

**Published by the Sheffield Parent Carer Forum** Written by parents, for parents! Autumn 2023 Issue 29 - FREE!

## Newsletter

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

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#### About us

We are an independent group of over 2500 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-today 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 todav!

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:**

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By phone: 0300 321 4721

#### By email:

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#### Website:

www.sheffieldparentcarerforum.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

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- Our rates are: Full page £150
  - 1/2 page £75
  - 1/4 page £37.50

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#### **NEWS**

# Family Fun Day narrowly avoids mud bath

It should have been our 10th Family Fun Day at Hillsborough Sports Arena – but after Tramlines left the site a muddy mess, it looked like we might have to cancel the event altogether.

Fortunately, we found another venue just down the road: Niagara Conference and Leisure Centre stepped in at the eleventh hour to host our popular event.

The venue proved to be a perfect replacement, accommodating all of our usual

attractions – from adapted cycles and bungee trampolines to various inflatables, dance and drumming workshops, a petting zoo and even a fire engine.

A total of 60 families attended the event, yet it never felt too busy – perfect for children who struggle with crowds and noise.

We are grateful to the Facey Family Foundation for funding our event again this year. We made the money go even further by drawing on the support of our fantastic partner organisations who provided activities, resources and volunteers.

"Calm environment, didn't feel overwhelming, friendly volunteers, loved the animals for calming quiet time" "Lots to do, not too busy, well organised" "We can be ourselves with no judgement and enjoy the day together. Excellent choice of food and activities"

#### Do you know someone who deserves an award?

We are looking for individuals who have made a real difference for parents of disabled children and young people in Sheffield – whether through their paid work, or through volunteer efforts.

If you know someone who fits this description. please nominate them for our David Woodhouse Community Award. The chosen recipient will be presented with a trophy, a cheque for £250 and

vouchers for a spa experience and a meal (or an alternative treat of their choice).

For more information and to download a nomination form, please visit our website (www. sheffieldparentcarerforum.org.uk/news/ dwaward2023). Nominations will be accepted until noon on 3 November 2023. The winner will be announced at our Annual General Meeting on 10 November 2023.



#### Parents' survey finds small improvements, but major challenges remain

Every few years, we carry out a survey of parent carers in Sheffield. The feedback we collect helps us to represent parents' views at strategic meetings with the Council and the NHS.

This year, 496 parents completed our questionnaire. The survey repeated many questions we had posed previously (in 2014 and 2019), allowing us to track changes in parental satisfaction over time.

We found that families with disabled children still face significant challenges. We recognise that work has been undertaken to address some of the issues raised, but our survey shows that families are not consistently feeling the benefits of this. Whilst it was encouraging

to see improved feedback in some areas, those gains tended to be modest and often stemmed from a low baseline. More work is needed to ensure that improvements continue and become embedded.

We have shared our findings and recommendations with Sheffield City Council. NHS Integrated Commissioning Board and Sheffield Children's Hospital Foundation Trust. All have welcomed our report and we are pleased to see their continued commitment to working with us and other partners to address the issues raised. To see their full statements. please go to www.sheffieldparentcarerforum. org.uk/news/sos2023/

#### Download the report

from www.sheffieldparentcarerforum.org.uk/about/publications

#### **Key findings**

- Waiting times for diagnostic assessments have surged. 80% of respondents reported having to wait for a year or more to have their child assessed.
- 38% of respondents said that they were "struggling" or "not coping" with their caring responsibilities. Only 40% of these parents were receiving support from social care services.
- There is a growing and often unmet need for mental health support – affecting not only children and young people with special educational needs and disabilities (SEND), but also their siblings and parents.
- 85% of respondents said that caring had affected their ability to work, and 67% said that their family was worse off financially as a result. 38% of respondents were in receipt of means-tested benefits.
- Three quarters of parents said that it was "difficult", "very difficult" or "impossible" to find suitable childcare for their child with SEND.
- Satisfaction levels varied significantly between school types. There was a slight improvement for mainstream settings and Integrated Resources (IRs) compared to 2019. However, only 30% of parents of children in mainstream schools felt that their child's educational provision met their needs, compared with 48% of IR parents and 72% of special school parents.

- Parental satisfaction with SENDSARS and the assessment process for Education Health and Care (EHC) plans had improved since 2019. However, this was from a very low baseline, and the percentage of parents who gave "poor" ratings was still very high.
- Only 16% of parents of children with EHC plans said that their child was getting all of the provision described in the plan, and a significant percentage reported problems with the annual review process.
- Parents highlighted capacity issues in many services that children and young people with SEND rely on. For some services, as many as three quarters said that their child was getting too little or no input.
- Compared to 2019, quality ratings had improved for education support services, deteriorated for many health services and remained fairly static for social care services.
- Despite recent work to address issues with the transition to adulthood, this area remains problematic, with a majority of parents reporting difficulties with the process. Respondents also highlighted a lack of information, advice and support around transition.

### Join our Autism in Schools parent groups!

Is your child's school taking part in the Autism in Schools project (see box)? If so, we invite you to take part in our monthly parent groups. No autism diagnosis required!

The project was set up to improve support for autistic students in mainstream secondary schools and will continue until March 2024.

Our role has been to establish and facilitate monthly parent groups within each participating school. Using feedback from parents, our project workers have been working with key staff to make improvements across the school for children and young people with special educational needs and disabilities (SEND).

Our project workers Sharon, Kathleen and Anna would love to see you at our monthly meetings. The groups warmly welcome parents of children with any kind of additional needs, not limited to autism; that includes children without a formal diagnosis.

For meeting dates, please follow us on Facebook (www.facebook.com/ SheffieldParentCarerForum) or contact our project workers.

#### **Participating schools**

- Chaucer
- Firth Park
- UTC Sheffield City Centre
- Yewlands
- Parkwood Academy
- Meadowhead
- High Storrs

**Project** worker:

Sharon Court

#### Fmail:

sharon.court@sheffield parentcarerforum.org.uk

#### Phone:

0300 321 4721 Extension 109

- Springs Academy
- Sheffield Park Academy
- Westfield School
- Notre Dame

**Project** worker:

Anna Marie **Emmett** 

Email: annamarie. emmett@sheffield parentcarerforum .org.uk

#### Phone:

0300 321 4721 Extension 108

- · Oasis Don Valley
- Outwood Academy
- Newfield
- Stocksbridge High School

worker:

Kathleen Green

#### Email:

kathleen.green@ sheffield parent carerforum.org.uk

#### Phone:

0300 321 4721 Extension 110





#### **NEWS**

## Lions, tigers and bears...

Oh my! We are so impressed with our member Nicola Havenhand, who raised an amazing £730 by organising a 15-mile walk and an Easter party.

During the event, six children and nine adults completed five laps of Rother Valley Country park, all dressed as characters from the Wizard of Oz. One of the participants, Jane, single-handedly raised over £400!

The walk was followed by an Easter party for children with additional needs, featuring a fantastic entertainer, face painting, a raffle and a range of art and craft activities.

Nicola said: "All the children had a wonderful time, and it was a joy and a pleasure to meet the families who attended the event. I am so grateful to all my friends and family who



worked tirelessly behind the scenes – I couldn't have done it without them!"

We used funds raised by Nicola to offer free places on our Makaton courses for families in receipt of means-tested benefits.

## Still searching for a Treasurer - can you help?

We've been on the lookout for a Treasurer for quite some time now, but haven't yet found the right person. Do you have the skills required, or do you know someone who does?

The ideal candidate would have some experience in charity finance and bookkeeping, with a commitment to serve a minimum term of two years. A working knowledge of QuickBooks would be a bonus, but training can be provided.

The Treasurer's responsibilities include monitoring and reporting on the financial health of our charity, ensuring accurate record-keeping, and supervising the preparation of financial reports, budgets, accounts, and audits.

This is an unpaid role, but expenses will be reimbursed. The time commitment is approximately 3-4 hours per month, which includes attending some of our committee meetings (virtually or in person).

For more information, please see www. sheffieldparentcarerforum.org.uk/supportus/volunteering-opportunities

If you are interested in this role, please email enquiries@sheffieldparentcarerforum.org.uk.

## Kids get creative over the summer

Finding accessible holiday activities for children with complex needs can be a real challenge – so we were delighted when local arts charity **Ignite Imaginations** offered to run free art workshops for our members' children during the summer holidays.

Flexibility is key for our families, and Ignite Imaginations were more than happy to allow older kids who enjoy "younger" activities as well as non-disabled siblings to attend the sessions, too.

Supported by professional artists, the children learnt how to use a range of new materials and techniques. The young participants grew in confidence and took great pride in showing off their creations.

"It makes art fun and engaging in a calmand relaxing atmosphere."



## SEND careers advice

Sheffield City Council's Community Youth Services have an Information, Advice and Guidance Team. Their advisors can provide specialist careers advice for young people who:

 have an Education Health and Care (EHC) Plan and attend a secondary special school in Sheffield in Y9-Y14

#### OR

 are aged 16-18 years and not in education, employment or training (NEET) (up to 19 years with an EHC plan)

The advisors can offer information, advice and guidance on careers, help with CV writing, job seeking, applications, interview coaching, input into EHCP annual reviews, group work, drop-ins and attendance at post-16 events and parent meetings. Their involvement is agreed with each school individually and may vary between settings.

Referrals are made by the school. If your young person is NEET, you can contact the service directly by emailing CYS\_IAG@sheffield.gov.uk or calling 0114 273 4462.

Please note, the service does not support young people in mainstream schools. Mainstream students with SEND should access the careers advice provided by their school.

## Proposal to create SEND post-16 centre on Peaks Campus

When the Sheffield College announced a decision to stop delivering courses at its Peaks Campus from September 2023, many parents of students with special educational needs and disabilities (SEND) were concerned. They worried that being forced to move from the small and quiet Peaks site to a large, busy campus like City or Hillsborough could overwhelm some young people.

Since then, a proposal has been put forward to create a specialist post-16 hub for students with SEND on the Peaks site.

A spokesperson for the College told us: "Earlier this year, The Sheffield College announced their intention to cease teaching and learning at Peaks from September 2023 and consulted with key stakeholders on how best to implement this decision. As part of this process, The Sheffield College have been discussing with Sheffield City Council the future use of the Peaks Campus for educational purposes, including exploring its

potential as a SEND Post-16 centre, with a focus on employment, independence and community participation. The Sheffield College are happy to say that these discussions are continuing, and they will keep people advised of any developments."

Whilst we welcome the proposal to create a specialist post-16 hub, we believe that with better foresight, the disruption for students could have been minimised. We remain committed to working with the College and the Council to ensure that any new provision is tailored to our young people's aspirations, interests and learning styles; that it provides the right sensory environment; that it links in with a range of community organisations to create more volunteering, work experience and employment opportunities; and that it has appropriately qualified staff and robust, transparent governance procedures.

## What do YOU think a SEND post-16 hub should look like?

Send your views to **enquiries@ sheffieldparentcarerforum.org.uk** 

#### Mental health website relaunched

The Sheffield Mental Health Guide (www. sheffieldmentalhealth.co.uk) is a website providing information about local and national mental health services, activities and resources. It was built by mental health charity Sheffield Flourish with funding from Sheffield City Council.

Following a re-vamp, the site now allows users to browse over



300 services and a range of free activities by selecting a category, such as "children and young people", "carers" or "culturally specific".

# Speech and Language Therapy Service under pressure

The number and complexity of children with speech and language difficulties in Sheffield has been increasing in recent years, resulting in an ever-growing waiting list for the Speech and Language Therapy Service.

It's good news, then, that the service has recently received some additional funding to increase its capacity. On its own, however, this will not be enough to meet need. To cope with the increased demand, the service is making some changes to the way it operates:

- From September 2023, speech and language therapists will change the way they work in special schools. They will identify one or two targets for each child and support those around them (school staff, parents etc.) with skills and resources to work towards these targets. Progress will be reviewed and new targets set as and when required.
- From October 2023, the service will start to move towards a locality model. This means that a senior speech and language therapist will work with schools in a geographic area to increase their knowledge and skills, create communication-friendly environments and

- identify those children who need a referral to specialist speech and language services at an earlier point. The new approach will initially be trialled in locality E (Meadowhead and Newfield families of schools) before being rolled out to other areas of the city.
- An online resource library (https://library. sheffieldchildrens.nhs.uk/speech-and-language-therapy-resource-library-directory/) has been created, allowing therapists to share training, resources and information more easily with parents, school staff and professionals. This resource is constantly being added to.

#### **Get involved!**

Join our Speech and Language Therapy subgroup where we are joined by a speech therapist and discuss proposed changes to speech and language therapy provision in Sheffield and give feedback.

We also have themes for each meeting where we discuss strategies to support your children. For meeting dates, please see page 25.

## Wellbeing course for carers

STEP (Short-Term Educational Programme) run a five-week online course for adults who provide unpaid care for a child or an adult. Courses run at various times throughout the year and focus on improving carers' mental and physical wellbeing.

To attend, you need to ask your GP, mental health worker or the Sheffield Carers Centre to make a referral. You must be registered with a Sheffield GP.

For more information, see www.shsc.nhs. uk/services/short-term-educational-programme-step/carers-wellbeing-course or call 0114 226 2660.

#### **NEWS**

#### Spaces available at speech and language group Small Talk

Small Talk is a speech and language therapy clinic run by the University of Sheffield for preschool children with speech, language and communication needs. They currently have a number of spaces available, starting on 4th October.

Sessions are free of charge and take place on Tuesday mornings between 10am and 12.30pm, in a building next to Weston Park Museum. Parents attend with their child for a 40-minute session each week. There are opportunities for parents to get together to support each other.

Children do not need a formal diagnosis and do not need to be on the caseload of a speech and language therapist.

During the sessions, postgraduate Speech and Language Therapy students work directly with the child. The students are supervised by two fully qualified speech and language therapists.

For more information about Small Talk, please visit https://hcsclinic.sites.sheffield.ac.uk

If you are interested in attending, please contact project lead Judy Clegg by emailing **j.clegg@ sheffield.ac.uk** 

### Emosi: a new therapy centre in Burngreave

Emosi is a new transcultural therapy centre based at Ellesmere Children's Centre in Burngreave. Funded through a two-year National Lottery grant, the centre provides assessment and play-based therapies for children aged 2-12 years who are experiencing emotional and behavioural challenges.

Emosi's culturally diverse and multilingual therapists offer a range of interventions, including:

- Music therapy
- Art therapy
- Attention Autism sessions
- Intensive Interaction sessions
- PECS development (Picture Exchange Communication System – a communication method based on visual symbols)

Children attend Emosi on a weekly basis, and the first six sessions are provided free of charge. If further sessions are required, families can purchase these at a subsidised rate of £42 per session.

Most schools are happy to allow children to attend during school hours, and every effort is made to allocate sessions at the start or end of the school day, or during lunchtime.

Emosi accepts referrals from a wide range of professionals, including school staff and social workers. Parents can also self-refer their child. A formal diagnosis is not required, but there is a waiting list.

For more information and to download a referral form, please visit: www.ellesmerecc. org.uk/emosi Alternatively, call 0114 276 5544 to speak to staff about the service.

## Peer Support Service Update

Our Peer Support Service continues to grow and develop in response to the needs and wishes of parents in Sheffield. Our main aim is to offer information, support, advice and guidance on all issues relating to special educational needs and disabilities (SEND). We work closely with other services and where appropriate signpost to organisations who have expertise in particular areas.



#### **Our Peer Support Team:**

All our Peer Support Workers have lived experience of caring for a child with additional needs and a good knowledge

of both local and national services. They are trained mental health first aiders and understand how stressful raising a child with additional needs can be.



Sharon Peer Support Manager



Peer Support Worker



Becca Peer Support Worker



Alison Peer Support Worker



Eleanor
Peer Support
Worker

## **Get in touch** If you would like to know more about the service or wish to access support, you can do so in the following ways:

- Call and chat to someone on our phone line you can ask a quick question or seek advice, guidance and signposting around a particular issue. Call us on 0300 321 4721 and select option 1 for our Peer Support Service. If we are not able to take your call, please leave a message and we will get back to you within a couple of days.
- Email peersupport@sheffieldparent carerforum.org.uk with a question or ask someone to call you.
- Talk to a Peer Support Worker if you attend a session or see them out and about.

#### **Our Services**



Peer Support Groups offer parents an opportunity to come together to support each other and share their experiences. All parents are welcome. These are currently running in seven localities across the city. If you are interested in joining a group, there is no need to book - just come along, new members are always welcome. If you would like a group setting up in your local area, please get in touch using the details on the previous page.



One-to-one support is available if you would like to have a more in-depth conversation about your situation and feel a longer session or series of sessions would be helpful. Call or email us to access support (see previous page).



Information sessions are being offered in community venues across the city. Topics include: introduction to autism, autism and anxiety, advocating for your child, exploring sensory needs, and many more. Places can be booked via our website: www.sheffieldparentcarerforum.org.uk/events. If there are other topics you would like to know more about, please let us know.

#### For information about our groups and events



For dates and venues of our peer support group meetings and information sessions, please see pages 24-26 of this newsletter.

#### Session dates are also advertised on our website

(www.sheffieldparentcarerforum.org.uk/events) and Facebook page

(www.facebook.com SheffieldParentCarerForum)

#### PEER SUPPORT SERVICES continued

## Support for dads and male carers

Over the last few months, we have been running a group for men who care for children and young people with SEND. The 'Men's Wednesday Club' runs on Wednesday evenings at 7-9pm every month at the Stephen Harrison Snooker Academy.

The group has been well received and valued by those who attend. Here's what some of our attendees have told us:

"It's OK not to be OK, and this is a place where that's recognised. Not judged. Just understood."

"It's been helpful to have a safe space for men to talk to other men going through this. It's a very 'mum' dominated world and us men can feel left out/ like a spare part. Plus, it gives us access to information and a way to ask questions or for help... and a game of snooker with other blokes is always good."

"Our journey as parents is often very different to that of other people... and having a peer group of other parents or carers who look after children with SEND is invaluable. Without wanting to play into stereotypes too much, within families that have children with SEND, it's often the women who end up taking on more of the caring and supporting role, researching information, as well as finding and joining networks of support. And so, men may well find themselves without a support network of friends and peers in the SEND community. A dads and male carers group offers us the chance to come together with others who share similar backgrounds. It gives us a chance to be listened to and to offload, to vent. But also, to listen to the

"Talking with other dads who have a had a similar experience in an honest and open place makes me feel I'm not useless when it comes to my child."

stories of others."

#### **SPCF** small grant events

As part of our Peer Support Service, we have funded some small events that enable parents and carers to come together to meet our Peer Support Team, get to know more about the services we offer and have access to support.

## Stephen Harrison Snooker Academy Snookerbility doubles competition

On 12 August we worked with the Stephen Harrison Snooker Academy to hold a Snookerbility doubles competition at the Snooker Centre.

19 young people and 23 parents attended the event. It was an incredibly welcoming environment, with all young people included at the level they needed. They were invited to join in the competition but were equally welcome to relax with the other activities available within the centre. A delicious pizza lunch was provided, complemented by some additional food generously donated by Wagamama's. Everyone enjoyed engaging with each other over lunch.

Both the young people and their parents really valued the event. One parent explained that it was the first social event their young

person had accessed in two years. This young person was made to feel Stephen Harrison MBE Academy

welcome, thoroughly enjoyed the day, and discovered a sport they may wish to continue in the future! What a wonderful achievement.

All the young people who attended were awarded a certificate at the end of the day to celebrate their achievements. This was a truly uplifting and inclusive day and our young people and their families were so lovely!



### Family event at ISRAAC

On 29 August, two Peer Support workers joined staff from the ISRAAC Somali Community Association to host a family event for children with SEND and their parents. While the children had fun, our staff were available to answer any questions parents had, listen to their worries and signpost them to relevant services. A private space with a translator was made available for parents

who wished to access oneto-one support. One parent said: "I found it really useful and appreciated I was able to see someone face to face."



The event was a huge success with over 30 parents and children taking part. Parents said they were impressed with how quickly they received a response to their enquiries and appreciated that Peer Support staff "were friendly, kind and non-judgemental".



All couples have their hurdles and difficulties. It stands to reason that raising children with special needs can present additional challenges to a relationship. Some of these are merely an intensified version of difficulties all parents face. For example, research has shown that it costs three times more to raise a disabled child than it does to raise a child without disabilities. Finding suitable childcare for disabled children is harder, and respite can be difficult to access. Many parents of disabled children live in a state of permanent exhaustion – a situation that, unlike for parents of non-disabled children, doesn't necessarily improve as kids grow older. Exhaustion and financial worries can take their toll on couples. cause friction and even separation.

Other challenges to relationships are unique to families with disabled children or specific to the disability itself - such as processing emotions of guilt or resentment towards the

partner, regarding the cause (or assumed cause) of the disability. There may be differences in the acceptance and reaction to the diagnosis, which can cause issues not just between parents but also within the wider family. Often the parent who is quicker to accept their child's diagnosis assumes the role of "expert" and pushes for interventions and support, while the other is still denying that anything is different about their child. Such disagreements can quickly escalate, with one partner feeling burdened and unsupported and the other pushed and overridden.

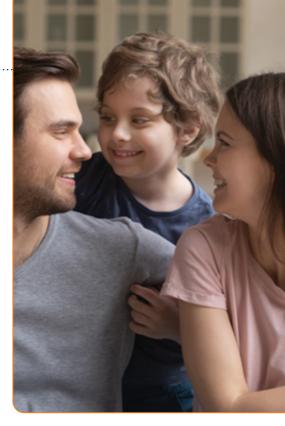
Annette Hines, host of the popular podcast Parenting Impossible: The Special Needs Survival Podcast (https://tinyurl.com/ycksbj3w), talks of carers' broken dreams. "When our children or our spouse don't live up to our ideal family image," she says, "it shatters our sense of accomplishment and well-being, contributing to the number of

divorces". Hines, who is a special needs lawyer, goes on to list the complications entailed in separation: legal fees, custody battles, child maintenance, etc. Needless to say, separation is not a decision taken lightly by parents of children with SEND - although, in some cases, it may well be the right thing to do. It is the last resort, and parents go to great lengths to avoid it. Sadly, many couples address their relationship issues too late - often turning to counselling to save a foundering marriage, instead of proactively investing into their relationship earlier on. Understandably so; with the demanding routine and responsibilities of carers, finding the energy and opportunity to engage in relationship-building exercises is often a pipedream.

Family consultant Or Schwarz Cohen, founder of Creative Family, runs couples' workshops around the world. Like Hines, she refers to expectation and disappointment as underlying causes of marital strife: "We sometimes view our children as our business card: when they don't fulfil societal expectations, when they misbehave, when people stare at them or judge them, we think – what does this say about me? Most parents would not direct their negative emotions towards the child, who they know isn't responsible for their disability, instead they take them out on their partner."

#### Awareness is everything

The solution lies neither in giving in to these emotions nor suppressing them, but in raising one's awareness of them. "Awareness is everything", says Cohen and goes on to emphasize the importance of reflecting on how we were all shaped by our experiences as children. "Parents need to recognise the difference between the child that they once were, and the child they now have, and see



that child for what they are, without projecting expectations onto them. When it comes to the relationship with their partner, they need to look at their own family history: what notions and values did they grow up with and have brought into the relationship? Are these aligned with their partner's? And if not, what can be done to accommodate both parties?"

According to Cohen, awareness helps us move beyond our knee-jerk reactions, look deeper and find solutions. She gives an example of a spouse who would go on weeklong sporting holidays with friends, leaving the other carer to cope on their own. The athlete had always envisioned an outdoorsy and adventurous family that would travel the world, and now, faced with the reality of their child's limited mobility, they escape the situation. "The solution would not be to judge but to show them what their

#### FEATURE continued

behaviour means to their spouse, and what it does to the relationship. We acknowledge that adventure is a value for them, but their partner values and needs stability and security. Perhaps three-day trips away from home would be enough? Maybe they could use their sporty spirit to organise suitable physical activities for their child? Or arrange childcare, so their spouse could join them for a couples' getaway? There can be many solutions, but it all starts with awareness: seeing who I am, who is in front of me – acknowledging each partner's expectations and finding a common path. My motto is 'let's make friends – maybe we'll end up falling in love'."

Staying positive is another key element: "When we shine a spotlight on the positive,

the positive grows, when we shine a light on the negative, the negative grows. This is why we need to concentrate on the strengths, AND not only to note the positive, but to describe it, giving authentic and specific praise to our child and partner."

When asked what tip she would give couples who can't attend her workshops, Cohen says: "You don't necessarily need therapy to develop awareness. Just take the time to look inside, to sit with yourself, sit with your partner, and ask each other 'what is important for us, what do we struggle with?' Just have these conversations."





#### Relate

is a charity offering affordable counselling, mediation and relationship workshops. They also support couples to achieve an amicable separation. **www.relate.org.uk.** 

The Sheffield Parenting Team have a free programme called "EPEC – Being a Parent Together" for parents looking to solve difficulties in their relationship (not specific to parents of children with SEND). To book, call 0114 2057243 or go to www. eventbrite.co.uk/o/sheffield-parent-hub-17631456258

The British Association for Counselling and Psychotherapy (BACP) has a therapist directory with an extensive list of private Sheffield-based relationship counsellors. See www.bacp.co.uk/search/Therapists

# Your marriage is not doomed: the surprising reality of partnership stability in families with disabled children

At first glance the statistic is disheartening. A quick google search warns of a whopping 80% divorce rate for parents with autistic children, compared to "only" half of the marriages ending in a divorce in the general population.

However, other studies paint a different picture of the correlation between children's disability and couples' durability.

For example, a 2008 study found that the divorce rate among parents of children with Down Syndrome is lower compared with parents of children without disabilities (7.8% compared to 10.8% in the control group).

In a unique long-term study, published by the American National Institute for Health in 2015, researchers followed the marriages of over 7,000 parents in a Wisconsin community, over a 50year period. They found no increased divorce rates in families with children with special needs. A surprising finding of the study was that while couples with many children were generally more prone to separation than couples with a small family, for families with a disabled child the result was reversed; couples with more children were more likely to stay together, possibly through the support of non-disabled siblings.

Blogger and advocate Calleen
Peterson calls the Wisconsin study
a ray of hope: "Your marriage will take
work and care, like any other person's
marriage, but you have just as much of a
chance to make it work as anyone else.
So ignore this statistic that gets thrown
at you and go spend time with your
spouse and child."

#### **Down Syndrome study:**

news.vanderbilt.edu/2008/01/08/ divorce-rates-lower-amongparents-of-children-with-downsyndrome-56798

#### Wisconsin study:

www.ncbi.nlm.nih.gov/pmc/articles/PMC4624231/#!po=1.33929

#### Calleen Peterson's blog:

www.parent.com/blogs/ conversations/are-divorce-ratesreally-higher-for-families-with-specialneeds-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...

Nine-year-old Harvey has raised an impressive £1,000 for the Motor Neurone Disease Association by successfully completing a 100-mile cycling challenge on his exercise bike.

Harvey embarked on the challenge to support his auntie Sue, who has motor neurone disease. Over a period of six weeks, Harvey diligently pedalled around four miles every night, mainly in the evenings before bedtime. To keep his energy up, Harvey would often listen to Queen's "Bicycle race" and music by George Ezra.

His mum Charlotte reports: "Harvey has autism and high levels of anxiety, but when he cycled, he could release all that built-up worry and frustration."

Throughout his cycling adventure, Harvey made little videos to document his progress, sharing them with his supporters. Charlotte says: "He is so funny and a real character - everyone said his videos were the highlight of their day, and I think they were Harvey's, too."

The cycling challenge not only improved Harvey's physical fitness and overall wellbeing, but also boosted his self-confidence. His proud mum says: "It showed him that he can do anything that he sets his mind to."



#### SUPPORT GROUP FOCUS

### **STARS**

STARS is an informal, closed, caring WhatsApp peer community run by adoptive parents for adopters in Sheffield. There are also linked STARS communities across South Yorkshire in Barnsley, Doncaster and Rotherham.

In the Sheffield STARS group, over 200 members openly discuss any adoption-related subjects, personal or otherwise. Adoptive parents can share with others who 'get it'. It's about knowing you're supported by your fellow local adopters, and not feeling isolated.

Adoptive parents can face some common issues in their families relating to grief and loss; attachment; identity; childhood trauma; and underlying undiagnosed neurodiversity or other conditions. Being part of STARS enables adoptive parents to know they are not alone and that there are others also walking the same road, with whom they can share their worries, stresses, emergencies, successes, joys and sense of humour!

Member posts cover many topics, and regularly include questions about the approval and matching panel; good news; accessing the Adoption Support Fund; school issues; information about post-adoption support; how to get an Education Health and Care (EHC) plan; questions about neurodiversity, foetal alcohol spectrum disorders and health assessment information; information about upcoming conferences, useful publications, service contact details and meetings; life story work; helping to develop future adoption services; social events (pub meetings, walks, ice skating, swimming, play centre meets; arranging playdates, etc.).

Members may also sometimes co-operate with other local services and organisations to

promote improvements in the experience of adopted and disadvantaged children.

If you are an adoptive parent or have been accepted into the formal process of adoption (or Foster to Adopt / Early Permanence) and you reside in Sheffield, it would be great to welcome you to Sheffield STARS. To join, just email us at sheffield stars@fastmail.com



STARS are part of our new subgroup for adoptive parents and kinship, foster and SGO carers – see page 24 for meeting dates.

### **Useful Contacts**

<b>0-5 SEND Service*</b> Works with young children (0-5+) with additional needs both in their homes and in settings	0114 273 6411 0-5SEND.SupportService@sheffield.gov.uk
ADHD Support Service Run by Family Action, this service provides information, support and training for families with a child with ADHD	0114 2412733 adhd.sheffield@family-action.org.uk
Autism and Social Communication Team* Supports mainstream schools to meet the needs of pupils with autism and related conditions	0114 2506800 (helpline 1-4pm) autism.educationteam@sheffield.gov.uk
Becton Hospital and Outreach Team* Provides education for children who are unable to attend school for medical or related reasons	0114 305 3121 jgibson@nexusmat.org
Child Disability Register A local register of disabled children aged 0-25	www.sheffield.gov.uk/childdisabilityregister
Children with Disabilities Team* Social work team for children and young people with disabilities	0114 273 5368 fieldwork-cdtbs@sheffield.gov.uk
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
Deaf/Hearing Impaired and Vision Support Services* Supports deaf / hearing impaired and visually impaired children aged 0-25 years and their families	Head of Service: bernadette.roe-dean@sheffield.gov.uk Deaf/Hearing Impaired: 0114 273 6410 rachel.dickens@sheffield.gov.uk Vision Support: 0114 2941201 sarah.blake@sheffield.gov.uk
Direct Payments Team* Provides support, advice and guidance relating to direct payments for children	0114 273 5985 Existing Direct Payments: DirectPayments.ILFTeam@sheffield.gov.uk General enquiries: childrensdpenquiries@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 General enquiries: educational.psychology@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	www.ipsea.org.uk
<b>Local offer*</b> 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
Opportunity Sheffield* Employment and skills service helping to break down barriers to employment	0114 229 6168 opportunity@sheffield.gov.uk
Paces Sheffield Runs a specialist school for children with cerebral palsy and other motor disorders, and a day service for adults.	School: 0114 2845298 office@paces-school.org.uk Day service: 0114 5510419 darren.walker@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
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 ssendias@sheffield.gov.uk www.sheffieldsendias.org.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 www.sheffieldcarers.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, and those who are affected by familial substance misuse.	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 5368 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

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

## Dates for your diary

#### Can't attend in person

but would like to join us online? Please let us know and we'll send you a meeting link. (Where suitable - the information sessions are not available as hybrid sessions.)

#### **Information and booking**

For more information and 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.

#### **November**

Thursday 2 November, 1 - 3pm at Primrose Family Hub

## Information Session: Exploring Sensory Needs

Learn about strategies and tools that can help children who struggle with sensory processing.

#### Booking essential.

Wednesday 8 November, 10am-12pm at St Mary's Church

#### **Education Subgroup Meeting**

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 need to book, just turn up.

#### November continued

Friday 10 November, 11am - 12pm at Sharrow Community Forum

#### **Annual General Meeting (AGM)**

This is an open meeting, all welcome! We'll hear a report from the chair, (re)elect our trustees, and review the annual accounts.

Please book your place so we can make

**Please book your place** so we can make sure we've got enough chairs and biscuits!

Tuesday 14 November, 12.30 - 2.30pm at Primrose Family Hub

## Information Session: Introduction to Autism

For parents of children with suspected or recently diagnosed autism. Learn about the main traits, challenges and strengths associated with the condition.

Booking essential.

Friday 17 November, 11am - 12pm at St Mary's Church

## Subgroup for Adoptive Parents and Foster Carers

For adoptive parents and foster, SGO and kindship carers of children and young people aged 0-25 years with SEND in Sheffield. Please join our subgroup to give feedback on services and processes for identifying and supporting SEND in looked-after and previously looked-after children. No diagnosis required! **Please book.** 

Thursday 23 November, 12.30 - 2pm at First Start Family Hub, Firth Park

## Information Session: Autism and Anxiety

This session will feature a presentation about autism and anxiety, followed by plenty of time for discussion.

Booking essential.

#### November continued

Tuesday 28 November, 12 - 2pm at Valley Park Family Hub

#### Information Session: Introduction to Autism

As previous.

Wednesday 29 November, 10am - 12pm

at Ryegate Children's Centre

## Information Session: Exploring Sensory Needs

As previous.

#### **December**

Sunday 10 December at at the Showroom Cinema

#### **Christmas Films**

Thanks to funding from Gripple Ltd., we'll be showing two films (titles tbc) without trailers and with the lights dimmed, the sound reduced and a separate room for relaxation during the screening. Free refreshments will be served before the film. **Booking essential.** Invitations will be sent to our members by SMS/email in November – respond quickly to avoid disappointment!

Wednesday 13 December, 10am - 12pm at St Mary's Church

#### **Transition Subgroup Meeting**

For parents of young people aged 14-25 years with special educational needs and/ or disabilities. We often invite officers from relevant services to attend and answer questions. We are a friendly group and there will be time to chat and swap information with other parents.

No need to book, just turn up.

#### **January**

Thursday 11 January, 10 - 11.30am

at Darnall Family Hub

## Information Session: SEND and Sleep

Learn about strategies to support children and young people with SEND who struggle with their sleep. **Booking essential.** 

Tuesday 16 January, 12.30 - 2pm

at Valley Park Family Hub

#### Information Session: Neurodisability and Eating

Learn about restricted and avoidant eating in children and young people with a neurodisability (autism, ADHD, learning disabilities etc.), and what can help.

#### Booking essential.

Friday 26 January, 10am - 12pm

at St Mary's Church

## Subgroup for Adoptive Parents and Foster Carers

As previous.

#### **February**

Friday 2 February, 10 - 11.30am at St Mary's Church

## Speech and Language Therapy and DLD Subgroup Meeting

For parents of children and young people with speech, language and communication needs, including Developmental Language Disorder (DLD). We will look at proposed changes to speech and language therapy provision in Sheffield and give feedback.

Please book your place.

## Dates for your diary continued

#### February continued

Tuesday 20 February, 12.30 - 2pm

at Sharrow Family Hub

Information Session: Autism and Anxiety

As on previous page.

#### March

Tuesday 12 March, 12.30 - 2pm

at Primrose Family Hub

Information Session: Neurodisability and Eating

As on previous page.

Tuesday 19 March, 12.30 - 2pm

at Valley Park Family Hub

Information Session: SEND and Sleep

As on previous page.

# Events already booked up? Don't miss out

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

#### **Peer support groups**

#### Monthly peer support groups:

Thursdays, 2 and 30 November, 10.30am - 12pm

Tinsley Community Centre, Ingfield Ave, Tinsley, Sheffield S9 1WZ

All welcome.

Fridays, 3 November and 24 November 9 - 11am

Manor Community Nursery, 33 Vikinglea Rd, Sheffield S2 1BE All welcome.

Wednesdays, 1 November, 6 December 12.30 - 3pm

Stocksbridge Children's Centre, 648 Manchester Rd, Stocksbridge, Sheffield S36 1DY

All welcome

Wednesdays, 18 October, 15 November, 13 December, 7 - 9pm

Stephen Harrison Snooker Rooms, Leeds Road, Sheffield S9 3TY

For dads and male carers.

#### Weekly peer support group:

Meetings held on Wednesdays during term time, 11.15am-12.45pm Common Ground Community Centre, Woodstock Rd/Machon Bank, Sheffield S7 1GR

All welcome.

For more meeting dates, please see www. sheffieldparentcarerforum.org.uk/about/ peer-support-service

## 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.

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	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	I am interested in volunteering with the Parent Carer Forum.	
Date of birth	Talon Galor Foldini	
Main disability		
Other disabilities		
	Signature	
School (name)	Date	
Child 3	Please note: By signing this form you	
Date of birth	consent to the Sheffield Parent Carer Forum storing your information. We will not pass	
Main disability	any of your details on to any third parties.	
Other disabilities	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	
School (name)	to opt out of this service at any time.	



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

Fold along here

