

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
Autumn 2015 - Issue 12 - **FREE!**

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About us

The Sheffield Parent Carer Forum is an independent group of over 1,000 parents and carers of children with disabilities and/or special educational needs.

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

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

Membership is free, join us today!

Fill in the membership form at the back of this newsletter to join.

Get in touch

By Post:

St Mary's Community Centre
Bramall Lane
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S2 4QZ

By phone: 0300 321 4721

By e-mail:

enquiries@sheffieldparentcarerforum.org.uk

Website:

www.sheffieldparentcarerforum.org.uk

Drop-in:

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



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St Mary's Community Centre



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

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- Full page £100
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- ¼ page £25

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to discuss your requirements.

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Design by 'Side of the Hill'

A very warm welcome to our Autumn Newsletter!

We are now a year into the reforms to the special educational needs system, which came into force last September. There is still a great deal of work to do around the reforms, especially with the transfer of statements to the new Education Health and Care (EHC) Plans. We always knew it would take time to embed the different processes, and the government recently extended the timescales local authorities have to observe when converting a statement into an EHC plan.

Several national charities have recently issued damning reports about the implementation of the reforms, which highlighted the importance of parent carers being aware of their rights and the processes involved. The article on pages 11-13 contains more information about this and also about our information sessions in October and November for parents and carers of children transferring from statements. We also have information available on our website, including the new SEN Code of Practice, and are already working on our next conference in March, details of which will be released in the near future. We continue to work with different services to ensure they are aware of the issues and problems that parent carers are reporting to us.

In this edition of the newsletter, you will find articles on attitudes towards disability in the African-Caribbean community, different experiences of parent carers and information around financial support. There is also a good example of how to make a café accessible which is indeed



a hidden gem! Many of the articles are written by our trustees and volunteers who freely give up their time. Our volunteers provide over 1,000 hours every year of volunteering support to the Forum. A wonderful example of this could be seen at our family fun day at Hillsborough Sports Arena in August, when volunteers came from a variety of companies including Gripple, Henry Boot, Lloyds TSB and Irwin Mitchell Solicitors and contributed to a very successful day. It is always heart-warming that people freely give their time in this way, and we are very grateful to the support and hard work that all our volunteers provide!

We hope you find the different articles and information useful. If you have any suggestions or ideas for articles you would like to see or contribute to future editions of the newsletter, please just get in touch.

Best wishes

Jayne Woodward, Co-Chair

Fun in the park!

On 21 August, 65 families with disabled children flocked to Hillsborough Sports Arena to enjoy a free family fun day, organised by the Sheffield Parent Carer Forum with funding from Sheffield City Council.

The event featured the ever-popular bungee trampolines, bouncy castles, adapted cycles and – a new addition this year – a miniature train, which was a big hit with young railway enthusiasts.

Children took part in a range of accessible sports activities and got into the groove at dance and drumming workshops.

But there was also plenty to do for those who preferred a quieter approach – such as arts and crafts activities, face painting, a mobile library van, or cuddling up with the animals from Heeley City Farm.

Jayne Woodward, the Forum's chair, said: "This was our fourth family fun day, and we do think that we are getting better at it every time we do it."

"We are very fortunate in that we always have lots of support from local organisations, like sports clubs, schools or the fire service. This year, we were also supported by a number of local companies: Gripple, Henry Boot, Lloyds TSB and Irwin Mitchell Solicitors all allowed their staff to volunteer at our event. We couldn't have done it without them!"



"Would you like to be kept informed about events like these?"

Just fill in the membership form at the back of this newsletter, and opt into one of our mailing lists – it's completely free!

Short break grants available now

Parents of disabled children and young people (aged 0-19) can once again apply for a one-off payment of up to £400 per family.

The money can be used for anything that gives parents a break from their caring responsibilities. For example, you could use it to fund day trips, a gym membership, cinema tickets, a carer to support your child to access an activity, etc.

The deadline for applications is 29 January 2016, and the money must be spent by 31 March 2016.

Eligibility

Families are eligible for the grant if the parent/carer is a Sheffield resident, Sheffield City Council has a responsibility for the disabled child/young person (e.g. education), AND one of the following conditions applies:

- The disabled child/young person receives the high rate care or high rate mobility component of Disability Living Allowance (DLA)
- The family received a short break grant last year as a result of submitting an Additional Information Form which is less than 12 months old
- The family already receives another form of assessed short break, e.g. residential respite, direct payments, SNIPS

If none of these conditions applies you may still be eligible, but will need to ask a professional who knows your family (e.g. GP or Health Visitor) to provide additional information.

How to apply

If you received the grant last year, you should have automatically been sent an application form.

Sheffield City Council have re-launched their popular short break grant scheme.



You can also download the form and guidance notes from the Council website:

<http://tinyurl.com/q52he9w>

If you require a hardcopy of the form or need to speak to someone about your application, please contact SENDIAS (Special Educational Needs and Disability Information Advice and Support, formerly Parent Partnership) on **0114 273 6009** or email CYPF_shortbreakgrants@sheffield.gov.uk.

Not eligible because your child is too old?

If you care for an adult (aged 18+) for 35 or more hours per week, you can apply for a "Time for Me" grant of up to £200. For more information, please contact Carers in Sheffield on **0114 354 0158** or email breaks@sheffieldcarers.org.uk.

Changes to specialist provision

Sheffield City Council has been working with local special schools to create additional capacity, in response to a surge in demand for specialist placements, particularly from learners with autism.

Satellite provision at Bents Green

This year, demand for places at Bents Green specialist school, which caters for youngsters with autism, outstripped supply by about three to one.

In order to accommodate the increased Y7 intake at the Bents Green site, all of the school's sixth form students are now being taught off-site - either at Autism Plus on Bridge Street or at Sheaf Training near the Northern General Hospital (see box).

In addition, a "satellite hub" has been created at Westfield Sports College in Sothall. Pupils accessing this hub are primarily being taught by Bents Green staff, but will be supported to access mainstream classes as appropriate. If successful, this model could be adopted by other mainstream/special school pairings across the city.

New provision for students with Asperger's

Additional provision has also been created for students with high-functioning autism or Asperger's Syndrome who are unable to access mainstream schooling due to mental health difficulties or school phobia. For many

Sheaf Training is a building owned by Sheffield City Council, which is used by a range of mainstream and specialist education providers, including two special schools (Seven Hills and Bents Green), Sheffield College, New Routes (a specialist post-16 programme) and the Home and Hospital Education Service. Students are on roll of these different providers, and taught by staff employed by them. It is envisaged that students on specialist courses will be able to access elements of mainstream vocational courses, e.g. horticulture, catering, health and social care or childcare, where appropriate.



The Kenwood Centre on Psalter Lane

years, this group of students was particularly poorly served, often receiving just two or three hours of home tutoring per week provided by the Home and Hospital Education Service (HHES), or being home educated by parents who felt they had no other option.

For these students, the HHES has created new provision at the Kenwood Centre on Psalter Lane (Y7-Y11) and at Sheaf Training (post-16 provision). Students are on roll of Becton School, which caters for children and young people with mental health difficulties, and access a highly individualised curriculum which can include GCSE and A-level courses.

Caring for students in crisis: Yew Tree Lodge

Yew Tree Lodge opened in late 2014. It caters for students who are in or headed for crisis and who are unable to access other types of provision, e.g. those who have been excluded from special schools or who have recently returned to Sheffield from specialist out-of-city placements.

Based in the former caretaker's house at Silverdale School, Yew Tree Lodge combines building-based one-to-one and small-group tuition with work placements and home visits. It is staffed by teachers from Sheffield College and Becton School and accesses support from a range of therapists.

A "local offer" of SEN and disability information

All local authorities have to publish a "local offer" – that is, a website with information about the support and services available to children and young people with special educational needs (SEN) and disabilities aged 0-25 years in their area.

You can access Sheffield's local offer at www.sheffield.gov.uk/localoffer.

The website includes information on:

- Childcare
- Sport and leisure activities
- Short breaks and other social care services
- Support groups
- Education (including detailed information about special educational provision at individual schools, colleges, etc.)
- Transition to adulthood
- Health services
- Transport

The local offer is part of a bigger website called the Sheffield Directory, which also includes information about services and support for disabled adults.



The local offer section of the site is maintained by SENDIAS (Special Educational Needs and Disability Information Advice and Support, formerly Parent Partnership), who can also support parents without an internet connection to access the information in the local offer. You can call them on **0114 273 6009**.

Sheffield's local offer includes a "rate and review" feature which enables users to rate individual services (including schools) – a bit like on Amazon or TripAdvisor! You can also give feedback on SEN provision in Sheffield generally. The local authority must publish a summary of the comments it receives, and say how it is going to address any issues raised. This should help to improve provision over time.

Free computer classes

iPads and tablets

A free 10-week course especially for carers, run by the Caring Sharing Project at Mencap & Gateway, Norfolk Lodge, Park Grange Road. Learn how to use all aspects of tablet technology, e.g. basic navigation, understanding Apps, taking photos, using videos, downloading music, using email and Facetime. Tablets provided, or bring your own. Starts Tuesday 15th September, 1-3pm - but they understand that parents may need to leave earlier to do the school run.

To book, call **0114 275 8879** or email scpoffice@sheffieldmencap.org.uk.

Computers for beginners

A friendly computer class for complete beginners – no stress. Sessions take place every Friday 1.30-3.30pm, at St Mary's Community Centre on Bramall Lane. No need to book, just turn up! For more information, call St Mary's Church on **0114 2230223**.



SEN funding pressures

Sheffield City Council is considering a raft of measures to reign in escalating SEN costs.

Council bosses are concerned about a potential overspend from the High Needs block of the Dedicated Schools Grant (DSG) – that's the main grant through which the government allocates education funding to local authorities.

The High Needs block is used to fund special schools, Integrated Resources, Pupil Referral Units, support services like the Autism Team, and top-up or "banded" funding for mainstream pupils. If expenditure were to continue to rise unchecked, the council would overspend this year's High Needs allocation by several million pounds.

Could the council find some more money elsewhere? Well, the DSG has two other funding blocks - one for mainstream schools (which includes funding for low-level SEN), and one for early years – and local authorities are indeed allowed to move funds between the three blocks. However, since the money has already been allocated, this is not a feasible option.

As a short-term measure, the council has reduced top-up funding for new applicants and instructed schools to make up the shortfall from their delegated SEN budgets – the larger the SEN budget, the bigger the reduction. Schools are currently being consulted on alternative ways of managing this reduction for the rest of the school year.

In addition, the council is consulting on long-term proposals to delegate most of its High



Needs funding to localities, each consisting of around 15-20 schools. These localities would use a city-wide set of criteria to allocate top-up funding to individual pupils. Schools would be required to maintain a "MyPlan" (support plan) for pupils in receipt of top-up funding. The council believes that this would result in a fairer, more responsive and more affordable system. If localities also had to fund specialist placements and SEN transport for pupils who live within their area, this would create a financial incentive to develop more inclusive provision locally.

Because that's another big draw on the education budget – more and more children in Sheffield are attending special schools. Which is perhaps to be expected, considering our city's recent baby boom. So why can't we just build more special schools to keep up with demand? According to council officers, our special schools already have more pupils on roll than Sheffield gets funding for – and the government is refusing to fund additional places. In order to stay within the budget, the council needs to reduce the number of special school places by around 6%. It hopes to achieve this by supporting more children to remain in mainstream schools, e.g. via intensive support from Educational Psychologists, increased use of split mainstream/special school placements, and the creation of more "satellite hubs" attached to mainstream schools (see page 6).

Help with transition

If you think your young person might need support from adult social care when they turn 18, the following sessions, run by the Sharing Caring Project at Mencap, could be of interest to you:

Transition support group

This group is for family carers of young people with a learning disability and/or autism. It gives parents an opportunity to get together to swap information and ideas and support each other through the different ups and downs of the transition from children's to adult services. There are monthly daytime and evening meetings, and your young person is welcome to attend a "Fitness Fanatics" group alongside the evening meetings (must be pre-booked). The next meeting dates are: 12 November, 6.30-8.00pm, at Sheffield Mencap & Gateway, Park Grange Road, and 10 December, 10.30am-12.30pm, at Sheffield Carers Centre, 5 Young Street.

Information session: Housing Options and Planning for the Future

This session will take place on Thursday 15th October, 10.30am-2.00pm, at Sheffield Mencap & Gateway, Park Grange Road. Find out about housing options for people with learning disabilities in Sheffield, how to access them and planning for the future generally.

For more information or to book your place, please contact the Sharing Caring Project on **0114 275 8879** or email **scppoffice@sheffieldmencap.org.uk**.



Free activities with ibk

ibk initiatives (www.ibkinitiatives.com) are offering free activities for disabled children and young people and their families:

Yoga & dance classes

Yoga takes place every Thursday (term time only), 5.30-6.30pm, at St Mary's Church, Bramall Lane, Sheffield, S2 4QZ.

Dance takes place every Thursday (term time only), 6-7pm, at the U-Mix Centre, 17 Asline Road, Sheffield, S2 4UJ.

The classes are aimed at disabled young people aged 10+. Siblings are welcome!

Family teas

Families with disabled children are invited to an evening of lovely homely food, good conversation, information sharing and laughter.



Teas take place every 6-8 weeks at St Mary's Church, and the next one is on Saturday 7th November, 5-7pm. Everyone is welcome!

Trips & residential weekends away

ibk initiatives have been able to secure some funding for trips and residential weekends away for disabled young people, either for free or at a very reduced rate. Please contact ibk to be kept informed about future trips and residential.

For more information or to book your place, please email **gabriella@ibkinitiatives.com** or call **0114 223 0236**.

New group for children who use communication aids

Does your child use an electronic communication aid? Alison Mackenzie, a recently-retired speech and language therapist with many years of experience in this area, would like to set up a parent-led group for children who use technology to communicate.

The group would be suitable for children who have little or no intelligible speech, but who show some emerging social skills (e.g. turn taking, role play) and an interest in using language to interact with others.

While children will benefit from being able to play with other communication aid users, parents will be able to swap tips and ideas and get advice from a qualified speech and language therapist.

Interested in joining?

Please contact the Sheffield Parent Carer Forum (see inside front cover), and we'll put you in touch with Alison. Meeting dates, times and venues are yet to be decided.

Mums of disabled children more likely to suffer memory problems

Put the keys in the microwave again? Walked into a room, but couldn't remember why? If you think you're more forgetful than your peers, you might be right...

A recent study by led by Jieun Song at the University of Wisconsin-Madison found that caring for a disabled child hastens the decline of your cognitive abilities, particularly memory – but only if you are a mum. For dads, caring did not result in a faster loss of memory skills.

The authors of the study hypothesize that this might be because mums of disabled children are more exposed to parenting stress, due to the fact that they usually do most of the childcare and housework. (We think it might also have something to do with chronic sleep deprivation!)



On a more positive note, the study also found that having a strong support system, a sense of control and a physically active lifestyle helped to protect mothers from accelerated cognitive ageing.

If your child has a statement of SEN and is due to move to move schools or enter further education in 2016, then their statement will soon be converted into an Education Health and Care (EHC) plan.

New legislation requires local authorities to replace all statements of SEN with Education Health and Care (EHC) plans by April 2018.

The conversion will normally be done in the year before your child starts school; moves on to junior school (Y2) or secondary school (Y6); or enters further education (Y11-Y13). Students in Y9 must also have their statements converted.

The conversion process

The first thing you hear about the conversion will probably be a letter from the local authority (LA) requesting your permission to share information about your child with the health service. It's important that you respond to this – if you don't, important health information (e.g. paediatrician's reports) may not be included in your child's EHC plan!

Next, your child's school will contact you to arrange a Transfer Review Meeting. This meeting will be held at school in place of the annual review meeting. Its purpose is to convert your child's statement into an EHC plan. The school should ask you which professionals should be invited to the meeting.

The school will give you two forms to fill in:

- The usual annual review form which asks you for your views on your child's progress over the past year, what they still find difficult, and what you think their next targets should be.



- A "person-centred" form to capture your child's aspirations, their likes and dislikes, and how they want to be supported. This information will form the basis of the EHC plan, and will be used to create a one-page profile with essential information about your child. You may want to complete this form together with your child and/or your child's teacher, TA or SENCO.

You then receive a letter from the LA giving you formal notice of the transfer review, and confirming the date and time of the transfer review meeting. You must be given at least two weeks' notice. The letter will ask you if you think that the assessment reports which the statement is based on (e.g. reports from Educational Psychology, Speech and Language Therapy, Autism Team) are sufficient.

- Tell the **SEN Assessment and Placement Team** if you think that any of the reports are out of date, or if new needs have come to light which have not yet been fully investigated. The LA must then seek new advice. Services have six weeks to respond.
- If you have any private assessment reports which you think would be useful, submit them to the LA now.

Transferring from a statement... continued

- If you gave permission for the LA to share information with the health service, any health professionals who have had involvement with your child in the previous 12 months will be invited to the transfer review meeting and asked to produce a report. If you want older health reports to be considered, tell the LA now.
- If your child is aged 16 or over, the LA will write to them directly. If you think your child lacks mental capacity to make decisions in relation to their EHC plan, you should inform the LA. Let them know if you want to act as your child's representative.
- A free service called "Independent Support" is available to help you through the conversion process. In Sheffield, this is provided by a company called **Core Assets**.
- Alternatively, you can also ask **SENDIAS** (a council-run service, formerly known as Parent Partnership) for information, advice and support.

The transfer review meeting

The transfer review meeting will normally be held at school and should be attended by the parents, the child or young person, an officer from the LA, relevant professionals and school staff. You can ask a friend, family member, personal assistant or other professional to accompany you. The meeting will normally be chaired by someone from the school, e.g. the SENCO.

Most of the transfer review meeting will be spent recording everyone's views about **four key topics**, using the information that has been put together and brought to the meeting:

- 1) what your child's strengths and interests are;
- 2) what helps them at the moment and what support is working or may be needed;

- 3) what you and your child want their future to be like, what kind of life you aspire them to live;
- 4) the key outcomes or things you want to change to make those aspirations become a reality.

If your child is in Y9 or above, the meeting must also cover planning for adulthood.

You must also be asked if you would like a personal budget. A personal budget gives you an overview of the money allocated to your child through the EHC plan. You can ask to receive some or all of this money as a direct payment, and purchase the provision yourself (subject to certain restrictions).

The SENCO will need to check they have all the information they need to send back to the LA.



Writing the EHC plan

The LA officer writes a draft EHC plan and sends it to you and your child's school. You then have 15 calendar days to request amendments and to tell the LA which setting (nursery, school or college) you want your child to attend. An LA officer must meet with you if you request this. If you have requested amendments, the LA will normally send you a revised draft of the plan. The LA aims to issue all draft plans before Christmas (except for those in Y9, whose draft plans will be issued in the spring).

- At this point, the LA can **ONLY** make changes requested by you – they can't change anything else in the text.
- Contact **Core Assets** if you'd like an independent supporter to check the draft plan for you.

The LA then finalises the EHC plan and sends it to you/your young person, the school and the professionals involved. The final EHC plan must be issued within 18 weeks of the start of the transfer review process, or within the statutory timescales for children at stages of transition, whichever is earlier. The statutory deadlines are: **15 February** for children due to move from infant to junior school and primary to secondary school, and **31 March** for young people due to transfer from secondary school to further education.

The EHC plan is then implemented. This means that the LA **must** arrange the special educational provision described in section F, the NHS Clinical Commissioning Group **must** arrange the health provision described in section G, and the setting named in section I **must** admit your child. Just like a statement, an EHC plan **must** be reviewed at least annually.

If you are not happy

If you are not happy with the education sections of final plan (sections B, F and I), you have the right to appeal to the SEN and Disability First-Tier Tribunal. You must do this within two months of the date of the final EHC plan.

If you are unhappy with the health or social care sections of the plan (sections C, D, G, H1 and H2), you need to use the complaints procedures of these services.

- It is best to try and resolve any issues while your child's EHC plan is still at the draft stage. SENDIAS can support you with this, or you may want to use an independent

disagreement resolution service (currently provided by Collis Mediation Ltd.).

Contact details

SENDIAS

Tel: **0114 273 6009**

Email:

ed-parent.partnership@sheffield.gov.uk

Core Assets

Tel: **0800 028 8455**

Email: **ISreferrals@coreassets.com**

SEN Assessment and Placement Team

Tel: **0114 273 6394**

Email:

ed-sensupportteam@sheffield.gov.uk

SEN and Disability First-Tier Tribunal:

Tel: **01325 289 350**

Email: **sendistqueries@hmcts.gsi.gov.uk**

Collis Mediation Ltd.

Tel: **07715 958 290**

Email: **info@collismediationltd.com**

Information sessions

Our Development Workers Anne and Eva will be running **FREE** information sessions about the transfer from a statement to an EHC plan. Sessions will be held at St Mary's Community Centre on Bramall Lane on Tuesday 20 October, 7-9pm and Friday 6 November, 10am-1pm. You only need to attend one of them.

Booking essential!

Please contact us on **0300 321 4721** or email **enquiries@sheffieldparentcarerforum.org.uk** to book your place.

Café culture

The summer holidays have come and gone, a time to spend with your children and family, visiting places and doing activities. For parents of children who cannot cope in different environments, this can be a challenging time. Noises, crowds and waiting make certain places very difficult to go to. So it's always nice to hear from other parents who have had positive experiences and can recommend places.

One such place I recently discovered was the Hidden Gem Café. I had seen the small "Café" sign near Bents Green special school for years, but only recently decided to check it out. It is run by the charity Work Ltd. which provides work opportunities for people with learning disabilities, helping them to develop life skills.

I was very pleasantly surprised, it was extremely welcoming and friendly. The lady I spoke to reassured me that I could ring ahead to order drinks and food, as my son finds it very difficult to wait. When we visited, the order came a few minutes after we sat down. There is a lovely outside area to sit with heaters and blankets,



so we were away from any noises that might have upset him. It was nice not to feel I had to explain my son's behaviour or that I was disturbing people when my son made noises and shouted out.

This summer we visited the café several times and even met with friends there. It might seem like such a small thing for families to do, go to a café, but for us it has been a great achievement that wouldn't have been possible without the lovely Hidden Gem.

By Maria Fernandes, Trustee

You can contact the Hidden Gem Café on 0114 2620094, or via their website www.hiddengemcafe.co.uk

Successful hospital appointments

Over the summer my daughter Stella had three hospital appointments, at different Sheffield hospitals. All of them went well, with my daughter remaining happy and the staff being able to carry out the procedures required. Hooray!

I put this down to a combination of flexible and understanding staff at the hospitals and careful advance planning.

The appointments, at the Royal Hallamshire and the Children's Hospital, were drop-in clinics for blood tests. I rang the clinics to find out when the quietest times were, and to explain my daughter's disabilities. She can find it difficult to wait and, if upset, will not comply with requests and may go into a meltdown - it would be impossible to do the required tests if she was upset. The departments said they would be ready for her when she came in, at a time we agreed. I took the names of the people

we spoke to and asked if they would be there when we visited.

This preparation paid off: when we arrived, there were patients in the waiting rooms, but we were taken through to the treatment room. The staff were very friendly and made Stella welcome. They listened to my tips about how to approach her, and I helped to hold her arm firm for the blood test. They were very quick!

At Charles Clifford Dental Hospital we again rang in advance. At the clinic we had to fill in a form and wait a short while, but there was a television and a small play area to keep my daughter distracted and we had her iPod with downloaded games and ear defenders. We were seen within five or ten minutes. Staff spoke slowly and clearly to Stella and the

consultant in charge arranged for Stella to have her x-ray immediately. I worked with staff to coax Stella into the x-ray machine and was able to stay and hold her while the x-ray was done.

All the staff were welcoming and happy to work with parents. I have to send a big thank you to the Haematology teams at the Royal Hallamshire Hospital, the Children's Hospital and Charles Clifford Dental Hospital for their help.

After these very positive experiences I shall approach future appointments with much greater confidence, using my knowledge of what went well.

By Joanne Ferguson, Trustee

Autism in the African-Caribbean community

My son was diagnosed with Autistic Spectrum Disorder on 10th August 2010, one week before his fifth birthday, and I remember it as though it was yesterday. I remember feeling fearful for his future. I remember thinking I am incapable of undertaking this. I remember thinking I had inflicted this upon my child, that it was my fault as a mum ... and I remember thinking how on earth would I tell my family.

I am first-generation Black British; both of my parents were born in Jamaica, and both of their families migrated to Sheffield when they were children. I am drenched in a rich Caribbean heritage - I always say I'm blessed to have the best of both worlds, because my Sunday dinner always includes Rice & Peas (Jamaican heritage) and Yorkshire Puddings (British heritage).

But in this instance, I felt less than blessed, *continues on next page*



because somehow I would have to tell my family that my beautiful boy has autism.

I bided my time and started to join groups for families with disabled children. Much to my disappointment, I was often the only black parent there ... am I to believe I am the only BME (Black Minority Ethnic) person with a non-typically developing child? If Sheffield is an ethnically diverse city, with some 19% of its population being from BME groups, why was I the only non-white parent in the room? Now more than ever, I needed to be around family for support, but couldn't tell anyone because I feared their responses; and I needed to be in support groups where people would understand my cultural heritage.

The level of isolation I felt is something unexplainable. I needed to talk to other BME families, to learn how to tell my extended families, but there was nobody to help educate me. Within the black-Caribbean communities, autism isn't widely understood or acknowledged, so I found myself not only saying my child had it, but I would also have to explain what it was (when in fact all I wanted was a hug). I am from a community where many believe that, if I was more disciplined with my son, he would grow out of it, which led me to leave many conversations feeling like a pretty crap parent. I also experienced a wider mentality of blame than I had envisioned, with many asking me who my son had gotten the autism from ... so I stopped telling people, I stopped going to family gatherings, and I started to isolate.

It felt like the blind leading the blind; I somehow had to parent myself on how to be a parent to my son, because I had no experience whatsoever of neuro-disabilities. He had no friendships, no play dates, no activities outside of the home. I was unhappy because I was failing my child, and I had no one to turn to who would listen without giving me unhelpful

advice about how to parent him. There have been days when I have thought about taking my life because the pain was too much, but then who would look after my son? So I had to wipe the tears away, try to get some sleep, and try to be a better parent tomorrow.

I'm not sure when things changed! I think it was a mixture of understanding my child better and being part of parent-led support groups. I had to accept that I would not see other African-Caribbean parents there, and I had to accept the fact that many of my loved ones may never understand what autism is or how their responses made me feel. And whilst accepting these things, I also made sure that, as soon as I was in a position to do so, I would reach out and help other black families in Sheffield who have disabled children, because so many are being missed and left to fend for themselves when they need support the most.

I am by no means implying that non-BME parents do not experience the same things as I have; I am merely hoping that my child and I will feel as though we are not the only black family in Sheffield going through this.

By Melissa Simmonds, Trustee

Have you experienced similar issues? Our contributors would love to hear from you! Call or email our office, and our staff will put you in touch with the right person.

Helping Hands

Supporting and strengthening families with disadvantaged children and young people.

We exist to maximise the outcomes for children and young people who face disadvantage or discrimination in their daily lives. We are parents and carers who support each other on many levels and welcome other like-minded families into our group. We have been a constituted group since 2012, but were able to do more structured activities in the last 12 months thanks to funding we obtained from Comic Relief.

Helping Hands provides a safe, non-judgmental environment for families to come together and play, to feel less isolated and share information and their experiences. We aim to do low-cost regular fun activities for all ages and abilities in Handsworth and surrounding districts.

Our activities have ranged from multi sports to swimming, Zorbing, street dance, rhythm and movement, street kick, crazy golf, crafts and much more.



Our children with often struggle in mainstream environments due to a lack of understanding by other families of their challenging behaviours. They are rarely invited to birthday parties or to friends' houses for tea because of their difficulties. Their siblings also have a tough time both living with the everyday challenging behaviours and with the additional problems of going out as a family to do mainstream activities. The parents and carers spend much of their lives advocating for their children, often with little time left for the fun things in life. We try and reduce the everyday pressures our vulnerable children face, which impact negatively on their lives and how they achieve at school. We aim to improve children's communication and social skills, confidence and self-esteem, by giving them a chance to explore and maximise their potential.

Stronger Together.

To join the group or to find out about our next round of activities, please contact:

Tracey Wild (Chairperson)
0114 221 5200 / 07837 836719

Donna Musson (Treasurer) 07594 121796
Lindsey Spencer (Secretary) 07912 661 556
Email: helpinghandsdssheffield@gmail.com

www.localgiving.com/helpinghands
www.facebook.com/helpinghandsS13
Twitter: @helpinghandsS13



Most of parents of disabled children are aware of the main disability benefits, such as Disability Living Allowance and Carer's Allowance. But there are other sources of financial support you might be able to access. Unfortunately, not many parents (or even professionals) know about them. Read on, and you might find yourself several hundred pounds per month better off...



Are you sure you are claiming all that you are entitled to?

Call Contact a Family's free helpline on **0808 808 3555** and ask for a benefits check.

Employment and Support Allowance

When your disabled child turns 16 they may be entitled to claim Employment and Support Allowance (ESA) which is a benefit paid to people whose ability to work is limited by disability or ill health.

Education

If your child is a full-time student they can claim ESA if they are also receiving Disability Living Allowance (DLA) or Personal Independence Payment (PIP). Part-time students are eligible to claim whether they get DLA/PIP or not.

Assessment

For new claimants the assessment period should usually last for 13 weeks. During this time your child will undergo a "work capability assessment" to determine two things:

1. if they have "limited capability for work" and are therefore entitled to ESA;
2. and, if so, which of two groups they should be in: the "support group" for more severely

disabled people, or the "work-related activity group" for those who may be able to move into work with support and training.

The assessment will usually involve completing a questionnaire and possibly a face-to-face assessment carried out by a health professional.

How much?

During the first 13 weeks of a claim – called the assessment period – a reduced basic rate of ESA is paid. After that, if your child is entitled to ESA, they will be placed in one of the two groups and will receive:

- up to £102.15 a week if they are in the "work-related activity group"
- up to £109.30 a week if they are in the "support group"

Some may also be entitled to an Enhanced Disability Premium of £15.75 a week.

Watch out!

- If your child has savings over £6,000 it may affect their claim.

- You can't claim Child Benefit or Child Tax Credit at the same time as your child claims ESA, so you may need advice about which to claim. Call Contact a Family's free helpline (**0808 808 3555**) and ask for a benefits check.

How to claim

Phone the Jobcentre Plus claim-line:

Telephone: 0800 055 6688

Textphone: 0800 023 4888

Remember to check how much your phone provider charges for 0800 numbers because this could be a long conversation!

Free childcare

Free childcare for three- and four-year-olds has been around for a while – but did you know that free childcare is now also available for disabled two-year-olds?

All three- and four-year-olds in England can get 570 hours of free early learning or childcare per year. This is usually taken as 15 hours each week for 38 weeks of the year, but you can use

You can also get a claim form (ESA1) from your local Jobcentre Plus office or download it from: <http://tinyurl.com/nzbnjh5>

More information

Disability Rights UK have a helpful factsheet on their website: <http://tinyurl.com/kswrnyt>

Contact a Family have published a booklet about PIP and other post-16 benefits: <http://tinyurl.com/okcw6z>

your hours over more weeks if your childcare provider is able to be more flexible.

Two-year-olds are entitled to the same number of free hours every year if they:

- have a statement of special educational needs (SEN) or an Education, Health and Care (EHC) plan OR
- receive Disability Living Allowance (DLA) at any rate

Some two-year-olds may also qualify if your family claims certain state benefits, for example Income Support or tax credits.

How to apply

Free childcare can be accessed at the beginning of the term after your child's third birthday (or second birthday if they qualify). You can apply up to 10 weeks before the end of the term in which your child turns two or three. To apply, call Sheffield City Council on **0114 273 4567** or call into First Point at Howden House.

Finding childcare

Free childcare places are available at approved nurseries, pre-schools, schools and childminders. Sheffield's Local Offer website has information about local childcare providers and the support they offer for children with additional needs or disabilities. Go to **www.sheffield.gov.uk/localoffer** and click on "Childcare".

If you don't have internet access, call SENDIAS

Protect your pension with Carer's Credit

Did you know that you will only get the full basic state pension if you have paid a certain amount of national insurance contributions? If you are not working or have a very low income because you are caring for someone, you could be losing out – unless you are claiming Carer's Credit.

Carer's Credit isn't a payment – it's a way of building up qualifying years for your state pension while you are not paying national insurance contributions through work.

Eligibility

To get Carer's Credit you must be:

on **0114 273 6009** and ask them to search the Local Offer for you.

Additional support

If you are struggling to find a suitable childcare provider for your disabled child, the Early Years Inclusion Team may be able to help; email **elizabeth.hodkin@sheffield.gov.uk** or call **0114 273 6411**. If your child has a diagnosis of visual impairment, hearing impairment or autism, you should contact the relevant support service instead – see pages 24-25 for contact details.

Know your rights

Childcare providers must not discriminate against disabled children, e.g. by refusing to admit them. To learn more about your child's rights, download Contact a Family's guide "Childcare for families with disabled children" from <http://tinyurl.com/psvxeo7>. Alternatively, call Contact a Family's freephone helpline (0808 808 3555) and request a hardcopy.

- aged 16 or over
- under State Pension age
- looking after one or more people for at least 20 hours a week

The person you're looking after must get:

- Disability Living Allowance care component at the middle or high rate OR
- Personal Independence Payment - daily living component, at the standard or enhanced rate

If the person you care for doesn't get any of these benefits, you may still be able to get Carer's Credit by filling in the "Care Certificate" part of the claim form and getting a health or

social care professional to sign it. You may qualify for Carer's Credit even if you don't qualify for Carer's Allowance.

You DON'T need to apply for Carer's Credit if you:

- get Carer's Allowance - you'll automatically get credits
- get Child Benefit for a child under the age of 12 - you'll automatically get credits

- are a foster carer - you can apply for National Insurance credits instead

How to claim

Download the Carer's Credit claim form from: **<http://tinyurl.com/c5cg7te>**

Or contact the Carer's Allowance Unit:

Telephone: 0345 608 4321

Textphone: 0345 604 5312

Extra tax credit payments

If you have a disabled child and get child tax credits, you could be missing out on up to £84 per week!

This is because you qualify for an extra payment called the "disabled child element" if your child gets Disability Living Allowance (DLA), Personal Independence Payment (PIP) or is registered blind.

If a child gets the highest rate of the DLA care component (or the daily living component of PIP at the enhanced rate) you qualify for a further payment called the "severely disabled child element".

The disabled child element is worth up to £60 per week, and the severely disabled child element is worth up to £24 per week.

However, the Tax Credits office won't know that you qualify for these extra payments unless you tell them that your child is on DLA or PIP!

How to claim

Contact the Tax Credits Office:

Telephone: 0345 300 3900

Textphone: 0345 300 3909

More information

Visit the Contact a Family website:

<http://tinyurl.com/qhl9h3c>

We have partnered up with Jobcentre Plus to offer free 'Benefits and Job Search Advice Sessions' for parents.

Dates: 3 November 2015, 10am-12pm
6 January 2016, 10am-12pm

Venue: St Mary's Church and Community Centre,
Bramall Lane.

Contact us now to book your free 20-minute slot!



Dates for your diary

All meetings will be held at St Mary's Community Centre, Bramall Lane, Sheffield S2 4QZ

October

Tuesday 13 October, 1pm - 2.30pm

Feeling good and functioning well

Wellness coach Jayne Spenceley is running a free taster class for parents of children with additional needs. Learn how to reduce feelings of fear and exhaustion, cultivate positive emotions and build your inner resources. The session will include a guided relaxation. Booking essential!

Tuesday 20 October, 7pm - 9pm

Information session: EHCP conversions

For parents of children with statements of SEN. Find out when and how your child's statement will be converted into an EHC plan, how to prepare, and what your rights are. **Places are limited and must be pre-booked.**

Friday 23 October, 10am-12pm

Health subgroup

Come and join our small group of parents who want to improve local health services for children with disabilities. All parents welcome, not just those of children with medical needs.

November

Tuesday 3 November, 10am - 12pm

Benefits and job search advice session

Talk to a specialist advisor from Jobcentre Plus to get advice on a range of benefits and/or getting back into work. 20-minute sessions available. Booking essential!

November continued

Friday 6 November, 10am -1pm

Information session: EHCP conversions

This is a repeat of the session held on 20 October.

Tuesday 10 November, 10.30am -12pm

Coffee morning

Come and chat to other parents and carers. Tea, coffee and CAKE! Pop in for a few minutes or stay for the whole session – no need to book. We welcome all parent carers, whatever their children's needs, whether diagnosed or undiagnosed, mild or severe. Pre-schoolers and home-educated children welcome.

Friday 20 November, 10am - 12pm

Annual General Meeting (AGM)

This is an open meeting, all welcome! After the AGM part (chair's report, election of trustees, annual accounts) we will hear updates from our parent reps about the work they have been involved in.

Monday 23 November, 10am - 12pm

Education subgroup

Please come along to talk to other parents about special educational needs (SEN), swap useful information, and help us influence education policy - particularly the implementation of the SEN reforms - in Sheffield. At this meeting, we'll be joined by a council officer who will talk to us about Sheffield's new Inclusion Strategy and the role of the MAST teams.

December

Thursday 3 December, 10.30am -12pm

Coffee morning

January

Wednesday 6 January, 10am - 12pm

Benefits and job search advice session

As previous. Booking essential!

Friday 15 January

Education subgroup

As previous.

Save the date!

We are planning to run an information day around health and therapy services for children with disabilities on

Tuesday 8 March 2016 10am-2.30pm.

An invitation will be sent to our email and text messaging lists nearer the time. Don't miss out – sign up today by completing the membership form at the back of this newsletter!

To ensure we have a big enough room, it would really help us if you could let us know in advance if you are planning to come along to any of these meetings.

(Please see inside front cover for contact details). For more event information, please visit our website: www.sheffieldparentcarerforum.org.uk/calendar



Does your child have ADHD?

Researchers at the University of Sheffield are studying ADHD, and testing some treatments to see how helpful they are in relieving symptoms and improving long term outcomes.

We are looking for as many families as possible to take part, so please get in touch.

Go to:
www.starsheffield.com

Or contact Philippa: 07543345046
p.fibert@sheffield.ac.uk

The School of Health and Related Research, University of Sheffield, Regent Court, 30 Regent St, Sheffield.



Advertisements: SPCF accepts no responsibility for advertisements. We urge families to check all references, preferably by telephone, and to ask for a DBS check.

Useful Contacts

ADHD Support Service Run by Family Action, this service provides information, support and training for families with a child with ADHD	0114 2750981
Autism Service* Supports mainstream schools to meet the needs of pupils with autism and related conditions	0114 273 6567 (helpline, 1-4pm) 0114 273 6412 (office) moira.bolan@sheffield.gov.uk
Carers in Sheffield Offers advice, information and support groups for anyone who provides care for an adult (aged 18+).	0114 272 8362 Website: www.sheffieldcarers.org.uk
Child Disability Register A local register of disabled children aged 0-19. Join up to receive the termly newsletter "What's Going On"	0114 271 7626 martina.capaldi@sch.nhs.uk
Children with Disabilities Team* Social work team for children and young people with disabilities	0114 273 5368
Contact-a-Family National charity which provides information and advice on any aspect of caring for a disabled child, including education and benefits	0808 808 3555 helpline@cafamilly.org.uk
Core Assets Provides independent information and support to families in relation to EHC plans (both for new entrants and for those converting from a statement/LDA)	0800 028 8455 isreferrals@coreassets.com
Direct Payments Team* Provides support, advice and guidance relating to direct payments	0114 273 5985
Early Years Inclusion Service* Works with young children (0-5+) with additional needs both in their homes and in settings	0114 273 6411 elizabeth.hodkin@sheffield.gov.uk cathy.wigg@sheffield.gov.uk
Educational Psychology Service* Works with families and staff in educational settings to support the education and development of children and young people	0114 250 6800 stuart.williams1@sheffield.gov.uk
Hearing Impaired Service* Works with deaf and hearing-impaired children and their families	0114 273 6410 caroline.chettleburgh@sheffield.gov.uk
Home and Hospital Education Service* Provides education for children who are unable to attend school for medical or related reasons	0114 255 7679 schofields@becton.sheffield.sch.uk
Independent Travel Training* Trains young people with disabilities/learning difficulties to use public transport to get to school, college and work placements	0114 205 3542 jill.siddall@sheffield.gov.uk

IPSEA National charity providing free legally-based advice on educational issues for parents of children with SEN	0800 018 4016 Email information service via www.ipsea.org.uk
Portage Home Visiting Service* Home-visiting educational service for children under three with additional support needs and their families	0114 273 6411 debbie.marshall@sheffield.gov.uk
Ryegate Children's Centre Assessment, diagnosis and therapy for children and young people with developmental and neurological problems	0114 271 7651
SENDIAS (formerly Parent Partnership Service)* Provides information, advice and support to parents of children with SEN/disabilities in relation to education, health, social care, leisure, disability benefits and support groups	0114 273 6009 disabilityinformationservices@sheffield.gov.uk
SEN Assessment and Placement Team* Deals with statutory assessments, statements/EHC plans, annual reviews, SEN transport and specialist placements	0114 273 6394 ed-sensupportteam@sheffield.gov.uk
Sheffield Children's Hospital	0114 271 7000 sheffield.childrenshospital@sch.nhs.uk
Sheffield Futures Learning Difficulties and Disabilities (LDD) Team Supports young people with learning difficulties and disabilities to make the transition into further education and employment	0114 201 2800 enquiries@sheffieldfutures.org.uk
Sheffield Young Carers Offers support to children and young people (8-25 years) who provide care for a family member, e.g. a disabled sibling	0114 258 4595 information@sheffieldyoungcarers.org.uk
Sibling Support Group Support group for children who have a brother or sister with a disability	0114 233 2908 simone.harper@burtonstreet.org.uk
Special Needs Inclusion Playcare Service (SNIPS)* Helps disabled children aged 5-18 access out of school activities / clubs to give their parents a break from caring	0114 273 4017 SnipsBusinessSupport@sheffield.gov.uk
Social Care Transition Team* Team of social workers who offer a transition planning service for young disabled people leaving full-time education	0114 273 5368 katarina.bajin-stone@sheffield.gov.uk
Transport Services* Provides transport services including home-to-school transport for pupils with SEN	0114 203 7570 transportservices@sheffield.gov.uk
Vision Support Service* Supports children with a visual impairment and their families	0114 294 1201 marion.broadhurst@sheffield.gov.uk
Within Reach Provides sport and physical activity for disabled people of all ages	0114 273 4266 activity.sheffield@sheffield.gov.uk

* Part of Sheffield City Council

FREE Education Health and Care Plan Support in Sheffield



Between September 2014 and March 2016 the Government has made funding available to provide specialist individual support to parents, carers, children and young people who are involved in an Education, Health and Care(EHC) Needs Assessment.

What does an Independent Supporter do?

Independent Supporters can provide parents and young people with time limited help and support to you during the EHC needs assessment and planning process.

The role of the Independent Supporter is to:

- Help you to understand the local EHC assessment process and local offer
- Act as an independent contact person throughout the EHC assessment process
- Focus on the task of helping of helping you to be fully involved in the transfer of a statement of SEN or LDA to an EHC plan
- Work with parents of children who are new to the EHC Assessment process
- Liaise across a range of local services to help gather information required for an EHC plan
- Provide information to parents and young people on personal budgets
- Signpost parents and young people to Sheffield SENDIAS when the issue is outside the remit of the Independent Supporter

For further information please contact us on:

Telephone: 0800 028 8455

Email: ISreferrals@coreassets.com

Website: www.coreassets.com/what-we-do/independent-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.

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.

Please glue here or seal with sellotape and fold along the dotted line

2

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

Fold along here



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