

#SpeakUp: Asperger's Children and Carers Together (ACCT)

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.

Asperger's Children and Carers Together (ACCT)

ACCT is a parent and carer-led support group for autistic children and young people and their families in Sheffield. We run social and activity groups for a variety of age groups, as well as regular peer support meetings for parent-carers which helps them find information, advice 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?

ACCT deliver regular peer support discussion sessions for parent-carers of autistic children and young people in Sheffield. Between April and June 2021, we dedicated 7 of these sessions to exploring people's experiences of health and social care services in Sheffield. We wanted to understand what the common themes were, and what could improve their experiences and those of other parent-carers.

Who did we speak to?



7 sessions, attended
by **83 people**



An online survey,
completed by **18 people**



Further comments received
via email and social media

All sessions ran via Zoom on Tuesday evenings from 7-9pm and were facilitated by Margaret Kilner (ACCT Trustee) and Nicola Hough (ACCT Manager), with discussions continuing via ACCT public and private Facebook groups and email.

Terminology and acronyms

Parent-carers attending Asperger's Children & Carers Together (ACCT) 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 below:

ADHD	Attention Deficit Hyperactivity Disorder	PALS	Patient Advice & Liaison Service
ASD	Autistic Spectrum Disorder	SALT	Speech and Language Therapy
CAMHS	Child & Adolescent Mental Health Services	SEND	Special Educational Needs & Disabilities
DLA	Disability Living Allowance	SENDIAS	SEND Information, Advice & Support
EHCP	Education, Health & Care Plan	SENCO	Special Educational Needs Coordinator
MAST	Multi Agency Support Team	SNIPS	Special Needs Inclusion Playcare Service

Key findings

Introduction

The majority of parent-carers accessing ACCT support are at post-diagnosis stage. They have been through the Autism diagnosis for their child(ren), so feedback on that stage is generally not current. Therefore, the majority of feedback related to health and social care services are related to experiences of post-diagnosis issues. For example, there is a lot of discussion around Education Health and Care Plans (EHCPs).

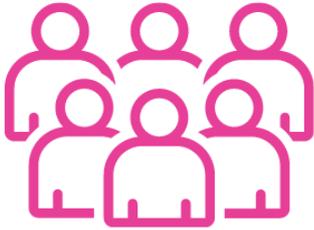
Having said that, we did receive one significant submission regarding the current experience of Autism diagnosis processes and delays, which we reproduce in full as a case study on page 14. The main body of our report describes the discussion points raised during wide-ranging parents' meetings and details the questionnaire responses.

Key findings were:

- **Information** about diagnosis and about relevant services and support is very **important but not always easy to get**
- **Peer Support** provides a vital route to accessing information and support, often filling gaps left by formal services
- **Navigating the system** and getting the right support can be very hard - often feeling like a battle
- **School** is a challenging environment for many children and young people, and **support provided is often not appropriate** for their needs
- **Applying for an EHCP is difficult** - external support (peer support, independent consultants) can make a real difference
- **Long waiting lists** (for diagnosis and support) are having a big impact on families
- Some Health and Care Professionals show good **understanding of how to work with autistic children**, but others do not appear to have the knowledge needed to do this well
- **Support for parent-carers** - there are many challenges involved in caring, and sometimes this isn't recognised as a responsibility over and above their parenting role. Some parents report feeling judged and not listened to by professionals

At the end of our report we have also made several recommendations, which we hope will help commissioners and providers of local services to make change which will positively impact families of children with autism.

Findings and feedback from parent-carer meetings



Our Parent-Carer meetings are designed to be facilitated peer-support sessions, led by the parent-carers themselves. Discussion topics are decided by the group, so our findings are based on the issues that parent-carers wanted to talk about each week. As noted earlier, many parent-carers who access ACCT services are at post-diagnosis stage for their autistic children and as such, discussions tend to be focused on issues related to support and services post-diagnosis. A summary of points raised during the sessions is below.



Some parent-carers shared positive experiences - sources of information and advice which have helped them, and services which have been supportive:

- People reported generally positive experiences of Becton School/Moncrieffe House after being referred there by CAMHS. People experienced a holistic approach which helped to integrate children back into school.
- It's helpful for parents to be able to access information and education about their child's diagnosis, such as the courses provided at Ryegate Children's Centre:
"My son has ADHD with lots of behavioural issues. I'm completing an 8 week course on ADHD. The course is great with lots of really useful information and advice."

Another parent-carer said they accessed the autism parenting course which was useful, but they said they could have done with knowing about it years ago. These courses were also recommended in the meetings when parent-carers mentioned things they were struggling with.

- Many parents recommended the Apple Tree centre for therapy. One person said their Speech and Language Therapy delivered over zoom was good.
- Peer support is useful, but can also be emotionally challenging - one parent, who was new to the ACCT group, said that it is interesting but overwhelming listening to other people's stories. Another parent said they enjoy listening to everyone talking as you can learn a lot from others.



Parent-carers of young children (pre-school aged) discussed early interventions and their experiences so far accessing services, advice, and information:

- One person with a 3 year old son said his Speech & Language review is coming up and he has some set targets. Other parents gave advice, suggesting writing down questions to take to the meeting.
- A new member asked for advice for her preschool child. Advice was given around service involvement, strategies, and communication. She was given information about Picture Exchange Communication Systems (PECS), Makaton, and use of language. Group members also made playgroup recommendations.
- One parent said they are waiting for a diagnosis for their 3 year old, but waiting times are currently up to a year.



Many parents spoke about issues their school-aged children were facing, and the challenges getting appropriate support for them in school:

- One person spoke about their son, who finds school challenging. It is a struggle getting him to school every day, and there is only one Teaching Assistant for three classes, meaning support is minimal.
- One parent said their son's school won't provide any one-to-one support for him.
- Another person said the transition back to school has been really hard. Their child is self-harming to avoid having to go, and the family feel very let down by the school and their lack of support. They said their child is mostly fine and happy during the school holidays.
- One person said support from their child's school is mediocre. Their child is going through some trauma as a result of the past year, and they feel let down by the school's response.
- Another person said their child is really struggling at school. When he gets angry at school the other children become scared of him, so he has been pretending to get angry so that he can get some time to himself. Outside of this there is no place for him to take a sensory break. Group members discussed this in relation to emotional scaling - he seems aware of when his feelings are escalating and is getting his needs met by hiding, but the school should be creating a safe space for sensory breaks.
- One person told the group their son said that *"school is so hard and friends are so hard"*. He is behind in class and doesn't get the help and support that he needs. He has ADHD and processing difficulties.
- The parent of a teenager said she was diagnosed late - after being initially accepting of her diagnosis, she then hated it. She is falling behind with school work, and her numerous tics are causing her distress.
- One person had to complain to the governors at her son's school regarding his support, and finally got a reply after six weeks. Since sending the letter, the school has been a lot better and they now have a great taxi driver for her son.
- A discussion took place about specialist schools and what is available in and around the city to include qualifications and buying in tutors for different interests such as art. General advice from the group was to go and look at lots of schools and ask questions to find the best fit.



For parent-carers of school-aged children, Education, Health and Care Plans (EHCPs) were also a popular topic of conversation:

- Many group members were starting the process of applying for an EHCP, and those who had completed the process previously were able to give information and advice, as well as linking to recorded webinars and other sources of support.
- Linked to this, peer support seemed to be helpful for many parent-carers in terms of learning about and applying for an EHCP - group members said they had received a lot of information about them by attending ACCT meetings.
- One person did say that their child's school had been the ones to recommend they apply for a EHCP, but did not mention receiving further information or support from them.

- Some people find it challenging to apply - one parent said that between trying to manage work and caring for two SEND children, he has made no progress with the application despite wanting to complete it.
- Several group members mentioned Bright Futures, an organisation which provides advocacy support to families going through the EHCP process. Parent-carers said Ruth Bright (Director) has very local knowledge, and she has delivered webinars for ACCT to help advise families which they recommend to members who are starting the EHCP process.



Parent-carers also shared experiences their families have had recently outside of school - some of which give an insight into the challenges of being a carer:

- There were group discussions about recent warm weather, and parents having battles with their children about appropriate clothing.
- One person talked about holidays, and how the first night is always challenging as her son transitions to the change.
- One person talked about how different each day is as a carer - her son had had a really good day yesterday but today had a big meltdown, trashing the house and hurting himself.
- One parent told the group he felt selfish for needing to do things for himself - group members reassured him that self-care is important but people empathised with this feeling. One person said that she feels guilty that her husband has to pick up the slack if she takes time for herself, but she is pleased when she is able to return the favour and do that for him.
- One parent said they finally got on the waiting list for clinical psychology, but had to go on a course first.



As part of these peer support meetings, group members shared a lot of useful information to help others in the meeting. A wealth of experience was shared on topics such as:

- Finding alternative provision for support in school
- Applying for an EHCP
- The transition to post-16 education
- The PIP process, and becoming an appointee
- Organisations which offer funding or activities to families, such as:
 - Family Fund, who fund holidays, laptops, white goods etc
 - Free carer passes for theatre visits and day trips which can be obtained with proof of Disability Living Allowance (DLA)
- Which organisations are currently open for referrals (for instance the Travel Assessment and Training Team, who organise travel support for children and young people between home and school)

Findings and feedback from our online survey:



During June 2021, we produced a survey questionnaire regarding parent-carer experiences of health and social care services for their autistic children. We received 18 responses, with parent-carers answering some or all questions. Major themes are summarised here, and we have included the full responses below.

Some participants expressed real frustration with the experiences they have faced. We have included all of these responses in order to accurately reflect the practical and emotional challenges faced by parent-carers when trying to access support.

Positive experiences:

- Individual staff members who showed understanding, and communicated well with the child(ren)
- Specific services at the Children’s Hospital, including the sleep clinic, continence clinic, allergy clinic, and PALS

Negative experiences:

- Long waiting lists
- Staff who were dismissive of autistic children’s needs, and of parent-carer’s knowledge of their children
- Inability to access services due to difficulties getting a referral
- Services not communicating with each other or with families

What people wish they had known earlier:

- How to navigate the health and social care system
- How to effectively advocate for themselves and their children

Could you share an example of a particularly positive experience you've had of health and social care services in Sheffield?
Extremely understanding and supportive GPs when I took my autistic child for an appointment.
Local dentist - always explains what she is doing and asks child if they are ok with what she is doing.
The sleep clinic at the Children's Hospital have been hugely supportive over the last few months. The staff are warm and approachable and completely non-judgemental. They have a good understanding of the needs of autistic children. My son has improved his bedtime routine and is waking less frequently in the night as a result.
The continence clinic at the Children's Hospital. They are completely non-judgemental of parents and have a good understanding of the needs of autistic children. They have advised me to take things very slowly with my son and not to put any unnecessary pressure on him.
My son was referred to clinics via his consultant at Ryegate.
Ryegate children’s services have been responsive to my children’s needs throughout the pandemic under difficult circumstances.

SEND dentist in Heeley has been fantastic!

[Consultant] at CAHMS is excellent.

Nice SNIPS worker.

We have had several positive experiences at Sheffield Children's Hospital, however I have always contacted PALS before any visit to ensure that they are aware of my son's autism before we attend appointment. As an inpatient this was done too and so when we were in hospital they were fully aware of his autism and they had prepared in advance.

We waited about a year for an appointment with an Occupational Therapist at the Children's Hospital. She was brilliant with us and our son, she understood the challenges he was facing and came up with helpful strategies. We have put into practice everything she taught us and shared information she gave us with other family carers. It only saddened us that he went so long without this input as the waiting time was so long.

Unfortunately nothing positive.

Am appreciating the support of MAST, although not sure they can change things. But they are supporting me around my son's emotional wellbeing and sleep and hopefully I can access their parenting course at some point.

Sheffield Children's Hospital Allergy care.

Could you share an example of a particularly negative experience you've had of health and social care services in Sheffield?

Waiting lists for everything, no support offered after diagnosis.

Charles Clifford dental hospital I felt were under prepared to deal with a child with autism and sensory issues.

Three years waiting list for CAHMS... aged out... NOW on waiting list with Sheffield Adult Mental Health for past 2.9 years... and counting. This service said there is no end in sight for when my son will be seen by them. Despite letters from GP's and specialist medical teams... we have never been seen. We've given up...

Nothing recently now we are in the system but lots of delays and fobbing off in the early days (many years ago).

We went to Ryegate for an appointment, to be told that we had been booked onto wrong clinic and we would have to come back. This caused distress to my son and a missed day at school.

My daughter was promised funding for a befriending scheme to now be let down by them.

During my daughter's ASD diagnosis, the SALT was very light hearted and casual in her assessment and delivery and not professional. This was very hurtful at a distressing time for us.

There are many, every time you ask for help at Ryegate they send you on another parenting workshop. It's not helpful, you want help for your child not a generalised workshop.

GP refusal to refer to adult autism services.

Refusal by SEND Assess and Review team to reassess when reports over ten years old.

SEND Assess and Review team providing inaccurate EHCP and not answering emails.

Our son had to have a blood test at the Children's. We told the nurse that he was extremely sensitive to pain and was likely to get very distressed. We told her he is autistic. She was dismissive and attempted to take blood without adapting her approach and ignored his obvious panic. This went on for some time until she went to get another nurse. The other nurse brought a pillow to help him get comfortable and was very focused on helping him to calm down, showing kindness while the blood was taken. There was no need for the first nurse to be determined to see for herself his distress. She could have listened to us in the first place and saved him a lot of upset. I dread to think how he will cope if he has to have another blood test. He still talks about it being the most terrible thing and the nurse being nasty.

Does not tie in with EHCP sections, Sheffield Children's have little knowledge about the EHCP process.

Yes. I got 5 special kids and they don't have any clubs around my area which is near Meadowhall. Social care manager been very very rude to me make me cry and I have tried to complain about the matter but manager threatened me.

Waiting times for assessment. We have been waiting over a year for autism assessment. How do I honestly, openly and helpfully communicate with my son and with others when I don't actually have a diagnosis.

Not being given access to Ryegate with an autistic /ADHD teen, being wrongly discharged by CAMHS and having to rejoin the hideously long list again.

Disjointed with lack of info about transition into adulthood and how this is different from children's services.

My experience with MAST was highly distressing and adversely affected my own mental health. We were referred through school. The intervention worker from MAST - and also the mental health worker from MAST - seemed to be convinced that my son did not have additional mental health needs on top of his autism (in fact he's about to start seeing a clinical psychologist at Ryegate because of his high levels of anxiety). They criticised my parenting throughout and suggested that the problem was my own mental health needs and not my son's. I felt bullied and manipulated by them and at one point broke down crying in a meeting and had to leave. They offered no help whatsoever other than a referral to an autism parenting course. They showed virtually no awareness of the needs of autistic children, nor of highly anxious children and no awareness whatsoever of the impact on the parents. Eventually my relationship with them broke down completely and I refused to have anything more to do with them. At this point they withdrew their services.

If there was one thing about health and social services in Sheffield you wish you'd known sooner, what would that be?

PPP parenting classes [Positive Parenting Programme]

That it is rubbish! That it is overloaded and thus unable to help.

I wish I had known that it would be a waste of time contacting MAST (although I appreciate that some people have had more positive experiences with them) and that it is not necessary for them to be involved if we are applying for an EHCP assessment. I also wish I had known that it's possible to get PA support for your child, and more about how this works.

I wish I had known how to be more assertive with school right from the beginning of my son's problems. I tried using SENDIAS but the representative just sat silently in meetings and didn't advise me of my rights.

I wish I understood more about how the educational psychology team at the Council worked. Will they only intervene if an EHCP is in place? If not, how do I get the school to refer my child to them at an earlier stage? What needs to happen for interventions to take place? If they say they can't see my child because he's not attending school, why can't they come directly to the house? I do not understand my rights in this regards. My son has now stopped attending school altogether and the ed psych team have done nothing to help him.

I wish I knew how to give CAMHS and Ryegate more information to base their decisions on when they are deciding whether or not to offer psychological support for a particular child. CAMHS rejected my son three times based on out of date information.

How the system and pathways works

Don't waste your time! It is a complete joke!

You need to be assertive and push to get the services you need

That they are often very poorly informed about autism yet they act like experts.

That you have to fight for any help you get

How they will do anything not to help when your child turns 16.

If they do some free activities around every area and specially Meadowhall area.

I think I am too soon along this journey to know the things I will one day wish I had.

What a battle it would be and preparing how I have to fight for everything.

Is there anything else you want to share that didn't fit into any of the above questions?

Learning about Bright Futures through ACCT has been helpful

The health care services just don't care and adult social care is a joke

The services need to do much more listening. We as parents have to force ourselves through patronising appointments, lectures and workshops, jump through so many hoops that don't benefit our children. It's a waste of time and money. There is very little understanding of what our children and young people really need. I also think the services don't know how damaging they can be. SEND parents are resilient by nature but I've seen many parents very close to the edge. The lack of empathy shown towards us is really shocking.

Dentistry. A few months ago after not having access to a dental check up for a very long time due to covid I came home from my son's check up and sobbed as I was told he had early warning signs of decay. I felt I had failed my son and I felt judged by the dentist. I have since discovered it is not uncommon for tooth cleaning to be a massive problem with other children on the spectrum as well. Why doesn't the dentist know and share this? Why was I made to feel terrible? How am I expected to find these things out when I have to wait so long for any official input?

Conclusion and recommendations

Conclusion

The discussions in the group highlighted the **strength and value of peer support** for those accessing it - both emotional support, and the practical information and advice provided can make a difference to peoples' circumstances. **External, independent support** from private agencies or voluntary sector organisations is also described as something which makes a difference to people - for example private therapy, consultancy support to apply for an EHCP, support from ACCT.

It's important to recognise that only a minority of families will have access to this kind of support, leaving **most reliant on formal, statutory services to meet their needs**. Yet this report describes that in many situations, there are **barriers** to accessing these services, and **gaps** in what is on offer, resulting in a significant negative impact on families.

We are concerned that these barriers will be amplified for many people as a result of race, ethnicity or socio-economic background, and it's important to highlight that peer support, while valuable, should only be a complement to 'official' information and support given through mainstream channels, not a substitute. There is a need for more information and support to be directly tailored and targeted towards families and communities who are currently under-served and under-represented if we are to achieve **equity** for families across Sheffield. There is also a clear need to address the significant gaps in services described here, and particularly the long waiting times for assessment and support.

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 with children with autism and their families:

- Organisations providing **peer support, advice and information** should be a priority in Sheffield's commissioning strategies.
- **Statutory organisations** on the pathways for diagnosis and support, should review **information** they share to ensure that it is accessible and actively shared with people in a timely way.
- **Voluntary sector organisations** supporting parent carers, could explore ways to reach a wider and more **diverse** range of families.
- **Waiting times** must be addressed - local health and care bodies (CCG, SCC, SHSC) should consider how resources can be made available to reduce waiting times. If

this is not possible within local resources, city leaders should be making strong representation to central government on this issue.

- **Autism training** to be mandatory for all health and care staff working with children and young people.
- **Listening to the voice of parent carers** - both in individual cases and on a system wide level, services should work to improve and develop the way they listen to the voices of parent carers.

Next steps for ACCT

We began fortnightly Parents' Meeting sessions via Zoom during the 2020 lockdown. Parent-carers tell us they find the sessions useful and Zoom is proving to be more practical for many parent-carers to attend compared to the previous quarterly in-person meetings we ran. We plan to continue to deliver these, and continue to encourage parent-carers to lead and guide discussions to cover particular subjects they are interested in and need advice or peer support with.

We are starting to use the discussion topics as an indicator of need and trying to follow-up where we can. This can involve contacting families individually to pass on relevant information/contacts, finding or producing resources to share more widely with the ACCT membership, and, as we did successfully during this funding, commissioning workshops and webinars covering topics that parent-carers indicated they needed more support with, such as EHCPs or Makaton, for which we commissioned and delivered a series of webinars and practical workshops.

All ACCT support groups are free of charge and open to all autistic children and young people and their families in Sheffield. The first step to accessing ACCT activities is to become a member of ACCT, which is also free. For more information and to join ACCT, please visit <https://acctsheffield.org.uk> or email enquiries@acctsheffield.org.uk.

Appendix

Case Study: A current experience of Autism (ASD) diagnosis in Sheffield

My child is waiting for an ASD assessment after the SENCO at their school asked our GP to make a referral in February.

At the end of June, we had a video appointment with a consultant who took a full history over about an hour. Unfortunately we weren't made aware that this was the purpose of the appointment, despite me phoning Ryegate to try to find out what the appointment would involve. All they could say was that it wasn't the assessment.

The time and location of this appointment had also been changed in the run up to the appointment which didn't help us to prepare our child for the appointment. The consultant was also not the one named on the appointment letter. There were questions about our child's early development that we couldn't answer as we didn't have the information to hand which was a shame.

The consultant was warm and polite but there was no advice or information given to us. At the end of the hour they said they would send out questionnaires for us and school to complete.

The consultant said that we should make sure these are returned quickly as the school holidays are imminent. In fact, three weeks later, we still haven't received the questionnaires and school closes for seven weeks in a few days.

We can realistically assume this will mean a 12 week delay minimum - three already lost waiting for the questionnaires, seven for the school holidays and then at least two for school to be able to complete and return to the Children's Hospital.

The consultant said that once the questionnaires are returned and then reviewed, if it's still indicated that they would benefit from assessment, they will be added to the waiting list for assessment.

If this happens in September this will be a total of eight months from referral, waiting to join a waiting list. As a desperate parent, unsure how to look after my child, experiencing great unhappiness within my family and terrible fear and anxiety, I need to understand why the Children's Hospital have designed the referral route like this? What benefit does it have for children, families and schools? How does this help children who may well be autistic and are not yet receiving appropriate support?

The consultant told us that the waiting time after the questionnaires are reviewed is 2 and a half years.

As parents we were totally floored by this experience and this news. Including the time we will wait pre-waiting list, this will be over three years, by which time our primary aged child will be in secondary school with no SEND support in place.

I want to protect our child's dignity so I won't detail their struggles here, but suffice it to say that the behaviours and emotional difficulties they experience are serious enough for parents, school and GP to seek help from the Children's [Sheffield Children's NHS Trust] so that we can attempt to meet their needs.

I feel so upset that the Children's doesn't understand the impact of delayed and late diagnosis on family well being and mental health, on family finances in preventing access to an appropriate level of disability related benefits and discounts, on access to adequate support in education, and access to activities and disability support.

As a family we have already been through this process once, as we have an older child who has been diagnosed Autistic. The waiting time from referral to assessment was just under a year, which was really hard to cope with. During the waiting time I did fear that our family would completely break down and it became increasingly difficult to keep them in school. But at the end of the wait, they received a diagnosis - this didn't mean much in terms of services that were provided to them - there was still nearly another year to wait for Occupational Therapy for example - but it meant we could start to learn how to be better parents to them.

We were then able to fight for the reasonable adjustments they needed to be put in place, which made a huge difference to their mental health, attainment, behaviour at school and at home, and ability to access clubs and activities. We were able to receive Disability Living Allowance which we put towards ongoing 1:1 support for them. We could also explain to our extended family the challenges our child faced and how they could best support us and include them.

Our family life is still very, very hard, despite diagnosis, but I wanted to explain the positive impact of diagnosis as I hope that this will help the Children's hospital to understand what they are denying to vulnerable children and young people with these terrible waiting times.

Adding a further two year delay means two more years of disengagement from education, and the awful battles that go along with that, lack of understanding from teachers who already struggle for resources to support children with a diagnosis, no access to reasonable adjustments, no access to the specialist team at Ryegate, no access to parent support, and financial loss.

Receiving appropriate disability related benefits can make a huge difference to the pressures families experience and the care they can provide to their child.

If a child were to be awarded the lower rate of Disability Living Allowance for care and mobility, over two years this amounts to a loss of just under £5,000, if the care element were at the middle rate this increases to nearly £9,000. At the highest rate for care and mobility, a family could lose out on nearly £16,000 over the two years. This doesn't even take into consideration Carer's Allowance or access to charity grants such as the Family Fund.

In our current situation with our younger child, as I said, we are floored and unsupported by the NHS, which doesn't seem to understand the importance of timely diagnosis. I feel despair at the prospect of watching them experience awful levels of distress without

proper support in place, but we are lucky, as we already know quite a lot based on our other child's diagnosis - what about families going through this for the first time? I feel a terrible dread and sadness about what these families and children must be going through.

We have started to look into the complicated and expensive process of private assessment, however, we are also aware that the NHS and Local Authority will not necessarily accept this. Our situation feels untenable and I wonder why the Children's does not prioritise Autism assessments. Are there any other referrals that take this long to get to assessment? Why are Autistic children being so neglected?

It would make a huge difference to see any evidence that the Children's is engaging with charities like ACCT and the wider community of Autistic families so that we are informed about changes to the referral routes and services and so that they can understand our lives and the way they impact our lives - both good and bad. Sadly we seem to be kept at arms length, and if this continues, further harm will be done to disabled children, while their needs go unrecognised.