to read and process information.”

“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.”

Accessing other support

We heard that the challenges people face in understanding forms and other information can make it difficult for them to access other forms of support.

³ <https://www.england.nhs.uk/ourwork/accessibleinfo/>

We heard from support workers that autistic people often experience difficulties when accessing assessments under the Care Act, 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.

The effect on autistic people and their families

The cumulative effect of these challenges can have a devastating effect on people's mental health and wellbeing. 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."

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."

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 diagnoses 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.

4. Options

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. 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 neurodiversity. This should be made available to all staff who may come into contact with people with ASC, 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 points. This should include a pathway for transition from child to adult services.

- The 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

5. **Contribution to corporate priorities**

Improving awareness of autism among professionals, and increasing access to support for autistic people and their families, will make a positive contribution to a number of the Council's corporate priorities. It will help to deliver the vision set out in the joint local plan, Happy, Healthy and at Home, and, by helping people stay in education and employment, help support the Economic Strategy.

6. **Recommendations**

The views of the Committee on the report and the options set out in Section 4 of Document requested.

7. **Background documents**

- Background documents are documents relating to the subject matter of the report which disclose any facts or matters on which the report or an important part of the report is based, and have been relied on to a material extent in preparing the report. Published works are not included.
- All documents referred to in the report must be listed, including exempt documents.
- All documents used in the compilation of the report but not specifically referred to, must be listed.

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

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

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

http://www.healthwatchbradford.co.uk/sites/default/files/autistic_spectrum_conditions_report_jan_17_0.pdf

<https://www.autism.org.uk/autismfriendlyaward>

8. **Not for publication documents**

None

9. **Appendices - None**