

Services for Adults with Autism Spectrum Conditions in Kirklees

Kirklees Summary Report -
Health Services Feedback



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Contents

1. Executive summary	2
2. Kirklees Adult Autism Service - the current picture	2
3. Why have we focussed on this issue?	3
4. What did we do to investigate?	3
5. What did people tell us, responses to the online survey	4
6. Our conclusions	10
7. Our recommendations	11
8. Appendices	12
○ 1 - Kirklees Case Studies	
○ 2 - Adult Autism Services Survey	
○ 3 - Adult Autism Services, Parents Partners and Carers Survey	

1. Executive Summary

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

We met with three ASC support groups, and received 19 completed surveys from adults with ASC, and 16 from the parents, partners, or carers of adults with ASC, all based in Kirklees.

The key concerns raised included:

- The lack of GP awareness and understanding about autism
- Difficulties getting GPs to refer the person with ASC for assessment
- Long waiting times for assessments and diagnosis
- The lack of clinical support post diagnosis
- Mental health services that don't appear to understand autism
- GPs having a poor understanding about female ASC traits
- There was positive feedback regarding some examples of support from community psychiatric nurses (CPNs) and care workers

These are some of the things people felt would improve their experience:

- Easier access to diagnostic services and shorter waiting times
- Better education and awareness about ASC for GPs, practice staff and the public
- Access to a Social Worker specialising in ASC with the right skills and understanding
- Support from people they know and can trust
- Autism friendly places and safe zones
- Crisis support when it is needed not weeks later
- Long term autism support as it is a lifelong developmental condition
- A range or menu of options for people with ASC to choose from
- Accessible and varied peer support groups and courses for people with ASC

2. Kirklees Adult Autism Service - the current picture

Adults with ASC in Kirklees who want a diagnosis can get a referral to the South West Yorkshire Partnership NHS Foundation Trust Autism Spectrum Disorder (ASD) Service via their GP, a consultant, or another Trust service. They then have to get special funding via the Individual Funding Request (IFR) process, before being allocated to a Provider for assessment.

In Kirklees there is no commissioned treatment pathway for ASC, but following a diagnosis of ASC there is a clear social care pathway, with support available from the

Richmond Fellowship service, where employment advisors focus on an individual's strengths and aspirations, and from Autism Plus who run social groups to help tackle isolation. New diagnostic and care plans are currently being developed but have not been agreed yet by the CCG and Local Authority.

The Kirklees Autism Improvement Plan is in the process of being updated, and there is also a Kirklees Autism Partnership Board includes members with ASC, although they are still looking for other adults with autism to join the board.

There has been an Annual Autism Show held in Kirklees for the last four years, with 50 organisations that offer services and support for children, young people and adults with autism, their parents and professionals attending in 2016. There are hopes that there will be another Autism Show in early 2018.

3. Why have we focussed on this issue?

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.

Following discussion with ASC support groups and seeking the views of people with ASC via online survey the concerns included:

- Long waiting times for an assessment or diagnosis
- A lack of clinical support once a diagnosis of ASC has been given
- The lack of understanding by some health professionals about how ASC can affect people and the need to make reasonable adjustments
- Systems and processes that are not autism friendly

4. What did we do to investigate?

- We visited peer support groups and listened to their concerns
- We spoke to professionals about the services that are being provided
- We gathered feedback from adults with ASC and their parents, partners and carers via online and paper surveys
 - There were 35 survey responses from people in Kirklees:
 - 19 responses from adults with autism
 - 16 responses from the parents/partners/carers of adults with autism
 - Of the adults with autism:
 - 13 had an ASC diagnosis
 - 3 had ASC but no formal diagnosis
 - 1 had a referral to the Autism Service and was awaiting an assessment
 - We also collected five personal stories/case studies

Community engagement

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

- No Limits Group - Kirklees (Huddersfield)
- PCAN group - Kirklees (Huddersfield)
- Be Just You group - Kirklees (Dewsbury)

5. What did people tell us, responses to the online survey

Several people reported difficulties in getting a referral or assessment, due to GPs not always taking them seriously, long waiting lists, and delays due to other cases being prioritised.

'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. I was told by one that they can't refer anymore but I can't remember what he said i.e., who to speak to because I was nervous and feeling anxious. I've been putting off going back again. It's also difficult to get my 10-year-old daughter assessed. School tell me to see my GP, but the GP tells me to speak to school. It was the same with my son 3 years ago. Eventually the GP referred him, he was on a waiting list for 2.5 years then was diagnosed with autism.'

'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.'

People had mixed experiences of getting a diagnosis, although none of the respondents had their diagnosis through the South West Yorkshire Partnership NHS Foundation Trust Autism Spectrum Disorder (ASD) Service.

'Process was age appropriate. We waited one year which given how long you wait now is not unreasonable.'

'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'

'Assessment, while a passport to help for those who are properly assessed, is a barrier to those who cannot access it.'

'Took years to get a diagnosis (around 7 years)'

People also experienced a lack of post diagnostic support in Kirklees.

'Received a letter explaining the diagnosis but no 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'

'I wasn't given any support after being diagnosed.'

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

There were also some comments relating to difficulties during transition to adult services.

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

'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.'

When asked to what extent their mental and physical health are affected by their ASC 16 people responded:

	A lot	A little	Not at all	Not sure
Mental Health	7	7	1	1
Physical Health	3	4	8	1

Respondents made references to a wide range of physical and mental health conditions that they had alongside their ASC including:

- Fibromyalgia, diabetes, severe pancreatitis, degenerative disc disease, severe allergies, eczema, anaphylaxis, epilepsy
- Attempted suicide, mental breakdown, low confidence and self-esteem, depression, psychosis, anxiety, paranoia

The following comment illustrates some of the difficulties people can have when dealing with ASC and a number of co-existing health conditions:

'I haven't worked since 2008 due to breakdown. Suffered chronic severe pancreatitis in 2014 with diabetes. I have degenerative disc disease n recently undergone back surgery. I'm in pain all the time I can't explain to Dr's without getting frustrated how I don't understand how my body won't work.'

And the difficulty of having an invisible disability was also highlighted:

'Because it is not a physical or obvious thing people do not understand my difficulties and assume that I don't have any. Because of my condition I am unable to communicate this.'

We asked people to tell us a bit more about the everyday challenges they face because of their ASC. Several people reported difficulties accessing GP services. Many of those difficulties link to a lack of autism awareness, with other respondents stating that GPs 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.'

'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.'

'Oh I never go to the doctors as it's difficult. We call the doctor out if it is necessary to do so. I feel it's difficult to attend the GP surgery, unfortunately the GP surgery doesn't understand this which causes suffering and isolation from the GP.'

'I avoid going to the GP or dentist, we get the GP to come out or the GP has to get in touch with me themselves to make an appointment. I had to go to St James's in Leeds for allergies but it is too far away and the buses were difficult.'

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.

'One other thing is the society to throw us to mental health services which are very very very bad as they don't understand autism and are very biased for things like bipolar, psychosis, etc.'

'...we are shoved into the mental health services which is scary and unpredictable.'

'It needs to be support 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.'

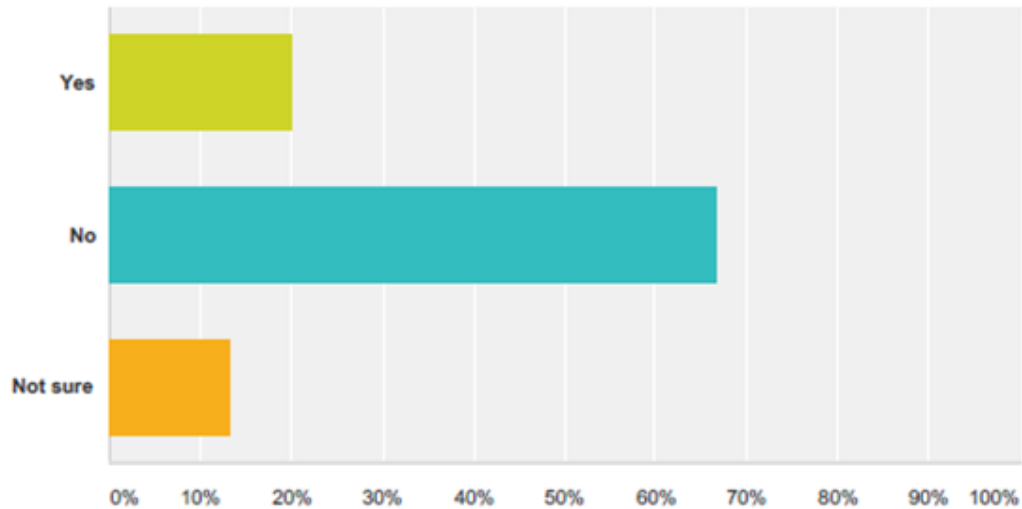
Several people commented that they struggled with the way services communicated with them, and were left feeling frustrated, dismissed or not taken seriously.

'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,

We asked for feedback about which people/groups/places give people the most help and support?

The biggest sources of support were family (62%) and Home Care Agencies (26%), then friends (18%), and Support Groups (18%). The sources of support that were accessed least were Social Workers (13%), and CMHT (6%) and telephone helplines (12%).

We then asked people if they received enough support to help them manage the effects of their ASC?



Out of the 15 respondents in Kirklees, 10 were not happy with the level of support they were offered.

'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".'

We asked if people would like more support, and if they did what kind of support that would be.

'Have some! There is a Social Worker specialising in ASC but I have no access to her.'

'They could have more social services for people with ASC. They also need more safe zones for people with ASC to go when they are feeling down.'

'To have some which are very knowledgeable and understand the condition well.'

'Education about autism what it is and what it does to people'

'You are supposed to know what you want but I need to be given options not just a blank sheet. I could give advice for other people with ASC but I can't do it for myself - I could make a list of things people with ASC need but cannot decide what I need myself.'

'Long term autism support like they get in Leeds and Bradford as their council supports ASC with great enthusiasm. Kirklees needs this as well as Calderdale as they have less too.'

We asked for people's thoughts about what could be done to improve services and support for adults with ASC in Calderdale?

'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.'

'They could have more social services for people with ASC. They also need more safe zones for people with ASC to go when they're feeling down.'

'I feel that we should have a long term autism specific social worker or someone from an autism team for long term as sometimes we are left with no support and can be invisible to the outside world.'

'More Autism specific groups like Leeds and Bradford has. Very rare in Kirklees and Calderdale'

'Help with getting them into work (voluntary, employment), to better educate regular people (neurotypicals), so they can associate with them better, and function into society.'

'Kirklees need to support adults in the way Calderdale do. They need evening group meetings, CBT support, courses, employment support etc.'

'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.'

'Communicate, communicate, communicate!! Speak to other people or organisations who understand the individual concerned if relevant and appropriate - in my case Specialist Autism Services (Leeds)'

'Listen to what clients want to achieve in life, and signpost them to appropriate 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.'

'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.'

'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'

'Having a good relationship with GPs and nurses is crucial for both people with ASC and their carers.'

'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.'

'There is still a lot of stigma around having ASC so some people do not want to admit to having it and so miss out on the support they need.'

'I'm not an idiot I'm intelligent but I get overwhelmed by strangers 'cos I can't work out if I can trust them.'

6. Our conclusions

The key overarching findings from the engagement are that:

- There are no clear diagnostic and treatment pathways for adults with ASC in Kirklees
- Some people are experiencing significantly long waiting times before assessment and diagnosis
- Several people with ASC have reported having mental health issues including attempted suicide, mental breakdown, low confidence and self-esteem, depression, psychosis, anxiety, paranoia
- Several people with ASC also reported problems with their physical health including fibromyalgia, diabetes, severe pancreatitis, degenerative disc disease, severe allergies, eczema, anaphylaxis, epilepsy
- Adults with ASC want more services and support in their local area, as travelling and using public transport can cause serious barriers to access
- Greater awareness of autism amongst health professionals, and a readiness to meet the needs of adults with ASC, would make a huge difference to the overall experience of those adults
- There are some simple, quick and low cost adjustments that could be made to help people with ASC access clinical services, e.g. having safe zones for people with autism

- There are some more intensive and specialist services that adults with ASC feel would be useful to them, including specific psychological therapy and access to Occupational Therapists.

7. Our recommendations

- For Kirklees CCG to use the feedback from people with ASC presented in this report, to help design and commission better services
- That consideration be given to how GP practices could be made more ASC friendly, including use of the Royal College of GP's [new toolkit](#) of resources
- That consideration be given to whether the mental health support available in 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.
- That consideration be given to how the parents, partners and carers of people with ASC can be identified and flagged up by the GP, so that they can receive extra support if they need it.

8. Appendices

Appendix 1 - Kirklees Case Studies

Case Study 1:

Communicate, communicate, communicate!!

ASC actually impacts every aspect of daily living, from sensory issues to communication difficulties. Every day is different and there are lots of variables which present a lot of difficulties, trying to adapt to each situation.

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 the same issue. Having autism, non-verbal gestures, body language, facial expressions, tone of voice etc. are all things I find particularly difficult and hard to understand and interpret, thus this often leads to a breakdown in communication, frustration on my part, and often being dismissed by the service or person in question.

I have been approved for funding to access more care. This has been financially approved and signed off by Kirklees Council, however it still has not progressed to the stage of me getting a PA.

This is bloody ridiculous as it's been over a year since the initial assessment! Needless to say I'm rather angry about this.

Some of the things I would like to highlight to the people who commission and deliver services for people with ASC are:

- Communicate, communicate, communicate!! Speak to other people or organisations who understand the individual concerned if relevant and appropriate - in my case Specialist Autism Services (Leeds)
- 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.
- Don't make assumptions!
 - No eye contact does not mean non-compliant.
 - Wearing a hoodie and hat does not mean aggression.
 - Being direct is not the same as being rude.

Case Study 2:

Adapt support to the needs of the individual

I have autism. I struggle to make friends and do not like social situations. I have anxiety and worry a lot. I struggle to see the positives. I have paranoid feelings and think people are looking or talking about me in a negative way.

I don't feel able to just go out. When I go out I don't feel comfortable about going home due to bad experiences in the past with local youths.

I am sensitive to noise and need reassurance what the noise was as I can think noises are directed at me. I also worry that I make too much noise, which will affect other people.

I attended school until the age of 16 and was aware of my autism but it wasn't until I left school that I became aware of the effects it has on me and the reason I feel people are negative towards me. Since school I have spent 5 plus years at home in my room, unable to build up the confidence to leave the house. This has had an effect on my whole life.

I currently receive 8 hours a week from Active Social Care, I use these in two 4 hour calls where I attend the office to vac and other light duties for some spends, and I go walking on a Tuesday, this gives me exercise and social time to talk to my carer. On Wednesday I am picked up at 6am and we sometimes go to the track to have a run as I used to be very good at athletics at school, then attend the offices at Bradley to do work experience. I may have the opportunity to do some more jobs for Active. I really like making my own money and being able to buy things for myself, I am currently working on being able to go to the shop myself but I am not ready for this at the moment.

The problem I have is I don't have any other hours remaining for my carer to take me as I will not leave the house on my own and make my way somewhere, this is due to my anxieties and it will cause me too much stress which develops into me blaming god for my disability and becoming very unhappy.

When I started receiving care from Active I usually decided that I didn't want to go and would cancel the care on a regular basis, Active staff worked with me to adapt my support to suit me and since receiving care from Active I have built a relationship with my first support worker and he encouraged me to leave the house to gain some fresh air and exercise, my problem was that I live on a busy street and at 10am-midnight all the shops are open and the street is always full of people, this is due to the mosque and deliveries for the shops, my support worker suggested we set off at 6am and go to an area he knew was quiet and had a good path as I do not like to be dirty.

This was difficult to begin with and I would panic every time we passed a member of the public and would always assume they had negative feelings towards me. This continued for 1 year and twice a week I would go out and walk for 2 hours. This continued until my support worker left the company and the new support workers being introduced I didn't feel I connected with, I eventually met a new support worker but he could only do 1 day per week and so this means I would only leave the house 1 day a week.

I was then introduced to a support worker that I knew from his job in the office and had spoken to on the phone whilst completing the quality assurance feedback. I now had my two days back and continued to walk for the following few months, until in a conversation one day one of my support workers asked what else I enjoy doing, one of my replies was vacuuming for my mother to receive a bit of spending money. He suggested that I could try and do work experience cleaning at the Active office. After agreeing this with my mother and the director of Active we began to Hoover the

offices one day per week starting at 6am before the staff have arrived and I left before 9am when they are due to arrive.

Over time I became more comfortable in this environment and stayed a little longer so I could meet the staff in the office, at first this was daunting and made me feel anxious to what they thought of me, but over time I feel I have got to know them and have developed a relationship with them 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. This developed into a regular thing I did and I looked forward to seeing the people in the office as this was my only social contact outside my family.

Some of the things I would like to highlight to the people who commission and deliver services for people with ASC are:

- I felt alone and lost for a considerable time in my life.
- That support must adapt to the needs of the individual rather than the other way around.
- Given the right opportunities I have been able to make progress in my life and come out of my shell to experience the world I am living in

Case Study 3:

I want more safe places to go

ASC affects me going out on my own, I need someone with me if I go outside the house. I am unable to follow bus routes and instructions to find places, and I don't know where anywhere is. Even getting to this group, mum has to bring me. Previously I used to be left somewhere and I couldn't find my way home and had to phone, I get lost anywhere apart from in my own house.

I like going to groups but it must be for something specific, not expensive and in a set place. I am good at the computer but can't do Word, but I can go to websites and download films, but I have no friends so can't share the films with.

I can't cook, shower properly, cream myself for my eczema - mum helps with this. I am getting more allergy based complaints as I get older. I like being at home, mum keeps a diary so I know what is happening every day. I am very talkative but I don't want to go to mental health groups as they don't speak literally.

I avoid going to the GP or dentist, we get the GP to come out or the GP has to get in touch with me themselves to make an appointment. I had to go to St James's in Leeds for allergies but it is too far away and the busses were difficult.

I had to get a letter from the GP so I could get a bus pass and they wanted to charge for it, the person who is acting as my advocate thinks this is discrimination.

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.

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, and some people who go to court go to prison.

Some of the things I would like to highlight to the people who commission and deliver services for people with ASC are:

- There are not enough support services.
- I would like more safe places to go.
- I would like more places to go to that don't cost a lot, and some help to get there.

Case Study 4:

Listen to what we want to achieve in life

ASC affects the way I relate to people, what to say and do, and how I feel.

Sometimes I try too hard to be close to someone, and make the wrong impression.

Talking to people is very hard for me: I very often rely on others to talk to me first, and finding something to talk about that others will want to hear is also almost impossible, as nothing much happens to me.

Also, I do feel very vulnerable, as situations can be very unpredictable for me, as I get frightened of being hurt physically, and I feel as though there is always a barrier between myself and others.

I have accessed many services and social groups, but have felt too high-functioning to benefit from just about all of them. This could have been due to my time in higher education, and exposure to mainstream society, but feeling disconnected due to my differences. Or it could have been because I was asking for too much, and they were unable to provide for me.

I am currently accessing an employment service Richmond Fellowship, and I am currently doing various voluntary roles, but finding a paid job is proving just about impossible, due to my lack of work experiences.

I have recently applied to go on a TV programme called The Undateables, but there is no guarantee that I will be successful due to the volume of applicants. I feel as though it is more suitable than any of the social groups I have attended. This could be due to my lack of life experiences.

Some of the things I would like to highlight to the people who commission and deliver services for people with ASC are:

- Listen to what clients want to achieve in life, and signpost them to appropriate services.
- Try and encourage them, where possible, to expand their comfort zones, and associate with regular people.
- Try and encourage them, where possible, to find work, preferably paid, but voluntary work is good, as well, as it helps them associate with regular people.

Case Study 5 - Caring for people with ASC is a full time job and very tiring

The support needed by the people we help, who have either diagnosed and undiagnosed ASC, varies from just needing to know the support is there if it is needed, to daily support with decision making, managing money, childcare, transport, advocacy, interventions with employers, relationship counselling, liaison with support agencies etc.

Because of this we have a very stressed lifestyle so lead a pretty unhealthy life, and we are very aware that we need to get as many interventions in place as we are both pensioners, but none of the support available is indefinite.

We do not feel supported as carers as our situation does not fit with either Carers Count or Social Services, as they do not understand autism. We have filled in two Carers Assessments but the support we give does not seem fit the criteria for support in Kirklees.

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.

He has no confidence and does not manage stress well and this can lead him to self-harm and destructive behaviour.

He is isolated and desperate for attention, and because of this his medical conditions feel worse to him which leads him to make much greater demands on the NHS than is necessary. As no one in the NHS understands ASC they just deal with the presenting symptoms, and he just keeps coming up with more symptoms...

Some of the things we would like to highlight to the people who commission and deliver services for people with ASC are:

- 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.
- It should not be too much of a hassle for carers of people with ASC to access support via a Carers Assessment.
- 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
- Having a good relationship with GP's and nurses is crucial for both people with ASC and their carers.

- 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.
- There is still a lot of stigma around having ASC so some people do not want to admit to having it and so miss out on the support they need.

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.

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

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

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

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

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)
- 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

25. 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

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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