

#### About us

We are an independent group of over 2000 parents and carers of children and young people with disabilities and/or special educational needs in Sheffield.

Our aim is to make sure the needs of our children are met. We understand the challenges you face on a day-to-day basis, because we are parents and carers too. We organise regular events where parents can meet each other. We can tell you about the most up-to-date sources of information for your children.

We are here to give parent carers a voice. By joining the Parent Carer Forum, we can work together to improve services for our children.

## Membership is free, join us today!

Fill in the membership form at the back of this newsletter, or go to

www.sheffieldparentcarerforum.org. uk/become-a-member

#### Get in touch By Post:

St Mary's Community Centre Bramall Lane, Sheffield S2 4QZ

By phone: 0300 321 4721

#### By email:

enquiries@sheffieldparent carer forum. or g.uk

#### Website:

www.sheffield parent care r forum.org.uk

#### Drop-in:

Currently by appointment only; please contact us to arrange a time.



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National Network of Parent Carer Forums
'Our Strength is our Shared Experience'
www.nnpcf.org.uk

#### Your advert here?

Would you like to advertise your products or services in our next newsletter? For a small fee, you could reach up to 6,000 families in Sheffield.

Our rates are: • Full page £150

• 1/2 page £75

• 1/4 page £37.50

Charity discounts available. Please call us on **0300 321 4721** to discuss your requirements.

If you wish to unsubscribe from this newsletter, please contact us on **0300 3214721** or email **enquiries@sheffieldparentcarerforum.org.uk** 

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Letter from the Chair

# A very warm welcome to the spring edition of our newsletter!

After what has been an incredibly difficult year for most, dare I say we are hopefully moving towards regaining some form of 'normality'? But I do ask myself, what is the 'new normal'? Spring is in the air and hopefully there is nicer weather on the way. A little bit of sunshine always makes me feel better!

By the time this newsletter goes out, most children and young people should have been reintegrated back into education, and I hope that things have gone smoothly. Please do contact us if we can support you in any way.

Once lockdown restrictions have been lifted, we will look at resuming our face-to-face meetings and workshops and holding some of our much-loved family events. We recognise that for many of you, our events are the most important part of our work, and we are keen to restart them as soon as possible. In the meantime, please do join us on Zoom for our virtual sessions (see page 22).

Over the past few months, we have continued to be involved with work taking place around supporting families who have children on the waiting list for an autism assessment. With over 1,000 children on this list, it is recognised that families need an offer of support whilst they wait. Sheffield City Council, Sheffield Children's Hospital and Sheffield Clinical Commissioning Group have together drawn



up a plan to contact all families on the list. Feedback from some of these calls shows there is demand for support around sleep and behaviour. If you are one of the families who have been contacted, it would be great to hear your thoughts, so please do get in touch.

Our organisation has a key role to play in improving communication and information for families. In recent months, we have worked hard to ensure that as much useful information as possible is included in the new autism resources on the Sheffield Children's Hospital website (see tinyurl.com/asdresourcesheffield).

I do hope that, when our next edition comes out, we will be celebrating the end of lockdown. I look forward to seeing our lovely families face-to-face soon – hopefully!

Best wishes, Katie Monette Chair

## Honouring a mum who found purpose in tragedy

A mum who set up a fund to support the mental health of LGBT+ young people after losing her own son to suicide is the winner of our David Woodhouse Community Award.

Claire McGettigan has raised over £14,000 in memory of her son Noah, who sadly took his own life in 2018, when he was just 15 years old. Noah was gav and a proud member of the LGBT+ community. He was also autistic and had been struggling with his mental health for many years.

The Noah Lomax Fund provides counselling and a hardship fund for LGBT+ young people through the charity SAYiT.

Claire is the second recipient of our David Woodhouse Community Award, which is funded from donations made in memory of David Woodhouse.

David's widow Deborah Woodhouse said: "I am very pleased to hear the award has gone to Claire because both me and David knew Noah as a child. He was a popular boy and very funny and I was devastated when he died. He went too soon."

She added: "I have been aware of the fundraising Claire has done in memory of Noah and to do this at a time of grief to help others is admirable and very brave. Claire's actions will have helped so many young people and leave a lasting legacy in Noah's name. She is a worthy winner for this award and I believe David would have thought the same."

Presenting the award, Forum trustee Jayne Woodward said: "Claire is a very fitting and worthy winner. To turn such a personal

tragedy into positive action and support is exactly the type of contribution we wished to recognise in David's memory when we first envisioned the award."

Claire said: "I feel honoured to have been given this award. It highlights the essential work Noah's Fund and SAYiT are doing with local young people within the LGBT+ community. Providing immediate LGBTaffirmative counselling and an emergency fund has proved to be a lifeline to so many young people."

"Losing Noah in such tragic circumstances has been devastating for us, but setting up and running his fund gives a positive focus... and as a self-proclaimed LGBT activist. Noah will be proudly looking on and willing us to grow and grow."

"I am very mindful of the sad circumstances leading to the creation of this award and I hope I do it justice."

Claire received a trophy, a cheque for £250 and vouchers for a spa experience and a meal.

The award is presented annually, and the next round of nominations will open in October 2021.

For more information about the Noah Lomax Fund or to make a donation, please visit https://localgiving.org/fundraising/ FlamboyantPink.

#### **New** on the web

#### Speech and Language videos

The Sheffield Speech and Language Therapy Service has created a series of videos called "Weekend Words". The videos show a range of strategies that parents can use at home to support their child's language development. They are designed to fit into everyday routines and play activities, and are suitable for children with a wide range of needs. Search YouTube for "Weekend Words Sheffield" or follow this link: https://tinyurl.com/1ix74b8x

### Mental health services during the pandemic

The Sheffield Mental Health Guide website has an overview of mental health services for children and young people during the pandemic: www.sheffieldmentalhealth.co.uk/covid/covid-children-and-young/



#### Guides to autism and ADHD assessments

Karen Arnold, Consultant Paediatrician at Ryegate, has written a guide that explains the assessment process for Autistic Spectrum Disorders. You can download it from https:// tinyurl.com/asdbooklet

There is a similar guide for ADHD assessments: https://tinyurl.com/adhdbooklet

#### Changes to local services

Local services for children and young people with additional needs (such as SENDSARS, Educational Psychology, or Speech and Language Therapy) are having to work differently during the pandemic. You can find more information about these changes on the Local Offer website:

https://tinyurl.com/sendservices

### Meeting demand for special school places

Demand for special school places in Sheffield continues to grow.

Sheffield City Council is working to create additional places at some of our existing primary and secondary special schools, in time for the start of the new academic year in September 2021.

The pandemic and construction difficulties have caused delays in the opening of two new special schools. The new Discovery school in the Norfolk Park area is now due to open in September 2022. A second special school is expected to open in September 2023, subject to planning and other approval processes. Each of these new schools will offer around 80 full-time places for learners aged 7-16 years with communication and interaction needs

(including autism) as well as social, emotional and mental health needs. Decisions have yet to be made about the level of complexity of needs that these schools will cater for.

Last September, three new Integrated Resources (IRs) for children with communication and interaction difficulties opened at primary schools in the north of the city (Beck, Whiteways and Hucklow). This created 30 additional IR places, but still more are needed. Sheffield City Council has asked schools to submit expressions of interest in creating or extending IR provision, and our representatives will be involved in evaluating these. It is expected that more IRs will open over the next few years.

## Feedback from members' survey

Every two years, we ask our members what they think about our organisation. This year, 125 people filled in our questionnaire – thank you to everyone who took part! The lucky winner of our prize draw for a  $\mathfrak{L}50$  shopping voucher was Noreen Ayub.

Below are some of the key messages from the survey. To read the full report, please visit our website: https://sheffieldparentcarerforum.org.uk/about/our-members



of respondents were confident or very confident that we can accurately represent parents' views.



of respondents said that being a member of our forum had made them feel better informed about services.



of respondents had engaged with us through our events, meetings or consultations.



said that they were better able to support their child with additional needs.



rated the information we had been providing during the pandemic as "good" or "excellent".

The engagement rate of 59% was lower than in previous years and may reflect the impact of the pandemic. For parents who had not got more involved, the main barriers were a lack of time generally, and events/meetings being held at times that were not suitable for them. Many respondents also said that they did not enjoy virtual meetings, or did not feel confident about joining them.

The survey confirmed that our activities are well aligned with parents' priorities: information and signposting, activities for children and families, and wellbeing and information sessions for parents.

When asked what burning issues they wanted us to focus on over the next year, recovery from the impact of the pandemic and better mental health support for children and parents topped the list. Increased isolation was a big issue for many families, and many respondents said they wanted us to focus on providing activities for children and families. As in previous years, respondents highlighted the need to improve support in education and the transition to post-16 education and adult services.

#### **NEWS**

## In response to the feedback from the survey, we will:

- Continue to provide the activities that our members say they value most: family events, children's activities, information and signposting, and information sessions and wellbeing activities for parents
- Restart our family events, like the family fun day, film screenings and JumpStars trampolining sessions, as soon as it is safe to do so
- Offer training in the use of the Zoom app
- Trial virtual meetings in the evenings to provide an alternative for working parents.
- Combat isolation by restarting our coffee mornings and outreach visits as soon as possible, and by using funding from the Health Lottery to offer additional opportunities for parents to meet
- Highlight the issues that our members have told us are most important to them, in particular Covid recovery. We will try to scrutinise how education catch-up funding is spent, and gather and represent feedback from parents in relation to this. We will work with partners to improve mental health support for children and parents, support in education, and transition to adulthood.

"Parent Stories have helped to cope with emotions"

"I got a short break grant - I didn't even know these existed until I saw the info you shared."

"Sheffield Parent Carer Forum always seems to be very much in touch with people on the ground and what are the issues for us that need to be explored/pursued."

"I found out about the MyPlan and that needs to be reviewed 3 times in a year, and what I can expect from SENCO at school. I feel confident to ask for help and I know from where to get that help."



### Calling all Black Asian Minority Ethnic parent carers!

We are committed to welcoming, listening to and representing ALL families with disabled children and young people in Sheffield but we recognise that we have struggled to capture the voices, experiences and concerns of the Black Asian and Minority Ethnic community within our city. We want to address this in an empathetic way.

We acknowledge that not all spaces will feel safe enough to express your concerns. Therefore, our volunteers Melissa Simmonds and Thaeeba Azam will create a safe space for Black and Brown parents and carers. We want you to feel comfortable to talk about the issues you are facing in getting your disabled children's needs met. By joining us, you will be able to help your own family and other families in a similar situation.

Melissa has been a trustee of our organisation for many years. She is a disability activist and parent of disabled children, who gives talks on

disability (especially autism) and race. Thaeeba is one of our longest-serving volunteers: vou mav have met her at our coffee mornings or outreach events.

We will start off with Zoom meetings in the spring, but are hoping to move to face-toface meetings later in the year. To attend these meetings or for more information, please contact Melissa by emailing melissa.simmonds@ sheffieldparentcarer forum.org.uk





## Worried about your child's language development?



The Sheffield Children's Speech and Language Therapy Service has an advice line for parents of children up to five years old and those who support them. Call 0114 **305 3956** on the first Friday of every month between 1.30pm and 4.30pm. Alternatively, please email dana.welch@nhs.net for

more information. You can also talk to your health visitor or local Family Centre (www.sheffield.gov.uk/familycentres).

If your child is school-aged, speak to your SENCO or GP about a referral to the Speech and Language Therapy Service.

## Volunteering opportunities

We have all become quite isolated during the pandemic. Now that most children are back in school, why not join us as a volunteer? You'll meet other parents, learn new skills and help to make life better for families in Sheffield. We currently have a range of volunteering roles available:





Parent representatives represent a wide range of views of parent carers from across Sheffield at meetings with the local authority and health services. They attend groups on transition, education, neurodisability, autism, EHC plans, Sheffield's inclusion strategy, and many more.



**Trustees** are responsible for the governance and management of our organisation. To help us be as representative as possible, we are particularly looking for parents from a BAME background, parents of young children with additional needs (0-5 years), and parents of children with physical disabilities. We are also looking for someone with HR expertise.



**Outreach volunteers** attend coffee mornings at schools and nurseries and run stalls at events to promote our organisation, gather parents' views, and provide peer support and signposting.



**PR volunteers** help us raise the profile of our organisation. Tasks include writing and distributing press releases, building relationships with local media outlets, and contributing to our social media accounts.



**Fundraising volunteers** help raise funds for our projects and events; no cold calling involved!

For most of these roles, the amount of time spent volunteering is completely up to you. Training and mentoring will be provided – we promise we won't throw you in at the deep end!

We will also reimburse any expenses you incur – such as additional data for your phone or travel expenses. We may also be able to pay you for your time; due to employment

legislation, we can unfortunately only do this if you are self-employed.

Interested? Please email us at enquiries@ sheffieldparentcarerforum.org.uk or call us on 0300 321 4721 to find out more.

For more information about our volunteering opportunities, please visit www. sheffieldparentcarerforum.org.uk/supportus/volunteering-opportunities

#### **Covid vaccinations**

Unpaid carers are included in priority group six of the vaccination programme. This includes people who receive Carers Allowance and those who are the main carer of someone at high risk from coronavirus.

Also included in group six are all adults (aged 16 or over) on the GP learning disability register. The learning disability register is a record of people with a learning disability who are registered with each GP practice. If your young person is aged 14 or over and gets invited to have an annual health check, then they are on that register.

The government has said everyone in group six will be offered their first dose of the jab by 15 April.

However, it is possible that some people may be missed because their medical records do not have a "carer" flag or "learning disability" flag. If you think that this applies to you or your young person, you should contact your GP surgery and ask them to update your medical record(s). Your GP should then invite you for vaccination.

You might also be able to book your vaccination via the national booking website: www.nhs.uk/conditions/coronavirus-covid-19/coronavirus-vaccination/book-coronavirus-vaccination/

# **Neurodisability training** for early years professionals

Our neurodisability training for early years professionals is now up and running. Sessions last three hours and are free to attend. Professionals can book their place via www.eventbrite.co.uk/e/early-years-neurodisability-training-tickets-140825915103

The aim of the training is to help early years professionals identify, support and signpost families of young children with neurodisabilities in Sheffield. There is a focus on autism spectrum conditions, but a lot of the information is also applicable to other neurodisabilities, such as ADHD or developmental delay. The training is jointly delivered by our parent trainers and staff from the local authority and health. All our parent trainers have experience of having a young child with additional needs and accessing services in the early years.

We used feedback from several sessions with parents and professionals to develop the content of the training. We are really pleased that so many people engaged with this, and it is evident that the training is much needed and welcomed. Most of the sessions are now fully booked, with over 220 professionals signed up to attend!

An independent consultant will evaluate the training to find out if it has increased professionals' knowledge and their confidence in supporting families. Ultimately, we hope it will mean that families get support earlier and feel less isolated.

For more information about the training, please email our project worker Amy Farry amy.farry@sheffieldparentcarerforum. org.uk.

## Supporting pupils with health needs in schools



A new project called "Health Needs in Schools" aims to improve support in schools for children and young people with medical needs.

There are 18 schools in Sheffield currently taking part in the project. These are:

**Special schools:** Talbot, Seven Hills, Bents Green, Norfolk Park, Woolley Wood, Rowan, Kenwood, Heritage, Mossbrook and Holgate.

Mainstream schools: Tapton, Southey Green, Wisewood, Hallam, Bradfield, Meynell, Forge Valley and Hillsborough, including any attached nursery and preschools.

Although the project is currently only working with a small number of mainstream schools, the information, resources and training will be made available to all schools.

The two nurses leading the project are currently working to:

- Identify the current health needs in schools and what support and interventions are in place or required to help manage these.
- Provide advice and support to schools in meeting the children's health needs.
- Develop a local policy for managing medical conditions in schools. This will give clear guidance for schools, pre-schools and nurseries when pupils attend with a health need.
- Provide support, advice and training to the schools to ensure that Individual Healthcare Plans (see box) are developed and implemented.

#### What is an Individual Healthcare Plan (IHCP)?

An Individual Healthcare Plan is a document that records important information about a child's medical condition. It says what needs to be done, when and by whom to ensure the child can make the most of school. Not all pupils with medical conditions need one, but they will be helpful for children with long-term and/or complex medical conditions. They are essential if there is a risk that emergency interventions

might be required. Schools should work with parents (and the child if appropriate) and relevant healthcare professionals to develop and review these plans.

If a child also has a special educational need or disability, the Individual Healthcare Plan should be linked to or become part of their Education Health and Care (EHC) plan or SEN support plan (MyPlan).

# Locked out: an update on Child Trust Funds



As many as 200,000 disabled children could be locked out of their savings held in Child Trust Funds. This is because they don't have the mental capacity to manage their money when they turn 18. Their parents face the prospect of having to pay hundreds of pounds in Court of Protection fees to access the money on behalf of their child. A parent-led campaign for less costly and easier access to Child Trust Funds is now starting to have an impact.

At the beginning of December 2020, the Government announced that most parents who apply to the Court of Protection to become a financial deputy just to access a Child Trust Fund will not have to pay the court fee (currently £365). Those who have already paid can request a refund.

Parents can already get help with court fees if:

- They apply before their child's 18th birthday.
- Their child is over 18 and has savings of less than £3,000 and receives certain benefits or has a low income.

Now parents of children over 18 can ask for help "due to exceptional circumstances" if the Child Trust Fund is their only asset, regardless of the amount in the fund. Applications for fees to be waived or refunded will be considered on a case-by-case basis.

In a separate move, The Investing and Saving Alliance (TISA) has proposed a solution which would give parents of disabled children who have up to £5,000 in their accounts and no other savings access to the money without having to apply to the Court of Protection. Most Child Trust Fund providers have agreed to these proposals, but so far the government has refused to back them.

Some Child Trust Fund providers, including BMO and OneFamily, have already introduced alternative routes for parents to access their child's savings. They will consider applications on a case-by-case basis.

## Not sure if your child has a Child Trust Fund?

Child Trust Funds were set up by the government for children born between 1 September 2002 and 2 January 2011. Even if you did not make any contributions yourself, your child's fund could now be worth up to £1,500. This is because the government made several payments into these accounts. To locate a lost Child Trust Fund, go to www.gov.uk/child-trust-funds/find-a-child-trust-fund.

# What should you do if your child has a Child Trust Fund and won't be able to manage their money when they turn 18?

- Write to your Child Trust Fund provider to see if they will release the funds.
- Decide if you need to apply to the Court of Protection to become a financial deputy.
- Go to https://tinyurl.com/COPfees and apply for help with Court of Protection fees.

## Parent carer participation

If you asked any of our trustees, staff or volunteers why they got involved with our organisation, they would all say, "because I wanted to make things easier and better for other parents in a similar situation".

This is the backbone of parent carer participation, which is what we are funded to do by Sheffield City Council and the Department of Education. We gather the views and experiences of parents of children with special educational needs and disabilities

from all over Sheffield through meetings, surveys, social media and events. Our parent representatives then report this information at meetings with council, education and health professionals, so that they can consider the needs of families when making decisions.

We know that our parent participation work is valued by our members and the professionals we work with: Some of the quotes from the participation survey demonstrate the positive impact of the work our parent representatives do:

## 98% of parents

who completed our membership survey were confident or very confident that we can accurately represent parents' views. "It has made me think differently and understand the issues better. It has broadened the discussions from just focusing on the child, to considering their family (siblings as well as parents/carers). This will lead to solutions/services that more effectively meet the needs of families and children."

# 88% of council officers, education and health professionals

who completed a recent participation questionnaire agreed or strongly agreed that parent carer participation has helped them to make informed decisions and provide better outcomes for children and young people with SEND.

"We have had extremely helpful feedback from parent carer rep regarding resources that were developed, what to include and how to word things to support parents in the best possible way. It has been vital to hear."

Do you want to make a difference for other families? We are currently recruiting parent representatives to attend meetings. Please see page 9 for information about volunteering with us.



There can be mixed feelings and expectations when your child gets referred on to another team or service. The initial relief that comes when things are finally happening, often after months of waiting, slowly gives way to apprehension. Who will call me? How often are they going to be in touch? Will I have to repeat my son's story again? These were some of the thoughts running through my head when my son was referred for support and guidance with his toilet training.

At this point I wasn't holding my hopes up too high. My son was four years old at the time, and the previous advice we'd had with toilet training a couple of years before had been very general. Any personal difficulties which I'd tried to explain over the phone were not considered.

Everything suggested so far had felt like another demand placed on us, and I was worried that we might be given yet more goals that we would struggle to achieve. This made me feel withdrawn and concerned it was just going to be another puzzle I would have to figure out by myself. Was it too much to hope for someone who could listen, be positive and help us to work out a good starting point in terms of supporting us as a family, together?

When I received that first introductory call from the continence team at Centenary House, I could not believe it when they not only asked me about my son, but also about any personal challenges we faced as a family. They gave us time to elaborate on some of the problems we were facing, and it really felt like they wanted to understand us so that they could support us in the best way possible. It was such a relief to be acknowledged in that way and it completely changed my expectations of how the team would work with us. They were on our side and wanted to support us from the start.

They were clear about who we'd be speaking to and how to contact them, which is so important when you have so many different services already involved with your child. Knowing who I'd be speaking to every time and having their contact details made everything much more personal and consistent. So far, they have been scheduling regular calls with us, which meant that I didn't have to waste time chasing appointments or worry about when we'd next hear from them. It also meant that we were able to remember exactly when to update them from, as opposed to waiting for months and then desperately trying to remember everything for that one call.

They were also happy to make enquiries after a phone call and feed back to us. The language they use is very positive, too: 'I can find out', 'I can ask', 'I'll do this next'. This was reassuring and made me feel more confident about asking questions; it is easy to feel intimidated when talking to a professional.

It felt like a weight had been lifted when they offered to make a call to my son's school to find out exactly how they were managing trips to the toilet under Covid restrictions. I know everyone is doing the best they can, but it was hard to get a clear picture of what was happening at school. This simple phone call on our behalf has made such a difference! We now have a plan in place where even the visuals implemented at school are consistent with the ones we have at home. It is encouraging how everyone is in contact with each other and knows what should be happening. Even though I still give updates on my son's progress when asked by his teachers, it feels like less of a struggle because of the coordination by the continence team.

Nothing that they have asked of us has felt unmanageable or impossible, and they always discuss any follow-up steps with us first. It means a lot that they celebrate the small wins we have achieved, and that they remind us that we are still doing well even when we are experiencing setbacks or have had an unproductive few weeks. Focusing on what my son could do, instead of what he couldn't, was heartening.

The approach is really paying off, and over the last few months we have seen some really positive changes and progress being made. I feel so lucky to have experienced such good practice from a team that has really made a difference and given me more confidence as a parent.

#### More information

For more information about Sheffield's community continence team, please visit:

www.sheffieldchildrens.nhs.uk/ services/community-continenceclinics/

to improve the lives of children and teenagers facing continence challenges. They run a free helpline on 0808 169 9949, which is open Monday to Thursday, 10am-2pm. Their website (www.eric.org. uk) has lots of useful information, including a toilet training guide for children with additional needs. They also sell continence products.

## Introducing the SCERTS Model

You might have heard that something called SCERTS is increasingly being used with autistic children in Sheffield. This article explains what SCERTS is and how it works.

#### Who is it for?

The SCERTS model is for people with autism spectrum disorders and related disabilities, such as difficulties with communication or emotional regulation. It was initially developed for pre-schoolers and primary school age children, but can also be used with teenagers and adults. In Sheffield, SCERTS is being introduced into early years settings, primary schools and secondary schools (mainstream and specialist).

#### What is it?

SCERTS stands for Social Communication, Emotional Regulation and Transactional Support. It is not a specific therapy or programme. It is a model that helps families, teachers and therapists from different services to work together to teach children how to regulate their emotions and communicate with others. Without such an overarching approach, there is a risk that a child could end up with lots of different interventions with unconnected goals. The ultimate aim is to improve the quality of life for the child and their family.

#### How does it work?

At the start, a professional (such as a SENCO, a therapist or a teacher from an education advisory service) works with the class teacher to assess the child's strengths and needs. They do this by observing the child and by talking to key people in the child's life. Based on this assessment,

parents, teachers and therapists decide together what outcomes they want to work towards, and the resources and strategies they will be using. These can be written into the child's MyPlan or Education Health and Care (EHC) plan.

Resources can include things like visual timetables, PECS cards, or sensory tools. Strategies can come from a range of established autism interventions, like Social Stories, Floortime, More Than Words, Pivotal Response Training or TEACCH. Where possible, strategies are embedded into everyday routines in different social situations, rather than having an adult work with the child in isolation.

#### What is the role of parents in this?

Parents and family members play a key role as the experts in their child. You should be involved in your child's initial assessment, in choosing the goals to work towards, and in implementing the strategies. You should be given resources you can use with your child at home. It is really important that SCERTS is used across all parts of your child's life, not just in school.

## How is SCERTS being introduced in Sheffield?

Some special schools in Sheffield have been using SCERTS for a number of years. In September 2018, the primary schools within the Fir Vale family of schools (Abbeyfield, Byron Wood, Hucklow, Whiteways, Owler Brook

#### **Examples of strategies and resources**

In order to encourage a child to make simple requests, we might put their favourite toy into a transparent container that the child cannot open themselves. We then teach the child to ask an adult to help them open the container to get the toy out.



For a child who finds it difficult to cope with emotions,

we might teach them to use symbols to name the emotion they are feeling. Symbols can also be used to help the child choose an acceptable way of dealing with that emotion.

and St. Catherine's) took part in a research project to trial the use of the SCERTS model in a mainstream school setting. This produced some positive results, and the model is now being rolled out across Sheffield.

So far, over 350 professionals have attended a two-day SCERTS training course (via Zoom, or face to face before the pandemic). This course was led by Emily Rubin or Amy Laurent, two of the creators of the SCERTS framework.

The professionals taking part in the training have included members of the Speech and Language Therapy Service, Educational Psychology, the Autism Education Team, SENCOs, teachers and teaching assistants, and members of the Neurodisability Team at Ryegate.

Some of these professionals are now taking part in additional training sessions that focus on adapting strategies to children's sensory needs.

#### What do parents say about it?

A few years ago, we were able to offer free places on a SCERTS training course to our members. Here's what they said:

"We attended the SCERTS training course and now use SCERTS exclusively in our son's home education programme. We had to go to tribunal to get home-based SCERTS provision written into our son's EHC plan, so that it would have to be funded by the local authority. The stress has been worth it, though, because our son has made incredible progress with it."

"I had a fantastic two days attending the SCERTS training with Emily Rubin. I learnt so much about this model and was able to use much of what was discussed in encouraging my son's speech and language at home. Although the SCERTS model has not been used in the schools my son has attended, I am thrilled that it is now being rolled out more widely in Sheffield. I know it will be of great benefit to many."

#### **FORUM STARS**

In this section, we celebrate your children's successes – from the small steps that perhaps only you noticed, to the big milestones everyone can see. So, get snapping, get writing, and tell us what your wonderful children have been up to...

Rehan is 14 years old and a Year 10 student at Silverdale secondary school.

His hobbies include online gaming, participating in quizzes, playing board games and attending various sporting activities and clubs.

Like most children, Rehan found the school closures very difficult. However, he was determined to not let this stop him from making the most of his remote learning experience. He quickly established a positive routine for himself, making full use of the support and resources provided by the school. During the first lockdown, work was set via Google Classroom. The school also offered online drop-in sessions that students could access if they needed additional help or support with their work. Rehan became a regular at these sessions - not always to get support, but sometimes just to have a chat and a catch-up with his friends and the staff.

When schools closed again after Christmas, Rehan was quick to adjust to remote learning once again. At this point, most of his lessons were taught live, which helped to provide structure and predictability during a very uncertain time.

His mum Thaeeba said: "We are extremely proud of the mature and responsible attitude to learning that Rehan has shown throughout the pandemic. Even though he was invited to attend school during lockdown, he made the choice to learn remotely from home in order to help reduce the



number of children in school. He has remained focused and motivated throughout."

Staff at Silverdale have been equally impressed. His teaching assistant said: "I see Rehan overcome barriers he's faced with by having a wonderful ability to absorb everything like a sponge; his memory skills are amazing and coupled with being a kind, generous, polite, thoughtful and determined young man, he is achieving so much and is a delight to be around. We hope that we will see him on Mastermind soon!"

Rehan's SENCO said: "Rehan has flourished at Silverdale and is going to continue to grow into a fine young gentleman with all the qualities needed to lead a happy and fulfilling life. What impresses me most about him is his determination to remain kind and caring, even when things are challenging, and life throws unexpected difficulties at him."

#### SUPPORT GROUP FOCUS

## **SHEDS**

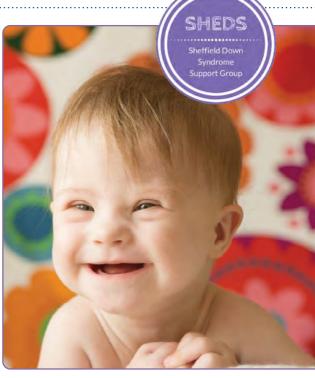
#### Sheffield Down Syndrome Support Group

SHEDS is a support group for families who have a child with Down syndrome and live in or around Sheffield. Their aim is for families to provide advice, support and friendship to each other and to exchange information on how best to support their children.

SHEDS has been in existence for over 10 years. The group is not a registered charity but is a voluntary support group affiliated to the national Down's Syndrome Association.

After having had to suspend meetings due to the pandemic, SHEDS are pleased to announce that they will be restarting their in-person Baby and Toddler Group from Monday 15th March at 10am in Greenhill (S8). The group is an encouraging space for parents with young children with Down Syndrome to share experiences and exchange information.

If you'd like to join them, please contact Bess at downsyndromesheffield@gmail.com for



more information. Currently, the group has limited spaces due to the pandemic, but will open their doors wider as soon as national restrictions allow.

SHEDS are also hoping to restart their other activities (such as monthly coffee mornings, family outings, summer picnics and play dates in the park) later in the year.

#### **Contact details**

Email: downsyndromesheffield@gmail.com

Closed Facebook group: www.facebook.com/groups/1443828745881468

Website: www.sheffielddownsyndrome.co.uk

## Help with sleep problems

Sleep problems are very common among children and young people with special educational needs or disabilities. Here are some organisations that can provide information, advice and support.





#### Information



about "Getting your teenager's sleep back on track" and "Getting a good night's sleep for school": https://tinyurl.com/familycentres



**Cerebra** have published a sleep guide for parents of children with brain-related conditions like autism, ADHD, Down Syndrome, learning disability, cerebral palsy or epilepsy: https://cerebra.org.uk/download/sleep-a-guide-for-parents/

**The Tired Out Hub** is a website created by the Family Fund in partnership with other charities: **www.tiredout.org.uk**. The hub provides information for families raising disabled children about bedtime routines, night waking, sleep facts and much more.

The Sheffield Children's Hospital have sleep resources for parents of children with autism and related conditions on their website: https://tinyurl.com/asdsleepresources

The Sleep Charity has resources on children's sleep problems, bedtime routines, bedroom environment, relaxation tips, diet and sleep, nightmares and night terrors, children with SEND, and babies and sleep on their website:

https://thesleepcharity.org.uk/information-support/children/

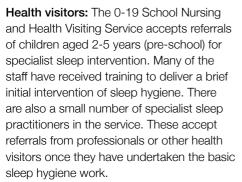
They also have resources on teenagers' sleep at https://teensleephub.org.uk/

**The Sheffield Parenting Hub** runs one-hour "Time to Sleep" Seminars (currently via Zoom). These are suitable for parents of children aged 1-18 years, and there are both general sessions and sessions for parents of children with autism. Book via this Eventbrite page: www.eventbrite.co.uk/d/online/sheffield-parenting-hub/

### Direct support



#### Children aged 0-5 years



Professionals can make referrals for sleep intervention via the Early Years Partnership Process or by email to **sheffieldduty**. **sleepreferrals@nhs.net**. Parents can self-refer to their own health visitor by ringing **0114 3053224** – more information can be found on www.sheffieldchildrens.nhs.uk/services/health-visiting.

#### Children aged 5 years and over

Parenting Hub: Some of the Parenting Specialists in the Parenting Hub have undergone sleep training by the Children's Sleep Charity. They can deliver direct sleep clinics and support families to create an individual action plan, along with regular follow-up calls whilst the plan is put into action. Generally, this support lasts for two to four weeks. A lot of this support is completed via Zoom and telephone contact. Parents can refer themselves by contacting sheffield.parenting@sheffield.gov.uk or

0114 2057243. The waiting time for a sleep

clinic is currently up to two months.

#### Children aged 0-16 years



Sleep Service at the Sheffield Children's Hospital: This service investigates and provides advice and treatment for children and young people with medical sleep disorders, such as obstructive sleep apnoea, narcolepsy, severe sleep walking, night terrors or unexplained nocturnal events. See www.sheffieldchildrens.nhs.uk/services/sleepservice/ for more information. Any healthcare professional can refer into this service if one of these conditions is suspected by sending a referral letter to the Sleep Consultant at Sheffield Children's Hospital.

A team of nurses and sleep practitioners also gives advice and intensive support for children with severe sleep disturbance. Parents should access the Health Visiting Team or Parenting Hub (see above) in the first instance and they will refer on to the sleep nurses at the Sheffield Children's Hospital if necessary. Sleep advice is also available from the specialist nurses for children attending the Ryegate Centre.

Cerebra Sleep Service: This service can provide 1:1 telephone support to parents of children with a brain-related condition (like autism, Down Syndrome, ADHD, cerebral palsy, learning disability or epilepsy, but also those without a diagnosis who are waiting for an assessment) whose sleep routine is non-existent or not working. Parents can refer themselves by completing this form: https://cerebra.org.uk/get-advice-support/sleepadvice-service/contact-the-sleep-team/



#### Dates for your diary



#### **Book your place**

Most of the meetings listed here will be virtual meetings held on **Zoom**. Please book your place via our website (**www.sheffieldparentcarerforum.org.uk/events**), and we will send you reminders and joining instructions. If you need help with this, or if you have any questions, please call our office on **0300 321 4721**.

#### **Makaton training course Level 1**

Fridays: 23 April, 30 April and 7 May 10am-12.30pm on Zoom

Run by the Speech and Language Therapy service, this course will teach you the Makaton signs from Stage 1 of the Core Vocabulary. We will practice together in a relaxed way and discuss hints and tips for Makaton signing. The cost is £21.45 per person, which covers all three sessions, manuals and certificate. **Booking essential.** 

#### Coffee morning with Educational Psychologist consultations

Wednesday 5 May, 10am-12pm on Zoom

This is a general coffee morning with private one-to-one consultations with an educational psychologist running alongside it. The consultations last 20 minutes and must be pre-booked. If you just want to attend the general coffee morning, you don't need to book; simply click on the Zoom link you find on our website to join the session.

#### **Transition subgroup meeting**

Tuesday 25 May, 10am-12pm on Zoom

This group is for parents of young people aged 14-25 years with special educational needs and/or disabilities. Please come and share your experiences, views and questions about the transition to post-16 education, college or employment, and to adult health and social care services. We are a friendly group and there will be time to chat and swap information with other parents. Please book your place.

#### **Education subgroup meeting**

Friday 25 June, 10am-12pm, on Zoom or at St Mary's Church

Please join our Education subgroup to talk to other parents about special educational needs, swap useful information, and help us influence education policy in Sheffield. This is a friendly and informal group, and new members are always welcome. No specialist knowledge required – being a parent is enough!

#### Makaton training course Level 2

Fridays: 11 June, 18 June, 25 June 10am-12.30pm on Zoom

This course will teach you the Makaton signs from Stage 2 of the Core Vocabulary and is for people who have attended the Level 1 course. The cost is £22.95 per person, which covers all three sessions, manuals and certificate. **Booking essential.** 

#### **Family Fun Day**

Sunday 11 July, 10am-3pm, Hillsborough Sports Arena

Our highlight of the summer! We're still confirming arrangements, but will hopefully be able to offer all the old favourites – from bungee trampolines to adapted bikes to exotic animals. Booking essential. Booking instructions will be sent to our members by email and SMS a few weeks before the event.

#### Don't miss out!

Sign up today by completing the membership form on our website (sheffieldparentcarerforum.org.uk/become-a-member) or at the back of this newsletter!

## New support group for adult siblings

Does your disabled child have older siblings who could do with a bit of support?

They might be interested in joining a new support group for adult siblings (aged 18 and over) of people with a lifelong disability.

Being a sibling can be a complex and challenging experience. This is a friendly group designed to offer support in a sibling-only environment, where every member can feel comfortable chatting about their own experience. The group is run by trained volunteer facilitator and fellow adult sibling, Olympia, and the first meeting will be on Thursday 25 March at 7pm, via Zoom.

Olympia said: "We're a brand-new group and are welcoming members from across Sheffield, South Yorkshire and beyond. Over the last year, I've found opportunities to chat to other adult siblings really helpful and would be happy to welcome any siblings to our group."

The group is part of the SibsNetworkUK. For more information about the group and to join, please visit the Sibs website: www. sibs.org.uk/support-for-adult-siblings/ adult-sibling-support-groups/.



#### **Useful Contacts**

<b>0-5 SEND Service</b> (formerly Early Years Inclusion Service)* Works with young children (0-5+) with additional needs both in their homes and in settings	0114 273 6411 elizabeth.hodkin@sheffield.gov.uk
ADHD Support Service Run by Family Action, this service provides information, support and training for families with a child with ADHD	07587 633179 adhd.sheffield@family-action.org.uk
Autism Education Service* Supports mainstream schools to meet the needs of pupils with autism and related conditions	0114 250 6800 (helpline, 1-4pm) autism.educationteam@sheffield.gov.uk
Becton Hospital and Outreach Team* (formerly Home and Hospital Education Service). Provides education for children who are unable to attend school for medical or related reasons	0114 255 7679 headteacher@becton.sheffield.sch.uk
Child Disability Register A local register of disabled children aged 0-19. Join up to receive the termly newsletter "What's Going On"	0114 271 7626 martina.capaldi@sch.nhs.uk
Children with Disabilities Team* Social work team for children and young people with disabilities	0114 273 5368
Contact National charity which provides information and advice on any aspect of caring for a disabled child, including education and benefits	0808 808 3555 info@contact.org.uk
Direct Payments Team* Provides support, advice and guidance relating to direct payments	0114 273 5985
Educational Psychology Service*  Works with families and staff in educational settings to support the education and development of children and young people	0114 250 6800 martin.hughes@sheffield.gov.uk
Hearing Impaired Service* Works with deaf and hearing-impaired children and their families	0114 273 6410 caroline.chettleburgh@sheffield.gov.uk
Independent Travel Training* Trains young people with disabilities/learning difficulties to use public transport to get to school, college and other education providers	0114 205 3542 jill.siddall@sheffield.gov.uk Indetravel@sheffield.gov.uk
IPSEA National charity providing free legally-based advice on educational issues for parents of children with SEN	Book a call-back via www.ipsea.org.uk
Local offer A website with information about support and services for children and young people with special educational needs and disabilities in Sheffield	www.sheffielddirectory.org.uk/ localoffer

Paces Sheffield A leading specialist centre for children with cerebral palsy and other motor disorders	0114 284 4488 info@pacessheffield.org.uk
Portage Home Visiting Service* Home-visiting educational service for children under three with additional support needs and their families	0114 273 6411 debbie.marshall@sheffield.gov.uk
Ryegate Children's Centre Assessment, diagnosis and therapy for children and young people with developmental and neurological problems	0114 271 7000
SSENDIAS* Provides information, advice and support to parents of children with SEN/disabilities in relation to education, health, social care, leisure, disability benefits and support groups	0114 273 6009 www.sheffieldsendias.org.uk ssendias@sheffield.gov.uk
SEN Statutory Assessment and Review Service (SENDSARS)* Deals with statutory assessments, EHC plans, annual reviews and specialist placements	0114 273 6394 sendassess&review@sheffield.gov.uk
Sheffield Carers Centre Offers information, advice and a range of services for carers, including parents of disabled children	0114 272 8362 support@sheffieldcarers.org.uk
Sheffield Children's Hospital	0114 271 7000 sheffield.childrenshospital@sch.nhs.uk
Sheffield Futures Learning Difficulties and Disabilities (LDD) Team Supports young people with learning difficulties & disabilities to make the transition into further education and employment	0114 201 2800 enquiries@sheffieldfutures.org.uk
Sheffield Young Carers Offers support to children and young people (8-25 years) who provide care for a family member, e.g. a disabled sibling	0114 258 4595 information@sheffieldyoungcarers.org.uk
Special Needs Inclusion Playcare Service (SNIPS)* Supports children aged 5-18 years to access short break activities to give their parents a break from caring	0114 273 4017 SnipsBusinessSupport@sheffield.gov.uk
Transport Services* Provides transport services including home-to-school transport for pupils with SEN	0114 203 7570 transportservices@sheffield.gov.uk
Vision Support Service* Supports children with a visual impairment and their families	0114 294 1201 joanne.hogg@sheffield.gov.uk

For changes to services during the pandemic, please see: https://tinyurl.com/sendservices

<sup>\*</sup> Part of Sheffield City Council

## **ADHD** support for families

Families of children and young people diagnosed with ADHD can get support from the Sheffield ADHD Project, run by national charity Family Action.



The project has been running in Sheffield for over 13 years. It supports families by raising knowledge and awareness of ADHD, providing strategies for managing the symptoms associated with it, and promoting the individuality and potential of those affected.

## The project provides two main services:

- Post-diagnostic consultations: These
  offer families a chance to discuss their
  child's diagnosis to ensure they fully
  understand it and to give basic advice.
   Staff also provide information on national
  and local sources of support.
- Managing ADHD groups: Following their post-diagnostic consultation, parents are invited to attend a Managing ADHD group. These six-to-eight-week courses provide ADHD-specific strategies on different topics, such as behaviour, emotional regulation or sleep. The groups are supported by the ADHD nurses from the Ryegate Centre, who deliver a session on medication, and the SSENDIAS service, who provide information, advice and support on a range of matters relating to special educational needs and disabilities. The groups also give parents

the opportunity to learn from each other's experiences, and many parents report that they gain emotional support from other participants.

The ADHD Project also provides training to schools and practitioners delivering services to families in Sheffield.

Due to the pandemic, there are currently no face-to-face sessions. Post-diagnostic consultations are taking place via telephone or video, and the Managing ADHD groups are successfully running via Zoom.

The ADHD Project welcomes self-referrals from parents of children and young people diagnosed with ADHD.

#### **Further information**

For further information or to make a referral, please contact:

#### adhd.sheffield@family-action.org.uk

You can also download a leaflet from: www. family-action. org.uk/content/ uploads/2020/02/ ADHD-Sheffield.pdf



## Sheffield Parent Carer Forum Application for Full Membership

Full membership is free and open to all parents and carers of children and young people (aged 0-25 years) with special educational needs and/or disabilities who live in Sheffield or access services in Sheffield.

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About you			
First name	Surname		
Street and house number			
Town/city	Postcode		
Email address (please print)			
Home phone	Mobile		
Your ethnic group (optional)			
About your disabled child/children	Please tick as appropriate :		
Child 1	Please add me to your email list.		
Date of birth	Please add me to your text messaging list.		
Main disability	Please add me to your postal mailing list.		
Other disabilities	I am happy to take part in consultations:		
	by phone by email		
School (name)	by post by SMS		
Child 2 Date of birth	I am interested in volunteering with the Parent Carer Forum.		
Main disability			
Other disabilities			
Ctrior disabilities	Signature		
School (name)	Date		
Child 3 Date of birth Main disability Other disabilities	Please note: By signing this form you consent to the Sheffield Parent Carer Forum storing your information. We will not pass any of your details on to any third parties. Members of our postal mailing list will receive a regular newsletter. Members of our email list and text messaging list will receive news updates and events information. You are free to opt out of this service at any time.		
School (name)			



Freepost RTBJ-SHTR-RRGJ Sheffield Parent Carer Forum St. Mary's Church Community Centre Bramall Lane SHEFFIELD S2 4QZ

Fold along here

