

# Report of the Senior Officer, Strategy, Change and Delivery, NHS Bradford District and Craven Clinical Commissioning Group to the meeting of the Health and Social Care Overview & Scrutiny Committee to be held on 17 March 2022

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**Subject: ASSESSMENT AND DIAGNOSIS OF AUTISM IN ADULTS IN BRADFORD DISTRICT AND CRAVEN**

**Summary statement:**

The report and appendices describe the Adult Autism pathway, shares experiences of patients through case studies, and summarises the position in relation to improvements to the assessment and diagnosis of autism spectrum disorder (ASD) in adults in Bradford, District and Craven.

In particular, the report details the plan agreed at the MH, LD and ND Programme Board and progress on implementation.

The Adult Autism Plan, as focusses on 3 key areas:

1. Continue to strengthen the Autism Assessment Pathway (adults) through expanding existing BANDS service to increase capacity and patient throughput
2. Engage with NHS and independent providers for rapid, short term, expansion in capacity for clinical assessments
3. Engage with ICS to explore system approaches to ASD assessment and diagnosis

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**Portfolio:**  
**Healthy People and Places**

## 1. Summary

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## 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 experience difficulty 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])

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

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. The value of the contract has increased from £98,000 in 2015 to £152,000 in 2021. Core staffing consists of:

|                       |           |
|-----------------------|-----------|
| Lead Autism Clinician | x1 FTE    |
| Autism HCA            | x1 FTE    |
| Admin                 | x 0.5 FTE |

Nice guidance states that the local autism partnership should lead on the development of a multi professional pathway and be responsible for ensuring people are trained (all front facing staff) and reasonable adjustments are made, etc. Adult Social Care Services plan to bring together a new vision/plan for integrated care and support pathways/networks including good information and advice, Early Intervention and Prevention (EIP) services will support individuals as well as diagnosis and pathways into adult social care/ housing/ disability employment advisors, etc.

The prevalence data contained in the 2019 Public Health report, LEARNING DISABILITY AND AUTISM IN BRADFORD - A Health Needs Assessment will be used to help understand potential demand for adult diagnosis services and will contextualise something of the challenge faced by commissioners and providers of services to support adults with needs linked to ASD.

<https://jsna.bradford.gov.uk/documents/Mental%20wellbeing/05%20Learning%20Disability%20Health%20Needs%20Assessment/Learning%20Disability%20and%20Autism%20in%20Bradford%20-%20April%202019.pdf>

### 3. Report issues

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.

The value of the contract has increased from £98,000 in 2015 to £152,000 in 2021.

**Issues** linked to core funding, rising numbers of referrals, the Covid\_19 pandemic, recruitment and retention have contributed to the accumulation of a significant waiting list and waiting time to access the service.

Throughout 2021 and 22, commissioners and providers have worked collaboratively to agree and implement an **Action Plan** to address these issues. The objectives of this plan, approved by the MH, LD and ND Programme Board, are to:

1. Continue to strengthen the Autism Assessment Pathway (adults) through expanding existing BANDS service to increase capacity and patient throughput
2. Engage with NHS and independent providers for rapid, short term, expansion in capacity for clinical assessments
3. Engage with ICS to explore system approaches to ASD assessment and diagnosis

**The key elements of the plan and ongoing implementation are:**

|           |   |
|-----------|---|
|           |   |
| <b>1.</b> | <b>Explore and identify sources of additional funding</b>   |
|           | Additional sources of funding have been identified: <ul style="list-style-type: none"> <li>a. £374,000 NHSE Transformation Fund Allocation, over 2 years</li> <li>b. £100,000 CCG non-recurring funds to outsource 100 assessments to SWYFT</li> <li>c. £100,000 BDCFT non-recurring funds to outsource assessments to independent sector</li> </ul>  |
| <b>2.</b> | <b>Recruitment Plan with explicit timeline</b>  |
|           | A Recruitment Plan with explicit timelines is being followed ( <b>see Appendix 1</b> ) <ul style="list-style-type: none"> <li>a) 1x band 8b Psychology post (1 WTE)</li> <li>b) 1 x Consultant Psychiatrist (.2 WTE)</li> <li>c) 1x Band 4 Support worker (1 WTE)</li> <li>d) 1x band 3 Admin/Support (.5 WTE)</li> <li>e) The above will create an MDT in Bradford to diagnose as per best practice. Staff to be in post by July 2022</li> </ul> |
| <b>3.</b> | <b>New BANDS dataset and monthly report to be implemented</b>   |
|           | A new Adult Autism dataset and monthly report is in place since November 2021 ( <b>see Appendix 2</b> )   |
| <b>4.</b> | <b>Lessons from the previous Leeds deep-dive to be reviewed</b>   |
|           | The BDCFT Business Support Team, in conjunction with operational and clinical staff, have completed a review of the service and the pathway, in particular the triage process, and have identified efficiencies leading to an increase in capacity for assessment and other activity.<br>( <b>see Appendix 3</b> )  |
| <b>5.</b> | <b>Engage with NHS and independent sector re outsourcing to reduce waiting list</b>   |
|           | <ul style="list-style-type: none"> <li>a) 100,000 BDCFT non-recurring funds to outsource assessments to independent sector</li> <li>b) 100,000 CCG non-recurring funds to outsource 100 assessments to SWYFT</li> </ul>   |
| <b>6.</b> | <b>Engage with ICS partners to explore a consistent and collaborative approach to delivery of adult autism pathway</b>  |
|           | BD&C CCG and BDCFT are engaged with all ICS partners in a newly formed Adult Neuro-Diversity Planning Forum   |
| <b>7.</b> | <b>Direct management support to be provided to service</b>  |
|           | BDCFT have dedicated internal resources to provide additional management support to BANDS   |
| <b>8.</b> | <b>Improve access to the Adult Autism Pathway</b>   |
|           | <ul style="list-style-type: none"> <li>a) Self referral pathway to be introduced</li> <li>b) Engage and educate referrers to improve quality</li> </ul>   |

## Outcomes

|    |  |
|----|--|
| 1. | Improve capacity of Adult Autism Pathway                               |
| 2. | Waiting times to access service to be reduced to NICE guideline levels |
| 3. | Improved access  |
| 4. | Improved quality of referrals  |
| 5. | Improved experience of the Adult Autism Pathway                        |

## Autism Pathway Diagnostic Assessment Process

- See Appendix 3

## Post-diagnosis support - Information from CBMDC

Information on current services and support available for both children and adults with Autism can be found on the **Bradford Local Offer**.

<https://localoffer.bradford.gov.uk/>

General information for adults with care and support needs can be found at **Connect to Support**. <https://bradford.connecttosupport.org/>

The Council is currently working to improve the range of support options available to adults with autism and neurodiversity through the appointment of a Transformational Lead for Autism within Adult Social Care and via the allocation of additional resources to the Health and Well Being Department's Commissioning function. Targeted new provision is being developed, with a recent example being a grant-funded pilot project by a User-Led Organisation (ULO) to offer 'Clubhouse' type provision in a city-centre retail outlet for people with Autism or Asperger's who are interested in video gaming and comic books.

## Support for families and carers

Support for families and carers of children and young people (up to 25 years) with special educational needs and disabilities (SEND) is offered by the **Parents' Forum for Bradford and Airedale**.

The **Carers' Resource** service provides support for carers who are defined as people who, without payment, provide help and support to a friend, neighbour or relative who could not manage otherwise because of frailty, illness or disability.

## Case Studies

- See Appendix 4

## 4. Options

The options for the future of the BANDS Adult Autism service are:

- 1a. Continue to strengthen the Autism Assessment Pathway (adults) through expanding existing BANDS service to increase capacity and improve patient throughput
- 1b. Engage with NHS and independent providers for rapid, short term, expansion in capacity for clinical assessments
- 1c. Engage with ICS to explore and implement system approaches to the Adult Autism Pathway

| Pros  | Cons                                       |
|---|--|
| Plan will strengthen an established service   | Recurring recruitment and retention issues |
| Retain health resources within BD&C 'place'   | Some new funding is fixed term             |
| Opportunity to engage with ICS level planning |  |
| Outsourcing will reduce waiting times         |  |

2. Re-procure the Adult ASD assessment, diagnosis and support pathway

| Pros  | Cons  |
|---|---|
| Delivering this service on a larger footprint may address recruitment and retention, issues | Market engagement suggests few providers in a position to bid for this service  |
|   | Growing demand vs limited capacity issues being experienced by all providers of this service.                         |
|   | The Adult ASD pathway Provider, BANDS, also delivers the ADHD pathway, decommissioning would destabilise this service |

**5. Recommendations**

- 5.1 Members are asked to support Option 1, to allow BDCFT/BANDS a reasonable period to strengthen the staff team, increase activity and improve outcomes. Waiting times will also be reduced through outsourcing.

**6. Background documents**

None

**7. Not for publication documents**

None

**8. Appendices**

- Appendix 1** Recruitment Plan with timeline  
**Appendix 2** Summary of Adult Autism monthly dataset report, Nov. 19 to Jan 22  
**Appendix 3a** Illustration of Adult Autism Pathway  
**Appendix 3b** Autism Pathway FAQs  
**Appendix 4** Case Studies x 2

**Appendix 1 – Recruitment Plan with timeline**

|                         |                  |              |                     | Values     |                        |
|-------------------------|------------------|--------------|---------------------|------------|------------------------|
| Funding                 | TYPE             | Band         | Expected Start Date | Sum of WTE | Sum of Full year costs |
| ☐ New monies            | ☐ PAY            | ☐ Band 3     | 01/03/2022          | 0.5        | 13,743                 |
|                         |                  | ☐ Band 4     | 01/03/2022          | 1          | 31,587                 |
|                         |                  | ☐ Band 8b    | 01/07/2022          | 1          | 74,141                 |
|                         |                  | ☐ Consultant | 01/07/2022          | 0.2        | 25,000                 |
|                         | <b>PAY Total</b> |              |                     | <b>2.7</b> | <b>144,472</b>         |
| <b>New monies Total</b> |                  |              |                     | <b>2.7</b> | <b>186,210</b>         |
| ☐ Baseline              | ☐ PAY            | ☐ Band 7     | 01/07/2022          | 1          | 54,348                 |
|                         | <b>PAY Total</b> |              |                     | <b>1</b>   | <b>54,348</b>          |
| <b>Baseline Total</b>   |                  |              |                     | <b>1</b>   | <b>54,348</b>          |
| <b>Grand Total</b>      |                  |              |                     | <b>3.7</b> | <b>240,557</b>         |

**Appendix 2 - Summary of Adult Autism monthly dataset report, Nov. 19 to Jan 22**

|    | A   | B             | C             | D             |
|----|---|---------------|---------------|---------------|
| 1  | <b>Autism Diagnostic Assessment monthly totals</b>                                |               |               |               |
| 2  | <b>Metrics</b>  | <b>Nov-21</b> | <b>Dec-21</b> | <b>Jan-22</b> |
| 3  | No referrals received   | 41            | 35            | 48            |
| 4  | No of referrals accepted  | 22            | 24            | 33            |
| 6  | <b>No of referrals rejected (breakdown of reason)</b>                             | <b>17</b>     | <b>9</b>      | <b>10</b>     |
| 7  | Refused By Service  | 16            | 8             | 10            |
| 8  | Inappropriate Referral  | 1             | 1             |               |
| 10 | No of people waiting for first Appointment  | 237           | 260           | 290           |
| 11 | No of people receiving first appointment in period                                | 3             | 5             | 2             |
| 12 | No of people waiting for Diagnosis  | 243           | 267           | 297           |
| 13 | Number of patients receiving confirmed diagnosis of autism                        | 0             | 1             | 1             |
| 14 | Number of patients receiving a diagnosis of no autism spectrum disorder           | 3             | 4             | 2             |
| 15 | Average time waited from referral to diagnosis of autism spectrum disorder (days) | -             | 479           | 509           |
| 17 | <b>Source of referrals (Breakdown)</b>  |               |               |               |
| 18 | General Medical Practitioner  | 40            | 34            | 46            |
| 19 | Internal Referral   | 1             | 1             | 2             |

**Appendix 3a: BANDS -Autism Pathway**

**Diagnostic Assessment Process**

**Referral** – Using E-referral BANDS Autism form on S1 and Guidance for referrers document – Self referral available from March 22



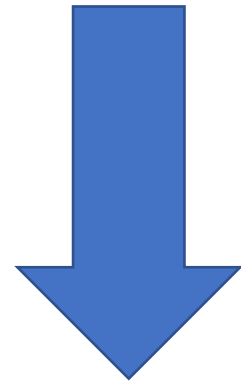
**Triage-**

Daily triage via Adult MH single point of access  
Accepted referrals allocated to BANDS (option 1)  
If referral redirected (option 2)




**Option 1 -Accepted**

Put on Autism Waiting List  
Acknowledgment letter to GP



**Option 2 -Redirected with advice**



Information pack with questionnaires sent out to client to be returned completed within 4 weeks



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graph TD; A[Report to the Health and Social Care Overview & Scrutiny Committee] --> B[Option 1 - Completed forms reviewed and questionnaires scored]; A --> C[Option 2 - No return of forms<br/>Call & letter to patient (wk 2)<br/>Call & letter to patient (wk 6)<br/>Close case wk 6]; B --> D[Parental / Informant interview completed (phone or videocall)]; C --> D; D --> E[Initial patient interview completed (phone or videocall)]; E --> F[Option 1 - Clinical decision made to continue with assessment]; E --> G[Option 2 - No Autism - signposted to another service- Assessment completed<br/>Report completed within 2 weeks - Discharge]; F --> H[ ]; G --> I[ ]
```

**Option 1** – Completed forms reviewed and questionnaires scored

4)

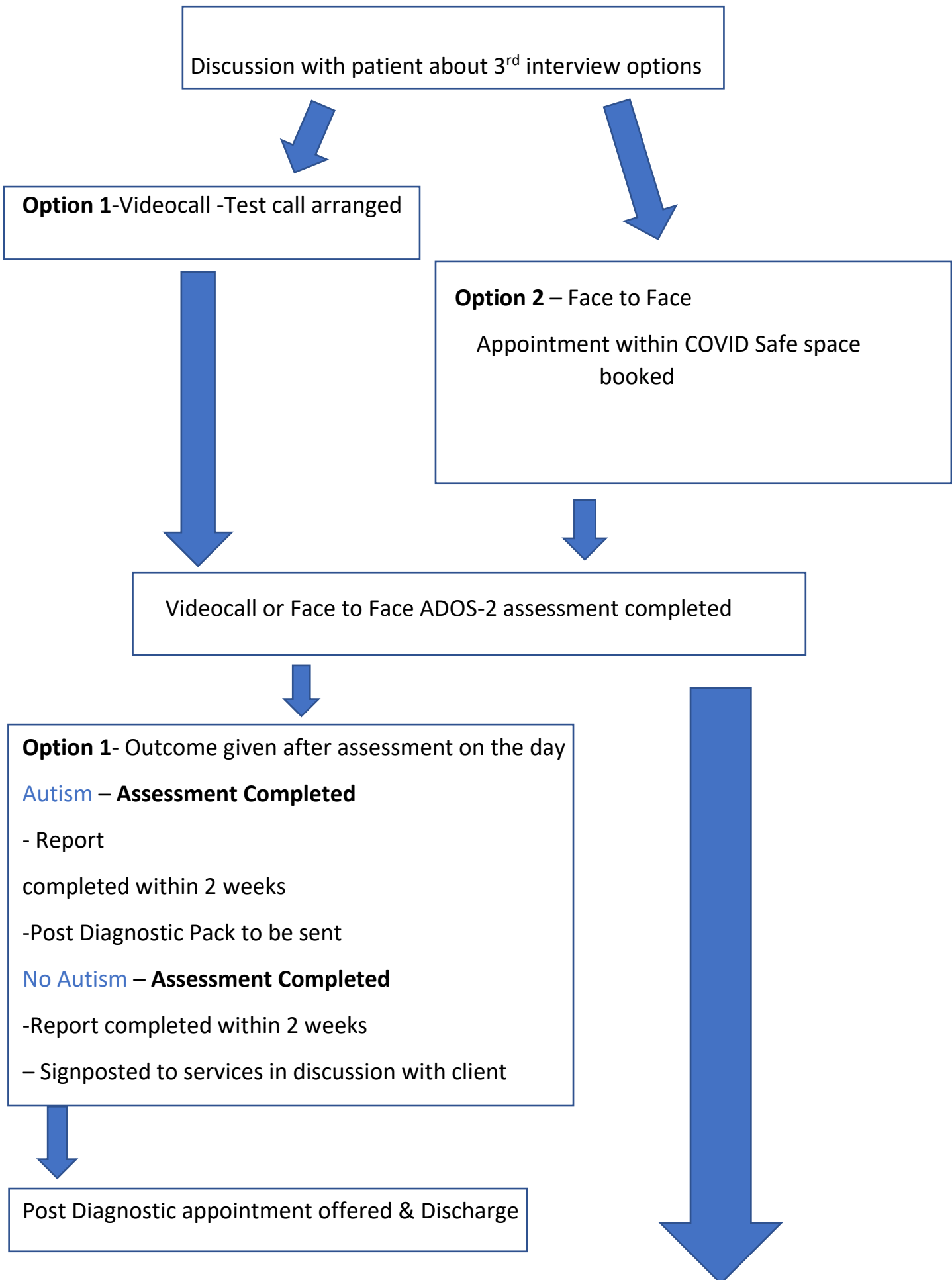
**Option 2** – No return of forms  
Call & letter to patient (wk 2)  
Call & letter to patient (wk 6)  
Close case wk 6

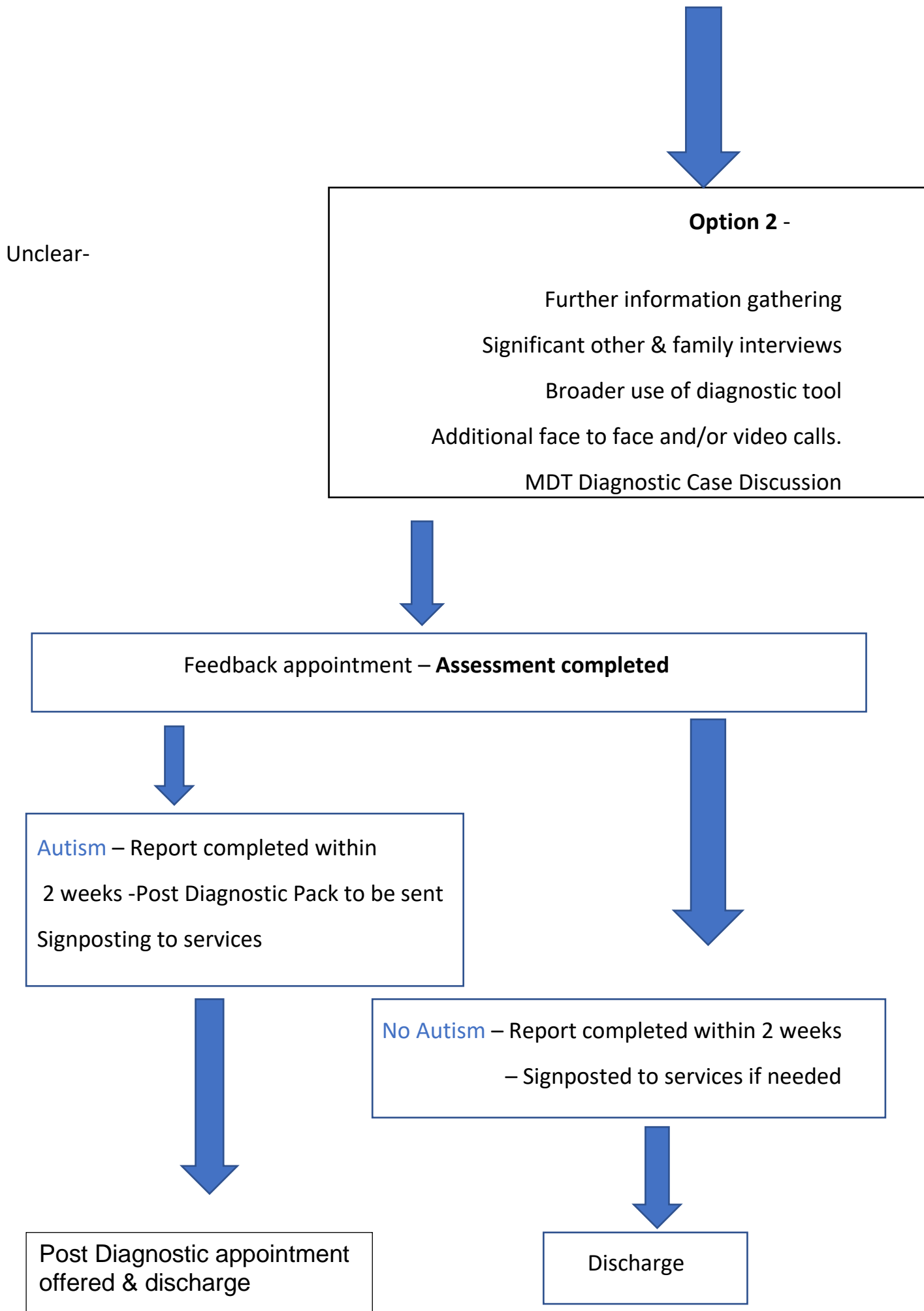
Parental / Informant interview completed (phone or videocall)

Initial patient interview completed (phone or videocall)

**Option 1** -Clinical decision made to continue with assessment

**Option 2** - No Autism – signposted to another service- **Assessment completed**  
Report completed within 2 weeks - Discharge





## Appendix 3b – Autism Pathway FAQs

### **Bradford & Airedale Neurodevelopmental Service (BANDS)**

#### **Autism Diagnostic Pathway Information**

##### **What happens to my referral?**

Referrals received by the service for a diagnostic assessment of Autism are routine and not urgent. Your referral will be recorded and put on our electronic record keeping system on the date it is received to be reviewed.

We receive a very high number of referrals and to ensure diagnostic assessments are offered to those who are most likely to have Autism, we will check if the referrer has provided enough information to make a decision to either accept or decline the referral.

The person who made your referral will be informed in writing of this decision and in some cases, when we are not able to decide, they will be asked to provide further information. We will ask that the referrer keeps you informed of any decision made about your referral.

The service is working in collaboration with the local CCG to reduce the length of time people are waiting, but if you are one of the people who have been on a waiting for some time and there has been a change in your circumstances, please ask your referrer to tell us about these so we can consider if there is any clinical need to prioritise your referral.

##### **When will I get an appointment?**

When we have accepted your referral, you will be contacted by letter and sent several forms and asked to return them to us by a specific date; this is to ensure there is no delay and we have all the information needed when we are ready to start the assessment.

Once we receive your completed forms, you will then be contacted to arrange your first appointment. If you can no longer attend this appointment, please contact the service as soon as possible so we can rearrange your appointment.

The offer of an initial appointment is not dependent on the answers you provide on the forms. Returning the completed forms will provide us with important information before your initial appointment and we ask that you answer the questions as accurately as you can. Should you have any questions or difficulties regarding any of these forms, please do not hesitate to contact the service.

If we do not receive the completed forms by the date specified on the letter (and you have not contacted us), or you do not attend your initial appointment, we will assume that an appointment with our service is no longer required, and we will close your referral without further contact with you. We will let your referrer know that we have closed your referral.

## Who carries out the assessment?



Stephen – Lead Autism



Hannah – Assistant Autism Clinician

A clinician will carry out your assessment appointments, we will let you know who that is.

All clinicians have specialist knowledge and training in Autism. The service meets regularly to discuss and agree the outcome of assessment appointments.

## What happens during the assessment appointments?

The first appointment will be an initial screening appointment and will determine whether your characteristics show any indicators of an Autism Spectrum Disorder. If it is clear at this stage, they are not Autism related, we will inform you and will try and direct you to other services that may be able to help you, or ask that you go back to your GP to discuss other options that may be appropriate for you. Otherwise, you will have further assessment appointments to complete the full diagnostic process.

During the assessment appointments you will be asked questions about yourself, including your developmental history, relationships with others and your current difficulties. Due to the number of the questions we ask related to your early life, it is useful if parents (or other close family members) are involved as they may be able to remember details that you cannot.

The assessment can be comprehensive and may involve using validated specialist assessment tools. Our service aims to work in accordance with NICE (National Institute for Health and Care Excellence) CG142 guidance on Autism to offer a service that meets best practice recommendations.

The assessment will not require a medical examination (for example physical examinations or the taking of blood).

### **Can someone support me with my appointments?**

It is your decision whether you bring someone to any face to face appointments with you for support if needed. Please tell us if you need any reasonable adjustments and we will accommodate these if we can.

### **How long will it take?**

The full diagnostic assessment is usually completed in 3 appointments, however there may be more if we need further information. The clinician who is carrying out your assessment will explain what will happen at each stage of the assessment process. Each appointment will normally last up to two hours with an opportunity for you to take a break if required.

**Please note that although we try to make environments as friendly as possible, waiting areas can be busy at times. You may want to get to appointments very early, but we advise against this. (Due to COVID-19 restrictions the details may change but we will keep you informed).**

### **What happens after my assessment?**

The outcome will be discussed with you and an assessment report will be sent to the person who referred you to our service and a copy will be sent to your GP if this is different. You will also receive a copy of the report unless you tell us otherwise.

### **What happens after I have been diagnosed?**

If you are diagnosed and meet the criteria for an Autism Spectrum Disorder, you and in some cases your family, may have a lot of questions. **You can discuss this when we feedback, but you will also receive a Post Diagnostic Pack with local and national information.**

### **Will I be diagnosed with Asperger's Syndrome?**

No. There are two diagnostic manuals used to diagnose Autism and we use the Diagnostic Statistical Manual 5<sup>th</sup> Edition (DSM-5), which will give a diagnosis of 'Autism Spectrum Disorder'.

We acknowledge that some people would like an Asperger's Syndrome diagnosis and it is up to everyone how they wish to describe their condition and what label if any they want to use.

### **What happens if I do not get a diagnosis?**

Many people who come for assessments do not receive an Autism diagnosis but find that the assessment process has helped them to find alternative explanations behind their difficulties. When we discuss the diagnostic outcome with you, we will make every effort to direct you to alternative support where possible to help you.

## Appendix 4 – Case Studies x 2

### Case Study 1 - Patricia

Patricia was referred for an autism assessment with BANDS after her care co-ordinator within CMHT noticed potential signs of a neurodevelopmental condition that. The care co-ordinator had sought advice from a member of the BANDS team and used supervision to explore the possibilities. A referral was agreed, and Patricia was continued to be supported by the mental health team.

Patricia was supported by her care co-ordinator to attend the appointments with the BANDS team. Following 6 appointments and a MDT Diagnostic Case discussion a diagnosis of Autism was reached.

Patricia was given the post diagnostic information alongside her care co-ordinator. And support was offered on how to make reasonable adjustments to how services communicate and share information with Patricia, to include her care plan and accessing psychological interventions.

Through the assessment the team were able to identify areas of Patricia's life where she may benefit from specialist support to help with improving her social skills and relationships. BANDS were able to advise on services and interventions locally that may be helpful and advised that a Care Act Assessment and referral to Adult Social Care will help identify access to those services and if financial support would be available.

Patricia went on to access a personal budget to employ a support worker/assistant who helped with developing social skills and attend Specialist Autism Services.

Patricia's self-esteem and confidence increased which in turn improved her overall mental health and wellbeing. She has developed meaningful relationships and greater independence.

### Case Study 2 - Mike

Mike was arrested following a serious assault on a colleague at work.

The assault occurred when a colleague had inadvertently used Mike's mug.

Mike is described as being 'odd' with few friends.

Mike is quiet and polite but makes the police officers feel uncomfortable because of his 'odd' manner.

The police officers contact the on-call GP who arranged for a psychiatric assessment.

Mike was assessed by the on-call psychiatry registrar while in the police station.

The psychiatrist interviewed him and observed that Mike did not make eye contact during the assessment.

Following concerns raised by the psychiatrist Mike is referred for an autism assessment from BANDS.

Following assessment Mike is diagnosed with autism and he receives a comprehensive report from the team that he can share with his employer should he so wish.

The report outlines some of the reasonable adjustments that could be considered for Mike to return to work.

Following a session of mediation with Mike and his victim Mike is able to return to work.

At Michaels request his diagnosis is shared with his work colleagues and an education session is held with all the staff to inform them about the common traits of autism.

Mike has now been fully integrated back into his workplace and his colleagues have a greater appreciation of his condition.