

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 22 March 2023

AA

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.

This report sets out the progress made in developing a new service model to assess and diagnose adults with autism spectrum conditions and the benefits for patients and referrers.

Acronyms and Abbreviations used

ASC; Autism Spectrum Conditions
BANDS; Bradford and Airedale Neuro Diversity Service
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

1. Summary

Following criticism of BANDS by HOSC and complaints from patients, which included concerns about the high number of people waiting, the length of time people had to wait and low levels of activity, a review was conducted and an Action Plan was agreed by the MH, LD and ND Partnership Board to address these concerns and improve the service, to be delivered through a multi agency Neuro Diversity Task & Finish Group.

Early in 2022, it became apparent, mainly due to the resignation of existing BANDS staff and an inability to attract new staff to the service, that the Action Plan could not succeed in delivering its objectives. Undeterred by this failure and recognising that a new, innovative approach was needed to break the cycle of failure for this service, the Neuro Diversity T&FG negotiated with a similar but more successful, service delivered by SWYPFT, to develop a partnership to deliver an innovative, sustainable model of service that would meet patients needs through quality improvements, a proven ability to recruit to posts and a service model which will close the gap between demand and capacity. It was determined that the entire Adult Autism Pathway should be redesigned in order to introduce pre and post diagnostic support options for patients.

This report and appendices provide an update to the report delivered to HOSC in August 2022.

The August 22 report updated on progress, challenges and revisions made to plans since March 2022 and set out the pathway to deliver a new Adult Autism Pathway. The new pathway would include 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.

A Project Plan was shared with detail of the steps required to realise the new pathway and services, including the increased financial investment required from commissioners, a detailed description of the new service model and a summary of the challenges faced in delivering this plan. The planned outcomes for the pathway were stated as;

- Improve capacity of Adult Autism Pathway to meet demand
- Waiting times to access service to be reduced to NICE guideline levels
- Improved quality of referrals
- Improved experience of the Adult Autism Pathway

Data was shared, demonstrating the gap between demand for this pathway and the growing gap in capacity to meet that demand, alongside an explanation of how the new Adult Autism Pathway would increase capacity from the current 40 cases per year to a projected maximum of 600 cases per year.

Plans for the Bradford Waiting List Initiative were shared. This project was commissioned from SWYPFT, to triage and assess 100 people from existing BANDS waiting list, by April 2023, utilising non-recurrent funding to temporarily increase the number of people assessed and to reduce waiting times for people on the BANDS waiting list.

In a Briefing Session in October, the NHS commissioner and the BANDS provider committed to return to HOSC in March 2023 to share outcomes;

- March 23- Report to full committees on performance – demonstrate 80% of projected assessments are completed.
- Demonstrate a plan for sustainability and continued improvement of service

The new service and pathway started in Jan 2023 and will expand through this year to manage up to 600 referrals and signpost patients to sources of community support.

This report sets out the progress made in developing a new service model to assess and diagnose adults with autism spectrum conditions and the benefits for patients and referrers, with detailed information on;

- Background to Adult Autism
- Project Aims and Objectives
- Bradford Waiting List Initiative
- Development of new Bradford District and Craven (BDC) Autism Assessment and Diagnosis Service for Adults.
 - Interim leadership cover
 - Referral Through GP ASSIST and Assessment Clinic
 - Clinical Triage
 - Communication
- Key service model developments
- Project Plan
 - Outcomes and benefits
 - Performance and Data
 - Referrals
 - People Waiting for a First Appointment
 - Diagnoses

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

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
- 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 reduce and end waiting times
- 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

Action 1; Bradford Waiting List Initiative (Appendix 1)

This project was commissioned to clear 100 people from the BANDS Autism Assessment waiting list. 127 people were identified from the waiting list, they were referred for assessment between 22nd September 2020 and 14th July 2021.

The project is 79% complete – 100 of the 127 people identified from the list have been discharged. The charts and narrative in Appendix 1 explain how many people have been seen to date by each part of the pathway, and which parts of the pathway are now complete.

Table 1; Bradford Waiting List Initiative

**Outsourcing
100
assessments
through
SWYPFT
Sept 2022 to
April 2023**

- Estate identified for local delivery of assessments
- Data sharing in place
- Clinical triage of referrals complete
- Staff recruited by SWYPFT
- Initial communication to patients complete – Appendix 2
- Activity commenced Sept 2022 – Appendix 1
- Project due for completion April 2023
- Project projected to exceed target – total no of patients; 127

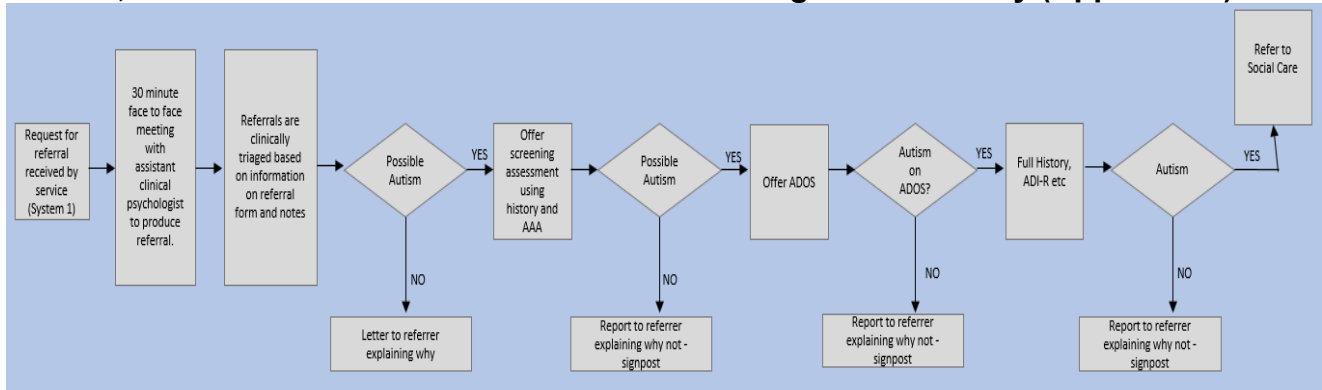
Action 2; Interim leadership cover for BANDS

From June 2022 the SWYPFT Adult Autism service provided cover for BANDS following the loss of all existing staff. This involved providing Referral Management cover and was funded from BANDS underspend due to vacancies. Additional input from Prof Adamou and other team members was received to improve processes and have meetings with local stakeholders.

Action 3; Development of new Bradford District and Craven (BDC) Autism Assessment and Diagnosis Service for Adults.

Recognising that the old BANDS model both undeliverable and unsustainable, a new service model was developed in partnership between BDCFT and SWYPFT. Since July 2022, Dr Sara Humphrey, clinical lead for LD and autism, joined the T&FG and has led on revising and improving the pathway, including the referral process.

Table 2; Revised Adult Autism Assessment and Diagnosis Pathway (Appendix 2)



Action 4; Referral Through GP ASSIST and Assessment Clinic (See Appendix 6)

Feedback from clinicians and patients has shown 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.

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

Patients will then 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.

Expert health professionals in autism will 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 an assessment.

The new Service will provide reports to patients and to referring clinicians detailing the outcome of this triage process and/or subsequent assessment.

Each person referred receives a letter from the new service, explaining what to expect.

Action 5; Clinical Triage

In order 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.

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.

Action 6; Communication


Every patient referred receives a letter explaining what to expect and next steps (**Appendix 3**). In addition, each referral results in a detailed clinical feedback letter from BANDS explaining outcome of referral. At whatever stage of the pathway a patient is discharged from the pathway, whether pre or post diagnosis, the patient will be send a letter explaining the reasons for discharge. Each person receives a second letter, at the end of the process, confirming the assessment outcome and explaining the reasons for the autism specialists decision.

What happens when I'm referred for an adult autism assessment




- 1

You have been referred for an adult autism assessment



- 2

You will be invited to a face-to-face appointment to gather more information for your referral. This will take about 30 minutes



- 3

The adult autism service check the referral to see if:


 - a. You already have a diagnosis
 - b. There is enough information from the GP or social worker
 - c. The information suggests you MAY have autism


- 4

If it looks like you might have autism, you will be sent a pack with questions to answer and send back.



- 5

An autism specialist called a 'screening clinician' looks at your answers and invites you to have a chat with them. This may take place over a few appointments. This part is called information gathering.



- 6

The autism team look at all the information together and decide what the outcome is. The outcomes will be either:


 - a. They're not sure and need to investigate a bit more
 - b. Yes, you have autism
 - c. No, you don't have autism (they might suggest you have a different condition)


- 7

The autism team will let you and your social worker or GP know the outcome. They will both tell you what support is available if you want it.



In partnership with:
 Bradford District Care NHS Foundation Trust
 South West Yorkshire Partnership NHS Foundation Trust
 Leaflet co-produced by Kirklees Autism Group



Adult Autism Project Key Components

Table 3; Key service model developments

	Old Service	New Service
Staffing	2.5	4.85 (part of a team of 32)
Finance	£65 k p.a.	£352,000 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. 2 years	12 weeks
Assessment Clinic	No	Yes
Clinical triage	No	Yes
Signposting	No	Yes

Table 4; Project Plan

Recruit to new posts, rebuild and sustain BANDS	<ul style="list-style-type: none"> • 2 x Band 7 psychology post The B7 posts are Physician Associates https://www.fparcp.co.uk/about-fpa/who-are-physician-associates We are piloting the role in Autism for the first time in the UK • 0.345 x Band 8c Clinical Psychologist • 1 x Band 8a Psychologist • 1 x Band 4 Psychology assistant • 0.5 Admin
Legacy Waiting List	<ul style="list-style-type: none"> • 544 people have been transferred from the old BANDS service • It would have taken the old service 13.5 years to assess this number of patients • The new service will take 24-36 months to reduce this list to 0, from when initial letters are sent to patients.

Table 5; Outcomes and benefits

For patients	<ul style="list-style-type: none"> • All patients will be offered initial appointment within the NICE recommended 12 weeks • Patients receive a letter after referral, explaining next steps • All triage and assessment engagements will be in a Bradford district and Craven location • All triage and assessment engagements will be in person, not virtual. • Waiting time from first contact to completion of assessment will be, on average, 20 weeks
For referrers	<ul style="list-style-type: none"> • Onus of collecting initial, detailed referral information is moved from the referrer (predominantly GPs) to the BANDS service through an initial, 30 minute face to face interview • Fewer call-backs asking for additional, or missing, information • Detailed clinical feedback letter from BANDS explaining outcome of referral.

Workforce

- Membership of a large, multi-disciplinary team with clinical sites across West Yorkshire
- Career development opportunities
- clinical and management support available
- Absence and leave cover included

Performance and Data

Evaluation of the service has 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. (Appendix 5)

Activity updates for the ‘Bradford Waiting List Initiative’ are produced bi-monthly – (Appendix 1)

Table 6; Adult Autism Monthly Data Report (Appendix 5)

Autism Diagnostic Assessment monthly totals															
Metrics	Nov-21	Dec-21	Jan-22	Feb-22	Mar-22	Apr-22	May-22	Jun-22	Jul-22	Aug-22	Sep-22	Oct-22	Nov-22	Dec-22	Jan-23
No referrals received	41	35	48	40	57	43	59	33	26	48	52	56	33	43	44
No of referrals accepted	22	26	35	29	34	28	44	30	18	37	41	35	21	31	26
No of referrals Undecided	0	0	0	0	0	0	1	0	0	0	0	0	0	0	7
Referrals rejected (breakdown of reason)															
Refused By Service	16	8	12	9	21	10	0	0	2	2	0	1	0	1	0
Inappropriate Referral	1	1	0	2	1	2	8	1	1	1	3	6	2	1	4
Incomplete referral request	0	0	0	0	0	0	5	2	5	8	8	14	10	10	7
No of people waiting for first Appointment	238	261	292	325	347	377	421	436	443	474	486	474	477	511	534
No of people receiving first clinic appointment in period	0	0	0	0	0	0	0	0	0	0	7	34	6	1	2
No of people receiving first Autism screening appointment in period	0	0	0	0	0	0	0	0	0	0	0	0	3	4	9
No of people receiving first appointment in period	3	5	2	1	8	3	0	1	0	0	29	34	8	0	3
No of people waiting for Diagnosis	244	267	297	329	358	366	421	437	444	475	516	532	545	577	556
Number of patients receiving confirmed diagnosis of autism	0	1	1	0	1	8	1	-	-	-					
Number of patients receiving a diagnosis of no autism spectrum disorder	3	4	2	2	0	4	0	-	-	-			1	2	5
Source of referrals (Breakdown)															
Community Mental Health Team	0	0	0	0	0	0	0	0	0	0	1	0	0	0	0
General Medical Practitioner	40	34	46	40	48	32	42	29	26	47	48	56	33	43	44
Total	41	35	48	40	57	43	59	33	26	48	52	56	33	43	44

Demographics

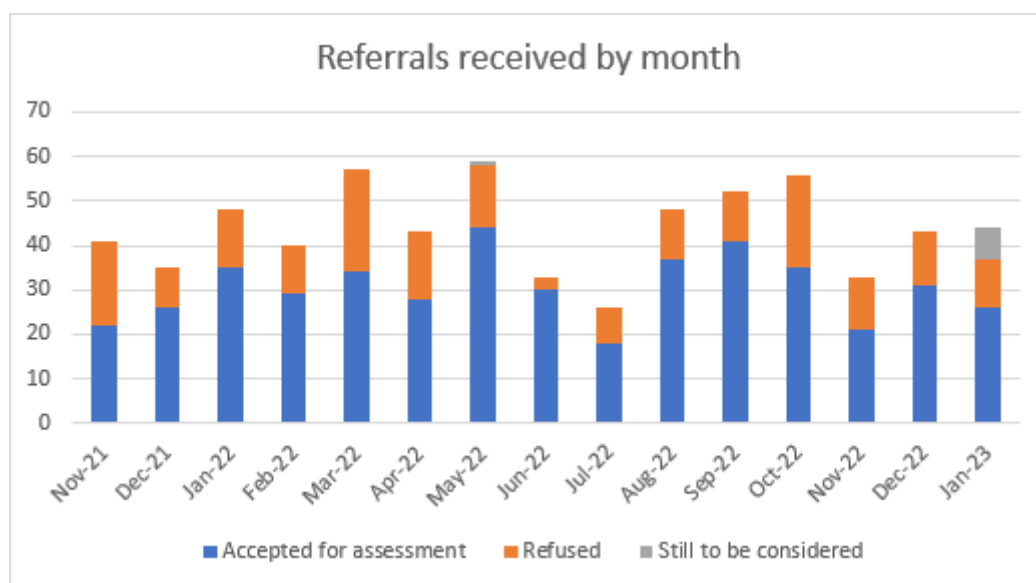
The service will collect basic demographic data of patients from GP records, to include;

- o age
- o ethnicity

Referrals

44 referrals were received in January; 26 were prior to the launch of the new pathway on 23rd January 2023, 18 were after this date. Analysis shows that the majority of referrals refused since June 22 are because the referral was incomplete. The introduction to the pathway of a 30 minute meeting with each person referred, in the Assessment Clinic, will mean that referrals will no longer be rejected for reasons of incomplete referral.

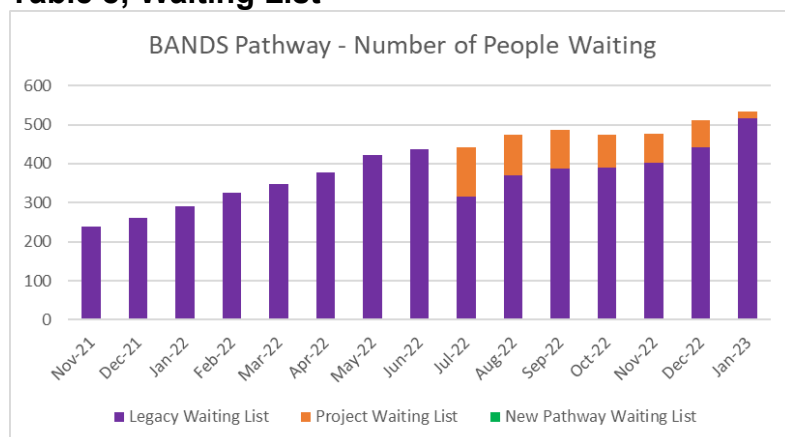
Table 7; Adult Autism Referrals Received by Month



People Waiting for a First Appointment

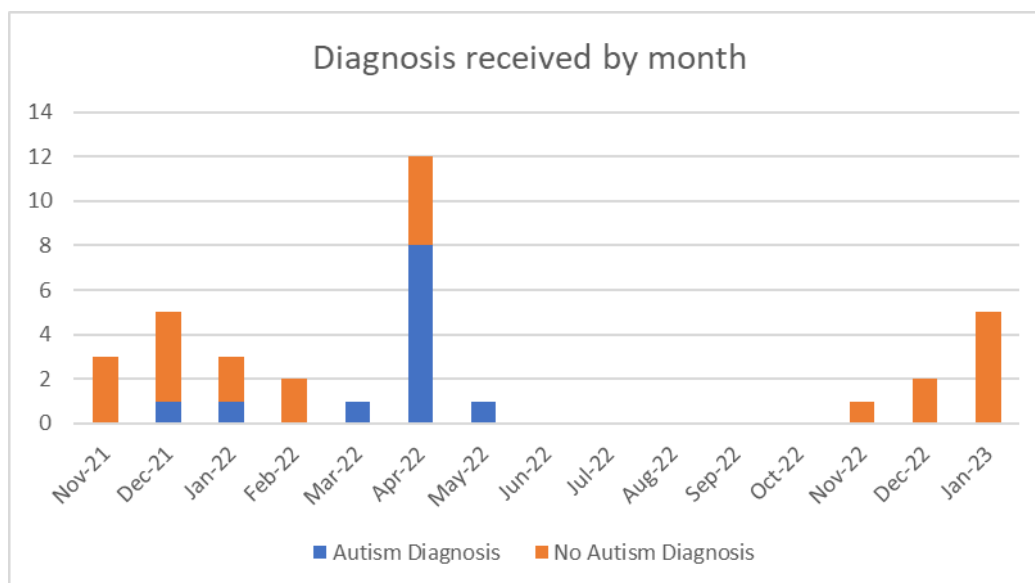
These are the numbers of people waiting prior to the launch of the new pathway. 517 are from the ‘Legacy Waiting List’ (the former BANDS waiting list) and a further 17 are some of the 127 people who were part of the SWYPFT Waiting List Project. All 534 were still waiting at the end of January. The remaining 17 who are part of the SWYPFT Project are expected to be seen or discharged by mid-April. There are no people formally waiting for assessment from the new pathway @ the end of January.

Table 8; Waiting List



Diagnoses

5 cases were concluded in January. All were confirmed as no autism. The 8 cases concluded since November are all part of the SWYPFT Waiting List Project.



Finance

A proposal was made to BDC Health and Care Partnership, in October 2022, for recurrent funding for a sustainable service model to assess and diagnose adults with autism spectrum conditions, at an annual cost of £350k pa, including clearing the backlog of 500 patients (18-24 months). NHS WY ICB funding is supported, for the period 2023/24, by NHSE grant funding of £187,000. The funding proposal was approved.

Current BANDS model	Independent sector providers	New Assessment and Diagnosis model
22/23 cost £76,500 p.a. for 40 assessments	22/23 cost £62,000 for 31 assessments	£352,000 pa, in total
£1,912 per assessment	£2000 per assessment	£408 per assessment, dependent on outcome of clinical triage process
£1,147,000 for 600 referrals	£1,200,000 for 600 referrals	£245,000 for 600 referrals, including interview, clinical triage and full assessment, where clinically appropriate.
		£107,000 to address the existing waiting list of 517 people

Case Studies; Bradford Project Case Studies x 2 – **See Appendix 7**

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. The Adult Autism project has liaised with YORLMC throughout and has

received feedback from the engagement group of the WY ICN Neuro Diversity Programme to influence elements of the pathway. Starting with the Bradford Waiting List Initiative and continuing with the new Adult Autism Pathway, the Service will provide 2 case studies in every six month period to demonstrate patient experience and impact. Friends and Family data will also be included in service evaluation.

Pre and Post Diagnostic Support for Adults with Autism Spectrum Conditions

A review has taken place of specialist and non-specialist support available to patient who have received, or are waiting for, an assessment for autism. Information signposting patients to those services will be shared with each person referred to the Bradford District and Craven (BDC) Autism Assessment and Diagnosis Service for Adults.

Through a WY ICB Neuro Diversity Programme scheme, in-person autism awareness training will be made available 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.

From April 2023, a WY pilot Adult Autism Hub will be available in Bradford, with 3 key elements of support;

- Offer 1: Pilot Mental Health Navigators
- Offer 2: West Yorkshire Autism Health Champions
- Offer 3: Autistic led Post Diagnostic Peer Support

See **Appendix 5** for information on new and existing support and services to expand awareness and support Adults with ASC.

Work has begun on a framework for a Neurodiversity Strategy for the district with an ambition to connect the work to Bradford City of Culture 2025, Bradford for All and with an ultimate ambition of making Bradford a Neurodiversity friendly city.

'Employment Matters' - a DWP funded Supported Employment programme (LSE) for 100 Autistic People funded to March 2025.

BDMC Adult Social Care wants to, where possible, support all Autistic People to remain in their own homes or live independent lives in supported provision. However, if specialist accommodation and support is needed we want to provide suitable and needs assessed provision that is person centred. We have run a 2 year project, due to end early 2023, working with both providers and people who use services to look at our current housing gaps and what people need from accommodation and services to live independently.

The current tender for a new round of Supported Living provision includes a specific lot for Autism and/or Neurodiversity in recognition of the particular support needs of this group.

4. Options

HOSC is 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.

5.0 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

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.

7. Background documents

None

8. Not for publication documents

None.

9. Appendices

1. Bradford Waiting List Initiative – Progress Update, Feb 2023
2. New Bradford Adult Autism Assessment and Diagnosis Pathway
3. 1st Contact Letter to patients re next steps
4. Pre and Post diagnostic Support
5. Bradford Adult Autism Monthly Data report
6. GP ASSIST Revised BANDS Adult Autism Pathway
7. Adult Autism Case Studies