

# Report of the Director for Health and Care Partnership to the Children's Overview & Scrutiny Committee to be held on 13<sup>th</sup> March 2024

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Subject: An update on Autism and ADHD assessment and Support

# **Summary statement:**

This report provides an update from the Healthy Minds programme for Bradford District and Craven. The focus of the report is an update on the current context and complexity that includes system challenges for assessment waits and Attention Deficit Hyperactive Disorder (ADHD) medication. The report will highlight the work currently taking place across our Partnership, including support that is being provided to those that are waiting.

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**Healthy Minds** 

## 1. Summary

- **1.1.** Meeting the demand for Autism and Attention Deficit Hyperactive Disorder (ADHD) assessments is a national challenge with a similar picture across Bradford District. The report will outline the context for this, and the work undertaken to address this, while recognising that national issues such as availability of trained workforce continues to hamper efforts.
- **1.2.** This report will focus on children and young people.
- 1.3. This report will outline some of work that has taken place to ensure children, young people and families are receiving support while waiting for assessment and post assessment
- **1.4.** The report will reference the challenge for ADHD medication, again this is set against a national issue affecting medicine supply.
- **1.5.** The report provides definitions of the different conditions, this forms part of our efforts to raise awareness, understanding and tackle stigma as part of our efforts to become a neurodiverse friendly place.
- 1.6. We seek the support of Members of Children's Services Overview and Scrutiny Committee in assisting us to supporting our families and communities by sharing the support available and having the awareness of the challenges faced. As we move towards a needs-led system, we recognise that we need to take families and communities on the journey with us, if we want to reduce the demand for diagnosis.

#### 2. **Definitions**

#### 2.1 Neurodiversity

'Neurodiversity' is the understanding that people think and feel, experience and interact differently with the world; that these differences are normal and to be expected and celebrated, not treated as deficits.

Autism, ADHD, dyslexia and dyspraxia are examples of neurodevelopmental conditions. They are 'spectrum' conditions, which means they come with a wide range of characteristics.

Autism, ADHD and other neurodevelopmental conditions are diagnosable by a trained professional. Only a small minority of any population will meet the threshold for diagnosis. A larger proportion will share some neurodivergent traits and characteristics, without meeting those diagnostic thresholds.

#### 2.2 Autism

Autism is a complex, lifelong developmental condition that typically appears during early childhood. It is a spectrum condition that affects individuals to varying degrees. The diagnostic criteria stipulate individuals will have persistent difficulties

with social communication and social interaction and will have restrictive and repetitive patterns of behaviours, activities and interests that limit and impair everyday functioning.

# 2.3 Attention Deficit Hyperactive Disorder (ADHD)

Attention Deficit Hyperactive Disorder (ADHD) is a condition where children and young people show a persistent pattern of inattention and/or hyperactivity—impulsivity that interferes with day-to-day functioning and/or development and is pervasive.

#### 3. Autism and ADHD Assessment

- 3.1 The autism assessment pathway is considered to have five stages:
  - 1. identification and referral
  - 2. screening and triage
  - 3. pre-assessment support
  - 4. autism assessment
  - 5. post-assessment support

While it is the responsibility of health partners to deliver the assessment, the whole pathway, i.e. the identification and referral, the screening and triage and the pre- and post - assessment support benefit from a partnership approach to ensure children and young people receive the support and care needed ahead of, and after, an assessment.

# 3.1 Autism and ADHD Assessment waiting times

- 3.1.1 NICE waiting time standard is 13 weeks from referral to the start of an assessment. This is a non-mandatory standard, which for neurodiversity assessments is rarely achieved by NHS or private providers. <u>Assessment and diagnosis of autism: what to expect Quick guides | NICE Communities</u>
- 3.1.2 Notwithstanding three business cases since 2018 to increase resource into the Autism and ADHD assessment pathway, challenges remain. This is due to numerous national challenges, such as the availability of a trained workforce and the increase in demand and the complexity of cases and awareness. In addition, we are aware and concerned by the proliferation of unreliable tools, sometimes available online or as smartphone apps, that claim to be able to screen for autism. The use of such a tool should not be seen as an alternative to proper assessment and diagnosis. However we recognise people use such tools and this creates further demand and expectations.
- 3.1.3 Since 2020, the demand for assessments has risen by 122% in Bradford District and Craven Health and Care Partnership (BDC). There is a rise of requests for dual (both Autism and ADHD) assessments. The current waits are approximately 140 weeks. There is approximately 300 referrals a month, with capacity to complete 88 referrals per month. This challenge is not unique to BDC, with other regional partners reporting similar and higher increases in waiting times.

- 3.1.4 There is a significant workforce challenge nationally with the availability of staff identified that can carry out/confirm Autism and ADHD diagnosis. Workforce challenges are further impacted by the rise in private providers in the region (note this is different to the private providers we have selected to help reduce waiting times).
- 3.1.5 BDC continued to offer assessment in the pandemic, which did positively affect waiting times, when comparing to regional partners.
- 3.1.6 Since 2021, schools are now able to make direct referrals for both Autism and ADHD assessment. Schools are now the biggest referrer for these assessments.
- 3.1.7 BDC are assured that the right CYP are being referred for assessment as 91% of all referrals go on to receive a diagnosis.
- 3.1.8 To try and reduce waiting times, BDC has outsourced 16080 cases to private providers since 2021. All vacancy factor monies, from unfilled and vacant posts, available across all providers has been used to further outsource, and this will continue.
- 3.1.9 Although waits for assessment are significantly longer than we would like due to both resource and workforce issues, the quality of assessments continues to remain in line with NICE guidelines and recommendations in both the under 7 and over 7 assessment pathways.
- 3.1.10 In order to ensure that those CYP that have significant vulnerabilities are not further disadvantaged a clinical prioritisation criterion has been implemented to ensure these children do receive timely assessment within 13 weeks.
- 3.1.11 BDC has worked hard to remove any prerequisite of needing a diagnosis to access support from health and education services, with access being led by needs not diagnosis.

#### 3.2 Special Educational Needs and Disabilities (SEND) Written Statement of Action

- 3.2.1 In March 2022 Bradford received a 'Written Statement of Action' following the joint OFSTED/CQC local area SEND inspection in March 2022.
- 3.2.2 This identified an area of weakness in relation to a number of areas including children and young people wait too long for assessments, treatment and diagnosis. There is insufficient support for children and young people with SEND who are waiting for provision, services, diagnosis or equipment.
- 3.2.3 One of those areas identified in the 2022 inspection feedback was Autism wait times were too long and children and families lacked information, support and signposting to support them waiting well, whist on the waiting list.

- 3.2.4 The WSOA action plan included 'Reducing waiting times for autism / ADHD assessment and strengthen the support offer whilst waiting for assessment' and included:
  - The Autism/ADHD service pathway is mapped, and all key stakeholders are aware of current service offer by March 2023
  - Referral criteria is reviewed and signed off and is shared with key stakeholders including children, young people and families by March 2023
  - Self-help, Universal and Early Help pathway is agreed by March 2023
  - Delivery of the support pathway for Autism / ADHD from self-help, universal offer and early help services by September 2023
  - Evidence of signposting to support whilst waiting for Autism/ADHD assessment by March 2023
- 3.2.5 There have been three monitoring visits following on from the March 2022 SEND inspection outcome and the development of the agreed WSOA plan initiated from September 2022. Assurance of BDC approach to Autism and ADHD has been sought at each monitoring visit.
- 3.2.6 During the October 2023 monitoring visit both the Department of Education (DfE) and NHS England were provided with additional information relating to Autism and ADHD and were able to acknowledge the challenges in our local area as well as the efforts the local system were undertaking. The DfE Commissioned SEND Adviser stated 'It was demonstrated that children can now access the services they require regardless of whether they have a 'diagnosis' or not'.
- 3.2.7 The Bradford district Local Area fourth SEND monitoring visit on 19 March 2024, will again seek information and progress in the system for Autism and ADHD assessment, provision and support and outlines steps to monitor impact and outcomes for CYP.
- 3.2.8 Autism and ADHD remain a key priority to address within our system, and this is evidenced by the Self Evaluation Framework (SEF), the Local Area Inclusion Plan (LAIP) and within both the Healthy Children and Family Board and Healthy Minds Board strategies.

## 3.3. Support while waiting and for those diagnosed – waiting well

3.3.1 This work forms part of our wider strategic ambition of keeping people happy healthy and at home, by ensuring a clear purpose to what we do, within our place through partnership working to support our population. We recognise there is work needed to provide support for children and young people while they are waiting for assessment.

- 3.3.2 BDC have good quality support services available for the population, however these are often locality based and have small resource associated. The ICS have been implementing and directing investment to help support more CYP with or without a diagnosis. BDC has removed any requirement for a formal diagnosis to access support from all services.
- 3.3.3 The following services have been developed, expanded or continue to be provided to those CYP that need them, regardless of a diagnosis:
  - The local offer, Healthy Minds and CAMHS website with consistent information around the assessment process and support offer
  - Clinical prioritisation criteria has been increased to ensure those most vulnerable are expedited for assessment. The criteria now includes, the Dynamic Support Register (DSR) cohort, CYP that have been excluded from school or are in alternative provision, children looked after, asylum seekers and refugees, CYP known to youth justice services and those at risk of a mental health admission.
  - Removing barriers to access support as part of the SEND work, services will no longer require a diagnosis to access the support on offer. The support offers in BDC will be provided based on need.
  - Ensuring universal offers that are provided, can meet the needs of neurodiversity within their existing offers to ensure all services are inclusive. Examples include:
    - Little Minds Matter
    - 0-19 Service
    - Family hubs
    - Mental Health Support Teams
    - · Special early attachment development service
  - School being able to make referrals for Autism and ADHD assessments have supported schools to better identify and meet need based on the evidence and information they provide to make the referral, enabling reasonable adjustments to be made in schools and if necessary, support plans and education health and care plans to be implemented.
  - **Parent and carer networks** based on peer support, operating from schools providing drop-ins, peer support to CYP and families and school-based support.
  - Barnardo's care navigator role (a lived experience post) is now in place, working
    as peer support offer for those waiting to sign post to support and offer peer
    support sessions to struggling families. This is available on all children and young
    people pathways.
  - Continue to work with Voluntary Community and Social Enterprise Sector (VCSE), which includes both AWARE and the Parent carer network. Aware provide a commissioned offer from Bradford Early Advice Team (BEAT) to families of those on waiting lists. This is well evaluated, and reoccurring funding. The Parent Carer network based on peer support, operating from schools, provides drop-ins and peer support. we are continually working hard to ensure we are reaching our diverse communities and are currently connecting with Bradford Stronger Together to meet the needs of the parents and families from our diverse

inner-city communities. **Specialist Autism Services** delivers a strengths-based Autism specific personalised learning programme, to develop social, communication and employment skills which empower members to engage with new opportunities, make informed choices, achieve their goals, maximising independence and inclusion.

- We have recently set up **Brad Starz**, a SEND youth voice group for people aged 14-24 who meet to discuss things that matter to them. Brad Starz is a group for young people aged between 14 and 24 that live or go to a school within the Bradford District and have a Special Educational Need and/or Disability (SEND)
  - Social Prescribing offer for children and young people with learning disabilities
    and Autism in four primary care network areas. This is well evaluated and we
    are working to see if this can be expanded.
  - Sleep support services. This is a new service which commenced in Oct 2023 and is being provided by The Together Trust. This service shares referrals closely with the Children's Community Support Team to offer a tiered offer of support. Evidence demonstrates that many of the families accessing the Together Trust have identified as having Autism or ADHD.
- Development of an Avoidant Restrictive Food Intake Disorder (ARFID) service. The CYP that will predominantly access this specialist service are likely to have neurodiverse needs.
- Autism Strategy being developed this will be all age and cover culture, arts, leisure, business and education.
- Autism Hub Bradford and Craven Autism AIM is a service for autistic adults living
  in Bradford (aged 18+) with little to no funded support. They will work with 17-yearolds as they transition into adulthood to let them know what services are available
  once they turn 18. They provide support to access your GP, information and
  signposting, and one-to-one peer support. They also run a mental health peer
  support group.
- Neurodiversity Social Work Service the Neurodiversity team is a hub of Social Workers and Occupational Therapists who are dedicated and skilled to work with people aged 18 + with autism and/or other Neurodiverse conditions. The team will be based within the Learning Disability and Preparing for Adulthood Service and sit alongside the existing Learning Disability Locality Teams.
- Schools are rolling out Autism Education Trust Whole school approach in Autism- District Wide and led by Local Authority
- Educational Psychology Service Work in a traded way for Bradford schools and on a referral basis with no diagnosis required. They can provide an individual or whole school/class advice around neurodiversity. This team are also involved in the neurodiversity Future Pathways project – approximately 38 schools are now trialling the Electronic Developmental Support Tool (EDST) which helps settings identify reasonable adjustments and teaching practices required to support YP who may be neurodivergent.

- My Needs App (Myne App) which supports Autistic and neurodiverse people to communicate their needs to healthcare and other services and can improve their experience and access of services. This App is in development and being codesigned. This is funded by West Yorkshire.
- **Kindness, Compassion and Understanding campaign** this is a young people led campaign that addresses themes of bullying in schools. Young people have driven this work and it's rolled out across schools in Bradford District and Craven. This has reached over 12,000 children with a specific cohort working with special schools reaching 2014 children aged 4-19.
- Most children and young people in the district spend a large proportion of their time in school. School can be both supportive and pressurised environments for children and young people. This is particularly true for those with autism and ADHD, who are at higher risk of experiencing mental health problems. We have a range of offers in schools to meet the social, emotional and mental health needs of and children and young people, and the staff supporting them. For example:
  - Mental Health Support Teams (MHSTs) are currently active in 45% of schools in Bradford District, expanding to 65% by 2025.
  - Schools without a MHST are supported by the Education-based Emotional Wellbeing Practitioners (EEWPs)
  - Both the above teams deliver a range of services, including training for school staff, group work and individual support for children and young people which includes autism awareness.
  - The educational psychology team runs the Bradford Healthy Minds Chartermark programme. This is a whole school approach to mental health, supporting schools to embed good practice into their day-to-day work;
  - A youth worker is attached to every school in the district to support students:
  - All schools have been invited to take up the School Nursing offer. This
    offers a range of services including drop-in clinics, and 1:1 support for
    children and young people with specific needs;
  - Healthy Minds has produced a Directory of Mental Health Services
     (healthyminds.services/assets/pdfs/hm\_thrive\_a5\_150923.pdf) to help
     schools to navigate the wide range of mental health services on offer in
     school and in the community.
- 3.2.1 **DATA One (Digitally Acting Together as One) programme** the team at Born in Bradford's Centre for Applied Education Research have delivered a series of **research projects**.
- 3.2.2 These offer new insights into the prevalence of autism across Bradford; the experiences of different communities in accessing assessment and support; and practical recommendations on how systems might be adapted to address disparities such as gender, ethnicity and poverty. These proposals have been published. The Committee may wish to review the report <a href="https://example.com/here.com/
- 3.2.3 **Shared unit on autism on the SystmOne platform**, which will be used by all three of the trusts delivering assessments to children. This will improve both information security and the quality of data available to oversee and hold systems accountable.

- 3.2.4 Electronic Developmental Support Tool (EDST) Is the development of a digital tool to help teachers identify and meet the needs of children with neurodiversity. This is currently about to enter into phase 2 of the pilot and will cover key stage one settings in 43 Bradford and Craven primary schools. For the first time, the tool will include a 'Digital Advice Bank', so that as teachers identify children's support needs, they are immediately able to find evidence-based approaches and techniques, which they can start using straight away.
- 3.2.5 **Data1** is about improving the neurodiversity pathway by implementing a needs-based approach throughout education and creating neuro diverse friendly environments. These will be developed in partnership with families, communities and professionals to achieve improved:
  - Neurodiversity awareness in communities and at school
  - Neurodiversity friendly environments
  - Helpful advice and strategies in school and at home
  - Identification of need via a new neuro diversity profiling tool in schools that will accurately identify (not a formal diagnosis) autism, ADHD and developmental language delay which will provide a suite of targeted support and advice.
  - Improved Information sharing
  - Access to diagnosis if still needed.
- 3.2.6 If Data1 is implemented district wide, the delivery of timely assessments will still remain a key part of this new systems approach for the majority of CYP.
- 3.2.7 **Neurodiverse city:** We want Bradford District and Craven to become a neurodiverse friendly district. We need to improve understanding of neurodiversity among the general population as well as those working with neurodiverse individuals. Being 'neurodiverse friendly' means adapting and creating inclusive environments, places, policy and services in which everyone can thrive both people with diagnosable neurodivergent conditions and those with neurodivergent traits. We will use the opportunities that the UK City of Culture Bradford 2025 brings to accelerate this ambition. As part of this work we have:
  - Launched the Neurodiverse city ambition in November 2023 with business and local organisations – this is aimed at ensuring we create good practices, tools and resources for people who are neurodiverse to access all opportunities.
     Examples shared on the day included the sensory rooms at Broadway and the Alhambra's inclusive approach to recruitment and employment.
  - Sharing lived experience of people and families
  - Developing resources the team are building capacity across the district, to adapt environments. This includes making resources available, where needed.
  - Working with UK City of Culture Bradford 2025 to ensure the programme is neurodiverse friendly and people are employed/involved.
- 3.2.8 **Healthy Minds strategy:** In January 2024, we launched our district wide Healthy Minds strategy and set out our approach to achieving key ambitions. With regards to Neurodiversity, our shared outcomes will be:
  - Bradford District and Craven to become a neurodiverse friendly district.
  - More people are accessing support within their local communities to live independently.
  - There will be a wider range of support and accommodation options for people with Autism and Sensory Impairments

• Increase the number of people recruited to and retaining meaningful employment.

The full strategy be found in the appendix.

### 3.3 West Yorkshire Deep Dive

- 3.3.1 This work commenced in March 2022 with the focus being across all ages for both Autism and ADHD. All five West Yorkshire places are represented as part of this work.
- 3.3.2 Objectives to work on together during 2023/2024:
  - To improve consistency in Autism and ADHD services, reduce wait time and to access assessment
  - to improve the availability of person centred, needs led, holistic support
  - to implement the 'Right To Choose' agenda consistently across West Yorkshire
  - To continue to embed co-production in the neurodiversity review, working with people with lived experience and professionals to create shared perspectives and learning to shape services.
- 3.3.3 To date there has been two West Yorkshire events that have taken place, the first of a series of Summits took place in December 2023 and the second Summit took place in February 2024. There has been good representation from Bradford at these events across health, social care, VCSE and the local authority.
- **3.3.3** This work has included extensive consultation and engagement with all stakeholder groups including people with lived experience, parent and carers and clinicians across all five places.
- **3.3.4** To achieve these objectives there will be task and finish groups and key areas of work:
  - **Right to choose**, which will include co-producing information and resources to the public.
  - **Data** work has started that will look at consistent metrics and collection of date for autism and ADHD.
  - **Assessment pathways** evaluate and share learning from pilots, working together and developing digital resources.

#### 3.4 ADHD Medication

This provides a brief overview of some the recent medication challenges for ADHD

- 3.4.1 A high proportion of CYP diagnosed with ADHD go on to receive medication for the condition. With the rise in diagnosis, there has been a rise in ADHD medication prescribed.
- 3.4.2 Only a healthcare professional (specialist pharmacist, non-medical prescriber or medical practitioner) can initiate and continue to prescribe ADHD medication. Workforce challenges remain for these professions.

- 3.4.3 Since September 2023, there has been a national shortage of ADHD medication. National guidance provided stated that there should be a pause on commencing new people on medication, to protect the supply for those already established on medication.
- 3.4.4 This was due to resolved by December 2023, however a new date has been provided of April 2024 by NHS England. Waiting times have increased as a direct result of this national shortage, however the section below will highlight what we are doing to support those that are waiting.
- 3.4.5 Clinical prioritisation criteria continue to be implemented to ensure those that are vulnerable and at risk are maintained on their medication.

In summary, we recognise that waiting times are long and demand is increasing. The partnership approach enables us to see children and young people in the whole. We have invested in a series of support and care approaches both in school and within pathways to ensure children and young people can access support regardless of a diagnosis. We have used private providers to maintain pace with assessment while work takes place at local, regional and national place to address the challenges of training, workforce and medication access.

### 4. Options

**4.1.** There are no options associated with the strategy or service deep dive

#### 5. Recommendations

- **5.1.** The committee are asked to note the update that sets out our approach to mitigating some of the significant challenges to ensure children and young people in Bradford District and Craven are supported.
- **5.2.** The committee are asked to support us in setting out towards a needs-led system and recognise the community engagement needed.
- 5.3. The committee is asked to support efforts to raise awareness of the Healthy Minds website (<a href="www.healthyminds.services/">www.healthyminds.services/</a>) and the Local Offer website (<a href="https://localoffer.bradford.gov.uk/">https://localoffer.bradford.gov.uk/</a>) which is specifically for those looking for help with SEND related services

#### 6. Background documents

**6.1.** There are no background documents

## 7. Not for publication documents

**7.1.** There are no not for publication documents

# 11. Appendices

Autism: A National Framework (Appendix 1)

NHS England » A national framework to deliver improved outcomes in all-age autism assessment pathways: guidance for integrated care boards

OFSTED/CQC SEND Inspection WSOA action plan (Appendix 2)



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Choice in Mental Health care (P44) (Appendix 3)



choice-in-mental-hea lth-care-v5 (2).pdf

Autism Assessment and Support Crisis- Child of the North (Appendix 4)



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#### Clinical Prioritisation Criteria



Clinical Priority for Neurodevelopment A

## **Healthy Minds Strategy**



Local Area Inclusion Plan

#### Self Evaluation Framework

- Bradford Local Offer
- Healthy Minds Mental health support in Bradford and Craven
- CAMHS Neurodevelopmental team BDCT