

# **Improving services for adults with autism in Calderdale**

**Presented to the Calderdale Council  
Adult Health and Social Care Scrutiny Panel  
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## **1. Report Summary**

**This report highlights a range of issues faced by adults in Calderdale who have, or who are seeking, a diagnosis of an autism spectrum condition (ASC).**

**We outline recent improvements to services, including the commissioning of a diagnostic pathway, and the funding of the Autism Hub which is now in its second year.**

**Despite these developments Healthwatch Calderdale (HWC) continues to hear regularly from adults with ASC, who are raising the same concerns as before, and whose lives are still being negatively affected by the lack of appropriate services and support.**

**We explain briefly what ASC is and how it can affect adults lives, including higher rates of suicide and mental health issues than the general population, as well as frequently having a range of co-occurring conditions such as Attention Deficit Hyperactivity Disorder (ADHD), dyslexia, dyspraxia, and epilepsy.**

**We clarify the benefits for adults who are on the autism spectrum of having a diagnosis, but also the difficulties they may face in trying to get an assessment.**

**Data included in the report shows that the diagnosis rate for adults with ASC in Calderdale is extremely low, and we believe that the reasons for this need to be explored.**

**We include a range of recommendations, some of which could be easy to action, such as improved data collection, increased training for professionals, and better understanding and use of reasonable adjustments.**

**Other recommendations may be more challenging, but may be achievable through new ways of working, and better collaboration between services.**

**We would like to thank all the experts by experience who have spoken to us about the issues they have faced, including members of the Autism Hub in Halifax who have welcomed us to their group and given us their valuable feedback. We would also like to thank members of the Calderdale Autism Strategy Group who have contributed their thoughts, and the Adults with Autism Service for the feedback and information they have given us.**

## **2. Introduction**

**Healthwatch Calderdale frequently hears from adults with autism spectrum conditions about a range of difficulties they face accessing suitable health and social care services.**

Issues have included, but are not limited to, the following:

- Difficulties accessing a diagnostic assessment
- Long waiting lists for assessment without indications of timescale
- Difficulties accessing a second opinion
- Lack of post-diagnostic services in Calderdale
- Low levels of autism awareness among professionals and in services
- Reasonable adjustments not being understood or put in place
- Lack of access to appropriate mental health care and support
- No general advocacy services available for support
- Very little support for families and carers of adults with autism

**In October 2017 we published our report, 'Adults experiences of Autism Services in Calderdale and Kirklees'. We wanted to increase our understanding of the difficulties people were facing, so we collected feedback from adults with autism, and their families and supporters, using online surveys and one-to-one engagement. The report highlighted a range of issues which were negatively impacting on the everyday lives of people with autism.**

**Since then there have been some positive changes:**

- a diagnostic pathway for adult ASC was commissioned by Calderdale Clinical Commissioning Group and has been in use since April 2018;
- the CCG also put extra funding into clearing the waiting list down to the NICE 3 month guidelines, and SWFYT has managed to achieve this;
- Calderdale Council funded a one-year pilot for an Autism Hub, which has since been extended for a further two years.

**But we continue to hear from people with autism spectrum conditions, who are still raising similar concerns as before, despite these improvements. We have brought this report to the Adult Health and Social Care Scrutiny Panel, to raise the voices and concerns of members of the public, with the aim of driving improvement in services for adults with autism in Calderdale.**

### **3. What is autism spectrum condition (ASC), and how does it affect people's lives?**

**ASC is a lifelong developmental condition affecting how people perceive the world and interact with others.** Autistic people see, hear and feel the world differently to other people. If you are autistic, you are autistic for life; autism is not an illness or disease and it cannot be 'cured'.

**The term 'autism spectrum' refers to the range of ways the condition presents itself in an individual.** This can vary greatly from person to person and throughout their life. All autistic people share certain difficulties, but being autistic will affect them in different ways. Some autistic people also have learning disabilities, mental health issues or other conditions, meaning people need different levels of support.

**Asperger syndrome is a form of autism, and is generally seen as someone with autism who has an average or above average IQ.** Due to changes in diagnostic criteria Asperger syndrome is no longer used as a diagnostic category, although some medical professionals may still use this term as certain people will have had a historical diagnosis.

### **4. Autism, mental health and co-occurring conditions**

**People with autism have a higher rate of mental health issues than the general population.** Autism is not a learning disability, or a mental health problem, however, there are higher rates of mental health difficulties in this community, such as anxiety and depression, when compared to the general population.

**Suicide rates for autistic people are much higher than the general population.** For autistic people without a learning disability, the rates have been found to be nine times those of the wider population (Autistica Report – 'Personal tragedies, public crisis' - 2016).

**Autism is often diagnosed alongside a range of other conditions.** It's important to support people with more than one condition in a way that meets all their needs, while understanding that the needs arising from autism are distinct. Other conditions that affect autistic people include ADHD, dyslexia, and dyspraxia, (NHS: Other conditions that affect autistic people - 2019), while between 20% and 40% of autistic people also have epilepsy, with this rate increasing steadily with age (Autistica Report – 'Personal tragedies, public crisis' - 2016).

## **5. Policy Context**

**The Autism Act (2009)** established the requirement for the Government to produce a strategy for meeting the needs of adults in England with autism spectrum conditions by improving the provision of relevant services by local authorities, NHS bodies and NHS foundation trusts.

**The first autism strategy, 'Fulfilling and Rewarding Lives'** was produced in 2010 and sets a clear framework for all mainstream services across the public sector to work together for adults with autism. It sets out seven quality outcome measures against which local areas in England can test how well they are meeting the aims of the Autism Strategy.

To help local areas work towards these outcomes, the document also sets out three key ambitions:

1. Local Authorities and partners know how many adults with autism live in the area.
2. A clear and trusted diagnostic pathway is available locally.
3. Health and social care staff make reasonable adjustments to services to meet the needs of adults with autism.

**This was updated in 2014 and published as 'Think Autism'**, and from this, fifteen priority Challenges for Action were identified by people with autism, carers, professionals and others who work with people with autism.

There are duties on local authorities and NHS bodies to act under the statutory guidance produced by the Government to accompany each strategy.

**Transforming Care Partnership Plan** - The Calderdale, Kirklees, Wakefield and Barnsley (CKWB) Transforming Care Partnership are working on a plan to improve services for people with a learning disability and/or ASC in our area.

## **6. Local Autism Self-Assessment 2018**

**The Public Health England Autism Strategy Self-Assessment** is intended to support local authorities to review progress in implementing the Government's Autism strategy 'Think Autism'. It covers areas including planning, training, diagnosis, care and support, housing, employment, the criminal justice system, and local innovations.

The latest submission from Calderdale covering 2017/18 is the main source of data letting us to compare Calderdale's performance with that in other areas.

## **7. The local population... facts and figures**

There is limited local data on the numbers of adults with ASC without a learning disability (LD) in Calderdale. This lack of local data is not unique to Calderdale.

- Calderdale has a population of 210,082 (LA Health Profile 2018), including 168,814 adults (86,631 females, 82,183 males)
- Based on current national prevalence rates it is assumed that 1.1% of the population would have ASC, suggesting that 1857 adults living in Calderdale have ASC. (This estimate is derived from the 1.1% prevalence rate applied to the 2011 UK census figures.)
- It is predicted that 44%-52% of adults with ASC would have a LD so between 817 and 965 adults with ASC in Calderdale would also have a LD.
- Therefore 48%-56% of adults with ASC would not have a LD, so between 891 and 1,039 adults with ASC in Calderdale would not have a learning disability, between 0.5% and 0.6% of the adult population in Calderdale.

## **8. Why is getting diagnosis important for adults?**

Access to a diagnosis of ASC is a major issue in a context where diagnosis or a label of some kind is essential to access services, and assessment for personalisation appears unlikely to take place without it.

- It may facilitate access to benefits, specialist services and support, or adapted mainstream services.
- Especially for those diagnosed in later life, it can be a relief and provide an explanation for challenges and difficulties they have faced, as well as providing a framework for understanding triggers which can help inform adjustments to make every day living more comfortable.
- Lack of diagnosis can contribute to a range of conditions including anxiety, depression and prolonged stress due to lack of explanation of symptoms, and behaviour not being understood by others.
- New initiatives due to be introduced in the next few years will make the recording of an ASC diagnosis in an adult's medical records even more significant; digital flagging in medical records of the needs of people with ASC is going to be introduced, including information about reasonable adjustments that can be used to help them; and annual health checks for adults with ASC are also expected to be introduced.

## **9. Ongoing discussions with Calderdale CCG in 2019**

As HWC has continued to hear from adults with ASC, and those seeking a diagnosis, we have been involved in discussions with Calderdale CCG, and representatives from the Calderdale Autism Strategy Group.

The aim of the discussions has been to get a better understanding of the issues that people are having, to find out more about the barriers they are facing, and to explore ways that the current situation for adults with ASC in Calderdale could be improved.

Key themes from those discussions have been:

- The South West Yorkshire Partnership Foundation Trust (SWYFT) contract – we were told this is usually rolled over year-on-year
- The ASC referral, triage, and assessment process
- The low number of adults being diagnosed with ASC in Calderdale
- Post diagnostic support for adults receiving an ASC diagnosis
- The lack of support for adults who do not receive an ASC diagnosis
- ASC diagnoses made by other services not being accepted
- Difficulties accessing a second opinion
- Lack of patient choice in accessing services
- Lack of mental health support for adults with an ASC diagnosis

Through correspondence with the Adults with Autism Service (AAS), which provides the ASC diagnostic pathway for adults in Calderdale, we have had answers to some of the questions we have asked, although not all have been fully answered.

For example, when we asked why Calderdale has such a low diagnosis rate for ASC in adults, with only 2 diagnoses made in 2017/18, and 4 made in 2018/19, the AAS response was:

- *'The SWYPFT Service is not thought to be different from other NHS Services using a similar pathway.'*
- *'Diagnostic rates of other Services may change as expertise and consistency in the diagnosis of Autism becomes more established in response to ongoing regional work on Integrated Care Systems.'*
- *'It is of concern that the referrals put forward in Calderdale are not for people who have Autism.'*

We feel this response does not properly address the issue, and believe it needs further scrutiny.

We also had concerns about the way patient feedback and demographic data was being collected, and while we are happy to see that this is being improved there is still further work to do.



## **10. Addressing the key themes**

### **10.1. The ASC referral, triage, and assessment process**

**Prior to 2015:** Adults seeking an ASC assessment were referred by their GP through an Individual Funding Request to the Sheffield Adult Autism and Neurodevelopmental Service (SAANS).

**In 2015:** The Adults with Autism Service (AAS) based at Manygates in Wakefield, was commissioned to provide an adult ASC diagnostic service, on a case by case basis via GP referral through an Individual Funding Request process.

**Then in 2018, funding was provided to commission an adult ASC Assessment and Diagnostic Service.**

Dr Steven Cleasby, the Chair of the CCG's Governing Body, stated:

*'With regards to autism in adults, the CCG has invested £60,000 of recurrent funding in commissioning a new assessment and diagnosis service from SWYFT, offering initial assessment and two follow-up appointments. This new approach started in April this year. We have also provided £40,000 of non-recurrent funding to reduce the waiting list which had built up before the service was available...'* (Calderdale CCG Freedom of Information Request Disclosure Log: Services for adults with autism (1819036))

**Since April 2018 the commissioned diagnostic pathway has been in place with AAS:**

- Referrals are accepted from Consultants, GPs, or other trust services, and social workers for the Social Care Pathway.
- A monthly local triage panel reviews the referrals to check if enough information has been provided to make a decision to either accept or decline the referral.
- If the referral is accepted, an initial screening appointment is made to meet with the person to determine whether they show any indicators of ASC.
- If they do, then further assessment appointments are needed to complete the full diagnostic assessment.
- The outcome would be discussed and an assessment report sent to the person who submitted the referral, to the patient's GP, and to the patient if they wish.
- Patients with a diagnosis of ASC are then offered up to 2 more appointments to discuss the implications of the diagnosis and what support may be helpful.

At the moment access to an ASC assessment is totally dependent on GP's input, their knowledge of the patient, and their understanding of autism and how it may present, which may be limited. The patient, who is the expert in their condition, does not get the opportunity to input into the form, in fact if they do that it can be a reason for the triage panel refusing to assess it.

Some areas, including the Leeds Autism Diagnostic Service (LADS) allow people to self-refer, which gives them the opportunity to fully explain why they are seeking an autism assessment, and to document in detail any difficulties they have had as a child or an adult which lead them to believe that they may be on the autistic spectrum. LADS recognised that having to be referred through GPs or healthcare professionals could be a barrier to accessing their service, so they decided to provide the option to self-refer.

*Feedback from AAS: 'Consideration of referrals by Triage Panels has identified the issue that poor clinical referrals can for some people restrict or delay access to the diagnostic assessment process. In response to this, the Service is in the process of further developing the Autism Referral Form to include an optional section for completion by the person seeking a diagnostic assessment to ensure the 'voice' of the service user is considered alongside the clinical opinion of the referrer at the earliest possible opportunity.'*

#### **Our Recommendations:**

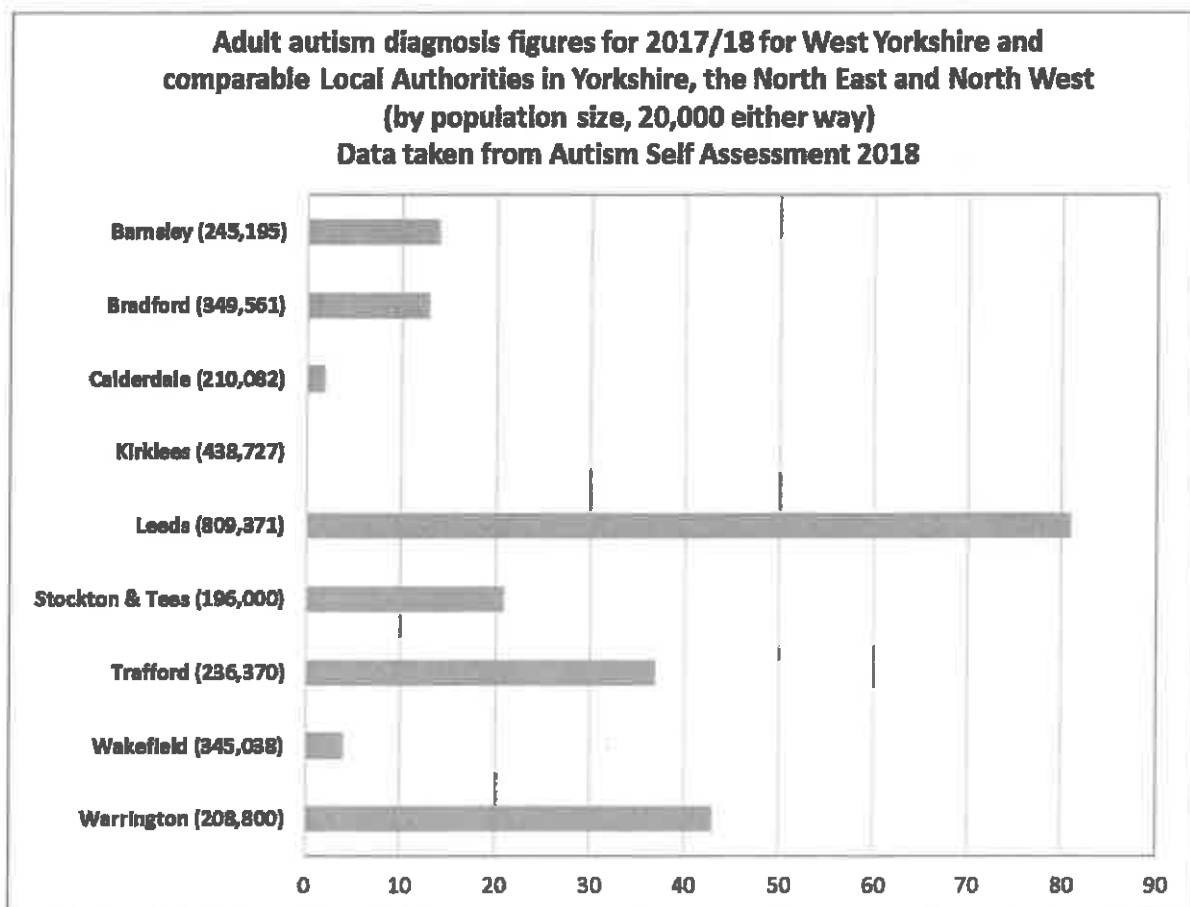
<b>ASC Referral Process</b>	<ul style="list-style-type: none"> <li>• Allow self-referrals</li> <li>• Increase the opportunity for patient input into the referral form</li> <li>• Training for GPs in completing ASC referral forms</li> <li>• Alternatively return to a model where referrals are accepted that have the support from a GP and/or Mental Health Practitioner and a face to face initial assessment is offered to all referrals.</li> </ul>
<b>ASC Referral Triage</b>	<ul style="list-style-type: none"> <li>• Provide the option for face to face triage assessment for all referrals</li> <li>• Training for GPs in recognising how ASC traits can present in adults</li> <li>• Support for individuals whilst they are awaiting an ASC assessment</li> </ul>
<b>ASC Assessment Process</b>	<ul style="list-style-type: none"> <li>• Consider whether using a broader range of formal assessment tools, including DISCO, would enhance the assessment process offering a more personalised service</li> </ul>

## 10.2. Low numbers of adults being diagnosed with ASC in Calderdale

Based on the data in the Autism Self-Assessment 2018, in 2017/18, only 2 adults received a diagnosis of ASC. Out of the 55 adults in Calderdale who were referred for an ASC assessment, only 2 received a positive diagnosis, a diagnosis rate of 3.6%.

**The difference in diagnostic rates across England.** This is highlighted by the 120 responses in the Autism Self-Assessment 2018 which included the number of adults diagnosed with ASC in 2017/18. The responses range from 0 to 432, and while the areas have widely differing population sizes, Calderdale with only 2 diagnoses in that year is within the lowest 1%.

The table below allows you to compare the number of diagnoses in Calderdale, other local authorities in West Yorkshire, and other local authorities comparable by size.



The total number of adult ASSC diagnoses in 2017/18 across all 120 areas which responded was 7,836: this would give an average of 65.3 diagnoses per area if they were all of a similar population size.

**In Calderdale in 2018/19 only 4 adults received a diagnosis of ASC.**

No of referrals considered by Triage Panel	<b>136</b> (84 male, 52 female)
No of referrals accepted by Triage Panel	<b>34</b> (23 male, 11 female)
No of referrals receiving a full diagnosis of ASC	<b>4</b> (2 male, 2 female)

We are grateful to the AAS for providing us with 2018/19 data for adult ASC diagnoses. This data shows that 34 of the 136 referrals for an ASC assessment were accepted by the Triage Panel, and of the 34 adults who received a full diagnostic assessment, only 4 received a diagnosis of ASC, a diagnosis rate of 12%.

**Comparative data for Kirklees and Wakefield has also been provided:**

Locality	Diagnostic Rate	Number assessed
Calderdale	12%	4 out of 33 people who required a <u>full diagnostic assessment</u> met the criteria for a diagnosis of ASC
Kirklees	35%	6 out of 17 of people who required a <u>full diagnostic assessment</u> met the criteria for a diagnosis of ASC
Wakefield	27%	4 out of 15 people who required a <u>full diagnostic assessment</u> met the criteria for a diagnosis of ASC

The low diagnosis rate in Calderdale for adults with ASC has been of concern for some time: *'There is an ongoing concern regarding the SWYFT diagnostic service as the diagnostic rates are very low. This leads to frustration and requests for a second opinion from the Sheffield diagnostic service. Calderdale CCG who fund the diagnostic service are aware of these concerns...'* (Report to Adult Scrutiny panel: 28/03/17)

**AAS responded:** *'It is expected the diagnostic rate in Calderdale will increase in 2019/20 as a result of referral triage and improved quality of referral information.'*

**Our Recommendations:**

<b>Service Data</b>	<ul style="list-style-type: none"> <li>• More local data is needed about rates of ASC diagnosis, ASC referral rates, and the referral-to-assessment times</li> <li>• Where appropriate, include age, gender, ethnicity, geographical location and commissioning area</li> <li>• The reason for the very low rate of ASC diagnosis in Calderdale needs to be explored and explained</li> </ul>
<b>Patient feedback</b>	<ul style="list-style-type: none"> <li>• Involve experts by experience in the monitoring and development of services</li> </ul>

### 10.3. Post diagnostic support for adults receiving an ASC diagnosis

There is no post diagnostic clinical treatment commissioned for adults receiving a diagnosis of ASC in Calderdale if they do not have a learning disability.

In Barnsley and Wakefield, AAS offer a health intervention pathway which may include a variety of different kinds of support from the multi-disciplinary team. Using a person-centred care plan support can include social skills training, psychological intervention, occupational therapy and organisational skills, access to health care and speech and language input.

In Kirklees there is a Specialist Social Worker who can offer a Social Care Pathway, including such things as the development of care packages and support to access to educational, social care and employment opportunities.

#### Our Recommendations:

<b>Post diagnostic support</b>	<ul style="list-style-type: none"> <li>• Provide a range of post diagnostic support for adults with ASC in Calderdale</li> <li>• Make it easier for adults with ASC to access post diagnostic support out of area if it is not available in Calderdale</li> <li>• Clarify the use of individual funding requests (IFRs) for funding counselling for adults with ASC</li> </ul>
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### 10.4. The lack of support for adults not receiving an ASC diagnosis

Following the outcome of the Diagnostic Assessment, AAS offers post-diagnostic support in the form of a specific post-diagnostic pack for those who do not receive a diagnosis.

*AAS responded: 'On completion of the diagnostic assessment process clinicians endeavour to signpost people to appropriate Services for further assessment, treatment and support...We acknowledge the potential impact for people not getting a diagnosis and clinicians working in the SWYPFT diagnostic pathway have undertaking training in the skill of 'Breaking Bad News' to people in the healthcare environment.'*

#### Our Recommendations:

<b>Post diagnostic support</b>	<ul style="list-style-type: none"> <li>• Enhance the support given to people who do not receive an ASC diagnosis so that they can access appropriate services and care.</li> </ul>
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## **10.5. ASC diagnoses made by other services not being accepted**

Even though Calderdale does not commission any post diagnostic services for adults with ASC, if somebody who already has a diagnosis, possibly before moving to Calderdale, is trying to access support via an Individual Funding Request, their diagnosis may well be called into question even though it was made by a qualified clinical specialist.

A number of people who have received a diagnosis of ASC in a different area, or by a service other than AAS, have had their diagnosis questioned when they have tried to seek support, and in some cases they have had their diagnosis of ASC 'undiagnosed'. This has happened to people with both private and NHS ASC diagnoses.

One client reported moving to Calderdale recently, but despite having a diagnosis of ASC from a neuropsychologist following extensive tests, she was told that she must be re-referred to AAS before she can seek any support, and that there is an 18 month waiting list for this.

### **Our Recommendations:**

<b>ASC diagnosis</b>	<ul style="list-style-type: none"> <li>• Clarify the position regarding ASC diagnoses made by services other than AAS</li> </ul>
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## **10.6. Difficulties accessing a second opinion**

If the individual is deemed not to have ASC, either at the triage or the assessment stage, they have great difficulty accessing a second opinion. There is a particular concern that people who have lived with the condition undiagnosed for years and have learnt to mask it are not getting a diagnosis.

### **Our Recommendations:**

<b>Getting a second opinion</b>	<ul style="list-style-type: none"> <li>• Clarify the use of individual funding requests (IFRs) to fund second opinions.</li> <li>• Clarify whether Patient Choice in mental health applies to ASC diagnostic assessments</li> </ul>
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## **10.7. Lack of Patient Choice in accessing services**

Healthwatch and many other professionals and individuals believe that Patient Choice in mental health should apply to ASC diagnostic assessments.

The CCG states that it is waiting for guidance on this from NHS England, but HWC is aware of an individual who recently obtained NHS funding for an alternative assessment at private provider, Axia, following a complaint to the CCG after being turned down for a local ASC assessment. Axia diagnosed the individual with ASC. Axia ASD Ltd, who provide a specialist neurodevelopmental assessment service, are well respected and have contracts with several CCGs and CAMHS.

There also needs to be clear guidance about the use of Individual Funding Requests (IFRs) for accessing a second opinion, or for funding specific counselling for adults with ASC.

#### **Our Recommendations:**

<b>Patient Choice</b>	<ul style="list-style-type: none"> <li>• Clarify the use of individual funding requests (IFRs) to fund ASC specific counselling</li> <li>• Clarify whether patient choice in mental health applies to ASC diagnostic assessments</li> </ul>
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### **10.8. Lack of mental health support for adults with ASC diagnoses**

While autism is not a mental illness, rates of mental ill health and suicide are exceptionally high in the autistic population. There is an urgent need for practitioners to understand and deal with the barriers autistic people face in accessing mental health support.

We have found that access to generic mental health services is very restricted for adults with ASC and we have heard reports of difficulties in obtaining mental health support (both crisis and ongoing) from many people with this condition.

One client, who has a range of difficulties including ASC and obsessive-compulsive disorder (OCD) explained that it had been very difficult to get any kind of mental health support. This client tried to access cognitive behavioural therapy but was told that because she had ASC she would not benefit from it, and she was not referred for any other support.

Another client with ASC reported that she received a support worker via her local mental health service. The woman had begun to connect her ASC with her anxiety and depression, but her mental health support worker was not trained in ASC and was uninterested in the connection between the ASC and anxiety. As a result, the CBT offered did not work for the client and she was discharged without support.

Another client suffers from depression and low self-esteem but cannot access mental health support because she has ASC.

The CCG states that it *'expects the mental health services it commissions to make reasonable adjustments for any particular needs that individuals may have, including autism. If an individual with autism needs specialist mental health support, they can be referred by their GP or another clinician through the CCG's Individual Funding Request process.'* (Calderdale CCG Freedom of Information Request Disclosure Log: Services for adults with autism (1819036))

Calderdale has generic mental health services suitable for people with primary mental health needs, however they do not have enough knowledge or awareness of ASC to adapt support for the people who approach them. Some individuals who have approach HWC have been told that ASC is their primary health need, and as such, they cannot access mental health support as SWYT are not commissioned to deliver ASC support. People come to HWC for support in trying to access services for ASC, as well as for help in accessing specific therapies such as Dialectical Behaviour Therapy (DBT), but these services are not commissioned routinely, therefore if people want to access them they have to submit an Individual Funding Request (IFR) to the local CCG.

#### **NICE Guidance:**

- for adults with ASC and a mental health condition, the NICE guidelines for treating the mental health condition should be followed, with modifications to make them more effective and accessible to people with ASC.
- where there are gaps in availability of psychosocial support, CCGs may need to work together with the local authority to commission additional interventions... Some individually tailored psychosocial support may be needed to help people with ASC to develop their social, communication and life skills'
- suggests that investment in services for people with ASC can lead to reductions in GP appointments, fewer emergency admissions and less use of mental health crisis services.

#### **Our Recommendations:**

<b>Mental Health Services</b>	<ul style="list-style-type: none"> <li>• Adapt mental health therapies to make them suitable for adults with ASC.</li> <li>• Increase understanding of autism and co-morbid conditions (mental health)</li> <li>• More choice in mental health services</li> </ul>
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## 11. Summary of Recommendations

Item	Recommendation	Responsibility
<b>ASC Referral Process</b>	<ul style="list-style-type: none"> <li>• Consider allowing self-referrals</li> <li>• Increase the opportunity for patient input into the referral form</li> <li>• Training for GPs in completing ASC referral forms</li> <li>• Alternatively return to a model where referrals are accepted that have the support from a GP and/or Mental Health Practitioner and a face to face initial assessment is offered to all referrals.</li> </ul>	
<b>ASC Referral Triage</b>	<ul style="list-style-type: none"> <li>• Provide the option for face to face triage assessment for all referrals</li> <li>• Training for GPs in recognising how ASC traits can present in adults</li> <li>• Support for individuals whilst they are awaiting an ASC assessment</li> </ul>	
<b>ASC Assessment Process</b>	Consider whether using a broader range of formal assessment tools, including DISCO, would enhance the assessment process offering a more personalised service	
<b>Service Data</b>	<ul style="list-style-type: none"> <li>• More local data is needed about rates of ASC diagnosis, ASC referral rates, and the referral-to-assessment times</li> <li>• Where appropriate, include age, gender, ethnicity, geographical location and commissioning area</li> <li>• The reason for the very low rate of ASC diagnosis in Calderdale needs to be explored and explained</li> </ul>	
<b>Patient feedback</b>	<ul style="list-style-type: none"> <li>• Involve experts by experience in the monitoring and development of services</li> <li>• Consider including adults with ASC in an Autism Reference Group</li> </ul>	

<b>Post diagnostic support</b>	<ul style="list-style-type: none"> <li>• Provide a range of post diagnostic support for adults with ASC in Calderdale</li> <li>• Make it easier for adults with ASC to access post diagnostic support out of area if it is not available in Calderdale</li> <li>• Clarify the use of individual funding requests (IFRs) for funding counselling for adults with ASC</li> <li>• Enhance the support given to people who do not receive an ASC diagnosis so that they can access appropriate services and care.</li> </ul>	
<b>ASC diagnosis</b>	<ul style="list-style-type: none"> <li>• Clarify the position regarding ASC diagnoses made by services other than AAS</li> </ul>	
<b>Getting a second opinion</b>	<ul style="list-style-type: none"> <li>• Clarify the use of individual funding requests (IFRs) to fund second opinions.</li> <li>• Clarify whether patient choice in mental health applies to ASC diagnostic assessments</li> </ul>	
<b>Patient Choice</b>	<ul style="list-style-type: none"> <li>• Clarify the use of individual funding requests (IFRs) to fund ASC specific counselling</li> <li>• Clarify whether patient choice in mental health applies to ASC diagnostic assessments</li> </ul>	
<b>Mental Health Services</b>	<ul style="list-style-type: none"> <li>• Adapt mental health therapies to make them suitable for adults with ASC.</li> <li>• Increase understanding of autism and co-morbid conditions (mental health)</li> <li>• More choice in mental health services</li> </ul>	

## 12. Glossary of terms

- **(ADHD) Attention Deficit Hyperactivity Disorder:** is a behavioural disorder that includes symptoms such as inattentiveness, hyperactivity and impulsiveness
- **(ADOS) The Autism Diagnostic Observation Schedule:** is a semi structured assessment for communication, social interaction and play for individuals who are suspected of having autism. This consists of standardised activities that allow behaviour to be observed.
- **(ASC) Autism Spectrum Condition:** is a lifelong developmental disability that affects how a person communicates with and relates to other people, and how they experience the world around.
- **(AAS) Adults with Autism Service:** This service provides diagnostic assessment and/or specialist interventions for people who are 18 years+ and do not have an intellectual disability across Barnsley, Calderdale, Kirklees and Wakefield.
- **(CAMHS) Children and Adolescence Mental Health Service:** this is a specialist service offering assessment and treatment for children and young people who have emotional, behavioural or mental health difficulties.
- **(CCG) Clinical Commissioning Group:** the organisation that commissions (pay for) local NHS services, including mental health services.
- **(Calderdale CCG) Calderdale Clinical Commissioning Group:** the organisation that commissions (pays for) local NHS services in Calderdale. They commission the ASC diagnostic pathway.
- **(GP) General Practitioner:** A doctor based in the community within a GP practice that treats patients and refers them on to additional services.
- **(HWC) Healthwatch Calderdale:** is the independent consumer champion for anyone in Calderdale who uses health and social care services. We use the views and experiences of local people as evidence to influence improvements in service provision.
- **(JSNA) Joint Strategic Needs Assessment:** is a document that looks at the current and future health and care needs of a local population to inform local planning and commissioning of services.
- **(NAS) National Autistic Society:** is a national charity supporting autistic people and their families, their aim is to improve the lives of autistic people across the UK.
- **(NHSE) NHS England:** oversees the budget, planning, delivery and day-to-day operation of the commissioning (funding) side of the NHS.
- **(NICE) The National Institute for Health and Care Excellence:** provides national, evidence-based guidance and advice to improve health and social care.
- **(SWYFT) South West Yorkshire NHS Foundation Trust:** The organisation that commissions mental health, community, learning disability and wellbeing services, including the AAS, across Barnsley, Calderdale, Kirklees and Wakefield.

### 13. Useful resources – links to online information

- [The Autism Act](#)
- [Rewarding and fulfilling lives](#)
- [Think Autism](#)
- [Autism Aware eBook](#) for GPs and hospitals, etc.
- [Autism Awareness Animations](#) developed by a member of the Halifax Autism Hub: (Menu in top-right corner, then 'Projects')
- [Autistica Briefings](#)
- [Autistica Report – 'Personal tragedies, public crisis'](#)
- [DoH: Statutory guidance for Local Authorities and NHS organisations to support implementation of the Adult Autism Strategy](#)
- [Healthwatch Calderdale report: Adults' experiences of Autism Services in Calderdale and Kirklees](#)
- [House of Commons: Mental Health and Suicide within the Autism Community](#)
- [London School of Economics National Autism Project report- THE AUTISM DIVIDEND: Reaping the rewards of better investment](#)
- [NAS Good Practice Guides](#)
- [NAS report – The Autism Act: 10 Years on - A report from the All Party Parliamentary Group on Autism on understanding, services and support for autistic people and their families in England](#)
- [National Autistic Taskforce \(NAT\) An Independent Guide to Quality Care for Autistic People](#)
- [NHS: Other conditions that affect autistic people](#)
- [NHSE: Choice in mental health care: Guidance on implementing patients' legal rights to choose the provider and team for their mental health care](#)
- [NICE Clinical Guidance: Autism spectrum disorder in adults: diagnosis and management](#)
- [Public Health England: Autism self-assessment framework](#)
- [Royal College of General Practitioners Information and a toolkit for GPs and practice staff, as well as patients, carers and commissioners](#)

## 14. Appendices – Links and attached documents

- [Service User Information, Autism Diagnostic Pathway - Frequently Asked Questions](#)
- [Referral form for the Service for adults with autism](#)
- [Autism in Adulthood- Guidance for Referrers](#)
- [Leeds Autism Diagnostic Service self-referral form](#)
- [Calderdale CCG Freedom of Information Request Disclosure Log: Services for adults with autism \(1819036\)](#)
- **Appendix 1 - Autism Referral Form - Part 2 (Optional): To Be Completed by The Individual Seeking a Referral**
- **Appendix 2 - Service user and Carer Involvement feedback - 17th July 2019, @Manygates Clinic**
- **Appendix 3 - Service for Adults with Autism Service user satisfaction questionnaire: Diagnostic pathway**
- **Appendix 4 - Service for Adults with Autism Service User satisfaction questionnaire 19/20SE12: Diagnostic Pathway and Assessment Screening results**

### Appendix 1:

**PART 2 (OPTIONAL): TO BE COMPLETED BY THE INDIVIDUAL SEEKING A REFERRAL**  
**Please write anything else you would like us to know to support your referral**

## **Appendix 2:**

### **Service user and Carer involvement feedback meeting 17<sup>th</sup> July 2019, @Manygates Clinic**

**Present** - Service User, Staff

**Discussion** - The purpose of the meeting was to look at the Diagnostic process of the Autism Pathway and to discuss what was good and what could be improved. Introductions were made and that all opinions were valid.

#### **Comments:**

- Experiences were that once in the system things progressed fairly quickly but it was a long wait to get there
- Referral process and getting through the first appointment not always informed of where the service user was
- Going to the home environment was a good idea- could be used more for some people
- Listen to the carer as well as the individual
- Never felt rushed in process
- Send Non-confidential documents by e-mail for some who would prefer this
- Put info in letters about some receptions not being manned.
- Photos of reception areas to inform people they have come to the right place.
- Consider lighting
- More information on parking please
- Rooms were generally ok
- Seeing the same person was good, students were fine
- No comments on the readability of information just overwhelming when given in one go. May be individual preferences though
- Appointments spaced out well – should be a couple of weeks between each not 6 weeks
- Would not want the whole assessment in one day as would be too stressful.
- AFG said process for him was quicker than expected
- Diagnostic report too clinical- too much clinical terminology did not understand. More focus on what made the clinician decide why he was autistic (more focus on the formulation basically)
- Perhaps a service user version of the report
- Explanation of the ADOS scores would be useful- cut off points- put in conversion table from the module booklet
- Confident of the knowledge of the team members seen
- On point of referral would like more information
- Update on progress of referral every 6 months.
- Statement about- What happens if I don't agree with the outcome. Perhaps this is too early to mention at this point. - Could it be provided later- At time of decision?

## Appendix 3:

### Service for Adults with Autism Service user satisfaction questionnaire: Diagnostic pathway

We would like to find out how satisfied you are with our service. Please tick in the box to indicate how much you agree or disagree with these statements

	Strongly agree	Agree	Neither agree or disagree	Disagree	Strongly disagree
I was able to contact the team if I needed to	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The team treated me with respect and dignity throughout the process	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I was given enough time to process information and discuss my difficulties and needs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I was asked about my preferred communication method	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am happy with the location of my appointments	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The room was comfortable and quiet	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I received enough information about the team when I was first contacted	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The pre appointment information pack explained the assessment process	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The pre appointment information pack was easy to read and understand	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The team involved were approachable, accessible and I found it easy to talk to them	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I was able to ask questions and the team were proactive in answering these	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The outcome of the assessment was clearly explained	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

I was given enough time to discuss the outcome of the assessment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am happy with the support I received from the team	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I was asked if I wanted my family, partner or carer to be involved in the process?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I was confident that the team had a good understanding of autism?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>What do you think is good about the service?</b>					
<b>What do you think we can improve on?</b>					
<b>Which locality do you live in?</b>					
<input type="checkbox"/> Wakefield <input type="checkbox"/> Kirklees <input type="checkbox"/> Calderdale <input type="checkbox"/> Barnsley					
<b>I give my permission for my feedback to be used in any publicity by the team</b>					
Yes      No      (please circle)					


**Thank you for taking the time to complete this questionnaire. Please return in the envelope provided.**



## Appendix 4:

### Service for Adults with Autism (SAA) Service User satisfaction questionnaire 19/20SE12: Diagnostic Pathway and Assessment Screening results.

See below an example of the questions and feedback, with the summary comments on the following page. A copy of the full questionnaire results can be provided if required.



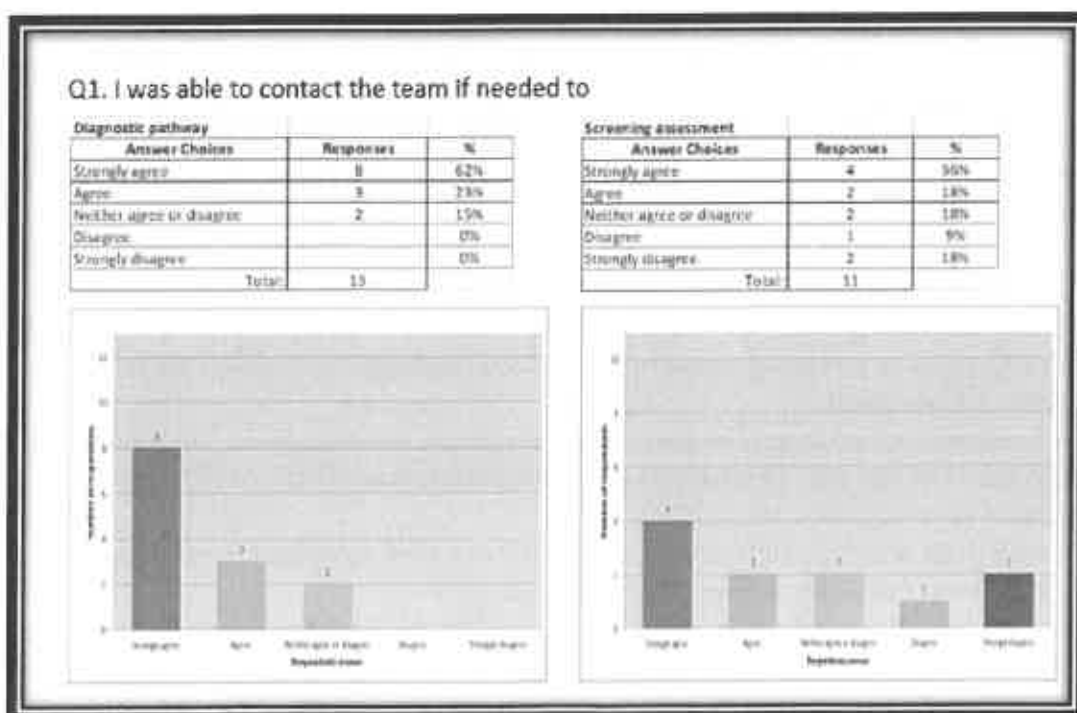
**South West  
Yorkshire Partnership**  
NHS Foundation Trust

## Service for Adults with Autism Service User satisfaction questionnaire 19/20SE12

### Diagnostic Pathway and Assessment Screening results

December 16 – June 2019

With all of us in mind



**In response to service user feedback we have updated the format of this report to show:**

- The feedback received from people who have had a full diagnostic assessment completed (Diagnostic Pathway)
- The feedback received from people who have had an initial screening assessment completed and did not meet the criteria for further diagnostic assessment of Autism (Screening Assessment)

**What you think is good about the Service...**

- Clinicians who completed assessments described as “friendly”, “intuitive, polite and understanding regarding the subject of autism”, “professional and an extreme pleasure to talk with”
- “Staff have zero room for improvement, the paperwork presents no issues and facilities are excellent”
- There are shorter waiting times to access the Service in some Trust localities “I received relatively early the appointment (without long waiting, like more than 12 months, or so). In this regard I was lucky”

**What you think we can improve on...**

- Making reasonable adjustments at clinic venues “the venue was too noisy and too many people around me to feel comfortable”, “I do not like bright lights and was more focused on the brightness of the light in the room hurting my eyes and giving me headache, “I think the seating could be better and more gentle in approach”.
- Equality in waiting times across Trust localities “The waiting times for an autism assessment is horrendous as it can take years in some instances before you are seen by a professional assessor but I appreciate also that a lot of people require this service”
- Avoid using language that not everyone understands “He kept on talking about politics scenarios which I told him I did not understand and had to repeat them constantly”.
- Letting people know what qualifications and training clinicians who complete the assessments have “More healthcare professionals with autism spectrum awareness needed. Especially in cases of aged autistic females”, “I think that a professional with understanding of Autistic spectrum would be of great help”.

**What have we done in response to your feedback...**

- We have amended the format of this report to show the feedback of those people who have had an initial screening assessment and those who have completed the full diagnostic assessment.
- Our Frequently Asked Questions Fact Sheet tells people what professionals will carry out the assessment and that all members of the Multidisciplinary Team (MDT) have specialist knowledge and training in Autism.
- We have dealt promptly with individual informal and formal complaints with support from the Trust Customer Service Team when required.
- We will update the feedback questionnaires to reflect the locality the person was seen. This will help us to address any issues with regard the clinical bases we are using across the Trust localities.

# Response Item 5

<b>Name of Scrutiny Panel</b>	Adults Health and Social Care Scrutiny Panel		
<b>Meeting Date</b>	Thursday 14 <sup>th</sup> November 2019		
<b>Subject</b>	Services for adults with autism in Calderdale – response to Healthwatch reports		
<b>Wards Affected</b>	All		
<b>Report of</b>	Sarah Antemes/Karen Midgley/Marios Adamou		
<b>Type of Item</b> (please tick✓ )	<b>Review existing policy</b>		
	<b>Development of new policy</b>		
	<b>Performance management (inc. financial)</b>		
	<b>Briefing (inc. potential areas for scrutiny)</b>		
	<b>Statutory consultation</b>		
	<b>Council request</b>		
	<b>Cabinet request</b>		
	<b>Member request for scrutiny (CCFA)</b>		✓

## Why is it coming here?

Scrutiny have expressed a wish to test the system's response to the recommendations made in the 2017 Healthwatch Reports into Adult Autism and issues raised in the new Healthwatch report on this subject.

## What are the key points?

Commissioners of adult autism services, and SWYPFT as the provider of services, have described in this report the actions taken to respond to the ten recommendations in the original Healthwatch Report published in 2017. The report also includes an initial response to a new report produced by Healthwatch, entitled 'Improvements in adult autism services in Calderdale'.

## Possible courses of action

- (a) Consider the actions taken by commissioners and providers as described in this report
- (b) Identify new recommendations emerging from the discussions with Scrutiny members and members of the public

## Contact Officers

Sarah Antemes, Head of Continuing Healthcare / Mental Health and Learning Disabilities, Calderdale CCG  
 Karen Midgley, Commissioning and Quality Manager, Calderdale Council  
 Sue Sutcliffe, General Manager – Community Services, SWYPFT

## Should this report be exempt?

No

## **1. Background**

- 1.1 In October 2017, Healthwatch published a report 'Adults' experiences of ASD services in Calderdale and Kirklees'. A separate Calderdale report was produced at the same time. The reports set out the results of Healthwatch's investigations into issues being raised in those areas by adults with diagnosed or undiagnosed Autistic Spectrum Conditions (ASC), regarding the services they were being offered. Healthwatch made a number of recommendations, and an update against these is provided in section 2 below.
- 1.2 Healthwatch has produced a new report 'Improving services for adults with autism in Calderdale'. This was received by the CCG and partners on 4<sup>th</sup> November 2019. The initial response from the CCG and partners can be found in section 3.

## **2. Update Against 2017 Recommendations**

- 2.1 The paragraphs below set out the action that has been taken by the CCG, the Council and SWYPFT in response to the recommendations in the 2017 report. **Recommendation 1 - Calderdale CCG, Greater Huddersfield CCG and North Kirklees CCG, and Calderdale Council and Kirklees Council Adult Health and Social Care Services, using the feedback from people with ASC presented in this report, to help design and commission better services.**

Calderdale Council used the feedback presented in the report to design and commission the Autism Hub (described on page 6 of this report). Calderdale CCG used the feedback presented in the report to develop the specification for the adult autism assessment/ diagnosis service (described in Appendix 1 of this report). The feedback was also incorporated into the equality impact assessment for that service.

**Recommendation 2 - A review of the diagnosis and treatment pathways for ASC with the aim of reducing waiting times for diagnosis and providing local post diagnosis clinical support in line with NICE guidance**

When the original Healthwatch report was produced, the CCG did not commission a specific service for adult autism assessment and diagnosis service – instead, a request had to be made by the individual's GP or another clinician for funding for a referral to be made, usually to SWYPFT. As there was no agreed service agreement in place, a backlog in assessments built up and in 2016/17 over 100 people who had received approval for their assessment from the Individual Funding Requests Committee were on a waiting list, with many waiting over 12 months. Most referrals went to SWYPFT, but without an indication of demand or the assurance of a contract or specification in place, SWYPFT did not have the capacity in place to see people within the recommended timescales.

The Healthwatch report enabled local CCGs to better understand the impact of the lack of a commissioned service, and they worked together to develop a service specification to ensure a consistent approach. After due process, SWYPFT was commissioned to provide the service.

Appendix 1 is a newly prepared report from SWYPFT on the adult autism pathway in Calderdale setting out information on the following:

- Summary of pathway
- Clinical assessment framework
- Activity flow (including waiting times)
- Autism diagnosis (including diagnosis rates)
- Service user feedback
- Notes

Since the service started, it has reduced waiting times to meet those recommended in NICE guidance.

**Recommendation 3 - A review of autism awareness training for GPs to reduce the barriers to individuals getting the support they need, and raising awareness of NICE guidelines on the recognition, referral, diagnosis and management of adults on the autism spectrum.**

The CCG shares guidance and good practice resources with GP practices; for example the Royal College of General Practitioners Autistic Spectrum Disorder toolkit. It has recently promoted the autism animations developed by the Calderdale Autism Hub members as an awareness raising tool.

The CCG will be working with the emerging Primary Care Networks to improve awareness and education

As part of the development of the new assessment/diagnosis service, SWYPFT developed guidance for referrers in partnership with GPs. This was shared with GP practices and other referrers.

The SWYPFT service provides feedback to individual referrers where a referral has not been accepted, and has recently updated its guidance, based on the experience of a year of running the service. This has also been shared with GP practices.

**Recommendation 4 - How GP practices could be made more ASC friendly, including use of the Royal College of GP's new toolkit of resources.**

The Royal College of General Practitioners Autistic Spectrum Disorder toolkit was shared with GP practices at the time it was produced.

The CCG recently took part in an event arranged by the Calderdale and Kirklees Patient Experience Group (PEG), which includes representatives from the main service providers in the area. The focus was on the reasonable adjustments providers should make for people with autism and people with ADHD. This included input from members of Calderdale Autism Strategy Group. A number of actions were agreed by PEG members. In addition, feedback collected from the people attending the Calderdale Autism Hub on this subject was shared with PEG members. The implementation of the actions agreed will be monitored through the PEG.

**Recommendation 5 - Whether the mental health support available in Calderdale and Kirklees is suitable for adults with ASC, or whether adaptations need to be made to enable them to access mental health services, including timely support in a crisis.**

The NHS standard contract requires that providers should make reasonable adjustments to enable those with particular needs to access and benefit from their services. The actions agreed from the session referred under Recommendation 4 will help with this.

The CCG is aware of the continuing issue relating to a lack of mental health support specifically for people with ASD, particularly in a crisis and is working with the West Yorkshire and Harrogate Health and Care Partnership on this subject.

The Partnership is running a project around barriers to people with ASD accessing urgent and crisis care (physical and mental health). The first part of the project will involve the co-production with individuals with ASD and their families/ carers of a regional report to identify barriers. The second part of the project is to identify opportunities to reduce these barriers and to initiate any changes within the Bradford and Graven area, looking for the potential to share and spread this learning across the Partnership. The project sponsor has been asked to ensure that people from Calderdale (and other Partnership areas) are able to feed into the project.

In addition, the Yorkshire and Humber Organisational Development Network (ODN) set up by NHS England is leading a programme of work involving wider stakeholders (including people with autism) across Yorkshire and will make recommendations to improve on the following topics:

- Physical health
- Sensory differences
- Crisis prevention/ Emergency support
- Communication
- Social skills
- Relationships
- Housing
- Living skills and self-care
- Wellbeing & Self- esteem

We expect the ODN report to be published in the next three months, and it will better advise us to address this recommendation.

Support is available in the voluntary sector, from organisation such as Healthy Minds (in particular Safespace, its out of hours support service for people in emotional distress) and Andy's Man Club.

**Recommendation 6 - How the parents, partners and carers of people with ASC can be identified and flagged up by GP practices to social services, so that they can receive extra support if they need it, particularly by raising awareness of the Carers Assessment among the carers of adults with autism.**

GP practices have various mechanisms for identifying carers and signposting them to appropriate support, including Carers Assessments. The CCG shares good practice guidance on this subject with practices, most recently a report from the Carers Trust 'Identification of carers in GP practices: a good practice document'.

A voluntary quality marker for GPs to use to register carers has been developed along with an online tool which is being launched on Carers Rights Day on 21 November. The West Yorkshire and Harrogate Care Partnership are promoting it and have developed a video for this purpose.

Generic carer support is available from Calderdale Carers, and Making Space provides specific carer support for people with mental health needs including Aspergers. Peer support groups open to carers are described under recommendation 7.

**Recommendation 7 - Increasing the availability of support available including advocacy services for adults with ASC and their carers, plus making a wider range of accessible support and social groups and activities available for adults with ASC in places where they can feel safe, including addressing barriers to access such as location, transport and childcare.**

Since the Healthwatch report, the Autism Hub, All Age Disability Service and 4Neurodiversity groups have been set up, and the Asperger's Group and the Autism Employment Service continue to provide support services. Further details of these are provided below.

### ***Autism Hub***

The Autism Hub has been running for 18 months. Specialist Autism Services provide weekly group and one-to-one sessions for information, guidance and support in Halifax. Around 12 people attend each week, they are male and female and aged 16-60+. The group is member led and they chose topics and activities for the group sessions, some members opt to lead a session from time to time, e.g. in art therapy, creative writing. It is great for developing skills and confidence, and the members are very supportive of each other and several friendships have formed which is really positive considering many people were lonely and isolated before they joined the Hub. The one-to-one sessions are for individuals or parents/carers who require information and advice, eg support with benefits claims, further information on ASC.

### ***All Age Disability Service***

This was set up following the All Age Disability Strategy 2017/18. It combines all social work teams that support adults and children with learning and physical disabilities and autism.

### ***4Neurodiversity (independent organisation supported by Calderdale Council)***

4Neurodiversity is a new autistic-led charitable organisation being set up to provide autism awareness and self-awareness training and consultancy, alongside its sister organisation The Society 4Neurodiversity, which is a member-led organisation offering support for a group of like-minded individuals facing similar issues.

### ***Aspergers Peer Support Groups***

These are held monthly, with one group in Halifax and an evening group in Hebden Bridge. They have been running for 8 years and around 150 people have attended in that time. Around 8-10 people attend in Halifax and 4-8 in Hebden Bridge. They are informal with free tea, coffee and snacks and lots of chat as well as a quiz, dominoes, chess etc. available at Halifax. The groups are great for increasing people's confidence and social skills and providing a sense of belonging that many people with ASC lack. A few members have moved into paid or voluntary work, or relationships since attending the groups. Parents/partners/carers have always been welcome to attend and many have. There is also an occasional group for partners, and a parents group jointly facilitated by the Council, Calderdale National Autistic Society and Unique Ways.

### ***Autism Employment Service***

Specialist Autism Services are commissioned to provide a weekly employment service in Halifax which is now in its 4th year. Around 12 people attend each week and referrals come from the Job Centre and other services as well as self referrals. They have two sessions one on work preparation including discussions around what to expect in the



workplace, mock interviews, work orientation visits to places of work eg McVities. The second session is for job search and preparing CVs and job applications. Several people have been successful in getting work placements, voluntary work or paid work, and all the members develop their skills and confidence, moving them closer to employment.

### **Autism Strategy Group**

This group consists of adults with ASC, parents/carers, and staff from the Council, CCG, SWYT, DWP, Education, Providers and NAS. It has been meeting quarterly for 7 years and oversees the implementation of the Adult Autism Strategy and is responsible for the National Autism Self Assessment Framework. A new All Age Autism Strategy is now being developed.

Currently Calderdale MBC commissions a statutory advocacy service from Cloverleaf, which provides Independent Mental Health advocacy, Independent Mental Capacity Act advocacy and Care Act advocacy.

One of the issues picked up in the Healthwatch report was the lack of advocacy services for adults with ASC and their carers. Although good support is available from Healthwatch and carers services, these offers remain limited. As part of the strengthening of support services locally, commissioners will consider any potential to improve advocacy services.

**Recommendation 8 - Improving service user feedback mechanisms for adults with ASC and their carers, using support groups but also seeking to access the views and experiences of people who don't attend these groups and might not get many opportunities to give their feedback.**

The CCG has worked informally with members of the Autism Strategy Group to receive and understand feedback from service users and those who have not received a diagnosis. The CCG is keen to develop formal mechanisms for feedback through groups and other forums, and would welcome the opportunity to develop such mechanisms with Healthwatch and partners.

**Recommendation 9 - Improving intelligence gathering in order to provide a local picture of autism, including the number of adults with ASC diagnoses in Calderdale, data on autism diagnosis waiting times, and data on the number of people caring for adults with ASC, and take up of the Carers Assessment .**

There are a number of sources of information that are used to provide a local picture of autism, as follows:

- Information from the Projecting Adult Needs Service Information (PANSI) and Projecting Older People's Population Information (POPPI) systems, developed by the Institute of Public Care on estimated prevalence of autistic spectrum disorders
- Latest prevalence studies on autism, estimating prevalence of 1.1% of the population being on the autistic spectrum

- Data that the CCG receives on activity, outcomes and waiting times relating to the SWYPFT assessment/diagnosis service as part of its regular contract monitoring.
- Information on the uptake of carers' personal budgets (a main outcome of a carer's assessment) – figures for 2018/19 show that of 440 carers awarded a carer's personal budget, 12 (2.7%) were carers of people with ASD/ADHD. 41 (9.3%) were carers of people with a learning disability and 94 (21%) were carers of people with mental health needs and some of these people may also have ASC.

**Recommendation 10 - Promoting and Increasing the number of autism friendly events, venues, services and employers in Calderdale and Kirklees, for example by publishing lists of autism friendly dentists and opticians, and holding ASC friendly events to celebrate World Autism Day on April 2nd.**

The Council has held an event around World Autism Day for a number of years. This year there was an awareness/fundraising event at Princess Buildings for Council staff, and key professionals were invited to the Autism Hub for an event involving the launch of autism awareness animations produced by the Hub.

The Vue cinema and Hebden Bridge Picture House have regular autism friendly screenings. Morrisons and Home bargains have weekly autism-friendly shopping hours.

The Autism Service Directory contains details of autism-friendly services. A new version has recently been produced, and will be added to the Council's website shortly.

The CCG regularly shares information about autism support and events with GP practices and other partners. In the last year, this has included:

- Autism hubs
- Autism employment support
- Aspergers Group
- Living Well Roadshow
- Launch of Ask Listen Do project
- Helping people with disabilities access GP online services

- 2.2 The CCG and partners have focused in the past two years on improving the experience of children and young people with suspected ASD and their families. The learning from that work will be used to inform work relating to adults with ASD.

- 2.3 Work is also taking place through the Calderdale, Kirklees, Wakefield and Barnsley Transforming Care Programme that will have an impact on some people with autism. This was set out in a report that went to the Health and Wellbeing Board in October 2019 entitled 'Learning Disabilities - "Call To Action" – Support and Long term planning for people with a learning disability placed in Assessment and Treatment provision' (this covers people with a learning disability and/or autism). The report is included for information at Appendix 2.

### **3. Initial response to the 2019 report**

- 3.1 The CCG, the Council and SWYPFT would like to thank the people who have contributed their experiences to the new report, and Healthwatch for pulling the report together.
- 3.2 The report needs to go through due process for the system (rather than individual organisations) to provide a response.
- 3.3 Adult ASD needs to be considered with other priorities that have been raised with the organisations across the system.

### **4. Conclusions**

The Council, the CCG and SWYPFT have taken on board the recommendations of the 2017 Healthwatch report and have taken appropriate action. They will now consider the new recommendations and respond accordingly.

### **5. Appendices**

Appendix 1 – SWYPFT: 'Adult Autism Pathway in Calderdale 2018- 20'

Appendix 2 – Calderdale CCG/Calderdale Council: 'Learning Disabilities- "Call To Action" – Support and Long term planning for people with a learning disability placed in Assessment and Treatment provision'

[https://www.calderdale.gov.uk/nweb/COUNCIL.minutes\\_pkg.view\\_doc?p\\_Type=AR&p\\_ID=69669](https://www.calderdale.gov.uk/nweb/COUNCIL.minutes_pkg.view_doc?p_Type=AR&p_ID=69669)

### **6. Background documents**

Healthwatch - Adults' experience of Autistic Spectrum Disorder services in Calderdale and Kirklees (2017)

<https://www.healthwatchcalderdale.co.uk/health-services-for-adults-with-autism/>

Healthwatch – Improving services for adults with autism in Calderdale (2019)  
*[in scrutiny paper pack]*

### **7. Documents available for inspection at**

See above



**Adult Autism Pathway**  
**CALDERDALE**  
**2018 - 2020**

**Date of Report: 30<sup>th</sup> October 2019**

**Service for Adults with ADHD and Autism**  
**Manygates Clinic**  
**Wakefield**

**1. SUMMARY**

The Service for Adults with Attention Deficit Hyperactivity Disorder (ADHD) and Autism forms part of the Trust (SWYPFT) specialist community services and has developed with investment from the five Clinical Commissioning Groups (CCGs) of Wakefield, North Kirklees, Greater Huddersfield, Barnsley and Calderdale and the two Local Authorities of Wakefield and Kirklees.

Commissioners across the localities purchase specialist pathways according to their own requirements from an autism pathway offer which includes “enhanced screening”, diagnostic assessment, post diagnostic support and specialist health and social care interventions.

The Service operates within a multi-disciplinary team (MDT) model of care and all clinical members of the MDT have specialist knowledge, training and experience in Autism. The specialist team includes a Consultant Psychiatrist, Specialty Doctors, Clinical Psychologist, Occupational Therapists, Nurse Practitioners, Speech and Language Therapist and Assistant Psychologists. There are specialist social workers who are able to work with people living in the Kirklees and Wakefield localities.

From April 2018 Calderdale CCG made a recurrent commitment to SWYPFT and commissioned an adult autism **diagnostic pathway** of 30 cases a year, including post diagnostic support.

In addition to the recurrent investment, there was a one off payment to process 89 cases on a waiting list of referrals with previously approved Individual Funding Requests for a diagnostic assessment of Autism by March 2020. This was delivered on time.

Since April 2018, referrals to the pathway are reviewed by a dedicated Triage Panel which includes representation from the Service and the CCG, including a clinical specialist in Autism and a General Practitioner. The Triage Panel meets on a bi-monthly basis in Calderdale.

Calderdale CCG have not commissioned a specialist autism intervention pathway, therefore any identified health & social care needs of adults who receive a diagnosis of autism have continued to be managed through referrals to local community services in Calderdale.

**2.**

### **AUTISM CLINICAL ASSESSMENT FRAMEWORK**

The Service clinical assessment framework for adult Autism aims to meet the NICE clinical guideline standards [CG142] and reflect best practice based on the current evidence base in the field. The assessment framework is reviewed and adapted to reflect the development of clinical knowledge and expertise and in consideration of available resources to deliver high quality clinical assessments.

Pre-assessment questionnaires (self and informant reports) are used to gather important information prior to an initial appointment with the Service including personal and family details and rating scales used to screen for ADHD, Autism and co-existing conditions.

The diagnostic assessment is undertaken by specialist practitioners trained in the use of formal assessment tools including AAA, ADOS-2 and ADI-R and is usually completed in between one and four appointments, with each appointment normally lasting up to two-hours.

The comprehensive assessment will include:

- Review of completed questionnaires and rating scales
- Assessment of core autism signs and symptoms that have been present in childhood and continuing into adulthood, including communication and sensory difficulties
- Early developmental history including specific speech and language difficulties
- Functioning at home, in education or in employment, including behavioural difficulties
- Past and current physical, mental health and other neurodevelopmental condition
- Observations of the person's behaviour during the assessments to establish if it is consistent with the condition

	<p>The outcome of diagnostic assessment stages are discussed and agreed by the multi-disciplinary team (MDT) prior to individual feedback to the service user and with consent of the individual, in the presence of a family member, partner, carer or advocate.</p> <p>For adults who meet the diagnostic criteria of autism (in accordance with the diagnostic Autism Spectrum Disorder criteria as defined by the Diagnostic and Statistical Manual of Mental Disorders DSM-5) are offered up to two post diagnostic support sessions to discuss in more detail the implications of the diagnosis, any concerns they have about the diagnosis and access to any future care and support.</p> <p>On completion of the diagnostic assessment, the clinician, in consultation with the MDT, will signpost or refer to appropriate mental health or social care services, irrespective of whether the person has a diagnosis of autism or not.</p>
<p><b>3.</b></p>	<p><b>ACTIVITY FLOW</b></p> <p><b>WAITING LIST BACKLOG</b></p> <p>At 1 April 2018 there were a total of 89 referrals waiting for diagnostic assessment of autism in Calderdale. Between April and December 2018 all those on the waiting list were contacted by letter and sent a pack to complete and return for an initial screening appointment to be allocated.</p> <p>A total of 75 people from the waiting list returned packs and were allocated an initial enhanced screening appointment by the end of March 2019.</p> <p><b>REFERRAL TRIAGE</b></p> <p>The Autism Triage process in Calderdale and other SWYPFT localities demonstrates a collaborative approach to ensuring an open, honest and transparent triage of referrals between those who provide (SWYPFT) and those who commission Adult Autism Services (CCG).</p>



Between April 2018 and August 2019 a total of 137 referrals have been considered by the Calderdale Triage Panel and 35 of these referrals were considered clinically appropriate to be entered to the diagnostic pathway. There are 22 referrals waiting for consideration at the next Triage Panel Meeting in November 2019.

When a referral is not accepted by the Panel, the referrer is informed by letter of the reasons why the referral cannot be accepted; in some cases this may be a lack of relevant information and the Service referral form and guidance for referrers is sent for the option of a re-referral to be made if considered appropriate. Between April 2018 and August 2019 there have been a total of 25 re-referrals, 7 of these referrals have been accepted further to additional information being provided.

For referrals not accepted by the triage panel, the correspondence sent to the GP would make any appropriate suggestions of further referrals for discussion and agreement with the person referred.

Since April 2019 there has been no waiting list for a diagnostic assessment of autism in Calderdale; referrals accepted by the Triage Panel have in most cases been offered an initial screening appointment within 12 weeks.

**PATIENT FLOW APRIL 2019 – March 2020**

Month	Calderdale CCG Patient flow: 30 case 2019/20			
	Trajectory	Actual	DNA/Cx	Remaining cases
April 19	3	4		
May 19	3	3		
June 19	3	1		22
July 19	3	3		
Aug 19	3	2		
Sept 19	3	3		14
Oct 19	3	3		
Nov 19	3			
Dec 19	3			
Jan 20	3			
Feb 20				
Mar 20				
				0
<b>Total</b>				

	<p>A monthly update of activity is sent to Calderdale CCG commissioners in a formal Key Performance Indicator report sent by the Trust Performance &amp; Information Team.</p>
<b>4.</b>	<p><b>AUTISM DIAGNOSIS</b></p> <p>The Service acknowledges there are differing diagnostic rates across NHS and Private providers who offer diagnostic assessments of Autism. These variations may be attributed to the quality of referrals, knowledge and experience of diagnostic assessors and the robustness of assessment processes, some of which often do not include the use of standardised assessment tools and commonly do not meet the standards recommended by NICE</p> <p>The experience of the Service suggests an approximate diagnostic rate of 20% (those people who meet the DSM-5 diagnostic criteria of Autism) from referrals identified at the initial enhanced screening assessment to require a full diagnostic assessment.</p> <p><u>Diagnostic rates in 2018/19.</u></p> <p>In Calderdale 4 out of 33 people (12%) who required a full diagnostic assessment met the criteria for a diagnosis of Autism Spectrum Disorder. Many people assessed in Calderdale during this period had been on a waiting list over a number of years and the low diagnostic rate is thought to have been influenced by the absence of the Specialist Triage.</p> <p><u>Diagnostic rates in 2019/20</u> (as of October 2019)</p> <p>In Calderdale 0 out of 6 people who required and have completed a full diagnostic assessment met the criteria for a diagnosis of Autism Spectrum Disorder; 6 assessments are ongoing</p> <p><b>SPECIALIST HEALTH AND SOCIAL CARE INTERVENTIONS</b></p> <p>Not everyone who has a diagnosis of autism will require specialist health &amp; social care interventions; for most people, support will be provided by informal networks such as family, friends and work colleagues or by local services and agencies that have experience in the area of support the person requires e.g. employment, housing,</p>

	<p>leisure and social groups.</p> <p>Research suggests that people who have a diagnosis of autism will also have additional mental health needs which will require specialist mental health input. In the other localities this is provided by the specialist autism service but in Calderdale by the generic services. In addition, people who have a diagnosis of autism require input to increase their functioning and potential. In the other localities this is provided by this specialist autism service.</p> <p>To ensure specialist autism interventions are offered to those who have autism, the referrer will need to provide confirmation that the person has a diagnosis of autism by providing a copy of a formal diagnostic report, a completed referral form to explain how autism is affecting the person and what issues they are asking for help with.</p> <p>Due to a surplus of CCG funding provided in 2018/19 (as part of the waiting list initiative) the Service was able to offer specialist intervention care plans for 2 people in Calderdale who received a diagnosis of autism from the Service. Both had a long standing history of contact with mental health services and have benefited from specialist autism interventions.</p> <p>The detail and positive outcome of these intervention care plans has been fed back to CCG commissioners to advocate the benefit of a local autism intervention pathway in Calderdale equitable to the commissioned pathways in Wakefield, Kirklees &amp; Barnsley.</p> <p>Specialist care plans included:</p> <ul style="list-style-type: none"> <li>• Mental health assessment by a psychiatrist and treatment of co-existing conditions in collaboration with colleagues in CMHT</li> <li>• Extended post diagnostic support that has helped the understanding of autism and impact on day to day life and that of their children, making small changes at home to improve activities and relationships.</li> <li>• Referrals to the Staying Well Project with positive engagement and increased community participation and collaborative working between services</li> <li>• Sensory assessment and plan by specialist occupational therapist</li> </ul>
<b>5.</b>	<p><b>SERVICE USER FEEDBACK</b></p> <p>The Service aims to gather feedback from everyone who has experience of accessing the Service. Questionnaires are sent in the post on completion of the autism</p>

diagnostic assessment process or on discharge from the intervention pathway.

Feedback comments include:

What you think is **good** about the Service .....

- Clinicians who completed assessments described as " friendly", " intuitive, polite and understanding regarding the subject of autism" , "professional and an extreme pleasure to talk with"
- Staff have zero room for improvement, the paperwork presents no issues and facilities are excellent
- There are shorter waiting times to access the Service in some Trust localities "I received relatively early the appointment (without long waiting, like more than 12 months, or so). In this regard I was lucky"

What you think **we can improve** on .....

- Making reasonable adjustments at clinic venues "the venue was too noisy and too many people around me to feel comfortable", "I do not like bright lights and was more focused on the brightness of the light in the room hurting my eyes and giving me headache" , "I think the seating could be better and more gentle in approach".
- Equality in waiting times across Trust localities "The waiting times for an autism assessment is horrendous as it can take years in some instances before you are seen by a professional assessor but I appreciate also that a lot of people require this service"
- Avoid using language that not everyone understands "He kept on talking about politics scenarios which I told him I did not understand and had to repeat them constantly".
- Letting people know what qualifications and training clinicians who complete the assessments have "More healthcare professionals with autism spectrum awareness needed. Especially in cases of aged autistic females", "I think that a professional with understanding of Autistic spectrum would be of great help".

In addition, we ask service users and carers to give us feedback on their experience of the ADHD transition process.

**Feedback comments In August 2019:**

- Getting information and different medication for my ADHD
- Holistic approach of the doctor

The Trust Friends & Family Test questionnaire is sent to all those who have agreed to the text appointment reminder service and includes free text comments to understand 'what was good', 'what would have made their experience better'

**Feedback comments in September 2019:**

- Very professional. Lots of ideas for next steps
- She made sure I understood everything. Asked if I had any questions then answered them
- Friendly and helpful staff
- Excellent staff

***No data returned in October 2019***

All feedback is confidential and valued to help us to know what we do well and what we may need to change or improve.

**Actions we have taken in response to recent service user feedback in the autism pathway:**

- We have amended the format of the service user satisfaction report to show the feedback of those people who have had an initial screening assessment and those who have completed the full diagnostic assessment.
- We have amended our Frequently Asked Questions Fact Sheet to tell people what professionals will carry out the assessment and that all members of the Multidisciplinary Team (MDT) have specialist knowledge and training in

**Autism.**

- We have updated the feedback questionnaires to reflect the locality the person was seen. This will help us to address any issues with regard the clinical bases we are using across the Trust localities.

The Service also provides details of the Trust Customer Services Team to raise compliments or complaints as part of the Service information pack. We have dealt promptly with individual informal and formal complaints with support from the Trust Customer Service Team when required.

The Service is currently undertaking an independent Accreditation process with the Royal College of Psychiatrists for Community Mental Health Services; the self-review process has included gaining feedback from adults who have a diagnosis of Autism and ADHD and their carer. Service users and carers were asked to complete a questionnaire and had an opportunity to meet with the independent peer review team to give face to face feedback.

**Feedback includes:**

Did the team tell you how long it would be before your first appointment, and keep you updated if needed?

Answers: 4 (44%) Yes 3 (33%) No 2 (22%) Unsure

Did staff treat you with compassion, dignity and respect?

Service User Questionnaire: Answers: 8 (89%) Yes 1 (11%) No

Relatives, Friends and Carers Questionnaire: 4 (100%) Yes

All service users spoken to on the review day said 'yes' and all carers said 'yes'.

Did staff listen to you and show understanding of what you had to say?

Answers: 8 (89%) Yes 1 (11%) No

Did staff talk to you in a way you can easily understand, without jargon?

Service User Questionnaire: 8 (89%) Yes 1 (11%) No

Relatives, Friends and Carers Questionnaire: 4 (100%) Yes

Were you given enough choice about your appointments if you wanted it? For example, when and where you were seen, whether you saw a man or woman, or if you wanted someone who spoke a different language?

Answers: 4 (44%) Yes 2 (22%) Unsure 2 (22%) No 1 (11%) Not applicable to me

6.	<p><b>NOTES:</b></p> <p>The detail included in this report aims to provide an overview of the Autism Pathway Service offer and the operational delivery of this in the Calderdale locality.</p> <p>It is hoped there can be recognition that the Service provides a specialist autism pathway that has robust and credible processes based in best practice that is evidence based to meet the needs of autistic adults.</p> <p>The needs of adults who identify with the diagnosis of autism (but do not meet the diagnostic criteria) and seek a diagnostic label falls outside of the remit of the Service, albeit nonetheless deserved of other services able to meet their often complex difficulties.</p>







**Calderdale MBC**

**Calderdale Health and Wellbeing Board**

<b>Date:</b>	<b>October 2019</b>	
<b>Wards Affected:</b>	<b>All</b>	
<b>Subject:</b>	<b>Learning Disabilities- "Call To Action" – Support and Long term planning for people with a learning disability placed in Assessment and Treatment provision.</b>	
<b>Report of:</b>	<b>Sarah Antemes Karen Midgley</b>	
<b>Type of Item (please indicate X)</b>	<b>Policy</b>	
	<b>Performance Management</b>	
	<b>Governance</b>	
	<b>Board assurance</b>	<b>x</b>
	<b>Consultation</b>	
	<b>Board request</b>	

## **Why is this report coming to the Board?**

The report is presented to HWBB to provide oversight and assurance regarding the Calderdale residents placed in Assessment and Treatment Units (ATUs) and the plans in place to ensure their safe and successful discharge to community based settings.

The report also covers Calderdale's approach to minimising the ongoing use of in-patient care for people with a learning disability and local plans to ensure that the correct good quality support and resources are available in Calderdale to support people with a learning disability and/ or autism.

## **What are the key issues for the Board?**

Assessment and Treatment Units (ATUs) should be used for brief medical and therapeutic interventions where community based services are unable to meet the needs of a person with a learning disability and and/or autism. Most people requiring this level of care will be detained under the Mental Health Act.

In 2011 an investigation into the treatment of people at Winterbourne View (run by Castlebeck) led to a wide scale government enquiry and the establishment of the Transforming Care Programme (TCP), to oversee the care and treatment of people with a learning disability and/or autism in ATUs. The programme is still live and is tasked with reducing the use of ATUs, keeping close oversight of any patients placed in ATUs and ensuring where treatment is required the length of stay is kept to a minimum and discharge plans are at the centre of the person's

treatment. As a result of this programme and wider concerns The Transforming Care Programme was established to ensure people with a learning disability receive the correct care and support and wherever possible remain in their local communities close to their families and networks of support.

The ongoing importance of Transforming Care was highlighted again in 2019 when a documentary on Whorlton Hall (Cygnet Care) was broadcast by the BBC highlighting continued institutional abuse of people with a learning disability.

Calderdale forms part of the Calderdale, Kirklees, Wakefield and Barnsley (CKWB) Transforming Care Partnership (TCP) which oversees the placement, care and discharge plans for people with a learning disability and/or autism who require inpatient care within an ATU. The TCP reports to the West Yorkshire and Harrogate Integrated Care System (WY&H ICS) Mental Health, Learning Disability and Autism Programme Board.

#### **What possible actions can the Board take?**

The board may seek further reassurances regarding the care and support of people with a learning disability and/autism placed in ATUs or out of authority specialist placements.

#### **Contact for more Information on this report**

**Sarah Antemes** - Head of Continuing Healthcare/Mental Health and Learning Disability services, Calderdale CCG.

**Karen Midgley** - Service Manager Quality and Market Development, CMBC

#### **Should this report be exempt**

**No**

## **Report to Calderdale Health and Wellbeing Board**

**Learning Disabilities- “Call To Action” – Support and Long term planning for people with a learning disability placed in Assessment and Treatment provision.**

### **1. PURPOSE OF REPORT**

This report outlines the actions required to ensure that people with a learning disability and/or autism in Calderdale receive timely and appropriate care and support. At times some people may require in-patient assessment and treatment, however the need for an acute admission can be minimised if the correct accommodation, support and therapeutic resources are available in Calderdale. This includes specialist accommodation and support that is available to people at times of crisis, commonly referred to as safe places.

#### **1.1 What Is the Transforming Care Partnership Programme?**

In October 2015, the Local Government Association (LGA), Directors of Adult Social Services (ADASS) and NHS England published the ‘Building the right support’ national plan and service model to develop community services and close inpatient facilities for people with a learning disability and/or autism who display behaviours that challenge, including those with a mental health condition. As part of the Transforming Care Partnership Programme (TCP), 48 TCPs were established across England with the aim of each one developing and delivering local TCP plans over a three year period from April 2016 to March 2019. Calderdale is part of the Calderdale, Kirklees, Wakefield and Barnsley TCP (CKWB).

The CKWB Transforming Care Partnership Plan TCP Plan was completed in June 2016. The image below captures the key components that are needed to deliver CKWB TCP plan.



Vicky Dutchburn (Greater Huddersfield CCG) is the CKWB TCP Senior Responsible Officer. Three priority work streams were established in June 2017, led by Board members:

1. Children and Young People
2. Early Intervention and Prevention of Admission
3. Market Development (including Workforce Development)

- 1.2** The CKWB partnership is led and hosted by Kirklees as over half of all the originally identified CCG funded CKWB TCP hospital patients originate from Kirklees. Each area/partner agency has a lead commissioner involved; all partners work together to deliver the programme at a local and regional level. The Calderdale leads are Karen Midgley (LA) and Sarah Antemes (CCG). The programme also has a dedicated project co-ordinator to oversee the delivery and co-ordinate national returns.

### Patient Cohort

- 1.3** Over the last three years significant progress on discharges has been made, across all partners and a number of stories of how with the right input and planning services have been developed to support the successful move of complex people back into community. Below are two stories that demonstrate how we have made a real difference to people's lives (NB they are anonymised and shared with consent)

#### **1.4 Arthur's story**

Arthur used to live in the community and had a close relationship with his mother and family but due to concerns about his challenging behaviour he was admitted to hospital in 2007, whilst there his behaviours worsened, there were frequent episodes of violence and he had to be cared for in a separate part of the ward from others. Due to distance it was difficult for his family and now elderly mother to visit regularly.

During 2015/16 CCG/LA staff worked closely with Arthur and his family and the placement to understand how to improve the situation where he was and also to agree how he may be best supported in the community. Commissioners worked with a provider to develop a bespoke placement as part of a farm complex in Manchester, this provided Arthur with safe space as well meaningful activity on the farm interacting with animals. Arthurs left hospital in October 2017 and whilst there have been some issues these have been successfully managed and he has remained in the community and he is in a much less restrictive setting. Arthur now sees his mother and sister regularly and has formed relationships with other members of the family.

It must be noted that sometimes providing complex solutions in community can be more expensive than hospital care and this is the situation in Arthurs case, it has however been the right thing to do and has led to a transformation in his quality of life.

#### **1.5 Sam's Story**

Sam is a young man with Autism; he first began to struggle with community living with his family at the age of 16. Despite help from the Specialist children's services from the Local Authority, Education and Health Sam continued to deteriorate to the point where he became a danger to his other siblings and in the community. Sam was prescribed a large amount of sedation and supported 2 to 1 at all times. Sam's family could not cope. Despite all efforts to support Sam and his family this was to no avail and Sam required hospital admission for assessment and treatment.

Once in Hospital Sam's conditions continue to deteriorate and he was moved to a specialist low secure hospital in Norwich. Sam saw his family only once a week, their dedication and love was evident throughout and their desire to support their son to return home always remained. Sam remained in hospital for 12 months.

Sam's story to this point is very similar to Toby's; Sam clearly needed hospital treatment and specialist services to help him. However, under Transforming Care, the CCG were able to organise regular Care, Education and Treatment Reviews with a focus on discharge, and were able to work closely with providers to ensure a service was in place to meet his needs upon discharge.

Sam and his Parents were involved throughout the process of planning for Sam's discharge. The long term plan was designed to enable a successful return to the community and work towards healing the relationship between

Sam and his family enabling Sam to develop independence skills into adulthood.

The CCG worked closely with a specialist supported living provider to provide Sam with both the right support and accommodation in the community to meet Sam's practical and emotional needs as a young man with Autism. Sam moved into his new home on 22<sup>nd</sup> December 2017, 2 weeks before his 18<sup>th</sup> birthday.

Sam's is less than an hour away from his family, he has a full activity plan and goes out every day, he lives with 3 other young man and is very settled. Sam has achieved a great deal in his new home, his relationship with his family has improved and he enjoys many activities with them. Sam's family believe this is the happiest they have seen Sam for many years and Sam tells the CCG he is happy.

#### **1.6 Current patient cohort**

Calderdale currently has 3 adults in ATUs and 3 adults in secure services who meet the Transforming Care Criteria. The ambition for Calderdale CCG in line with Transforming Care expectations is to have a maximum of 2 ATU and 2 forensic beds.

#### **1.7 ATUs**

The CCG is responsible for the commissioning and case management of all people placed in a hospital environment (NB this excludes forensic services) The Continuing Care team work closely with an allocated case manager from LA with regards to all individuals. All patients receive regular Care and Treatment Reviews (CTR), these are multi agency meetings to scrutinize the care and treatment the person receives and ensures that firm plans are in place to support discharge. Family members and experts by experience are invited to these meetings as a matter of course and their input is key to ensuring that the hopes and aspirations of the individual inform future plans. There are plans in place to support the movement of all 3 people who currently in an ATU.

One person has been admitted for a short term piece of work and it is planned that he will return to be supported by family shortly. Plans are in place to support the move of one person later this year to a service in Calderdale. The third person has extreme behaviours that lead to the destruction of his environment and the development of a bespoke building has been required in order to provide a sustainable placement in community. It is planned that he will live there with 5 other people with similar needs supported by a specialist staff team; this placement will open Summer 2020. Whilst this means that he remains in hospital in the meantime it has been agreed that this is in best interests and it supports a slow transition with involvement throughout in a way that he can tolerate. There are weekly calls from the team with this person to discuss progress as well as regular visits to see him.

## **1.8 Forensic services**

NHSE is responsible for the commissioning and case management of all people in secure services. It is expected that they work with case managers from CCG/LA in order to plan the discharge and step down of people.

There are currently 4 people in secure services however of this number one person has only just been transferred in October from an ATU following concerns about increasing levels of risk. #

Transition work is ongoing to support the imminent move to community of one young adult.

The CCG is working with NHSE to seek appropriate placements for the other 2 people who have specific risk profiles and require bespoke placements in order to support their successful move into community and safely manage any associated risks for the individuals and/or others.

## **1.9 Children and young people**

There are currently no young people in inpatient settings as 2 people turned 18 this year and accounted for above. Through the use of CETRs it is hoped that admission to hospital can be avoided and more appropriate solutions put in place. However in the event that this happens it is important that joint working between children's and adult services is robust. This will ensure a proactive approach to seeking the right community solution in a timely manner for those young people moving to adulthood.

## **1.10 Market development**

The CKWB TCP has developed a market strategy and worked with providers to give clear direction to the market about the needs for the population of CKWB now and going forward. As part of this work it has become clear there is a need to develop some specialist bespoke individual accommodation for our most complex people with behaviours that are very challenging in order to enable them to step down from hospital and have a successful move into the community.

**1.11** Partners have worked closely with NHS England and have secured capital funding for a bespoke accommodation development to support people with very complex needs. The Mayman Lane development is in Batley and includes provision for one Calderdale patient who has struggled in other community settings, experiencing several placement breakdowns and admissions to hospital. The development is being built in close partnership with people who will live there and family members to ensure that the environment can meet each person's needs and personal design preferences. This accommodation is scheduled to be ready summer 2020 for people to move into.

**1.12** CKWB TCP has contributed to the development of a Yorkshire and Humber regional framework for specialist supported living. This framework has been

developed to ensure that there is good supply of skilled local providers who can be commissioned to provide support to people with complex needs once suitable accommodation has been found.

- 1.13** Calderdale commissioners have worked with local and regional providers to strengthen the quality and range of local services and support. This has included re-shaping some local residential and nursing provision to ensure that it is fit for current and long term needs and working with regional service providers to develop bespoke services that have enabled people to return to the community.

### **Early intervention and management of crisis**

#### **Risk registers**

- 1.14** The CKWB TCP has overseen the development of all age dynamic risk registers in each local area. The purpose of the risk register is to provide early identification of people at risk of crisis and to put the right support in place, it has a traffic light system to identify those at highest risk. South West Yorkshire Partnership Foundation Trust (SWYPFT) oversees these risk registers and work with partners to ensure that anyone who is experiencing crisis or significant health or emotional difficulties is supported.

#### **1.15 Community Learning Disability Service**

Calderdale CCG has worked with SWYPFT to develop their local community service and to develop an Intensive Support Service. This service was established to offer in reach therapeutic support to people with a learning disability either in family homes or commissioned provision. This service is available to people on the dynamic risk register offering support to people with an aim of avoiding unnecessary hospital admissions. The team includes psychology, speech and language therapy, physiotherapy, specialist nurses and support staff. The team works closely with other professionals, providers and families to offer intensive support to people in crisis or to help to return people to local provision from in patient or out of area placements.

People at risk of admission also receive a preventative CTR in order to put plans and support in place to ensure that the person remains in the community or within their current placement.

#### **1.16 West Yorkshire & Harrogate ICS**

Commissioners and NHS providers are working together to develop new models of care and to identify services can be best provided across the wider ICS footprint in order to deliver improved service delivery and outcomes for patients. There are 2 key developments with regards to learning disability services.



### **1.17 Forensic Outreach Liaison Service**

This service has been jointly commissioned by all CCGs, with Leeds as the lead commissioner and SWYPFT as the provider of services. The purpose of this team is to provide a community forensic service that is initially to support the transition of people from secure services and support into the community and then to provide the specialist support working with community teams and other stakeholders to manage people with a higher risk profile in the community

### **1.18 ATU services**

There are currently 3 NHS ATUs provided across the ICS footprint. In line with the expectations of Transforming Care work is ongoing across the ICS to review the current services and make recommendations about future provision. The service provided by SWYPFT is the Horizon Centre and is based on the Field head Hospital site in Wakefield. At the current time Calderdale CCG does not have a contract in place with SWYPFT for any beds at the Horizon Centre but will commission on a spot purchase basis with SWYPFT or the independent sector. This will be reviewed as part of the findings and recommendations from the ICS work.

### **1.19 Quality assurance**

Both the CCG and LA have systems in place to ensure that all individuals have as a minimum an annual review that takes place at their home/placement, families/carers are also invited to be part of this review. This review will not only review their needs and the appropriateness of their placement but will also look in detail at evidence of care/incidents/complaints, the environment and staffing. Some people will have more frequent reviews in particular those placed out of area or in a hospital setting. Where there are any concerns identified local systems or other sources this will trigger an early review.

Whilst the LA take the lead with regards to contract monitoring for local services there is an integrated approach with the CCG around contract compliance and a multiagency approach to any safeguarding concerns in line with the Calderdale Safeguarding Strategies for adults and for children.

The scandal of Winterbourne and more recently at Whorlton Hall has demonstrated how vulnerable people have been the victims of abuse whilst in hospital settings. Whilst we as commissioners try to ensure that we have the right checks in place to alert us to concerns and review individual placements on a regular basis we cannot be complacent, abuse can happen anywhere, especially where there are vulnerable individuals.

It is the responsibility of everybody to reflect upon recent events and to understand the 'ingredients' in those situations that led to such abuse and to think about how we can prevent this happening in the future. As a local system we have agreed to work with our staff and providers to explore this and identify how we train and support staff as well as work with individuals

and families to ensure that they feel empowered to speak up when they are not happy. It is important that as partners across systems we think about our part in helping to prevent abuse happening and to ensure early identification of concerns.

The Transforming Care programme was due to end in March 2018. However there was significant concern around the number of people who remain in inpatient settings the programme has been extended to the end of March 2020.

## **2. Recommendations**

It is recommended that HWBB support the current approach and drive the ambition of the LA and CCG commissioners to ensure people are supported wherever possible to remain in their local communities and that where an admission to an inpatient hospital setting is required that this is short term and informed by an individual plan with clear person centred outcomes for the person concerned. All placements will be reviewed on a frequent basis to ensure that they are meeting the need of the individual and providing treatment/care and support that is of a high standard.

## **3. Key Issues/Next Steps**

- 3.1** Maintain ongoing oversight and review of people on the risk register and/or in hospital placements and provide quality assurance.
- 3.2** Continued development of specialist services including Mayman Lane to ensure that bespoke accommodation and support is available at a regional level where there is a specialist need and not enough demand to develop separate services in each locality.
- 3.3** Ongoing re-design of local provision and work with existing providers to ensure that the needs of the local population can be met by Calderdale services and support wherever possible. Plans include the re-configuration of short breaks and emergency accommodation in a new building from 2021. This provision will ensure that people can be supported in the event of a family crisis or breakdown of their existing placement and allow a period of assessment and reduce the need to look at out of area or ATU provision.
- 3.4** LA and CCG commissioners are working together to identify gaps in local provision and to look at how accommodation and support can be developed in Calderdale to reduce the need for out of area placements. Provision in the local community ensures people can stay close to their families and support networks and ensures that commissioner and care managers have greater oversight of the quality of the provision. Local gaps include supported living services for people with a learning disability and autism and plans are in place to look at how this type of support can be commissioned in Calderdale to ensure that people can return to the local area.

#### **4. Conclusions**

Whilst a considerable amount of work has been done at a regional and local level to reduce the use of ATU provision and ensure that people are supported to leave hospital and wherever possible move onto to community provision, there are still a number of ongoing actions and opportunities for Calderdale.

The LA and CCG need to ensure that there is oversight of the quality of all provision and that providers are offered the correct support and guidance to deliver good quality person centred services. There are still some gaps in local provision that mean some people continue to require out of area provision in order to meet their needs.

**For further information on this report, contact:**

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**The documents used in the preparation of this report are:**

1. CKWB Transforming Care Plan [www.greaterhuddersfieldccg.nhs.uk/wp-content/uploads/2016/06/Transforming-Care-Partnership-Plan.pdf](http://www.greaterhuddersfieldccg.nhs.uk/wp-content/uploads/2016/06/Transforming-Care-Partnership-Plan.pdf)
- 2.
- 3.

**The documents are available for inspection at:**

