



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!

Autumn 2022 Issue 27 - FREE!

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About us

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

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

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

Membership is free, join us today!

Fill in the membership form at the back of this newsletter, or go to www.sheffieldparentcarerforum.org.uk/become-a-member

Get in touch

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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

St Mary's Community Centre



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

Your advert here?

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

Our rates are:

- Full page £150
- 1/2 page £75
- 1/4 page £37.50

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

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

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NEWS

Fun in the sun!

Almost 70 families attended our Family Fun Day at the end of August. The event was, as always, hugely oversubscribed, with twice as many people wanting to attend as we had places.

Families relaxed at Hillsborough Arena in glorious late-summer sunshine, knowing their children would not be excluded or judged.

We worked hard to offer a wide range of accessible activities, and to keep queues, crowds and noise to a minimum.

The biggest hits included a fire engine, bungee trampolines, inflatable gladiators, craft stalls and adapted cycles.

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

"Great range of activities. My daughter really enjoyed the stalls, crafts, rides and food! Thank you for a lovely day"



"Great event that is so inclusive and very well thought out and planned. A great asset. It is great it is never overpopulated, which provides a calm atmosphere."

Looking for leisure activities for your child?

We have an overview of specialist and inclusive sports and leisure providers on our website: <https://sheffieldparentcarerforum.org.uk/information/leisure/>

Many providers also have listings on Sheffield's Local Offer website. You can filter these listings by age group, type of activity, location and more. Take a look at the 'Things to do section' on www.sheffielddirectory.org.uk/localoffer



Free art sessions brighten up summer

We teamed up with local arts charity Ignite Imaginations to run free art workshops for children with additional needs during the summer holidays.

The weekly sessions at Sharrow Community Forum were funded by a grant from BBC Children in Need. They were aimed at disabled children aged 7-11 years, but siblings were also welcome – as were older kids who enjoy ‘younger’ activities.

Mel Frith, who attended the sessions with her two children Madi and Albert, said: “If it wasn’t for the art sessions and my daughter’s weekly SNIPS club provided by the council, we wouldn’t have gone anywhere all summer. There was nothing else available that my children could access.”



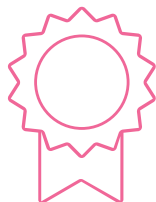
Do you know someone who deserves an award?

We are looking for people who have made a real difference for parents of disabled children in Sheffield – whether through paid work, or through volunteering.

If you know someone who fits the bill, please nominate them for our David Woodhouse Community Award. The successful nominee will receive a trophy,

a cheque for £250 and vouchers for a spa experience and a meal (or another treat of their choice).

Please see our website (sheffieldparentcarerforum.org.uk/news) for more details and a nomination form. Nominations close at mid-day on 4 November 2021. The winner will be announced at our Annual General Meeting on 11 November 2021.



Get help with your child’s transition to adult social care

Sheffield City Council has recently set up two new teams to support young people with the transition from children’s to adult social care services.

The Preparation for Adulthood Team (PAT) consists of eight workers from children’s social care. It supports young people aged 14-17 years.

The Transitions Team consists of seven workers from adult social care. It supports young people aged 18-25 years.

The teams operate as one service. They only support young people who are in education with an Education Health and Care (EHC) Plan.

The Transitions team is currently working hard to address the backlog of cases of young people aged 18+ who are still waiting to make the transition to adult social care.

The Preparation for Adulthood Team is starting to attend annual review meetings of 17-year-olds who have an Education, Health and Care (EHC) plan and an identified social care need. When capacity allows, they will extend this service to teens aged 16 and 15 years.

It is important for parents to be aware that there is no automatic referral into either team, even if a young person is known to children’s social care. Referrals can be made by the



young person, their parent or carer, allocated children’s social care worker (from MAST, SNIPS, Children with Disabilities Team), education provider or other health or social care worker. Consent from the young person (or their parent or carer if they are unable to consent) is required, so you should be aware if a referral has been made.

How you can request a referral as a parent:

If your young person is under 18, call the Safeguarding Hub on **0114 273 4855** and ask for a referral to the Preparation for Adulthood team.

If your young person is over 18, call First Contact on **0114 273 4908**. State that you believe that your young person will need support from adult social care and that you would like to request a referral to the Transitions Team.

Please note, the Transitions Team will only get involved if your young person is still in education and has an EHC Plan. If that’s not the case, your request will be dealt with by another social care team.

Autism in Schools project extended

A project aimed at improving support for autistic students in mainstream education has been so successful that it will be extended to more schools in Sheffield.

During its first year, the project ran at ten mainstream secondary schools in the city. It aimed to improve the school environment, relationships between staff, parents and students, and access to early intervention. Health professionals, parents and young people worked together to develop a training programme for school staff.

A key part of the project were the parents' and young people's groups that ran at the participating schools. National charity KIDS

set up the young people's groups, and our forum's project workers ran monthly parents' meetings. These were open to parents of children with any type of special educational need or disability – not just autism.

Parents reported that the groups helped to improve their communication with school staff. Some parents found it easier to raise issues through the SPCF project workers rather than talk directly to the school; others said they had learnt about resources and adaptations like toilet passes they didn't know they could ask for.

The project will continue to work with the original schools to embed the work that has already taken place. New schools are being recruited at the moment, and a list will be published on our website later in the autumn.

Could you be our next Treasurer?



This is a key role within our established and thriving organisation.

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

Duties of the Treasurer include: monitoring and reporting on the financial health of the organisation; ensuring that proper records are kept; and overseeing the production of financial reports, budgets, accounts and audits.

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

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

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

New Peer Support Service for parent carers

We are delighted to announce that our new Peer Support Service is off the starting blocks. Sharon Blagden has been appointed as Peer Support Manager and is currently recruiting a number of Peer Support Workers. The new workers will all have lived experience of caring for a child with additional needs and a good understanding of local services.

The Peer Support Workers will be out and about making contact with families in community venues from October. As part of their role, they will offer parent carers:

- Confidential one-to-one support via telephone, video call or face-to-face meetings in a community space (flexible appointment times)
 - Information sessions about common issues
 - Drop-in sessions where parents can meet other parents facing similar challenges
- The service will be available to all parents of children and young people (0-25 years) with additional needs in Sheffield. A formal diagnosis is not required.
- Information, advice and signposting to relevant services
 - For details of information and drop-in sessions, please visit sheffieldparentcarerforum.org.uk/events (from October 2022)
 - To book a one-to-one appointment with a Peer Support Worker, please visit sheffieldparentcarerforum.org.uk/about/peer-support-service (from November 2022)



Sharon Blagden

Free hotel accommodation for unpaid carers



Carefree is a national charity which aims to give every full-time unpaid carer access to a short break. Hotels donate vacant twin and double rooms for one or two nights, plus breakfast where possible, for a carer and their companion (adult or child, but not the cared-for person). After registering

with the site, carers can browse available options and submit a request for a specific hotel on specific dates. There is a £25 admin fee. For more information, please see: <https://carefreespace.org>

Short Break Grants available now

Families of disabled children (under 18 years old) can apply for a Short Break Grant of up to £400 from Sheffield City Council. The grant is means-tested and is only available to families who are not already receiving another short break service, like a SNIPS club, overnight respite or direct payment. For information about eligibility criteria and the application



process, please visit the Council website: www.sheffield.gov.uk/social-care/short-breaks. The closing date for applications is 31 January 2023, and the grant must be spent by 31 March 2023.

New service set up to prevent mental health crises

A new keyworker service has been set up to prevent kids with autism and/or a learning disability being unnecessarily admitted to mental health hospitals.

The service currently supports children and young people up to the age of 25 who are inpatients in a mental health hospital or at risk of being admitted to one.

In the future, the service hopes to support a wider group of autistic and learning disabled youngsters, such as those who are adopted or looked-after, or in transition between services.

Each keyworker holds a small caseload of families that they support directly. They work with young people and their families to find

out what they need and work alongside services to make sure the right help is found.

The support looks different for every family, but can include arranging reasonable adjustments to help a young person attend an appointment. It can also include attending meetings alongside a family, making necessary referrals, offering advice to supporting professionals, and raising challenges and barriers faced by families at a senior level.

To access the service, you need a referral from a professional who knows your child, such as a social worker or CAMHS professional. The keyworker service can be contacted at syicb-sheffield.cypworkers@nhs.net

Tips for completing DLA forms

A benefits expert from national charity Contact has recorded three videos that take you through the process of filling in an application form for Disability Living Allowance (DLA).

You can watch the videos and read lots of helpful tips on Contact's website: <https://tinyurl.com/3rnafhcc>

Safe Places

Safe Places is a local scheme which aims to support adults who may feel vulnerable when they are out and about in Sheffield. If someone needs assistance, for example if they are lost, ill or frightened, then they can enter the nearest safe place to get help.



You can identify participating venues by the "Safe Places" sticker in their windows. There is also a Safe Places app which can be voice activated and which will direct you to the nearest open Safe Place.

For more information, please see www.sheffieldsafeplaces.co.uk

New Health Needs in Education Service launched

A new service has been set up to support pupils with physical health needs to get the best out of their education.

It is for children and young people aged 0-25 years with physical health needs, long-term conditions or medical problems that impact on their education.

The service currently only supports children who attend schools in locality A, B and E, as well as pupils in state special schools and schools that are part of the Tapton School Academy Trust – these were part of an earlier pilot project. Over time, it will be extended to children at any nursery, school or college in Sheffield.

The service can provide support, information and signposting for families and also for staff in education settings. This could include staff training or help with writing a health care plan for an individual child.

Parents and young people can self-refer into the service. Professionals can also refer with the parents' (or young person's) consent. You can contact the service by email on scn-tr.healthinschoolnurses@nhs.net

Post-16 coffee mornings at Sheaf

Do you have questions or concerns about your young person's transition to adulthood?

Sheffield City Council's new Post-16 SEND Officer will be hosting a monthly coffee morning at Sheaf Training where you can ask questions and swap information with other parent carers. The sessions are open to all parent carers, not just parents of Sheaf students.

Location: Sheaf Training, Norwood Drive, Sheffield S5 7BH.

Time: 9.30-11am

Dates for the 2022/23 academic year: 19 Oct, 16 Nov, 14 Dec, 25 Jan, 22 Feb, 29 Mar, 26 Apr, 24 May, 28 May.



Changes to SEND funding for mainstream schools



Sheffield City Council is changing the way it allocates funding for pupils with special educational needs and disabilities (SEND) to mainstream schools.

The aim is to distribute SEND funding to schools more quickly and more consistently, and to improve accountability. There is more funding for high-level SEND available this year, so this is not about making cutbacks.

However, as with all changes, there is a potential for misunderstandings, so here is a short summary of the changes:

- The changes only relate to funding for pupils with “high needs”. These are children whose special educational provision costs more than £6,000 per year. (Schools are expected to fund provision below this level from the notional SEN funding they receive directly from the government.)
- For the past few years, high-needs funding has been allocated to schools by localities. Localities are groups of schools that are close to each other and work together. Each locality used slightly different mechanisms for distributing high-needs funding to schools.
- From September 2022 onwards, all localities will use the same arrangements. High-needs funding will now be allocated in two parts:
 1. an initial block funding allocation that all schools will get without having to ask for it.
 2. additional targeted funding that schools have to request from their locality.
- Some schools in some localities will receive less funding up-front than they did in previous years. This does not mean that

their SEND funding has been cut. It just means that they will have to actively request more targeted funding and explain how they will use it. This could be funding for individual children or for groups of pupils.

- As in previous years, the council will retain a small amount of funding for emergencies and exceptional cases. Schools can request this funding from the council.

Further funding changes are planned for the next few years. These include a proposal to calculate the cost of special educational provision set out in Education Health and Care (EHC) plans, using agreed funding bands. Funding for EHC plans would go directly to schools. Whether and how this proposal will be implemented depends on the outcome of a local consultation as well as national policy changes that are due to be announced later this year.

More information

For more information about school SEN funding, go to the Learn Sheffield website (www.learnsheffield.co.uk/Partners/inclusion-task-force), click on the button “SEND Support” and scroll down.

Annual health checks for young people with learning disabilities



If your child has a learning disability and is aged 14 and over, their GP should offer them an annual health check.

This is because people with a learning disability often have poorer physical and mental health than other people. It also gives your young person a chance to get used to visiting the doctor. They should have an annual health check even if they are under the care of a hospital paediatrician.

The annual health check is an opportunity, when your child is well, to meet a nurse or GP and go through a checklist to try and avoid problems getting missed. Management of conditions such as

asthma, epilepsy or constipation can be discussed. It is a time to check healthy eating and weight, and screen for conditions such as diabetes or high blood pressure that are easily missed. It is a time to arrange blood tests if needed and to plan vaccinations for flu, tetanus and Covid, both for your child and yourself as a carer.

We have some useful tips for parents to help you get the most out of the appointment on our website:

<https://tinyurl.com/yw4aruva>

For easy read information and videos about annual health checks, please visit: <https://tinyurl.com/mfu53tvn>

If your child is eligible for an annual health check but hasn't been invited

Although most GPs now offer annual health checks, they don't have to. If you think that your young person should have been invited:

- Contact your GP and ask if your child is included on their learning disability register. This register helps practice staff to identify patients who may need extra help or support. Anyone with a learning disability can ask to go on it.

It is for people of all ages, and you don't need to have a formal diagnosis of learning disability.

- If your child is not on the register, ask the surgery to include them and offer them an annual health check.
- If the surgery is unable to offer an annual health check, ask if you can go to a nearby surgery to have it done.

If you are unable to access an annual health check for your child, please email syicb-sheffield.childrenscommissioning@nhs.net

Cost of living crisis

The cost of living crisis is hitting families with disabled children particularly hard. This winter, it's more important than ever to make sure that you are claiming all the financial support you are entitled to. Here are some steps you can take to make sure that your family doesn't lose out.

1. Check that you are claiming all the benefits that you are entitled to.

Disability Living Allowance (DLA) is the main benefit for disabled children under the age of 16. It's not means-tested, so it doesn't matter what your income or savings are. A formal diagnosis is not required; instead, you need to show that your child needs extra care or supervision, and/or that they have problems getting around. You could get between £24.45 and £156.90 a week, depending on the level of help your child needs. DLA is an important "passport benefit", which means it may entitle you to other benefits and support. More info: www.gov.uk/disability-living-allowance-children

Personal Independence Payment (PIP) is the main benefit for disabled people aged 16 and over. It's not means-tested and worth between £24.45 and £156.90 per week, depending on the person's level of need. Like DLA, PIP is an important passport benefit. More info: www.gov.uk/PIP

Carer's Allowance is the main benefit for carers and worth £69.70 a week. To be eligible, your child or young person needs to receive the middle or highest care rate of DLA or the daily living component of PIP. You must spend at

least 35 hours per week caring for them, and you can't earn more than £132 a week after tax, National Insurance and expenses. Only your earnings (not your partner's!) are counted, and it doesn't matter what savings you have. More info: www.gov.uk/carers-allowance

Universal Credit is a means-tested benefit for people aged 16 to 64 who are out of work or on a low income. The amount you can get depends on your income, savings and other circumstances. If you have a disabled child, you may be entitled to additional payments under Universal Credit. More info: www.gov.uk/universal-credit

There are many other benefits that you (or your disabled young person if they are over 16 years old) may be able to claim. To find out:

- Use a benefits calculator, for example benefits-calculator.turn2us.org.uk
- Call Contact's helpline on **0808 808 3555**. Their advisors can provide initial advice on the benefits you may be entitled to. They may also offer you a telephone call-back appointment with a specialist family finance advisor.



2. Get help with your household bills.

You may have heard that the government has created a package of measures to help families with rising energy costs. These include a one-off payment of £650 for low-income families and £150 for those on disability benefits. These payments will be made automatically – you don't have to apply for them.

However, you may be able to get additional help with your gas, electricity, water, internet and telephone bills, which is not automatic. For example, you might be able to get up to £150 off your energy bills under the Warm

Home Discount scheme, or have your water bills capped under the WaterSure scheme.

- To find out what support you might qualify for, visit Contact's website: <https://tinyurl.com/ybzty23k>
- Alternatively, you can get free water and energy advice, tailored to your situation, by email or telephone from Scope's Disability Energy Support service. Visit www.scope.org.uk/disability-energy-support/ to register. (You will need to state that you are applying on behalf of your disabled child, with their consent.)



3. Find out if you can get a disability grant.

Many charities give grants to families with disabled children in order to help with things like essential items, specialist equipment, therapies, and holidays. These grants do not have to be paid back. Many – but not all – are means-tested. Some charities accept applications directly from families, others require a professional to make the initial application.

- Sheffield City Council offers a Short Break Grant (see page 8).

- The Family Fund is the UK's largest provider of grants for families raising disabled or seriously ill children (0-17 years) on a low income: www.familyfund.org.uk
- Turn 2 Us have a useful grant search tool: <https://grants-search.turn2us.org.uk/>
- Disability Grants have information about grants for disabled children and adults: www.disability-grants.org

Need urgent support?

Call Sheffield City Council's Community Helpline on **0114 273 4567**. They can help you to navigate through a wide range of hardship grants and support schemes.

Debt problems?

Sheffield Citizens Advice provides free, local, independent debt advice. Call them for free on **0808 278 7820**. Alternatively, get in touch with Step Change, a national debt charity: www.stepchange.org



Skin-picking disorder

Dermatillomania: what it is, and what to do about it.

Skin is the human body's largest organ, so it is only natural we would give it attention. Sometimes, we may give it negative attention: we've all squeezed the odd pimple, or maybe we bite our cuticles when we're nervous. However, if someone spends hours picking at their skin, if picking causes deep tissue damage or if it interferes with their daily life, either by being time consuming or by obliging them to cover parts of their skin and avoid certain activities – then they may be suffering from dermatillomania.

Dermatillomania – also called excoriation syndrome or skin-picking disorder – is a form of Body Focused Repetitive Behaviour (BFRB). Other BFRBs are compulsive hair pulling, nose picking, nail biting, hair eating etc. People may suffer from one type of BFRB or from several. BFRBs are currently classified as a form of Obsessive Compulsive Disorder (OCD) and are often linked to anxiety. However, research also suggests they have a lot in common with substance abuse disorder and may be viewed and possibly treated as an addiction as well as a compulsion.

The percentage of BFRB sufferers among people with autism and ADHD is significantly higher than in the general population (up to 25% compared to 5%). This may be due to higher levels of anxiety, or the behaviour may be a form of sensory stimming - research on this point is still ongoing.

Unfortunately, dermatillomania is still a relatively unknown condition. When not dismissed as a bad habit, it's often misdiagnosed as self-harm. While impact on the skin may appear similar, it's important to distinguish between the two: self-harmers seek pain when they injure themselves, but skin-pickers seldom experience pain as they pick. They often report a sensation of "trance", a relief from stress and anxiety, and even pleasure while they are engaged in picking. Thus, while self-harm involves the wish to hurt oneself, dermatillomania is self-grooming gone rogue. Skin-pickers are also less likely to use tools such as knives or scissors for picking, possibly because part of the addictive element is the contact between hand, skin, and sometimes mouth.

That said, dermatillomania does cause bodily harm; if left untreated, it could result in permanent tissue damage and scars, but also lead to serious and even dangerous medical complications such as contracting various bacteria, MRSA, staph infection, cellulitis or sepsis, through open wounds and sores.

In addition to its physical impact, dermatillomania comes with a heavy emotional burden. Sufferers experience shame, self-loathing and isolation. Other side effects are depression and fatigue, low self-esteem and body image issues, avoidance of intimacy and difficulties at school and in the workplace.



Despite its severity, dermatillomania can often go undetected. Teenagers and even children are very apt at concealing their picking. If you think your child may be picking, watch out for long periods spent in the bathroom, unexplained blood stains on clothes and bedding, preference for long sleeves in the summer or reluctance to visit the seaside or the pool. Other signs could be frequent nose bleeds from nose picking, sudden limping as a result of picking feet or toes, refusal to remove caps or hats due to wounds on the scalp, etc.

Helping someone with dermatillomania is not easy. To start with the don'ts: do not shame your child for it, or use threats to make them stop, as this will only make them retreat and hide their picking. Resist the urge to say: "don't pick!". Understand that picking is not a choice or a bad habit but a compulsion. Instead, you could direct them to an alternative activity that offers a similar sensation, such as peeling plaster off a wall, tearing a piece of cloth, squeezing out tubes etc., or encourage them to use a sensory or fidget toy (like this finger-picking stone for example: <https://tinyurl.com/4ktfbp97>). You could hold and massage their hands and fingers, and if picking has already occurred: disinfect and dress the wound, while remaining calm and non-judgmental.

A key in fighting dermatillomania is recognising triggers. Notice when the picking occurs: is it at school, during certain activities or after meeting certain people? Try to reduce any situation that causes the anxiety which leads to picking. If your child picks when they are bored or distracted, offer an active or interactive pastime. If they tend to pick when they are in the bath or shower, remove mirrors and offer to keep them company in the bathroom. Encourage your child to recognise their personal triggers and picking patterns by keeping a skin picking log on paper, or by using an app such as www.skinpick.com/app.

In addition, reduce any possible skin triggers. For example, if your child picks mosquito bites, protect them from getting bitten in the first place. If they pick their facial acne, consult your GP about preventing acne outbursts. If their nails or toenails are the problem area, keep nails short and offer them manicure or pedicure. While this may seem excessive, the more you reduce the triggers, the better. If you think of dermatillomania as similar to substance abuse, imagine how hard it must be if the substance you are trying to avoid is always with you wherever you go.

Beyond family support, it is important to seek professional help. Your first address is your GP. Be prepared that you may need to explain

what the condition is, as not all doctors will be familiar with it. They will then be able to refer you to suitable therapies.

The following methods have proved effective in treating dermatillomania and other BFRBs:

Cognitive Behavioural Therapy - works on habit reversal and impulse control training. Unfortunately waiting periods for CBT in Sheffield are very long.

Conversation therapy – a longer psychological path. While therapists specialising in BFRBs are few and far between, many counsellors with knowledge of OCD would be able to help.

Medication – medication used for managing OCD and anxiety can also help reduce the urge to pick.

Group therapy and support groups – With therapy being difficult to access, support groups, whether overseen by professionals or peer-led, can be extremely helpful, especially for young people. With the shame and isolation experienced by sufferers, such groups offer a safe space to talk about dermatillomania with people who share the condition. Attendees can exchange experience and tips, and find accountability buddies for undertaking no-picking challenges. OCD Action (<https://ocdaction.org.uk>) organises in-person group meetings in Sheffield for people aged 16+ across the OCD spectrum. Email sheffieldocdgroup@rethink.org or call **07766 950479** for details. They also have online meetings for adults and a dedicated online group for 16-20-year-olds.

There are also several Facebook groups, online forums and Instagram accounts dedicated

to dermatillomania. These groups are mostly private, and posts can only be seen by members, but you should be aware of the privacy risks involved in social media. Users should also be mindful of triggers in the form of pictures, and check whether engaging with such content is beneficial to them.

An important note to carers: if your child is already seen by Ryegate or CAMHS, inform them about your concerns over dermatillomania, and push for help. If picking occurs in school, talk to the SENCO and teachers about how to assist your child by preventing picking, or offering help after a picking episode (“distract/disinfect” is a useful shorthand).

Finally, the best remedy for dermatillomania is raising awareness about it. BFRB Awareness Week takes place during 1-7 October. Please help keep the conversation going.

More information

Bfrb.org

A research and education organisation offering information, brochures and toolkits for sufferers, educators and family members.

Skinpick.com

A private online therapy provider. Their website publishes articles with current scientific research.

Pickingme.org

An advocacy group run by skin-pickers. They offer community support and raise awareness through initiatives such as writing and drawing around dermatillomania.

Percy Jackson & The Lightning Thief

BY RICK RIORDAN, PUFFIN BOOKS 2005 - *Reviewed by Eleanor Cantor*

Percy Jackson and the Olympians is a bestselling fantasy series centred around the adventures of a kid with ADHD and dyslexia, in a world populated by characters from Greek mythology.



Since the 2005 release of the first novel – “Percy Jackson and The Lightning Thief” – the books have been embraced by readers and teachers worldwide. With a new TV series in the making, it’s time to take a close look at the original book.

12-year-old New Yorker Percy Jackson is a troublemaker and a failing student, bullied by his peers at school and his boorish stepdad at home. Little does he know that his ADHD and dyslexia are signs of supernatural powers. His life changes when he discovers he’s actually a demigod: his mother, who sacrificed herself for his safety, is human, while his biological father is Poseidon – god of the sea. As it becomes unsafe for him to remain in the human realm, he journeys to “Camp Half-Blood” – the demigods’ boarding school – only to soon set off again on a dangerous quest, accompanied by two friends: fellow camper Annabeth, and a satyr named Grover.

If this sounds familiar, it’s no coincidence. Author Rick Riordan makes no secret of having been inspired by Harry Potter. The parallels between the books, however, are a tad too abundant, even given the long tradition of emulation in the fantasy genre.

Lack of originality aside, we ought to ask whether Percy Jackson is a helpful role model for neurodiversity. Riordan famously wrote the story for his son, who has ADHD. Yet reading the book, the hero’s ADHD seems rather incidental. One of the first rules of good writing is “show don’t tell”, but Riordan does too much telling and not enough showing. Instead of letting us

experience ADHD and dyslexia through his eyes, Percy tells us: “I did X because of my ADHD.” We don’t gain insight into impulsive outbursts or inner confusion. Instead, we’re told how his identity is discovered by a monster when he struggles to pronounce its name, or that he “impulsively” saves his friends instead of running for his life. These ADHD/dyslexia references, despite Riordan’s good intentions, seem at best sloppy if not tokenistic.

It’s also questionable whether a book that’s used to spark conversation about disability can be so ableist: Camp Half-Blood kids train to excel in physical skills. They win each other’s respect through violent pranks as well as genuine bravery in battle, but their powers are all nature rather than nurture; after all, they’re born of divine ancestors. The fact that their strength is innate doesn’t leave much hope for the rest of us mortals to achieve greatness.

All that said, Percy Jackson is a fun read. Riordan is a master of comical anachronisms. His depiction of Ares, the war god, as a leather-clad motorcyclist is a good example of his humour. Despite the predictable plot twists, kids stay engaged with the story.

Overall, this is not a book that gives children an alternative to the masculine, naturally strong, gifted, and fearless superhero-model, or teaches them that bravery can take many forms, but if it makes them stick with their reading and teaches them a thing or two about Greek mythology along the way, maybe that’s good enough.

Planning for the future

Do you worry about what will happen to your disabled child when you are no longer able to care or be involved? The “Carers Together” team at Sheffield Mencap has over 15 years of experience of supporting the carers of people with a learning disability and/or autism.

We asked them for some practical steps that families can take to start preparing for the future. Here’s what they told us.

There is no ‘right’ time to start planning for the future, but it can help to start thinking about whether you have the right support in place now and what would happen in an emergency. It can be helpful to think about this before starting future planning.



Step 1: Get the right support in place

It can be hard to think about the future if your young person is not being supported to have a good life now. Making sure that the right support is in place for them now helps build strong relationships between services and helps families to have the confidence to make further changes when the time is right.

If you think your young person needs or will need support from adult social care, you could request a referral to the Preparation for Adulthood Team or Transitions Team (see page 5). You could also ask the Sheffield Carers Centre to carry out a carer’s assessment, but please note that this is only available to carers of adults.

Step 2: Plan for emergencies

Preparing for emergencies and thinking through ‘what if’ scenarios is a key step in getting ready for the future; it hopefully brings some reassurance to all, as well as providing key information for long-term plans. This could include making an emergency plan that sets out how long (if at all) your young person can be on their own safely, what daily tasks they need help with, how they communicate and other issues. The emergency plan should be shared with various key people, like your social worker, GP, emergency contacts and family members if they are part of it.

The Sheffield Carers Centre and the Carers Together team (see box) can help you create an emergency plan.

Step 3: Prepare for the future

Once you have the right support in place to continue to cope now and feel more confident about what will happen in an emergency or crisis, the following tips will help you to plan and prepare for the longer-term future:

Start talking and listening: It can be hard to discuss some of these issues and it can feel overwhelming. However, it is important to have these conversations with other family members, as people may have different ideas or expectations of what will happen in the future.

The Carers Together team (see box) can help you with this.

Find out about housing options and how to access them: Have a chat with your child’s social worker, care manager or carer support worker (if they have one) about what accommodation options are out there. Sometimes families like to visit different types of accommodation so they can get a better idea of what’s available.

For more information about housing options, see tinyurl.com/36wra8zm

Put your financial affairs in order: Make a will and consider setting up a Discretionary Trust if you are thinking of leaving any money or property to your disabled child. By setting up a trust, you ensure that their inheritance does not affect any means-tested benefits they receive. Similarly, it is worth looking at appointee services and starting to get advice about who is available to support your relative to look after their finances in the future.

Mencap’s Wills and Trusts Service offers help and advice, including online seminars and downloadable guides: www.mencap.org.uk/advice-and-support/wills-and-trusts-service

You could also book a 1:1 legal advice session with the Sheffield Carers Centre.

Find out more

Come to our “Planning for the Future” workshop on 20 October 2022, 10.30am-12.30pm, at St Mary’s on Bramall Lane.

To book your place, go to www.sheffieldparentcarerforum.org.uk/events

Get support

The Sheffield Carers Centre offers information, advice and a range of services for all unpaid carers.

See sheffieldcarers.org.uk or call **0114 272 8362**

The Carers Together team supports family carers of people aged 16+ who have a learning disability and/or autism. Email carersprojects@sheffieldmencap.org.uk

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...



Oscar is 10 years old and has autism.

He loves to spend time with his kitten called Nala and loves to game on his PC and Switch.

Oscar is also an accomplished fundraiser. He recently completed a 24-hour gaming marathon for SANDS, the stillbirth and neonatal death charity. Last year, he walked 100,000 steps during the Easter holidays to raise money for Sheffield Children's Hospital. A couple of Christmases ago, he raised money by making and selling reindeer food. The money went towards getting the names of two local boys into the book of remembrance at Grenoside crematorium.

Oscar is currently planning a fundraising activity in aid of a local cat rescue.

Star of this issue:

Oscar George



Star of this issue:

Harvey Powell



Harvey is 15 years old. He was diagnosed with autism and severe language disorder last year.

For two years, Harvey was severely bullied at school. Things got so bad that his parents ended up taking him out of school. Harvey then had to wait seven months for a new placement. He now attends an alternative provision for three days a week and loves it.

While he was out of school, Harvey found a passion for go-karting. His mum Vicky reports: "Go-karting literally saved him during a very difficult time. He has a real talent and is excelling in the sport. He now has his own go kart and is beating lap records and entering competitions. He

has told me that he is only truly happy when he's got his helmet on."

Vicky added: "We are currently looking for sponsorship to help Harvey progress to the next level. Please contact us on vpowellcvpowell@yahoo.co.uk if you'd like to help!"



SUPPORT GROUP FOCUS

Epilepsy Action

Epilepsy Action has a national network of Talk and Support groups for people affected by epilepsy.

The Sheffield Talk and Support group meets once a month and welcomes parents and carers of children and young people with epilepsy. The sessions offer the opportunity for people to ask questions and discuss a range of topics such as safety, independence and education. The group offers a friendly listening ear to those whose lives have been affected by epilepsy and gives them an opportunity to share experiences and learn from one another in a supportive environment. As the group is open to everyone affected by epilepsy, there is also the opportunity for parents and carers to learn about epilepsy from those who live with the condition.

Epilepsy affects around 600,000 people in the UK - around one in every 100 - and 87 people are diagnosed with the condition every day. Each year, Epilepsy Action directly helps around 2 million people, whilst campaigning to improve epilepsy services and raising public awareness of the condition. In addition to the Talk and Support groups, the free Epilepsy Action Helpline (0808 800 5050) is available to offer emotional support, reassurance, information and advice to people with epilepsy, or carers of people with epilepsy, when they need it most.



Find out more about other local support groups:

You can find information about other local support groups on our website: sheffieldparentcarerforum.org.uk/information/support-organisations



The Sheffield Talk and Support group meets on the second Thursday of every month at 19.15-20.45pm. The meetings are held at United Reform Church, 60 Norfolk Street, Sheffield S1 2JB. If you'd like to join the next meeting, please register your attendance by visiting www.eventbrite.co.uk/o/epilepsy-action-sheffield-branch-40195562043 Epilepsy Action also offers a virtual parents and carers support group aimed specifically at those who look after a child or young person with epilepsy. For more information about these groups, please visit www.eventbrite.co.uk/o/epilepsy-action-parents-talk-amp-support-virtual-44103265823

Useful Contacts

0-5 SEND Service* 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	07587 633179 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 Head of service: deborah.page@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
Local offer* A website with information about support and services for children and young people with special educational needs and disabilities in Sheffield	www.sheffielddirectory.org.uk/localoffer
Paces Sheffield 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@pacesheffield.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 sseudias@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 Children's Hospital	0114 271 7000 sheffield.childrenshospital@sch.nhs.uk
Sheffield Young Carers Offers support to children and young people (8-25 years) who provide care for a family member, e.g. a disabled sibling	0114 258 4595 information@sheffieldyoungcarers.org.uk
Special Needs Inclusion Playcare Service (SNIPS)* Supports children aged 5-18 years to access short break activities to give their parents a break from caring	0114 273 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

* Part of Sheffield City Council

Dates for your diary

Venue addresses

More Rehab:

40 Little London Road,
Sheffield S8 0UH

St Mary's Church & Conference Centre:

Bramall Lane,
Sheffield S2 4QZ

Can't attend in person

but would like to join us online? Please let us know and we'll send you a meeting link.

Book your place

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

October

Thursday 11 October, 10.30am -12pm

at [More Rehab](#)

Coffee morning

Monday 17 October, 10am -12pm

at [More Rehab](#)

Education subgroup meeting

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

Thursday 20 October, 10.30am -12.30pm

at [St. Mary's](#)

Planning for the future

Do you worry about what will happen to your disabled child or young person when you are no longer able to care or be involved? Led by experienced case workers from Mencap's Carers Together team, this session will provide you with practical tips and ideas of things your family can do to prepare for the future of the young person you support.

Booking essential.

October continued

Wednesday 26 October, 7pm - 9pm

on [Zoom](#)

Safe Space for Black and Brown parent carers

November

Thursday 3 November, 10am -11.30am

at [St Mary's](#)

Speech and Language subgroup meeting

This group is for parents of children and young people with speech, language and communication needs. We will look at proposed changes to speech and language therapy provision in Sheffield and give feedback.

Please book your place.

Thursday 10 November, 10.30am -12pm

at [More Rehab](#)

Coffee morning

November continued

Friday 11 November, 10am -11am

at [More Rehab](#)

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!

Monday 14 November, 10am -12pm

at [Flying Fish Studios](#)

Free craft session for parents: Metal embossing

Metal embossing is an ancient art form, where you use a stylus on the surface of a metal sheet to create a raised 3D design. You have lots of choice as to what design you choose to make. **Booking essential.**

Friday 25 November, 10am - 2pm

at [St Mary's](#)

Post-16 Information Day

Find out about post-16 options for your young person and what support is available for their transition to adulthood. Browse information stalls, talk to representatives from different services and attend workshops about specific aspects of transition. **Booking essential.**

Wednesday 30 November, 7pm - 9pm

on [Zoom](#)

Safe Space for Black and Brown parent carers

Safe Space meetings for Black and Brown parent carers

We acknowledge that some parents from Black and Asian Minority Ethnic communities may not feel confident about attending our typical meetings. Therefore, we are running a monthly Zoom session for Black and Brown parent carers, chaired by our volunteers Melissa and Thaeeba. Sessions take place on the last Wednesday of each month at 7-9pm.

Zoom details: Meeting ID 882 7654 8347, Passcode 027695

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!

Don't miss out!

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

More dates on page 26!



Dates for your diary *continued*

December

Monday 5 December, 10am -12.30pm
at Flying Fish Studios

Free craft session for parents: Christmas wreath making

Create a Christmas wreath using a mixture of new and recycled materials, in whatever colours you choose! Feel free to bring your own materials to add to your wreath too. **Booking essential.**

Saturday 10 December
Showroom Cinema

Christmas films

Thanks to funding from Gripple Ltd. we have once again booked the Showroom Cinema for a private film screening. This year, we are showing two films (titles to be confirmed) – one for younger children, and one for older ones. The films will be shown 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 in November – respond quickly to avoid disappointment!

Tuesday 13 December, 10.30am -12pm
at More Rehab
Coffee morning

January

Thursday 12 January, 10.30am -12pm
at More Rehab
Coffee morning

January *continued*

Tuesday 17 January, 10am -12pm
at More Rehab

Transition subgroup meeting

This group is 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.

Friday 20 January, 10am -11.30am
at More Rehab

Speech and Language subgroup meeting

This group is for parents of children and young people with speech, language and communication needs. We will look at proposed changes to speech and language therapy provision in Sheffield and give feedback.

Please book your place.

February

Tuesday 7 February, 10.30am -12pm
at More Rehab
Coffee morning

March

Thursday 9 March, 10.30am -12pm
at More Rehab
Coffee morning

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 :

- Please add me to your email list.
 Please add me to your text messaging list.
 Please add me to your postal mailing list.
I am happy to take part in consultations:
 by phone by email
 by post by SMS
 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.

Tear along here

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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**