

Report of the Bradford and Craven Health and Care Partnership to the meeting of the Health and Social Care Overview & Scrutiny Committee to be held on 14 March 2024

AB

Subject: UPDATE ON PROGRESS AND OUTCOMES – ADULT AUTISM PATHWAY AND ASSESSMENT AND DIAGNOSIS OF AUTISM IN ADULTS SERVICE, BRADFORD DISTRICT AND CRAVEN

Summary statement:

The Bradford and Airedale Neurodevelopment Service (BANDS) was commissioned in 2015 to provide triage, assessment and diagnosis for both ASD and ADHD for adults (over 18) in Bradford, Airedale, Wharfedale and Craven.

This briefing and appendices relate to Adult Autism services only, there is no reference to similar services for children.

Commissioners and providers are pleased to share evidence and data, within this report, to evidence that all outcomes and objectives for the Adult Autism Pathway have been met, or are well on the way to being met.

Acronyms and Abbreviations used

ASC; Autism Spectrum Conditions

BANDS; Bradford and Airedale Neuro Diversity Service

CBMDC; City of Bradford Metropolitan District Council

HOSC; Health Overview and Scrutiny Committee

BDC ICB; Bradford district and Craven Integrated Care Board

SQC; System Quality Committee

PLT; Place Leadership Team

T&FG; Task and Finish Group

ASC; Adult Social Care

VCS; Voluntary and Community Sector

Portfolio:

Healthy People and Places

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1. Summary

The Bradford and Airedale Neurodevelopment Service (BANDS) was commissioned in 2015 to provide triage, assessment and diagnosis for both ASD and ADHD for adults (over 18) in Bradford, Airedale, Wharfedale and Craven.

This briefing and appendices relate to Adult Autism services only, there is no reference to similar services for children.

Following criticism of BANDS by HOSC and complaints from patients, which included concerns about the service model, value for money, the high number of people waiting and the length of time people had to wait, a review was conducted and an Action Plan was agreed by the MH, LD and ND Partnership Board to address these concerns and commission a new service model.

Following several failed attempts to expand the existing BANDS service model, it was recognised that a new, innovative approach was needed to address the growing gap between demand and capacity for adult autism assessment and support. A critical aspect of this approach involved facilitating a partnership between the existing BANDS service and the larger, more successful service delivered by SWYPFT. In addition, a substantial increase in financial investment was agreed by Bd&C Health and Care Partnership, from £65,000 p.a. to £352,000 p.a.

It was agreed that the entire Adult Autism Pathway should be redesigned in order to introduce pre and post diagnostic support options for patients. WY ICB, BDCFT, SWYPFT and CBMDC worked together to create the new Bradford district and Craven Adult Autism Pathway. The new pathway is centred on principles of partnership to deliver an innovative, sustainable model of service that meets needs through quality improvements, a proven ability to recruit to posts and a service model which is closing the gap between demand and capacity. The new pathway includes an expansion of specialist and non-specialist support available locally to autistic adults, alongside a new Autism Assessment and Diagnosis Service delivered in partnership between BDCFT and SWYPFT.

The planned outcomes for the new pathway are;

Outcome	Objective
Improve capacity of Adult Autism Pathway to meet demand	Delivery capacity to meet demand of 600 referrals per annum
Waiting times to access service to be reduced to NICE guideline levels	Reduce average waiting time to 12 weeks
Improved quality of referrals	Reduce number of referrals refused due to quality to <5%
Improved experience of the Adult Autism Pathway	Reduce number of complaints
Improve non-clinical support options	Offer signposting to non-clinical support options Support development of additional non-clinical support options

Commissioners and providers are pleased to share evidence and data, within this report, to evidence that all outcomes and objectives for the Adult Autism Pathway have been met, or are well on the way to being met.

2. Background

Autism is a lifelong neurodevelopmental condition, the core features of which are persistent difficulties in social interaction and communication and the presence of stereotypic (rigid and repetitive) behaviours, resistance to change or restricted interests. The way that autism is expressed in individual people differs at different stages of life, in response to interventions, and with the presence of coexisting conditions such as learning disabilities (also called 'intellectual disabilities').

People with autism also commonly have trouble with cognitive and behavioural flexibility, altered sensory sensitivity, sensory processing difficulties and emotional regulation difficulties. The features of autism may range from mild to severe and may fluctuate over time or in response to changes in circumstances. (*NICE Clinical guideline [CG142]*)

"The greatest discomfort for autistic people can be the social one. For me, I was confused by the way people behaved."

Chris Packham, CBE and National Autistic Society Ambassador

[Autism Assessment UK](#)

1% of the general population is estimated to have autism and 50% of those to have intellectual disability. For Bradford the autistic only population is calculated at 3,147 by 2025 (*Pansi dataset*).

In response to section 2 of the Autism Act 2009, the Department of Health published '*Fulfilling and Rewarding Lives*', *The Strategy for adults with autism in England (2010)* <https://webarchive.nationalarchives.gov.uk/ukgwa/20170207052351/https://www.nao.org.uk/wp-content/uploads/2009/06/0809556.pdf>

The Government's vision is that 'All adults with autism are able to live fulfilling and rewarding lives within a society that accepts and understands them. They can get a diagnosis and access support if they need it, and they can depend on mainstream public services to treat them fairly as individuals, helping them makes the most of their talents'. It outlines five quality outcomes:

1. Adults with autism achieve better health outcomes
2. Adults with autism are included and economically active
3. Adults with autism are living in accommodation that meets their needs
4. Adults with autism are benefiting from the personalisation agenda in health and social care, and can access personal budgets

5. Adults with autism are no longer managed inappropriately in the criminal justice system

3. Report issues

Adult Autism Project Overview

Strategy

- Mental Health, LD and ND – one of five BDC HCP priorities
 - Parity of Esteem
 - Learning disability / neurodiversity access and outcomes

Aim:

- Deliver a clinically led, resilient Adult Autism pathway providing clinical triage, assessment, diagnosis and support.
- Respond to new referrals within the NICE target of 12 weeks
- Provide information, training and advocacy across the health and care system

Challenges:

- Growing number of referrals – 600 per annum against capacity for just 50 assessments per annum
- Workforce issues – resignations and recruitment difficulties
- Demand and capacity gap – 560 people per annum added to waiting list

Commissioning intentions:

- partnership between BDCFT/BANDS and SWYPFT, building on the principles of the WY Integrated Care System
- joint recruitment to posts, building on SWYPFTs reputation and success
- Revised model of service, to deliver a better patient experience and value for money
- Revised Adult Autism pathway, increasing the quality of referrals which leads to better outcomes and expanding options for support
- Expand non-clinical support options, including support with education, social and employment

3.1 Adult Autism Project Timeline

Date	Key Development
June 2022	<p>Interim leadership cover for BANDS</p> <p>The SWYPFT Adult Autism service provided cover for BANDS following the loss of all existing staff. Additional input from Prof Adamou and other team members was received to provide Referral Management cover, improve processes and have meetings with local stakeholders.</p>

<p>July 2022</p>	<p>Development of new Bradford District and Craven (BDC) Autism Assessment and Diagnosis Service for Adults. See Appendices 1 & 2</p> <p>A new service model was developed in partnership between BDCFT and SWYPFT. From July 2022, Dr Sara Humphrey, clinical lead for LD and autism, joined the T&FG and led on revising and improving the pathway, including the referral process.</p>
<p>Sept. 2022</p>	<p>Bradford Waiting List Initiative commenced. See Appendix 3</p> <p>This project was commissioned to manage 100 people from the BANDS Autism Assessment waiting list. 127 people were identified from the waiting list, they were referred for assessment between September 2022 and June 2023.</p>
<p>January 2023</p>	<p>Referral Through GP ASSIST commenced</p> <p>A large proportion of referrals were returned to GPs, requesting more information. This process was time consuming and inefficient. Feedback from clinicians and patients show that GP appointments are not ideally suited to gather the detailed and complex background needed to determine whether a patient needs to receive an assessment for autism.</p> <p>From January 2023, GPs who wish to refer an adult patient to be screened for assessment for autism only need to send basic information to the new service, through ASSIST. Following this development, no referrals were returned for further information.</p>
<p>April 2023</p>	<p>Launch of new Adult Autism Assessment service.</p> <p>All patients referred receive an invitation by the Service at Hillside Bridge Health Centre, Bradford, to a 30-minute face to face interview (assessment clinic) to gather appropriate information and complete a referral.</p> <p>Expert health professionals in autism review the information gathered during this referral completion along with other information on file and determine whether the patient has sufficient indicators of autism suggesting they need assessment.</p> <p>Clinical Triage</p> <p>To better prioritise need, the new service model includes a clinical triage step, so only the people who may have Autism are offered an assessment. Clinical triage is guided by utility, maximisation of benefits, and prioritisation based on clinical criteria and is commonly used for other conditions in medicine. Our clinical triage approach for Autism is not focused on excluding people, but on identifying people who are more likely to be diagnosed; as such, it is looking for positive indicators of Autism and not negative ones. If such indicators are found, then the person is considered clinically appropriate for an assessment, and if not (and on the contrary, negative indicators are also found), then the person does not need to be assessed. SWYPFT have evaluated this triage approach with a single-blind study, and out of 52 patients who were triaged as not needing an assessment but subsequently offered one, none ended up with a diagnosis.</p>

	<p>This approach has been supported by primary care practitioners in Wakefield, Kirklees, Barnsley and Calderdale, where it has been in use for over four years.</p> <p>Communication. See Appendices 4 & 5</p> <p>The new service provides reports to patients and to referring clinicians detailing the outcome of this triage process and/or subsequent assessment.</p> <p>Each person referred receives a letter from the new service, explaining what to expect. Additional information is provided in a leaflet and website signposting patients to sources of support in their local communities, particularly Wellbeing Hubs and Social Prescribing services.</p> <p>This model was subsequently endorsed by inclusion in the NHS England ‘National Framework to deliver improved outcomes in all-age autism assessment pathways’, https://www.england.nhs.uk/long-read/a-national-framework-to-deliver-improved-outcomes-in-all-age-autism-assessment-pathways-guidance-for-integrated-care-boards/</p>
<p>May 2023</p>	<p>Autism Awareness Training</p> <p>In-person autism awareness training, delivered by Leeds Aim, is provided to Social Prescribers and to the 6 Wellbeing Hubs, so that they can better engage with, and support, autistic adults to access community, education, employment and health resources.</p>
<p>July 2023</p>	<p>Adult Autism Hub. See Appendix 6 for a sample report from the Bradford and Craven Autism AIM Pilot.</p> <p>Working in partnership with Leeds Aim, WYICB and CBMDC, a 12 month pilot Adult Autism Hub is available in Bradford, with 3 key elements of support. Bradford and Craven Autism AIM is a pilot service for autistic adults in the area who have little or no other funded support. The project model is based on the Leeds AIM approach of utilising the teams lived experience (85% of the team are autistic) and professional knowledge/skills in providing support to help clients develop self-advocacy skills and give information/ support to reduce barriers of access to wider services or develop strategies that may reduce this need.</p> <p>It was given pilot funding by the West Yorkshire and Bradford District and Craven ICB to offer information and signposting, 1-2-1 Peer Support with a focus on post-diagnostic help, support to help access GP/health services and support to navigate mental health services.(Mental health work utilising existing Comic Relief autism mental health equity focused funding is also being utilised to add value)</p>
<p>Sept. 2023</p>	<p>Supported Employment</p> <p>CBMDC launched a local supported employment initiative (LSE) for people with autism. This new service will support 100 Autistic people into paid employment and is funded until March 2025.</p> <p>NHS/SACAR; Autism Works – provides a tailored supported employment programme to increase confidence, employability and overall health</p>
<p>Dec. 2023</p>	<p>Neurodiversity Social Work Service,</p> <p>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</p> <p>be based within the Learning Disability and Preparing for Adulthood Service and sit alongside the existing Learning Disability Locality Teams.</p> <p>The overall focus of the Neurodiversity Team is to work with people to enable them to live a good life, by working in a neurodiverse friendly way to understand the person, their strengths and what is important</p>

	to them. The team will work creatively, to find solutions to make a positive impact on people’s lives.
May 2024	<p>Broadway – All-age Sensory Room The Broadway Sensory Room is a project funded by organisations across the H&SC system in partnership with the Broadway Shopping Centre.</p> <p>The Sensory Room is a specially designed environment that provides a sensory experience to people, young or old, with a wide variety of different abilities. Perfect for anybody with sensory challenges or in need of a safe and distracting place to return to a state of calm, making the shopping centre a more inclusive space for Autistic people and people with sensory issues.</p> <p>The build is planned to be completed in May 2024 and Commissioners are now working with the Broadway team and their contracted event co-ordinators to plan a launch event of the sensory room. The launch will have a creative arts focus and a grant application has been submitted for funding to secure a relevant performance artist for the day. The launch will follow the blueprint for the Burnley Sensory Room, which has included training centre staff in autism and neurodiversity awareness.</p>
2024 /25	<p>Planned Adult Autism Assessment Developments The concept of camouflaging or masking in autism is related to the social communication and social interaction deficits, It involves use of specific behavioural and cognitive strategies to adapt to the non-autistic social world and minimise the visibility of social difficulties. While the concept of masking or camouflaging is supported by the development of self-report measures and its association with mental health difficulties, ongoing research is needed to further validate and refine this concept.</p> <p>The Service has introduced training and a tool to explore the presence of these making behaviours during the referral completion appointment. Apart from the observations about behaviours linked to autism, specific effort is made to also explore masking behaviours particularly in females.</p>

3.2 Performance and Data

Evaluation of the service had been challenged by the absence of data covering 2015 to 2021. A new BANDS monthly data report was agreed with BDCFT and has been in place since Nov 2021. Significant additions were added to the dataset in 2023. As part of the development of the new service model, additional manual analysis of data is undertaken by SWYPFT. A full set of monthly data reports is available in **Appendix 7**

Bradford Autism Assessments - Progress Update: 23 January to 31 December 2023

The South West Yorkshire NHS Foundation Trust, in collaboration with the Bradford District Care Foundation Trust, initiated the Bradford Autism Assessment Pathway on 23rd January 2023. This update delineates activities and differentiates between new referrals on the updated pathway and legacy cases. Outcomes of the Waiting List Project concluded in June 2023 were reported separately.

Key Points/Developments:

Recruitment:

- Nearly all positions in the Autism pathway have been filled. One remaining vacant psychology post will be advertised with a mid-January closing date.
- New personnel are trained and fully operational.

Legacy cases:

- Outreach to legacy waiting list individuals is underway to confirm interest in assessment, with all contacts planned by 31st March 2024.
- The initial caseload of 506 has reduced to 354. Almost half of those discharged have been seen, the others did not engage or have moved away from Bradford.

Requests for Referral received since 23/1/23:

- 599 requests received; referral rates have increased by 20% in recent months.
- 442 individuals seen to date; a small number discharged for non-engagement or other reasons.
- 71 found suitable for assessment; 60 have had first appointments, and 54 individuals have completed the process.

REPORT CONTENT

This update is based on a manual collection of data from SystemOne and other service held records. It has three sections:

1. THE PATHWAY – A description of the pathway and how this compares to the recommended NHSE pathway for adults.
2. REQUESTS FOR REFERRAL TO THE NEW PATHWAY – Details of activities relating to all requests since the pathway launched on 23rd January 2023
3. LEGACY REFERRALS RECEIVED BY THE FORMER BANDS SERVICE – Details of activities and information relating to legacy referrals received by the former BANDS service.

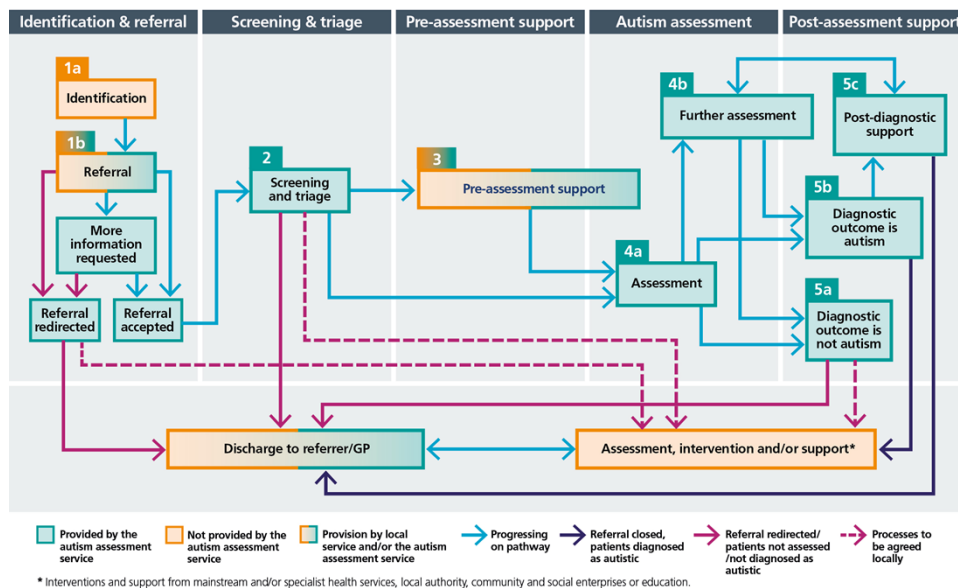
A. THE PATHWAY

There are three distinct steps to the pathway:

1. 'Requests for Referral' Management
2. Screening & Triage
3. The assessment

The chart below shows the 5 steps in the NHSE recommended pathway and how many Bradford cases typically flow through Steps 1, 2 and 4 commissioned from this Service in a 12 month period.

The Autism Assessment Pathway



Cases: 600 580 n/a 100-120 n/a

'Requests for Referral' Management

GPs do not submit referrals to this Service, they submit 'Requests for Referral' with the intention that clinical appropriateness for assessment is determined by Autism experts. This step allows the individual more time to explain their needs and the reason why they believe they may have Autism.

When a Request for Referral is received, it is reviewed to check basic personal information to ensure the individual meets the criteria for the commissioned pathway e.g. Are they registered with a Bradford GP? Are they aged 18+?

If they meet the criteria, then the request is accepted.

The Service expects to receive circa 600 requests per year and 97% of requests are accepted at this stage. All of these go on to screening & triage.

Screening & Triage

As recommended in the recently published NHSE Guidance for ICB's [NHS England » Operational guidance to deliver improved outcomes in all-age autism assessment pathways: Guidance for integrated care boards](#), the pathway includes screening and triage by a panel of clinical experts to ensure that an autism assessment is appropriate. The referral collection form is based on recommendations from this guidance.

Each person is invited to a **Referral Clinic**, a 30 minute appointment to discuss why the person feels they need an autism assessment and gather relevant referral information. The appointment gives them much more time than a regular 8 minute appointment with the GP and can enhance the information provided for triage. The majority of appointments are face to face at Hillside Bridge Health Centre in Bradford, but some appointments are held remotely via video conferencing. The Service also takes this opportunity to seek consent to view other relevant health records that might help to determine if an assessment is appropriate.

A panel of Autism experts then review the information available to them and determine if an assessment is clinically appropriate. This step is called **Triage**. If the panel agree that an Autism assessment is appropriate, then it is **at this point** that the person is referred to the Autism Assessment pathway. Circa 15-20% of monthly requests are referred for assessment (approx. 100-120 people per year).

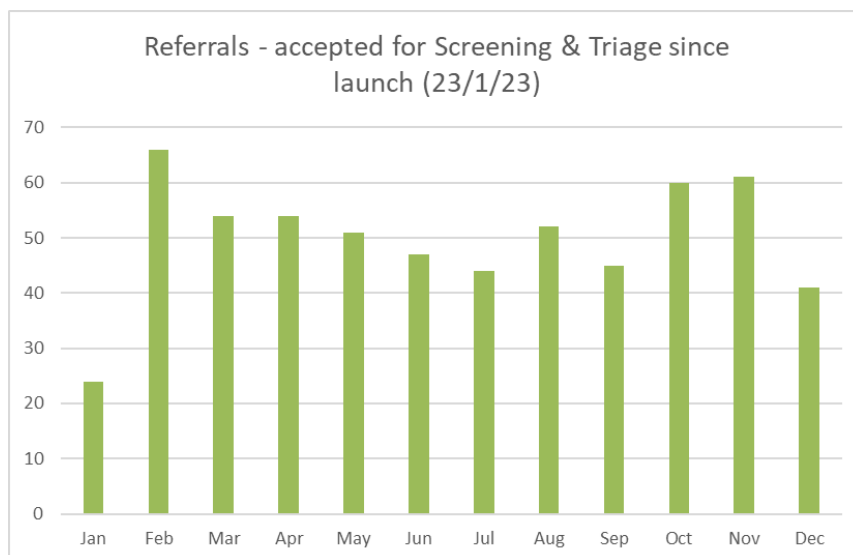
The Assessment Process

When referred for assessment, the person is sent a self-questionnaire pack that provides information for several clinical tools. When this pack is returned, the person is offered an **initial assessment appointment**. Further appointments with the person and/or family members may be needed before a decision is made about whether the person has Autism or not.

B. REQUESTS FOR REFERRAL TO THE NEW PATHWAY

Request for referral activity

Approx 599 electronic requests have been received since launch. Referral rates have increased in October and November, but the average referral rate is only slightly higher than to the twelve months to Dec 2022.



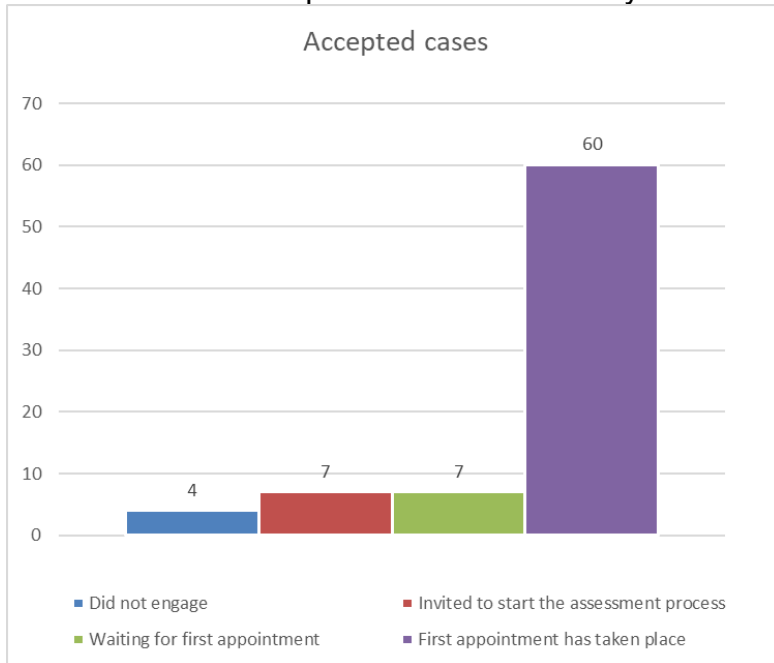
Screening & Triage

To date, 442 (80%) of the 567 people accepted for screening & triage have attended a referral clinic. 33 people have been discharged as they did not engage, 5 others moved away or withdrew from the process before they were seen. There are currently 87 people waiting for their referral clinic to take place, 35 of these have an appointment booked in the next 4 weeks.

From the 442 people seen since launch, 3 were discharged as they decided they did not want to be assessed or moved away from the area. 7 are waiting to be considered by the Triage Panel. To date, 432 referrals have been considered by the Triage panel. 361 people do not meet the criteria for assessment and 71 people have been identified as appropriate.

The Assessment Process

60 of these 71 appropriate cases have already had their first assessment appointment and 5 have been offered one in the next four weeks. 4 were discharged as they did not engage with the assessment process. 2 others are yet to return questionnaire packs.



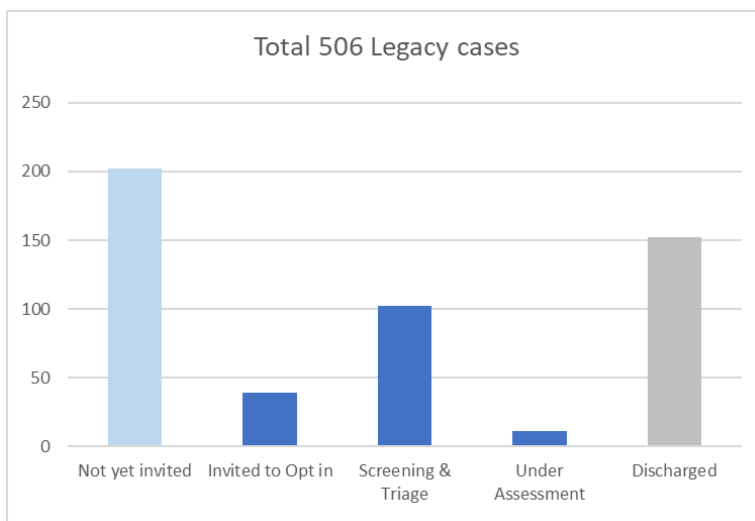
Diagnostic Outcomes

40 individuals have been told they do not meet the criteria, 10 (25%) have been informed that they do have Autism. All have been signposted appropriately. 13 people are still under assessment. **Note:** The diagnostic rate appears low but note that assessments did not start until April 23 and the rate may be distorted by some of the more complex cases being still under assessment.

C. LEGACY REFERRALS RECEIVED BY THE FORMER BANDS SERVICE

Total Referrals

The number of people on the legacy list from the former BANDS was 506. This chart represents those 506 cases on the pathway:



Opt In Letters

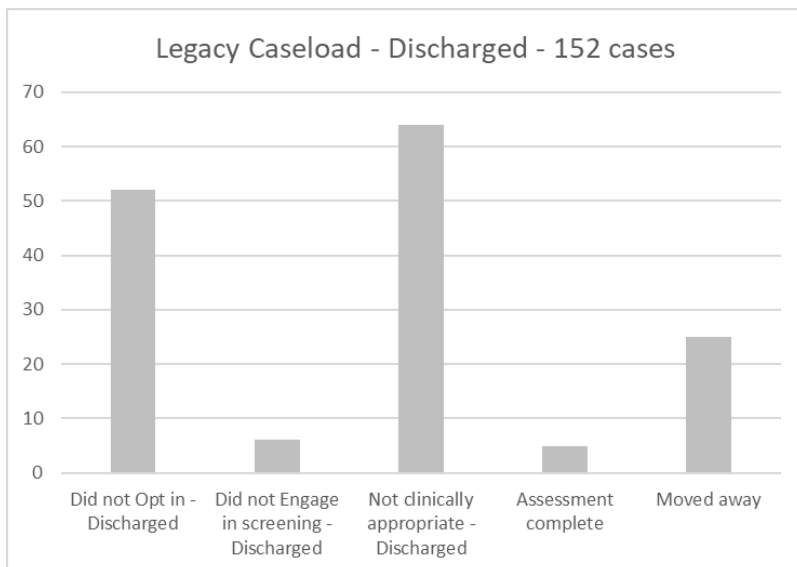
As these individuals were referred to the former BANDS pathway, each person is being contacted to inform them of the new pathway and to ask them if they would still like to be considered for assessment. Everyone referred prior to 30/6/22 has been contacted, there are still have 202 people to contact, all of these will be contacted before 31/3/24.

The response rate is approx. 75% (based on responses due back before the end of December).

Discharges

152 people are already discharged.

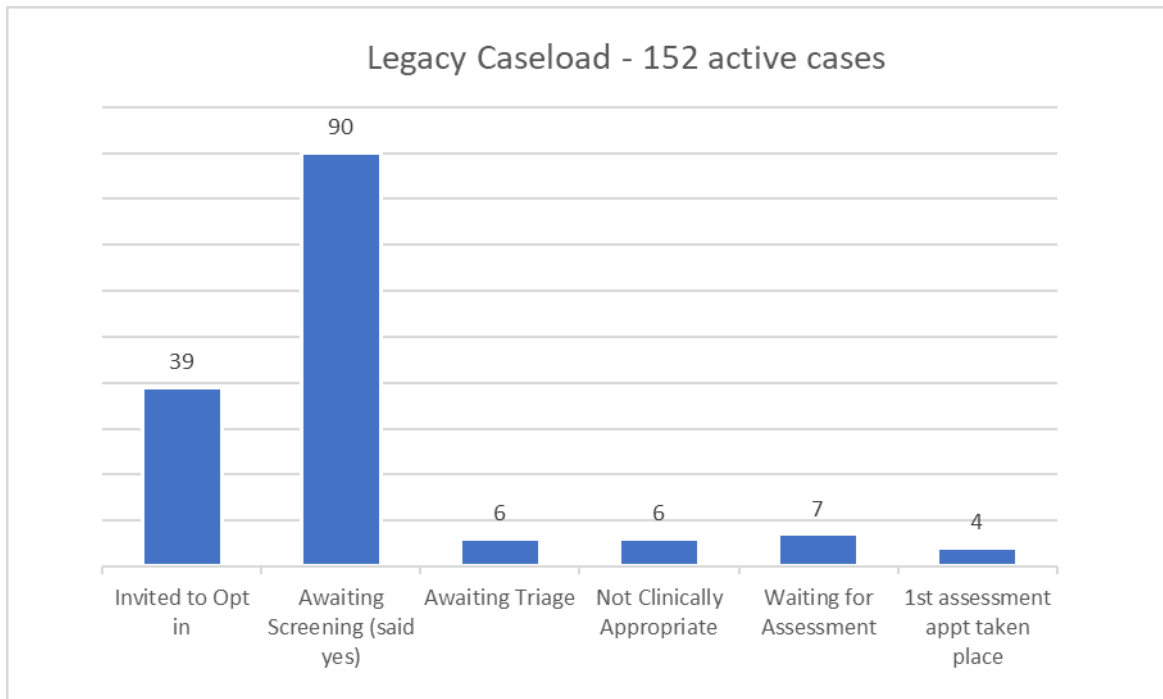
- An audit showed 25 people have moved away from Bradford or passed away.
- 52 did not respond to opt-in letters.
- 6 were invited for screening but did not engage and were discharged.
- 64 were triaged but did not meet the criteria for assessment and were discharged.
- 5 people completed their assessment and were discharged.



Open cases

There are 354 people still on the caseload. 152 of these are 'active'- contact has been made.

- 39 of those contacted and are yet to respond to opt in letters.
- 90 have responded and are waiting for their screening appointment.
- 6 have had a screening appointment and are waiting to be considered by the triage panel.
- 6 people have been considered by the triage panel and are to be informed that an assessment is not clinically appropriate.
- 7 people were accepted at triage and are waiting for their first assessment appointment to take place.
- 4 people have already started the assessment process.



Diagnostic Outcomes

To date 16 people have been identified for assessment. 5 assessments are complete, the individuals have been advised that they do not have Autism and have been/will be signposted to appropriate support.

Waiting Times

The 'oldest' case on the list of open cases is a person referred in May 2021. This person has been seen in a referral clinic and his referral will be considered by the Triage panel in January. There are 22 other people on the open list referred in 2021. All of these have been contacted, 2 are yet to respond and confirm they would still like to be seen.

The majority of the current waiters were referred in 2022. 156 of these have been contacted and to date 93 have confirmed they would still like to be seen.

Autism Overall Monthly Data (Legacy Waiting List + New Monthly Referrals) See Appendix 7

Autism Diagnostic Assessment Monthly Totals														
Metrics	Jan-23	Feb-23	Mar-23	Apr-23	May-23	Jun-23	Jul-23	Aug-23	Sep-23	Oct-23	Nov-23	Dec-23	Data Source	
REFERRAL DATA (Recorded within SystemOne)														
No referrals received	44	68	53	50	55	51	47	51	42	57	53	43	BDCFT	
Male	20	32	18	21	23	26	23	24	14	30	23	19	BDCFT	
Female	24	36	35	29	32	25	24	27	28	27	30	24	BDCFT	
Other	0	0	0	0	0	0	0	0	0	0	0	0	BDCFT	
No of referrals accepted	33	68	53	50	47	45	42	51	42	57	52	35	BDCFT	
Male	12	32	18	21	18	23	19	24	14	30	22	16	BDCFT	
Female	21	36	35	29	29	22	23	27	28	27	30	19	BDCFT	
Other	0	0	0	0	0	0	0	0	0	0	0	0	BDCFT	
No of Referrals rejected (breakdown of reason below)	11	0	0	0	8	6	5	0	0	0	1	8	BDCFT	
Refused By Service	0	0	0	0	0	0	0	0	0	0	1	7	BDCFT	
Inappropriate Referral	4	0	0	0	8	6	5	0	0	0	0	0	BDCFT	
Duplicate Referral Request	0	0	0	0	0	0	0	0	0	0	0	1	BDCFT	
Incomplete referral request	7	0	0	0	0	0	0	0	0	0	0	0	BDCFT	
WAITING LIST INFORMATION -Waiting at end of period														
No of people waiting for first Referral Clinic Appointment										540	508	467	422	BDCFT
Longest wait for referral clinic										1055	900	930	961	BDCFT
No of people Waiting for Triage										13	12	16	13	SWYPFT
Longest wait for Triage										50	791	773	830	SWYPFT
No of people Waiting for Assessment (first Autism Screening appointment)										22	23	12	13	SWYPFT
Longest Wait for Assessment (first Autism Screening appointment)										808	776	819	867	SWYPFT
WAITED INFORMATION (Patient Activity)														
Referral clinic (Information Gathering)														
No of people receiving first referral clinic appointment in period	2	15	82	45	45	40	51	42	31	67	64	48	BDCFT	
Average wait from referral date to first Referral Clinic appointment								46.5	34.7	281.3	288.4	475.6	BDCFT	
First Assessment Appointment (First Autism Screening Appointment)														
Metrics														
No of people receiving first Autism assessment appointment in period (First Autism Screening Appointment)	9	5	2	5	8	5	5	8	9	8	16	8	BDCFT	
Average wait from referral date to first autism Assessment (first Autism Screening appointment)								151.7	206.7	397.1	161.5	381	BDCFT	
Diagnosis														
Number of patients receiving confirmed diagnosis of Autism	0	3	2	1	0	0	3	2	0	2	2	1	BDCFT	
Average time waited from referral to diagnosis of autism (days)		754.3	793.5	680			158	131		185	182.5	220	BDCFT	
Number of patients receiving a diagnosis of 'No Autism'	5	4	4	2	4	6	2	10	5	5	12	3	BDCFT	
Average time waited from referral to diagnosis of 'No Autism' (days)								162.3	156	315.6	177	137.3	BDCFT	
PATIENT DATA														
Number of referrals open at end of reporting period							0	583	588	561	520	467	BDCFT	
DISCHARGE DATA														
Discharges Breakdown by End Reason														
Not Recorded								0	0	0	0	9	BDCFT	
Client transferring to specialist care								0	0	0	0	1	BDCFT	
Discharged - No further treatment appropriate								62	31	61	56	50	BDCFT	
Discharged - Patient did not attend								2	3	2	3	3	BDCFT	
Discharged - Patient died								0	0	0	2	0	BDCFT	
Discharged - Patient Requested Discharge								0	0	0	1	0	BDCFT	
Discharged - Treatment completed								2	2	1	10	8	BDCFT	
Data Cleansing								1	0	0	0	0	BDCFT	
Discharged - Refused to be Seen								1	0	4	14	28	BDCFT	
Discharged - Moved out of the area								0	1	16	6	0	BDCFT	
Total Discharges								68	37	84	92	99	BDCFT	
General Medical Practitioner	44	68	53	50	55	51	47	51	42	57	53	43	BDCFT	
Other Agency	0	0	0	0	0	0	0	0	0	0	0	0	BDCFT	
Total	44	68	53	50	55	51	47	51	42	57	53	43	BDCFT	
Additional Metrics														
No of people receiving first appointment in period	3	16	84	45	47	41	52	42	31	67	64	48	BDCFT	
No of people waiting for first Appointment	535	585	551	545	545	544	523	529	536	505	464	420	BDCFT	
No of people waiting for Diagnosis	556	615	641	667	664	658	599	578	585	556	519	465	BDCFT	

Autism Overall Monthly Charts(Legacy Waiting List + New Monthly Referrals)



3.4 Case Studies; Bradford Adult Autism Project Case Studies x 2

Recognising the unique experience of individuals referred to the service and collecting information that identifies themes and trends is an important part of ongoing service development. Please note the additional points relating to these case studies, which were completed by one of our Physician Associates working in Bradford.

- The pathway is compliant with the NHSE Guidance [NHS England » Operational guidance to deliver improved outcomes in all-age autism assessment pathways: Guidance for integrated care boards](#). These studies reflect the recommended steps.
- In these examples, the time period between Information Gathering and Screening & Triage was about 2 months. This is because of technical issues we had with Bradford systems in the early part of the collaboration that created some bottlenecks for triage. These issues are completely resolved now and Screening & Triage generally takes place within 2 weeks of Information Gathering.
- Assessment appointments are generally offered within 30 days of Screening & Triage. Cases that exceed this time frame are generally because the individual has not responded to questionnaires within appropriate time scale.

Bradford Project Case Study #1 Service for Adults with Autism

Patient Details

Mr AAA is a 56-year-old, gentlemen currently living in Bradford.

Reason for referral

Mr AAA was referred for an Autism assessment on the 15th of May 2023 by his GP. The referral was initiated by his sister – who following the passing of his mother,

had taken over care of Mr AAA. His family had long suspected he may have Autism, however had struggled to gain a formal assessment. There were concerns around his behaviors in the workplace, mainly difficulties in his relationships with co-workers and in addition to this, his sister must provide significant support for his activities of daily living.

They cited difficulties in Mr AAA's ability to develop friendships, inappropriate behavior in social situations, communicating with people and not knowing how to verbalize his thoughts or feelings. He also appears to have strange collections.

Information Gathering

Mr AAA first attended a referral clinic appointment on the 31st of May 2023 to ascertain if his initial referral was appropriate. During the clinic appointment, there was evidence of difficulties in respect to his social communication, interaction and he described unusual interests and fixations not appropriate of someone of his age.

Screening & Triage

The information and clinical observations were used to assess the clinical appropriateness of offering an Autism assessment. This decision was made by a panel of experts in Autism who determined that Mr AAA needed an assessment.

Assessment 1

He then attended a screening assessment accompanied by his sister, on the 19th of September 2023. This appointment lasted over two hours. During the appointment, Mr AAA was observed to show deficits in social communication, interaction and presented with restrictive behaviours and interests. Furthermore, through the information collected, there appeared to be long standing difficulties in respect to his level of functioning. This screening assessment indicated a need for a formal assessment using validated diagnostic tools as recommended by NICE CG142.

Assessment 2

Mr AAA was assessed using the Autism Diagnostic Observation Schedule (ADOS-2) – a gold standard diagnostic tool on a rescheduled appointment on the 15th of December 2023, following a cancellation of a prior appointment. On the ADOS, Mr AAA scored very highly – 16. Mr AAA's case was then put forward to discuss at MDT.

MDT discussion Outcome

At the final MDT discussion, it was concluded that Mr AAA meets the criteria for autism spectrum disorder on the 21st of December 2023.

He was provided the outcome and had the opportunity to discuss his assessments. His carer was also contacted and provided with further information around support for carers and to answer any additional questions. Mr AAA was sent the reports, along with the post diagnostic pack, which includes information around ASD, charities and services designed to support people with autism and further information around his rights and the support he may be able to access.

Feedback from Service User Carer

"The process was quicker than I anticipated as I was initially told I may wait several years to get my brother assessed. As a family, we were especially pleased with the

outcome as it allows us to provide support but also help us understand our brother. The information sent has allowed us to understand his rights and he has since been able to access better support at work and seems happier as a result.”

Bradford Project Case Study #2

Service for Adults with Autism

Patient Details

Mr XXX is a 25-year-old gentleman currently living in Bradford.

Reason for referral

Mr XXX was referred for an Autism assessment on the 13th of July 2021 by his GP. The referral was initiated by Mr XXX himself. He has had longstanding concerns that he may have Autism dating back to 2014. He cites difficulties in social situations as he has a tendency to overthink situations and has longstanding low mood and anxiety.

Information Gathering

Mr XXX first attended a referral clinic appointment on the 25th of October 2022 to ascertain if his initial referral was appropriate. During the short referral clinic appointment, there were some difficulties observed in respect to his nonverbal communication and social interaction.

Screening & Triage

The information and clinical observations were used to assess the clinical appropriateness of offering an Autism assessment. This decision was made by a panel of experts in Autism who determined Mr XXX warranted an assessment due to his current presentation.

Assessment 1

Mr XXX initially did not attend his first appointment March of 2023, and was then offered a second screening assessment, which he attended on the 5th May 2023 on his own. This appointment lasted over three hours. During the appointment, Mr XXX presentation was observed to improve as the assessment progressed. As he became more comfortable, his eye contact was socially modulated, and he engaged in back-and-forth communication appropriately. He shared humour, including the use of sarcasm. There was also an absence of repetitive or restrictive behaviours, including no sense of rigidity, no inflexible nonfunctional routines, and no specific interests. Mr XXX also reported a turbulent and dysfunctional childhood and feelings of low mood and anxiety from an early age. He has previously had contact with CAMHS and has long term difficulties with his food intake. Mr XXX also has a dependency on Cannabis and is currently using 2-3g of the drug a day.

During the assessment he screened positive for panic disorder with agoraphobia and generalised social anxiety disorder using the M.I.N.I. (*Mini International Neuropsychiatric Interview (M.I.N.I) which is designed as a brief structured diagnostic interview for the major psychiatric disorders in adulthood.*)

Mr XXX's case was then discussed in MDT.

MDT discussion Outcome

At the final MDT discussion, it was concluded that Mr XXX **does not** meet the criteria for autism spectrum disorder on the 8th of June 2023.

MDT noted how within the assessment, Mr XXX engaged in reciprocal conversations, demonstrated appropriate nonverbal communication, and did not have the required repetitive or restrictive behaviours expected in ASD.

Mr XXX was contacted to discuss the outcome of his assessment with clear rationale as to how he did not meet the criteria. There was long discussions and the opportunity to ask questions of the clinician. Mr XXX was given recommendations and information in respect to local services such as “My Wellbeing College” “Mind in Bradford” and how to access support for his substance use. He was also aware that he could discuss a referral to CMHT with his GP.

Feedback from Service User Carer

“I was initially upset at the outcome as I had thought I might be autistic. However, reading the report and discussing the outcome was helpful for me to understand differences between how I act and Autism. It also helped me understand how my anxiousness affects me and liked the information on local services who I contacted.”

3.5 Complaints, comments and concerns Jan 2023 to Jan 2024

	Total	Closed	With drawn	Current	Upheld	Not Upheld	Partially Upheld	inconclusive
Concerns	14	12	1	1		11	2	1
Dis-satisfied	2					2		
Complaints	0							
MP Complaints	1	1				1		

	Total	Discharge Arrangements	Customer Services	Service Provision	Length Of Waiting List	Diagnosis Problems	Failure to Follow Procedures
Concerns	14	2	4	5	1	1	1
Dis-satisfied	2	1			1		
Complaints	0						
MP Complaints	1				1		

	Service User	Relative/Family Member	MP.	Total
Concerns	12	2		14
Dis-satisfied	2			2
Complaints				
M.P. Complaints	2		1	

It has been noted there are more appeals from patients in Bradford, then from other areas. This suggests the complaints pathway would benefit from review. A process map, identifying roles and responsibilities between the partners should be developed so that patients receive a timely and informed response to comments or complaints. This will be addressed in the first annual review of the service, in March 2024.

3.6 Conclusion

This data and narrative updates included in this report provide evidence that the outcomes and objectives for the Adult Autism Pathway have been met, or are well on the way to being met.

Capacity of the assessment and diagnosis service has been increased from 40 cases per annum to 600 cases per annum, to meet existing demand

Waiting time for initial assessment has been reduced from approx. 12.5 years to 15 weeks. When the legacy waiting list is cleared, in approx. 12 months, the waiting time will be less than the NICE recommended 12 weeks

Quality of referrals has been improved through the introduction of GP referral through GPASSIST and the introduction of the 30 minute in person initial assessment meeting.

Improved experience of the Adult Autism Pathway is challenging to evidence as this service is not included in BDCFT Friends and Family Test. Complaints and comments from the adult assessment and diagnosis service requires further development to integrate communication to patients from BDCFT and SWYPFT.

Non-clinical support options have been extended through the addition of online and postal signposting to Community Wellbeing Hubs and Social Navigators. A pilot Adult Autism Hub was launched and funding is being applied for to continue this resource.

	Old Service	New Service
Staffing	2.5	4.85 (part of a team of 32)
Finance	£65 k p.a.	£352,000 p.a.
Demand	600 cases p.a.	600 cases p.a.
Activity	40 cases p.a.	600 cases p.a.
Cost	£1,625 per referral	£590 per referral
Referrals	Referral form completed by GP	Request through GP ASSIST. Referral form completed by service.
Access	Approx. 12.5 years (500 people waiting @ 40 assessments per annum)	15 weeks and reducing
Assessment Clinic	No	Yes
Clinical triage	No	Yes
Signposting	No	Yes

4. Options

This is an update report for information only, with no options for consideration required.

5. Contribution to corporate priorities

This plan supports the BDC HCP priority; Parity of esteem for access and outcomes for people with Learning disability / neurodiversity

6. Recommendations

- 6.1 Members are asked to support the developments to the BDCFT/SWYPFT service model to develop a new Adult Autism Pathway and service model to assess and diagnose adults with autism spectrum conditions and the benefits for patients and referrers.
- 6.2 That it be noted that all project objectives have been met, or are on target to be met, and the new service is now operating as 'business as usual'.

7. Background documents

None

8. Not for publication documents

None.

9. Appendices

- 1. New Adult Autism Assessment Process Map
- 2. New Adult Autism A&D Pathway
- 3. Bradford Autism Waiting List Project Final Report
- 4. Letter to patients re next steps
- 5. Autism Support Leaflet and Website
- 6. Bradford and Craven Autism Aim September Report
- 7. Adult Autism monthly data Dec 2023