

Access to Services for People with Autistic Spectrum Disorder.

Interim Report
2017

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Healthwatch St Helens Support Team





Background

Over time Healthwatch St Helens has collected stories from local people about the services that are available for people with Autistic Spectrum Disorder (ASD). Many of the people we spoke to felt anxious or uncomfortable about sharing their views and feelings with commissioners or medical professionals.

In our public consultation of 2016, one of the main areas of concern that came out was the lack of services for people on the autistic spectrum. We received various experiences and stories from local people and in targeted outreach to ASD support groups, highlighting the difficulties in getting a diagnosis and then receiving adequate support and treatment once a diagnosis is made.

Consultation method

We developed a task & finish group to look at the issues local people were facing. One of the group's tasks was to design a questionnaire with support from St Helens Carers Centre and from people with first-hand experience of trying to obtain a diagnosis and access further support.

In addition, we drew on information we had previously and combined it with new experiences that we purposely sought out to give us further evidence of what people feel about services.

We also collected stories in narrative form from people who have ASD and from their parents and carers. For some people, this was the best way to express their feelings and they chose it over completing the questionnaire.

How we engaged with people with ASD and their parents and carers

In the past some groups had been reluctant to speak out but we identified two local groups with whom we already had a relationship, who were prepared to share their views with us. By building up relationships and rapport over time with the people we spoke to, we were able to gain their trust and encourage them to speak freely.

We went along to their regular group meetings and gave them the opportunity to speak to us in private if necessary or write their experiences down.

The other experiences were case studies taken over time from people who approached us for support.

We would like to make it clear that we do not report what was told to us as being absolute fact, and we fully acknowledge that what people tell us is based on their perception of the service they received.

What we know about services in St Helens

The Neurodevelopment Pathway Steering Group was established to address the issues relating to diagnosis in St Helens. People around the table included representatives from schools, speech and language services, community paediatrics, psychiatrists and parent carers.

Our attendance at the Neurodevelopment Pathway Steering Group has given us better understanding of the challenges faced by providers in St Helens. Many voiced their frustrations around the system in place that had contributed to a backlog of children waiting to be referred for diagnosis, which, in turn had led to further frustration and confusion for parent carers.

Difficulties in employing appropriate staff has been a large contributing factor to the backlog for diagnosis and actions have been taken to address this.

In relation to the old ASD pathway, there was a coordinator and admin support worker, both of whom left their roles in the last year. The new neurodevelopment pathway includes a consultant psychiatrist, with part-times hours dedicated, a full-time clinical lead, a full-time pathway coordinator and full-time admin support.

What local people told us

The following experiences that were relayed to us by local people identify other areas of concern than the waiting time for diagnosis or referral.

Male, 19

Passed “from pillar to post” by mental health services.

Had an assessment by 5 Boroughs Partnership at Harry Blackman House. Was hearing voices - had it all brushed off as symptoms of autism and low mood.

Assessment at Whiston Hospital - was hearing static on the television and seeing the lightbulb change shape - again felt like symptoms were being brushed off as part of his condition.

Whatever he experiences is always put down to being due to autism or anxiety. Feels he has enough self-awareness to know what's due to autism and anxiety and what isn't.

Male, 59

Used to be under a doctor at Vista Road. Had to complain about the care coordinator who didn't seem to ‘get it’. Believed that she thought he was trying to ‘work the system’ to get benefits.

Had 16 sessions of Cognitive Behavioural Therapy (CBT) which weren't effective. The therapist sent a report to Dr D and he was discharged and referred to Open Mind, who disagreed with Dr D's recommendations.

Once discharged he felt very alone and in "no man's land". Saw his GP again when he started to feel angry and wanted to strike out at the people annoying him. Referred to a psychiatrist which was effective.

Psychiatrist referred to adult autism services. When he heard nothing for months he spoke to his GP who made another referral. He was then contacted and told he was on the waiting list for assessment. Had an appointment at Willis House and was told he was then put on the waiting list for a more in-depth assessment.

Over a year between the first referral and getting a more in-depth assessment for position on the autistic spectrum.

Inconsistency between services. They don't always agree on diagnosis or treatment and there is poor communication between services.

Believes that lack of funding is partly the reason for the inconsistencies. Understands that money is tight but feels that if services communicated better, the service people get would be better.

Male, 36

The mental health team at Whiston Hospital have done a good job but it's not consistent across services.

Moved to supported housing and support worker was "amazing". Other staff were bad and made false accusations about people.

Services don't communicate well and don't explain the roles of the staff.

Female, now aged 20

K was diagnosed at 17 years after she experienced many problems through her childhood and teens, including the suggestion that she was deaf. She was always a quiet child and a late developer.

K had periods throughout her childhood where she would not eat and didn't talk much and was discharged from CAMHS after a number of months with the suggestion that it was just in her nature.

K spent lots of time with her sister and her mother feels that this disguised many of her difficulties, which became more apparent when they didn't spend so much time together. She showed signs of depression in her teens but this was attributed to the usual teenage problems and teachers said she was doing well in school.

When K admitted she was self-harming she was referred back to CAMHS. At one of the appointments a psychologist referred to her as autistic without it ever being mentioned to either K or her mother before. K did some research on the Internet and identified as being someone with autism.

After K continued to have problems with eating, she had a long wait to see the eating disorder service as she was not considered an emergency. The family were impressed with how much support they received but her mother feels the gaps in receiving treatment for her eating disorder and CBT, as well as changes in staff were unsettling for K. Continuity was reported as being a constant problem.

K was reluctant to be diagnosed with ASD for fear of being bullied but her mother persisted in seeking a diagnosis for her so that she could have support at college. She reports having to read all of her books and revision notes to K in order for her to take her GCSEs. The family believe that this would not have been necessary if she had a diagnosis and could have accessed support in school.

K and her family acknowledge that labelling someone with a condition can have its own problems but feel that in this case, without a diagnosis K would not have been able to access the support she required to succeed in college and university.

The family also describes the transition between children's services and adult services as traumatic.

Male, 16

Mother fought for 2 years to get increase in support hours. Single-parent carer to autistic boy who has severe epilepsy and can have bouts of double incontinence. Believes the communication between Children's Services and parents is 'atrocious'.

Increase in support hours were agreed but not implemented for 4 months. Mother was mentally and physically exhausted by her caring responsibilities and with having to pursue answers from Children's Services.

Male, 23

Diagnosed with autism and struggles with depression and anxiety but gets 'fobbed off' by doctors saying it is part of the condition he has. Also struggles with the practicalities of day-to-day living, and it has been said by people close to him that he needs a support worker.

Has been under the Mental Health Assessment Team and discharged but found it difficult to access the mental health system again. It has taken 3 GP referrals over a year, before anyone took him seriously. Has a 5-month wait

for therapy. Two psychiatrists have said in the past that he may have traits of bi-polar disorder but will not give the label.

Male, 19

Has Asperger's and mental health problems. Parents felt they were being 'passed from pillar to post' by Adult Services. They were physically beaten by their son on several occasions during a family trip away.

The parents asked Social Services to remove their son from the family home and in response were offered a respite bed that wasn't available for another 2 weeks, which impacted on the health of his parents.

The family made a complaint to 5 Boroughs Partnership Trust about the way the family felt they were treated by the mental health team.

Parents report that Willis House would not take their son as he has a GCSE so did not meet their criteria. However, other mental health professionals the parents spoke to stated that he was not their responsibility as he has a learning disability so the social worker should 'sort it out'.

The parents are appalled by the lack of support to care for their son.

The young man's sister stressed that the family needed help and have been asking for it 'desperately', for years. She says there have been some attempts, but the number of let-downs have outnumbered the lifelines offered.

Family friends report times when they have witnessed the young man physically and verbally abusing his parents. They also mention occasions when he has threatened to stab his mother, 'when she's not expecting it'.

They express their concerns about the family's safety and believe that the young man is a danger to himself and the people around him.

Female, 11

A, diagnosed at age 5. The parents were mostly able to cope and didn't feel that much intervention was required. They also felt there was stigma attached to asking for help.

The parents felt that A needed to develop more independence and confidence and they identified a social group she could attend. A began attending the group but the volunteers who ran it found it increasingly difficult to cope with her and requested someone go along to support her.

The parents felt that a family member accompanying her was defeating the object as it would discourage her from mixing with other young people and developing her social skills. This was when they decided they needed to ask the Learning Disabilities Team for A to have support to attend the group.

When A's mother contacted Healthwatch St Helens to share her experience in relation to this report, it had been 10 months since A's initial assessment and there had been no contact from the Learning Disabilities Team to say whether she met the criteria for support. It was 3 months since her request for support for A to attend the social group.

The Healthwatch Support Team followed this up with the Learning Disabilities Team and contact was made with A's mother. A's mother stated that she had completely lost faith in ever receiving any support for A at that point.

Male, 8

8-year-old boy with ADHD (Attention Deficit Hyperactivity Disorder) and PDA (Pathological Demand Avoidance Syndrome).

Family moved to St Helens to be near family. Parents felt that he would have some friendship in the form of his cousins if they were closer as they don't foresee him developing other friendships.

Parents paid for private diagnosis of R's condition as they could not cope any longer with his conduct. Behaviours in the past have involved climbing fences thought to be impossible for a 6-year-old (his age at the time) to climb, running away, kicking and punching mother and pushing his mother down stairs, causing a miscarriage.

Appointment with Paediatrician at the Bridge Centre in early 2016. Parents found the paediatrician to be rude and condescending. At first appeared to be engaging with R but began to speak to him as though his behaviour was caused by poor parenting. Mother describes his approach as 'airy-fairy'.

Paediatrician talked to R about taking deep breaths when he feels he is going to lose his temper which led parents to explain an incident when the Police had to be involved. Mother reports paediatrician laughing at this point and then suggesting a parenting course.

Mother had expected to discuss medication for R and eventually refused to leave the office until something was prescribed. The paediatrician prescribed medication but did not discuss options or talk about side-effects.

R became calmer on the medication but his outbursts were more aggressive. At one point his mother told a paediatrician that she needed help and was close to calling Social Services to ask them to take her son into care. The response was that she should do that if she felt it necessary and that they would see her and R in three months at his next appointment.

Unable to get R to go to school, mother contacted Social Services and a duty social worker was allocated. Mother felt the initial assessment went well, however a report was produced that accused mother of being cold, having

no emotional warmth and refusing to apply sanctions. The suggestion was made that the mother only cared about own career after she expressed concerns about the amount of time she has to take off when R would not go to school. R and his younger brother were placed on the Child in Need register and mother was led to believe that they would be taken into care if one of them presents at A&E.

Mother fought to get an Education Health and Care Plan (EHC) for R which was turned down with the justification that a referral to SEN provision would meet R's needs. Mother persisted and EHC was awarded which led to support that a private diagnosis would not.

Male, 12

Boy with ADHD, now aged 12, went to panel and was referred for Autistic Diagnostic Observation Assessment (ADOS) after inconclusive result. The video equipment was broken and the ADOS was not recorded. Feedback later stated that N was making eye contact so couldn't have ASD and his signs and symptoms could be attributed to some unrest in the family home at that time. Mother also believes that N was not communicating as well during the ADOS as was claimed.

Parents paid for private diagnosis and received a diagnosis of high-functioning autism.

Female, 6

J, diagnosed with autism and ADHD in 2016. Mother first had suspicions that she could have autism when she was 3 years old. J didn't like loud noises, and certain smells made her feel sick. She also didn't like the sound of people breathing and didn't like certain shops.

GP made referral when J was 3. She was already in nursery and both the GP and nursery staff noticed that showed signs of ASD as she fixated on certain things and liked routines and boundaries.

J was allocated a 'Play Nurse' for 12 months. Her mother says she was very good but didn't make a lot of difference to her daughter.

Her ADOS assessment in May 2015 was short by 1 mark for a diagnosis of autism. An Educational Psychologist monitored J over a period of time within the school setting and believed that she PDA (Pathological Demand Avoidance). The school SEN Coordinator was very supportive.

J went onto the ASD pathway and the belief that she had PDA was dismissed at a panel meeting. The mother believes that none of the reports had been read by any of the panel members. The mother was told that J would be re-assessed in 12 months. She was diagnosed with ADHD in July 2015 but could not be prescribed medication as she was under 6 years old.

In October 2015, both J's mother and staff at her school noticed that she had begun to exhibit sexualised behaviour. This resulted in social workers coming to the house to ask questions; however they went to the wrong house and divulged confidential information to neighbours.

When a meeting was held in November 2015 to discuss a complaint that J's mother had made about another issue, she only felt she was listened to when she spoke about the situation of the social workers going to the wrong house.

It was agreed that J could go back on the ASD pathway and she was diagnosed with autism and ADHD in September 2016. An Educational Health Care Plan was put in place for 1 to 1 support and speech and language therapy.

J has seen approximately 7 different paediatricians which the mother considers to have provided no consistency. Occupational therapy has been withdrawn through lack of funding and there has been no contact from speech and language services. The mother feels there is poor communication between health services and the education system with the schools doing what they can.

Comments from parents of young people on the autistic spectrum

- *Everything is a fight to get the right diagnosis and support.*
- *Barnardos won't help children with SEN if they are on the ASD pathway.*
- *Educational Psychologist made a snapshot decision on 10 minutes of seeing my child. There is no permanent psychologist (in St Helens).*
- *Attitude of the Paediatrician is that the parent is viewed as emotionally unstable. It took me courage to go alone with my child to deal with a professional to get the best for my child.*
- *It took me 3 years to see an Educational Psychologist. (4 have left St Helens MBC for different reasons).*
- *Had to tell Social Worker how to do her job regarding respite.*

In your words...

"Credit to all staff at Central Surgery. Doctors McCourt, Parker and especially Dr Richardson. All staff do a fab job, but those are outstanding. Nurses Katie and Rachel and brilliant".

"I felt like I was in no man's land..."

"The service is good when you get it but it's not consistent."

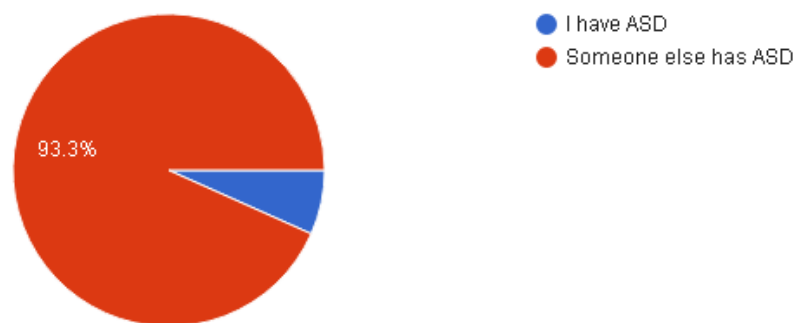
"I just feel like our family is one step away from being a news story of, "We saw it coming, but we'll learn from this"..."

"Everything is a fight"

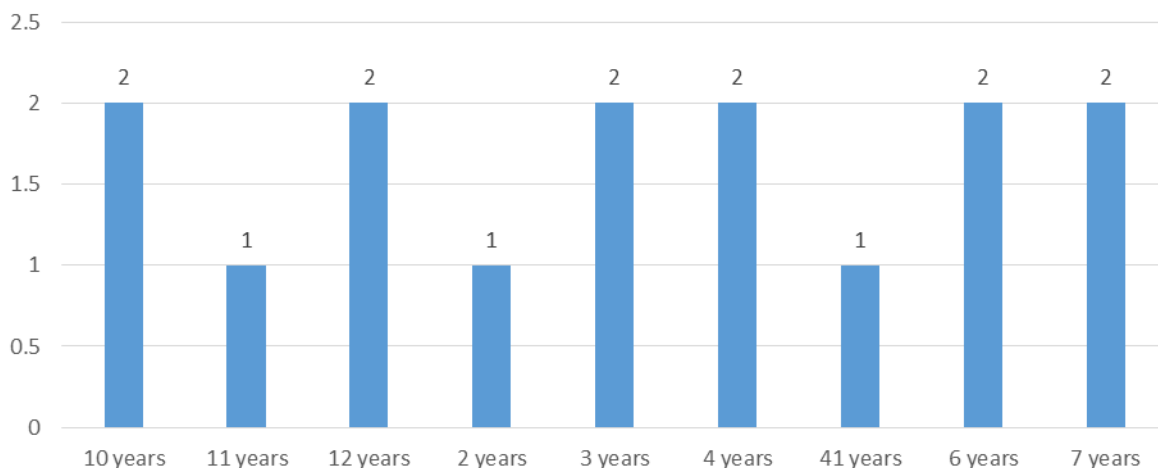
What our questionnaire told us:

Do you have ASD or are you telling us about someone who as ASD?

15 responses

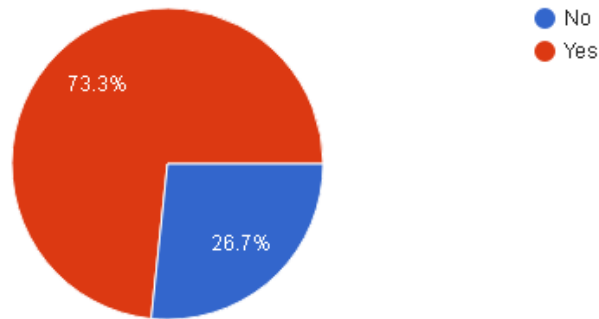


Count of How old are you / they now?

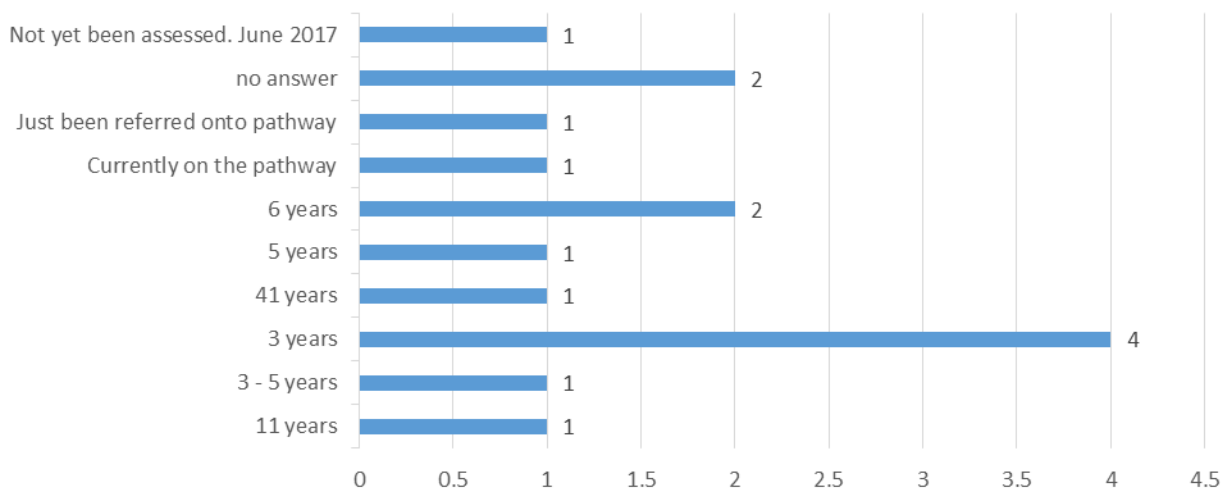


Were you / they assessed via St Helens Autism Spectrum Pathway (SHASP)?

15 responses

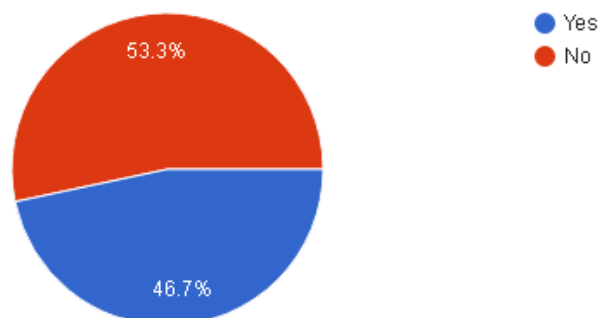


If so, how old were you / they when you / they were assessed?



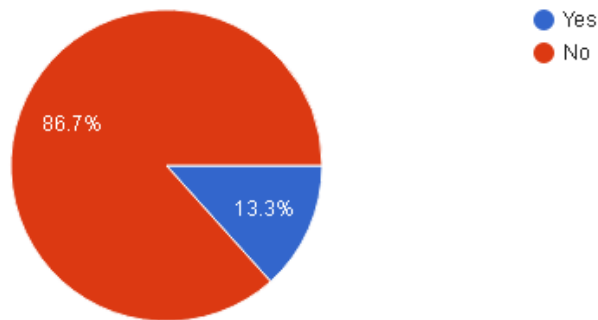
Was a diagnosis of ASD made?

15 responses

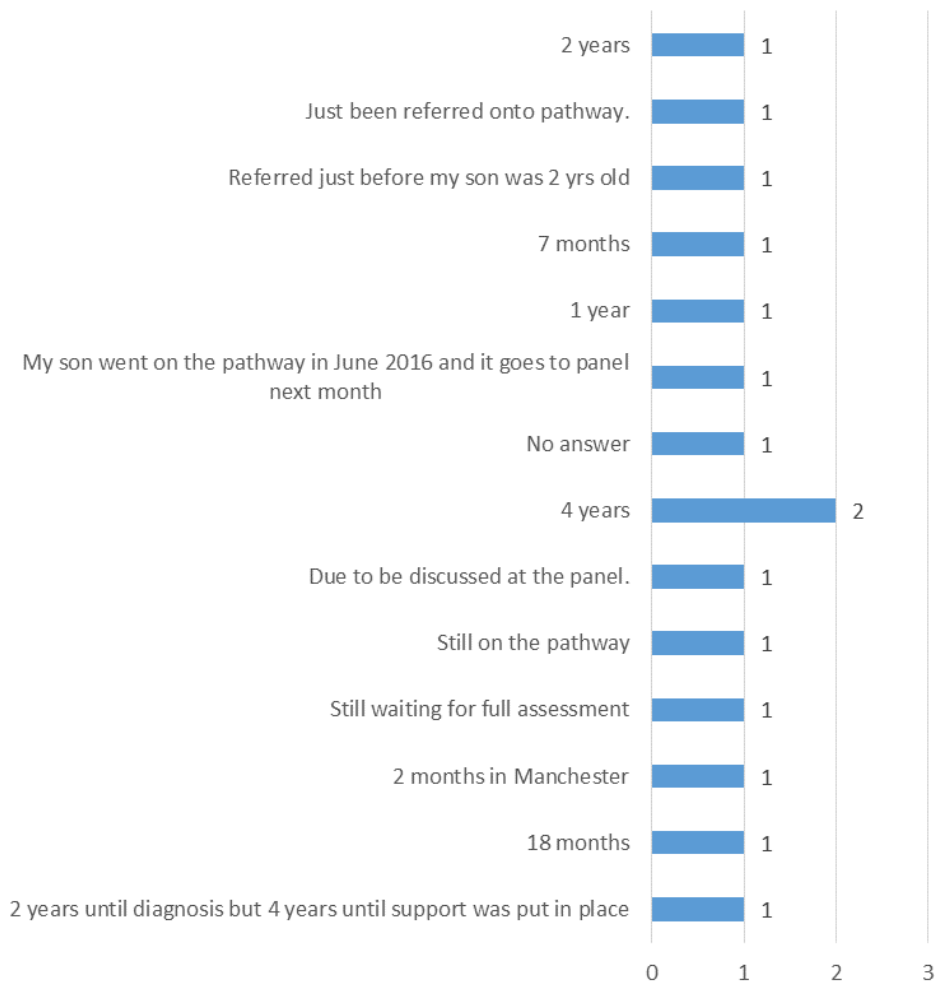


If No, have you / they had a diagnosis via any other service, e.g. privately?

15 responses



If there has been a diagnosis of autism or an autistic spectrum disorder, how long did it take from the point of referral on to the SHASP to receiving a diagnosis?



Responses to the following questions in our questionnaire can be found in Appendix 2

- What Services Have You / They Tried To Access?
- What Was Good About The Services You / They Have Received So Far?
- Can You Tell Us Anything That Would Have Made Things Better?
- Can You See Any Gaps In The Services Provided?
- Is There Anything Else You Would Like To Tell Us About Your Experiences?
- Is There Anything Else You Would Like To Tell Us About Your Experiences?

Conclusion

Themes have emerged from our consultation activities that communication between services is poor and support is inconsistent. Some of the people who spoke to us felt that the support is good but trying to get it in the first place is difficult.

Some parents told us that they paid for a private diagnosis, as did 13% of people who completed our questionnaire, which indicates that it has not been explained to them that St Helens Clinical Commissioning Group does not accept private diagnoses.

We felt it was interesting that less than half of the people assessed received a diagnosis of autistic spectrum disorder. It is worth considering whether more referrals were made than were appropriate which could have, in turn, contributed to the length of time that children have spent on the waiting list.

Also interesting finding was the difference in time that people spent on the pathway. Our results showed the shortest time anyone spent on the pathway in St Helens (from the people who completed our questionnaire) was 7 months and the longest period was 4 years. This again demonstrates the inconsistency in people's experiences. However we do acknowledge that a contributing factor could be the complexity involved in diagnosis in some cases.

Communication is clearly an issue with some parents being unaware as to where their children are in relation to being assessed. Some parents were under the impression that their children were already on the pathway when in fact they were in the pre-pathway observation period.

In general, Healthwatch St Helens feels that in many cases, people feel that they, or their children have 'slipped through the net' or will be passed from 'pillar to post' and as a result have lost trust that they will receive diagnosis or support.

Recommendations

- **Clearer communication with parents around which stage their child is at regarding assessment.**
Parents are confused as to where their children are on the pathway and in some cases unclear as to whether the child is on the pathway at all.
- **Provide consistency in what is provided to people with ASD both before and after diagnosis.**
- **Be clear with parents that private diagnoses will not be accepted.**
Parents are paying to have their children diagnosed in the belief that this will lead to them receiving support.
- **Maintain communication with parents of children with ASD, or adults with ASD after referral or assessment to avoid the belief that nothing is being done or is going to be done for them.**
- **Improve communication with parents around the suggestion of parenting courses.**
Parents are interpreting the suggestion of attending parenting courses as a criticism of their parenting skills. More effort is required to explain that these courses are designed to help parents to communicate more effectively with their children, according to their individual needs, and their ability as a parent is not being called into question.

Healthwatch St Helens acknowledges that some of the intelligence we have collected is a reflection of how individuals felt they were treated or how they interpreted what was communicated to them.

We do, however feel that there is a clear message around lack of communication which is reflected in our recommendations.

We will revisit the work around autistic spectrum disorder when the newly designed neurodevelopment pathway is up and running in order to observe whether local people are now receiving a better, more consistent service.

We look forward to being able to compare the experiences included in this report with people's experiences under the new system.

Acknowledgements

Thanks to : -

Everyone who completed our questionnaire

Everyone who spoke to us and shared their experiences

The task & finish group

- Stephanie Adams
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- Michelle Hughes
- Ciaron Ineson
- Brenda Smith
- Francis Williams
- Joan Young

St Helens Autism & Asperger's Society

Parents Meeting Parents

ADDVanced Solutions

Janet Roberts - Healthwatch Support Team

Claire Jones - Halton & St Helens VCA

Lynne Daffern - Healthwatch Support Team

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Appendix 1



Access to Services for people with Autistic Spectrum Disorder (ASD)

Healthwatch St Helens want to find out what people in St Helens think about accessing services. You can complete this form with information about your own experiences as someone with ASD or those of someone you live with or care for who has ASD.

Do you have ASD or are you telling us about someone else who has ASD?

I have ASD Someone else has ASD

How old are you/they now?

Were you/they assessed via SHASP?*

(*St Helens Autism Spectrum Pathway) Yes No

If so, how old were you/they, when you/they were assessed?

Was a diagnosis of ASD made? Yes No

If no, have you/they had a diagnosis via any other service, e.g. privately?

Yes No

If yes, please give details below

If there has been a diagnosis of autism or an autistic spectrum disorder, how long did it take from the point of referral on to the St Helens Autism Spectrum Pathway to receiving a diagnosis?

What services have you/they tried to access?

What was good about the services you/they have received so far?

What was not so good about the service you/they have received so far?

Can you tell us anything that would have made things better?

Can you see any gaps in the services provided?

Is there anything else you would like to tell us about your experiences?

Would you like to help us with our work around services for people with autism by giving us an anonymous case study?

If you would, contact Jayne on: 0300 111 0007 or email:

jparkinson@healthwatchsthelens.co.uk

Appendix 2

What Services Have You / They Tried To Access?

- LAST/SALT, lot of OT involvement, physio, continence team
- ICASS and School SEN provision
- Occupational Therapy, Physiotherapy, Paediatrician. My daughter was also diagnosed with cerebral palsy when she was 1 yr old therefore accesses other health services such as ENT and the orthopaedic surgeon.
- My son has accessed SALT, Paediatrician, Occupational Therapy, Educational Psychologist, CAMHS but we are waiting to hear from Barnardos. The physiotherapist has discharged him.
- Portage last April
- My daughter was under the Occupational Therapist but didn't see her once and discharged her, and also tried SALT but the woman was ill and she wasn't replaced. My daughter attends mainstream school but gets no 1 to 1 support.
- SALT and the Continence Team.
- "The Health Visitor and GP made the referral 18 months ago. The Portage Worker came every week for 12 weeks then passed over to the Pathways Team at the Bridge Centre. We are waiting for the sensory course for my son to go on.
- Also accessed the Speech Therapist."
- "Just started portage with Fran. Had 2 sessions and it's gone well."
- "My son has had a 12 week therapy session on the pathway and had portage.
- The Health Visitor made the referral for OT, Physio and Speech & Language"

What Was Good About The Services You / They Have Received So Far?

- Everything has to be assessed via school, ie ed psych. Newton County Primary very good, Bridgewater community paed team
- Nothing
- The paediatrician started 'the ball rolling' when he contacted the pathway who then contacted the school.
- I was in denial about my son's autism for a couple of years then the Educational Psychologist got in touch with me along with SALT, the Physiotherapist, the Language and Social Communications Service and Communications Service and Inclusion Officer. The educational Psychologist got the ball rolling when she came into nursery where my son was attending.
- Nothing
- The Occupational Therapist has been brilliant and referred him onto the Sunflower course. She emails me regularly. The Educational Psychologist has also been really good. She had a meeting with me and explained everything.
- We were referred to portage by the health visitor. The lady from Portage still comes to the house and the nursery to see my son until he gets into school or a gets a diagnosis.
- None because my daughter never had any support.
- The Continence Team are good and given things for my son to try but he is not bothered as yet. SALT use picture cards and do home visits once a month. Once he was in nursery there are no home visits.
- The Portage collect the evidence and my son has made good improvement with the Speech Therapist.
- Portage service is excellent. Gives help and advice and tips.

-
- My Health Visitor spotted the signs at 1 year old but was told that my son was too young. She referred him to the Paediatrician who then referred my son onto the pathway straight away when he saw him. Everyone who has been involved have all listened to me.

Can You Tell Us Anything That Would Have Made Things Better?

- Everything in one place - Ed psych, OT, paed - take child in once a week. Within a month have everything sorted, see child at panel.
- ADOS specifically for deaf children
- If the paperwork had not been lost in the first place we would have had the ADOS a lot sooner. This delayed the process by 6 months.
- Better communication and better response times.
- If the assessment process hadn't been delayed for so long his education wouldn't have suffered. Also if they had listened to my opinions instead of 'treating me as if I was stupid.'
- It has taken so long (2yrs) to be told he has not got ASD. There are no regular updates. I'm having to chase up paperwork all the time. Better communication and a better sense of urgency would help.
- There doesn't seem to be any communication within the Pathways office. Pathway should be collecting evidence but portage ends up ringing round to collect everything. They don't answer phones and don't reply to emails.
- To get some kind of support and follow-up from her diagnosis. We think she has Asperger's rather than autism. We think she needs one to one and we are trying to get an appointment with the school.
- No. My son was on the pathway for 7 months and I was told to expect 6 months so I'm so pleased how quick they have been.
- Would be better if there was a follow-up and there is no communication from the Pathways Team in between the waiting period. We have been waiting for 8 months and there should be updates in between.
- I asked the Health Visitor to bring my daughter's 2 year check forward. She is an only child and I had no other child to compare with. She doesn't have any language. To bring the 2 year check forward so that any issues are picked up earlier.
- Timing - it's been a long time coming.

Can You See Any Gaps In The Services Provided?

- ADOS specifically for deaf children
- The old pathway didn't inform us of where we were in the pathway. The new pathway is about supporting and communicating with parents and not just about the diagnosis. The new referral process is supposed to be easier and not just tick-boxes anymore.
- Now have a pre-pathways and then pathways.
- Professionals not listening and a long process.
- It's such a long process on the pathway. It took 6 months before we saw the paediatrician in January 2017
- Finding a way to challenge the diagnosis and not seeing my daughter as a whole person. (school)
- None
- Lack of follows during the waiting period. More speech therapy.
- It would be good to have 2 portage sessions a week.

Is There Anything Else You Would Like To Tell Us About Your Experiences?

- Good people but even they get frustrated. Feeling of fighting all the time but in the end it's economical
- We are going to get a diagnosis via 'Deaf' CAMHS. There was no support for parents so I set this group up. (Jigsaw)
- My daughter is currently on the pathway and is due to be seen next week. The pre-pathway is 6 months. Been on the pathway is 18 months, so she could have been there much sooner.
- Jigsaw is a really good support for the parents.
- It took 2 years from my son age 7 til 9 being on the pathway, to be told that he was not on the autism spectrum. I contacted the ombudsman who then ordered a re-referral for an assessment. This then took another 2 years before he was diagnosed as having ASD. I now have the bit of paper that says I was right all along. It has left me feeling very angry that no-one listened. There was no support afterwards such as coping strategies, training, respite. I have applied for respite lots of times but they say I don't need it.
- The woman from CAMHS was rude on the phone. Someone else from CAMHS came into the school and had a meeting and made a referral to Barnardo's. We are currently waiting for an appointment. We had been rejected by Barnardo's 3 times. The first time the form was not filled in properly. The second time we were rejected for whatever reason. The third time they said the family had not been in touch when we had.
- There is no communication. One person says I have enough evidence for a diagnosis and another says i don't have enough but they haven't got the evidence together between them. The paediatrician's report got lost so had to ask for another. It's been very stressful and not slept for worrying. If it wasn't for portage we would be nowhere. All I want is for my little boy to get the support he deserves. There is no sense of urgency. The Smarties group gives me the support and I can be myself while children do the activities.
- My daughter attended private nursery who made the referral onto the ASD pathway. In the meantime she transitioned into school. We are having difficulty trying to see the head teacher (deputy) as we are trying to get the school and SENCO together. We have been waiting since November and it's now March.
- Rainhill Nursey is very supportive of my son's needs.
- The actual services and work done so far with my son has been pretty good.
- Since portage my daughter has been sitting down and making eye contact.

Is There Anything Else You Would Like To Tell Us About Your Experiences?

- Good people but even they get frustrated. Feeling of fighting all the time but in the end it's economical
- We are going to get a diagnosis via 'Deaf' CAMHS. There was no support for parents so I set this group up. (Jigsaw)
- My daughter is currently on the pathway and is due to be seen next week. The pre-pathway is 6 months. Been on the pathway is 18 months, so she could have been there much sooner.
- Jigsaw is a really good support for the parents.
- It took 2 years from my son age 7 till 9 being on the pathway, to be told that he was not on the autism spectrum. I contacted the ombudsman who then ordered a re-referral for an assessment. This then took another 2 years before he was diagnosed as having ASD. I now have the bit of paper that says I was right all along. It has left me feeling very angry that no-one listened. There was no support afterwards such as coping strategies, training, respite. I have applied for respite lots of times but they say I don't need it.
- The woman from CAMHS was rude on the phone. Someone else from CAMHS came into the school and had a meeting and made a referral to Barnardo's. We are currently waiting for an appointment. We had been rejected by Barnardo's 3 times. The first time the form was not filled in properly. The second time we were rejected for whatever reason. The third time they said the family had not been in touch when we had.
- There is no communication. One person says I have enough evidence for a diagnosis and another says I don't have enough but they haven't got the evidence together between them. The paediatrician's report got lost so had to ask for another. It's been very stressful and not slept for worrying. If it wasn't for portage we would be nowhere. All I want is for my little boy to get the support he deserves. There is no sense of urgency. The Smarties group gives me the support and I can be myself while children do the activities.
- My daughter attended private nursery who made the referral onto the ASD pathway. In the meantime she transitioned into school. We are having difficulty trying to see the head teacher (deputy) as we are trying to get the school and SENCO together. We have been waiting since November and it's now March.
- Rainhill Nurse is very supportive of my son's needs.