



#SpeakUp: Autism Hope Sheffield

What is #SpeakUp?

#SpeakUp is Healthwatch Sheffield's micro grants programme, offering funding of between £500-£1000 to not-for-profit, voluntary, and community groups. The purpose is to run a project which will reach out to people across Sheffield, and hear what matters to them in relation to health and social care.



By working with groups which are already trusted partners in their communities, we can make sure we're hearing from even more people, including those whose voices aren't often heard by decision makers.

Autism Hope Sheffield

Autism Hope are a support group for parents and carers of children with autism. We are based in North Sheffield and meet weekly, providing a space for friendship, understanding and support.



Healthwatch Sheffield

Healthwatch Sheffield Healthwatch Sheffield helps adults, children and young people influence and improve how NHS and Social Care services are designed and run. We're completely independent and not part of the NHS or Sheffield City Council. We want to understand your experiences, and help your views to influence decision-makers in the city.





Background

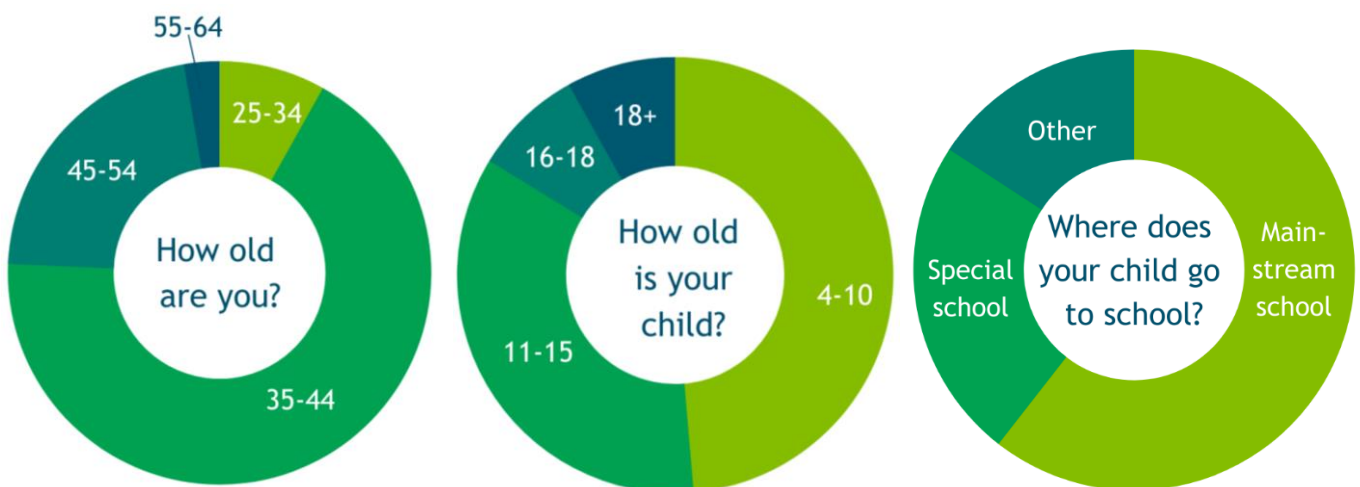
Why did we carry out this project?

We wanted to understand the experiences of parents who have accessed support for their autistic children and for themselves. We support families who are at various stages in their journey - from awaiting diagnosis, to navigating multiple complex systems in health, social care, and education. We want to share these parents' perspectives in the hope that it can lead to a better and more streamlined experience for families in the future.

Who did we speak to?

We spoke to **the parents of 37 children** via individual questionnaires. Each parent told us about their experiences getting a diagnosis for their child, as well as accessing subsequent support.

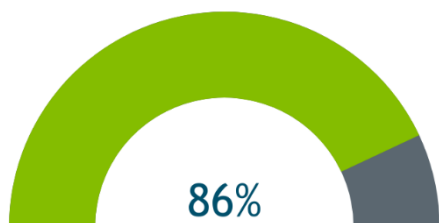
We asked parents about their age, their children's age, and where their child goes to school:



'Other' answers in the last question included children who were no longer in education, or who were currently under the Sheffield Inclusion Centre.



We also asked parents about the diagnoses their children had received. 32 parents said their child had been diagnosed with Autistic Spectrum Disorder, while another 2 said their children were awaiting formal assessment/diagnosis for autism.



Most children also had additional diagnoses - 86% (32 children) had two or more conditions. After Autism, the most common diagnoses were ADHD (11 children), Anxiety (8 children), Sensory Processing Disorder (7 children), Learning Disabilities (5 children) and Speech/Language issues (5 children).

Other diagnoses included Tourette’s Syndrome, Dyslexia, Pathological Demand Avoidance (PDA), Cerebral Palsy, and genetic or chromosomal disorders.

Terminology and Acronyms

Parent-carers attending Autism Hope meetings have usually engaged with a large number of health and social care services, and have been navigating this system for some time now. As such, their discussions contain a lot of ‘system speak’ and acronyms. We have included a list of common acronyms used in this report below:

ADHD	Attention Deficit Hyperactivity Disorder	PALS	Patient Advice and Liaison Service
ASD	Autism Spectrum Disorder (ASD and Autism are used interchangeably in this report)	PDA	Pathological Demand Avoidance
CAMHS	Child and Adolescent Mental Health Services	SALT	Speech and Language Therapy
CBT	Cognitive Behavioural Therapy	SENCO	Special Educational Needs Coordinator
EHCP	Education and Health Care Plan	SEN(D)	Special Educational Needs (and Disabilities)
MAST	Multi Agency Support Team	SIL	Supporting Independent Living
PA	Personal Assistant	SNIPS	Special Needs Inclusion Playcare Service

Key findings

Getting a diagnosis



We asked parents which service or setting had first picked up an issue/concern in their child (people were allowed to select more than one answer). In most cases, a concern was first raised by a parent, health visitor, or school.

Answers not listed in the table were only mentioned by one person each - college, primary inclusion, community paediatrician, and the Speech and Language Team.

Approximately half the children had concerns raised about their development before they started school, either through their parents, health visitor, hospital, or nursery. Concerns were first raised about most of the other children when they were in school. However, some children were diagnosed much later:

“My daughter has been let down all through mainstream school. Social services have known there was something but never listened to, that is until she went to college who picked up on things and phoned me”

Which service or setting picked up an issue/concern in your child?	Number of parents
Me (parent)	10
Health Visitor	10
School	9
Nursery	4
GP	4
Hospital	2



What worked well?

Some parents said their child’s diagnosis had gone smoothly. When asked what had gone well, these were the most commonly mentioned reasons:

- Health visitors who acted proactively during early check-ups (this was especially noted when the child had an older sibling with Autism):

“Our health visitor made everything so easy”

- Having a supportive team in their child’s school or nursery (teachers or a SENCO), who helped them access the assessment and diagnosis process:

“I had the schools full backing and his teacher [saw] what most wouldn’t”

- Services or teams advocating for them:

“Mast and school were ringing up Ryegate saying he wasn’t coping and he needed to be seen ASAP”



- The assessment process at Ryegate Children’s Centre - once children had been referred and had an appointment, many parents said they were happy with how this process went:

“Once we were seen by consultant at Ryegate, I was impressed with their professionalism and the process of being diagnosed”

- Other positives included where individual professionals (such as their GP) listened to parents’ concerns and took them seriously. Some parents also appreciated being able to access information resources such as Ryegate’s range of workshops:

“Having a GP that listened and understood and referred me at the first appointment instead of asking me to wait and see how he developed as I know sometimes happens”



What didn’t work well? What would have made the process easier?

Parents also told us what didn’t work well during their child’s diagnosis, and what would have made the process easier. This question elicited more responses than the previous one.

- The most common issue parents raised was professionals not listening to them, or not taking them seriously when they raised concerns. 11 parents shared experiences like this:

“I should have been listened to both from the GP and nursery as I knew there was something wrong with my son”

“GP [should have] agreed to send referral to Ryegate instead of saying it was migraines and telling school to do the referral if they were concerned!”

- Waiting times were mentioned by 8 parents, who said that initial waiting lists for diagnosis delayed the support their children could access:

“We had to wait a year for Ryegate which is too long [...] Since it took her so long to engage in school, she is now 3 years behind her peers”

- Some parents told us that professionals had questioned their parenting, or suggested that their children were just poorly behaved. Linked to this, some parents were not happy that they were referred to Ryegate’s parenting workshops before their child could go on a waiting list for assessment:

“labelling parents as not parenting properly”

“Please listen to parents more and not just blame us for our child’s behaviour and send us on parenting courses!”

- Better engagement with school staff was highlighted as an area for improvement by 6 parents, who said they would have appreciated more



support from their child's teachers, and better training for school and nursery staff to pick up on issues:

"First school should have been much more helpful... I didn't even see a SENCO there"

- Some parents spoke about additional issues, such as a lack of communication between different services/teams, being passed from service to service, and having to jump through hoops to get referrals.



Feedback from parents of older children

Parents of older children (aged 18+) shared slightly different experiences to those of younger children.

- One parent told us about difficulties transitioning from children's to adult's services:

"Between 16-18 was not good. Adult services were difficult to access and process was stressful"

- Another parent said that when their child was younger, they weren't able to get a diagnosis, so they only began accessing services as a teenager:

"My daughter has been let down all through mainstream school. Social services have known there was something but never listened"

- One family felt the need to access private care for their adult child because they didn't find the Adult services offered on the NHS appropriate for the care he needed:

"Due to these issues I have used private services to address need"



Fighting for the right care

Another notable point to come out of the questionnaires is how often parents used terms such as "battle" and "fight" to describe their experiences of getting a diagnosis for their child. This paints a stark picture of what the experience has been like for their whole families. Parents said things like:

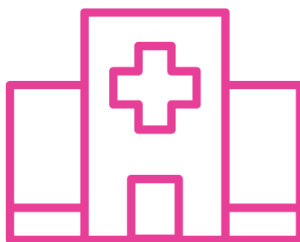
"Having to fight for a diagnosis of your child so they can get the appropriate support and care should not be that difficult"

"having to fight to get recognition that your child needs [...] diagnosis"

"I don't feel I have the energy to battle for these things for my daughter"

"had to fight from 6 months to 10 years"

Accessing support from services



We asked parents about their experiences accessing support from statutory health and social care services.

On average, **parents had accessed 7 services or teams** for their child’s care. The table below shows the 12 most common services or teams mentioned by parents:

Which services have you used?	Number of parents	Which services have you used?	Number of parents	Which services have you used?	Number of parents
Ryegate Children's Centre	32	MAST	21	Occupational Therapy	13
GP	28	Autism Team	20	Early Years Team	12
Children's Hospital	26	SNIPS	17	Psychologist	12
Speech and Language Therapy	23	CAMHS	17	Continence Team	4

Other services accessed by fewer parents included Educational Psychology, Dental Teams, Nutrition Team, Adult Mental Health services, Genetic Services, and Play Therapy.

We asked parents to tell us in more detail about the services they used - what worked well, what didn’t, and any suggestions they had to improve experiences for families. Their responses are summarised in the following pages.

Ryegate Children’s Centre



Overall we heard 33 comments about Ryegate, with most experiences containing both positive and negative aspects. 14 people mentioned that waiting times were too long, even if they then went on to have positive interactions with the service:

“Good when finally seen but the waiting times are horrendous”



Outside of waiting times, 16 people made largely positive comments, which focused on staff treating them and their child as individuals:

“Good team saw my daughter. Didn’t just accept what school said. Took time to properly assess and observe”

13 people shared experiences which were less positive. After waiting times, the most common issue was lack of support after diagnosis:

“Once diagnosed kind of just left to deal unless you constantly chase them”

People also shared stories of being unable to get help for their children in a crisis:

“Consultant no help, just wrote notes on how things were going. On last session my son said he wasn't happy at school and felt like he wanted to die. In same breath [they] signed us off. Let my son down massively when he was at his most needing time.”

Suggestions for improvement largely centred around managing the waiting lists:

“I understand there is a long waiting list, but it would be good to have more of an idea of when we will be seen and how the system works”

“I think it would be helpful to have a letter once referral received outlining process, waiting times and maybe signposting to support services. This way parents know what to expect rather than just being left in limbo”

Other suggestions were around consistency of consultants, improving the waiting area for older children, introducing a self-referral pathway, greater involvement of children in their treatment plans, and improved follow up information/support.

GPs



30 people shared comments about their GP. 17 parents shared very positive experiences, where GPs listened to them and what their children needed:

“Our doctor was very understanding and made regular appointments to check on how my daughter was whilst waiting for her CAMHS referral”

“GP will listen when I say what adjustments needed for my daughter”

13 people shared experiences of their GP being less helpful. This was often about values and behaviours of staff, or their ability to engage children with Autism:

“GPs can sometimes struggle with my son”

“A lot of GPs still have old fashioned views on Autism”



“Don’t feel that they recognise the importance of early diagnosis. Was told to wait and see and discuss concerns with school.”

Some parents also shared suggestions on how GP services could improve:

“A quiet room in all GP surgeries for children who struggle with waiting”

“Need to have a longer appointment for people with additional needs and keep continuity with the same GP”

“More training in SEN children is needed if they are to make an informed decision on whether or not to refer a child to services needed”

“What may have helped us was a more detailed referral - this might have got us onto a waiting list for assessment at Ryegate sooner”

Children’s Hospital



21 parents told us about their experiences visiting the Children’s Hospital. Most of them (16 parents) had very positive stories to share, talking about caring staff and good facilities:

“Excellent service very caring”

“Great quiet room”

“Open appointment should we need to re-engage”

Other parents shared ways that the Children’s Hospital could improve the experience for them and others:

“Difficulty when having to wait, copy of letters take ages to receive”

“They could improve the visibility of the PALS service as not all parents know they can help make appointments easier with quiet rooms and no waiting”

Speech and Language Therapy



We heard from 25 parents about Speech and Language Therapy (SALT).

10 parents did have positive experiences, though some wish they could get more regular appointments:

“Doesn’t lay blame anywhere, on school, child, you. Always really good”



“Proactive at onward referrals. Communication with parents is good”

“Good service but appointments could be more regular”

Most people who had negative experiences told us about being unable to access the service, or not getting as much support from them as they had hoped:

“Cannot access due to nursery being in Rotherham”

“Once my daughter was at a level they finished working with her saying she no longer needs help even though her speech is still delayed”

“Can't get referral as he talks!”

“One session and discharged us”

Other parents said they had accessed the service but it didn't work for them:

“Total failure! Denied [...] for almost 2 yrs. Finally got it back but pointless”

MAST



24 parents told us about their experiences with MAST. Only 5 people shared overall positive stories, 2 of which focused on support from the SIL team:

“Sills are brilliant. Brilliant support for me, fights my corner”

“The people who helped us were great and gave good advice”

14 people were unhappy with the support they received. Many comments focused on MAST referring them to parenting courses - some parents found this unhelpful, while others felt it was casting a judgement on their parenting:

“Awful experience, made to feel rubbish”

“Not enough knowledge of children with SEN, parenting courses not appropriate”

“No help, sent on parent workshop [...] It was no help and didn't work for kids with ASD/ADHD children”

“the parenting classes on offer were completely inaccessible for parents who work [...] come across as very judgmental”

“Signposted to parenting classes - not helpful, waste of time and money”

Some parents had a more mixed experiences, and said that the support they received depended on the professional they interacted with:

“Had some very good mast workers and actually helped my family but also had a bad worker who just blamed bad parenting on myself”



“2 totally different experiences! It was amazing and helped throughout the diagnosis process. After diagnosis was extremely rude and tried blaming parenting even though we had full diagnosis from Ryegate.”

Autism Team



19 parents told us about the Autism Team and the support they received. Only 5 people told us about positive experiences, and not all of these were wholly positive:

“Spoke on phone to them a few times given some good advice”

“Reports helpful for EHCP [but] offered suggestions on classic ASD, which my son is not. Then suggested sensory diet, which we had already done”

“Helped my daughter in her previous school and gave advice to school too but schools don’t always listen or do what the Autism team suggest.”

12 people told us about negative experiences - many of these focus on the fact that it is difficult to get through to anyone:

“Hard to get through the line so don’t always bother calling them as don’t have time to wait on hold.”

“Nightmare to get hold of anybody, long wait for return telephone calls.”

Some people told us that their children fall through a gap in provision because they live in Sheffield but their school/nursery is elsewhere. Others felt that the service was not well advertised and they didn’t know what support they could access.

SNIPS



19 parents told us about support from SNIPS. 10 people were positive about the clubs they were able to access:

“Brilliant, someone actually listened and wanted to know about my son”

“Good clubs for my son that he enjoys”

6 people shared less positive experiences, largely about difficulties accessing SNIPS support:

“Had a years wait. Paid for a very expensive club myself [...] Then sent to a club that didn’t work, kept following up for more options, never got back to me...2 or 3 times more”

“Contacted SNIPS about PA provision (my child does not cope well in school provided after school clubs) and was disappointed with lack of help/support



for low needs children who still struggle, but this is a system wide issue I have found when children are 'not autistic enough'”

Parents had a lot of ideas for how the SNIPS service could improve their experience. Most of these focused on the fact that many parents don't know about the service (even sometimes when they are currently using it):

“The clubs are good but the service isn't known enough and I only found out about them through another parent.”

“I have recently realised I have been using this service as my daughter attends ACCT (Asperger's Children & Carers Together) which she finds helpful and engaging.”

Other suggestions were about improving accessibility:

“Tried but failed to get my child into SNIPS activities/clubs. More funding is needed so that more children can access this service.”

“Make it easier to access. Bring back the £400 grant!”

CAMHS



19 parents spoke to us about accessing CAMHS. 5 people shared positive experiences, praising the support and advice they were offered:

“My daughter's clinician is great. She made my daughter at ease and informs me on things I need to know. She also gives me great advice too.”

“Helped both myself and my child understand anxiety more and realised my child had autism as well as anxiety.”

“Particularly liked their parent carer coffee and information mornings.”

Most parents (14 individuals) shared less positive experiences, saying their children were let down by CAMHS or that the service wasn't right for children with autism:

“Really let us down, didn't help apart from give CBT therapy that didn't help my son at all and they also blamed parenting.”

“Referred [...] because of suicidal thoughts and actions at home and school. Couldn't offer anything because he said he wouldn't engage in treatment, even though he said he wanted to kill himself and he knew how he was going to do it. Not fit for purpose!!! Needs to account for ASD anxiety, ADHD and PDA traits...which it doesn't.”

“Massive let down have failed my child big time”

“Received better support for my son from private services”

7 people mentioned a very long wait time, including some who had a positive experience once they were within the service, and some who highlighted that



accessing the system was complicated:

“Very long waiting list. Booking team separate to psychologist booking. Lots of miscommunication.”

We also heard suggestions for improvement:

“Need to be more creative in the help/therapy that they can offer children on the spectrum”

Occupational Therapy



11 parents shared experiences of accessing Occupational Therapy for their children. Most of these were positive experiences, with some areas for improvement. Positive experiences focused on thorough support and dedicated staff:

“Excellent we have had lots of support and great service”

4 parents did state a wish for sensory assessments/profiles to be incorporated into this service:

“Should provide a sensory assessment for children diagnosed with autism”

Other aspects parents thought could be improved included increasing the number of sessions children could access, and the high staff turnover in the service which means they are regularly handed over to a new therapist.

Early Years Team



We heard from 11 parents about the Early Years Team - most were very positive:

“Early years team were great, made regular visits and kept me informed.”

One parent didn't feel they were offered enough support, while another didn't feel they were taken seriously:

“Didn't listen to us. Refused to acknowledge our concerns.”

Parents suggested additional training for staff in the service:

“Need more training and awareness also to listen to parents concerns”

“Look for signs/training in girls with autism”

They also said that the service could improve their experience of transitioning to other teams:

“As soon as a child is diagnosed and are now under the care of the Autism Team Early Years have to stop helping and this felt quite abrupt.”



Psychologist



We received 14 comments about psychologists, split evenly between positive and negative experiences:

“Was referred to one from CAHMS and they have been a big help”

“Have not seen one in 5 years, as my child has profound learning difficulties I don’t think this is good enough”

Some people’s experience depended on how they accessed a psychologist:

“Ed phycologist great, suggested loads in school. Saw my son a few times. Great report. Phycologist CAMHS couldn’t offer anything”

Waiting lists for psychologists were mentioned by 3 parents, including one who has yet to be seen:

“Been waiting over 3 years!”

“Too long for waiting times to initial assessment and treatment - not acceptable [...] needs to be spent to improve this service and its accessibility”

One parent had lost faith in psychologists they could access through the NHS:

“Lack of support through statutory services led to use of private therapists”

Dental team



4 parents spoke about specialist Dental Teams, and had largely positive experiences:

“Brilliant dental team that go into my sons school”

“Charles Clifford spot on, fantastic. Talk to mum, talk to child. They give her a passcode, so if not ok will stop”

One person couldn’t access the dental team at Charles Clifford when they needed it, but found good service elsewhere:

“Had nearly 6 months wait from Charles Clifford to remove teeth when daughter had tooth decay [...] Final removal at Children’s was excellent. Great check ups at local NHS dentist”



Other services

Some parents also told us about other services they had accessed:

Continence team *“discharged as he wouldn't cooperate, issue still not resolved.”*

Continence team *“good and offer good advice”*

Sleep clinic *“far too long waiting time it took us almost 4 years to get help, once saw them they were great”*

Oncology team *“have always been amazing”*

Play Therapist *“excellent and provided very good support - paid privately”*

Child Missing School Team *“exceptionally speedy called on Monday, meeting on Wednesday, referral processed to our choice of school Wednesday afternoon.”*

Out of school provision *“paid by school. Helped my son massively get through school without being permanently excluded.”*

Community Learning Disability Team *“have been brilliant”*

Physiotherapists *“are great with assistance/advice/support plans - [staff] need to stop changing so often!”*

Access to specialist services/teams in school

We asked parents if any of these services or teams were available to access in their child's school setting.



For the 22 parents whose children were in mainstream school or nursery, 16 (73%) said no specialist support was available. Only 3 said their child was able to access specialist support in school (2 mentioned SALT support and 1 a psychologist). For remaining parents, 1 did not know if support was available, 1 said their child

had low needs and managed with the support of their teacher and SENCO, and 1 said it depends:

“The school have put some things in place. Due to lack of funding and staff cuts it is not always possible”

Parents whose children attend a special school reported much more engagement with specialist services within the school, though this was not always consistent:

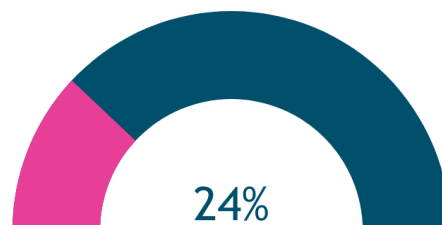
“Supposed to have speech and language and OT. Did have some art therapy until staff left.”

Accessing support as a parent-carer



As well as talking about their experiences accessing treatment and support for their children, we asked parents about their experiences seeking support for themselves as carers. We asked about any support they have accessed, any barriers to accessing support, and what they feel they'd benefit from.

When we asked "Do you feel you have had support for your own wellbeing and mental health?", only 24% of parents (9 of 37) said Yes. 23 parents said No. Some parents gave different answers or provided additional information, such as:



"I was already getting support for my own mental health. Have never had support regarding the fact my child is completely dependent on me"

"A few unhelpful suggestions from the MAST worker nothing apart from that"

"I was supported really well from health visitor but when she was no longer with us I felt a little lost"

"I feel it was the opposite. Being Judged, scrutinized and blamed for your child's behaviour and not being taken seriously or listened to can really make your mental health suffer"

"Not professionally, only friends and other parents in groups"

"I work in mental health so can help myself but do find it very overwhelming"



What have you accessed and what has your experience been?

4 people said their primary support is family/friends or peer support groups:

"My support is through my family, friends and my lifestyle and not through support from services"

Some parents had accessed formal support and found this helpful:

"Medication! Support sessions at school"

"Used silver cloud, found helpful"

"I had IAPT [Improving Access to Psychological Therapies] then referred to EVA therapy was fabulous"

"Safe families I have a support worker I can contact [...] as and when needed"

One person was less happy with their support:

"Had counselling, didn't help"



What have been the barriers to accessing support?

Fear of judgement was a major barrier - parents mentioned worrying that seeking help would make it seem like they couldn't care for their children:

"I had my parenting skills judged and blamed before he got a diagnosis so I was scared they would think it was my fault after all"

"Fear of being branded a bad mother. Kids taken off you"

Many parents also said they hadn't been offered help - suggesting that services are not recognising their caring role in addition to their parenting role, and the impact this can have on wellbeing:

"Never have I been asked from health professionals how I am or if I need any help"

Parents also raised practical barriers to accessing support such as time or money:

"Making time - you have that much on with appointments and looking after the child that your physical health and mental health doesn't get taken care of properly"

"Expense - I would have benefitted from private therapy"

Another barrier was not knowing what support was available:

"I have never really paid attentions to my own mental health as I have always been busy with my children. I did then start having feelings of depression but I didn't know where to turn"



What would help you now, or would have helped you in the past?

Parents said they want to be listened to and believed by professionals when they raise concerns about their children:

"Someone to listen to me in her younger years instead of being judged and made to feel to blame and for her not to be treated like a naughty child when she wasn't"

Parents also want to be given more information, and at an earlier stage:

"Knowledge about what is out there for my child and myself like support or who is best to get advice from and certain things"

Improved access to support groups was also highlighted, with a particular need for groups which are accessible outside of work times, and can cater to children with varying levels of support need:

"Signposted to support groups earlier with parents who have children with similar needs"



“Easier access to local authority SEND groups.”

“More groups/support for low-needs children and their parents. Just because our needs are low, doesn’t mean we should not have those needs met.”

Improved access to respite care would help parents to take a break:

“More PA hours. £400 short break payment we used to get would have paid for gym to help relax”

“Short breaks grant to offer respite and help mental health”

Many parents also wanted someone to speak to - some defined this as access to formal therapy or other mental health treatment, while others simply described needing someone who understood or who asked them how they were:

“Mental health support being offered from the start when my child was being diagnosed”

“I should have been offered counselling after my son nearly died instead of just having to deal with everything.”

“Knowing I could speak to someone who understood what I was going through and could help”

“For parental check ins- after diagnosis, during consultations. To maybe offer parent/carer meeting without the child to be able to be fully honest without fear of being heard by the child/misunderstood by the professional”

“Being asked regularly how everything was and listening to the answer”



Final thoughts - What is the one thing you really want to get across?

We asked this to give parents the space to speak about what was important to them. Some issues have been touched on earlier in the report, while others have not. Many parents used this space to talk about larger issues they saw in the health and social care system, and the impact navigating this has had on them as parent-carers.

Additional funding is needed to support children with Autism and their families:

“Please let the system have more funding for all services as our children need it and deserve it”

Waiting times are too long, meaning intervention and support is delayed:

“Waiting times are unacceptable. Can waste a few years of a child's life”



Parents need more information about the support that is available:

“Parents need more help knowing what help is available especially when English is your second language”

“If your child isn't attending school [...] it can be hard to access support. It has been hard to know what help is available and how things work”

Parents are not always listened to by professionals, and feel their parenting is being judged. They have to fight for the right support for their children:

“Professionals do not listen to me. I'm ignored and judged based on past mistakes made by professionals. I'm made to feel stupid and worthless, like I'm a bad parent”

“Parents know their child, please listen to their concerns”

“Constant fighting with LEA, school, other professionals, believe what WE say WE are the experts”

Parent-carers need better access to mental health support, as well as support and understanding from health and care services more widely:

“Funding for services especially mental health support for both children on the Autistic Spectrum and their parents. There really is a crisis around this”

“Special needs parents need more support and understanding”

“We aren't crap parents we love our kids. We want what's best for them in terms of school and we NEED a break or we won't be able to cope”

“Most people only access support when the situation is really bad [...] the support is not available as quickly as it should be. Most people are only a small step away from crisis and the impact on them and the child can be significant”

Many parents felt their child had been let down by services, and that some services are not fit for purpose:

“My child has been failed in so many ways as have I”

“[We need] early diagnosis in girls, people to recognise naughtiness isn't always to blame they are just scared, confused and can't cope if changes happen or if things become too loud”

“CAMHS and Rygate are not really fit for purpose”

“NHS SALT is really not good. Barely any input, no support for her”

Health professionals need more training to understand Autism:

“There needs to be more training of health professionals in Autism”



Increased support is needed to help families navigate education and school:

“There needs to be more special schools in Sheffield and more support when making the decision over school as the pressure really affected me mentally”

“Need proper support for my son when he moves to secondary”

“Support available to keep kids in mainstream school so they don’t fall further behind their peers or have to battle for very little places in special schools”

Other issues or ideas raised by parents were:

“There needs to be more funding for sensory needs assessments”

“There should be one medical system which all services can access. Each service can then see input from other services and treatment can be more specific and tailored to each individual”

“Low needs children and their families are often forgotten in a strange state of limbo both before and after diagnosis. Being “not autistic enough” is preventing us from accessing the support he and I need to thrive, rather than just survive or get by”

“We should be able to access services will ease priority booking for appointments to fit around carers needs and to be properly acknowledged for what we do!”

“If there is a child with additional needs in a family please make it easier for them to be diagnosed as there is a link between siblings”



Recommendations

The recommendations below are based on the findings in this report, as well as ideas shared by participants. These recommendations are aimed at commissioners and providers of health and social care services working children with autism and their families:

Diagnosis -

- It is often parents who first notice signs of autism in their children. **A Clear route to raise this** along with a central point of information about the assessment process should be available.
- Children are missing out on vital support while waiting for an assessment. **Interim support** should be offered, but should be tailored to need - for example groups and courses are not accessible for everyone; alternatives should be available.
- **Waiting lists** for diagnosis are unacceptably long - reducing waiting lists should be a priority.

Services -

- Many parents are accessing multiple services or teams; **systems for better information sharing** between these teams should be developed to improve communication.
- Services to take note of specific **feedback** raised about their service in this report - to respond, and to consider how to make their own feedback routes more accessible to parents.
- **Clear information about what services can offer** should be shared with families when their child is first identified as having additional needs.

Support for parent-carers -

- Not many parent-carers we spoke to are accessing formal support, but many report feeling stressed, exhausted, or overwhelmed. **Support needs to be more pro-active** - consider where services can **reach out** to parent-carers to offer support and/or signpost to support.
- **Feeling judged is a barrier to accessing help** - messaging from professionals needs to directly tackle this to reassure parents that they are there to support, not judge. They should be mindful of this in all interactions with families.
- Increased **respite options** for parents need to be developed.



Education -

- **Improved support to help families navigate through education** - for example; support to understand ECHPs, and good information about transitions to secondary school should be readily available. This support should be tailored to the needs of families, and offered pro-actively in some communities to ensure **equitable access**.

Involving parent-carers -

- Parents of children with autism have a wealth of knowledge and experience which could help drive improvements. All services, including Schools, should consider how they can **work collaboratively** with parents so that their **insight** can help shape services and ways of working.
- **Peer support** works well - there needs to be good signposting and referral routes to peer support, but also investment in organisations who can provide this.