

The logo for the Sheffield Parent Carer Forum is a blue speech bubble with a white interior. Inside the bubble, the text 'Sheffield Parent Carer Forum' is written in red and black. The background of the entire page is a close-up photograph of a young woman with long dark hair smiling, with a young girl with bangs leaning her head against her cheek and smiling.

Sheffield
**Parent
Carer**
Forum

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
Spring 2013 Issue 7 FREE!

Services under pressure

A look at the Autism Service, CAMHS and Speech & Language Therapy

Roll on the credits!

A personal account of going to the cinema with a disabled child

Grants for families

Get funding for equipment, therapies, holidays and more

SEN reforms gather pace

Find out what the changes will mean for your child

About us

The Sheffield Parent Carer Forum is an independent group of 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
Sheffield
S2 4QZ

By phone: 0300 321 4721

By e-mail:

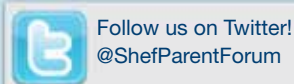
enquiries@sheffieldparentcarerforum.org.uk

Website:

www.sheffieldparentcarerforum.org.uk

Drop-in:

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



Your advert here?

Would you like to advertise your products or services in our next newsletter? For a small fee, you could reach around 4,000 families in Sheffield.

Our rates are:

- Full page £100
- ½ page £50
- ¼ page £25

Please call us on **0114 252 1913** to discuss your requirements.

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Welcome to our Spring Newsletter!



The prospect of sunnier days and spring flowers is very welcome at the moment. You can't get through a news programme or paper these days without hearing about cuts to services and how bleak the financial position is. It has felt like this has been happening for some time now, but still the news gets bleaker. The Fair Deal for Sheffield campaign suggests we are getting penalised more than other more affluent parts of the country. It begins to feel like a double whammy when those cuts seem to be targeting the most vulnerable people and services, and it is no accident that disabled people are being demonised in the media to make those changes more palatable. Several services that our children rely on are struggling – either as a result of cuts, or because funding has failed to increase in line with caseloads. Our article "Services Under Pressure" on page 12-13 examines the impact on three important local services.

Our aim at the Forum is always to work with service providers to make life easier for everyone; to ensure parent carers get a proper voice and are heard, and

also ensure they are properly informed and supported. We had a successful post-16 information day at St. Mary's during a snowy Wednesday in January, and over 110 parents came together to find out information about the transition process. Events like these always come with their own buzz, and it was good to see so many parents catching up with each other, learning and sharing together. There is always a spin off when services and organisations come together, and there have been positive spin offs already from that day.

It's not all work though, and our panto in December was another grand day out for our families. We hope to make that a regular event and put on more events, so our families can enjoy time together in a relaxing and supportive environment.

As ever, if you have any suggestions, ideas or comments, please let us know. Any spare time – we would welcome your involvement.

Best wishes

Jayne Woodward, Co-Chair

Disabled children enjoy Christmas panto



On Sunday 16th December, students from the University of Sheffield Light Entertainment Society (USLES) performed a free panto for members of the Sheffield Parent Carer Forum.

The University Drama Studio on Glossop Road provided the perfect backdrop for the students' rather unusual interpretation of "A Christmas Carol". Featuring pie-throwing ghosts, a dame with anger management issues, and a lovestruck housekeeper with a talking cat, this wasn't your usual Dickens fare!

After the show, excited children queued to receive presents from Father Christmas, sponsored by Sainsbury's supermarket on The Moor.

Jayne Woodward, the Forum's Co-Chair, said, "We organise events for our members throughout the year, but the panto is by far the most popular one. For many of our families, this is the only kind of performance they are able to enjoy together. We hope we can do another one next year!"

We've moved!

After almost three years at the Sheffield Carers Centre, we've moved into new accommodation at St Mary's on Bramall Lane.

We will always be grateful to the Carers Centre for the encouragement and support they have given us over the years, but we had well and truly outgrown the space available. Our new office provides enough room to accommodate our expanding team of paid staff and volunteers, which reflects our rapidly increasing membership – 673 families and 92 professionals at the last count!



Please note that calls to our new telephone number **0300 321 4721** are charged at the local call rate, and are included in most bundles. The number is portable, so should we ever need to move again, we can just take it with us!

Post-16 event attracts record turnout

Over 170 people – parents, professionals and disabled students – braved the January snow to attend the Forum's information day on post-16 provision at St Mary's.

Visitors browsed information stalls provided by 25 organisations, including special schools, colleges and universities, as well as a wide range of local and national charities and support services.

A busy programme of workshops offered parents the opportunity to explore different aspects of transition in more detail. Topics included changes to welfare benefits, legal issues, transition to adult social care and health services, and post-16 education.

And if that still left questions unanswered, parents were able to use the "Meet the Manager" session to seek clarification directly from managers of children's and adult services.



Eva Juusola, the Forum's development worker, said: "It's really difficult to find good, up-to-date information about the post-16 offer in Sheffield. That is why we've compiled a transition timeline, which lists key dates and events in the transition process from Y9 onwards. We are keen to work with service providers to develop better information for families."

The transition timeline, presentations and notes from the event, and a range of other useful documents about transition are available for download from the Forum's website:

www.sheffieldparentcarerforum.org.uk/page/transition-post-16-provision

Hardcopies of the transition timeline will also be distributed to all secondary schools in Sheffield. To request a copy, please ring **0300 321 4721** or email enquiries@sheffieldparentcarerforum.org.uk



Help us improve our training package!

The Sheffield Parent Carer Forum has developed a training package to increase awareness of the needs of families with disabled children among teachers and other professionals. Because we are constantly trying to improve the training we offer, we would love to hear from parents about their experiences in dealing with teachers, doctors and health workers, staff at after-school clubs or any other professionals your child has been in contact with.

Good communication between professionals and parents is vital to ensure our children have the best possible experience when they access services. With our training, we want to help those who support our children understand what life is like for families who have a child with a disability, and encourage them to overcome barriers to communicating with us parents.

Over the last year, the Forum has trained a group of parents of children with disabilities to deliver the training sessions. Feedback received so far shows that using examples drawn from the personal experience of parents is an especially powerful tool to engage our trainees and get our message across.

To further improve our training package, we are looking to widen the range of real life examples, to include the stories of parents of children with different disabilities



and special educational needs. Could you help us, by sharing examples of how your child's disability impacts on your life and that of your family? Are there any positive or negative examples of communicating with professionals, such as teachers, nursery staff, doctors, nurses, social workers, therapists, youth workers etc. that you could tell us about?

While we will use your examples to illustrate the reality of life with a child with a disability, we will treat any information you give us as confidential and will only use it anonymously.

Please contact our office if you would like contribute to the improvement of our training by sharing your experiences.

By Jochen Kortlaender, volunteer and parent trainer.

Volunteering opportunities



Trolley project

In our last newsletter, we featured an article about the difficulties that supermarket shopping with a disabled child can present – from a lack of suitable shopping trolleys, to unsympathetic staff. A couple of parents got in touch to offer their help, but we still need a few more volunteers to do some “mystery shopping” and give feedback to supermarkets. Please get in touch if you'd like to get involved!

Fundraising dads

Okay dads, we get it, coffee mornings are not your thing. But perhaps a meeting in the pub to do something useful wouldn't be so bad? One of our members, Chris, is looking for volunteers to set up a dad's fundraising group. Experience of writing funding bids, organising fundraisers, or running marathons for charity would of course be great, but enthusiasm is more important! To find out more, please leave your details with our office and Chris will get in touch.

Free training for school staff!

To introduce our “Working together with parents” training, we are offering a **FREE session for school staff.**

When: Tuesday 23rd April, 9.30am-12.30pm

Where: St Mary's Conference Centre, Bramall Lane

Suitable for: Anyone who works with children with special needs in an education setting, such as SENCOs, classroom teachers, TAs, lunchtime supervisors, office staff.

Learning outcomes:

- To be able to look beyond the label to identify the needs of the child
- To understand the parents' perspective on successful inclusion
- To gain an insight into the challenges a family with a child with special needs faces
- To be able to create effective working partnerships with parents

Places are limited to 16 participants and will be allocated on a first come, first served basis.

To book your place, please contact Anne on **0300 321 4721**, or email training@sheffieldparentcarerforum.org.uk

Support Service Consultation

Last autumn, the Sheffield Carers Centre ceased to provide an information, advice and advocacy service for parents of disabled children and young people, which it had been running for many years.

This was due to a city-wide reorganisation of carer support contracts, in addition to non-council grant funding coming to an end.

The Carers Centre is now only funded to support carers of **adults**. Both the Carers Centre and the Parent Carer Forum voiced concerns about this development.

Since October 2012, Sheffield City Council has been providing an interim service through a dedicated worker and telephone line (**0114 261 8765**). This service currently sits with the Parent Partnership Service, an “arm’s length” council service which normally only helps with education-related issues. The interim service can provide information, advice and support for parents of disabled children in relation to health services, social care, and welfare benefits.

As part of an evidence-gathering exercise, the council has asked the Sheffield Parent Carer Forum to find out what sort of information, advice and support parent carers need the most - and whether they are currently getting it. Do they need legal advice? Help with benefit applications? Sorting out problems with direct payments? What support is already being provided? And if there are gaps, what is the best way to fill them?

Please help us answer these and other questions by completing our questionnaire at www.surveymonkey.com/s/ParentsAsCarers. If you haven't got internet access, you can call us on 0300 321 4721 to request a hardcopy.

We know that questionnaires only tell us half the story. To dig a little deeper, we've also arranged a series of consultation meetings:

22 April, 7-9pm, at the Quaker Meeting House

24 April, 12-2pm, at the Quaker Meeting House (lunch provided)

26 April, 10am-12pm, at St Mary's Community Centre

Please let us know if you'd like to come along, by calling **0300 321 4721**, or emailing enquiries@sheffieldparentcarerforum.org.uk.

Each participant will receive a £15 shopping voucher as a thank you (limited to one voucher per family, 10 participants per meeting).

Please take part in our survey to ensure that parent carers receive the support they need!



Sheffield moves towards banded funding system

Sheffield pupils with high levels of additional needs have been allocated to funding bands. This is part of national changes to the school funding system, which will be implemented from April this year. Under the new system, mainstream schools will have to fund special educational provision (e.g. teaching assistant support, resources) up to a threshold of £6,000 per year per pupil, from their delegated school budgets. Above this level, local authorities will be expected to provide top-up funding for individual pupils, via locally determined funding bands. (£6,000 per year equates to around 10 hours of Teaching Assistant support per week.)

Last autumn, mainstream schools in Sheffield were asked to identify pupils for whom they were providing support costing more than £6,000 per year, and match them to funding bands using descriptors of need. Returns were moderated by a panel to ensure consistency across the city.

This audit of mainstream pupils has now been completed, and a total of 539 pupils have been allocated top-up funding (see box). Parents of these pupils will only be notified if their child's provision changes as a result of funding decisions. To find out if your child has been allocated top-up funding, please contact their school.

Banding decisions can be appealed by submitting new or revised information to the SEN panel after April. If your child has a statement of SEN which specifies the amount and type of support they should get, this provision can only be changed through an annual review, NOT as a result of a funding decision.

Children about to enter the special school system and those whose needs have changed can be put forward for top-up funding to the SEN panel from April onwards. The funding reforms will also affect special schools and Integrated Resources (IRs), who will receive £10,000 per planned place, plus any additional top-up funding allocated to their pupils via the banded funding approach.

In the first instance, special and IR school pupils in Sheffield have only been banded nominally, in order to minimise school budget fluctuations. Over time, these pupils will also be banded individually at transition points (starting with pupils currently in Year 6).

The post-16 and Early Years sectors will also be moving towards a banded funding system. No decision has yet been taken regarding pupils currently attending independent specialist provision.

Breakdown of top-up funding allocated to mainstream pupils for 2013/14

Funding band A	(£2,000 top-up funding/year)	179 in primary schools, 86 in secondary schools
Funding band B	(£4,000 top-up funding/year)	149 in primary schools, 52 in secondary schools
Funding band C	(£6,000 top-up funding/year)	58 in primary schools, 11 in secondary schools
Funding band D	(£9,000 top-up funding/year)	3 in primary schools, 0 in secondary schools
Funding band I	(individual package)	1 in primary school, 1 in secondary school

Post 16 Education Under Review

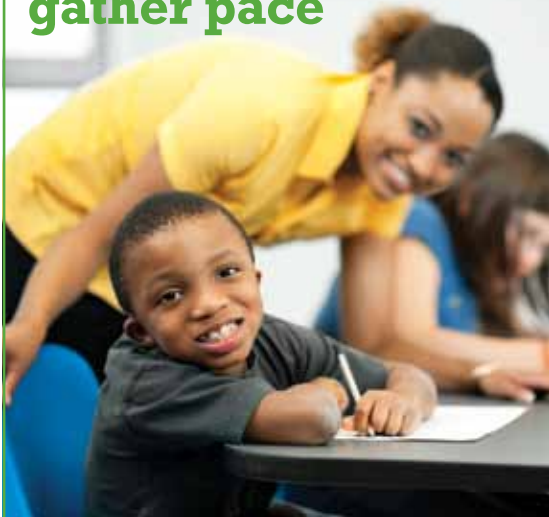
Sheffield City Council is reviewing the way students with learning difficulties and disabilities access specialist post-16 provision.

At the moment, how many days per week a student with moderate/severe learning difficulties will spend in post-16 education is largely determined by the type of setting they attended for their pre-16 education. Students who stay on at Talbot, Seven Hills or Bents Green (the only special schools with sixth forms in Sheffield) currently receive five days of education per week.

By contrast, students with learning difficulties who transfer to a foundation learning programme at a general further education provider (e.g. the Practical Skills courses run by Sheffield College), usually find that their provision drops down to three days per week. This inequity is due to the way how funding was distributed in the past. The funding system, however, will change in April this year, when local authorities will be put in charge of allocating post-16 funding to providers via a banding system (see previous article).

Sheffield City Council wants to use this opportunity to make the system fairer for all students. This may mean moving towards a four-day week in post-16 specialist education, with – possibly – some employment-related or leisure activity on the fifth day. To achieve this, the Council plans to develop the capacity of a wider range of providers, including the voluntary and community sector.

SEN Reforms gather pace



In early February, the Government published the Children and Families Bill, which lays the foundations for major reforms to the special educational needs (SEN) system in England.

Exactly what the new legislation will mean in practice is unclear. This is because Parliament may still make changes to the Bill, and because much of the detail will be included in the statutory regulations and the revised SEN Code of Practice, which will be published later this year.

So it's probably not helpful to go into too much detail at this stage. Instead, we've summarised what we think are the pros and cons of two key elements of the Bill: the introduction of Education, Health and Care plans, and the Local Offer.

Education, Health and Care (EHC) Plans

EHC plans will replace statements of SEN. They will be similar to statements, but will widen the scope beyond education, to include health and social care provision. EHC plans will extend the protections currently offered by statements up the age range, to include young people in further education and apprenticeships up to the age of 25. This should lead to a smoother transition to post-16 education and training, and improve the support provided at college.

While the concept of EHC plans has been broadly welcomed, many organisations have expressed concerns that the reforms don't go far enough. The key issue is that EHC plans will, in essence, still be education plans. They will only be available to those with special educational needs; children with disabilities but without SEN will not be eligible.

And there's another, closely related, issue: despite assurances that EHC plans will consider the "whole child", the Bill doesn't place any new legal duties on the NHS and local authorities to deliver the health and social care parts of the plan. Parents will only be able to challenge the special educational element of the plan by appeal to the SEND Tribunal – for the rest, they'll have to seek redress somewhere else. (NB health care or social care provision which is made "wholly or mainly" for educational reasons, is to be treated as educational provision for the purpose of the plan.)

As with statements, there will be no nationally prescribed eligibility criteria for EHC plans. It will be up to local authorities to decide where they set the bar - and if EHC plans turn out to be more costly than statements, that bar is likely to move higher.

Transitional arrangements between the current and the new system have yet to be worked out. One idea being considered is that existing statements would be converted to EHC plans at key transition points, probably without a reassessment of the child's needs.

The Local Offer

Local authorities will have to publish a local offer, detailing the support they expect to be available to children and young people with SEN in their area. The local offer will cover a wide range of provision, including education, health, social care, transport, training, transition to adulthood, and help with independent living. This should make it easier for families to find the services they need.

The local offer could also improve local accountability, as local authorities will have to publish comments they receive on their local offer, and their response.

So far, so good. But can the local offer deliver what the Government sees as one of its key functions – to ensure that the needs of children with SEN but without EHC plans are met?

There are three threats to this ambition:

- 1) the Bill's failure to place a legal duty on local authorities to actually provide what is in the local offer – it won't be enforceable;
- 2) the Government's decision not to include national minimum standards of provision in local offers;
- and 3) the austerity measures which are forcing local authorities to cut back on non-statutory services.

Please note that these reforms are subject to change, and will not be implemented until September 2014 at the earliest. **Until then, the current SEN system remains in force.**

Services Under Pressure

With the NHS having to save £20bn by 2015, and Sheffield City Council facing £50m of cuts in 2013/14 on top of cuts made in the last two years, our public services are feeling the pain.

Whilst disabled children's services in Sheffield appear to have got off comparatively lightly, several are groaning under vastly increased caseloads. We examine developments in three local services: Speech and Language Therapy, the Autism Service, and CAMHS (Child and Adolescent Mental Health Service).

Speech and Language Therapy

Across the UK, the number of school pupils with speech, language and communication needs has risen by around 70% in the past six years. This trend has been attributed to a number of factors – such as improved survival rates of very premature babies, the recent “baby boom”, earlier identification, and even increased television viewing.

Whatever is causing this increase, we're certainly not immune to it in Sheffield. Referrals to our local Speech and Language Therapy Service have shot up by 23% since 2010, putting huge pressure on an already under resourced team. The average caseload of a school therapist in Sheffield now stands at 450 children.

Sheffield's lead commissioner for children's health services has been meeting with Parent Carer Forum representatives and is using their feedback to improve services. We are very pleased that paediatric speech and language therapy has now been identified

as one of NHS Sheffield's commissioning priorities for the next financial year, with plans to sustain current funding and prioritise additional investment. But before we break open the champagne, here's a sobering thought: it is likely that any additional funding will be swallowed up by the increase in new referrals, and is unlikely to improve the therapist-to-child ratio overall.

Autism Service

The Autism Service, which supports pupils with autism and related disorders in mainstream schools, has also seen a sharp increase in new referrals – averaging 25 per month over the past year. Since 2010, the team's overall caseload has increased by almost 250 pupils, reaching a total of 1,047 in January 2013. As with speech and language needs, the increasing prevalence of autism reflects a national trend.

However, unlike the Speech and Language Therapy Service, the Autism Service is not expecting a funding increase. Staffing levels are likely to remain at eight full-time equivalent posts (four teachers and seven teaching assistants), one of which is currently vacant but will be recruited to.

In response to the increased workload, the team has decided to refocus its efforts on specific groups of children, whilst building capacity in schools through a more systematic staff approach to training. This will be complemented by outreach services provided by special schools and integrated resources (IRs) to mainstream schools.

Moving forward, the Autism Service will continue to provide targeted support for children at stages of transition (e.g. pre-

school/Reception, Y6/Y7) and for those who are particularly vulnerable or at crisis point (e.g. at risk of permanent exclusion). Children with autism and related disorders who fall outside these year groups and categories will no longer be supported as a matter of course.

The Autism Service will continue to collaborate with the Ryegate Children's Centre, and will be notified when a child receives an autism diagnosis (subject to parental consent). However, children will no longer be automatically referred to the service following diagnosis. Referrals can be made by schools and parents, and will be accepted if the child meets the criteria for vulnerability described above.

CAMHS (Child and Adolescent Mental Health Service)

Last year, cuts to the community CAMHS budget caused waiting times to soar, with some young patients waiting up to 44 months to be seen. Local Asperger's charity ACCT, with support from the Parent Carer Forum, successfully highlighted this issue with councillors and commissioners.

Additional one-off funding was used to offer brief interventions and face-to-face triage to those already on the waiting list. According

to NHS commissioners, this had the desired effect of reducing waiting times. All community CAMHS teams are now aiming to hit the 18-week referral-to-treatment target by April 2013.

The new waiting list figures, however, do not include those youngsters whose referrals were “bounced” from CAMHS to MAST (Multi-Agency Support Team) – something that appears to be happening with increasing frequency, and not always appropriately. Inappropriate referrals cause frustrating delays for families, who then have to be re-referred to CAMHS. NHS commissioners are working to address this issue by developing clearer referral pathways and guidance for GPs.

Feedback from parents also highlighted the lack of appropriate mental health services for older teenagers, who currently have to be discharged from CAMHS when they turn 16. We are delighted that a proposal to commission community CAMHS up to the age of 18 is being considered as a priority for the next financial year. Commissioners are working with providers of mental health services to try and reach an agreement on this. Subject to approval, the extended service would start operating during the second half of this year.

Tell us your views!

Do you think service managers and commissioners are responding to budget pressures in the right way? How will your child be affected? Please get in touch and tell us what you think.

Call us on **0300 321 4721**, send an email to enquiries@sheffieldparentcarerforum.org.uk, or talk to us at one of our meetings (see page 21-22). We will feed your views back to decision-makers.

Grants for families with disabled children

Did you know that it is three times more expensive to raise a child with severe disabilities than a child without a disability?

Here are some charities and trusts that can help you meet some of those extra costs:



Family Fund

Helps: low-income families raising a disabled or seriously ill child aged 17 or under. Eligibility is based on entitlement to certain benefits and tax credits, e.g. Income Support, Housing Benefit, Working Tax Credit.

Funds: items that make life easier such as household appliances, equipment, driving lessons or computers. Also awards holiday vouchers for Butlins, Haven or Thomas Cook.

Info: www.familyfund.org.uk
08449 744 099

Caudwell Children

Helps: children aged 18 or under who have a disability or chronic illness. Household income must not exceed £45,000 per year (excluding benefits).

Funds: mobility and sensory equipment, treatment/surgery which is not available in the UK, therapies for children with Cerebral



Action for Kids

Helps: disabled children and young people aged 25 or under with physical or learning disabilities. Applicants must provide financial details to show that they are unable to buy the equipment from their own resources.

Funds: mobility aids and other equipment that facilitates independence and is not available on the NHS, such as custom built-wheelchairs and trikes, therapeutic equipment and communication aids. Items are provided on a permanent loan scheme, which enables the trust to help with maintenance and repair.

Info: www.actionforkids.org
020 8347 8111



Palsy, brain injuries or autism, group holidays for children fighting life-threatening illnesses and their families, and specialist disability sports equipment.

Info: www.caudwellchildren.com
0845 300 1348



Cerebra

Helps: children aged 16 or under who have a neurodevelopmental condition, e.g. brain injury, autism, ADHD, cerebral palsy, Down Syndrome, Epilepsy, learning disabilities. Household income must not exceed £60,000 per year (excluding benefits).

Funds: up to 80% of the cost of equipment and services that will improve the quality of the child's life, e.g. buggies, wheelchairs, touchscreen computers, trampolines, weighted blankets, etc. Will fund therapies such as speech and language therapy or music therapy up to a maximum cost of £500 (conditions apply).

If your child gets middle or higher rate Disability Living Allowance, you can also apply for a £350 voucher towards making a will and setting up a discretionary trust for your disabled child - really important, as otherwise any money left to your child would be taken into account for means-tested benefits and social care services when they become an adult!

Info: www.cerebra.org.uk
01267 244200



Happy Days Charity

Helps: children and young people aged 3 to 17 years with disabilities or special needs. Household income must not exceed £25,000 per year (not including DLA and Carers Allowance).

Funds: short respite breaks (2-4 nights) for families in the UK. Financial details and a supporting letter from a suitable professional are required. Will also fund activity holidays, day trips and theatre trips for groups (e.g. support groups, special schools).

Info: www.happydayscharity.org
01582 755999

This is just a small selection of charities and trusts that provide grants for families with disabled children. To search for more grants, have a look at these websites:

www.disability-grants.org is run by a family carer and lists a large number of disability grants.

www.turn2us.org.uk is a charitable service which helps people access welfare benefits, charitable grants and other financial help. You can search their online database, or call their freephone helpline on 0808 802 2000.

Need help completing application forms? The Sheffield Parents as Carers Advice Service can support you. Call them on 0114 261 8765, or email parentsascarers@sheffield.gov.uk

Sheffield's disability information service SIGN (telephone 0114 266 9476, email sign@sheffinfoink.org.uk) has a list of funding sources for families with disabled children, including where to apply for help with equipment, mobility aids and holidays.

Dyspraxia Foundation Support Group

In 2009 I decided to write a book with the aim of supporting individuals with dyspraxia and sharing my personal experiences of the condition. Dyspraxia is generally recognised to be an impairment or immaturity of the organisation of movement. Associated with this may be problems of language, perception and thought.

On my "to-do list" for the following few years I kept writing "to set up a voluntary support group." I wondered if I would achieve it, but decided to take a deep breath and thought, "what's the worst that could happen?" I haven't looked back; the group has been going for over a year now.

Even though I have to juggle quite a lot with working full time as well, I constantly think as long as I am doing my best I will keep going. The group meets once a month at The Circle in the centre of town and originally there were two meetings, one for children and parents, and one for adults. I think it ended up understandably tricky for parents and children to attend in the evening so the group naturally formed into a young persons and adult group. I would never turn anyone away if they were a parent or child as I hope to provide support to anyone who needs it, and to point people in the right direction for help if I can't provide a solution.

The group has had several speakers talking about topics such as self-esteem and work support. Incorporating fun activities such as bowling also builds confidence within the group and helps towards social interaction.

I would like to set up a forum to help people



who may not be able to attend the meetings to make contact with others. This may be an on-going project as I have a wedding to plan this year, but it will be still be in my plans.

I think with more understanding about dyspraxia and other hidden impairments, individuals can be allowed to flourish; everyone in the group has something to offer.

If you would like any further information about the meetings please email sarah.sheffielddyspraxia@hotmail.co.uk.

You can also obtain information from the Dyspraxia Foundation website (www.dyspraxiafoundation.org.uk) under "About us" – "Local groups" – "Sheffield"

By Sarah Johns, local volunteer co-ordinator for the Sheffield and South Yorkshire area

New support group for Specific Language Impairment (SLI)

Children with SLI have difficulty with talking and understanding language, without having an associated condition like autism, cerebral palsy, hearing impairment, or general developmental delay.

One of our members, Genna White, who is herself mum to a boy with SLI, would like to set up a support group for children with SLI and their families.

This would be run as a "play and stay" group, where children with SLI could play together while their parents get a chance to meet with families in a similar situation, share their knowledge, and make new friends.

Genna has already identified possible venues and researched funding for the group.

If you have a child with SLI and would like to get involved, please call Genna on **07967 135505**, email gennabayston@hotmail.com, or like her Facebook page: www.facebook.com/SliSpecificLanguageImpairmentSupport

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Paces Sheffield

"For me, as a mother, I know that Paces is the right placement and exactly what our son needs. He has shown improvement and will continue to have the opportunity to develop all his skills as any other child does."
Parent

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e. info@pacesheffield.org.uk

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FAMILY SUPPORT

Parent & Child, Nursery
Primary, Secondary, Apprenticeship
Leaving the world behind programme

To find out more give us a call and we will be happy to arrange your visit.

Roll on the credits!



Going to the cinema is something that has always brought me great pleasure, and is something that I wanted to introduce my children to, hoping that they might find as much enjoyment in it as I do and that it would be a happy shared experience.

Taking my oldest child to the cinema was wonderful. He really enjoyed it and quickly got the hang of expected behaviour at the cinema - no talking, sit still and, latterly, no mobile phones! We graduated from 'animated animals' type films through action films to challenging and thought provoking films. However my younger child has autism and learning difficulties and her lack of social and verbal understanding and unusual and disruptive behaviours meant that I couldn't take her to ordinary cinema screenings.

Luckily for us a few years ago the Showroom Cinema started an autism and disability friendly cinema screening once a month, called KIC Start-Kids Inclusive Cinema. The film would be shown without adverts, with lighting levels higher than usual and sound levels lower than usual, and as the rest of the audience would be families with children with autism and disabilities you would be in the company of people who understood and were used to the unique behaviours of our children.

In the early days I had to have a bag of food and sweet treats to bribe my child to stay in her seat, and if that didn't work I sat her on my lap to prevent her wandering off. Even these measures sometimes failed, and then I crawled round the cinema after her, trying to coax her back to her seat. But gradually she sat for longer periods, and more recently has even started to appear interested in the film itself. The February screening was Mulan, and it was exceptional in that she managed with just one ice cream and no other sweets, and watched the screen for most of the time.

But the very best bit for my child is dancing at the front of the cinema to the end credits as they roll. She even seems to know when they will start, so maybe she does understand what is going on in the film after all.

So why not come along and try something new with your children?

Details of the Showroom KIC Start screenings are on their website www.showroomworkstation.org.uk/showroom/inclusivecinema. Their KIC Start films are currently on the first Sunday of each month at 1pm up to and including March 2013. However, as a result of customer consultation the Showroom management have decided to change this to the third Sunday of the month, starting from 21 April 2013, to avoid a clash with the Cineworld showings, see below. Thank you to the Showroom cinema for being so helpful - now we can go to the cinema twice a month.

Cineworld at Centertainment Sheffield has recently started autism friendly screenings, on the first Sunday of the month, starting at 11am. Again details are on their website www.cineworld.co.uk/whatson?cinema=54 (then select 'Autism Friendly' from the 'Screening Type' menu). The Cineworld screenings are in a bigger cinema than the Showroom and feel more like ordinary cinema, so might be a useful stepping stone between the Showroom KIC Start and ordinary film screenings.

Maybe we might see some of you at these screenings in the future? We will be the ones dancing at the front to the end credits of the film.

Joanne Ferguson, SPCF Trustee and volunteer.

Living without a diagnosis



Jack, my third child, was born almost a month early. Looking back, I think the midwives saw something that was not quite right, but nothing was said at the time. Jack was an easy, happy baby and fed well. He didn't seem to need sleep much, but I only really started to worry at 12 weeks when he still wasn't holding his head up. Jack was referred to Ryegate for assessment, but the doctors found nothing conclusive, and he was kept under observation for the next two years. Meanwhile Jack continued to miss all his developmental milestones, eventually sitting when he was one year old and crawling at two.

When he was two and a half Jack had his first epileptic seizure. Typical of others that would follow, it was very subtle (no shaking) but severe. Jack spent a number of days in intensive care and temporarily lost the use of the left side of his body. This episode gave

new impetus to finding a diagnosis and Jack had blood tests, a lumbar puncture, CT and MRI scans. All came back negative. Later that year Jack was referred to Great Ormond Street which resulted in more tests, but still no diagnosis.

It took a year to get Jack's seizures under control. He continued to develop slowly and started to walk by his third birthday, but his lack of speech was more obvious by then. By this time I was desperate for a diagnosis because I wanted to know how to plan for his future. I spent hours researching rare conditions on the computer, Jack had more genetic tests and we visited a specialist in Manchester, but he remained undiagnosed.

When Jack started school we asked to have him assessed for autism.

Continued on next page...

Dates for your diary

I thought that having a label rather than no label would be helpful and it probably has been. But ASD did not adequately describe Jack. It allowed people to overlook his physical difficulties and made him more vulnerable to accidents.

Caring for Jack was challenging and rewarding, but having no diagnosis made it harder and more isolating.

I stopped working when Jack's epilepsy started. No diagnosis meant no support group. I avoided going out and meeting new people as I found it difficult to explain Jack; I could hardly launch into a detailed account of his medical history with someone I had only just met. I am sure some people thought that we just hadn't bothered to find out what was wrong with him.

Jack's lack of diagnosis caused many problems. For example, when his physiotherapist was on long term sick leave Jack was not offered a replacement because nobody knew how to prioritise his case. I was told by another health professional that other children were "more deserving" than Jack. Filling in forms and getting access to services and benefits was more difficult.

Jack is nine now. He is a beautiful, happy and loving child. He still has all his difficulties but we are learning to cope with them. Last year Jack was given a clinical diagnosis of Angelman Syndrome, a rare neuro-genetic disorder. However, we are still waiting for confirmation of this diagnosis from more detailed genetics tests. I am plucking up courage to appeal Jack's DLA decision and slowly getting used to saying "my son is an Angel".

Having an undiagnosed condition is actually quite common. It is thought that about 50% of children with learning disabilities and approximately 60% of children with multiple congenital problems do not have a definitive diagnosis. Living without a diagnosis can be very isolating; families often feel that they don't 'fit in', find it difficult to answer questions about their child and don't know what the future holds.

I found support and friendship through my involvement with the Sheffield Parent Carer Forum, but there is a national charity called SWAN UK (Syndromes Without A Name) which offers support and information to families of children with undiagnosed genetic conditions. Their contact details are: website www.undiagnosed.org.uk, email SWAN@geneticalliance.org.uk, telephone **020 7704 3141**.



April

Monday 22nd April, 7-9pm,
Quaker Meeting House, 10 St James St.

Wednesday 24th April, 12-2pm,
Quaker Meeting House (lunch provided)

Friday 26th April, 10am-12pm,
St Mary's, Bramall Lane

Consultation Workshops

Sheffield City Council have asked us to find out what an information, advice and support service for parents of disabled children should look like (see page 8). Please come along to one of our workshops and tell us what kind of support would really make a difference for you. Each participant will receive a £15 shopping voucher as a thank you (limited to one voucher per family, 10 participants per workshop). **Booking essential!**

May

Friday 10th May, 10am-12pm,
St Mary's, Bramall Lane

Education Subgroup Meeting

Please come along to our Education subgroup to talk to other parents about special educational needs (SEN), swap useful information, and help us influence education policy in Sheffield. This is a friendly and informal group, and new members are very welcome!

Friday 17th May, 10am-12pm,
St Mary's, Bramall Lane

Quarterly Open Meeting

Our quarterly open meetings are an opportunity for parents to meet our trustees, paid workers and parent representatives, and get an update on the work they've been involved in.

June

Thursday 6th June, 10am-12pm,
St Mary's, Bramall Lane

Workshop: Sex and Relationship Education

We've asked local charity Parent to Parent to run a workshop about sex and relationship education for us, because we know this can be a difficult topic for parents of children and young people with special needs. This workshop will look at what can help families understand this subject, with practical group work and a wide range of resources and information to look at.

Friday 7th June, 10am-12pm,
St Mary's, Bramall Lane

Health Subgroup Meeting

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

Wednesday 26th June, 12.15-2.15pm,
Voluntary Action Sheffield,
33 Rockingham Lane

Workshop: Combining Paid Work and Caring

We've invited Janet Mearns, from national charity Working Families (www.workingfamilies.org.uk), to talk to us about combining paid work and caring for a disabled child. Janet will be able to answer questions about topics like flexible working, taking parental leave, etc. As Janet is based in London, we were unable to arrange an evening session – but we hope that some working parents will be able to drop in during their lunch break.

Free lunch provided. Booking essential!

Dates for your diary cont.

June continued

Friday 28th June, 10am-12pm,
St Mary's, Bramall Lane

SEN Transport Meeting

This is an opportunity for parents to meet with officers from the SEN Transport Service and help shape home-school transport in Sheffield.

July

Friday 5th July, 10am-12pm,
St Mary's, Bramall Lane

Education Subgroup Meeting

Please come along to our Education subgroup to talk to other parents about special educational needs (SEN), swap useful information, and help us influence education policy in Sheffield. This is a friendly and informal group, and new members are very welcome!

Advertisements

THE ANAT BANIEL METHOD

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or email billwindle@hotmail.com
www.anatbanielmethod.com



We have rooms which offer a range of sensory experiences that benefit a variety of different people including those with learning and physical disabilities, those on the autistic spectrum and those with behaviours that challenge. They can also help with the development of babies and young children and supplement traditional learning methods.

We also offer an outreach service for disabled people and inclusive theme-based activity/social events.

For more information or an informal chat call Debbie, Jane or Leanne on the following numbers or check out our website.

Like us on Facebook and follow us on Twitter

Inspire Sensory and Outreach Services CIC, Paces Campus, Packhorse Lane, High Green, Sheffield, S35 3HY

• 0114 2844530 • 07449 321737 • 07449 301336
• 07450 884209 • www.isoscic.co.uk
• info@inspiresensoryandoutreachservicescic.co.uk

Sheffield Parent Carer Forum Application for Full Membership

Full membership is FREE and open to all parents and carers of disabled children and young people (0 - 19) 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
 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

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

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

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