

Newsletter

For parents and carers of children and young people with disabilities and/or special educational needs in Sheffield

Published by the Sheffield Parent Carer Forum

Written by parents, for parents!

Spring 2018 - Issue 17 - FREE!

Two children, two journeys

What's it like to have two children diagnosed with different disabilities?

Pages 12 & 13

Finding a job

Support for disabled youngsters looking for work

Pages 20 & 21

Disability grants

Where to get funding for home improvements, breaks, equipment and more

Pages 16 & 17

Support at university

How to help your disabled child transition into uni life

Pages 18 & 19

About us

We are an independent group of over 1,700 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 to join.

Get in touch

By Post:

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

By phone: 0300 321 4721

By email:

enquiries@sheffieldparentcarerforum.org.uk

Website:

www.sheffieldparentcarerforum.org.uk

Drop-in:

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



Find us on Facebook!



Follow us on Twitter!
[@ShefParentForum](https://twitter.com/ShefParentForum)



Irwin Mitchell Solicitors are proud to contribute to the production of this newsletter.

We are able to offer guidance to you and your family on a wide range of legal services, from future planning and challenging decisions relating to social care, healthcare and education through to expert advice if you have suffered medical negligence or a serious injury or illness.

www.irwinmitchell.com/personal

For free initial advice please contact:

Anna Stacey on freephone **08000 232233**

or **anna.stacey@irwinmitchell.com**

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**

Design by 'Side of the Hill'. Printed by Volta Creative Ltd. Views expressed in this newsletter do not necessarily reflect the views of Sheffield Parent Carer Forum. Sheffield Parent Carer Forum does not endorse any organisations, products or services mentioned in this newsletter. Please contact us before reproducing any material contained in this newsletter. We welcome articles from parents, professionals and practitioners. Please contact us to discuss possible contributions. Sheffield Parent Carer Forum is a registered charity and a company limited by guarantee. Company number: 7226540. Charity number: 1145913

A very warm welcome to our spring newsletter!

Roll on summer!

Welcome to our spring 2018 newsletter, although it really doesn't feel like spring with the weather we have experienced recently! I hope that you weren't affected too much, and that the school closures and SEN transport cancellations didn't prove to be too stressful.

There seems to be so much happening at present. I have been Chair for almost a year now and I really don't know where the time has gone. The Forum is going from strength to strength and we are attending more and more meetings. Our name is certainly being recognised by more services, which means that the views of our families are reaching more people and shaping services available in Sheffield for our children and young people with SEND. Please keep contacting us with your experiences – good and bad!

March saw the first anniversary of our Jumpstars trampolining sessions, which continue to be well attended. It is always nice to see so many families enjoying themselves. We have set up new advice sessions with SENDIAS, we've given away free theatre tickets to our members, we continue to run monthly coffee mornings and there are lots more exciting events planned for the future.

We have now reached the end of the transition from the old SEN system to the new one, and we wonder what the



focus will be on next. I'm sure it will not come without its challenges, but you can rest assured that the Forum will be here to support all families with children and young people with SEND.

I hope you enjoy reading this latest edition which is once again packed full of essential and useful information. However, we are really struggling to fund the 6,000 paper copies per issue, which we distribute to families, services and schools across Sheffield. Therefore, if you know of any companies that could contribute towards the cost of this newsletter, we would be delighted to hear from you.

Best wishes,

Katie Monette
Chair

Could you **sponsor** this newsletter?

Our newsletter has been a trusted source of information for families with disabled children in Sheffield since 2010. We currently print 6,000 copies twice a year, which we distribute to our members and a wide range of organisations, including all schools in Sheffield.

We would really like to continue publishing a print version because that is what families tell us they want - but it is getting harder and harder to raise the money for this.

Do you own, or work for, a business looking to support a local charity? In return for sponsorship, we would include their logo and possibly a free advert. Please get in touch if you have any suggestions!



Volunteer with us!

We are looking for a **Fundraising Volunteer** to help us raise money for our popular family events and the newsletter.

Don't have much time? This role allows you to work as and when you can, either from home or from our office.

Don't have any fundraising experience?

Not a problem. We'll provide training and ongoing support. You'll be able to start small before progressing onto bigger bids as you become more experienced.

Don't want to do any cold-calling?

We wouldn't expect you to. The role mainly consists of researching potential funders, adapting and printing off letters, and tailoring bids to individual organisations (with support).

Interested? Then we'd love to hear from you! Please call Eva or Anne on **0300 3214721** for a chat.

Gripple continues to fund Christmas film

We are delighted that local manufacturer Gripple will once again fund our inclusive Christmas film. This popular event has become a firm fixture in our calendar. We have booked the Showroom Cinema for Sunday 9th December 2018, and a link to the booking form will be emailed to our members nearer the time.

G RIPPLE



Accessible video about having an operation

Sheffield Children's Hospital Foundation Trust has created an accessible video about having an operation. The video stars Rhona, one of our volunteers, and her lovely son Rory. It shows what happens when Rory has an operation at the Children's Hospital, and uses video footage, Makaton narration and Widgit symbols. You can watch it at:

www.youtube.com/watch?v=c4gVGmllu7c

Rhona said: "We were delighted to be approached by the Children's Hospital and asked to help them make a short video for children who use Makaton. They already had a few videos covering different sorts of hospital visits, but the anaesthetists really wanted one specifically for children who use signing and symbols. Rory and Makaton signer Chris really enjoyed the experience, and the hospital's own communications team did a brilliant job of knitting the whole thing together. Everyone involved was very pleased with the result and we all hope that the intended audience finds it useful."

Ray of Hope celebrates 15th anniversary



Running a parent support group takes huge amounts of time, commitment and energy – so hats off to the trustees and volunteers at Ray of Hope, who have kept this fabulous charity going for 15 years!

To celebrate this milestone, the group hosted a special anniversary party at Medieval Mayhem soft play centre.

Interested in joining?

Ray of Hope run fortnightly parents' meetings at Eskdale Community Centre and monthly soft play sessions at Medieval Mayhem on Neepsend Lane.

For more information, please join their closed Facebook group:

www.facebook.com/groups/47995953452/

The EHCP annual review process

The Council for Disabled Children has published an animation for parents that explains the annual review process for Education Health and Care (EHC) plans: <https://tinyurl.com/ycqejd4>



Councils race to meet EHCP transfer deadline

Does your child still have a statement of special educational need (SEN)? Then you probably know that this document must be converted into an Education, Health and Care (EHC) plan by 31st March 2018.

This date marks the end of a lengthy transition period from the old SEN system to new legislation that was introduced back in 2014.

However, many local authorities are facing challenges in meeting this deadline, and Sheffield

is no exception. By mid March, Sheffield still had 96 statements left to convert. For all but 10 of these, draft EHC plans had been sent to parents. Sheffield's Head of SEN Tim Armstrong told us that he was confident that almost all conversions would be finalised by the deadline.

But how will this rush to the finish line impact on quality? And what happens once all the conversions are done – how likely is it that poor EHC plans will be improved through the annual review process? Tim acknowledged that annual reviews had taken a back seat recently, but pledged to invest time and resource in supporting the annual review process going forward.

The government's Department for Education is monitoring the situation and has advised that there will be follow-up with any local authorities that breach the deadline. They have also emphasized that councils must not sacrifice quality for speed.

How worried should you be if your child is left with a "zombie statement"? The government has said that any statements that are still in place after 31st March will continue to have legal status. That means that both the provision and the placement set out in the statement must continue until an EHCP transfer review has been completed and a final plan has been issued.



New wellbeing drop-in service for young people

Door43 is a new drop-in service for young people aged 13-25 years.

The service is run by Sheffield Futures and focuses on early intervention and low-level support (i.e. not suitable for those who are in crisis and/or need medical treatment).

Young people can just pop in and have a confidential chat with a health and wellbeing practitioner. Those who prefer to have an appointment can contact the service to arrange this.

Door43 provides:

- Low-level support on a range of social, emotional, practical and health-related issues
- Access to counselling provided by Interchange Sheffield
- Information, advice, guidance and signposting to other services

- Sexual health information and advice
- Direct access to substance misuse support
- Practical support, and supported referrals to a wide range of other services
- A weekly wellbeing café (Tuesdays 5-7pm) where young people can socialise, be creative and have fun.

Opening times:

Monday – Friday 9am - 5pm
Open late on Tuesday until 7pm
Saturday 9.30am - 12.30pm

Contact details:

Sheffield Futures
Star House
43 Division Street
Sheffield S1 4GE

Tel: **0114 201 2774**

Email: **Door43@
sheffieldfutures.org.uk**



Special Educational Provision under review

The government has given funding to local authorities to carry out a strategic review of their special educational provision.

This includes provision made by mainstream and special schools, nurseries and colleges, integrated resources, and specialist support services like Educational Psychology or the Autism Team.

The review sits within the context of school funding reforms (see page 10) and additional infrastructure funding to help local authorities improve facilities for pupils with additional needs. Sheffield will get almost £1.5 million of extra capital funding over a period of three years.

To kick-start the review, Sheffield City Council asked a range of interested groups (parents, schools, professionals etc.) for their views. We submitted a summary of feedback we had received from parents over the past two years.

A consistent theme emerging from this call for views was the need for a continuum of provision, with more graduated steps between different



types of provision. The council have said that they want to look at the following areas:

- Improving support for mainstream schools
- Strategic commissioning of integrated resources and/or special school-led “hubs” in mainstream schools
- Strategic joint commissioning with partners and neighbouring local authorities of provision for the most complex needs (out-of-city placements)
- Improving physical access to mainstream settings
- Reducing pressure on special schools

The next steps will be to map Sheffield's current range of provision, carry out a data analysis, and develop a model that aims to close gaps in provision.

Have
your say!

To contribute to the strategic review, you can either contact us or email Cathie Tandy in the council's Prevention and Early Intervention Team (catherine.tandy@sheffield.gov.uk).

Regular updates about the review and opportunities to get involved will be published on our website:

www.sheffieldparentcarerforum.org.uk



SEND Tribunal powers expanded

When Education, Health and Care (EHC) plans were introduced in 2014, the new legislation failed to address a major flaw in the system: the lack of a single route of redress. Although EHC plans were intended to be holistic, families were still only able to appeal to the Special Educational Needs and Disability (SEND) Tribunal about the educational aspects of their plan. Disputes about the health and social care aspects had to be resolved through separate complaints processes. This issue is now being addressed.

A two-year national trial will expand the powers of the SEND Tribunal to make non-binding recommendations about the health and social care aspects of EHC plans, alongside the special educational aspects. This means that families

will be able to appeal against sections B, C, D, F, G, H and I of an EHC plan. The trial starts on 3 April 2018 and will only apply to local authority decisions or EHC plans issued or amended after this date.

Although the trial brings families one step closer towards having a single route of redress and should encourage a more joined-up approach, two major issues remain. Firstly, tribunal recommendations for health and social care partners will be “non-binding” – which means that, unlike decisions on education, they don’t have to be followed. Secondly, local authorities and health commissioners will be able to claim reimbursement of costs incurred in taking part in the trial, up to a maximum of £4,000 per case – but there is no equivalent grant for parents, who may well incur additional costs if hearings become longer or more complex.

NEED ADVICE?

We have a list of organisations offering free legal advice on our website:
www.sheffieldparentcarerforum.org.uk/resources/legal-support

NEW! Advice sessions for parents

We have teamed up with Sheffield SEND Information Advice and Support (SENDIAS) to run bi-monthly advice sessions for parents.

SENDIAS (formerly known as Parent Partnership) is a council-run service which provides free, impartial and confidential information, advice and support for children and young people with special educational needs and disabilities aged 0-25 years, and their parents.

We currently alternate between open drop-in sessions with groups of parents, and advice clinics where you can book individual appointments. A worker from SENDIAS will attend both types of sessions to answer questions about anything SEND-related, such as support in school or college, EHC plans, SEN transport, health and social care services, disability benefits, and much more. Please see pages 22 & 23 for dates.

Speech and language therapy reduced for mainstream pupils

The Sheffield Speech and Language Therapy Service has been experiencing significant capacity issues in recent months. These were caused by EHCP assessments and conversions, an unprecedented increase in new referrals, and unavoidable staff absence such as sick leave.

As a temporary measure, the service stopped providing some review sessions for mainstream pupils during the Spring term 2018. Work with children attending early years settings and special schools was unaffected. The service also continued to see new referrals, carry out EHCP-related activity and work with children with very



complex needs and speech/pronunciation difficulties in mainstream schools.

Sheffield Children's Hospital senior management and health commissioners have told us that they are hopeful that the service for mainstream pupils will resume as normal after the Easter holidays. We are keeping a close eye on the situation and will publish updates on our website (www.sheffieldparentcarerforum.org.uk).

If you are worried about the impact of these measures on your child, please contact the Speech and Language Therapy Service on **0114 226 2333**.

Sheffield pupils miss out on high needs cash

Sheffield pupils with complex needs will not be getting the funding boost many had hoped for, due to the way the government is phasing in funding reforms.

From April 2018, the government will introduce a new national funding formula for "high needs". This is money given to local authorities to fund provision like special schools, integrated resources, top-up funding for mainstream schools and specialist support services like the Autism Team.

Sheffield has historically been one of the worst-funded big cities in England and has been struggling to finance an increasing number of special school places from a budget that just hasn't kept pace. The new formula should be addressing this – but it falls far

short. This is because the government has capped the increase at 3% per year, to keep the introduction of the new funding system "affordable".

Information shared by the Education and Skills Funding Agency (ESFA) suggests that, based on the current demographics and profile of Sheffield pupils, high needs funding for Sheffield in 2018/19 should be £60.4m. Due to the 3% cap, however, it has been set at £53.7m – a £6.7m shortfall. To put this into context, Sheffield is planning to spend £21.7m of this year's high needs budget on special schools, £3.7m on independent specialist placements, and £2.1m on top-up funding for children in mainstream schools.

In the long term, funding for high needs should increase – but in the short term, the council will be struggling to balance the books, and our children will feel the impact of this.

A young girl with blonde hair in a ponytail, wearing a pink shirt, blue jeans, and a blue backpack, is walking away from the camera along a chain-link fence. She is holding a small stick or pencil in her right hand. The background shows green grass and trees under a clear sky.

South Yorkshire named “hot spot” for school exclusions

Sheffield, Barnsley, Rotherham and Doncaster are among the ten local authorities with the highest exclusion rates in the country, figures published by the Department for Education have shown.

The report has prompted education watchdog Ofsted to write to all secondary head teachers in the worst-performing areas to raise concerns about the high rates of fixed-term exclusions. Schools in these areas will also have their use of exclusions scrutinised as part of the Ofsted inspection regime.

The announcement sparked a debate about the causes of high exclusion rates, with education secretary Damian Hinds claiming that some head teachers are excluding pupils who may bring down their performance in the league tables. Teaching unions hit back saying that cuts to school budgets and support services, as well as the relentless focus on exam results, are to blame.

The government has now launched a review of exclusions, led by former children's minister Edward Timpson. The review will examine how and why schools use exclusion, what drives the variation in exclusion rates, and why some

groups of children are more likely to be excluded than others. For example, almost half of all exclusions – fixed-term and permanent – are of pupils with special educational needs.

In Sheffield, the council has set up two “inclusion panels” – one for the primary sector and one for the secondary sector – to try and bring down exclusion rates. Schools can refer pupils who are at risk of permanent exclusion to these panels, which are made up of head teacher representatives, local authority officers and other professionals. The panels will look at each case and develop an action plan, which always includes some outreach work from the most appropriate key service.

Have your say!

As part of the review of exclusions, the government has launched a call for evidence, which will run until 6th May 2018. You can submit your views here:

<https://tinyurl.com/ya85hd7r>

Concerned about exclusions?

We have lots of useful local information on our website:

**[www.sheffieldparentcarerforum.org.uk/
resources/education/school-exclusions](http://www.sheffieldparentcarerforum.org.uk/resources/education/school-exclusions)**

Two children, two very different journeys

What is it like to get a diagnosis at birth, compared to going through a lengthy assessment process with a three-year-old? Lizzie Marcer has experienced both with her sons Leo and Sam. Here she describes their two very different journeys.

Our story starts ten years ago when Leo was born. Once I looked into Leo's eyes, it was clear to me that he had Down Syndrome. At this point my brain went into freefall; everything seemed to happen in slow motion. Shortly afterwards a doctor said that she had serious concerns about our baby. A blood test confirmed the diagnosis, and Leo was put into the special care baby unit for close monitoring. The following days went by in a blur. I think we cried and talked a lot and tried to process what this diagnosis meant. A social worker arrived with a big folder of information about Down Syndrome and put Leo on the disability register. A senior consultant took us to one side and explained his vision of how Leo would affect our lives. This was very stark: he stated that Leo would be a terrible burden on our family, and that we should consider having him fostered or adopted. We certainly hadn't given the hospital any reason to believe that this was our intention. By this point we had accepted that Leo had a different number of chromosomes but felt grateful that he was medically fit.



Before long, we took Leo home and started our lives as a family of four. There were lots of medical appointments, but we started to settle into life. We explained to Leo's brother Oliver that Leo was built with slightly different Lego bricks, and that this would make him find a few things difficult.

Leo's development over the next few years was slow, but he had good support from a team of skilled professionals. This included physiotherapy, speech and language therapy, occupational therapy and his own neurodisability consultant who pulled all the support together. Leo had a statement of special educational needs from the age of three, and one-to-one support was in place when he started at his local mainstream school. Leo is currently in an integrated resource within a mainstream school where he is very happy and settled.

Sam's story is very different.

Sam was always a discontented baby. He never woke up happy. He was always screaming and crying. In all other ways, however, he seemed to be developing normally.

At around 18 months we noticed that Sam was rotating his hands (we thought he was copying his brother Leo). Aged two, the hand rotating increased, and Sam also started walking around tables and hedges and looking out of the corner of his eyes. He became obsessed with water play, fans and car wheels. Then his speech development began to go off track; he was fixated on certain words and used them repeatedly out of context. It was hard to engage his attention, and he darted around a lot.

These were difficult days. As I researched Sam's behavior, I became more and more convinced that something was wrong. I worried that I wouldn't be able to cope with a second child with complex needs. For a long time, I didn't tell my family and friends about my concerns, because I couldn't bear to see their pain.

Things came to a head when Sam started nursery. He was prone to sudden aggressive outbursts and needed constant one-to-one support to keep him and the other children safe. At this stage, the Early Years Inclusion Team became involved and Sam was referred to the Ryegate Children's Centre. At the age of three, after an 18-month wait, Sam was diagnosed with Autism Spectrum Disorder.

Sam now attends the same mainstream school that Leo went to. After a long battle, he has a high level of support in school but is yet to be awarded an Education, Health and Care Plan. He finds the school environment very challenging and spends much of his time away from the mainstream class.



Looking back, our experiences could not have been more different. Part of this is down to the length of time taken to get a diagnosis. When your child's difficulties are apparent at birth, you have an idea of how things may develop. The slow realisation that all is not well with a child with no obvious impairment, however, can be very difficult to come to terms with.

Of course, Sam and Leo have very different needs – but that only partially explains the differences we have experienced. A much larger factor are the austerity cuts that were introduced between the two children's births. These cuts have had a devastating impact on the health, education and social care services our children need.

Ten years ago, support was offered proactively. Now, everything has to be fought for. I feel that this is hugely unfair on parents who are already drained by sleepless nights and the demands of their complex children.

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...

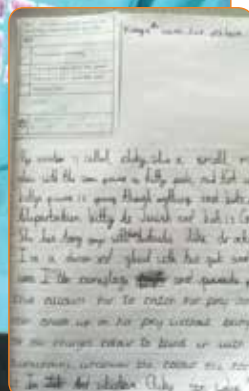
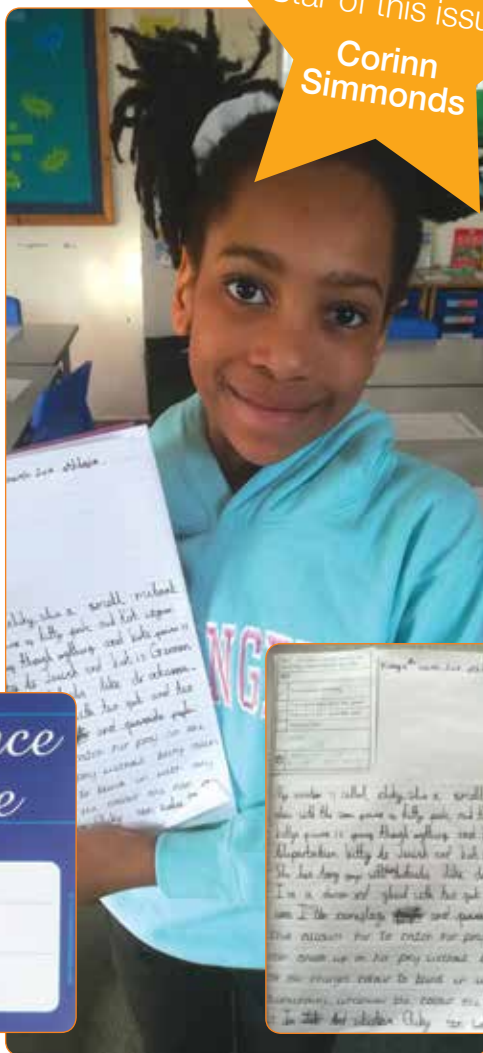


This is Corinn, who is eight years old and a Year 4 pupil at Porter Croft CofE Academy. Corinn has worked very hard to gain her pen licence. To get this, she had to be able to produce "fluent and legible handwriting", and this achievement was acknowledged by giving her a pen licence certificate and card and a black pen to write with.

Corinn is a very determined person and was motivated to improve her writing to gain her reward. She worked tirelessly for several months until she finally received it in March 2018.

The award has improved her confidence in her ability to write and helped her to feel more mature. Corinn said, "I am very happy that my handwriting is neater and cursive. I am now allowed to write in black pen for all my lessons and homework. Now I want to improve my drawing and be the best in my class."

Star of this issue:
Corinn Simmonds



SUPPORT GROUP FOCUS

Sheffield and Rotherham PDA Support Group

We are a parent-led support group for those who have children, young people or adults with PDA, or suspected PDA.

Whilst it is primarily for parents, carers or extended family members, it is also for anyone interested in the condition who wants to know more.

Our groups are friendly, informal and supportive. We offer you a bit of breathing space, emotional support and practical advice. A place to come where you can learn more about the condition, ask questions, discuss any concerns you have, find out about local and national services and organisations and build friendships with others in a similar situation to yourself. We also have literature you can look at and some you can take away.

The groups alternate between Sheffield and Rotherham monthly and you are most welcome to attend both. We have deliberately set up a daytime group in Sheffield and an evening group in Rotherham to reach a wider group of people. If you would like to come, please see our meeting schedule opposite:

What is PDA?

PDA stands for Pathological Demand Avoidance. It is a behaviour profile that is seen in some individuals on the autism spectrum.

More information is provided on page 26.

Sheffield Daytime meetings

Meetings for Sheffield run on a Thursday unless otherwise specified.

Time: 11.30am-1.30pm

Dates: 26th April, 28th June

Venue: All Good Stuff
Academy of Makers
Butchers Works
72 Arundel Street
Sheffield S1 2NS

Rotherham Evening meetings

Meetings for Rotherham run on a Wednesday unless otherwise specified.

Time: 6.30pm-8.30pm

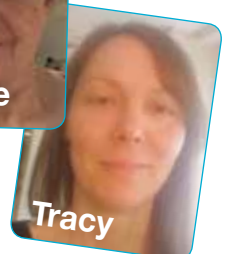
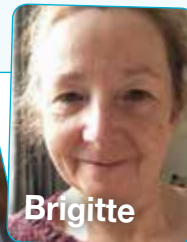
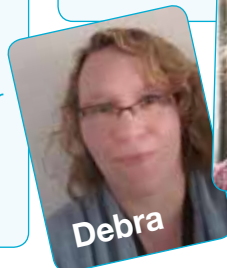
Dates: 30th May, 25th July

Venue: Three Horseshoes
(upstairs room)
133 Bawtry Road
Wickersley
Rotherham S66 2BW

Contact email:

pda.rotherhamsheffield@gmail.com

Please note: Emails are usually picked up approximately one week before the next meeting, therefore, apologies for any delay in responding to inquiries.



Grants



Grants for Carers

The Carers Trust currently has a grant fund open for carers aged 16 and over (including parents of disabled children). Carers can apply for grants of up to £300 for items or activities that will benefit them in their caring role, such as:

- Breaks for carers, with or without the person they care for
- Items for the home, including cookers, fridges, beds and washing machines
- Driving lessons and other travel costs relating to caring roles
- Courses and materials to develop carers' skills and personal development
- Home repairs
- Short-term or time-limited replacement care.

For further information and to apply, please contact Sheffield Carers Centre on **0114 278 8942** or email **office@sheffieldcarers.org.uk**

They will need to complete a supporting statement for you on the application form.

Funding for home improvements

WellChild Helping Hands is a home improvement programme which, with volunteers from local companies, transforms gardens (including fencing) and bedrooms for children and young people aged 1-18 years with complex care needs. WellChild have completed projects for children with a wide range of disabilities and needs, such as spina bifida, muscular dystrophy, autism and visual impairment. They can also help families who have children who have not yet been diagnosed.

Applications are considered for any property, providing that it is the main place of residence for the child named in the application. If your application is successful and you live in council, housing association or a privately rented property, WellChild will ask for permission from the owner of the property before the project begins.

For more information, please visit **www.wellchild.org.uk**, telephone **01242 530007** or email **info@wellchild.org.uk**.

Please note: Applications for Helping Hands' grants are currently closed but should reopen in May/June 2018.

Family Fund



Family Fund is the UK's largest charity providing grants to families raising disabled or seriously ill children. They support children with a wide range of conditions, up to the age of 17, by providing grants for family breaks, sensory equipment, clothing, garden fences, white goods and much more. Families eligible for Universal Credit, Child Tax Credit, Working Tax Credit, housing benefit or income support are eligible to apply. If you do not receive any of the above, you can still apply, but they will need some extra information about your household income.

For more information:

please visit www.familyfund.org.uk
or call **01904 550055**.

Funding for driving lessons

Young disabled adults in receipt of the enhanced rate mobility component of Personal Independence Payment can learn to drive at 16 years. Once you have your provisional licence from the DVLA, you can apply to the **Motability Grant Scheme** for help with the cost of up to 40 hours of driving lessons with a national driving school.

You qualify for the grant if:

- You already have a Motability Scheme vehicle or you have one on order; AND
- You are in receipt of a means-tested benefit such as Income Support or Working Tax Credit; OR
- You are in full-time education or training (up to 25 years of age) and you or your parents/guardians receive a means-tested benefit.

For more information, please visit

www.motability.org.uk/charitable-grants
or telephone Motability on **0300 456 4566**.

Equipment grants

Newlife is the UK's largest charitable provider of essential equipment to meet the specialist needs of children with significant disabilities, life-threatening/limiting conditions or terminal illnesses aged 0-18 years. They can provide funding for beds, buggies, wheelchairs, seating systems, and much more. They also have a loan service for emergency equipment, specialist play therapy toys and "comfort capsules" for terminally ill children.

For more information and to check eligibility, please call their free helpline on **0800 902 0095** or visit **www.newlifecharity.co.uk**

Find more grants

Turn 2 Us have a grants search tool: **www.turn2us.org.uk**

Disability Grants UK have a database of charities and trusts that provide funding towards the cost of disability equipment, housing, holidays and more: **www.disability-grants.org**

Support at **university**

We are all familiar with the struggle of getting our children through primary and secondary education: the battles to get their needs identified and ensure they are supported so that they can perform to the best of their ability. University education and the consequent move to independent study and living can seem a goal too far and unattainable.



**More
information
about DSA**

In this article, our trustee Jayne Woodward, who also works as a Disability Adviser at the University of Sheffield, explains how to help your child transition into university life and ensure they are supported throughout their studies.

Universities have a duty under the Equality Act 2010 to ensure disabled students are not treated unfavourably by reason of their disability and will have specialist services to support them. These services will talk to students who disclose a disability about their support needs and liaise with the appropriate internal departments, services and external agencies. Typical support will be for exam access arrangements (such as extra time, rest breaks, technology or a separate exam room), a learning support plan advising tutors how to support the student appropriately, and support facilities in the library. Additional support is available through workers such as note takers, library support, study skills tutors and mentors.

The key to accessing support is to have some form of written documentation to confirm the student's disability and support needs. This could be medical letters or diagnostic assessments. For specific learning difficulties such as dyslexia, some universities will accept confirmation of exam access arrangements as interim evidence whilst full diagnostic assessments are obtained. Many universities will fund (wholly or in part) the cost of these diagnostic assessments.

Whilst the disability service will be responsible for putting in place internal institutional support (exams, learning plans, etc.), they can also help students apply for Disabled Students'

Allowances (DSA), which will pay for most support that has a financial cost.

The process for applying for DSA is usually piggy-backed onto the student loan system. However, you do not need to claim for financial support to be eligible. DSA are not means-tested, and students do not have to repay them.

To qualify for DSA, the student must have a physical or mental impairment that has a substantial and long-term negative effect on their ability to carry out normal daily activities. This will include specific learning difficulties.

An Education Health and Care Plan is not sufficient evidence in itself and will need to be supported by other documentation. Once a student has been confirmed as eligible for DSA, they will usually be invited to attend a regional assessment centre. There are centres located around the country, and we currently have four in Sheffield. At the appointment, an assessor will discuss the student's support needs and suggest strategies, human support and technology that can assist them to break down the barriers that exist for them. DSA will then fund the cost of the agreed support. After the appointment, the assessor will write a report which can also help the disability service put the most appropriate support in place for the student.

Detailed information about what DSA can pay for, eligibility criteria and the application process is available on the government website: **www.gov.uk/disabled-students-allowances-dsas**

Finding and keeping a job

What support is available in Sheffield to help young people with disabilities and health conditions to find and keep a job?

If the young person is still in education:

Sheffield Futures provide careers advice. They run careers clinics at schools across Sheffield, and drop-in sessions at Star House on Division Street. They also have a specialist team of advisors who work with young people in special schools. Sheffield Futures can help with job hunting and finding training opportunities and apprenticeships.

Contact: **0114 2012800**
enquiries@sheffieldfutures.org.uk

Jobcentre Plus have Schools Advisors who work with young people aged 12-18 years (up to 25 years for those with an EHC plan). They can help with things like CVs, applications, interview techniques and work experience placements, both through group sessions at school and on a one-to-one basis. They are happy to talk to parents too!

Contact: **07717348334**
rachel.milner@dwp.gsi.gov.uk

Sheffield College and Sheaf Training offer Supported Internship courses for young people with EHC plans. These courses primarily consist of work placements with local employers, but also offer the chance to study for relevant qualifications, as well as English and Maths. Wherever possible, students are supported to move into paid employment at the end of the programme.

Contact: Sheaf Training **0114 4031007**
Richard.smith@sheffield.gov.uk

Sheffield College **0114 2602600**
louise.burton@sheffcol.ac.uk

If the young person has left education:

Jobcentre Plus have a specialist advisor (Eleanor Bamber) for young people with disabilities aged 18-25 years who are not in employment, education or training (NEET). Eleanor can provide one-to-one support within the jobcentre or run group sessions on topics such as disclosing a disability to an employer, reasonable adjustments, how to overcome barriers to employment etc. Eleanor is happy to be contacted by parents too.

Contact: **07881035397**
Eleanor-.bamber@dwp.gsi.gov.uk

Jobcentre Plus can refer those who need a higher level of support on to a new programme called Better Working Futures. Run by Reed in Partnership, this programme focuses on helping disadvantaged groups (particularly people with health conditions or disabilities) to find and sustain work. Employment advisors work with participants for up to 15 months, with an additional six months once participants are in work. The offer includes one-to-one meetings, better-off calculations, support to access local services, funding for travel, interview clothing or external training, and



workshops and support to address complex needs and barriers, such as housing or money issues. Referrals can only be made through Jobcentre Plus.

Sheffield Futures run a programme called Talent Match for young people aged 18-24 years who have been NEET for 12 months or more. They help young people overcome barriers to employment through one-to-one work with a specialised coach. The coach and the young person work together to explore training, work and personal development opportunities. Some support is also available to help with childcare, transport, clothing for interviews and other barriers to work.

Contact: **0114 2012800**
enquiries@sheffieldfutures.org.uk

If the young person is already working or has a job offer:

Access to Work is a government grant scheme which is aimed at supporting disabled people to take up or remain in work. Grants can be given for a wide range of interventions that help to break down barriers to work.

For example, communication support at job interviews; a reader for somebody with a visual impairment; a specialist job coach for a person with a learning disability; specialist aids and equipment; awareness training for colleagues; help towards taxi fares for someone who cannot use public transport; alterations to premises; or access to a mental health support service.

To qualify for the scheme, the young person must be aged 16 or over and have a disability or health condition (physical or mental) that makes it hard for them to do parts of their job or travel to and from work. They must also be employed or self-employed; have received a job offer; or be on an apprenticeship, traineeship, supported internship, work trial or work experience. Support is also available for job interviews.

There is no set amount for an Access to Work grant, and how much an individual will receive depends on their circumstances. Grants are capped at £57,200 per year.

Contact: **0800 1217479**
www.gov.uk/access-to-work/apply

Dates for your diary

All meetings will be held at:

St Mary's Community Centre,
Bramall Lane,
Sheffield S2 4QZ
unless otherwise indicated.

Book your place

To book your place on any of the events listed here, please visit our website www.sheffieldparentcarerforum.org.uk/events or call our office on **0300 321 4721**.

April

Friday 27 April, 10am - 12pm

Education subgroup meeting

Please come along to 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! No need to book, just turn up.

May

Tuesday 1 May, 10am - 12pm

Transition subgroup meeting

This group is for parents of young people aged 14-25 years with special educational needs and/or disabilities. Please come along and tell us what's happening in schools and colleges, and with social care and health services. Your views and experiences will help us influence transition in Sheffield. We are a friendly group and there will be time to swap experiences and information with other parents over tea, coffee and cake!

Please book your place.

May continued

Thursday 10 May, 10.30am - 12pm

Coffee morning

Tuesday 15 May, 10am - 12pm

Parent workshop:

Supporting speech sounds

This workshop is for parents of children who have problems with speech sounds. A speech and language therapist will explain how and when speech sounds develop and demonstrate general games and strategies for supporting speech sound development and Cued Articulation practice (a speech cueing system that uses hand shapes).

Booking essential!

Tuesday 15 May, 6 - 7pm

Jump Inc. Meadowhall, Vulcan Road

JumpStars inclusive trampolining session

June

Tuesday 12 June, 10am - 12pm

Transition subgroup meeting

As previous.

Wednesday 13 June, 11am-1pm

SEND advice drop-in

This is a drop-in session for parents and carers of children and young people (0-25 years) with special educational needs and/or disabilities (SEND). You'll be able to talk to a worker from SENDIAS about anything SEND-related. For example, you may want to ask about your child's support in school or college, EHC plans, SEN transport, health and social care services, disability benefits, and much more. Please note: This is an **open group session** with other parents. No need to book, just turn up.

June continued

Thursday 14 June, 10.30am - 12pm

Coffee morning

Tuesday 19 June, 6 - 7pm

Jump Inc. Meadowhall, Vulcan Road

JumpStars inclusive trampolining session

Wednesday 27 June, 10am - 12pm

Parent workshop: Using visuals at home

Run by a speech and language therapist, this workshop will focus on using objects, photos, pictures and symbols to support children with communication difficulties at home.

Booking essential!

July

Friday 6 July, 10am - 12pm

Education subgroup meeting

As previous.

Tuesday 10 July, 10.30am - 12pm

Coffee morning

Tuesday 17 July, 6 - 7pm

Jump Inc. Meadowhall, Vulcan Road

JumpStars inclusive trampolining session

Dates after July

For events after July 2018, please visit...

www.sheffieldparentcarerforum.org.uk/events/

Coffee mornings

Our coffee mornings are run by our friendly volunteers Thaeeba and Pat. They are open to all parent carers, whatever their children's needs, whether diagnosed or undiagnosed, mild or severe. Pre-schoolers and home-educated children are welcome too. Pop in for a few minutes or stay for the whole session – no need to book. You can be sure of a warm welcome and plenty of tea, coffee and cake! Meetings are held at St Mary's Community Centre, Bramall Lane, Sheffield S2 4QZ.

JumpStars inclusive trampolining sessions

These are discounted, disability-friendly trampolining sessions for children with additional needs and their siblings, held at the new Jump Inc. centre near Meadowhall. Only Sheffield Parent Carer Forum members are eligible to attend. **Sessions must be pre-booked and pre-paid online.** A link to the booking form is published on our website and circulated to our email list a couple of weeks before each session.

Save the date!

We are delighted that Sheffield City Council will once again fund our hugely popular Family Fun Day! This year's event will take place at Hillsborough Sports Arena on Friday 3rd August at 10am-3pm. Booking essential. Invitations will be sent out to our members in June/July.

Don't miss out!

Sign up today by completing the membership form at the back of this newsletter!

Useful Contacts

ADHD Support Service Run by Family Action, this service provides information, support and training for families with a child with ADHD	0114 4782980
Autism Service* Supports mainstream schools to meet the needs of pupils with autism and related conditions	0114 273 6567 (helpline, 1-4pm) 0114 273 6412 (office) moira.bolan@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
Core Assets Provides independent information and support to families in relation to EHC plans (new applications and annual reviews)	0800 028 8455 isreferrals@coreassets.com
Direct Payments Team* Provides support, advice and guidance relating to direct payments	0114 273 5985
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
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 stuart.williams1@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 work placements	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 our area	www.sheffielddirectory.org.uk
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
SENDIAS (formerly Parent Partnership Service)* 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 disabilityinformationservices@sheffield.gov.uk
SEN Assessment and Placement Team* Deals with statutory assessments, statements/EHC plans, annual reviews and specialist placements	0114 273 6394 ed-sensupportteam@sheffield.gov.uk
Sheffield Carers Centre (formerly Carers in Sheffield) 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
Sibling Support Group Support group for children who have a sibling with a disability	0114 233 2908 laura.westmorland@burtonstreet.org.uk
Special Needs Inclusion Playcare Service (SNIPS)* Helps disabled children aged 5-18 access out of school activities / clubs 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
Within Reach Sport and physical activity for disabled people of all ages	0114 273 4266 sccphysicalactivityandsport@sheffield.gov.uk

* Part of Sheffield City Council

What is PDA?*

PDA stands for Pathological Demand Avoidance. It is a behaviour profile that is seen in some individuals on the autism spectrum.

People with PDA share difficulties with others on the autism spectrum in social communication, social interaction and restricted and repetitive patterns of behaviours, activities or interests. In addition, they are driven to avoid everyday demands and expectations to an extreme extent. This demand avoidant behaviour is rooted in an anxiety-based need to be in control.

For a child with PDA, even ordinary daily tasks such as getting dressed, eating a meal and going out (even to an enjoyable place) can be very challenging. They will often go to extreme lengths to avoid demands, e.g. by refusing, making an excuse, distracting, negotiating or doing or saying something shocking. If these avoidance strategies fail, the child may have a meltdown, which is best viewed as a panic attack. This may take the form of challenging behaviour, withdrawal or some children may run away.

The key features of a PDA profile are:

- Resisting and avoiding ordinary demands
- Appearing sociable but lacking depth in understanding
- Excessive mood swings and impulsivity
- Comfortable in role play and pretend play, sometimes to an extreme extent
- Obsessive behaviour, often focused on real or imagined people.



Further information is available from the PDA Society;

visit **www.pdasociety.org.uk**
or email **info@pdasociety.org.uk**.

There is no advice line, but you can request a telephone call-back by email.

*Adapted from the leaflet "A Parent's Guide to Pathological Demand Avoidance (PDA) - Part of the Autism Spectrum", PDA Society

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.

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

Child 1

Date of birth	
Main disability	
Other disabilities	
School (name)	

Child 2

Date of birth	
Main disability	
Other disabilities	
School (name)	

Child 3

Date of birth	
Main disability	
Other disabilities	
School (name)	

Please tick as appropriate :

<input type="checkbox"/>	Please add me to your email list.		
<input type="checkbox"/>	Please add me to your text messaging list.		
<input type="checkbox"/>	Please add me to your postal mailing list.		
I am happy to take part in consultations:			
<input type="checkbox"/>	by phone	<input type="checkbox"/>	by email
<input type="checkbox"/>	by post	<input type="checkbox"/>	by SMS
<input type="checkbox"/>	I am interested in volunteering with the Parent Carer Forum.		

Signature

Date

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.

2

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

Fold along here



Positive Change for our Children and Young People
with Disabilities and Special Educational Needs