Autism Spectrum Disorder

Investigation Report

March 2019

Contents

Disclaimer

Please note: This report is based upon feedback provided to Healthwatch North Lincolnshire from members of the public. The findings are based upon individuals' perceptions, which are not verified for factual accuracy.

What is Healthwatch?

We are the independent champion for people who use health and social care services. We exist to make sure that people are at the heart of care. We listen to what people like about services and what could be improved. We share their views with those with the power to make change happen. We also help people find the information they need about services in their area.

We have the power to make sure that people's voices are heard by the government and those running services. As well as seeking the public's views ourselves, we also encourage services to involve people in decisions that affect them. Our sole purpose is to help make care better for people.

In summary Healthwatch is here to:

- Help people find out about local care
- Listen to what people think of services
- Help improve the quality of services by letting those running services and the government know what people want from care
- Encourage people running services to involve people in changes to care

Why this subject?

The Emotional Health and Wellbeing Group, run by North Lincolnshire Clinical Commissioning Group (NLCCG) and attended by Healthwatch North Lincolnshire (HWNL), advised that they wished to find out more about the experiences of people who were accessing services for ASD. In addition HWNL received queries from parents about who to contact for an ASD diagnosis. Parents also contacted HWNL about where to get support and the lack of support available for those with an ASD diagnosis. The types of comments received included:

- If children have assessments then they need more to do, for example, sensory tubes to help prevent them from becoming distracted
- Feelings that hospital patient's ASD is not taken into consideration especially when providing information to the patient about their illness or treatment
- Families caring for those with ASD being unsure how to access support themselves

The overall aim of this investigation was to identify areas for improvement in the current diagnostic pathway and establish what additional support parents, caregivers and guardians feel is needed. This was achieved by gathering experiences through: focus groups, interviews and surveys.

Introduction

"Autism spectrum disorder (ASD) is the name for a range of similar conditions, including Asperger syndrome, that affect a person's social interaction, communication, interests and behaviour".[1]

Those with Autism can exhibit a number of traits including: repetition, selective behaviour and finding some social situations and communications difficult. The effects of Autism differ between individuals and historically a variety of terminology has been used to distinguish this and the diagnostic position, for example:

- **Asperger's syndrome**, where the person has issues with social communication but does not have a "clinically significant delay in language or cognitive development"[2]
- **Classic Autism / Autistic Disorder** referring to those who "have significant language delays, social and communication challenges, and unusual behaviours

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[1] https://www.nhs.uk/conditions/autism/

[2] https://www.autism.org.uk/about/diagnosis/criteria-changes.aspx

and interests. Many people with autistic disorder also have intellectual disability."[3]

- **Pervasive Developmental Disorder** where people "usually have fewer and milder symptoms than those with autistic disorder. The symptoms might cause only social and communication challenges."[3]

In addition the term 'low functioning' or 'high functioning' has been used to describe Autism. Those classed as high functioning usually require lower levels of support with daily activities and communication and typically have less severe characteristics of the condition.[4] In contrast those with low functioning autism require higher levels of support and have more severe traits.[5]

Incidence of ASD - National

Nationally about 700,000 people have Autism[6] with men being more likely than women to have an ASD diagnosis[7].

Children with ASD may be identified as having Special Educational Needs (SEN). This is when they have "…a learning difficulty or disability which calls for special educational provision to be made for him or her."[8]

2018 figures from the Department for Education, looking at State-funded primary, secondary and special schools, suggest that the majority of children with SEN who have been assessed with a primary need of ASD go to mainstream school (primary (47,583), secondary (38,725) and special schools (33,601)) (Department for Education, 2018a, Table 8[9]).

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[3] https://www.asws.org/WhatisAutism.aspx
[4] https://www.healthline.com/health/high-functioning-autism#asperger's-syndrome
[5] https://www.autismparentingmagazine.com/low-functioning-autism/
[6] http://www.autism.org.uk/about/what-is/asd.aspx
[7] http://www.autism.org.uk/gender
[8] http://www.legislation.gov.uk/ukpga/2014/6/part/3/enacted
[9] https://www.gov.uk/government/statistics/special-educational-needs-in-england-january-2018

Incidence of ASD - Local

Information passed to HWNL from NLC's Public Health department highlights an estimated maximum of 360 cases of ASD amongst 0-19 year olds within North Lincolnshire[10].

Information published by the Department of Education in January 2018 shows that for North Lincolnshire:

- 92 primary school aged children (in state-funded schools) had a SEN where the primary need was ASD, which represented 5.2% of those with a SEN in this group (Department of Education, 2018b, Table 16[11])
- 86 secondary school aged children (in state-funded schools) had a SEN where the primary need was ASD, which represented 6.4% of those with a SEN in this group (Ibid, Table 17[11])
- 64 children attending special schools had a SEN where the primary need was ASD. This represented 22.3% of those with a SEN in this group (Ibid, Table 18[11])

The figures suggest that 242 school aged children had a SEN where the primary need was ASD.

In 2016 Child and Adolescent Mental Health Services (CAMHS) undertook 92 full neurodevelopmental assessments, 55 were for ASD and of those 78% had a diagnosis confirmed (NLCCG, 2017, p28[12]). The North Lincolnshire Children and Young People's Emotional Health and Wellbeing Transformation Plan 2015 –2020 states that the high rate of diagnosis reflects "that the consultation and advise model for the pathway is being effective and only subjecting children, young people and their families to a full assessment, when necessary" (Ibid[12]).

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[10] Information from NLC's Public Health Department

[11] https://www.gov.uk/government/statistics/special-educational-needs-in-england-january-2018

[12] http://www.northlincolnshireccg.nhs.uk/data/uploads/publications/north-lincolnshire-children-and-young-peoplers-emotional-health-and-wellbeing-transformation-plan-2015-n2020.pdf

Patient Experience - National

The 2016 National Autistic Society School Report looked at the impact the 2014 Children and Families Act had for children and young people with ASD. As part of the research for this report 980 parents' (Moore, 2016, p4[13]) and guardians were surveyed. Their feedback included:

- 74% of respondents revealing that they had difficulty obtaining the required "educational support" for their child (Ibid, p6[13])
- 69% mentioned waiting over a year from initially highlighting issues to their child's needs being met (Ibid[13])
- A quarter stating that they would have preferred "a different type of education for their child" (Ibid, p13[13]) with 42% of those wanting "an autism-specific specialist school"(Ibid[13])

Healthwatch England analysed information provided by 33 local Healthwatch on services for those with Autism. From this four themes were identified:

1. "Understanding and Knowledge" – including some professionals not always recognising autistic signs and a lack of GP knowledge around referral systems (Healthwatch England, no date, p2[14]).
2. "Waiting times" – including differences in the amount of time taken to get a diagnostic assessment (Ibid[14]).
3. "Support for parent carers" – encompassing uncertainty as to where to go in a crisis and not being "offered the right support and information from the beginning" (Ibid[14]).
4. "Communication and Coordination" – including inadequate communication between services and the need for improved information (Ibid, p2-3[14])

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[13] https://www.autism.org.uk/schoolreport2016

[14] https://www.healthwatch.co.uk/sites/healthwatch.co.uk/files/children_and_young_people_with_autism_-_findings_from_the_healthwatch_network_0.pdf

The Healthwatch England report also highlighted differences nationally in the diagnostic pathway (Ibid, p3[14]) and mentions that in many areas there is no "single unified service available to cover autism services" (Ibid[14]). It goes on to say that "A single service could provide relief for the strain on CAMHS services and ensure healthcare professionals know where to send families for support and guidance" (Ibid[14]).

Local Strategy / Pathway

The North Lincolnshire Children and Young People's Emotional Health and Wellbeing Transformation Plan 2015 –2020 suggests uncertainty on whether North Lincolnshire's Autism Spectrum Disorder (ASD) pathway and follow-up support meets the needs of autistic children (NLCCG, 2017, p53[15]).

One of the statements in North Lincolnshire's Autism Commissioning Strategy is to "Develop a cost effective referral pathway for autism available in every area, which GPs, mental health practitioners and those working in the voluntary sector are aware of and can follow" (Hall, 2011, p2[16]). One of the outcomes of this would be the creation of "Explicit links to the Children's Services diagnosis model and pathway" (Ibid[16]).

In North Lincolnshire ASD assessments for children under five are carried out at the Child Development Centre (CDC). For older children assessments are carried out by CAMHS "with on-going treatment and review delivered in partnership with Pediatrics and Education" (NLCCG, 2017, p28[17]).

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[15] http://www.northlincolnshireccg.nhs.uk/data/uploads/publications/north-lincolnshire-children-and-young-peoplers-emotional-health-and-wellbeing-transformation-plan-2015-n2020.pdf

[16] Appendix A http://www.northlincolnshireccg.nhs.uk/data/uploads/publications/adult-autism-commissioning-strategy.pdf

[17] http://www.northlincolnshireccg.nhs.uk/data/uploads/publications/north-lincolnshire-children-and-young-peoplers-emotional-health-and-wellbeing-transformation-plan-2015-n2020.pdf

The North Lincolnshire CAMHS service is commissioned to assess and diagnose children and young people suspected of having ASD. They are not commissioned to undertake follow-up support for those with ASD but can signpost to other organisations[18]. CAMHS assessments include parents, caregivers and guardians completing an over the telephone questionnaire and meeting with CAMHS, along with their child, to discuss the issues experienced[1818].

The CAMHS assessment process involves information gathering through liaising with professionals working with the child including; school staff and carrying out observations in the child's or young person's school or college and at CAMHS base, St Nicholas House, Scunthorpe[18]. ASET are also involved in the liaison process and schools should have contacted ASET before referral and gone through a process of using the Support Strategies Document in school. The document allows school professionals to identify concerning behaviors and to work with the child and family on related strategies. CAMHS also work with the child suspected of having ASD and undertake psychometric assessments[18.]

Sometimes CAMHS will recommend that families wait and watch the situation rather than have a full assessment at the current time. This allows the child more time to develop before a diagnosis is given.

In North Lincolnshire parents, caregivers and guardians may access the CAMHS service through different routes such as through their local GP or school, however they cannot refer themselves.

Local Support Services

In North Lincolnshire the local authority's Autism Spectrum Education Team (ASET), helps support children with their educational needs and provides information and

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[18] http://camhs.rdash.nhs.uk/professionals/north-lincolnshire/diagnostic-care-pathway/

training for parents, caregivers and guardians[19]. In addition the local authority’s Complex Behaviour Team can help families, who have a child with ASD, if the child’s behavior at home becomes particularly challenging”[20]

Support groups in North Lincolnshire for autistic children / young people and/or their families include:

- **ASET / CAMHS Coffee mornings -** ASET now also run coffee mornings with CAMHS for parents of newly diagnosed students.
- **Carers Support Service -** The Carers Support Service holds the contract for providing support to parents, caregivers and guardians in North Lincolnshire. Help includes giving parents opportunities to talk to other carers in a group setting and supporting siblings 8-15 years old.[21]
- **Magic Moments -** A charity supporting autistic children and their families. The aim of Magic Moments is to raise money to fund holidays, short breaks, day trips and recreational activities for autistic Kids, their families and carers, as well as offer short term respite for siblings.
- **Consultancy, Advocacy and Training (CAAT)** – provides support for Autistic people and training and consultancy for organisations[22] CAAT have held various support groups at Café Independent in Scunthorpe.
- **Parents in Participation (PIP) -** This group consists of parents, caregivers and guardians who look after a child with special needs. At the group members can give their views. PIP run coffee mornings held at various locations across North Lincolnshire and hold Parent Autism Support Groups.

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[19] https://www.autismlinks.co.uk/support-groups/group-support-yorkshire-and-humberside/northlincolnshireautismspectrum?region

[20] http://www.northlincslocaloffer.com/directory-item/?provider=Q29tcGxleCBCZWhhdmlvdXIgVGVhbQ%253D%253D&redirect_back=http%3A%2F%2Fwww.northlincslocaloffer.com%2Fdirectory%2F%3Fsearch%3DComplex%26list_LO_Early_Years_category%3D%26list_LO_Primary_category%3D%26list_LO_Secondary_category%3D%26list_LO_Young_Adult_category%3D%26list_Area%3D%26LkthDATa%3DiePFbuBf%26iqporXRINKhe%3Dl3_mYQuwt96T%26LkthDATa%3DiePFbuBf%26iqporXRINKhe%3Dl3_mYQuwt96T

[21] https://www.carerssupportcentre.com/nl/parent-carers/

[22] https://caatorg.co.uk/

Approach

In order to facilitate contact with the families of children with an ASD diagnosis, HWNL worked with:

- The RDaSH Lead for the North Lincolnshire diagnostic pathway
- The Lead teacher for Autism - NLC's Autistic Spectrum Education Team (ASET)
- The Teacher in Charge of Primary Provision – Also from NLC's ASET

Firstly, focus groups were held with parents, caregivers and guardians who attended training organised by the ASET team. This provided HWNL with an opportunity to find out about the support offered and what parents, caregivers and guardians felt about the diagnostic pathway.

Two focus groups were held; one for those who had children at primary school and the other for those with children at secondary school. The information gathered from the groups was then used to create questions for the in-depth interviews with parents, caregivers and guardians who had children with ASD.

Promotion of the interviews included:

- Asking those attending the focus groups if they would like to be involved
- Use of Facebook and Twitter to target those who may be interested
- Advertising in HWNL's Newsletter (Jul-Aug 2018)
- Our Engagement Officer attending and raising the matter with the Parent PIP Forum

Seven semi-structured interviews were then held in July 2018 at locations suitable for participants including; the Learning Development Centre, Scunthorpe; Normanby Gateway, Scunthorpe; and at interviewees' homes. The interviews were recorded and later transcribed in order to identify themes.

Themes identified from the interviews included: professionals not taking ownership of referrals, difficulties with the criteria for accessing CAMHS, schools not recognising children who may have ASD and poor post diagnostic support. In order to ascertain how widespread these issues were and to gather a wider range of views a survey was created, targeted at parents, caregivers and guardians. This was then given to certain key groups who kindly assisted in distributing to the public including:

- The Carer's Support Centre, Brigg
- ASET Team
- NLC
- NLCCG

The survey was also put on Healthwatch North Lincolnshire's (HWNL's) website.

During the interviews participants referred to schools as being key to the referral and diagnostic process as well as mentioning the support given from schools. A second survey was therefore created to ascertain the schools perspectives of the referral and diagnostic process. The survey also gave schools the opportunity to tell HWNL about any support they would like. Schools and colleges contacted included all local:

- Primary schools
- Infant and Junior schools
- Secondary Schools
- Special Schools
- Colleges

Unfortunately only two fully completed responses were provided from schools and colleges meaning that the information given could not be classed as representative of the wider education system. The results have therefore not been shared in this report.

Limitations of the Study

Two areas of research limitation were encountered during the project, which may have impacted upon the overall findings. The first was that the number of participants willing to be interviewed was lower than anticipated at seven. It was hoped that the supporting survey would generate more responses to add weight to the findings of the interviews or challenge perceptions, however, only 13 responses were received from the public survey and only two survey responses were received back from schools.

The difficulty in encouraging the public to respond lead to the extended timescales and numerous different approaches to gain a greater sample size which included attempting to enlist the support of partners to enable us to reach current service users. Despite these efforts the response rate remained low.

The second limitation is due to the recentness of the experiences of those who completed the survey. Some of those surveyed received a diagnosis for their child(ren) over 12 months ago; indeed some were over five years ago. However, despite this the feedback does provide useful insight as to how families feel when faced with a child presenting with additional needs, and of what they specifically find important to them, regardless of the current service provision, therefore the feedback has been kept within the report.

Findings

Focus Groups

We held two informal discussion groups with parents who attended, post diagnostic support, training sessions organised by ASET. One of these groups was with the parents, caregivers and guardians of primary school children; the other was with the parents, caregivers and guardians of secondary school children.

Feedback from the discussion groups highlighted that there were many different ways that people accessed help, for example, through the education system or the GP, but all felt that the process should be consistent and have clarity.

Some focus group participants mentioned that if a child could make eye contact or communicate then they would not be referred. It was also suggested that help was easier to get for lower ability children and that services were reluctant to diagnose primary school aged children.

Some participants mentioned feeling lost and overwhelmed, with parents, caregivers and guardians in both focus groups, mentioning their struggle, fight and determination to get help.

Parents, caregivers and guardians also felt that nobody was looking at the whole picture as children behaved differently at home and at school. They also commented on having to do their own coordination and chasing between services and that an advocate was needed.

Finally, there seemed to be a lack of post diagnostic support and a lack of support for the wider family. Diagnosis was given but nothing further offered, making diagnosis the finishing point.

Interviews

Referrals, Waiting and Acceptance

Ownership of Referrals

Two Interviewees mentioned professional's lack of ownership around referrals, leaving families stuck in the middle between education services and the medical profession.

One interviewee explained that for nearly a year the GP and school passed ownership between themselves. The interviewee mentioned that their GP **"batted it back to the school, who batted it back to the doctors, who batted it back to school who batted it back to the doctors".**

A second interviewee explained that the school nurse had undertaken visits at home and school and felt their child showed signs of ASD. The school nurse felt that child should be referred to CAMHS or an educational phycologist. However, the parent explained that they spoke to the head SENCO who would not refer, saying that ASD was a medical condition and therefore a medical professional would need to refer the child. Following this the parent went to their GP, however someone had cancelled the appointment "***because the GP doesn't deal with Autism. You need to go through the education"***. After the parent questioned this a locum doctor saw the child.

Signposting and Acceptance

Six interviewees commented on school staff not recognising their child's autism. Some interviewees mentioned that the signs of ASD were put down to other issues such as; adoption, attachment, naughtiness, tiredness and immaturity, with one interviewee saying that the signs were "***just generalised all the time, all the time…if I'd waited for school we'd be at the start of the whole thing right now"***. In some cases interviewees had a perception of not feeling heard despite raising concerns directly.

Two interviewees alluded to schools lack of accountability when they do not pick up signs of childrens' ASD, for example, ***"it'd just be nice if there was some place you could go where people had to answer for things like why the school didn't pick these things up".***

One parent mentioned that each time they took their child to the Consultant they were told to wait another six months as the child may develop further when they start school. The parent wasn't confident that this was the right decision;

'Surely that would have happened by now but you don't argue with the doctors too much do you?"

The parent also mentioned that often the consultant was a different person each time they visited, which raised concerns over continuity of care and the information provided.

CAMHS – Criteria for Access

Four interviewees mentioned potential difficulties with CAMHS agreeing to assess children, for example, one parent commented that they went through a telephone questionnaire with CAMHS and it was explained that the only reason that the referral was accepted was because the child had nurture support at school and that the referral may not be accepted by CAMHS ***"even if you get your letter and your GP says 'I believe this child has autism', CAMHS don't necessarily have to agree with that"***

Another interviewee explained that, following their telephone call with CAMHS, CAMHS spoke to a college representative who explained that the young person was already speaking to the school counsellor. The parent explained that this wasn't the person CAMHS needed to speak to and that counselling was not what was required. ***"So…that changed it and we went forward. So there was already a stop point if you weren't persistent".***

One interviewee explained that their GP referred them to CAMHS but it was sent back. CAMHS decided that there was no case to open on this occasion. The child later received an assessment after being re-referred by their GP. Following this the child then ***"came out with this whole host of diagnoses and we had gone from being told our child was just naughty, to actually there is a lot going on"***

Finally, another interviewee explained that a child in their care had been referred and accepted before they had responsibility for the child, and so had missed two appointments .This child was refused an appointment. ***"You're playing the chase game. You have to prove that this child has a need all over again, even though they've accepted in the past that the child does have a need. It's hard, it's really hard".***

Assessment

Child Development Centre Assessment

Only one interviewee had had experience of dealing with the CDC for an assessment just as their child was turning five. The Health Visitor requested a full assessment, which was arranged quickly. At the assessment an explanation was provided on what would happen, however, the parent felt that the setting was not age appropriate.

"when the other children were crying or screaming, my child would sit and cover their ears and wouldn't interact with the other children at all but was absolutely fine with the adults"

The parent was also concerned that the assessment had signed their child off with no speech and language issues. However their child said something straight after the assessment that was not understood. The parent was then worried that their child had not been understood all the way through; ***"I thought you just signed him off. Why, can't you understand him?".*** The parent reported that the child was later assessed by CAMHS and given an ASD diagnosis.

Overall satisfaction with the CAMHS Service

Once CAMHS was accessed most interviewees were very satisfied with the overall service, for example one interviewee said ***"it was amazing. It was the nicest process I have ever been through".*** Parents, caregivers and guardians specifically gave positive feedback on the following areas:

- Waiting times to access the service (generally three to four months but quicker than expected)
- Staff attitude and professionalism
- Information provided about the process / what to expect at appointments
- Having named contacts within the service who would look after their case allowing for consistency

However, two interviewees mentioned that the assessments had had an impact on them. One mentioned feeling like a ***"bystander"*** in their child's diagnosis, whereas another mentioned their distress at watching their child struggle and trying to understand a game that was used during the assessment. One commented that despite the ***"lovely"*** nature of the assessor "***I just wanted to get up and say stop it, you can see he can't do it, stop".***

Reports

Understanding the CAMHS Report

Three interviewees commented on the reports produced by CAMHS. It was acknowledged that the report contained facts on who could help post diagnosis; it provided telephone numbers and gave information on books that could be read. However, it was felt that the report was not easy to read and that understanding the abbreviations used in the report was an issue;

"I don't know what any of it means I couldn't figure it out. I could Google it and I could figure it out but even then abbreviations in Google could mean a million different things".

Some of the interviewees expressed that their understanding of the implications for the child's future were left unclear following receipt of the CAMHS report.

"you've got the cold facts there but what does that actually mean? What are your expectations as a family and as a child, as the young person, what are your expectations for your future?"

Another parent commented that although they had an appointment with CAMHS to go through the report which they found useful, they felt that it was a case of ***"let's discuss it for an hour and crack on"***

How interviewees felt after diagnosis

Interviewees had a sense of relief and justification once their child received the ASD diagnosis;

"Justified in, you know, in getting the diagnosis in the first place".

One interviewee explained that when they received the ASD diagnosis for one of their children, they were "***devastated"*** due to the range of diagnoses given and said regarding school **"we *felt we were just sending you to the Lions every day and everybody's just made out that you were naughty".***

Two interviewees also commented on how they felt about their children being identified as having autism. One wondered whether, as the child got older, they would regret the diagnosis, ***"the child has got a label and as much as you don't want that label because that child is going to carry that with them but in the same breath the issues are there".*** Another was concerned that ***"maybe when the child is older they will hate the whole thing and wish it didn't exist."***

Education Services - meeting children’s needs

A mixture of comments were received about the support and adjustments provided to children from schools. The feedback highlighted the importance of schools adjusting to meet children’s needs and suggests a lack of consistency in the way schools and colleges, in North Lincolnshire achieve this. One parent gave the example of their child being predicted a grade E in a subject, for their General Certificate of Secondary Education (GCSE), and their discussions with the school around this. The parent wondered whether an alternative subject would be more appropriate. “***What’s the point of wasting two years on a forecast of an E, when a child can be doing practical subjects where they are getting B or a C.”*** However, it was felt the school was unable to accommodate this meaning that the child had to take the subject in which an E was forecast.

In contrast another parent praised the school their child attended and the support received; ***“Our school are very good they have a family support team so there’s a family support worker that if you’re struggling with issues at home, they will do home visits and help with routines and things like that, they are outstanding”.***

Additionally three interviewees highlighted the importance of teachers using the correct language and behaviours to communicate with autistic children in order to achieve the best results. One interviewee explained that if the teacher broke instructions down, the child could then manage to follow them; “***she broke it all down into tiny little bits and the child was doing it and got in a lot less trouble”.***

Another interviewee explained that their child’s teacher would telephone them saying that the child would not speak to them in class. When the parent questioned the child about this they replied; “***but she’s told me that I mustn’t talk in class so I think she’s trying to trick me and then she’s going to tell me off”.***

An interviewee explained that their child was put into a ***“quiet room”*** where the staff ***“would try and slowly bring the child back down”*** to manage their behaviour. However, it was felt by the parent that that staff only had to say ***“that’s not appropriate come on you need to come out”*** and this would be a more effective way to manage the behavior of this particular child. This further highlights the need of staff in schools to use the correct language and understand the needs of children with autism.

Health Professionals Understanding

Two interviewees gave examples of the issues that they had had with health professionals' interaction with them and their autistic children. One explained that they had attended Scunthorpe Hospital's Accident and Emergency (A&E) department and explained to a member of staff that their child had ASD;

"Health professionals have no idea … she still spoke to my child in a way that you would speak to anyone else".

The second interviewee explained that their child had gone to the dentist and felt that the dentist appeared surprised that the child's parent had accompanied given the child's age. The parent explained that the reason for this was detailed in their notes and that the dentist should have understood why the parent would want to accompany their child ***"because if he'd asked my child questions they wouldn't have answered him. You would have thought that as a health professional he would have been aware of that and appreciated it"***

Joining-up services

For some families various agencies were involved. Two interviewees specifically mentioned having to coordinate information themselves rather than relying on professionals. One interviewee said ***"you have to do it yourself"*** and the other explained that ***"nobody took control of anything… I coordinate all of that…and make sure the minutes are right, make sure everyone's done their actions".***

Parents / caregivers and guardians questioning themselves

Five parents remembered questioning themselves, pre-diagnosis, over matters concerning their child's ASD. This included wondering whether they were seeing issues that did not exist, for example, one interviewee said "***you'd go for your play and stay and you'd sit there and you'd watch your child playing so nice, doing lovely, and then you come out and you think no it's just me I'm mad***".

Some Parents also wondered if their child's behaviour was due to parenting skills rather than an actual condition, for example, one interviewee said ***"you have to question your parenting first off, like are you doing the right things?"***.

Another mentioned feeling as though they were to blame;

"what have I done wrong? Have I brought my child up wrong, what difference could I have made in how I brought up my child?"

One parent mentioned that since diagnosis they had blamed themselves for not fighting hard enough at an earlier stage. They felt that if they had fought harder then their child may not have experienced as many problems.

Post-Diagnostic Support for families and children with ASD

Overall Support

Some interviewees mentioned sources of useful support and information, which included accessing general support through the National Autistic Society Website and finding YouTube clips of people explaining how the diagnosis had affected them.

Emotional support, for interviewees, was mostly provided by friends and family. Financial support came from the Disability Living Allowance and Max cards. It was mentioned that Max cards can be useful in helping eligible families access social activities and entertainment at a reduced rate or for free.

The majority of interviewees however explained that overall there was a lack of professional support available, aside from that provided by ASET. One interviewee said that ***"you spend the first bit thinking right OK I've got the diagnosis so all this help is going to come now and … I've had no help I've had no appointment with the new Kaleidoscope people that I've put my name down for"***. (the parent was referring to the Carers Support Service)

Another example included***: "you were just kind of left bobbing up and down in a diagnosis. Is there something really wrong with my child? And how do we help them".***

Two interviewees also mentioned specific examples where a lack of professional support was likely to negatively impact upon their children. One said that their child requires sensory support but that "***the commissioners don't recognise it".*** The other parent, expressed concern over the support available for young people diagnosed with "high functioning" Autism and that ***"there's no help in terms of employment or anything or advice about employment or what do you want to do with your life? Is that a good idea or not…ASET don't cover that so where are you?"***

Finally, one parent mentioned that CAMHS do not offer ongoing support, however, Ryegate in Sheffield does offer this service but that this wasn't made clear to them when they had to choose between the two services for their child's assessment. "***We thought CAMHS would offer the same service as Ryegate but it's only afterwards that you're told oh no we're diagnostics only".***

Kaleidoscope

Before January 2018 Kaleidoscope provided post diagnostic support to families who had autistic children. Two interviewees mentioned positives for Kaleidoscope including: it's location and that it provided a specialist service to whole families that had a child / children with disabilities and additional needs.

However, two other interviewees felt that the meetings they attended at Kaleidoscope were aimed at younger children, for example, one interviewee said that Kaleidoscope staff explained "***We can do play dates***" but that everyone in that meeting was "***looking round thinking why do we want play dates?***"

Carers' Support Service

From January 2018 the Carers' Support Service have provided support to families with autistic children. Feedback given on the Carer's Support Service included there being no holistic family support. It was pointed out by one interviewee that unlike Kaleidoscope, Carers' Support do not provide support to the whole family; ***"We had care as a whole unit. Individual care is no good"***.

A lack of communication was also highlighted by one parent who was still waiting to hear from Carers' Support after putting their name down at a course held by ASET.

A third interviewee wanted support information relevant to their situation, instead of having to look through entire brochures to find the required section. They also felt the groups were not accessible at the times held; "***they were in the middle of the week in the middle of the day***".

Autistic Spectrum Education Team (ASET)

Most interviewees complimented the ASET team. One interviewee commented specifically on ASET's course: Supporting Social Communication and Interaction – A course for Parents and Professionals (SCIP). They explained that whilst the course was ***"brilliant"*** it was not necessarily the staff who worked with their child that ended up on the course with them. It could be a professional dealing with a different child: ***"The only thing that I found really disheartening was that the lady that came from the school onto the SCIPS course with me doesn't deal with my children. She's dealing with another child who hasn't got a diagnosis but my child had a diagnosis and didn't have the benefit of that carer"***. However, it is not known who made the decision to select the member of school staff to attend the course, or the circumstances around this.

Support for siblings

The need for support for siblings was highlighted by three interviewees.

One parent explained that their children find having a sibling with ASD very difficult to cope with ***"they adore the child but find the aggression very difficult. They just avoid each other or fight. They don't understand the child's aggression and they don't understand why they lash out".***

Feedback also suggested a need for age appropriate support through counselling, especially for older siblings. For example one interviewee mentioned that their child had a sibling who was 20 and, therefore would not ***"want to come and do cut and stick. The sibling might want to have a chat to somebody about the child's diagnosis for instance and what that might mean".***

Concerns for their child's future

Four interviewees mentioned concerns they had for their child's future. It included; whether the child would be able to live independently, get a job or access financial support;

"I can't imagine how my child is going to be if they can't find work and have to make a claim for benefits".

Advice interviewees gave on how to deal with the process

Interviewees were asked what advice they would give to others who may be going through the referral and assessment process. The message from five participants was to keep going and be persistent. One interviewee explained that they felt it important to be "resilient" and suggested parents "***be confident in what you know about your***

child and what you're observing; write a diary, go with hard and fast facts, observations. Demonstrate a pattern and go in and don't take no for an answer".

In particular one interviewee gave their opinion of the importance of being persistent with schools, saying that ***"My experience is the school doesn't do anything off it's own back, you have to be a pushy parent".***

Another parent said they found the process ***"absolutely exhausting"***

Suggestions for Process Improvements

Interviewees made suggestions as to what would help improve the process and the support received post diagnosis. This included; having a clear and concise diagnostic pathway, a unified process between counties, making courses accessible to all by giving access to childcare and providing leaflets for teachers and other professionals explaining the best way to talk and communicate to children and young people with autism.

Finally, interviewees also identified the aftercare and support following a diagnosis as an important area for improvement. This included:

- More discussions around how it feels to have a diagnosis, the future and what the diagnosis means.
- Only seeing the people who are relevant to that families situation
- A list of parents who would be willing to be contacted to help others and bounce ideas off. (The list should be fluid so people do not have to stay on it long term).

ASD Survey (public)

This survey was designed for parents, caregivers and guardians, who have children diagnosed with ASD. Thirteen people completed the survey, however, one person completed their survey for two children. For the purposes of this report the two children will be counted separately in the question analysis, bringing the total number of responses to fourteen.

Profile

Children's ages at the time of the survey

Age	*Number of children*
3-5	2
6-10	4
11-16	4
16-18	0
18+	2
Did not answer	2

Length of time since diagnosis

Age	*Number of children*
Under 1 year ago	3
1-3 years ago	2
4-5 years ago	1
6-10 years ago	6
11+ years ago	1
Waiting for a diagnosis / referral	1
Did not answer	0

Feedback also showed that seven children had received a dual diagnosis. In four cases this was ASD and ADHD.

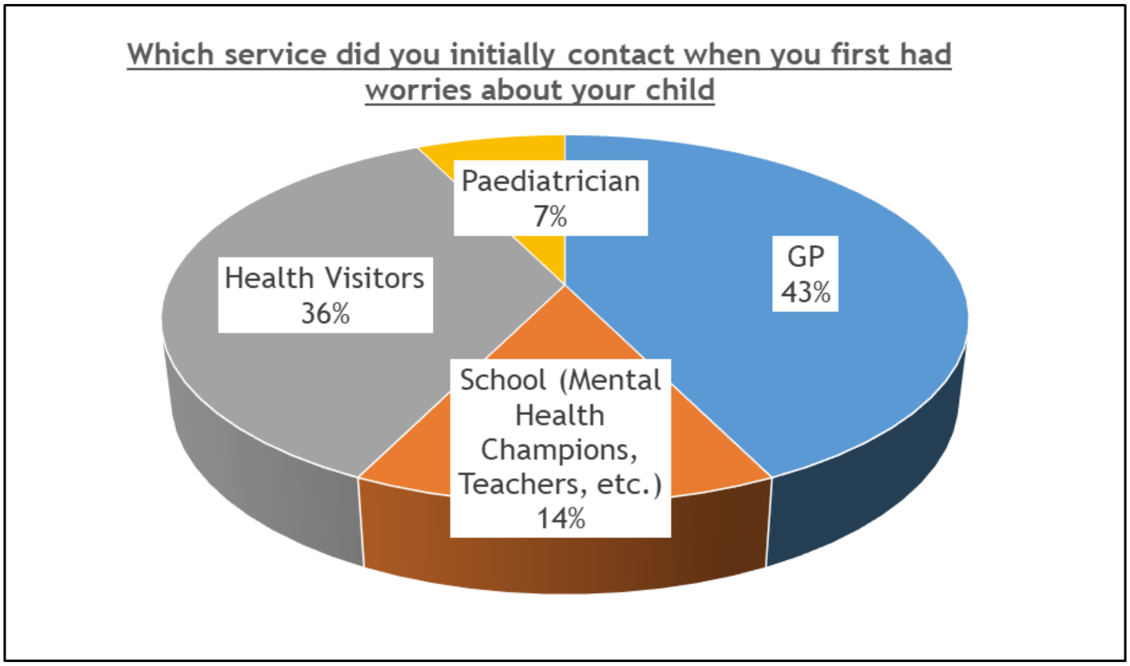
Participants were asked what type of school their child had attended at the time they received their ASD diagnosis; most said mainstream primary school. Following diagnosis the majority of participants said that their children attended special schools.

School Type	*School attended at the time of diagnosis*	*School attended after diagnosis*
Mainstream Primary School	6	4
Mainstream Secondary School	3	1
Special School	2	5
Sixth Form College	0	0
Independent Specialist College	0	0
Did not answer	3	3

Eight children had an EHCP and six did not. Only one of the six children who did not have an EHCP had requested one.

Referral

When asked which service they initially contacted when they had worries about their child most participants (43%) said their GP, with health visitors being the second most common (36%).



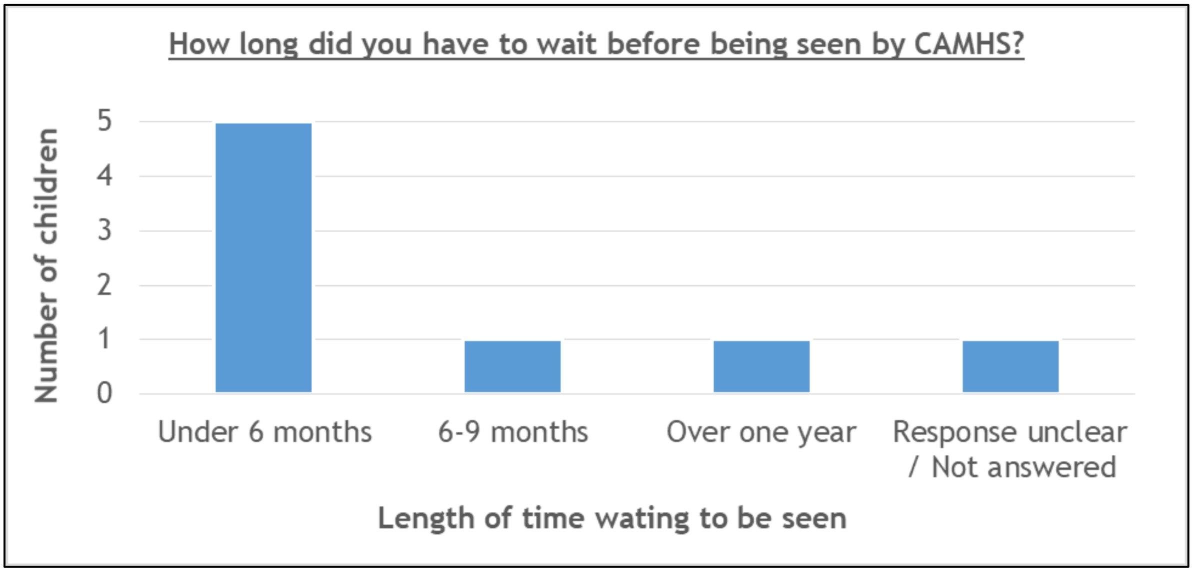
Referral for assessments were made from a variety of services, however, the majority (five) had been referred by their GP.

Service referring children for assessment	***Number of Respondents***
GPs	5
Health Visitors	3
Pediatrician / Pediatrics	3
Child Development Coordinator	1
East Riding Social Communication Panel	1
Psychology	1

CAMHS

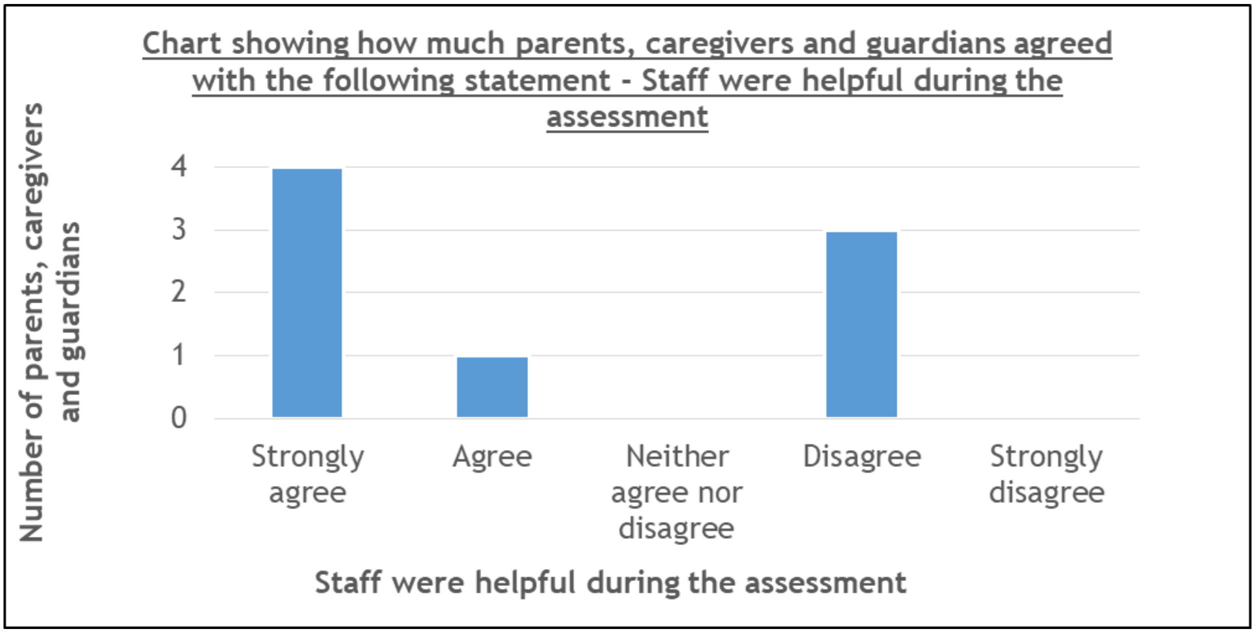
Eight parents said that they were referred to CAMHS for an ASD assessment. Two children were referred more than once. One comment on this was that the ***"1st diagnosis was not recognised by pediatrician"*** another comment highlighted a parent's persistence in seeking a diagnosis; **"… I insisted [child] be assessed again or I be given a name to go down the private route. At this point [child] was agreed to be assessed again".**

The following chart reveals that most children were seen under six months from referral.



This coincides with the interview feedback that suggested waiting times for assessment was not an issue for families. However, recent information given to HWNL from NLCCG suggests that the length of time waiting for assessments has now increased and is now being addressed[23].

Interviewees also gave positive feedback on staff attitude and professionalism. The following chart highlights respondents' opinions about the helpfulness of staff.



Of the eight parents who said they had been referred to CAMHS five either agreed or strongly agreed that staff were helpful during the assessment. However, comments about staff helpfulness were mixed, for example one respondent said **"The Ancillary staff were great but the pediatrician was rude, uneducated and dismissive".**

Positive feedback was given from interviewees on the information provided on the assessment process. The next chart shows that five survey respondents either agreed or strongly agreed that CAMHS had kept them fully informed.

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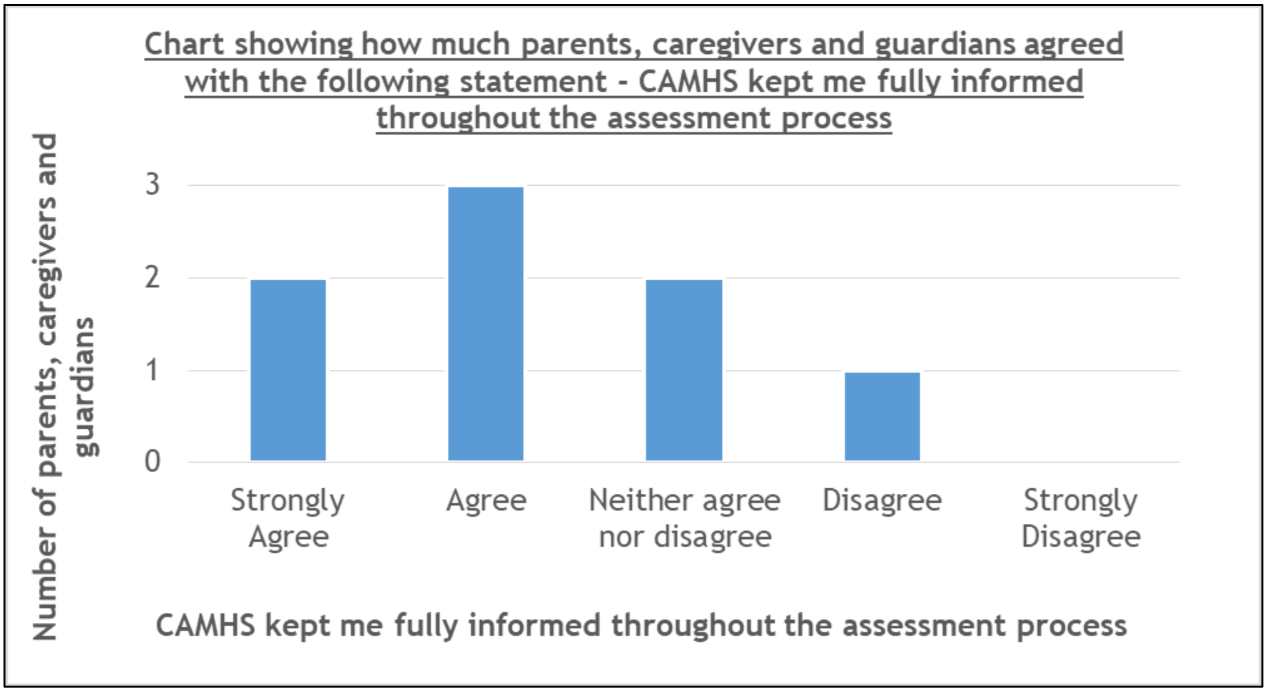
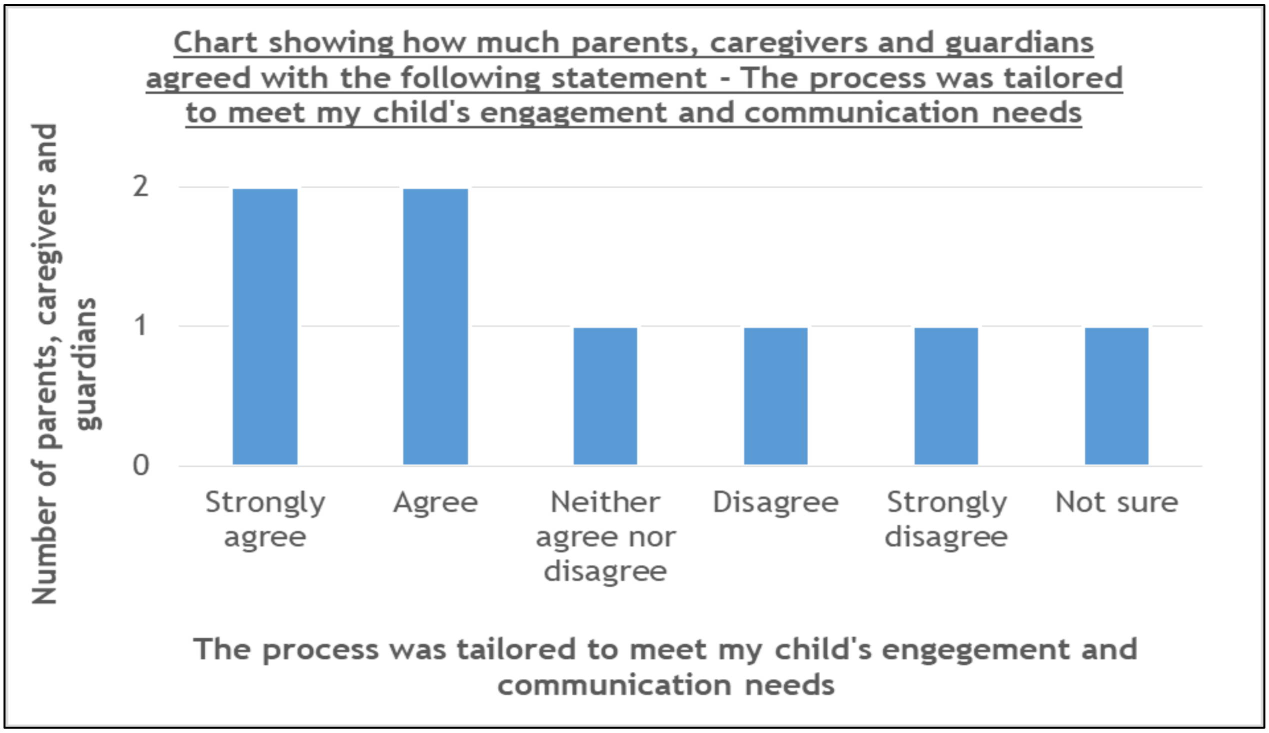
[23] Information from NLCCG presented at the SEND Standards Board Oct 2018

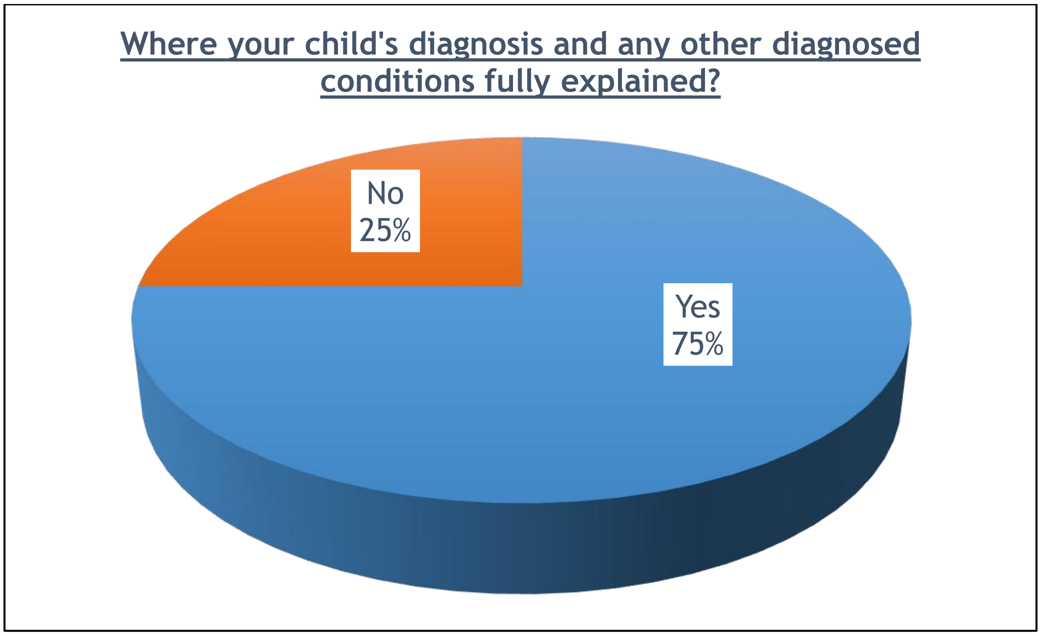


Respondents were asked whether they agreed that the assessment process was tailored to meet their child's engagement and communication needs. Of the eight whose children were referred to CAMHS, half either agreed or strongly agreed, with two disagreeing or strongly disagreeing.



One positive comment was received about the assessment process; the respondent commented: ***"Yes there were many reports over the years and various observations and evidence to support diagnosis"***. However, two other comments mentioned that the assessment process was lengthy.

When asked if their child's diagnosis was fully explained, 75% said yes.



Respondents were asked how their families felt following diagnosis. From the eight people who had been referred to CAMHS, five responses were received highlighting similar issues to those from the interviews such as: wishing their child had been diagnosed earlier, worries for the child's future and having a sense of relief, for example one respondent said **"A sense of relief. It was what we had already been expecting to hear and now we had an answer, a response for others".**

Post - Diagnostic Support

Respondents were asked what different / additional support they would have liked to have received at the point of their child's diagnosis. Two respondents mentioned more support for their children, one of these expanded on this saying that wanted more age appropriate support because; **"Groups, support networks etc all seem to be geared**

up for young children - toddlers”. They also explained that their child **“has a very restrictive diet and I would have liked/would still like help and advice without having to suffer having to get a referral to a dietician”.**

Respondents were asked about which professionals they were in contact with for ongoing support regarding their child’s condition. The following table highlights the responses:

Service	**Number of respondents (whose child had been assessed by CAMHS)**	**Number of respondents (who child had not been assessed by CAMHS)**	**Total**
GP	4	2	6
CAMHS	3	0	3
Paediatrician	2	4	6
School Nurse	1	0	1
Social Worker	1	0	1
ASET	1	0	1
Learning Disability Team	1	0	1
Portage	1	0	1
Clinical Phycology	1	0	1
Dentist	1	0	1
Transitions Team	1	0	1
SENCO	1	0	1
No Services	2	0	2
Prefer not to answer	1	0	1

Overall more respondents received support from their GP and Paediatrician following their child’s diagnosis.

Respondents were asked whether they had had support from the ASET team. The following table highlights the responses given

Response	Number of respondents (whose child had been assessed by CAMHS)	Number of respondents (whose child had not been assessed by CAMHS)	Total
Yes	2	2	4
No	4	0	4
I am not aware of ASET	2	4	6
I know about ASET but do not require their support	0	0	0

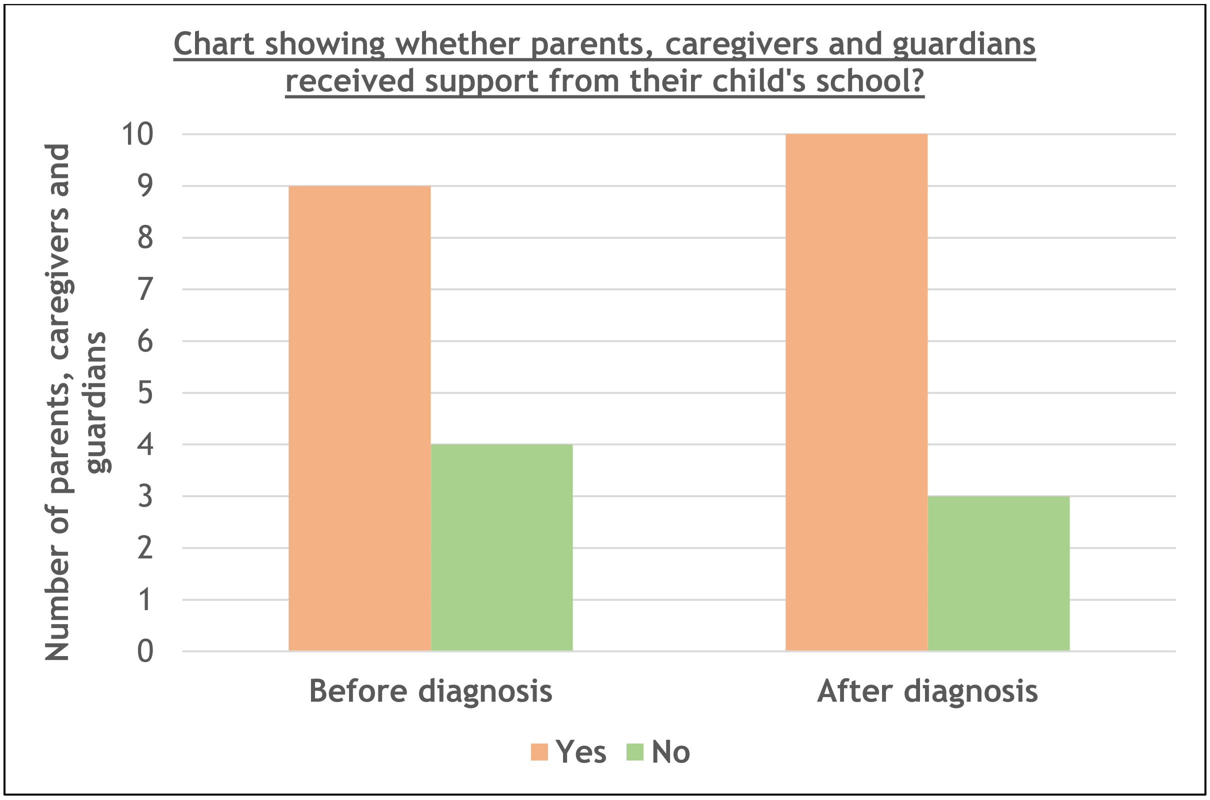
Four said that they had received support from the ASET Team, four said that they did not have support from the ASET team and six were not aware of ASET. Interestingly two of those who said they were unaware of ASET had had their child assessed through CAMHS.

Four comments were received about the ASET team, two of these coincide with the interview feedback giving compliments around the service offered including the training courses available. One comment mentioned attending ASET in January and the final comment mentioned attending meetings at school: **"Meetings at school where I was patronised. I am studying masters in autism spectrum and know what I am doing".**

Respondents were also asked whether they had received assistance from the Carer's Support Service. Their responses are shown in the following table:

Response	Number of respondents (whose child had been assessed by CAMHS)	Number of respondents (whose child had not been assessed by CAMHS)	Total
Yes	3	3	6
No	2	0	2
I'm not aware of the Carers Support Service	2	1	3
I know about the Carers Support Service but do not require their support	0	2	2
Not answered	1	0	1

Parents were asked whether they received support from their child's school both before and after diagnosis. The next chart reveals that most schools were supportive both before and after diagnosis.

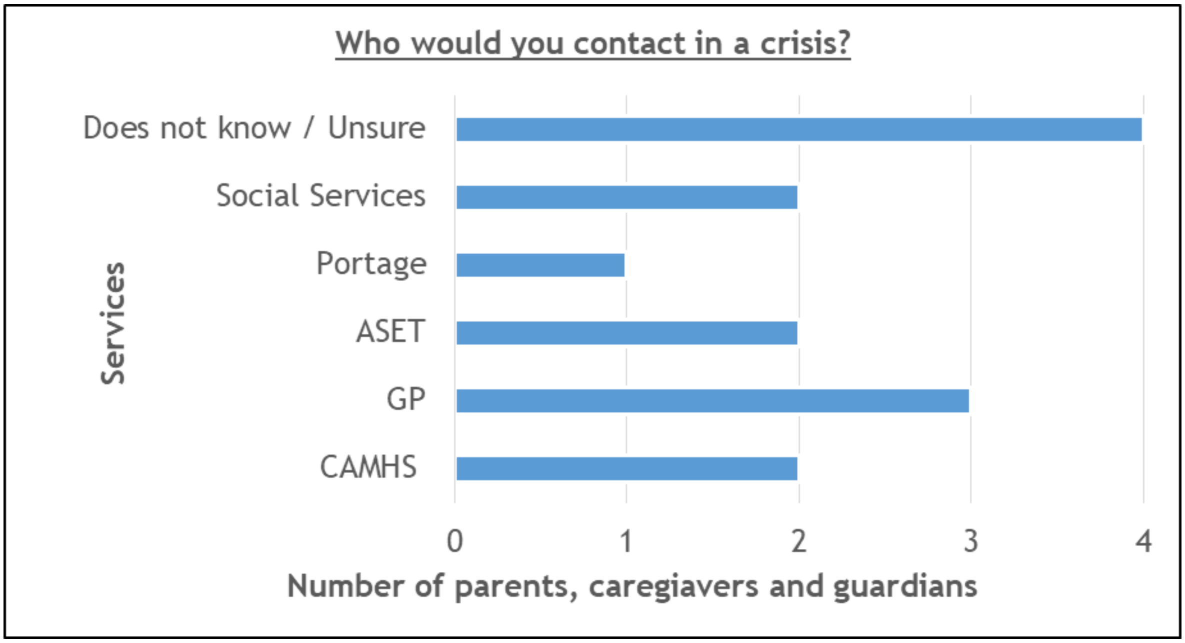


Three respondents positively commented on the support schools provided before diagnosis. One specifically mentioned that their child had 1:1 support through a teaching assistant and that the whole school was taught “**how to say good morning to everyone in Makaton at assembly**”**.** However, they did go on to state that secondary school was more difficult **“as children get older they are expected to 'fit in' and many autistic people cannot! Schools have to adapt to them and not the other way around. I constantly hear this from parents that the school doesn't understand! Small adjustments make a huge difference to these young people and allows them to function to learn and most importantly to feel they 'fit in.' Some schools 'get this' more than others. Some teachers make great adjustments, really simple and they are the ones who get good outcomes as children learn and enjoy learning”.** This comment echoed the opinions of some of the interviewees in that changes by school staff can help autistic children achieve the best results.

Comments received about respondents’ experiences of support after diagnosis were mostly positive and included one respondent who noted that they **“continue to support us all and keep in regular contact. I know I can contact the SENCO with any queries”.**

One respondent commented on support both pre and post diagnosis; **“One to one implemented, measures were put into place to help [child] cope - visual timetable, safe space etc”.**

Respondents were asked who they would contact in a crisis. Some gave more than one answer. The following chart shows that the majority of respondents were unsure as to who they would contact with GPs being the second most common answer.



Finally, respondents were asked what additional ongoing support they would have liked but did not receive. Answers included help, support and advice for parents on property adaptations and behavioral management. It also included support for children with ASD through age appropriate activity groups and support with anxiety and issues associated with teenage years.

Conclusion

ASD Diagnostic Pathway

1. Overall, families felt the need to fight in order to be referred to diagnostic services, for example, it was mentioned that professionals from education and medical services passed on the ownership of referrals. This came through in the advice from interviewees on how to deal with the process, which included comments on persistency and resilience. There was also an expression of relief and justification once diagnosis had been confirmed.
2. Participants of the focus groups seemed unclear on the process of getting a referral into CAMHS as there were many avenues to access the service. They felt the process should be clear and consistent.
3. Some interviewees questioned the information CAMHS based their judgements on when deciding whether to assess children including those spoken to within school. There was also a perception amongst focus group attendees that services were reluctant to diagnose primary school aged children. We are however aware that the local transformation plan now suggests that all children who need an assessment are getting one and that robust criteria is now used to select those who need assessments.
4. Positive experiences of the diagnostic pathway have been highlighted including: the professionalism of CAMHS staff, the information provided by CAMHS on the assessment process and the waiting times to access the service.
5. Some interviewees felt that the report from CAMHS was not easy to understand; with the use of unexplained abbreviations in reports being highlighted.
6. The surveys showed that some respondents were not aware of the ASET team or Carers' Support Service and in some cases their children had been assessed by CAMHS, suggesting either a missed opportunity for promotion of support services or that this information was not being taken on board by parents during the assessment process.

7. One interviewee had had experience of the CDC for their child's assessment. The parent felt that the setting was not age appropriate and was left feeling unsure as to whether their child had been understood properly during their assessment.
8. Focus groups attendees felt that nobody was looking at the whole picture as children behaved differently at home and at school.
9. Interviewees felt that schools were reluctant to identify when children were struggling, despite some parents raising their concerns; two interviewees believed that schools had a lack of accountability.
10. Interviewees' suggestions for improving the process included: more discussions around how it felt to have a diagnosis, the future and what their diagnosis meant. It was also suggested that there should be a clear pathway and that people should only see relevant professionals.

Post Diagnostic Support and Interaction with Professionals

1. The survey results identified that most schools were supportive both before and after diagnosis. However, some interviewee comments suggested a lack of consistency in how schools in North Lincolnshire were meeting the needs of children and young people, with some being successful and others falling short. The importance of teachers using the correct language and behaviours to communicate with autistic children was also highlighted through interview and survey feedback. It was suggested that there should be leaflets for teachers and other professionals explaining the best way to talk and communicate to children and young people with autism.
2. Two examples were given of medical professionals' negative interactions with autistic children and their families. Further information on ASD or and how to communicate with Children with ASD may have helped.
3. Overall ASET were complimented and this included praise for their courses. However, it was felt that child care could be problematic for those attending.

Indeed it was suggested during the interviews that child care for the courses would help parents.

4. The majority of interviewees felt that overall there was a lack of professional support available, other than that provided by ASET. This included; a perception that those who had “high functioning” autism had less support than those who were “lower functioning”; it also included no sensory support being available, a lack of knowledge as to how to access crisis support and a lack of older sibling support.
5. Some parents were worried for their child’s future including whether they could live independently, get a job or access financial support.
6. Comments received about Carers’ Support included; an observation that there was a lack of holistic family support, so the carers may be supported but not the whole family unit. The relevance of some information sent to parents was also questioned along with a comment about a lack of communication.
7. Some parents mentioned that they had to coordinate information between services with focus group participants feeling that an advocate was needed.
8. Two survey respondents felt that they would have liked more support for their children at the point of diagnosis. Following diagnosis some survey respondents would have liked more support for the children with ASD, some respondents also mentioned that help, support and advice for parents on property adaptations and behavioural management. Interviewees also suggested a list of parents who would be willing to be contacted to help bounce ideas off, and the creation of leaflets for teachers and other professionals explaining how to communicate with young people and children with autism.

Recommendations

North Lincolnshire CCG and North Lincolnshire Council should utilise information contained within this report to help inform the future development of the ASD diagnostic pathway. Particular areas of consideration in this development include:

1. Guidance to be established for potential referring professionals (including educational, medical and social) that explains the referral process along with baseline symptoms or criteria that might trigger a referral.
2. Monitoring systems to be implemented to determine where referrals are coming from and that referral criteria is being adhered to.
3. As part of the referral and assessment process, define how information about a child is to be coordinated, so that the onus is not placed on parents to do this.
4. The development of a process that ensures that the correct professional involved in a child’s care across health, social and education settings, is involved in the assessment and fact finding process, to ensure the most accurate assessment of the child is achieved.
5. A number of parents/guardians felt that the assessment process does not adequately assess the differences in behaviour displayed at home and in school. The process for behavioural assessments to be reviewed to contribute to the achievement of an accurate assessment.
6. Communications to parents to be improved throughout the pathway, with explanations provided as to why specific decisions have been made, for example, if it is determined that a child does not need an assessment. Written communication should be in plain English and free of jargon to ensure there is clear understanding for the parent.
7. Whilst a referral should automatically be made to the ASET team upon diagnosis, feedback suggests this is not always happening. Processes should be reviewed to ensure these referrals to ASET take place in all appropriate cases.

8. Despite the availability of the Local Offer, parents have fed back perceived gaps in local support, specifically financial support available and preparing their child for transition to adulthood (eg. employment prospects). Processes should be reviewed to ensure that the Local Offer is up to date and that parents/guardians are signposted to the full range relevant support services available.
9. The provision of training for parents/guardians to be reviewed to ensure that it is appropriate and accessible around their child care needs and allows for inclusion of the wider family unit.
10. The ASET team's page on the Local Offer advises that support is offered to siblings of individuals with autism. This support is information only, for example, teaching about Autism, rather than emotional support. The feedback received suggests that parents are not always aware that this is available. The process for assessing if considering the needs of a sibling is a need of the family, and how they are directed to support should be reviewed.
11. Consideration should be given to facilitating a peer support group of parents/guardians. Healthwatch North Lincolnshire would be happy to support the CCG and Council in the development of this.
12. Information and guidance relating to how to communicate with an individual with autism should be circulated to educational, medical and social care professionals. Such guidance produced by the likes of the National Autistic Society is already in existence and could be circulated relatively easily.

HWNL recognise that since the occurrence of some of the reported experiences contained in this report, changes have been made to local services and pathways for autism, and that others are underway. However, it is still important to bear reference to past experiences documented in this report to ensure that they continue to be addressed in future service delivery.

Next Steps

HWNL will be taking the following steps.

The report will be distributed to the following:

- Those who participated in the interviews
- Survey respondents who requested a copy
- North Lincolnshire Emotional Health and Wellbeing Group
- North Lincolnshire Clinical Commissioning Group (CCG)
- North Lincolnshire Child and Adolescent Mental Health Service (CAMHS)
- North Lincolnshire Council (NLC) Education Services
- Autism Spectrum Education Team (ASET)

Acknowledgements

We would like to thank members of the public who participated in our focus groups, interviews and surveys and the two school representatives who completed our schools survey. We also wish to thank the Emotional Health and Wellbeing Group along with staff at CAMHS and NLC’s ASET for their support during this engagement.

Finally, we would also like to thank Healthwatch volunteers who assisted staff in gathering patients’ views.

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