



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 2013 Issue 8 FREE!



Top tips for PIP

Get ready for the transfer from DLA to PIP when your child reaches 16

Activities for teens

We've compiled a list of specialist clubs for disabled teenagers

Moving up

A parent's account of moving to mainstream secondary school

All change?

The SEN system is changing - but what will it 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.



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to discuss your requirements.

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Welcome to our Autumn Newsletter!



We have been lucky with the sun this summer, and we certainly felt the benefit of good weather for our Family Fun Day at Hillsborough Sports Arena at the end of August. Almost 250 members enjoyed the different activities available - from African drumming to Zorb balls, helped by volunteers from Sheffield Wednesday's National Citizen Service programme. It was very much a collaborative event (thank you to PACES for the last-minute loan of the chairs!), and collaboration has been a thread running through many of our activities this year. Read about our "Knowing Your Rights" conference on page 5, which we held at St. Mary's in June, co-hosted with Mencap, the Sharing Caring Project, Irwin Mitchell Solicitors and Carers in Sheffield. There was a lot of keen interest in the changes to benefits.

The gradual replacement of DLA by PIP will impact on many families and you can find more information inside. You will also find more information about the bedroom tax, written by Douglas Johnson from the Sheffield Law Centre.

We welcome our new sponsors of the newsletter, Irwin Mitchell Solicitors, and if you have any burning legal issues for future newsletters, let us know – also look out for the free legal advice sessions we will be holding regularly at St. Mary's.

All these partnerships ensure we keep working as effectively as possible for our parent carers. With all the new changes afoot in education, health and social care, it is as important as ever that we continue to work with service providers in the local authority, as well as establish new links within the health service. We must ensure our children are at the forefront of everyone's minds and service planning.

We always love to hear from you - members asked for more positive stories about our children, and if you are willing to contribute a story, anecdote or first-hand experience, do get in touch!

Best wishes

Jayne Woodward, Co-chair



On 29 August 2013, members of the Sheffield Parent Carer Forum enjoyed a fun-packed day out at Hillsborough Sports Arena.

The event had been organised by the Forum in partnership with Sheffield Wednesday's National Citizen Service programme.

Prior to the event, parents from the Forum had provided training and advice to the young NCS volunteers, to help them plan activities for children with a wide range of impairments.

Zorb balls proved a big hit with youngsters, as did bouncy castles, African drumming and dance workshops, adapted cycles, and a whole host of sports and craft activities.

Children also enjoyed visits from a real-life fire engine, a mobile library and even Sheffield Wednesday mascot Ozzie Owl!



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!

‘Knowing your Rights’ event

On 13 June 2013, over 120 parents of disabled children and adults attended a conference at St Mary’s to learn about their rights as family carers.

The event, which had been organised by the Sheffield Parent Carer Forum, Mencap, Sharing Caring Project and Carers in Sheffield with generous funding and support from Irwin Mitchell, was a great example of successful partnership working.

Delegates attended presentations on benefits changes and how to challenge decisions, then split up into three workshops which focused on the transition from DLA to PIP, the adult social care assessment process, and educational provision for children with special needs.



Missed the event?

You can download all the presentations and handouts from www.irwinmitchell.com/activities/knowning-your-rights

Or have a look at our “Quick Guide to PIP” on page 18, which includes most of the tips from the workshop.

You’ll also have another chance to attend the Mencap workshop ‘Top tips for the adult social care assessment process’ this autumn (see next article).



Transition support from Mencap

Transition Support Group

The Sharing Caring Project at Mencap (part of Carers in Sheffield) has set up a new support group for parents/carers of young people with learning disabilities aged 16-21 who are going through the transition process from children's to adult services.

The group will meet at the Sheffield Carers Centre on Bells Court (off Trippet Lane) on the second Thursday of each month, between 10am and 12pm.

Transition Clinics

These clinics are aimed at parents of young people with learning disabilities/autism who are approaching transition (aged 16+). There will be two sessions this autumn: a daytime one on **4th October, 10am-1pm**, and an evening one on **10th October, 6.30pm-9pm**. Both sessions will take place at Sheffield Mencap & Gateway, Norfolk Lodge, Park Grange Road.

Workshop: Top tips for the adult social care assessment process

This practical session is suitable for family carers of people with a learning disability aged 16+. Topics covered will include the adult assessment process and self-directed support process, top tips and advice on what families



can do to prepare, and your rights as family carers.

Date and Venue: **26th September, 10.30am-12.30pm**, at Sheffield Mencap & Gateway, Norfolk Lodge, Park Grange Road.

For more information or to book a place, please contact the Sharing Caring Project on **0114 275 8879**.

Email scpoffice@sheffieldmencap.org.uk

Concerns over SNIPS waiting lists

Over the past few months, several parents have contacted us to express concerns about long waits of up to six months to access the Special Needs Inclusion Playcare Service (SNIPS).

SNIPS provides training, mentoring support and grants to help mainstream providers include children and young people with additional needs.

We contacted SNIPS manager Amanda Hill, who confirmed that waiting times had gone up due to staff depletion. However, the service has now recruited five new mentors and expects waiting times to disappear shortly. Families who feel they are in urgent need should contact SNIPS on **0114 273 4017** or email **CYPDsnips@sheffield.gov.uk**.

Have you got comments about SNIPS you want to feed back? Then come to our meeting with Amanda Hill on 27 September, 10am-12pm, at St Mary's (see page 21).

Rowan School to be rebuilt and enlarged

Sheffield City Council has secured funding from the Department for Education to rebuild and enlarge the Rowan Specialist School in Totley, to enable it to cope with increasing demand. The Rowan School caters for primary aged children with complex speech, language and communication difficulties, including autism.



Visual resources for health appointments

The Sheffield Speech and Language Therapy Service is currently looking at ways of making hospital visits and other health appointments easier for children with communication difficulties.

Therapists met with members from our Health subgroup to get their views on a range of visual resources, such as picture and symbol supports explaining what to expect during appointments, customisable schedules, and “tell me where it hurts” picture boards.

To request visual supports for your child's forthcoming health appointment, please contact your child's speech and language therapist directly. The therapist will be able to adapt the resources to suit your child's needs.

A single 'front door' for short breaks

Short breaks are services offered to families to give them a break from caring for a disabled child.

This can include holiday play schemes, Saturday clubs, overnight respite, direct payments, befriending services and more.

From September 2013, all referrals and requests for short break services will be processed through Prevention and Assessment Teams (PAT), which will act as a single point of contact for all services to children. The Prevention and Assessment Teams are the joining up of two existing services – MAST (Multi-Agency Support Team) and Children's Social Care.

The Special Needs Inclusion Playcare Service (SNIPS) will be aligned to the three PAT Teams, which are organised into three service areas across the city: North, East and West. SNIPS will continue to provide training, mentoring support and grants to help mainstream childcare providers include children and young people with additional needs, but will also become much more involved in developing local community provision.

The overarching aim of the new service is to ensure that the right children receive the right support at the right time and are included.

As part of a new referral process, a new form called a "Family CAF" (CAF = Common Assessment Framework) has been developed. This form looks at the needs of the whole family, not just the needs of the disabled child.

It replaces the old-style CAF. A Family CAF can be completed by any professional who knows the family, such as a teacher, GP, youth worker or MAST worker. Once a Family CAF has been received, the PAT team will decide how the family should be supported; this could be by SNIPs or by a social worker.

Contact your local PAT

North

Sorby House, 42 Spital Hill,
Sheffield S4 7LG

Tel: 0114 233 1189 or 0114 203 9591

East

Shortbrook Primary Site, 1st Floor,
Westfield Northway, Sheffield S20 8FB

Tel: 0114 205 3635 or 0114 203 7463

West

Old Sharrow Junior School,
South View Road, Sheffield S7 1DB

Tel: 0114 250 6865 or 0114 273 4491



Support for parent carers

Earlier this year, Sheffield City Council had asked us to help them find out whether current support services for parents of disabled children were meeting local needs. We gathered parents' views through a combination of questionnaires (139 responses) and consultation workshops (21 participants), and found some interesting results:

- 43% of questionnaire respondents answered “Yes” to the question “Have you ever sought information, advice or support in relation to caring for your disabled child, but couldn’t find a service that offered what you were looking for?”
- There was a clear message from the workshops that parents would like to receive practical support to access and coordinate services. Parents felt that this would best be provided via a key worker system.
- The main areas parents wanted help with were: benefit applications, renewals and appeals; child health services; support at school or college for their disabled child; leisure services for their disabled child; and support with managing their child’s behaviour.
- Parents confirmed that they would like to receive all their information, advice and support from a single source, but delivered in a variety of ways (e.g. telephone helpline, support at meetings, home visits etc.).
- Many parents faced additional barriers, such as having a disability or long-term illness themselves, having more than one disabled child, or also caring for an adult.

Workshop participants also raised issues in relation to specific services (e.g. SNIPS, Direct Payments, childcare, respite) and made suggestions for improvement. Whilst some of this feedback extended beyond the remit of the consultation, it is nevertheless very important. At the time of going to press we are working with officers to identify how this feedback can be shared with senior Council officers.

A full consultation report can be downloaded from our website, and a response from the Council will also be published there later this year.

Please visit www.sheffieldparentcarerforum.org.uk/page/consultations, or call us on **0300 321 4721** to request a hardcopy.

New autism helpline

The Sheffield Autism Team has set up a new telephone support line for parents, carers and professionals. The helpline will be staffed Monday to Thursday from 1pm to 4pm (term time only), and the number to call is **0114 235 8056**.

Please note: the Autism Team can only support children and young people with autism and related disorders who attend **mainstream** nurseries, schools and colleges in Sheffield.

Uncertainty over SEN reforms



It's been hailed as the **“biggest overhaul of the special educational needs (SEN) system in 30 years”** - but with less than a year to go until full implementation, families are still unsure what the reforms will mean in practice.

Given the complexity of the SEN system, this is perhaps unsurprising – after all, who's got time to read through pages and pages of draft legislation? And even if you did, that would still only give you the high-level architecture of the reforms. Much of the detail will reside within the new SEN Code of Practice; but a rough first draft of the Code, published in March, fails to provide clarity on many key points. This may be because the Department for Education is waiting to incorporate learning from the pathfinder authorities who are currently testing out the reforms. There is also a possibility that some crucial details (such as eligibility criteria, or the format of EHC plans,

see below) could be left to local authorities to determine.

“Crucial details could be left to local authorities to determine”

So, what do we know? The Children and Families Bill, which is currently before Parliament, tells us that statements of SEN will be scrapped and replaced with Education Health and Care (EHC) plans, which are intended to be more holistic and person-centred, and can go up to 25 years. Families with an EHC plan will also have the option of receiving a personal budget to purchase support for their child. Local authorities will have to publish a “local offer” detailing the range of services available for children with SEN and their families. And School Action and School Action Plus will be replaced with a single category called “Additional SEN Support”.

Overall, the Children and Families Bill is a mixed bag – it extends some statutory duties (eg. to academies) but reduces others, and frequently falls short of the “root and branch” reform that's really needed to address the failings of the current system. To give you an example: the government has introduced a very welcome new duty on Health to make the health provision set out in the EHC plan.

However, there is still no equivalent duty on Social Care, and no single point of appeal – which means that parents would have to use

three different appeals procedures for the health, education and social care elements of the plan. Several national charities are campaigning vigorously for these shortcomings to be addressed.

Legislation, however, is only a part of the equation. Children's Minister Edward Timpson has said that he wants to see a culture change across all services, which puts children and families at the heart of the process. The current buzzword is "parental co-production" – that is, parents being involved in strategic decision making as equal partners from the start. It is what parent carer forums across the country have been trying to do for years, with varying degrees of success, but with unwavering enthusiasm.

Here in Sheffield, parents have yet to be involved in the implementation of the reforms. We know that a local EHC plan template has been developed, and that there will be a consultation with parents later this year – but that's not really "co-production", is it? Work on Sheffield's local offer has yet to start, but we are hopeful that we'll really get cracking on it this autumn – with parents driving the process.

And let's not forget the elephant in the room: cost. Compiling and maintaining a local offer is a huge task. EHC plans will probably be more time-consuming to write and maintain than statements. If Personal Budgets take off, economies of scale could be lost. Where will all this extra money come from? Some of the pathfinder authorities have indicated that a tightening of eligibility criteria may be on the cards. We'll be watching closely!



Save the date

We're planning an information day for parents about the SEN reforms, and have pencilled in the 14th of March 2014. To be confirmed shortly!

Free legal advice sessions

We have teamed up with local law firm Irwin Mitchell Solicitors to offer free 30-minute advice sessions to parent carers in Sheffield.

Solicitors will be able to give advice on a wide range of personal law matters, including wills, power of attorney, setting up trusts, special educational needs (SEN) provision, appeals against benefits decisions, and more.

Sessions will be held at St Mary's Community Centre on Bramall Lane on the following dates:

Wednesday 2nd October, 10am-12pm

Monday 4th November, 12pm-2pm

Friday 13th December, 10am-12pm

Booking is essential; please contact our office on **0300 321 4721** or email **enquiries@sheffieldparentcarerforum.org.uk** to book a slot.

Bedroom tax and disabled children

The bedroom tax affects low-income families - whether in work or not - in Council or Housing Association properties. It reduces housing benefit awards for tenants who are deemed to have one or more 'spare' bedrooms in their homes.

For example, a couple with two teenage daughters aged 13 and 15 living in a 3-bedroom house will have their housing benefit reduced by 14% because the girls are expected to share a bedroom. For a family deemed to under-occupy by two or more bedrooms, the cut would be 25%.

In Sheffield, about 7,000 households are affected. The policy discriminates against disabled people, who may need extra space because of adapted accommodation, storage for medical or disability equipment or because disabled children may need separate bedrooms.

A policy that discriminates against disabled people may well be unlawful. Previous court cases found that equivalent regulations did discriminate against disabled people. In the Gorry case, the Court of Appeal judged that some children with severe disabilities - in this case a child with Spina Bifida and another with Down's Syndrome - could not be expected to share a bedroom.

More recently, though, a court ruled that the new rules did not discriminate against disabled people. The case is now likely to go to the Court of Appeal so the law is still not clear.

If your disabled child needs to have their own bedroom because their severe disability means they cannot share with a sibling, make sure you tell the housing benefit office. New government guidance says that local councils must allow an extra bedroom in such a case. Letters or reports from doctors, consultants or therapists will help to back this up. If the council refuses, there is a right to appeal to an independent tribunal.

In addition, families with a disabled child could apply to the council for a discretionary housing payment (DHP). As its name suggests, this is paid at the discretion of the council but can help to top up housing benefit.

Written by Douglas Johnson

Equality Rights Worker at Sheffield Law Centre
(visit www.slc.org.uk or call **0114 273 1501**)

More information

Sheffield City Council
www.sheffield.gov.uk/benefits or
call **0114 273 6777**

Disability Rights UK
www.disabilityrightsuk.org/bedroom-tax

Contact a Family has template letters for challenging bedroom tax decisions
www.cafamily.org.uk/news-and-media/need-help-challenging-bedroom-tax-decisions or call **0808 808 3555**

Sheffield Green Party factsheet
www.sheffieldgreenparty.org.uk/2013/04/05/bedroom-tax-leaflet/



Introducing our brand new column!



Mhairi Walker, Solicitor

Starting with this issue, solicitors from local law firm Irwin Mitchell will answer legal questions posed by our readers.

Do you have a question you'd like to ask Irwin Mitchell? Then please get in touch by 31 January 2014, and with a bit of luck, your question might be featured in our next issue.

Question: "My son has a learning disability but can appear more capable than he actually is. I am worried that the PIP assessment will underestimate my son's difficulties, as he tends to underplay his condition. There is also a risk that he might refuse to engage in the assessment interview, or miss important deadlines. What advice can you give?"

Answer: "Attending a face-to-face assessment can be a daunting prospect, particularly for vulnerable individuals and their

parents, but here is some advice to help you through it.

You can accompany your child to the face-to-face assessment, as can another family member, a friend or an advocate. You are allowed to play an active role in helping your child to answer questions, and you should do so especially where they are unable to give an accurate and truthful account of their disability and how it affects them. If your child is unable to communicate verbally, you should answer questions on their behalf.

You should give as much detail as possible to the assessor about your child's disability, and you should not understate it. You should try to give examples of how your child's disability impacts on their everyday life, and if you keep an "examples diary", give a copy of it to the assessor as well as any other additional evidence you have.

If your child isn't able to travel for an assessment due to a medical condition, you can request a home visit. This may, however, require a recommendation and supporting evidence from a GP or another healthcare professional. The recommendation should clearly state why your child would be unable to travel. Similarly, if you consider that attending at a face-to-face assessment would be highly distressing for your child, you could request a home visit. The guidance is less clear on this point, but it is likely that strong supporting evidence would be required.

If you feel that the assessment your child underwent was not fair or was not conducted properly, you should seek the advice of a solicitor."

Answer provided by Mhairi Walker, Solicitor
(Public Law Department)

Activities For Teens

Several parents who responded to our last members' survey said that they would like more information about things to do for disabled teenagers. We've compiled a list of specialist clubs and activities - please let us know if you are aware of any others!

Sheffield Futures Youth Clubs

Sheffield Futures run four clubs for young people with disabilities aged 13-25 years, which provide opportunities to get involved in lots of different activities. Trained staff can provide support and advice about a wide range of issues including school, jobs, careers, family and relationships, and signpost to specialist services. The clubs also organise school holiday activities and residential.

Where and when:

Herdings Central: Wednesdays 7pm-9pm at Herdings Youth Centre, Morland Road

Hi 5s: Thursdays 6.30pm-9pm at Com.unity, Westfield Centre

Leo's Club: Mondays 6.30pm-9pm, at Centre in the Park, Guildford Avenue

S Club 5: Tuesdays 6pm-8.30pm, at Earl Marshall Youth Centre, Heathcote Street

Cost/access:

£1 per session, admission managed by club

Contact:

Cheryl Ridge **07736 708051**

cheryl.ridge@sheffieldfutures.org.uk

ACCT - Teenage Youth Club

ACCT (Asperger's Children and Carers Together) run a fortnightly club for teenagers with Asperger's Syndrome and high-functioning autism. Activities include arts and crafts, football, a computer suite, pool table, outdoor activities, a chill-out area and trips out. The aim is for the teenagers to have fun, chill out and make new friends. There are lots of workers on hand to offer support if needed. ACCT also run school holiday clubs.

Where and when:

Alternate Wednesdays 7pm-9pm, at St Mary's Church, Bramall Lane

Cost/access:

Free, admission managed by club

Contact:

07527 824034

enquiries@acctsheffield.org.uk

Sheffield Mencap – Gateway Clubs

Sheffield Mencap run year-round weekly social clubs for young people with learning disabilities. Activities include snooker, a disco, art and crafts, baking and plenty of chatting in the coffee bar. There is also a performing arts group called 'Shine Out' (currently operates a waiting list). Support is provided by a small staff team and volunteers (no 1:1 support provided, but people are welcome to bring their own).

Where and when:

Fridays 6.30pm-8.30pm for 8-15 year olds;
Tuesdays 7pm-9pm for 16-25 year olds;

Shine Out (for 8-16 year olds) fortnightly on Saturdays 10am-12.30pm. All clubs run at Norfolk Lodge, Park Grange Road.

Cost and access:

£2 per session plus £5 annual membership fee, admission managed by club

Contact:

Elaine or Gareth **0114 2767757**
developmentmanager@sheffieldmencap.org.uk

Burton Street Foundation – REACT Youth

The Burton Street Foundation run a Saturday club for a mixed-age group of young people with a wide range of disabilities and additional support needs. Activities offered include sport and exercise, arts and crafts, cookery, music workshops, discos and much more.

Where and when:

Saturdays (34 weeks/year), at the Burton Street Foundation, 57 Burton Street

Cost and access:

Free, via SNIPS referral only
(tel. **0114 273 4017** or you can email **cypdsnips@sheffield.gov.uk**)

Contact:

Julie Melville **0114 233 2908**
julie.melville@burtonstreet.org.uk

The Burton Street Foundation also run a holiday scheme for young people aged 13-19 years who have a learning disability, physical disability or behavioural problems. Access to this service is via SNIPS.

Sheffield Hallam University Clubs

Interact is a monthly club for young people aged 11-15 years with Asperger's Syndrome. Each session includes a variety of games, role play and fun activities.

Where and when:

Monday 6pm-8pm, at the HUBS, Paternoster Row. Next meetings: 2nd December, 27th January, 24 February, 24th March

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The Jigsaw Project is a befriending support scheme which matches Hallam University students with children and young people aged 5-18 years who have Autism or Asperger's Syndrome.

Where and when:

The student will visit the child/young person in their home at a time convenient for both the family and student, usually 1 hour a week during term time.

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The HUB is a monthly social club run by trained student volunteers for young people with autism. Sessions include quizzes, board games, craft activities, outings.

Where and when:

First Tuesday of each month from December, 6pm-8pm, at the HUBS, Paternoster Row

Cost and access:

Free, access is via an application form

Contact for all Hallam clubs:

Nicky Taylor **0114 225 5005**
n.taylor@shu.ac.uk

Sheffield University Computer Club

Computer Club is for children on the autistic spectrum aged 8-15 years. Parents will need to stay in the building but are provided with refreshments in a separate room. There is a ratio of one volunteer to every child.

Where and when:

Saturdays in term time, 9.45am-10.45am (8-11 year olds), 11am-12pm (11-15 year olds) at the Students' Union on Western Bank.

Cost and access:

Free

Contact:

Helen Giorgi **0114 222 8547**
helen.giorgi@sheffield.ac.uk

Specialist Sports Clubs

Sheffield has a large number of specialist sports clubs which cater for a wide range of disabilities, age groups and interests - too many to list here!

For an up-to-date list of sports and leisure clubs:

- Visit the 'Within Reach website' (www.withinreach.org.uk) or contact Kimberley Ashmore on **0114 2734 266** email Kimberley.ashmore@sheffield.gov.uk
- Search the Ask Sid database (www.asksid.net), or ask the disability information service 'SIGN' (**0114 266 9476** or email sign@sheffinfolink.org.uk) to print off a list for you.

- Search the Sheffield Help Yourself database www.sheffieldhelpyourself.org.uk

Please note: The Sheffield Parent Carer Forum does not recommend, authorise or take responsibility for any of the organisations, services and activities mentioned in this article. Whilst every care has been taken to ensure that the information contained in this article is correct, we do not accept any responsibility for any error or omission. We strongly recommend that you contact the organiser before setting out to attend a session.



New Service for Brain Tumour Patients



National brain tumour support charity brainstrust has recently announced that it is piloting a new regionally focused service in Sheffield and South Yorkshire.

The focused regional service is the first of its kind for brain tumour patients. It is based on a unique coaching model, and is being run by Pete Burchill from Hillsborough. Pete, himself a parent carer, has been tasked with the role to grow the service because of his unique experience. Pete says, "To be told that your child has a brain tumour is one of the most distressing pieces of news that you can be told. The diagnosis and associated treatments can bring a huge range of difficult practical, emotional and financial challenges for the whole family and survivors are often left with a number of disabilities or special needs."

Helen Bulbeck, Director of Services at brainstrust says, "We know that brain tumour patients face many challenges that are unique to their condition. This is a really exciting time for brainstrust, but more so for the people in Sheffield and South Yorkshire, who will be

the first to benefit from our move to deliver a robust, dedicated regional support service that is based on 7 years of accumulated national insight into the needs of brain tumour patients and carers."

brainstrust's resources, all provided free of charge to patients and carers, include a 'brain box' toolkit for recently diagnosed children (this is also available for adult patients), a website which shares a wealth of accredited information, 'Meet Up' support groups, and 24/7 phone and email support.

The charity's ethos is centred on being "as useful as possible" to those that need their help. It develops bespoke, personalised programmes of support, which can range from brief interactions, answering simple questions, to dedicated long term coaching and counselling support for the families that need it.

The service that Pete and brainstrust are offering is accessible from the point of diagnosis to help parents and carers throughout their journey. To find out more, simply email pete@brainstrust.org.uk, call Pete on **07741 316277** or visit the website www.brainstrust.org.uk



The Snaggle Tooth Splat is a book produced by brainstrust, aimed at helping parents discuss a brain tumour diagnosis with children.

Personal Independence Payment

A new disability benefit called Personal Independence Payment (PIP) is being phased in to replace Disability Living Allowance (DLA) for people aged 16 to 64. DLA will continue as a separate benefit for disabled children under 16.

PIP has already been introduced for all new claims by adults over 16 years. From October 2013, the following groups of existing claimants will be moved off DLA, and will be invited to claim PIP instead:

- Young people who turn 16 after 6 October 2013
- Adults over 16 years whose fixed-term DLA award comes up for renewal, or who report a change in their condition

All other adults claiming DLA will be reassessed for PIP from October 2015 onwards.



How to claim

The Department for Work and Pensions (DWP) will write to your child as they approach 16 and invite them to claim PIP. Your child (or you as their appointee, see below) will need to telephone the DWP to start the claim within one month of receiving this letter. The DWP will then send you a paper questionnaire (online claims forms will be available from spring 2014), which must be completed within one month. Most people will then be asked to attend a face-to-face assessment.

Please note: There will be no automatic transfer from DLA to PIP - even people who have an indefinite or "lifetime" award of DLA will need to apply for the new benefit!

How does PIP compare to DLA?

PIP is similar to DLA in that it is not means-tested, not taxed and not treated as income in calculating other benefits. Like DLA, it has two parts or “components” - a “Mobility” component based on the person’s ability to get around, and a “Daily Living” component based on their ability to carry out everyday activities. People can qualify for either or both of these components. Each component can be paid at either the “standard rate” or the “enhanced rate”. The table below shows how PIP rates correspond to DLA rates:

| DLA Component | PIP Component | Weekly Rate |
|-----------------|-------------------------|-------------|
| Care (low) | - | £21 |
| Care (middle) | Daily Living (standard) | £53 |
| Care (high) | Daily Living (enhanced) | £79.15 |
| Mobility (low) | Mobility (standard) | £21 |
| Mobility (high) | Mobility (enhanced) | £55.25 |

Like DLA, PIP is an important “passport benefit”, which can help people qualify for other benefits. For example, you may be able to claim Carer’s Allowance if your child gets the Daily Living component of PIP at either rate, or access the Motability scheme if your child is eligible for the enhanced Mobility component of PIP. If your child is awarded PIP you may also qualify for an increase in your other benefits. It’s a good idea to get a benefits check done!

PIP differs from DLA in the way that eligibility is assessed, and the criteria used. While DLA assessments are fairly subjective, PIP aims to introduce a measure of “objectivity” by way of a points-based system. Entitlement to PIP depends on how your child’s disability

affects their ability to carry out 12 specific activities necessary for independent living, such as preparing food, washing and bathing, communicating verbally, engaging with people face to face, planning and following journeys, or moving around. Points are awarded for each activity, and the more difficult your child finds an activity, the more points they score. The scores for the different activities are then added together to determine whether your child qualifies for the Daily Living and/or Mobility component, and at what rate.

PIP is also very different from DLA in that most people will have to attend a face-to-face assessment undertaken by a health professional (in Sheffield this is done by ATOS).

“Important information if your child is approaching 16!”

Top tips for PIP*

- ✓ Apply for appointeeship if your son or daughter lacks the capacity to manage their own financial affairs. This will allow you to deal with all aspects of your child's benefits once they turn 16. Ask the DWP to send you an appointee application form to complete. You can do this when you phone them to start the PIP claim.
- ✓ Before you start filling in the PIP form, read through the 12 activities and decide which "descriptors" (qualifying criteria) apply to your child. Use the "Extra information" boxes to explain why. Give as much detail as possible!
- ✓ Include any written evidence you have, eg. letters from your child's consultant, GP, speech and language therapist, etc. Do NOT delay your claim to get extra evidence – you can send this in later, or take it along to the face-to-face assessment.
- ✓ Make sure that the professionals you list on the form know how your child's disability affects them on a day-to-day basis (as the DWP may contact them). If they don't know your child well, make an appointment and give them a copy of the completed PIP form
- ✓ Staple any additional pages to the form (so they don't get lost) and do NOT mark any additional evidence as "confidential" (otherwise it can't be passed on to the DWP).
- ✓ Keep a photocopy of your form and any supporting evidence you have submitted.
- ✓ Don't miss the deadlines! You have one month to telephone the DWP from the date of the notification letter, one month to complete and return the questionnaire, and one month to ask the DWP to reconsider your child's claim if you disagree with their decision.
- ✓ To prepare for the face-to-face assessment, write down what a "typical day" looks like for your child (you can also send this in with the questionnaire).
- ✓ Your child has a right to take a companion along to their assessment, and they can request a home visit. Please see page 13 for further advice regarding vulnerable claimants.
- ✓ After the assessment, ask the DWP for a copy of the assessment report as a reference point for future reviews/applications or to challenge future decisions.

Further advice

Disability Rights UK have published a guide to claiming PIP: www.disabilityrightsuk.org/personal-independence-payment-pip (or call **0207 250 3222** for a paper copy).

'Contact a Family' can do a benefits check over the phone; call **0808 808 3555** or visit www.cafamily.org.uk

The Sheffield Parents as Carers Advice Service can help you complete benefit forms. Call **0114 261 8765**, or email parentsascarers@sheffield.gov.uk

You can get free advice from a solicitor at our new legal drop-in sessions (see page 11 for dates and venues).

Dates for your Diary

September

20th September, 10am-12pm
St Mary's Community Centre, 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!

.....

27th September, 10am-12pm
St Mary's Community Centre, Bramall Lane

Meeting about SNIPS and Direct Payments

This meeting is for parents who are currently using SNIPS and/or Direct Payments and want to feed back their experiences, and those who are thinking of applying and want to find out more. The meeting will be attended by Council officer Amanda Hill, who manages the Direct Payments team and SNIPS.



October

2nd October, 10am-12pm
St Mary's Community Centre, Bramall Lane

Legal Advice Sessions

See page 11.

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16th October, 10am-2pm
St Mary's Community Centre, Bramall Lane

Parent Workshop: Statements, Annual Reviews and Appeals

Organised with fundraising from ACCT. SEN advocate Evelyn Ashford, founder of Educational Equality, will hold an empowering workshop for parents of children and young people with special educational needs (SEN). Evelyn will guide you through the "statementing system" - from statutory assessment to annual review, school placement to tribunal appeal. Questions and answers welcomed in an informal atmosphere. You are welcome to bring your child's statement for Evelyn to review.

.....

18th October, 10am-12pm
St Mary's Community Centre, Bramall Lane

Health Subgroup Meeting

Come and join our 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! At this meeting we will discuss visual supports for health appointments (page 7) and our campaign for "health passports".

Dates for your Diary continued...

November

4th November, 12pm-2pm
St Mary's Community Centre, Bramall Lane

Legal Advice Sessions

See page 11.

.....

8th November, 10am-12pm
St Mary's Community Centre, Bramall Lane

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.

.....

22nd November, 10am-12pm
St Mary's Community Centre, 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!

.....

29th November, 10am-12pm
St Mary's Community Centre, Bramall Lane

SEN Transport Meeting

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

December

4th December, 10am-12pm
St Mary's Community Centre, Bramall Lane

Parent Workshop - Using pictures to support your child's communication

Led by therapists from the Sheffield Speech and Language Therapy Service, this workshop will be a sharing of ideas for supporting your child's communication, play and independence skills through visually supported daily routines and activities. There will be two separate sessions running at the same time - one for parents of nursery/primary aged children, and one for parents of secondary aged children.

.....

13th December, 10am-12pm
St Mary's Community Centre, Bramall Lane

Legal Advice Sessions

See page 11.

Let us know

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

For more event information, please visit our website:

www.sheffieldparentcarerforum.org.uk/calendar

Holidays with Disabled Children



Holidays! A word guaranteed to provoke either an “oh no!” or “oh yes!” reaction from many a parent. If you are in the “oh no!” camp, please read on.

As a family with a severely autistic, non verbal, older child, going on holiday had always been a challenge. How exactly do you get stains out of a holiday home carpet? Answer - after 1 hour of cleaning, simply move the furniture over it! (sorry, Centre Parks). Some incidents we can now look back on and see the funny side of, but the stress of managing our child in the various holiday homes just added to the overall pressure of our holidays.

After a particularly stressful holiday we made a decision not to holiday all together again. My husband and I took turns to take our other children away, whilst the other one stayed at home with our disabled child.

This continued for a few years, until a chance conversation with a friend led to us staying at a ‘disabled-friendly’ holiday home in Cornwall. One with wipe clean surfaces (no carpet!) and a walled, secure garden. You can’t under estimate the pleasure of being able to sit, (relax) and have a cup of tea, safe in the knowledge your little Houdini won’t be able to scale the garden walls. There were other little things, like the plugs had safety covers and the house was devoid of ornaments and knick knacks, so we didn’t have to waste time

putting them all out of reach and then putting them back again. Sometimes it’s these little things that can make a difference to your stress levels and overall enjoyment to your holiday. It may not work for everyone, but we found staying in a disabled-friendly holiday home worked for us.

So, where can you find disabled-friendly holiday homes? Here are some resources you might find useful:

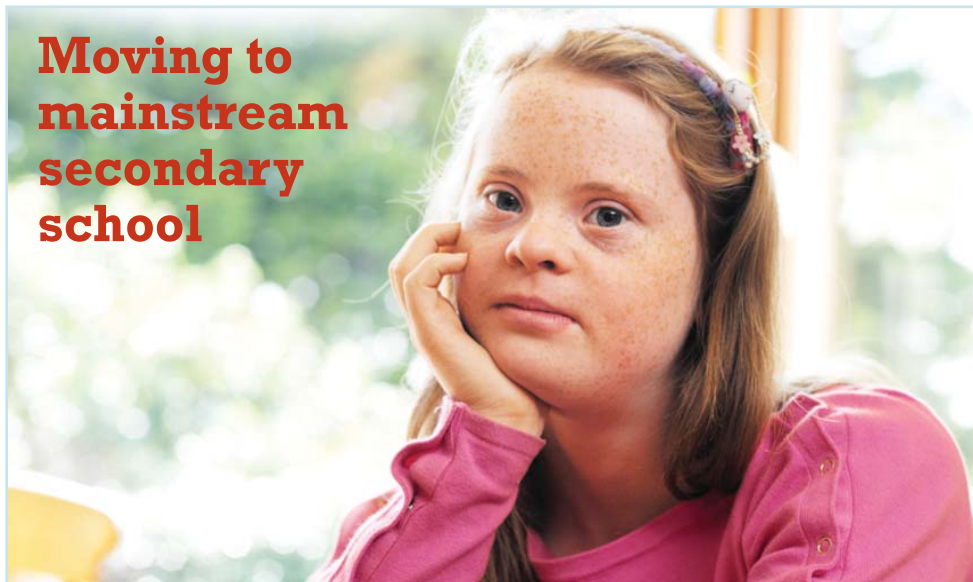
Disabled Holiday Directory are a specialist travel agency, call **0800 993 0796** or visit **www.disabledholidaydirectory.co.uk**

Tourism for All is a national charity dedicated to making tourism welcoming to all. Visit **www.tourismforall.org.uk** or call **0845 124 9971**. They also run a website - Open Britain (**www.openbritain.net**), which has information about accessible holidays in the UK.

The Rough Guide to Accessible Britain – Family Days Out is a directory of family-friendly attractions, all visited and reviewed by disabled people and their families, visit **www.accessibleguide.co.uk/familydaysout**

Online tips-sharing forum **Netbuddy** has lots of holiday-related information for parents and carers of people with a learning disability **www.netbuddy.org.uk/info-packs/holidays/**

Moving to mainstream secondary school



The decision to continue in mainstream or choose a special school is a difficult one for many of us with a child who has a disability as they move up into secondary school education.

There are clearly individual reasons why it may be better to choose special school or mainstream, in addition to external factors such as availability of places. There are no perfect answers but our job as parents is to find the best fit and understand how to make it work. For our daughter Louise, who has Down Syndrome, we would have looked for an Integrated Resource (IR) place within a mainstream setting to bridge that gap, but since there are no secondary IRs for students with learning difficulties in Sheffield, we went down the mainstream path.

These are a few thoughts from our experience of going down the mainstream route.

Preparing for transition

With the junior school staff we tried to think what the main challenges might be. Louise had several visits in the summer term to explore the new campus with a map and camera, meet staff and take photos of the place and people. With hindsight she could have done with more practice on the stairs (the one-way rule was confusing - "if you go up on the right and down on the right, why don't you crash?"), more practice with the school bell (there were two bells 5 minutes apart, instead of one – what did that mean?) and as for the toilet seats, they were black, not white (disaster... I hadn't thought about that one!). The book of photos was great for preparing at home at the beginning of September, and the school did another one for Y8, which was really helpful.

Numbers of staff

It is a big ask for any child to go from a single form tutor in Y6 to one for every subject in Y7. Add on to that the team of teaching assistants (TAs) who may be supporting your child, and we found there were 20+ adults involved. 20 people who needed to get to know Louise and her quirky behaviour, not to mention 20 people for her to understand with *their* quirky behaviour! In our first term, this was a bit overwhelming, and so the school decreased the TAs involved and decreased some of the subjects. This made it easier for Louise, and easier to share solutions across the team.

Changing classrooms every lesson

The difficulty of moving between lessons was, and still is, an issue. There are probably several layers to why Louise finds this hard. Ending an activity, packing up and moving on always takes her more time than most people have got, even if she is given plenty of warning. Moving out of a room into a loud and busy corridor is scary. Not having a clear idea of what she is moving on to is enough reason to stay put. The staff worked with me to find solutions. Firstly, they used a traffic light system to prepare for the bell going off, but that wasn't very successful. Secondly, they allowed Louise to leave the class early to avoid the rush. This did help, but like a lot of tricky areas, it was not solved once and for all. After a period of time, it went pear shaped again. This time, a sticker was given for each good 'leaving class' episode, leading to a

piece of chocolate at the end of the school day. This was the answer!

What I draw from this comes back to attitude; a willingness to try and try again, an openness to look at ideas from outside (we got advice from the Down Syndrome Association at one point), huge patience and perseverance. I also have to remind myself that my daughter's challenging behaviour doesn't stem from a desire to be naughty or unpopular; on the contrary, she loves to get it right and be praised. It just is incredibly hard for her to get it right, and so, much encouragement is needed.

Behaviour strategies

If behaviour has been an issue in junior school, it may improve with maturity, but probably not during the demands of the first term in Y7. Key staff need to understand strategies and solutions that have worked before and that are appropriate for the developmental stage your child is at. The head of the learning support team has been very approachable, and has enabled us to meet and discuss these issues. A willingness to use social stories and reward charts, which are not usually used in secondary school, has been helpful. Flexibility is key. For example, the reward system in place for all Y7s is stickers leading to an end-of-term reward. This was not immediate enough, but thanks to a TA who noticed her behaviour improve when lunch was next, it was realised that food was a good motivator. Several areas have improved with a daily reward chart and the promise of one square of chocolate at home time.

Sanctions

In the same way that motivators and rewards need to be maturity appropriate, so do sanctions. This needs discussion with the school, but a punishment two days after the event is meaningless compared with an immediate response, and needs to be time limited, eg. ten minutes. Bottom line is that sanctions generally don't work very well anyway, and positive feedback is so much more powerful.

Communication

Meeting with the learning support staff separately has been really helpful. My daughter may be the cause of many challenging situations, but she hates being in trouble and being talked about just as much as we all do. Early on in Y7, a chat over her head at the end of a school day led to her tugging on my sleeve and whispering, "Tell her I've got Down syndrome!" in a rather exasperated voice! So, a willingness to discuss some issues in a separate meeting has been much appreciated. The use of a home-school book is helpful, as long as key staff use it.

So what would I look for in any educational setting? Staff who are prepared to talk and try new ideas, who are prepared to be flexible if one way is not working, and who are willing to persevere. A sense of humour is essential and the patience to count to thirty (minimum!) before wading in.

It probably doesn't matter much what setting these staff are in but when you find them, be grateful!



Useful Contacts

| | | |
|---|--|--|
| ADHD Project Provides information, support & training for families with a child with ADHD. | 0114 321 1705 0114 321 1702 | sheffield@family-action.org.uk |
| Autism Service* Supports mainstream schools to meet the needs of pupils with autism & related conditions. | 0114 235 8056 (Helpline) | moira.bolan@sheffield.gov.uk |
| Child & Adolescent Mental Health Service (CAMHS) Specialist mental health service for children & young people & their families. | 0114 226 2348 | |
| Children with Disabilities Team* Social work team for children & young people with disabilities. | 0114 273 5368 | |
| Contact-a-Family National charity which provides information & advice on any aspect of caring for a disabled child, including education & benefits. | 0808 808 3555 | helpline@cafamily.org.uk |
| Direct Payments Team* Provides support, advice & guidance relating to direct payments. | 0114 273 5985 | amanda.hill@sheffield.gov.uk |
| Early Years Inclusion Service* Works with young children (0-4) with additional needs both in their homes & in settings. | 0114 239 8336 | elizabeth.hodkin@sheffield.gov.uk cathy.wigg@sheffield.gov.uk |
| Educational Psychology Service* Works with families & staff in educational settings to support the education & development of children & young people. | 0114 250 6800 | mary.collins@sheffield.gov.uk |
| Hearing Impaired Service* For children who are hearing impaired. | 0114 239 8336 | caroline.chettleburgh@sheffield.gov.uk |
| IPSEA National charity providing free legally-based advice on SEN/education. | 0800 018 4016 | Email information service via www.ipsea.org.uk |
| Parents as Carers Advice Service* Provides advice and support relating to benefits, social care and health services. | 0114 261 8765 | parentsascarers@sheffield.gov.uk |
| PAT (Prevention & Assessment Teams)* Single point of contact for all services to children. Processes all referrals/requests for short break services. | n: 0114 233 1189 e: 0114 205 3635 w: 0114 250 6865 | northmast@sheffield.gov.uk eastmast@sheffield.gov.uk westmast@sheffield.gov.uk |
| Portage Home Visiting Service* Home-visiting educational service for children under three with additional support needs and their families. | 0114 239 8336 | debbie.marshall@sheffield.gov.uk |

| | | |
|--|---------------|--|
| Ready Steady Go Groups* Free "stay and play" sessions for young children (0-5) with additional needs. | 07837 188995 | linda.wright@sheffield.gov.uk |
| Ryegate Children's Centre Assessment, diagnosis & therapy for children & young people with developmental & neurological problems. | 0114 271 7637 | |
| SEN Assessment & Placement Team* Deals with statutory assessments, statements of SEN, annual reviews, transport & specialist placements. | 0114 273 6394 | ed-sensupportteam@sheffield.gov.uk |
| Sheffield Children's Hospital | 0114 271 7000 | sheffield.childrenshospital@sch.nhs.uk |
| Sheffield Information Giving Network (SIGN) Specialist information service for families raising children with significant health needs, SEN or disabilities. | 0114 266 9476 | sign@sheffinfoolink.org.uk |
| Sheffield Parent Partnership Service* Provides impartial education-related information, advice & support for parents of children with SEN. | 0114 261 9191 | ed-parent.partnership@sheffield.gov.uk |
| Sibling Support Group Support group for children who have a brother or sister with a disability. Also runs drop-in advice sessions for parents. | 0114 233 2908 | philip.hazelhurst@burtonstreet.org.uk |
| Special Needs Inclusion Playcare Service* (SNIPS) Provides training, grants & mentoring support to help clubs include disabled children aged 5-18. | 0114 273 4017 | cypdsnips@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 |
| Targeted Mental Health in Schools (TaMHS) Provides training to school staff to improve children's emotional wellbeing & mental health. | 0114 321 1722 | sheffieldtamhs@family-action.org.uk |
| Transport Services* Provides transport services including home-to-school transport for pupils with SEN. | 0114 203 7570 | transportservices@sheffield.gov.uk |
| Visually Impaired Service* Supports children with a visual impairment and their families. | 0114 239 8336 | marion.broadhurst@sheffield.gov.uk |



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I have worked as a homeopath for 13 years, including running clinics for SureStart and working with children with autism and other disabilities.

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Email: info@sensorybound.co.uk

Tear along here

Sheffield Parent Carer Forum

Application for Full Membership

Membership is FREE and is open to all parents and carers of children and young people with disabilities and/or special educational needs who live in Sheffield or access services in Sheffield (FULL members), and the professionals/practitioners who work with them (ASSOCIATE members).

About you

☐ I am a parent carer ☐ I am a professional/practitioner

First name Surname

Job title (associate members only)

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 ☐ email ☐ post ☐ text

☐ 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.

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Positive Change for our Children and Young People
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