

# Adults' experiences of Autism Services in Calderdale and Kirklees



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# 1. Executive Summary

Healthwatch Calderdale decided to investigate issues being raised in Calderdale and Kirklees by adults with diagnosed or undiagnosed Autism Spectrum Conditions (ASC), regarding the services they were being offered.

When adults with ASC are diagnosed in Calderdale and Kirklees there is no post diagnosis clinical service available for them. While there are services available in some surrounding areas, commissioners have suggested that there has not been considered to be a significant enough number of people with autism in the area to warrant establishing a pathway to these services, and this has led to a postcode lottery for people living with ASC.

Healthwatch Calderdale also became aware of huge differences in the diagnosis rates for ASC depending on which service provided the assessment. Adults from Calderdale and Kirklees are currently referred to the Autism Spectrum Disorder Service based in Wakefield where the diagnosis rate is around 25%, but previously assessments were carried out by the Sheffield Adult Autism and Neurodevelopmental Service (SAANS) where the diagnosis rate is approximately 90%.

Healthwatch Calderdale wanted to find out about people's experience of adult autism services in Calderdale and Kirklees, so they visited support groups and collected the views of adults with ASC and their partners, parents and carers via an online survey. In total they visited eight ASC support groups in Calderdale and Kirklees, received 70 completed surveys, 42 from adults with ASC, and 28 from the parents/partners/carers of adults with ASC, plus 13 case studies.

## The key concerns raised included:

- Difficulties getting a diagnosis due to lack of GP awareness and long waiting lists.
- Lack of post diagnostic clinical support and appropriate mental health care for adults with ASC.
- Low levels of awareness and training for professionals and front line workers about ASC and the reasonable adjustments that would help people.
- Support groups were acknowledged to be helpful for some adults with ASC, but they are few in number and not accessible for everyone.
- A lack of support for carers of adults with ASC, with the majority not having had a Carers Assessment to ascertain their needs.

## People felt their experience would be better if they had:

- An improved diagnostic pathway with shorter waiting times and the option of out of area diagnosis, followed by post diagnostic clinical support in their local area.
- Better post diagnostic support to help with managing the effects of ASC including communication issues, hypersensitivity, difficulties with social situations, and day to day problems with planning and organising.

- Assistance from ASC trained social workers, mental health workers, PAs, support workers and advocates, to provide consistent support to help people live normal lives.
- A wider range of managed ASC friendly support and social groups in accessible venues to suit the needs and interests of more people.
- More support for and awareness of the needs of people caring for adults with ASC.

Healthwatch in Calderdale and Kirklees would like to see Calderdale and the Kirklees Clinical Commissioning Groups (CCGs), and Calderdale Council and Kirklees Council Adult Health and Social Care Services drawing up plans to help address the concerns expressed by adults with ASC and their carers.

Healthwatch Calderdale and Kirklees would then like the opportunity to review progress against the plans 12 months from the publication of this report.

## 2. Calderdale and Kirklees Adult Autism Services - the current picture

### Health

Adults seeking a diagnosis have to get specific funding through their GP, via the Individual Funding Request (IFR) process, then a referral for a diagnostic assessment can be allocated to a provider, generally the South West Yorkshire Partnership NHS Foundation Trust (SWYT) Autism Service based in Wakefield. This makes the experience of being referred for diagnosis very variable, as there is no consistent, established pathway for diagnosis. There is currently no treatment pathway.

The current positive diagnosis rate for ASC via the SWYT Autism Service is 26% in Kirklees, and 24% in Calderdale, but this is expected to increase as a new screening process has been introduced, which is done by a professional trained in autism using a validated diagnostic tool. This should ensure that only the people most likely to be diagnosed with ASC enter the longer diagnostic process, as well as helping to reduce the waiting times.

In Calderdale the waiting time between a referral being made and receiving a diagnostic assessment can be over two years. In Kirklees, as of 31/05/2017, there were 162 adults waiting to be seen by SWYT Autism Service, of these 32 had been waiting less than six months, 29 had been waiting up to a year, 47 had been waiting up to two years, and 54 had been waiting over two years.

### Social care

In Calderdale there is a directory of services that can be accessed by people with ASC which is regularly updated:

<http://www.thecalderdaleautismnetwork.co.uk/downloadables/downloadable8.pdf>

There are two peer support groups for adults with ASC running in Halifax and Hebden Bridge, a support group for partners which meets monthly in Sowerby Bridge, plus the new Autism Transition Parents Group for parents and carers of young people (aged 14-25) which meets monthly in Halifax. There are also specialist employment workshops available in Halifax run by Specialist Autism Services. Calderdale also has an Autism Strategy Group with a range of professionals and adults with ASC and carers. An annual event for World Autism Awareness week has been held for the last few years including information stalls and speakers with ASC.

In Kirklees there is a Specialist Social Worker who is able to offer a Social Care Pathway, which may include such things as development of care packages and support to access educational, social care and employment opportunities. There is also a comprehensive website detailing the support available for adults with autism, <http://www.kirklees.gov.uk/beta/health-and-well-being/autism.aspx>, which includes a video showing about coping strategies and including real life stories of adults with autism in Kirklees. It also includes a community directory of autism support organisations. Employment support is provided by the Richmond Fellowship and an Annual Autism Show has been held for the last four years, to inform people about the services on offer. Kirklees also has an Autism Partnership Board which includes representatives with ASC.

## Voluntary organisations

There are a few voluntary organisations and charities in Calderdale and Kirklees that support adults with ASC, including:

- The National Autistic Society Calderdale branch which provides support to people diagnosed with autism or on the waiting list awaiting diagnosis for autism, plus a number of different monthly activities, an active Facebook group and a monthly newsletter. This is a charity and relies on volunteers to run activities.
- Huddersfield Support Group for Autism, an autism support group run by families for families.
- Be Just You, a new support group for adults with autism in Kirklees, run by Autism Plus, a charity that supports adults and young people with autism, learning disabilities and mental health conditions across Yorkshire and Humber.
- Specialist Autism Services is a non-profit organisation which had a contract to deliver a supported employment programme in Calderdale for adults on the autism spectrum.

Not all adults with ASC are comfortable attending social groups, and some prefer groups that are more focussed around providing activities. There are specific gaps in the availability of support groups for adults with ASC, notably for those who work and want to access groups in the evening, although the Hebden Bridge Asperger's/ASC Peer Support Group, and the Partners Group and Parents Group are evening groups to try to address this. There is also a lack of support groups that are accessible for BAME adults with ASC, and an unclear picture of other reasons why adults with ASC from some communities might not be accessing available support.

## 3. Why have we focussed on this issue?

Since April 2016 Healthwatch Calderdale has been contacted by several people with concerns about the assessment, diagnosis and treatment of ASC in adults. In Kirklees, at the Autism Show in 2016, people spoke to Healthwatch Kirklees about the lack of support available to people with ASC and delays in diagnosis.

In addition, the Clinical Commissioning Groups in Calderdale and Kirklees are currently reviewing their Adult Autism diagnostic and treatment pathways, therefore it proved timely to conduct the survey into people's experiences at this point so that people's feedback could inform the process.

## 4. What did we do to investigate?

### Research methodology

- We reviewed the comments and complaints we had received prior to commencing our engagement work, and used this learning to influence the design of our survey
- We gathered feedback from adults with ASC and their parents, partners and carers via online and paper surveys (Appendices 2 & 3)
- We visited peer support groups and listened to their concerns
- We spoke to professionals about the services that are being provided
- We gathered 13 more detailed case studies, 12 from adults with ASC, and one from a carer. 3 of these are featured in the report, with others added as Appendix 1.

### The survey

A survey was designed and made available as an online and paper-based document. Healthwatch Calderdale staff could use this to get information about the experiences of adults with ASC based in Calderdale and Kirklees and their parents, partners and carers. It contained a mix of closed, multiple choice and open ended questions.

An introduction to the questionnaire survey set out its purpose and matters pertaining to confidentiality and how any findings would be used.

The survey for adults with autism asked about people's experiences around getting a referral, having an assessment, and receiving a diagnosis. We asked how ASC affected their lives, and where they got most of their support from. We then asked what support they would like in the future, and how they thought local services could be improved for people with ASC.

The survey for partners, parents and carers of adults with ASC also asked about the everyday challenges faced by people who live with or care for an adult with ASC, whether they had been offered a Carers Assessment to assess their needs, and what support they had received.

### Case Studies

A simple case study template was designed which gave respondents the opportunity to tell us three things:

- How their ASC affects their life?
- A personal story/experience about how their access to health or social care services has been affected by their ASC.
- What they would like the people who commission and deliver services for people with ASC to learn from their story

In some cases, the template was emailed to people for them to complete themselves, but in several cases Healthwatch Calderdale staff met with people and helped them to fill in the form.

## Community engagement

In March and April 2017 Healthwatch Calderdale visited the following groups in Calderdale and Kirklees to seek their views and to ask for their feedback via the survey and case study:

- Calderdale Asperger's Peer Support Groups:
  - Friday group (Halifax)
  - Evening group (Hebden Bridge)
  - Partners group (Sowerby Bridge)
- Calderdale National Autistic Society coffee morning (Halifax)
- World Autism Awareness Week event - Calderdale College
- No Limits Group - Kirklees (Huddersfield)
- PCAN group - Kirklees (Huddersfield)
- Be Just You group - Kirklees (Dewsbury)

The purpose of the survey was explained to the groups, and people were supported to complete a questionnaire and/or case study, or encouraged to complete them online if they were happier doing that.

Healthwatch had initially considered running focus groups to discuss people's issues, but this was not found to be effective as many of those attending did not want to speak up in a group setting, but were happy to fill in the survey on their own, or with support from a Healthwatch Calderdale representative, or via the internet in their own time.

The surveys were promoted via the Healthwatch Calderdale and Kirklees websites, and were included in Facebook and Twitter posts. Information was also shared with over 30 different community groups as well as with Calderdale and Kirklees Council and Clinical Commissioning Groups. Details were also circulated through a variety of online newsletters.

## Professional Feedback

Healthwatch Calderdale sought feedback from a number of professionals working with adults with ASC in Calderdale and Kirklees, in order to find out their understanding of the services on offer, and any issues they were aware of.

We met with Dawn Collins who is the Calderdale Council Carers Development Worker who facilitates the Calderdale Asperger's Peer Support Groups, Professor Marios Adamou who is a Consultant Psychiatrist in neurodevelopmental psychiatry (ADHD and ASD) with SWYT, Gary Wainwright who is the Joint Lead Officers for Autism with Kirklees Council, and Deborah Wortman who is a qualified psychotherapist/counsellor working with several adults with ASC and who also runs Aspire Autism Training. We also had email feedback from Dr Graham Hill, a Consultant Psychiatrist at SWYT.

## Accessing services is a postcode lottery

It was generally acknowledged that the services provided for adults with ASC in Calderdale and Kirklees could be improved, as currently a full diagnostic service is not commissioned, but provided on a case by case basis, and there is also no commissioned post diagnostic clinical support.

Some neighbouring areas commission a more comprehensive package, for example in Barnsley and Wakefield adults diagnosed with ASC are offered a health intervention pathway which includes a variety of different support from a multi-disciplinary team following the development of a person-centered care plan. Interventions could include social skills training, psychological intervention, occupational therapy and organisational skills, access to health care and speech and language input.

In Kirklees adults with ASC have no access to a health intervention pathway, but there is a Specialist Social Worker who is able to offer a Social Care Pathway which may include such things as development of care packages and support to access to educational, social care and employment opportunities.

In Calderdale adults with ASC have no access to a health intervention pathway or Specialist Social Worker support, therefore the main source of support has been via the peer support groups facilitated by the council, and since April 2016 via 'Preparing for Work' workshops provided on a weekly basis by Specialist Autism Services.

## Differences in diagnosis rates for ASC

Another issue that highlights discrepancies between the services available in different areas is that previously the Sheffield Adult Autism and Neurodevelopmental Services (SAANS) was commissioned to provide diagnoses, and had a rate of positive diagnosis for ASC of 90%.

Then following the Autism Act (2010) councils were required to develop a local diagnostic pathway, so the Service for Adults with Autism (SAA), based in Wakefield, was commissioned by SWYT, and following this the rate of positive ASC diagnosis fell to just 25%. It should be noted that the SAANS and SAA assessments use different formal diagnostic tools, but they both use ones recommended in the NICE Clinical Guideline 'Autism spectrum disorder in adults: diagnosis and management'.

### **Concerns about the criteria for diagnostic assessments**

One person felt that the SAA based in Wakefield might be taking too narrow a view of diagnosing ASC, and that they might need a broader basis for assessment to pick up adults who have learnt to adapt and to some extent mask the condition. For instance, when looking at school reports which state that there were no significant issues, it could be that they successfully blended into the background at school but then had a meltdown at home.

### **Long waiting times**

Another professional commented that *'The waits have been excessive and frustrating for both service users and professionals alike. As an example, I have a service user who has just started the assessment process, for whom the referral was received and funding in place, and who was placed on the waiting list on 2/5/14. This person's wait has been 33 months. This is typical for the people I referred at that time.'* It was however acknowledged that a new screening process which was implemented in April 2017 is likely to reduce the waiting times for assessments.

### **An example of good practice**

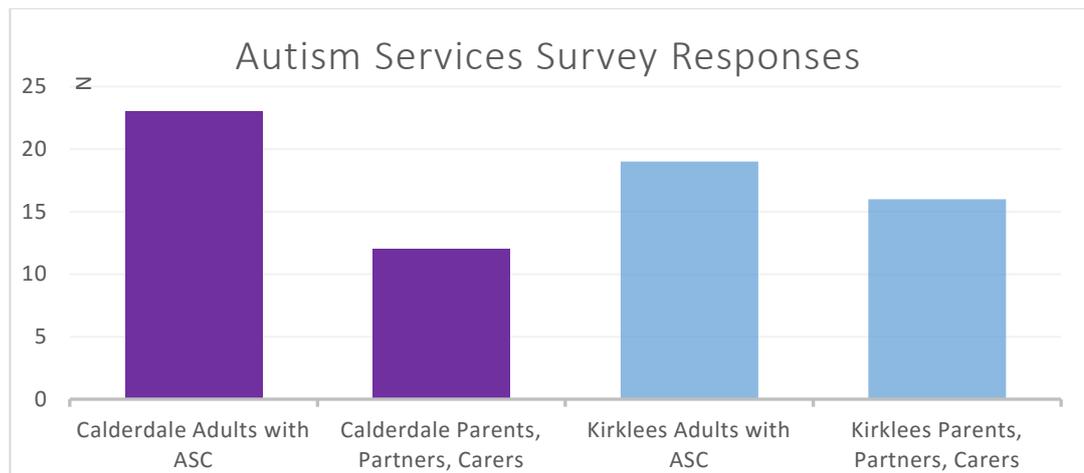
An example of good practice was flagged up, the Burnley Autism Resource Centre, run by Action for ASD. This is a free service for adults with Asperger's Syndrome or high functioning autism which has no waiting list, and is preventative as it supports adults with ASC with a range of support from one to one low level support, adult social groups, social events and drop in sessions, with the aim of reducing the need for social services intervention.

## 5. What people told us

### Who responded?

There were 70 responses to the survey.

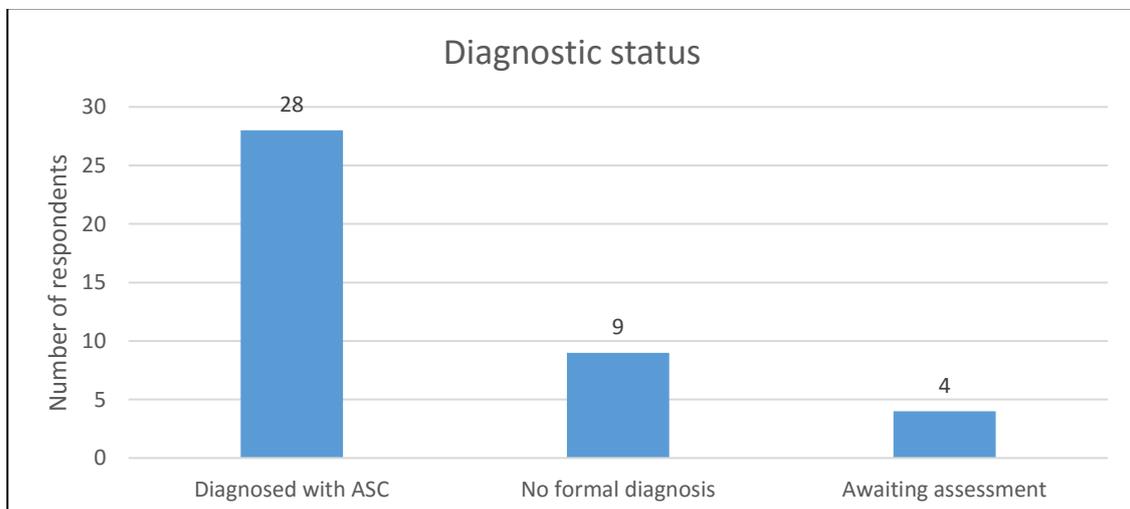
- Of the 42 adults with ASC who responded to the survey 23 were from Calderdale, and 19 were from Kirklees.
- Of the 28 parents, partners and carers for adults with ASC who responded to the survey 12 were from Calderdale, and 16 were from Kirklees.



### The adults with ASC

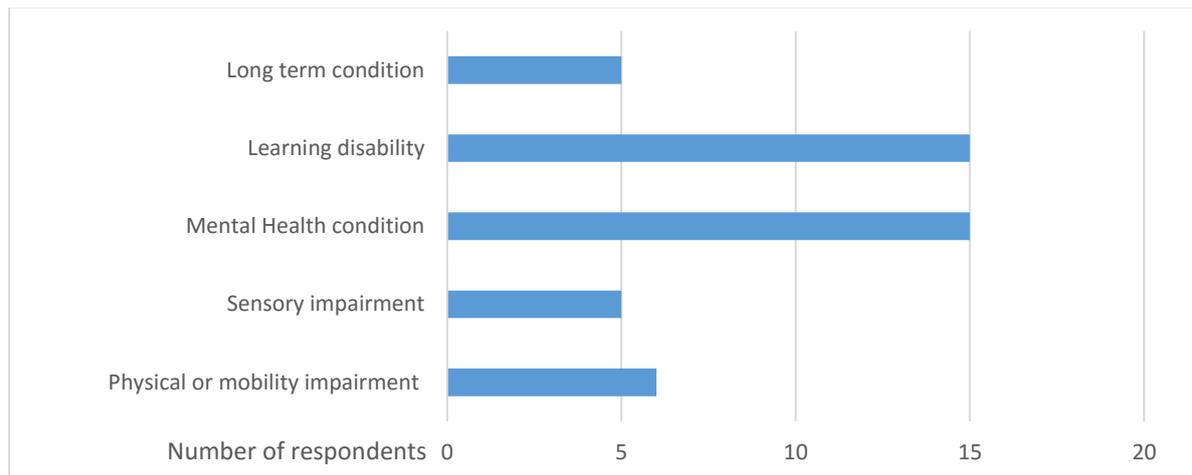
**Age & Gender:** The ages of the adults with ASC who responded ranged between 21 and 60, and were fairly equally male and female.

**Diagnosed or not:** We asked if respondents had an ASC diagnosis, were awaiting a diagnostic assessment, or had no formal diagnosis. Of the 42 respondents, the majority, 66%, had a formal diagnosis of ASC, 9% were awaiting a diagnostic assessment, and 21% did not have a formal assessment.



**Ethnicity:** The majority were white British, with one Pakistani and one Caribbean responder.

**Disability:** When asked if they considered themselves disabled 29 responded, with 23 saying they did consider themselves disabled, while six people did not. 24 people also gave an insight into the type of disability they live with:



In addition, there were a number of health conditions that adults with ASC and their parents, partners and carers mentioned in the survey responses and case studies. The following are some of the co-existing conditions that adults with ASC reported:

- Mental health conditions including attempted suicide, mental breakdown, low confidence and self-esteem, depression, psychosis, anxiety, paranoia, bipolar, eating disorders, and agoraphobia.
- Physical health conditions including fibromyalgia, diabetes, severe pancreatitis, degenerative disc disease, severe allergies, eczema, anaphylaxis, epilepsy, ADHD, pain and fatigue.

**Caring responsibilities:** When asked if they ‘look after or support a family member, friend or neighbour because of a long term physical disability, mental ill health or problems related to age’, 30 adults with ASC responded, with nine stating that they have caring responsibilities.

### The parents, partners and carers of adults with ASC

**Age & Gender:** The ages of the parents, partners and carers who responded ranged between 40 and 70 and they were predominantly female.

**Ethnicity:** The majority were white British, with one Indian and one Eastern European responder.

**Disability:** When asked if they considered themselves disabled, 16 parents, partners and carers responded, with four saying they did consider themselves disabled, while 12 people did not.

## How people's lives are affected by ASC

Adults with ASC all experience the condition differently, and this came across very clearly in the responses we received. Many really struggle to maintain a normal life with very little support, and at great cost to their health and wellbeing:

*'I have never had any help or support. I have a previous diagnosis of bipolar as well as ASC and ADHD. I find it amazing that I can manage at all, and be highly productive. I have worked since I was 12 years old, put myself through university, had four children and been married three times. I am a very productive member of society, and yet I struggle horribly on a daily basis and I am given no help.'*

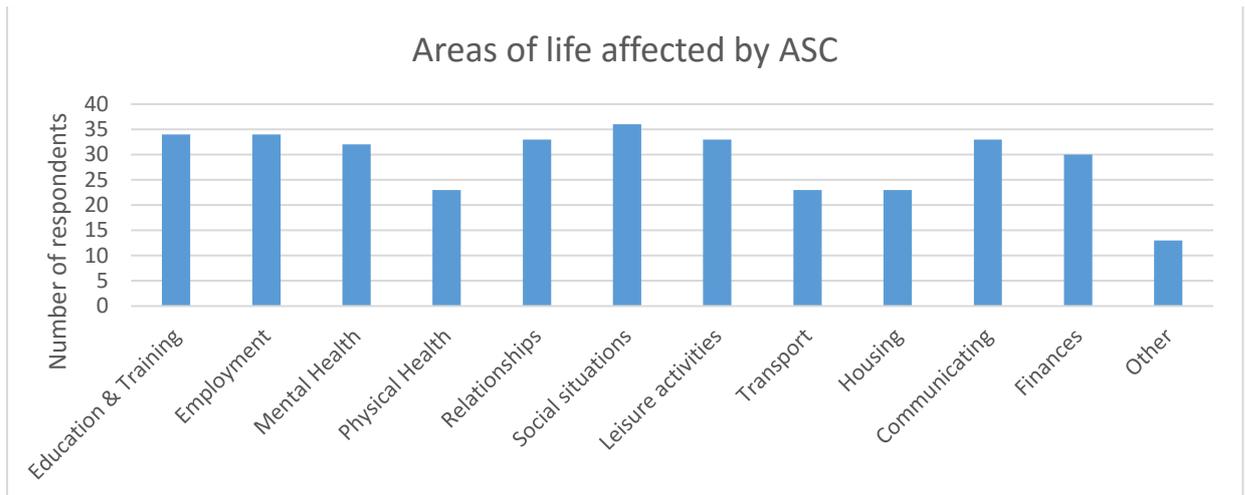
Some people find it very difficult to operate in the everyday world as ASC affects their senses in so many ways:

*'ASC means I see, feel, and sense the world differently. I have no solid I. I feel more like many particles than a solid body. I find it hard to know where I end and you begin. I find it hard to organise my experiences into clear stories and communicate these. I do not understand your facial expressions but I do feel them. Sounds hurt me. Colours have taste and words and letters have colours and each word you say has a tone and I hear that tone much louder than conceptual meaning of the word.'*

And one person, although acknowledging that ASC can be painful, wanted to highlight the pleasure that they got from some aspects of the condition:

*'I am keen to mention the enjoyment I get from aspects of my Autism, for example I really enjoy learning languages and reading fiction, to a degree that seems exceptional compared to mainstream people. I also love being alone which is a distinct advantage given that people who don't want to be alone are often forced to be. I mention this because I don't like the idea that Autism is something people suffer from. Of course, there are painful aspects.'*

To get a clearer picture of the challenges adults with ASC face, we asked for feedback on which areas of their lives were most affected. 37 adults with ASC responded:



- 36 people responded that their ASC affected **social situations** for them:

*'I struggle with going out as I get overwhelmed easily and have panic attacks, I like to know what I'm doing in advance, I don't use the phone unless I have too, I find work very stressful and difficult. I struggle in new situations and can't socialize much as it's very tiring.'*

*'Shopping is often impossible for me because of music played in shops. I also find restaurants too noisy now as well, and many many social situations are painfully difficult for me because I feel deeply hurt when I am left out.'*

- 34 people responded that their ASC affected their **education and training**:

*'University is so overwhelming because there are so many people that go around in large groups, I usually end up not attending because it exhausts me. When I do attend it takes me the same amount of time that I was in attendance the equivalent of quiet time for me to get over it.'*

*'Being an undergraduate has been extremely difficult. It has taken me 5 years to do an undergraduate degree because university puts so many barriers in my way. In effect I have been penalised financially because of my disability.'*

- 34 people responded that their ASC affected their ability to get **employment**:

*'I have been able to get jobs but I have either had to leave because my position has become untenable or I have been managed out. I'm struggling to get a job now because of competency based job applications and interviews. I can't cope with their ambiguity.'*

*'I struggle to get a job as I don't do well in an interview. I have low confidence so I struggle a little talking to people I've just met.'*

*'I struggle on a daily basis maintaining a very responsible job. People don't realise how affected I am. I am frequently close to losing everything given the severity of my anxiety.'*

- 33 people responded that their ASC affected their **physical health**:

*'Suffered chronic severe pancreatitis with diabetes. I have degenerative disc disease and recently undergone back surgery. I'm in pain all the time I can't explain to Drs without getting frustrated how I don't understand how my body won't work'*

- 33 people responded that their ASC affected **relationships**:

*'I am extremely anxious about being in new places or with unknown people and so because of my physical and verbal tics I am always trying to fit in and not very good at it.'*

*'I find it difficult to tell people that I am autistic as sometimes people do not know how to respond and treat me with kid gloves or patronise me.'*

- 33 people responded that their ASC affected their ability to take part in **leisure activities**:

*'There are some groups on but always during the day which is no good for young people at college or adults who may have a job. They also tend to be for people with learning disabilities and are often not suitable for people with autism.'*

- 33 people responded that their ASC affected **communication** for them:

*'I very often struggle with what to say and do, I take what people say literally, and participating in conversations can be difficult, even impossible for me, and transition is extremely difficult for me.'*

*'When trying to access specific services, e.g. council offices, doctor's surgeries, etc., it's the communication problem - myself not understanding what the professional is trying to say and convey, and vice versa me same issue... this often leads to a breakdown in communication, frustration on my part, and often being dismissed by the service or person in question.'*

*'I hate answering the phone, and going into new situations, I struggle with meetings with school and to be assertive. I find noisy environments overwhelming'*

- 32 people responded that their ASC affected their **mental health**:

*'My mental health is continually affected by social failure when I am out trying to be part of me local community. I often feel really bad and sometimes self-harm because of not being able to keep up socially or join in in activities I go to that I care about, even though people seem very nice but I still get left out and no one notices.'*

*'I suffer frequent bouts of anxiety and depression and I suffer suicidal ideation regularly. My confidence has suffered so much over the years that now I feel useless.'*

- 30 people responded that their ASC affected their **finances**:

*'Direct payments often don't work for autistic adults, it's all too much to organise and keep track of.'*

*'I am also unable to organise my own support even though I currently get DLA (and I'm terrified I might not qualify for PIP). My fears about benefit changes also drive my eating disorder and self-injury.'*

*'I am having problems with my benefits, I was on DLA then ESA but now I have to go to court due to not sending back a letter about PIP within 14 days. After I had a PIP assessment a letter came with the wrong information, e.g. that I went to college on my own. I only had 14 days to write back to them, but I sent it back late, so now I have to go to court'*

- 23 people responded that their ASC affected their ability to use public transport:

*'Public transport is exhausting. I have to arrive at work an hour early to recover from time on a crowded train. Most worryingly, my job is at risk because of excessive sick leave caused by exhaustion - I work in a call centre, which can be draining if I'm having a bad day.'*

*'I wouldn't be able to do a bus journey independently - I require a person with me for comfort reasons'*

- 23 people responded that their ASC affected their access to **appropriate housing**:

*'I also struggled to get enough sleep when living in a city because I could not screen out any noise however slight. Even now I can only live in a detached house as any noise from neighbours is very stressful.'*

- In addition, the high levels of **anxiety, fear and isolation** that people with ASC can have also featured in the comments:

*'I suffer from stress caused by not being able to tolerate inconsistencies with routine, this has left me very isolated.'*

*'I have no social life at all really. I struggle on a daily basis maintaining a very responsible job. People don't realise how affected I am. I am frequently close to losing everything given the severity of my anxiety.'*

*'I am very frightened about if I ever need to go to A&E because I don't know how to cope with going to Huddersfield and getting back and there is no one I can turn to for support.'*

## **Section summary**

It is clear that adults with ASC in Calderdale and Kirklees face a range of day to day problems related to their condition, and that this causes them some difficulties that people without ASC would be less likely to encounter.

The problems they face can include:

- Sensory issues, often to do with hypersensitivity to sound or touch, which can inhibit their ability to go out and interact with their local community or access services.
- A range of communication issues, including services not making reasonable adjustments when they are aware that people have ASC and have particular communication needs, such as needing to have information written down for them, or needing more time to take on information and respond to it.
- Finding social situations difficult which can lead to them struggling to get involved in work, education, and having a social life, as well as their ability to access welfare benefits.
- A lack of awareness within professionals and the public about ASC and how it can affect people, meaning that people don't understand unusual aspects of behaviour, such as not being able to wait in a noisy crowded waiting room or go on public transport due to sensory issues or difficulties coping with unpredictable situations.
- A sense of loneliness due to being isolated from their local community, as they can find groups of people difficult to cope with, leaving them feeling that they are not accepted and valued.
- Difficulties getting medical health professionals to understand them and take them seriously, which can make the referral and diagnosis process even more daunting.

It is apparent that many of these issues interlink; that a lack of awareness of ASC and an unwillingness from public and private sector organisations to make reasonable adjustments to enable people to with ASC to live fulfilling lives, often leaves adults with ASC in vulnerable and isolated situations.

These, and other difficulties that they face, leads to people with ASC facing barriers and inequality due to their disability. This can then have an impact on their health and mental wellbeing, and lead to long term and devastating impacts such as unemployment and debt, which in turn can lead to loss of confidence and self-esteem and damage their sense of self.

## Experiences of the ASC diagnostic and treatment pathway

### Seeking a Referral

Some people experienced difficulties when seeking a referral, either because their GPs were unsure of the process, or weren't happy to refer them for a diagnosis. Also because there is a sizeable waiting list, and high priority cases go to the top of the list, some people have ended up waiting for years before getting an assessment. Due to these extensive waits, sometimes the process for accessing a diagnosis of ASC changes, and it becomes unclear how the person should proceed.

If a referral is not forthcoming the advice is to regularly update the GP about any changes, especially if the problems associated with ASC get worse, as this could move the person up the waiting list.

*'Waiting for more than 3 years, been back multiple times to doctors as they keep changing how I am to proceed with getting my diagnosis.'*

*'I have recently approached two different GPs to ask about being referred for an assessment. They both brushed off my initial questions and didn't seem to take me seriously.'*

*'we asked time and time again for a diagnosis; the first from a psychologist in Calderdale who said no, she didn't have autism; the second, third and fourth times asking our GP who said no. So the experience was very difficult both times that we eventually had a diagnosis and very, very emotional. Although the result was what we had expected and hoped for, it was all very hard to cope with.'*

*'One of our clients, an older man, has been on the waiting list for an ASC/ADHD assessment for the past three years, and cannot be given any idea of how long he will have to wait as he is not a priority case.'*

*'I was advised this morning to harass my Dr to keep sending referrals, but I have the chance of being blacklisted or struck off.'*

Some people find the whole process of seeking a referral via the NHS too daunting or are put off by the long waiting lists before having an assessment. In some of these cases they can pay for a private clinical assessment which is a much quicker process. Our first case study, Ann's story, exemplifies this experience.



**Why did Ann feel she needed to pay for a private autism assessment instead of using the NHS?**

Ann believed she might have autism because she had struggled with some aspects of life for a long time. She wanted to understand why that was and what she could do about it. As the process to get a diagnosis via the NHS as an adult in Calderdale is complex, with a long waiting list, she decided to get a private assessment. Even though it cost her £500, having a diagnosis has given her peace of mind, and now she feels like she really knows who she is...

We use people's stories to highlight problems, and encourage the NHS to change and improve its services.  
Tell us your story today.

**healthwatch**  
Kirklees

**healthwatch**  
Calderdale

After Ann's son was diagnosed with autism she did an online Autism Spectrum Quotient test and was surprised by her high score. Ann did some more research and found out about the different ways to get a diagnosis, and the differing diagnosis rates depending on which area does the assessment. She also went to some of the autism peer support groups and talked to people about their experiences.

Ann's GP surgery had put everything down to anxiety, and as she had already been given a course of Cognitive Behaviour Therapy (CBT) and counselling, with no mention of autism, she didn't feel she could ask for a referral, and it didn't help that she was always being seen by different doctors.

Ann also found the thought of going through the NHS assessment process in her area very daunting. She would have had to get special funding via her GP using the Individual Funding Request process, and then if she was successful she would still have been a long wait before an assessment, with only a small chance of a positive diagnosis.

Because of this Ann decided to pay to have a private assessment. She only had to wait one month for the assessment, which consisted of completing two questionnaires and a three-hour appointment. It was a good experience as they made accommodations for her needs, and were easy to talk to.

Ann said 'If I had known I had autism when I was younger it could have made a big difference to my life. I never knew who I was, but now it all makes sense.'

Ann now feels very positive about her future as the diagnosis has made her feel more confident in herself. 'Now I know why CBT didn't work but I can now look at other things that might work, and I have already found ways to help me manage how autism affects my life.'

It cost Ann £500 to get her private diagnosis when she could have used the NHS, but the NHS process for getting an assessment for autism in Calderdale is complex and time consuming. How many other people could have been put off seeking a diagnosis and just given up?



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## Getting a Diagnostic Assessment

Only two people responded that they had had their assessments via the SWYT Autism Service, with seven people getting their diagnoses through the Sheffield Adult Autism and Neurodevelopmental Services (SAANS), and others via services in Bingley, Ossett, Manchester and Kendal.

When asked ‘How would you rate your experience of being diagnosed?’, people’s experiences ranged equally from very good to very poor, (24 respondents).

*‘The doctors gave a terrific service where diagnosis was conducted over a period of around 3 to 4 months to gain a clinical decision’*

*‘It was a very stress-free interview, and the diagnosis was very quick.’*

There were several positive comments related to diagnostic assessments, (particularly in Sheffield), especially where people found the service was quick and stress free, and felt they were being kept informed throughout the process.

*‘The diagnostic process involves a visit to Sheffield and a long interview for my husband, a discussion with me alone, and then a combined discussion. This meant that I felt included and understood more about what it meant for him to be on the spectrum.’*

*‘SAANS was an exceptionally good service and I would highly recommend it.’*

*‘After an initial diagnosis of Social Communication Disorder by SWYT Wakefield my son asked for a second opinion and was referred to Sheffield. The process there was much less stressful and patient friendly. They had no hesitation diagnosing him as having an Autistic Spectrum Disorder.’*

There was also a significant amount of negative feedback about long delays in getting a diagnosis.

*‘we have been waiting well over 3 years for him to be seen at Wakefield for a diagnosis and still no timescale for when our son will be assessed shocking wait’*

*‘Quite a slow process, over two years to get diagnosis. wasn’t really sure what was happening.’*

*‘Took years to get a diagnosis (around 7 years)’*

For some people the diagnosis provided a relief, but others were left stressed and confused by the process.

*‘It was a relief to be able to understand my son’s difficulties and to learn how to support and enable him in a more positive and constructive way. He was also keen to understand his difficulties.’*

*'After various rigorous assessments, a diagnosis confirmed what we suspected with a full explanatory report and recommended support at a £100 an hour for a total of 80 sessions, unfortunately we spent all our savings on an assessment in the place'*

The long waiting times that people experience sometimes can lead to difficulties with their studies and employment, as universities and businesses are unlikely to make reasonable adjustments without a clinical diagnosis. This can result in people failing courses, losing jobs, and getting into debt. It can also impact on their health and wellbeing if they are left to struggle with the effects of ASC without any support.

*'I waited over 12 months to get an appointment at Wakefield and they said I didn't have autism but Social Anxiety Disorder. I then had to fight for a second opinion which I was initially refused. I failed my 3rd year at Uni because they wouldn't provide support without an official diagnosis. I lost my job because they wouldn't make reasonable adjustments because I didn't have an official diagnosis'*

Our second case study comes from Sue who had an extended wait for her ASC diagnosis.

Zoom in (Ctrl+Plus)



## Why did Sue have to wait such a long time for her autism diagnosis?

Sue was aware that she had some autistic traits, and because she needed support with her university studies she wanted an official diagnosis. However, it took two and a half years and a second opinion before she got the correct diagnosis.

We use people's stories to highlight problems, and encourage the NHS to change and improve its services.  
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Kirklees

**healthwatch**  
Calderdale

Sue approached her GP to request a referral for a diagnosis of autism as she wanted some support while she did a university course. Funding was approved for her assessment but then she found out she would have to wait about 12 months for an appointment. She was extremely upset because she couldn't get the correct support at university or reasonable adjustments at work without an official diagnosis.

She was finally seen a year later, but was told that she did not meet the diagnostic criteria for autism, so she decided to ask for a second opinion. She was then told that funding for a second opinion would not be granted which made her feel very stressed and upset and resulted in her having to take time off sick from work.

Her GP then helped her to challenge the funding decision and she was awarded funding for a second opinion. She finally received an autism diagnosis in August 2016, but it had taken a full two and a half years to get. Having the autism diagnosis meant she could now access the correct support at university, but the long struggle to get it had caused her a great deal of psychological distress, loss of earnings and put her into debt.

If Sue could have been diagnosed sooner it would have saved her a great deal of stress and allowed her to get the support she was entitled to when she needed it. Relying upon getting a diagnosis to get support in your workplace or educational establishment often means that people with autism struggle for extended periods of time when there is support and adaptations available that would make working life more straightforward.



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## Post Diagnostic Support

Even when people have been given a diagnosis of ASC there is no post diagnostic medical treatment in Calderdale and Kirklees:

*'Received a letter explaining the diagnosis but not one to explain how they had come to that conclusion or indeed any further treatment/ follow up. So we got a diagnosis ... but there was no real help or assistance for us as a family'*

*'There should be something on offer post diagnosis, not just given the diagnosis and left to work it out yourself.'*

*'I didn't feel as I was offered anything in my area as a follow up. I felt as if I had been given a big label, 'ASC and ADHD' and then left high and dry.'*

## Transition to Adult Services

There were some comments relating to difficulties during transition to adult services which referenced a lack of support and a continuing struggle to get a diagnosis:

*'Help with the transition from children's services to adult services- in my experience support stopped in my teenage years at a time I needed it.'*

*'I was informed this morning after being messed around for 11 years and not been seen, to be told now he has just gone into adult services that's the waiting list is years, however if feathers are not ruffled or updates asked then he would be taken off the list'*

There are some common issues experienced by adults with ASC in Calderdale and Kirklees seeking a diagnosis or treatment, including:

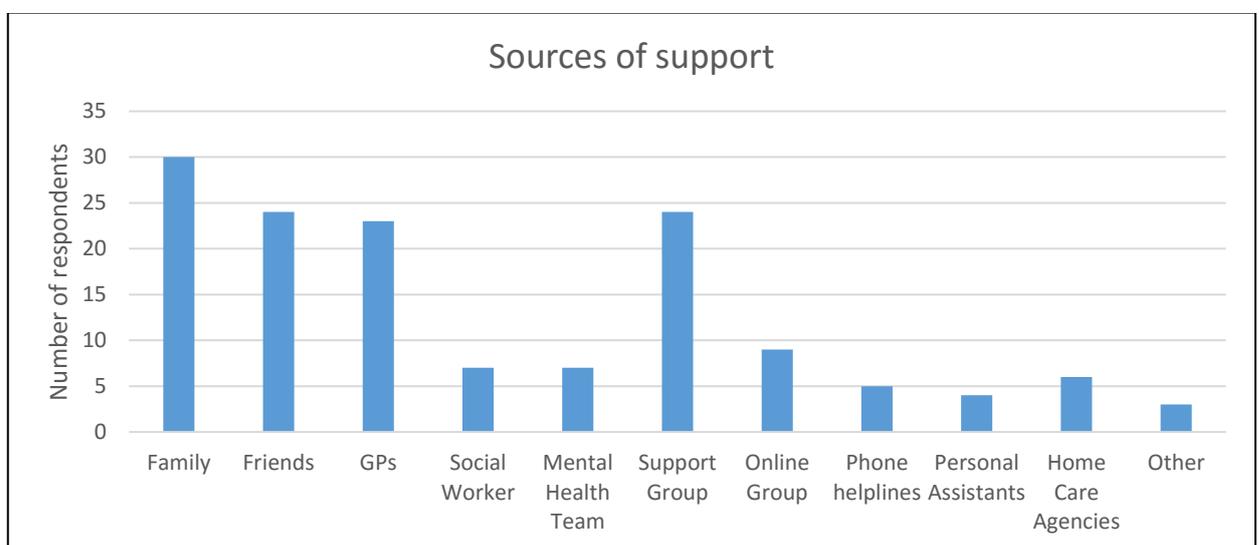
- Long waiting times - there were several instances of people waiting years for a diagnostic assessment. This can cause people major problems as while they are awaiting a referral or diagnosis there is no support for them and their condition may deteriorate while they are waiting, or they could be in danger of losing their job or failing in their studies.
- A lack of clarity about when people might be assessed - due to having a system where those considered to be in most need are prioritised to the top of the waiting list, some people stay low on the list and are not given any timeframe for when they might get an assessment. This is particularly difficult for people with ASC as they often struggle to cope with unpredictable situations.
- The lack of a consistent diagnostic threshold for diagnosing ASC across specialist services - This can cause situations where people can receive a diagnosis of ASC from one service and are then 'undiagnosed' by another, or where they are diagnosed as not having ASC by one service then get a second opinion from another service where they do receive an ASC diagnosis.

- A lack of post diagnostic clinical support in Calderdale and Kirklees - This can lead to people receiving support that is not appropriate, for example CBT that has not been adapted for people with ASC is unlikely to be effective.

## Accessing support for people with ASC

### Access to support

When we asked adults with ASC if they received enough support to help them manage the effects of their condition, out of the 35 respondents 27 of them were not happy with the level of support they were offered. We also asked for feedback about which people/groups/places give people the most help and support and 36 people responded:



While there were positive comments about some sources of day to day support:

*'I have low confidence and self-esteem and this can make me feel very unhappy and at times suicidal, my current support worker helps me realise that the world isn't always negative towards me and sometimes people are not getting at me but having a completely separate conversation not about me. Having him there stops me spiralling down into a negative frame of mind and it keeps me positive and accepting of my life, we also play pool and go running together and this is really helping me to feel better.'*

*'After an awkward beginning to my job my manager and colleagues now work with me with understanding. I have previously been fired from most jobs I have worked at.'*

*'I get a lot of support from my dog who helps me to assess social situations and to stay calm by stroking and relating to her. I get support from being in nature and at my allotment and from doing creative activities which calm me and help me communicate my inner world.'*

Unfortunately, some people really struggle to get support they need:

*'Sadly, I get more support from a pro ana online forum than anywhere else [pro ana means people who promote eating disorders as a lifestyle choice rather than an illness]. It is the only place I can get non-judgemental support, and be honest without risking losing my friends.'*

Some people got help from support and social workers, although there seems to be a lack of consistency in the services on offer, and a shortage of staff that are trained or experienced in working with adults with ASC:

*'Through our psychiatrist, we have received help from now our third support worker, who have all approached their job very differently. The care we received has mostly been positive but has ranged from counselling (or discussing problems) to being given introductions to other services. There does not seem to be a cohesive approach to this service.'*

*'Following his Social Care Assessment my son received very limited support. A Social worker with no experience of ASD was assigned but was not successful.'*

*'He does not have a Social Worker to advise him of the services and support that are available to him. Frankly he does not appear to be on anyone's "radar"'*

## **Accessing GP services**

Several people reported difficulties accessing GP services. Many of those difficulties linked to a lack of autism awareness and poor communication:

*'I would like more understanding from my doctor as they think I'm just anxious and don't take me seriously.'*

*'I am scared of the doctors now I live in Calderdale. They talk to me like I am a child on the whole and they are not informed or very curious.'*

*'I feel very intimidated and worried about going to the Dr's. I worry that the Dr will think I am exaggerating my symptoms, but actually I think I don't communicate my reasons for being there very well.'*

*'I also have a lot of difficulty with doctors whose English isn't good enough, as I am very quiet and semi-verbal when stressed and misunderstandings happen that I am unable to speak up to correct.'*

Other respondents stated that GP's did not understand their needs or make reasonable adjustments to enable them to access GP care:

*'My medical records say that I need home visits but GPs refuse to do this. The GPs also refuse to give me the meds I need to help me manage my fibromyalgia pain, and this has led me to meltdown.'*

*'I am not getting general treatment from my GP as I refuse to go - they don't treat me with respect, there is no female doctor, and the male doctors are really intolerant. I have a history of suicide attempts but only the female doctors have asked me about my mental health.'*

*'My GP surgery is pretty good because I can wait in a room on my own, but the queue at the reception desk can be impossible and still lead me to leave without being seen. I find book on the day appointments impossible because I need to know when I get up what my plan for the day is, and also I need to see a female doctor. The more stressed I am the less likely it is that I can say what I need to when I get to see a doctor.'*

## **Accessing Mental Health Services**

Some people felt that the mental health services were not set up to deal with people with ASC, and that they were not easy to access, especially in a crisis.

*'Most of the time we manage and manage well, but when things are difficult they go bad really quickly and if you ask for help it would be weeks before any is offered. We did ask for some mental health help at the time when she was struggling and she has 4 weeks ago and nearly 5 months after, been offered counselling.'*

There was also concern that the Community Mental Health Team (CMHT) are not supporting people with ASC:

*'My GP has referred me back to the CMHT for my mental health and eating issues, but they say my autism means I am not part of their remit any more, and I couldn't access eating disorder support because I'd need to travel'*

*'Since I lost my CMHT support I'm often having problems because I don't manage to make phone calls, and also I have no emotional support network and I know if I tell friends about mental health issues I lose them.'*

*'I live pretty much without support since the CMHT dropped me due to cost cutting and changing the criteria so autistic adults are no longer in their remit.'*

*'A community mental health nurse was appointed to help me in whatever way needed and we found her to be very helpful but she was transferred and I was then appointed a social worker based at a much further distance. This did not work so well'*

Adults with ASC appear to have the impression that mental health services are not available to you if you are living with ASC. Healthwatch have checked with Community Mental Health Teams to establish what this message should be. Mental health services are in place to help people with primary mental health issues; this means that if someone with autism is experiencing a mental health condition at a severity that meets their thresholds, the mental health services are still available. They do not offer services to support people with the impact or issues arising due to their ASC if ASC is their primary issue. There is a need for this explanation to be made clearer to adults with ASC who feel they cannot access mental health services anymore.

## Accessing autism specific support

The lack of accessible and appropriate autism specific support was highlighted by several people:

*'There is no autism specific support in Calderdale, and centralising services in general is making things really hard too. I need support at home or very nearby, not in Halifax and certainly not in Wakefield or Leeds.'*

*'I seriously need some autism specific support and therapy/counselling, but when I was offered 10 counselling sessions at Sheffield Asperger clinic the CCG turned down the funding, said I should do four psychology sessions there, which worked out more expensive! The clinic agreed with me that to do four sessions would just be cruel as I would barely have started and I'd be finished.'*

*'I also have a physical disability and have social care help to live independently, but my autism was never factored into the assessment and my staff have no formal knowledge of autism.'*

Several people commented that they struggled with the way services communicated with them, and were left feeling frustrated, dismissed or not taken seriously.

*'When trying to access specific services, e.g. council offices, doctor's surgeries, etc., it's the communication problem - myself not understanding what the professional is trying to say and convey, and vice versa me same issue... this often leads to a breakdown in communication, frustration on my part, and often being dismissed by the service or person in question.'*

In one case, an individual highlighted that their main source of support was family, and when that wasn't available for a short time, support services were not able to manage their care needs.

*'My mum is my main help and carer so when my mum went into hospital for an operation I had some help from the Carers Trust, but I only got two hours help a day and all I had to eat was crisps and pop and I didn't get out of the house at all.'*

## Section summary

It is clear that while there are some good examples of person centred support by ASC trained workers, there are a lot of gaps in the support for adults with ASC. This can affect them reaching their potential, completing their education, gaining employment, and having relationships, and could also lead to them developing mental health problems and becoming increasingly isolated.

- Adults with ASC sometimes struggle to negotiate many of the services and procedures that are part of everyday life, and without access to ASC trained support and social workers they can end up with difficulties managing their finances, housing, and relationships, as well as struggling with basic day to day issues like eating, sleeping and cleaning.
- Several people had problems accessing a range of health services, from GP practices that expect people to book appointments on the same day, or wait in

noisy waiting rooms, to GPs that refuse to make home visits or don't take people's concerns seriously.

- Several people also reported that they used to have support from the Community Mental Health Team, but that this was now not available to them.
- Some people found the peer support groups on offer helpful as a way of socialising and getting support and information, but other people were not able to access them because they were not accessible for them or because they were not comfortable in group situations.

## What would make things better

### In diagnosis?

There were suggestions for improving the referral process, including allowing self-referral and clearer guidelines. Several people felt that it is important to make it easier to get a diagnosis, with shorter waiting times and more local support available both pre and post diagnosis. There was also a specific mention of the difficulties adults can encounter in getting a diagnosis if they don't have parents able to verify childhood traits, and also that there needs to be more understanding of ASC traits in females.

*'We need services locally where people can self-refer for diagnosis, and it needs to be possible to get diagnosis without input from a parent or someone who knew you in childhood, as some people just don't have anyone who can do this'*

*'As soon as the panel award the right for a referral to the consultant the person and their parent/carer should be contacted and appropriate referrals for support put in. This could prevent a lot of deterioration before the first appointment which has been an 18months wait for us.'*

*'Diagnosis is a barrier and needs to be more accessible, as without one people cannot get support or ask for reasonable adjustments to be made.'*

*'Easier access to diagnostic services, locally, post-diagnostic support, ongoing support with mental health and practical issues, ongoing support to access local community.'*

*'I would like there to be clear guidelines about who refers children and adults for an assessment for ASD and for GP's to have more understanding about female traits.'*

### In supporting people with ASC?

There were several comments asking for better post diagnostic support, including social skills training, occupational therapy and organisational skills, as these interventions, which could help adults with ASC manage the day to day challenges they face, are not available in Calderdale and Kirklees.

*'I would like some occupational therapy to help with my tactile defensiveness and sensory overload and I would like some physical therapy to help me calm down and rest.'*

*'Occupational therapy addressing day to day organisation, planning and decision making. I get very 'stuck' in thought loops and find it hard to move forward practically.'*

Support for coexisting mental health conditions was requested, along with support to help peoples general wellbeing:

*'My mental health disorder leads me to suffer pain and I have benefitted in the past from acupuncture, for the pain, stress relief and digestive disorders.'*

*'I would like support to allow/help me learn to relax more as I often get wound up by the situations at work and can't wind down and relax easily.'*

*'Eating disorder support and Autism specific counselling or autism specific psychotherapy - within walking distance. Someone I can contact by email or text any time when things get stressful or something practical needs organising sooner rather than later'*

Support with everyday living also featured, with requests for more support from Community Psychiatric Nurses and Personal Assistants:

*'I don't need a huge amount of support, but I do need help to get and keep my flat clean, keep on top of phone calls, look after my mental health needs, get out and about a bit and do new things, and to keep an eye on my eating disorder.'*

*'CPN and support worker at home - CPN to help with mental health issues, support worker to help with getting out more and practical stuff like phone calls and accessing my local community'*

*'I need a personal assistant access to leisure facilities, because I am overweight cause by binge eating when I'm stressed and swimming is a good stress reliever but I don't have the resources to go.'*

The need for consistent support from people that adults with ASC and their families are familiar with was also a key feature in the comments, along with the accessible advocacy services:

*'I need support from people I can see regularly and feel comfortable with - my CPN doesn't provide help for me but makes me feel comfortable.'*

*'ADVOCACY services that can be accessed without making phone calls. Advocate who understand that an autistic person can appear very verbally competent but still have severe difficulties and vulnerability. Recognition that even the most able autistic adults are likely to be socially isolated and it isn't wrong to need a professional just to talk to about day to day stuff - it can be vital to mental health.'*

*'I am too scared to ring and ask for help because when I do people ask a thousand questions and it's like I have to get diagnosed or prove I need help all over again. The only support I get I have to go through a very stressful experience to get which is filling out forms and there is no help to do this.'*

There also needs to be support for families to enable them to continue to deliver the incredibly valuable contribution that they make to ensuring a person with ASC has the care they need.

*'We would like to be taught intervention techniques as a whole family so we can collectively help our son and thus having a better chance in the community and be more acceptable and also manage his emotions better.'*

*'There should be post diagnosis therapies of some sort, behaviour management courses for groups of parents, information about support groups that aren't just for autistic kids, there are quite a few around, and some sort of crisis care that isn't only accessible when your child is either in A and E or a police cell. A child on the verge of being expelled from college or losing an apprenticeship or job is a child in crisis and their life will be much worse if they lose that place.'*

A wider range of accessible support and social groups and activities for adults with ASC was also requested:

*'More accessible groups - now the support group is at Laura Mitchell, not library - not friendly, brings back bad memories, lots of locked doors.'*

*'We also think that there should be some organised Social Groups for young adults with ASC, as there has been nothing since he turned 18 years of age.'*

*'The swimming pool should have autism friendly sessions because I'm limited to when I can go because I can't cope with too many people.'*

### **Increased autism awareness**

The need for autism trained social workers and support workers to help adults with ASC manage their lives better, and also support their families was highlighted:

*'I am unable to organise my own support and also very worried by the idea of being supported by unqualified people with no useful experience of autism, mental health issues and fatigue and pain in the same person.'*

*'A named care coordinator is necessary, who knows and has a lot of experience around autism and autism related mental health issues, and complex needs services for people who have combinations of autism spectrum conditions, mental health issues and physical disability needs.'*

*'When someone does understand autism it makes a huge difference. I once had a support worker who was dyslexic and her experience of life was near enough*

*to some of mine that she was a great bridge in helping to explain the reality of my autism needs to other people*

The need for awareness raising and better training for professionals was also highlighted, along with the necessity for making reasonable adjustments and making processes more autism friendly:

*'Perhaps spreading the word among professionals and lay people, so that they understand people with autism - who I know are all different so this is not easy. This would be especially helpful if we got away from the Rain Man/ IT expert/male brain lazy definition of autism and tried to get people to understand that females present differently and therefore don't necessarily fit what the recognised 'symptoms' are.'*

*'ASC makes it hard to articulate what you need, and if a GP is dismissive and jumps to conclusions that makes it even more difficult. Possibly slightly longer appointments for people with ASC would help, as well as more awareness, as it helps to know people understand.'*

*'There needs to be better awareness raising and training about ASC as the current training is very limited, and unless people have direct experience of people with autism they don't know what needs doing.'*

*'Community workers need to have an understanding of ASC so that they understand how people become excluded'*

*'Try to understand the difficulties in communication. I have often been told I am being aggressive and forceful. It's more frustration at not understanding. Repeat if asked, and be patient.'*

Support to access employment, and to help to raise the awareness of employers about ASC was suggested:

*'He would benefit from help to access a full time job, as his current jobs are very "bitty" and do not have long-term prospects or fully utilise his capabilities as a university graduate.'*

*'Support in educating my employers in how my condition affects me and what they can do to help.'*

People also wanted DWP to have a better understanding of the issues faced by people with ASC:

*'Support to help me convince people like the DWP that telling me to go and get a job is not at all useful, without the help they don't seem to be able to provide, because they're not capable and/or willing to deal with people with mental health issues, and they don't even attempt to understand us.'*

*'I have just been awarded 0 points in an application for PIP because I was unable to communicate my everyday difficulties. The main challenge is that because I am intelligent and I don't look Autistic, no one believes that I have Autism or that I have difficulties.'*

## Safe spaces for adults with ASC

Several people wanted places where adults with ASC could go to and feel safe:

*'They need more safe zones for people with ASC to go when they are feeling down.'*

*'I would like a space where I can go and ask for help with practical things like phone calls. I would like someone not to treat me like I am stupid or pathetic for needing help. I would like a quiet place where I can go and sit and be with other autistic people and people without loud coffee machines and screaming.'*

*'Quiet, affordable and accessible housing for people with sensory issues, where pets are allowed.'*

## Section summary

Both adults with ASC and their parents, partners and carers came up with a number of ideas that would make things better for people with ASC in Calderdale and Kirklees.

- Key to these was improving the diagnostic pathway, reducing waiting times, and a more transparent process with better communication so that people know what is happening to them.
- Several people also wanted the option of an out of area diagnosis at a clinical setting they had researched and felt confident about using.
- A range of post diagnostic clinical support was also asked for, to help people deal with the challenges ASC creates for them, and help them achieve their potential, have better health and wellbeing, and have the chance to become part of their local community.
- Better support for people with ASC and coexisting mental health conditions was important to a number of people, with requests including more CPNs as well as autism adapted counselling.
- Personal assistants, and ASC trained support workers and advocates to help people deal with day to day living also featured, with the need for consistent and reliable support from people they know and trust being very important.
- More awareness raising and training about ASC should be provided for professionals and front line workers, so that they understand how it can affect people, and the reasonable accommodations that should be made to help them.

## Feedback from parents, partners and carers

Most of the feedback from parents, partners and carers has been incorporated into the main body of the report, but there were two areas where we asked about their specific experiences.

## Everyday challenges

We asked parents, partners and carers to tell us a bit about the everyday challenges they face as someone who lives with or cares for an adult with ASC.

The support which parents, partners and carers give to people with ASC is wide ranging and can cause them a great deal of stress as there appears to be very little support for the them:

*'Broken sleep. Chaotic behaviour. Poor personal care. Disastrous finances. Major depression. Concerns about potential suicide. Self-medicating with cannabis. No help from GP. Having to work full time and deal with all this causes me massive stress and misery. I have nowhere to turn.'*

*'I need to support my son with the following; He needs time and patience in verbal communication- life is too busy and he gets left behind in this. Time keeping. Needing reminders of upcoming events or appointments. Clear written instructions for daily household tasks. Prompting to carry out necessary phone calls (i.e. to doctors, dentists, applying for universal credit, jobs etc.) Emotional wellbeing - affected by isolation/ self-isolation/ difficulties with emotional literacy Difficulties in everyday speech communication'*

*'The help she requires never stops. Although she can get about (she drives) she is totally dependent on me emotionally and also financially dependent although she does have a part time job. She needs constant help with time keeping, making arrangements to do things, support to get her to work, support for her day to day care, emotional support when things go wrong, practical support to help... Although she is a lovely person with a great sense of humour she finds life very difficult and this reflects on my day to day care.'*

## **Carers Assessments**

Many carers are entitled to have their needs as a carer assessed by social services and support put in place to meet their eligible needs.

When we asked parent's, partners and carers if they had had a Carers Assessment only two out of the 14 people who responded had had one:

*'My son has had a diagnosis since he was 6 and he's 18 and only just found out about this'*

*'I have spoken to someone who was supposed to help me as a carer. She visited once or twice; referred me for a grant and then met me at a 'holiday home' locally for breaks for people who are carers for me to see if it would suit. (It didn't but it was nice to be told about it.) And then I haven't heard from this service for months.'*

The need for support for families to help them deal with the stresses and strains of caring for adults with ASC was highlighted:

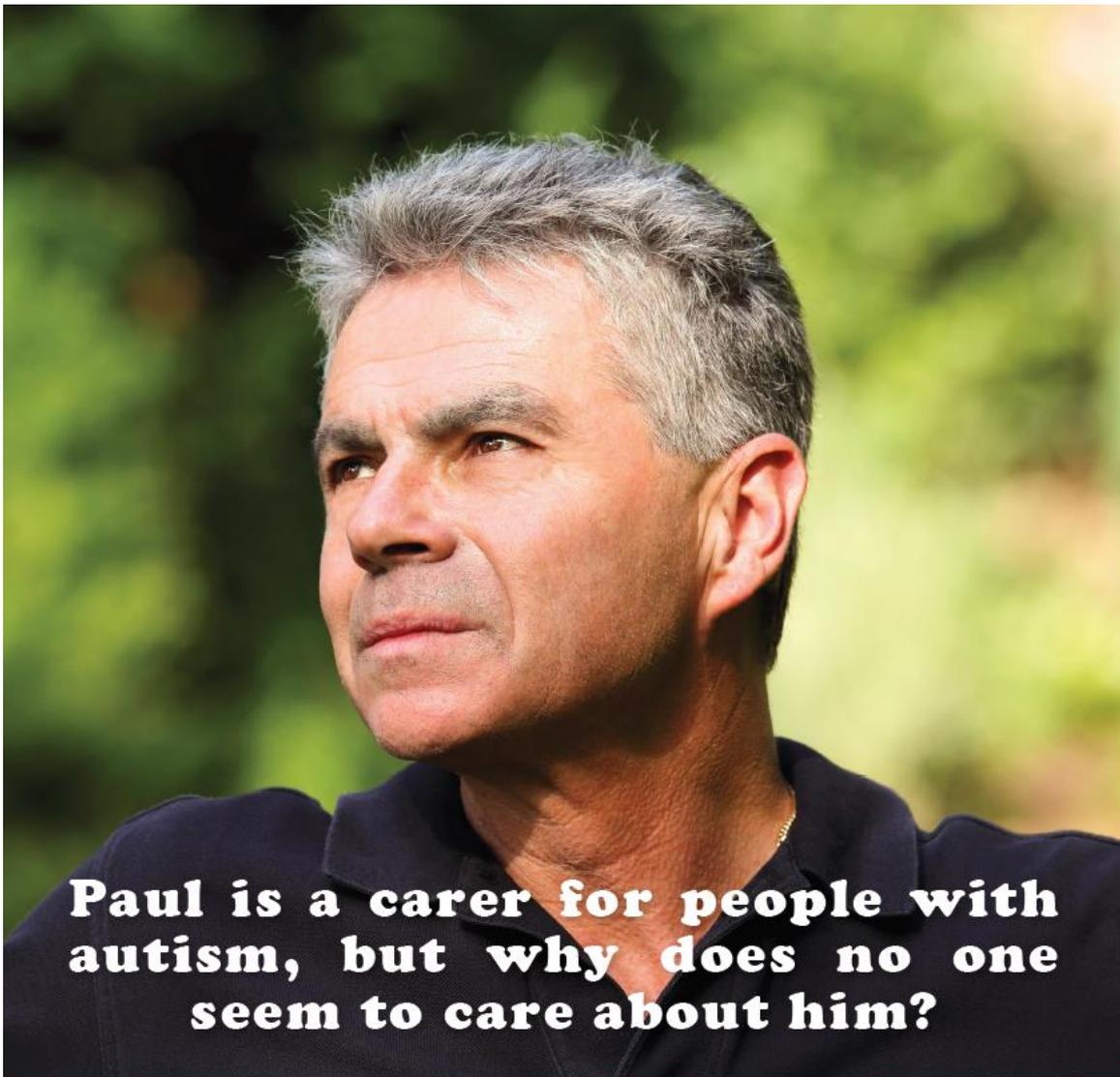
*'Start looking for people who are providing care for people on the ASC spectrum, as due to the needs they are dealing with they have a great deal of stress which can affect their health. It isn't just individuals with ASC that need support, their families do too.'*

## Section summary

It was important to get the views of the people who live with and care for adults with ASC, as they are the people who know them best, and who are there for them day in and day out. There were a few common themes that emerged from their feedback:

- In some cases, adults with ASC are being cared for by elderly parents or carers. As well as being a carer they may have age related health and financial issues to deal with themselves.
- Caring for someone with ASC can be very stressful and isolating, and carers would benefit from more support and understanding themselves.
- Very few of the carers who responded had been offered a Carers Assessment, so it would be unlikely that social services would be aware of any additional needs they might have due to their caring responsibilities.

Our final case study is Paul's story of his experiences as a carer.



**Paul is a carer for people with autism, but why does no one seem to care about him?**

Paul cares for several people with autism, which involves daily support with decision making, managing money, childcare, transport, advocacy, mediating with employers, relationship counselling, and liaison with support agencies. For Paul, who is a pensioner, this means a very stressful life, but why is there no support for him?

We use people's stories to highlight problems, and encourage the NHS to change and improve its services. Tell us your story today.



Paul supports several people who have either diagnosed and undiagnosed autism, and has found that caring for people with autism is a full time job and very tiring. Because of this he has a very stressful lifestyle and is not always able to make the best decisions for his own health.

Paul does not feel supported as a carer, as although he has filled in two Carers Assessments the support he gives to people does not seem fit the criteria for carers support in Kirklees.

Having people close at hand that you know and trust can make a massive difference for people with autism. Do current carers' assessments value this highly enough, do they ask questions that identify how intensive being this type of carer can be, and can better help be made available to carers of autistic adults?

To stop carers like Paul from becoming overburdened by caring responsibilities, Paul thinks services could:

- Start looking for people who are providing care for people on the autism spectrum, as they may be under a great deal of stress which could affect their own health and wellbeing.
- Improve training and awareness raising about autism for health and social care professionals at all levels so that they understand the needs of people with autism and those of their carers.
- Reduce the stigma and barriers encountered by people with autism so they do not miss out on the support they need and risk of being excluded from society.
- Improve access to diagnostic services for people with suspected autism, as without a diagnosis people cannot get support they need or ask for reasonable adjustments to be made.
- Make getting support via the Carers Assessment easier and more accessible

If Paul was better supported, he could look after his own health and wellbeing more effectively, and be better able to support the people he cares for.



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## 6. Our conclusions

### **Autism - a spectrum condition**

The majority of the adults with ASC who responded to this engagement would be seen as having high functioning autism or Asperger Syndrome. This can mean that they can appear to be competently communicating and managing with their ASC issues. They are doing their best to live life as normally as possible, but often due to the challenges their condition imposes on them this is very difficult and can cause them and their families a great deal of stress and unhappiness, and make it very difficult for them to achieve their potential. In some cases, the people we spoke to could be studying, going to work, or raising a family, but instead are struggling every day to maintain a façade of normality, and may live on the verge of failing their course, losing their job or damaging their relationships due to their condition. They need appropriate support in place, along with reasonable adjustments for their condition, to be able to maximise their potential and to thrive.

### **ASC - an invisible disability**

The disabilities of adults with ASC are largely invisible, and because of this they might not get the support and understanding that they need. When resources are under threat it can seem counter intuitive to offer support to people who appear to be just about managing, but lack of support could result in them needing inpatient treatment, becoming unemployed, homeless, dependent on welfare benefits, involved with the criminal justice system, in danger of premature mortality, or even attempting suicide. The 2016 'Personal Tragedies, Public Crisis' report from the UK charity Autistica found that autistic adults with no intellectual disability die an average of 12 years earlier than the typical population, driven in large part by suicide.

### **Access to diagnostic services in Calderdale and Kirklees**

In Calderdale and Kirklees there are a number of difficulties for adults seeking to access diagnostic services. The diagnostic pathway is not easy for people to access as they have to apply on an individual basis to the CCG using an Individual Funding Request for funding for the assessment. There is then a long wait for an undetermined time before people receive a clinical assessment from the commissioned provider which has around a 25% positive diagnosis rate for ASC.

The long wait teamed with a relatively low likelihood of getting an ASC diagnosis can lead to a lot of uncertainty and leave people waiting for a diagnosis without the support they may need during that time. If they are one of the 75% of people that do not receive an ASC diagnosis they may go on to seek a second opinion from another provider that has a significantly higher ASC diagnosis rate, but to do this they have to go through the process again.

If the outcome of the assessment is that the individual is not on the autistic spectrum, this has no impact on the symptoms or issues that the person is facing. Although they may not be deemed to be autistic, they are still struggling, and there are significant shortfalls in support for those individuals.

Without a diagnosis of ASC, it is often difficult for employers or higher education establishments to put additional support in place that would help someone to work or learn to their full capacity, especially if this involves additional financial and resource investment. This can create barriers that mean individuals who are struggling in the

workplace or learning environment due to communication difficulties or problems with being organisation, who could be helped to succeed, often don't get what they need.

### **Access to post diagnostic clinical support in Calderdale and Kirklees**

There is currently no post diagnostic clinical pathway so that even if a diagnosis of ASC is received, there is no commissioned ongoing clinical support. In some other areas there is access to evidence based support such as social skills training, occupational therapy and organisational skills which is specifically adapted for the needs of adults with ASC, but there is no such support available in Calderdale and Kirklees. This begs the question, of the value of getting an ASC diagnosis in Calderdale and Kirklees if the appropriate services and support are then not available.

### **Access to support for coexisting mental health conditions**

In the 'The Autism Dividend' report, (London School of Economics and Political Science, 2017), it states that 80% of autistic people, at some point in their lives, have mental health problems such as anxiety and depression, and the majority of those people rate their anxiety as the number one problem in their lives. In Calderdale and Kirklees there is a recognised gap in services for adults with ASC and coexisting mental health conditions. Mental health services need to make reasonable adjustments to the support they provide so that people with autism can receive a good service, but the feedback we received suggests that people are struggling to get appropriate mental health support with their co-existing conditions. Several people acknowledged that they had received support from the Community Mental Health Team in the past and that it had been very beneficial, but that this support was now not available to them, due to their autism. We believe that the message about what is available has been poorly communicated to these people.

### **Awareness, training and reasonable adjustments**

There is a need for much greater awareness of ASC and the different effects it can have on people, especially by professionals and frontline workers, not just in the medical sphere, but also in social services, housing, transport, employment and the benefit systems. There is a legal obligation under the Equality Act 2010 to put reasonable adjustments in place which would help to avoid discrimination against people with ASC and to reduce the barriers they face in accessing services and support, but without the awareness and understanding of the condition these are unlikely to be put in place.

GPs in particular, need to have much better awareness about the condition as they are the gatekeepers to the diagnostic process. To this end the resources that the Royal College of General Practitioners has produced, since they identified ASC as a clinical priority in 2016, can be useful as it includes information and a toolkit for GPs and practice staff, as well as patients, carers and commissioners:

<http://www.rcgp.org.uk/clinical-and-research/toolkits/asd-toolkit.aspx>

### **Support for Carers**

The contribution and needs of carers supporting individuals, and sometimes families with more than one member with ASC, needs to be recognised. Without them the extra burden on the health and social care system could be overwhelming, but the burden on carers who could themselves have medical conditions or have difficulties

due to old age, can be very hard to bear. The needs of carers should be assessed so that they can be offered appropriate support, but it was clear from the survey respondents those carers were not routinely offered a Carers Assessment, so may slip through the net. This may cause particular problems for carers who are getting older and struggling without support. A diagnosis of any form of autism should act as a trigger to offer a Carers Assessment to all those supporting the diagnosed individual, so there need to be systems in place to ensure that social services are notified about all ASC diagnoses and offer Carers Assessments to everyone involved in their care.

### **What people have said is most useful**

The people that were of most support to adults with ASC in Calderdale and Kirklees were their family and friends, support groups and GPs. Advocacy is also an effective way to support people, as it is a reasonable adjustment that enables people to more fully participate in decisions about their care and treatment as well as manage their day to day lives, but this is another area where there is a gap for adults with ASC in Calderdale and Kirklees.

### **Prescriptive definition of support**

The adults with ASC in this study have been able to clearly articulate the types of support that they need; often, the support they ask for is to assist them whilst they do something for themselves, and to help them put building blocks in place that help them to achieve something, e.g. access to occupational therapy to help them order and arrange their life, implementation of reasonable adjustments, and availability of advocacy. The impression they get is that, because they need facilitative support rather than practical support, they are ineligible for assistance, or this kind of assistance is not available.

Just because their needs aren't those that are currently catered for in mental health services, and through adult social care, doesn't mean that those needs aren't significant or valid. There is a need to think more creatively about how adults with ASC could be supported.

## **7. What should happen now?**

Healthwatch Calderdale and Healthwatch Kirklees appreciate that there are many challenges facing local providers and commissioners that mean that developments regarding diagnosis and support for ASC will be complex. Below, we have listed a set of recommendations that reflect the feedback we have received from the adults with ASC and their carers. We ask that full consideration be given to these recommendations and that some indication be given as to what work is being done or will be done that goes towards meeting these.

We recommend that consideration be given to:

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.

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
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.
4. How GP practices could be made more ASC friendly, including use of the Royal College of GP's new toolkit of resources.
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. *Healthwatch Calderdale has been in contact with the National Autistic Society and SWYT to discuss this already, and there is ongoing work taking place.*
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.
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.
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.
9. Improving intelligence gathering in order to provide a local picture of autism, including the number of adults with ASC diagnoses in Calderdale and Kirklees, 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
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.

In response to the recommendations, Healthwatch Calderdale and Healthwatch Kirklees ask that plans be shared with us regarding how the recommendations relevant to the organisations are being or will be addressed.

We would then like to meet with the organisations involved to assess any progress made 12 months after the publication of this report.

## 8. Limitations and assumptions of this study

- The sample size for the survey was relatively small, although there were similar issues expressed by several respondents. While the survey was promoted to over 30 groups in Calderdale and Kirklees, it is likely that there are a large number of adults with ASC that are not involved with any groups due to the constraints of their condition, and who might not have heard about the survey.
- The majority of the respondents to the survey were White British, but this might not necessarily reflect lower levels of ASC in the minority ethnic population, rather it could be due to there being fewer support groups that are accessible to BAME adults with ASC in Calderdale and Kirklees.
- Representation in the survey may have been limited by the ability to access the online survey. To counteract this Healthwatch Calderdale visited ASC support groups to give people the opportunity to be supported to complete the forms on a one to one basis, and completed the survey over the phone for some people who were unable to attend the groups.
- The respondents identifying as adults with ASC had in some cases confirmed clinical diagnoses while others did not. The assumption is made that all people identifying as having ASC do indeed have the condition.

## 9. Acknowledgements

We would like to thank the professionals and groups listed below for the information and support they have provided with this piece engagement work:

- Dawn Collins, Calderdale Council Carers Development Worker
- Professor Marios Adamou, Consultant Psychiatrist, SWYT,
- Gary Wainwright, Joint Lead Officer for Autism, Kirklees Council, and
- Deborah Wortman, psychotherapist/counsellor, Aspire Autism Training.
- Dr Graham Hill, Consultant Psychiatrist, SWYT
- Calderdale Asperger's Group
- Calderdale National Autistic Society
- Calderdale College
- No Limits Group - Kirklees
- PCAN group - Kirklees
- Be Just You group - Kirklees

## 10. References

- ‘Autism spectrum disorder in adults: diagnosis and management’, NICE (Last updated 2016)
- ‘Autistic Spectrum Disorders Toolkit’ Royal College of General Practitioners (2016)
- ‘Personal Tragedies, Public Crisis’, Autistica (2016)
- ‘The Autism Dividend: reaping the rewards of better investment’, National Autistic Project, LEMMI Valentina, KNAPP Martin, RAGAN Ian (2016)

## 11. Appendices

### Appendix 1 - Additional case studies



## **Why is John left without support after being given a diagnosis of autism?**

Diagnosis is often thought to be the key to accessing the services you need, but after being diagnosed with autism John found that there was no post-diagnostic clinical support available in his area. He has been left feeling like he is going round in circles, as the services he contacts for support keep passing him on without giving him the help he is seeking. This has affected his ability to lead a fulfilling life, and led to the breakdown of his marriage and the loss of his job.

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Kirklees

**healthwatch**  
Calderdale

Four years ago John was diagnosed with autism but he has continued to struggle with the condition as there is no treatment available in his area. This has had an impact on his mental health, as well as on his relationships, job and studies.

For a short time he had an interim social worker, but then he was signposted to Adult Social Care who told him that they are not responsible for his outstanding clinical needs, and then his local NHS Foundation Trust told him that they are not getting funding to support his clinical needs.

John feels that no one seems to be taking responsibility for providing support, 'I am constantly being told what people can't do for me, and that services are being cut, and that there is no money for services'.

He feels undermined and misunderstood when he tries to explain or complain about the difficulties he is having, 'I am appalled at how little Autism Awareness there is in the statutory services - they need to have awareness, knowledge and training about autism and to make reasonable adjustments when communicating with people they know are on the spectrum'.

John says it would help him and other people with autism if there was:

- Greater coordination between health and social care services;
- Improved training for professionals about autism;
- Increased understanding about how to make reasonable adjustments;
- Post diagnostic support available locally where he needs it;

All John wants is to lead a normal life and achieve his potential, but since his diagnosis four years ago he feels he has been stuck in the gaps in the system with no consistent support or care.



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**Please turn the noise down, it hurts!**

Clare has autism and is extreme sensitive to sound, so she finds the noise at her GP surgery unbearable, and she has the same problem at the local swimming pool. But when she asks for the music to be turned down she is met with scepticism and resentment by the staff.

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Kirklees

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Calderdale

Clare has autism, and when she visits her local GPs surgery for her own or her children's appointments she finds the sound of the music playing on the radio in the reception area unbearable, so she cannot wait in the surgery without feeling stressed and punished by the noise.

When she asks if the music can be turned down the staff are unwilling to do this as they say it helps with patient confidentiality. Clare wishes they could understand that it takes a great deal of courage to ask for noise to be turned down and if they agree to do it, they should not show resentment.

Clare said 'They should understand how stressful noise is for some people. The difficulty for people with hyper-sensitivity to noise is that the effect on them is not visible, or measurable. However, we feel as distressed as if listening to a fire alarm or gunfire.'

Noise sensitivity affects a lot of people, including people with autism and dementia. It would be better for some people if we took it seriously and just kept the noise down, especially when people let us know it is a problem for them.

It is just one of the easy adjustments we can make to help people with autism feel accepted and more comfortable in the outside world.



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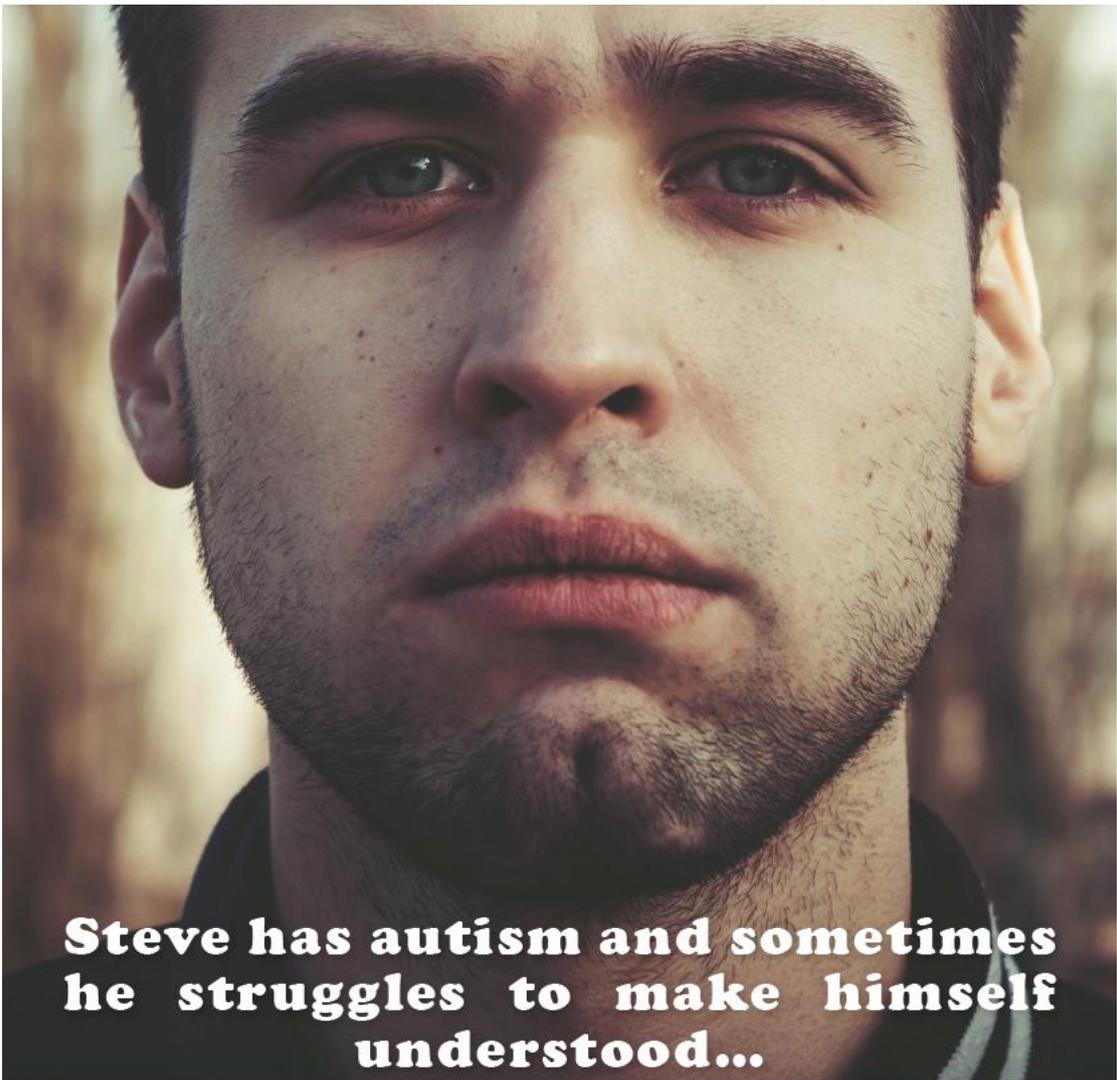


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**Steve has autism and sometimes he struggles to make himself understood...**

Steve has autism and it can make communicating with other people really difficult. Sometimes people like his GP don't understand this which can make Steve feel very frustrated. He would like people to make allowances for his condition and not write him off.

We use people's stories to highlight problems, and encourage the NHS to change and improve its services. Tell us your story today.



Steve has autism and it impacts on every aspect of his daily life, from sensory issues to communication difficulties. When he tries to access services at the council offices or at his doctor's surgery, it is difficulties with communication that cause him problems. Sometimes he doesn't understand what the professionals are trying to say to him, or they don't understand what he is trying to get across to them.

Due to his autism Steve finds that non-verbal gestures, body language, facial expressions, and tone of voice are all difficult to understand and interpret, and this can lead to serious breakdowns in communication. This can make him feel very frustrated, and lead to him being dismissed by the very services who might have been able to offer him support.

Steve would like people to understand a few simple things that would help them to be able to communicate better with him:

- Try to understand the difficulties in communication some people with autism can have. Steve has often been told he is being aggressive but it is more to do with frustration at not understanding or being understood.
- Try to speak to people or organisations who know and understand him to learn about how his autism affects him.
- No eye contact does not mean non-compliant, and wearing a hoodie and hat does not mean aggression.
- Please repeat if he asks you to, and be patient.

By being more understanding, and giving Steve a bit more time to communicate, his trips to the GP and council offices could be a lot less stressful and help him to get the support he needs.



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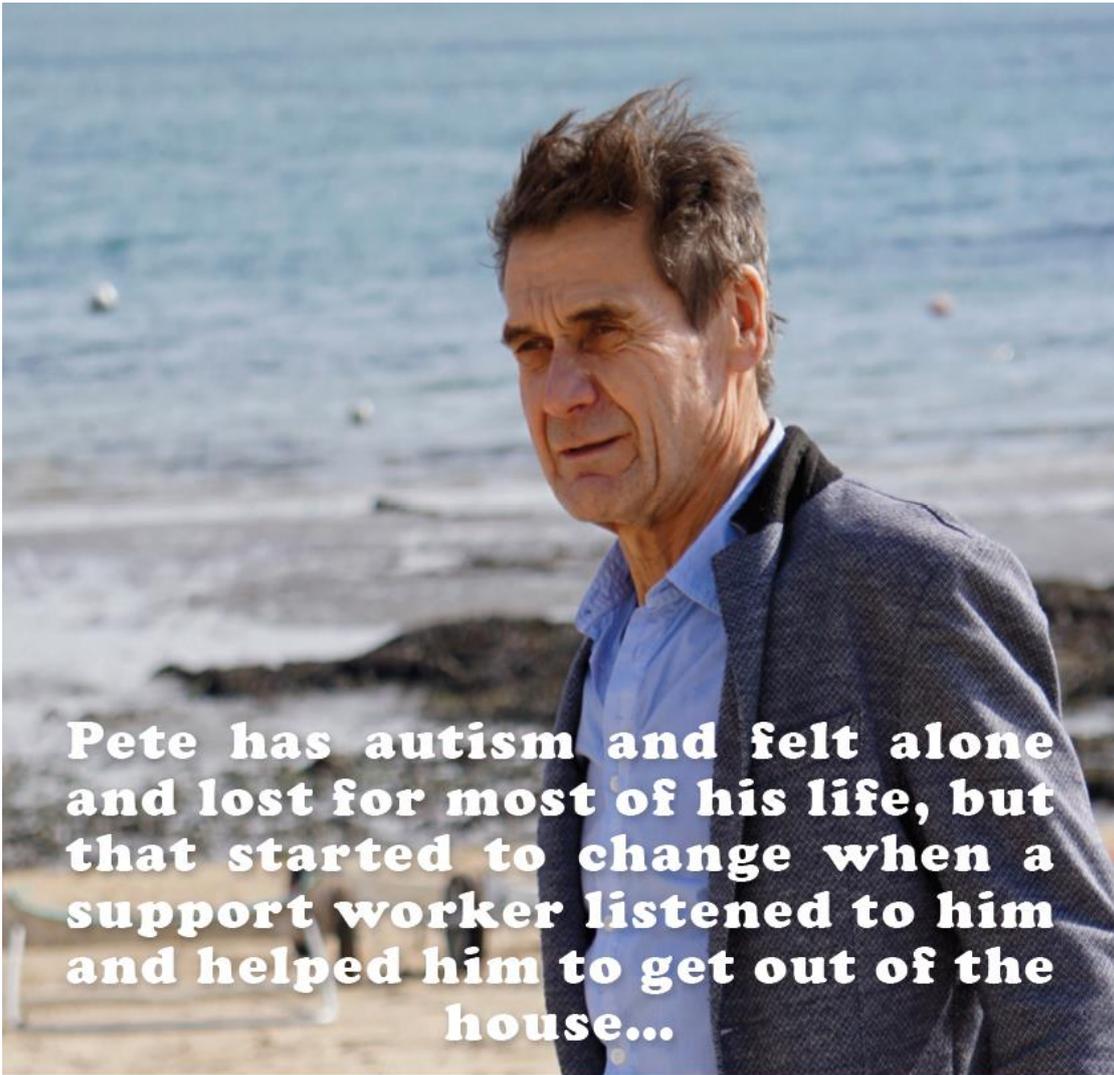


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**Pete has autism and felt alone and lost for most of his life, but that started to change when a support worker listened to him and helped him to get out of the house...**

Pete is anxious, worries a lot and is sensitive to noise. He didn't like going out as he feels intimidated by people. He has started to get his confidence back since he has begun to get help from a social care organisation that has adapted the support he gets to his specific needs and is giving him the right opportunities to help him come out of his shell.

We use people's stories to highlight problems, and encourage the NHS to change and improve its services. Tell us your story today.

**healthwatch**  
Kirklees

**healthwatch**  
Calderdale

Pete has autism, and because of this he struggles to make friends and does not like social situations. He wasn't really aware of the effect his autism had on him until he left school at 16. He then spent over five years at home in his room, unable to build up the confidence to leave the house.

Now Pete gets 8 hours a week social care support which gives him the opportunity to go for walks and doing a little work in places where he feels safe. As well as getting some exercise, and having the chance for some social time to talk to his carer, he is earning some money and is starting to develop relationships with more people.

Pete is lucky, the social care company that supports him has listened carefully to what he wants and has designed an individually tailored support plan which is helping him to be more independent, develop skills and reach his goals and aspirations.

'Staff encouraged me to leave the house to gain some fresh air and exercise. I live on a busy street and from 10am-midnight all the shops are open and the street is always full of people, so my support worker suggested we set off at 6am and go to an area he knew was quiet and had a good path, or we go to the track to have a run as I used to be very good at athletics at school. I then do work experience in an office where I have started to develop a relationship with some of the staff which helps my social skills. I like to hear I have done a good job and I like the reward I receive for my work, this gives me purpose and means I now can realistically afford the things I want to buy. I look forward to seeing the people in the office as this is my only social contact outside my family. I am currently working on being able to go to the shop myself but I am not ready for this at the moment.'

Pete felt alone and lost for a large part of his life, but now that he is getting support that has been adapted to his needs he is starting to come out of his shell.



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## Appendix 2 - Adult Autism Services Survey

### Adult Autism Services in Calderdale and Kirklees

Thank you for taking part in this survey.

Healthwatch Calderdale would like to know more about your experiences of being an adult with an Autism Spectrum Condition (ASC) in Calderdale and Kirklees, and the support you get from health, social care and community services. We want to find out what works well and what doesn't work so well.

We also want to hear from the parents, carers, and partners of adults with ASC. We have created a separate survey for parents, carers and partners which you can complete at this link: [Adult Autism Carers Survey](#) - We would like feedback on:

- Your experience of getting a diagnosis, or trying to get one
- The support you get from health, social care or community services
- How easy it is to access the services you need to help you live the life you want

Don't worry if you don't have feedback about all of those things, we would like to hear your feedback on any of these areas, so you can fill in as many or as few questions as you would like to on this survey.

If you have any questions about this survey or if you need any support to complete it, please do not hesitate to give Healthwatch Calderdale a call on 01422 399433, or email [info@healthwatchcalderdale.co.uk](mailto:info@healthwatchcalderdale.co.uk).

Please note that any views you share will remain confidential, and no personal identifiable information will be shared when reporting on the findings of the engagement.

The deadline for completing this survey is Tuesday 25th April 2017.

1. Which area do you live in?

- Calderdale
- Kirklees
- Other (please say)

2. Which of these statements best describes you?

- I have been diagnosed with an autism spectrum condition
- I have an autism spectrum condition but no formal diagnosis
- I have had a referral to the Autism Service and am waiting for an assessment
- I am the parent/carer of an adult with a diagnosed autism spectrum condition, and I am completing this survey on their behalf.
- I am the parent/carer of an adult with an autism spectrum condition but no formal diagnosis, and I am completing this survey on their behalf.
- I am the parent/carer of an adult with an autism spectrum condition who has a referral to the Autism Service and is waiting for an assessment, and I am completing this survey on their behalf.
- None of the above

### Gathering your views

This survey is gathering the opinions of people with autism spectrum conditions and their carers. As you have selected "None of the above" for the previous question, the remaining survey questions would not be applicable to you.

We are still interested in your views on services for adults with autism spectrum conditions in Calderdale. Please feel free to share your views below.

#### 3. Which of these statements best describes you?

- A professional working with adults with autism spectrum conditions
- A volunteer working with adults with autism spectrum conditions
- Someone interested in autism spectrum conditions
- Other (please specify)

#### 4. Please tell us your thoughts about adult autism services in Calderdale and/or Kirklees.

### Waiting for an assessment and diagnosis

#### 5. Please rate your experience of waiting for an assessment and diagnosis of ASC.

Was it:

- Very good
- Good
- Acceptable
- Poor
- Very Poor
- Please explain your rating:

### Your experience of diagnosis and assessment

**We would like to know about your experiences of referral, assessment or diagnosis by South West Yorkshire NHS Partnership Foundation Trust (SWYT) Autism Service, also known as the Service for Adults with Autism Spectrum Disorder, based in Wakefield.**

6. Were you diagnosed through the SWYT Autism Service?

- Yes
- No
- I don't know

7. If no, please tell us where you were diagnosed.

8. How would you rate your experience of being diagnosed?

- Very good
- Good
- Acceptable
- Poor
- Very poor

Please explain your rating:

## Adult Autism Services in Calderdale and Kirklees

### Social Care Assessment

9. Following your diagnosis, have you had a Social Care Assessment?

- Yes
- No
- I don't know

I don't know (please specify)

10. Please tell us about any support you received following the Social Care Assessment e.g. practical assistance in your home, help with paperwork such as bills and letters, access to recreational facilities such as day centres and drop in clubs, assistance with travelling, supported living or residential care.

Please give details:

11. Please rate the support you received:

- Very Good
- Good
- Acceptable
- Poor
- Very Poor
- Please explain the reason for your rating:

Please tell us how having an autism spectrum condition (ASC) affects your life:

12. To what extent are these areas of your life are affected by your ASC?

	A lot	A little	Not at all	Not sure
Education & training	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Employment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Mental Health	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Physical Health	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Relationships	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Social situations	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Leisure activities	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Transport	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Housing	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Communicating	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Finances	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Other (please specify)

13. Please tell us a bit more about the everyday challenges you face because of your ASC, e.g. shopping, going to the doctor, dealing with phone calls, etc.

14. To what extent do you get help and support from these people/groups/places?

	A lot	A little	Not at all	Not sure
Family	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Friends	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Doctor	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Social worker	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Mental Health Team	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Support group	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Online group	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Telephone helplines	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Personal Assistant	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Home Care Agency	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Other (please specify)

15. Do you think you get enough support to help you manage the effects of your ASC?

- Yes
- No
- Not sure

16. If you would like more support, please tell us what kind of support that would be.

17. What do you think could be done to improve services and support for adults with ASC in your area?

18. We would like to collect some real life stories to show how Autism Spectrum Conditions affect people's lives.

We have a short template you could use to write down your story yourself, please contact Jo Budgen at Healthwatch Calderdale (details below) to get a copy, or if you would prefer us to help you to write it please let us know so that we can arrange to do this.

Jo Budgen, Healthwatch Calderdale, Elsie Whiteley Innovation Centre, Hopwood Lane, Halifax, HX1 5ER Tel: 01422 399433

Email: [jo.budgen@healthwatchcalderdale.co.uk](mailto:jo.budgen@healthwatchcalderdale.co.uk)

Any part of the case studies that we use will be anonymised, with identifying personal data removed to ensure your confidentiality.

The deadline for collecting peoples personal stories is Tuesday 25th April 2017.

If you would prefer it if we got in touch with you please enter your contact details in box below:

## Adult Autism Services in Calderdale and Kirklees

### Equality monitoring

**It's really important to Healthwatch Calderdale and Healthwatch Kirklees that we ask as broad a range of people as possible for their views . To make sure that we do this, we ask people to give us some information about themselves, and we review this regularly to check we are not discriminating against any group of people by not asking for their views.**

**If you can, please take the time to give us this information.**

19. What is the first part of your postcode? e.g. HD1, WF10, BD4, LS13, HX6

If you would prefer not to say, please leave the box blank

20. What sex are you?

Male

Female

Prefer not to say

21. How old are you? e.g. 42

If you would prefer not to say, please leave the box blank

22. Which country were you born in?

If you would prefer not to say, please leave the box blank

23. Do you belong to any religion?

Buddhism

Christianity

Hinduism

Islam

Judaism

Sikhism

No religion

Prefer not to say

Other (please specify)

24. What is your ethnic group?

- Asian or Asian British: Indian
- Asian or Asian British: Pakistani
- Asian or Asian British: Bangladeshi
- Asian or Asian British: Chinese
- Black or Black British: Caribbean
- Black or Black British: African
- Mixed or multiple ethnic groups: White and Black Caribbean
- Mixed or multiple ethnic groups: White and Black African
- Mixed or multiple ethnic groups: White and Asian
- White: English, Welsh, Scottish, Northern Irish, British
- White: Irish
- White: Gypsy or Irish Traveller
- Other ethnic groups: Arab
- Prefer not to say
- Any other ethnic group

25. Do you consider yourself to be disabled?

- Yes
  No
  Prefer not to say

26. Types of impairment:

If you selected yes to the question above, please tick all that apply

- Physical or mobility impairment (such as using a wheelchair to get around and / or difficulty using your arms)
- Sensory impairment (such as being blind / having a serious visual impairment or being deaf / having a serious hearing impairment)
- Mental health condition (such as depression or schizophrenia)
- Learning disability (such as Downs syndrome or dyslexia) or cognitive impairment (such as autism or head-injury)
- Long term condition (such as cancer, HIV, diabetes, chronic heart disease, or epilepsy)
- Prefer not to say

27. Are you a carer?

Do you look after, or give any help or support to a family member, friend or neighbour because of a long term physical disability, mental ill-health or problems related to age?

Yes  No  Prefer not to say

28. Are you pregnant?

Yes  No  Prefer not to say

29. Have you given birth in the last 6 months?

Yes  No  Prefer not to say

30. What is your sexual orientation?

- Bisexual (both sexes)
- Gay (same sex)
- Heterosexual/straight (opposite sex)
- Lesbian (same sex)
- Other
- Prefer not to say

31. Are you transgender?

Is your gender identity different to the sex you were assumed at birth?

Yes  No  Prefer not to say

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Again, thank you for taking the time to complete this survey today.

Healthwatch Calderdale is pulling together all the feedback that people have shared with Healthwatch across Calderdale and Kirklees. Please note that any views you share will remain confidential, and no personal identifiable information will be shared when reporting on the findings of the engagement.

If you would like to know more about the results of this survey or if you want more information about what will happen to your feedback please contact us [info@healthwatchcalderdale.co.uk](mailto:info@healthwatchcalderdale.co.uk)

## Appendix 3 - Adult Autism Services, Parents Partners and Carers Survey

### Adult Autism Services in Calderdale and Kirklees - survey for parents, partners and carers

Thank you for taking part in this survey.

Healthwatch Calderdale would like to know more about your experiences of being a parent, partner or carer for an adult with an Autism Spectrum Condition (ASC) in Calderdale and Kirklees. We would like to find out about the issues you face and the support you get, including what works well and what doesn't.

We also want to hear from adults with ASC, so we have created a separate survey for them which can be accessed via this link: [Adult Autism Survey](#)

We would like feedback on:

- Your experience of supporting an adult with ASC in Calderdale and Kirklees.
- The support you get from health, social care or community services as a parent, partner or carer of an adult with ASC.
- Any ideas you might have that could improve the services and support for adults with ASC and their parents, partners and carers.

Don't worry if you don't have feedback about all of those things, we would like to hear your feedback on any of these areas, so you can fill in as many or as few questions as you would like to on this survey.

If you have any questions about this survey or if you need any support to complete it, please do not hesitate to give Healthwatch

Calderdale a call on 01422 399433, or email [info@healthwatchcalderdale.co.uk](mailto:info@healthwatchcalderdale.co.uk)

Please note that any views you share will remain confidential, and no personal identifiable information will be shared when reporting on the findings of the engagement.

The deadline for completing this survey is Tuesday 25th April 2017.

#### 1. Which area do you live in?

- Calderdale
- Kirklees
- Other (please say)

#### 2. Which of these statements best describes you?

- I am the parent/partner/carer of an adult with a diagnosed autism spectrum condition
- I am the parent//partner/carer of an adult with an autism spectrum condition but no formal diagnosis
- I am the parent/partner/carer of an adult with an autism spectrum condition who has a referral to the Autism Service and is waiting for an assessment

## Adult Autism Services in Calderdale and Kirklees - survey for parents, partners and carers

### Waiting for an assessment and diagnosis

3. Please rate the experience of waiting for an assessment and diagnosis for an adult with ASC.

Was it :

- Very good
- Good
- Acceptable
- Poor
- Very poor

Please explain your rating:

### The experience of diagnosis and assessment for adults with ASC

**We would like to know about the experiences of assessment or diagnosis by South West Yorkshire NHS Partnership Foundation Trust (SWYT) Autism Service, also known as the Service for Adults with Autism Spectrum Disorder, based in Wakefield.**

4. Did your partner/relative receive their ASC diagnosis through the SWYT Autism Service?

- Yes
- No
- I don't know

5. If no, please tell us where he/she was diagnosed.

6. How would you rate their experience of being diagnosed?

- Very good
- Good
- Acceptable
- Poor
- Very poor

Please explain your rating.

### Social Care Assessment

7. Following their diagnosis, have they had a Social Care Assessment?

- Yes
- No
- I don't know

I don't know (please specify)

### Support following Social Care Assessment

8. Please tell us if they have received any support following their Social Care Assessment, e.g. practical assistance around the home, help with paperwork such as bills and letters, access to recreational facilities such as day centres and drop in clubs, assistance with travelling, access to supported living or residential care.

Please give details:

9. Please rate the support they received:

- Very good
- Good
- Acceptable
- Poor
- Very poor

Please explain the reason for your rating:

### Have you been offered or requested a Carers Assessment?

10. Many carers are entitled to have their needs assessed by social services and support put in place to meet eligible needs. Have you had a Carers Assessment to assess your needs as a carer?

- Yes
- No
- I don't know

I don't know (please specify)

### Support for Carers

11. Were you found to be eligible for support following the Carers Assessment?

- Yes
- No

## Support offered to Carers

12. What support were you offered?

13. How would you rate the support you were offered?

- Very good
- Good
- Acceptable
- Poor
- Very poor

Please explain your rating:

## Tell us about your experience of supporting an adult with ASC

14. Please tell us a bit about the everyday challenges you face as someone who lives with or cares for an adult with ASC.

15. If you would like more support to help deal with these challenges please tell us what kind of support that would be.

16. What do you think could be done to improve services and support for adults with ASC and the people who care for them in your area?

### Equality monitoring

**It's really important to Healthwatch Calderdale and Healthwatch Kirklees that we ask a diverse group of people for their views about these initiatives. To make sure that we do this, we ask people to give us some information about themselves, and we review this regularly to check we are not discriminating against any group of people by not asking for their views.**

**If you can, please take the time to give us this information.**

17. What is the first part of your postcode? e.g. HD1, WF10, BD4, LS13, HX6

If you would prefer not to say, please leave the box blank

18. What sex are you?

Male

Female

Prefer not to say

19. How old are you? e.g. 42

If you would prefer not to say, please leave the box blank

20. Which country were you born in?

If you would prefer not to say, please leave the box blank

21. Do you belong to any religion?



24. Types of impairment:

If you selected yes to the question above, please tick all that apply

- Physical or mobility impairment (such as using a wheelchair to get around and / or difficulty using your arms)
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- Long term condition (such as cancer, HIV, diabetes, chronic heart disease, or epilepsy)
- Prefer not to say

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Do you look after, or give any help or support to a family member, friend or neighbour because of a long term physical disability, mental ill-health or problems related to age?

- Yes
  No
  Prefer not to say

26. Are you pregnant?

- Yes  No
- Prefer not to say

27. Have you given birth in the last 6 months?

- Yes  No
- Prefer not to say

28. What is your sexual orientation?

- Bisexual (both sexes)
- Gay (same sex)
- Heterosexual/straight (opposite sex)
- Lesbian (same sex)
- Other
- Prefer not to say

29. Are you transgender?

Is your gender identity different to the sex you were assumed at birth?

Yes

No

Prefer not to say

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