

Dear Holly,

Thank you so much for sharing this summary report on the Speak up projects. We took the opportunity to consider these at Sheffield Children's Executive Team this morning, looking at both the individual reports and the broader themes arising from all the projects and wanted to share our thoughts and responses with you.

We agreed it would be helpful to provide specific feedback from Asperger's Children and Carers Together (ACCT) and Autism Hope and this is attached; this has helped us to reflect on and respond to each of the recommendations in the report. We are working in partnership with the CCG, SCC, Sheffield Parent-carer Forum (SPCF) on a Neurodevelopment Improvement Programme to co-produce and design pathways and test new models of care. We know there is a great deal to do to improve care and many of the projects within the programme seek to address the themes from the #speakup grants and other feedback/workshops we have been holding over the last few months.

### Cross Cutting Themes

We are really committed to ensuring the services we deliver are informed by and co-produced with children and young people, their families and carers and aim to ensure everyone is culturally competent.

We have launched a Trust wide engagement and involvement improvement to acknowledge that:

- We can deliver better services and care, in terms of access, experience and outcomes, when we work together with C&YP and families
- When everyone; regardless of race, gender, disability, poverty or any other factor, has agency to shape their experience we will be able to deliver better health outcomes
- We will focus on those seldom heard communities and voices so that we are attentive to their needs and are able to improve services specifically where this impact Health Inequalities

We expect our work to take a number of forms including building relationship within key communities/partners, direct patient/family co-production conversations and exploring new lived-experience roles. An awareness raising programme of work linked to health inequalities is being shaped – starting with Roma Cultural awareness raising. This will move onto focus on the needs of the Somali community and also Autism and LD awareness.

One of Sheffield Children's goals is to grow an increasingly diverse workforce so that families are better represented in the professionals that support them. Our Diversity and Inclusion networks are really taking shape now and promoting greater understanding and Allyship.

The need for clear information across all our services has also resulted in a big programme of work to refresh and renew our patient information into a library. The library is available to anyone provided with the link, this means our colleagues can share resources with patients and families. This will help complement work like the South Yorkshire 'Healthier Together' website, on which we are a major partner.

Thank you again for sharing the reports and specific feedback from ACCT and Autism Hope. Our Clinical Lead Consultant Paediatrician for the Neuro-development pathway, Dr Karen Arnold, will make contact with

Ruth Brown  
Chief Executive

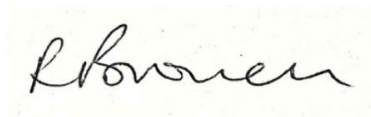


Sarah Jones  
Chair

both organisations to meet with them to make some personal relationships as well as the more formal responses via the Speak Up work. The lead of ACCT had already been in touch with Dr Arnold about working together over improving access, so it is timely to receive this report. Dr Arnold has also met with the team from Sparkle before and the team work very closely with the Sheffield Parent Carer Forum, so it will be good to build those personal relationships with other important stakeholders.

Thank you once again for sharing the report – do let me know if there is anything further you would like to discuss or areas we can engage as organisations together. Thank you for all you continue to do.

Yours sincerely



**Ruth Brown**  
Chief Executive

## Feedback on Issues Identified in #SpeakUp Small Grants Programme Report

### Sheffield Children's NHSFT

Speak Up Grant	Identified areas for improvement	Action set out in Healthwatch report	Action Underway/already taken	More to do
Asperger's Children and Carers Together (ACCT): Experiences of diagnosis & Support for Children with Autism	1. Parents spoke about lengthy waiting lists for assessment and diagnosis delaying access to support for their children.	1.1 Parents, who are often the first to notice signs of Autism in their children, should have a clear route to raise this.	<ul style="list-style-type: none"> <li>Worked in collaboration with Sheffield Parent Carer Forum to devise and deliver training to early years staff around listening to parents and recognising children with additional needs as early as possible. Strong emphasis on autism in the training. Also covered referral routes.</li> <li>Plan to enable SENCOs to refer for ASD assessment in the new academic school year</li> </ul>	Currently actively seeking additional funding to roll out to cover primary and secondary age children and to deliver to wider workforce across the city
		1.2 Waiting lists for diagnosis are unacceptably long. Local health and care bodies (CCG, SCC, SCFT) 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.	<ul style="list-style-type: none"> <li>SCFT is working in partnership with the CCG, SCC, Sheffield Parent-carer Forum (SPCF) on a Neurodevelopment Improvement Programme to co-produce and design pathways and test new models of care</li> <li>The SCFT programme of work on Autism and ADHD has shifted focus onto reducing waiting times - pieces of work are ongoing within the autism assessment team at Ryegate to trial different ways of gathering information to decide who needs to go on the list for an assessment, undertaking assessments in different ways however this will not be improved quickly due to the waiting list size.</li> </ul>	Plans to have a community paediatrician based in each locality with closer working links with the schools and SENCOs in their locality. They will attend school panel meetings where SENCOs can bring children with additional needs (with and without a diagnosis) for discussion and advice specific to those children.
		1.3 While waiting for assessment, children are missing out on vital support. Interim support should be offered and tailored to individual need.	<ul style="list-style-type: none"> <li>Schools informed when a child accepted on to the waiting list and advised to put autism strategies in place.</li> <li>Local authority working closely with SENCOs to ensure a conversation takes place between SENCO and parent/carers so that parents/carers can be signposted to the right resources to support them and their child.</li> <li>SCFT website has lots of resources and links and videos of the support package offered after diagnosis is now available to all <a href="#">Autism support - Sheffield Children's</a></li> </ul>	

			<a href="https://www.sheffieldchildrens.nhs.uk">NHS Foundation Trust (sheffieldchildrens.nhs.uk)</a> <ul style="list-style-type: none"> <li>• A booklet has been produced to outline assessment process and what support is available whilst awaiting assessment.</li> <li>• The booklet covers most of the areas highlighted by parents/carers in the detailed feedback reports.</li> <li>• Post-diagnostic offer is about to be re-shaped this will mean that for those children who do not need further interventions they will be discharged but for those with specific medical needs these will be addressed/supported. We will also be working closely with schools, Psychology and CAMHs to ensure the right support is available</li> </ul>	
		1.4 Statutory organisations should review information they share along the diagnosis pathway to ensure that it is clear, accessible and actively shared in a timely way.	<ul style="list-style-type: none"> <li>• Review of information undertaken as part of actions above</li> <li>• New video on what to expect at an assessment being developed</li> </ul>	It is the intention to use the new patient portal system to send out regular communications to families on the waiting list to update about current waiting times, remind families about the resources, provide relevant timely advice eg in Aug send additional advice about transitioning back in to new school year, in Nov/Dec send info about managing Christmas celebrations with changes in school routine and sensory overload etc.
	2. Parents found that processes in place were difficult, lack of timely on-ward referrals and not feeling like they were not being listened to by professionals and having to	2.1 Systems for better information sharing between the various teams involved should be developed to improve communication.	<ul style="list-style-type: none"> <li>• An Information Sharing Agreement has been put in place to enable the sharing of information between SCC and SCFT. Further work in train.</li> <li>• New Single Point of Access for ADHD and Autism works with schools to collect information and to share outcomes and work with other partners such as Early Years and ASC team is in hand.</li> <li>• LD/autism passports have been developed and promoted with key groups and as families attend appointments to give them a voice during care.</li> <li>• City wide Neurodevelopmental Improvement</li> </ul>	

	fight to be heard.		<p>Programme – listening to what’s needed from parents directly through 6 workshops held this year. The feedback is being themed.</p> <ul style="list-style-type: none"> <li>Working with professionals across the system to grow awareness on Autistic children’s needs so that families do not have to fight to be heard.</li> </ul>	
		2.2 Services should take note of feedback raised in the Autism Hope report, which contains detailed experiences of specific services – to respond, and to consider how to make their own feedback routes more accessible to parents.	<ul style="list-style-type: none"> <li>This report has been noted in the Neuro-development Improvement Programme and the projects within it are building on this and the workshop/ survey feedback received.</li> <li>The Clinical Lead Consultant Paediatrician Dr Karen Arnold will be making contact direct with Autism Hope and ACCT to develop our relationships and gain their valuable feedback into the future</li> <li>We are building better feedback processes into our assessment journey.</li> </ul>	
		2.3 Autism training to be mandatory for all health and care staff working with children and young people.	<ul style="list-style-type: none"> <li>Autism training will be mandatory for all staff at SCFT in the coming year – this had been hoped to be delivered through the Oliver McGowan training but this has been delayed and so an alternative has been agreed.</li> <li>Increasing focus on early intervention through the Neurodevelopmental Improvement Programme including training offer for all early years settings - 216 Early Years staff trained to identify potential autism and support families in 2021 through HEE funded Sheffield Parent Carer Forum Project. Training now on line</li> </ul>	
	3. Parents reported not feeling they could access support out of fear of being judged	3.1 Few parent-carers we spoke to were 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	<ul style="list-style-type: none"> <li>Neurodevelopment Improvement Programme workshop run in May 2022 focused on how to better support parents/carers to inform future work. The outputs are being themed and next steps will be co-produced in the Neurodevelopment programme.</li> <li>Autism in Schools project running parent support groups in 10 secondary mainstream schools – hope to expand this from Sept 22</li> </ul>	

		support.	<ul style="list-style-type: none"> <li>Working with professionals across the system to grow awareness on Autistic children's needs so that families do not have to fight to be heard.</li> </ul>	
		3.2 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.	<ul style="list-style-type: none"> <li>Ongoing work through training offer/conversations etc</li> </ul>	
	4. Education	4.1 Improved support (pro-active and tailored to the family's needs) to help families navigate through education – e.g. support to understand ECHPs, and good information about transitions to secondary school.	<ul style="list-style-type: none"> <li>See section 3.1</li> <li>Additional work being undertaken as part of the SEND Accelerated Action Plan Programme on Transitions to address this</li> </ul>	
	5. Involving parent-carers	5.1 Parents of children with autism have a wealth of knowledge and experience which could help drive improvements, both in individual cases and on a system wide level. 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.	<ul style="list-style-type: none"> <li>Involvement and co-production are key principles of the Neurodevelopment programme</li> <li>There is a Sheffield Parent Carer Forum representative on the Neurodevelopmental T&amp;F group as well as all workstream groups</li> <li>Neurodevelopment Programme has run 6 workshops for parents/carers and staff to help identify issues and co-produce solutions</li> <li>Neurodevelopment Programme survey received over 500 responses from parents/carers.</li> <li>Engagement also undertaken with voluntary organisations to seek parental views of those in seldom heard groups</li> </ul>	
		5.2 There needs to be good signposting and referral routes to peer support, but also investment in organisations who can provide peer support, advice, and	<ul style="list-style-type: none"> <li>Training and awareness of SCFT colleagues (section 2.3) and ability to signpost into Peer support service run by SPCF to be launched in the Autumn 2022 (service currently being co-designed with parents)</li> <li>Links being actively made with community groups such</li> </ul>	

		information.	as ISRAC centre which enables signposting to community peer support such as their What's App group for parents of children with autism and other additional needs	
Children, young people and families in Pitsmoor, Burngreave and Fir Vale		Statutory organisations should use targeted and culturally-competent ways to engage with Sheffield's diverse communities. They should recognise where communities have a lack of trust in formal services/professionals and develop commissioning plans which take account of this, shifting more resource to ensure that trusted community-based services are able to meet the needs of communities. They could learn from existing community sector organisations which have built strong and trusted relationships within their local areas.	<ul style="list-style-type: none"> <li>• Awareness raising programme of work linked to health inequalities is being shaped – starting with Roma Cultural awareness raising. This will move onto focus on the needs of the Somali community and also Autism and LD awareness.</li> <li>• Project ongoing to deliver neurodevelopmental clinics and assessments in schools with high population of children from communities where there has been lack of trust including Page Hall and Pitsmoor.</li> <li>• Our Diversity and Inclusion networks are also promoting greater understanding and Allyship.</li> <li>• One of the trusts key goals is to grow and increasingly diverse staff group so that families are better represented in the professionals that support them.</li> </ul>	