

Newsletter

Sheffield Parent Carer Forum | September 2010 | Issue 2



Family Fun Day, 11th July 2010

A warm welcome to the second edition of our newsletter!

The summer holidays now seem like a distant memory as the onslaught of the school year begins again in earnest, with all the trials and tribulations that can bring.

One of the highlights for me this year has certainly been the Family Fun Day we held on 11th July at Norfolk Heritage Park. The sun shone brightly and it was just a glorious day to get together with our families in a lovely setting and relaxing atmosphere (see pages 8/9).

I know it can sometimes be a real struggle to relax when you are out – it is not just whether the activities and facilities will be appropriate, it is also the either overly-sympathetic or condemning stares and tuts to contend with. “Going out” tends to resemble more of a military exercise: the organisation and supply chain; can we get in and out without being detected; with minimal casualties and collateral damage; and *will we be able to go again?* Seeing so many children and families in such an accepting and

relaxing environment filled my heart with joy and pride. Let’s do it again (but this time without the food queues!!).

In respect of the business end of the Forum, we are now busy preparing for our next Parent Carer Conference on the 11th of October (see page 2), which this time will have a focus on Education. We are also looking at producing roadshows and information evenings, so look out for details about these coming out soon.

At present, our highest priority is to ensure the survival of our organisation beyond April next year, which is when our current funding (most of which comes from the Aiming High for Disabled Children parent participation grant and Sheffield City Council) runs out. So far, neither central nor local government have made a commitment to continue funding parent forums. We are only just beginning to find our feet as an organisation, and it would be such a waste to let us flounder for lack of resources at this crucial stage! We’ll be lobbying hard for the money we need to continue our work.

Of course for the Forum to mean

anything, we need as many parents and carers to be involved as possible. This can be from being a member and receiving newsletters and updates; to sitting on parent-only groups; to meeting with officers and professionals and having your say; to helping out regularly with admin and envelope stuffing - there does seem to be an endless list of jobs, and any help at all is gratefully received! We also want to hear from professionals.

The nature of being a parent or carer of a disabled child means that the time and energy you may have available is limited indeed, so do not feel you have to make a big commitment to make a difference. We are all in this together and to borrow that well-known phrase – “Every little helps”.

I hope you enjoy the newsletter and find the articles interesting. If you would like to submit an article for future editions, want to get involved in any way, or have any suggestions at all, please contact us - details on the back page. We look forward to hearing from you and meeting you at our forthcoming events.

Best wishes

Jayne Woodward (Co-chair)

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We've become incorporated!

It's official - the Sheffield Parent Carer Forum is now a fully-fledged organisation in its own right!

Our registration as a company limited by guarantee was approved by Companies House on the 17th of April 2010, and we held our first Annual General Meeting (AGM) a few days later. At the AGM we dropped the "Interim" from our name, approved our constitution, elected a 13-strong management committee, and presented an annual report and accounts. Minutes can be downloaded from the "Resources" section of our website.

We are planning to convert to a Charitable Incorporated Organisation (CIO) structure once this becomes available (hopefully next year).



Forum to hold 3rd Parent Carer Conference

Date: 11th October 2010

Time: 10am to 2.30pm, lunch included

Venue: St. Mary's Church & Conference Centre, Bramall Lane, Sheffield

It's that time of the year again! Here at the Sheffield Parent Carer Forum, we are busy planning our 3rd Parent Carer Conference, and we hope that many parents/carers of children and young people with disabilities and/or special educational needs will be able to attend.

This time, we've decided to focus on the topic of **Education**. We know from parents' feedback that whilst there are pockets of excellence, many disabled children are not having a good experience in Sheffield's schools, particularly in mainstream. We are working with the Council to change this, and we need your views to be able to represent as many parents as possible. Please come along and have your say!

The conference will include:

- Opportunities to meet other parents
- A consultation on a proposed new strategy for meeting pupils' additional needs in Sheffield (the "Inclusive Learning Strategy", see page 6). Parents will be able to attend a presentation about the

strategy, ask questions, and complete a consultation questionnaire.

- Group work on education-related topics
- A wide range of information stalls, e.g. on post-16 education, short breaks/respite, childcare, local parent support groups, and more

The conference is FREE of charge and lunch and refreshments are included!

Meet other parents and have a chat - newcomers are welcome! Just look out for the parents' badges and we will meet you on arrival. We are sorry that we will not be able to offer a crèche facility this time.

To book your place, please complete the enclosed booking form and return it to our freepost address, to arrive no later than Tuesday 5th October.

If the form is missing, you can also register via our website (www.sheffieldparentcarerforum.org.uk) or by calling us on 0114 2521913 (but please use the online or paper forms if at all possible!).

Forum membership reaches 270

Membership of Sheffield Parent Carer Forum now stands at 240 full and 31 associate members, with a good spread across Sheffield's postcodes.

Our members' children have a wide range of impairments, with Autism, BESD (Behavioural Social or Emotional Disorders), physical disability, moderate learning difficulty, and Down Syndrome being the most common.

Green paper on SEN pupils

The new government has announced it will publish a green paper on children with special educational needs (SEN) and disabilities in the autumn.

At a reception hosted by Every Disabled Child Matters (EDCM) on the 6th of July 2010, Children and Families minister Sarah Teather said that she wanted to work with the voluntary sector and parents to form the questions that the green paper would cover.

She said that the paper would cover parental choice regarding where children go to school and "end the

bias towards mainstream schools but ensure it is up to parents to determine the best education for their child".

The green paper will also look at the issues around transitions into adulthood and "the bureaucratic mess that is assessment".

Sarah Teather's announcement followed EDCM's plea to the government to state what every disabled child and their families could expect from the government in national policy and commit to ensure disabled children and their families are involved in all strategic planning.



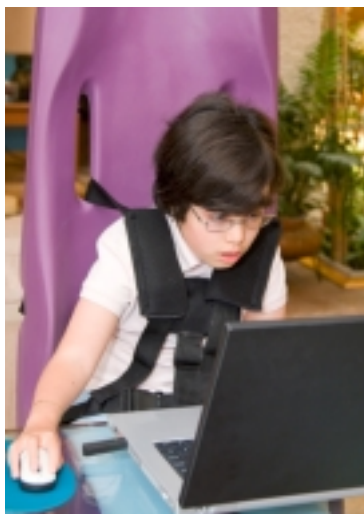
New right of SEND appeal for parents

Up until now, parents who were unhappy with the outcome of an Annual Review of their child's Statement were only able to appeal to the Special Educational Needs and Disability (SEND) Tribunal if the local authority decided either to amend the Statement or to cease to maintain it. There was no right of appeal when an authority decided to leave the Statement as it was.

From 1st September 2010, parents will have a new right of appeal to the SEND Tribunal if a local authority decides not to make any changes to their child's Statement following an Annual Review.

This will affect those Statements whose deadlines for Review fall after September 1st (bearing in mind that the date of an Annual Review is the date when the authority make their decision, NOT the date of the Annual Review Meeting).

Free computers with assistive technology



The Government's Home Access Team is offering FREE COMPUTERS WITH ASSISTIVE TECHNOLOGY to school-age children with severe disabilities or special educational needs who come from a low-income family.

Home Access packages with Assistive Technology are limited and will be awarded on a first-come, first-served basis.

For more information, please visit www.dotcommunity.org.uk and click on the link "Home Access", or call the Home Access Grant Administration Service on 0333 200 1004.

Support Group News

ACCT becomes short breaks provider

Asperger's Children and Carers Together (ACCT), a local support group founded by parents in 2006, is pleased to announce they have been successful in receiving funding from the Local Authority under the Aiming High for Disabled Children short breaks funding and will be providing high quality "breaks" for children with Asperger's Syndrome.

ACCT is a registered charity supporting approximately 160 families in Sheffield. ACCT supports the needs of the whole family by providing an office with information and resources, children's club, teenagers' youth club and groups, weekly parent/carer drop-in sessions and monthly parents' meetings. This new funding will pay for staff, including a Service Manager,



Tristan Chan, and play workers, to support the children. Some of ACCT's activities will move to Autism Plus at the Coleridge Centre to provide more facilities for families, children and young people.

Deborah Woodhouse, Co-founder and Director said, "We are absolutely delighted to receive this funding. ACCT is a much-needed and popular group and many families, young people and children rely on our support. We will now be in a position to provide fortnightly sessions for teenagers and children including a youth club and trips and outings for children over the age of 8. We will also continue to provide a children's club for all children from 0-12+. ACCT is expanding the places provided so we are advertising our service and hope families with children 0-19 approach us for more information" (see below for contact details).

To become a member of ACCT or to access any of our services, telephone Claire Wood, ACCT's Administrator on 0114 252 1911, or email acctsheffield@hotmail.co.uk

LDD Strategy update

The LDD Strategy is now called the "Sheffield Strategy for Children and Young Persons with a Disability".

On the 22nd of June the 0-19+ Partnership Board held a workshop that focussed on disability. There was good attendance from across the board including parents/carers, the voluntary sector, NHS Sheffield and the Local Authority. There were presentations from some parents/carers, who praised the democratic process by which the strategy had been developed, but expressed concerns about the need for the strategy to lead to real change on the ground. By way of illustration, some parents shared their personal stories and concerns. Soul and Fame, a young people's action group who works across the city also gave a presentation. The draft strategy was presented and discussed as part of the workshop.

Following the discussions that took

place at the workshop, the strategy has continued to be developed taking account of the points raised. The commitment to reflect the input concerns of all stakeholders has remained central to this. It is intended to undertake additional wider, qualified consultation from the 31st of August until the 1st of October (details of where to send comments below, but please also see the coversheet). The revised draft is also being presented to the relevant Senior Leadership Teams across the Council allowing for comment and is scheduled to return to the 0-19+ Board at the next business meeting on 28th October for sign-off. Once approval has been given, it is envisaged that it will be scheduled into a full council meeting prior to moving to implementation stages.

This process will continue to be overseen by the LDD Strategic Partnership Group of which Sheffield Parent Carer Forum are members. If

you require any further information, please contact Mark Alexander, Team Manager Strategy Delivery, on 0114 239 8336 or e-mail mark.alexander@sheffield.gov.uk

The strategy will be available on the NHS Sheffield website, Sheffield Parent Carer Forum website, Schoolpoint, Sheffield City Council website, Family Information Link website and the 0-19 Partnership Board website. Some hardcopies will be available from SIGN at Ryegate, in Ryegate waiting areas and in Sheffield Information Link's Leopold Street office. Comments should be sent to:

E-mail: cypd_ldd_strategy@sheffield.gov.uk

Post: Team Manager, Strategy Delivery, 575 Queen Mary Road, Sheffield S2 1EE

By Mark Alexander, Team Manager Strategy Delivery

Parent to Parent

Discussions about sex and relationships can be very difficult for any parent to tackle with their children. It can feel embarrassing; it can be difficult to know what and how much information to give; and when is the right time and age to do this? These issues become only more difficult when your child has a disability.

Parent to Parent is a local registered charity which has the aim of increasing parental confidence and skills in talking to their children about these subjects. The charity trains parents as peer educators, so workshops are held in an informal and friendly way. Sessions usually last two hours and there is a range of enjoyable and interesting activities, which aim to encourage parents and carers to share and learn from each other. The aim is that parents will leave feeling more confident and gain some ideas on

how they wish to communicate with their children and young people about sex and relationships. There is also a wide range of booklets available which introduce children and young adults to the subjects in a very accessible way.



Feedback from previous participants:

"It gave me more confidence to answer questions and access information from leaflets and books I never knew existed!"

"I gained insight from other parents on how they tackled the subject"

"I realised that I wasn't alone"

"Sex is not taboo in our house, but I still need to encourage them to talk about emotions"

"I hadn't really thought about some of the areas young people get their information"

For more information please visit the Parent to Parent website: www.sexualhealthsheffield.nhs.uk/projects/5-7.php, or contact their Development Worker Kath Broomhead on 0114 226 1917.

If you are interested in attending a workshop, please contact the Forum and let us know whether a day or evening session would suit you best (contact details are on the back page).

News from the INDEX

A big "hello" from the Sheffield Index to all those families who receive the Parent Carer Forum's newsletter! The Index is the Child Disability Register for Sheffield – we're here to help get information out to parents who need it and to get parents' views on the services they receive. We collect and supply information for planning, to ensure that children with special needs and their families are included in planning services. The Index also provides statistical information to the Government and the Local Authority, as well as circulating relevant information, ideas and news to families via our termly newsletter, "What's Going On".

So, being registered on the Index gives you another way to have your say about the things that matter to you. It also allows you more opportunities for finding out about what is going on in the city and how you can reach these services. That is

why we are striving to make the process of registering on the Index as smooth and easy as possible. I am therefore happy to announce that the Index has a brand new Questionnaire – and it's only four pages long! Many of you reading this newsletter will already have registered your child on the Index, but if you know of anyone else (friends or colleagues) who might benefit from the services the Index provides then please pass it on! It's easy to get hold of the new questionnaire too! Just give me a ring or email me; my contact details are listed below.

Finally, I wanted to ask parents, carers and young people for their views on another proposed change to the way we do things here at the Index. At present, when a parent registers their child they receive a paper confirmation certificate, which states that the named child/young person is enrolled on the

Index. After hearing from some parents that this certificate is easily damaged and is not ideal for carrying around, we thought about replacing it with a registration card. This would be the size of a credit card and would essentially hold the same information as the certificate, including the child's/young person's name and Index's contact telephone number. We thought that this might be a more attractive and longer-lasting option, as well as being more practical for a parent - or indeed a young person - to carry about when they need to. I just wanted to ask parents what they thought about this idea and I welcome any comments, on both this and the new questionnaire.

By Martina Capaldi

Children's Disability Information
Liaison Officer Tel. (0114) 2717626

Email: martina.capaldi@yahoo.co.uk

Meeting Individual Needs in Sheffield's Schools

"As a parent, you are only ever as happy as your least happy child."

I recently came across this quote in a magazine and it made me think of the unhappy parents of unhappy children I've met over the years. A common cause of unhappiness: a school that wasn't meeting the child's special needs, and an obscure system that didn't sufficiently challenge poor practice.

While some parents are lurching from crisis to crisis - exclusions, bullying, battles over statements and school placements – many others are kept awake at night by the gut-wrenching feeling that with every term that passes without appropriate help and support, their child's life chances are slowly being eroded.

Our children deserve better than that. Their classmates, siblings, teachers and parents deserve better than that. The question is: how long will it take to reach a tipping point where change just has to happen?

There are some indications that things are starting to move. Sheffield Local Authority recently completed a review of the formula used to fund its mainstream schools, with a particular focus on the funding of pupils with special educational and additional needs. On the 25th of May, the Schools Forum approved the new funding model (see box) to go for



consultation with head teachers and governors.

The outcomes of the consultation, which closed in mid July, will be fed back to the Schools Forum at a meeting on 28th September 2010. If approved, the changes would take effect from April 2011. Parents are welcome to attend this meeting as observers — please see the "Calendar" section of the Forum website for more information.

In addition to the funding formula, the Local Authority is reviewing its overall

approach to meeting the needs of pupils with additional needs in ALL of Sheffield's schools. On 26th May, Cabinet approved a consultative paper outlining how the needs of pupils with additional needs in Sheffield's schools could be met (the "Inclusive Learning Strategy" or ILS for short) and gave permission for city-wide consultation.

The consultation on the ILS will run from 1st September to 15th October 2010, and we urge all parents to take part. You can complete an online questionnaire at: www.sheffield.gov.uk/inclusivelearning or pick up a paper version at your local school, childcare centre, nursery, library or First Point.

Our Parent Carer Conference on the 11th of October will include a presentation on the Inclusive Learning Strategy, with opportunities to ask questions and breaks to allow parents to complete the questionnaire during the session.

Between October and December 2010, the outcomes of the consultation will be evaluated by a multi-agency Steering Group which includes representatives from the Parent Carer Forum.

In January 2011, a report on the consultation will be submitted to Cabinet. Any trials and pilots approved by Cabinet will run between January and December 2011, with evaluation of the pilots and wider implementation of the strategy scheduled for 2012.

To enable parents to feed their questions and comments back to the ILS Steering Group and other strategic groups, the Parent Carer Forum has set up a parents-only group on education. This is a friendly, informal group which meets once a month during school hours at a city centre location – please check the calendar on our website, or ring 0114 252 1913 for details.

We hope you will be able to come along and tell us your views!

By Eva Juusola (Development Worker)

The new funding model for mainstream schools proposes to:

- Increase the proportion of delegated school budgets focussed upon meeting individual needs from 6% to 9%
- Increase accountability for schools' use of their delegated individual needs funding
- Shift the emphasis away from social deprivation and towards pupil progress and attainment as key indicators for allocating individual needs funding to schools
- Allocate a minimum level of individual needs funding to all schools
- Gradually increase top-up funding for exceptional needs from currently £0.5m to £4.3m per year
- Review funding levels and working methods of support services

Aargh! or How not to lose your child in a public place



In the midst of a bustling plastic brick theme park, it had gone too quiet. Panic ... a terrifying menagerie of headless chicken and rabbit in headlights, headache and nausea to swiftly follow, as we frantically searched for our son lost just minutes after entering the park ...

I think most parents will recognise those agonising moments or minutes when a child is out of sight until they are found. I was reminded of this listening to a recent interview where a mother had lost sight of her (autistic) son at a music festival. The son was absolutely fine and a kind individual had him stay with her whilst his parents were located. As many of us will recognise, her son was unable to communicate information of who he was with or how to contact his parents and so it took what must have seemed like a lifetime for them to be reunited. After their experience, the parents had the idea of using temporary tattoos and managed to source tattoos that gave the instruction to "ring mum/dad" and their mobile number. The tattoos have the advantage of not being rubbed or washed off easily. These tattoos can be sourced from America but are quite expensive (www.tottoos.org). There are alternatives – some theme

parks offer labels to affix to your child with a mobile number so that parents can be contacted immediately, some parents use t-shirts or badges. This means that the necessary information can be identified quickly, especially if your child has communication difficulties.

The Child Safe Zone Scheme is also being rolled out around the country. If you lose your child in a Child Safe Zone, you just need to ring the number displayed on stickers or posters for direct contact with a local security team. All CSZ offer free wristbands allowing children to carry their parent or guardian's contact mobile number safely. Dispensers are available as you enter the Zone. Check on the website (www.childsafezones.co.uk) to see whether your activity currently supports the scheme.

You can also buy reusable wristbands via the web (e.g. from www.kiddymania.co.uk or www.familysafeplus-shop.co.uk), or put a card in your child's pocket such as the Autism Alert card (www.autism.org.uk/card) or a home-made one which can provide contact details and other relevant information. Of course bracelets and pendants have been available for a long time which can detail medical

and specific needs. You can also purchase alarms on a key fob so if your child wanders off you can press the alarm to locate a child quickly, although a piercing alarm going off in their pocket could cause great distress to some children!

Some advice from www.hintsandthings.co.uk is to take a photograph with you of the child, which will assist others help you in the search. Never put a home address as personal information on labels. Dress the child in bright colours for external clothing that will help you easily and quickly spot the child.

When much of the advice we try to give our children is not to talk to strangers, it can be difficult to explain how to approach strangers to ask for help.

Advice from www.uk.missingkids.com states, "if your child is able to speak, explain to your child that, if they become separated from you, they should look for a trusted adult such as a security guard in a shop, a policeman or member of shop counter staff wearing a name badge, or a mother with children who will be able to help them".

Some children may benefit from a "social story" that explains in a few short sentences what they should do if they become separated from their parent or carer.

Role-play can also help some children prepare for the eventuality of getting lost in a public place.

Just a few minutes extra planning before setting out can save enormous stress later and help you enjoy your planned activity. If you have good ideas or suggestions that we can share with other parents, please let us know!

By Jayne Woodward (Co-chair)

Family Fun Day



Sheffield Parent Carer Forum held its very first Fun Day for children with disabilities and their parents, carers and siblings on Sunday 11th July. The event was held at The Centre in the Park, Norfolk Heritage Park, using both the indoor facilities and the huge parkland surrounding it.



Where to start? Well, as primary event organiser (a "first" for me), the day dawned rather apprehensively: would anyone turn up? Would there be enough food? Would the weather hold? Had I actually remembered to book the venue.....I need not have worried!



We were thrilled to play host to over 300 people in total – a wonderful mix of children and young people with a range of disabilities, with families in tow. The sun shone all day so attendees were able to enjoy all the outdoor activities without recourse to waterproofs.



The two bouncy castles were a massive hit and were well and truly bounced for the whole day. Also very popular were the two orienteering courses and the "mini beast" hunts – possibly the latter was less popular with the "mini beasts". There were some very grumpy-looking beetles and bees on the day – all were safely released back into the wild.



Also outdoors were the megastars of the day – three of South Yorkshire Fire and Rescue's finest, who brought their appliance with them. They were a brilliant bunch and wonderfully funny and attentive to children and adults alike. One of the favourite comments we received on our graffiti wall was, "I loved the firemen. Especially the big daft one". Says it all really. Much excitement ensued when the lads got a real "shout" and sped across the park to the appliance, taking their shirts off as they went. This



was oddly popular with a number of Mums.....!!!!

Indoors, we were extremely fortunate to have the services of two of the most fabulous face-painters I've ever seen. Both toiled without stopping for four hours, with queues stretching all down the corridors. Tiny fairies, butterflies and assorted superheroes gradually emerged, to the delight of children and adults alike. One young girl had a replica of her Mum's tattoo done on her arm, each element of which represented a sibling.

"My favourite part was the young lad who (once I'd described what you do with the bug equipment) duly brought me bee after bee after poor bee, and was very pleased with himself. Also loved the Dad who, obviously worried about missing Madame Zucchini, rushed passed me exclaiming, "where is vegetable lady, where is vegetable lady?". His wife and I had a good laugh at his expense!"
- Catriona Laing (Trustee)

In the Community Hall, drumming workshops proved very popular: one very astute young person noted on the graffiti wall, "You can do your own beat but they all sound fab together". Later on, the tremendous Madame Zucchini put on a hilarious show – with vegetables – and then helped the children to make mini vegetable sculptures. A number of parents commented that this was a brilliant idea that they could try out at home. Suddenly, you could feel the summer holidays seeming a little less daunting!

We were delighted to have representation from South Yorkshire Police in the form of a Community Support Officer, who provided information on how the

Family Fun Day cont.

Police work within the local communities. The Officer was very popular with the children, as were her colleagues who arrived to collect her at the end of the event. Much irregular use of the lights and sirens had our visitors in gales of laughter, and a few lucky youngsters were treated to a look inside the vehicle and even allowed to switch on the siren.

Alongside the Police stall, we were really pleased to have a representative from Sheffield City Council who was present to consult parents and young people about what type of facilities they'd like to have in Community Playgrounds. Feedback from attendees was very diverse and interesting. Sheffield Information Giving Network (SIGN) also had a stall with loads of really useful information, as did Asperger's Children and Carers Together (ACCT).

Children who were feeling a bit overwhelmed by the day were able

to use the Chill-Out Sensory room, with soft lights, music and other sensory equipment (kindly lent to us by ACCT) – this proved very popular. Many thanks to Gavin and Pat for giving up their day as volunteers to look after their visitors.

Loads of lively and creative fun was provided by David and Sue Roe and their fabulous children, who spent the day tirelessly supporting children in the Arts and Craft area. Wonderful, imaginative offerings emerged, including decorated pyramids, Mexican Eyes and assorted paintings.

Lunch was provided by Hartley's Sandwich Shop: loads of tasty rolls, sausage rolls and cakes which went down a treat with our guests. A somewhat disorderly queue formed in the corridor, with all the activities having given everyone a healthy appetite. Lessons learned – we'll do that bit differently next time.

So, a busy and highly enjoyable day all round. Sincere thanks to everyone who gave their time, ideas and support, both in the planning and execution of the day. The setting was fabulous and all the staff at Norfolk Park were tremendously helpful and supportive. It was a really great team effort: back to that astute young drummer and the graffiti wall comment – "You can do your own beat but they all sound fab together" Indeed.

By Claire Wood (Business Support)

Photographs by Adrian Richardson (www.adrianrichardson.com)

To see more photos of the event, please go to www.flickr.com, click on "Search", and select "People". Enter "Sheffield Parent Carer Forum" into the text box and click on "Search" again.



The childcare headache: A parent's story



Get together a group of parents of children with disabilities or special needs, and the conversation invariably moves towards childcare. Who's got it? How did they get it? Is care available out there for our children with skilled, trained professionals to support their individual complex difficulties? This has been a personal dilemma for me for many years and as a consequence I was happy to join the DCATCH group (see p. 11) that is trying to improve childcare for families with disabled children here in Sheffield.

I know that many families with children with additional needs find it difficult to access appropriate childcare that allows them to live relatively ordinary lives and work and earn a living to support themselves and their families. My child has Asperger's syndrome, life-threatening allergies, sensory problems, asthma and anxiety and has in the past had up to 50% of time out of school. During the very early years,

before we had a formal diagnosis, we did a lot of juggling caring for our children. They attended a small nursery, my parents helped out, I worked part-time and we as parents shared caring: a similar tale to many other families. However, as it became apparent our child had physical and other difficulties, it became much more difficult to keep on working. He had a couple of hospital stays and often nursery would telephone to say he wasn't well and could we come and get him. We both had relatively demanding jobs and faced the dilemma every morning when he wasn't well of assessing just how ill he was, which one of us could look after him, or could we ask anyone else to help? Exhaustion and guilt played a prominent part in our lives. More than once I'd go into work with my boy in my arms, pick up files, bring them home and continue working once my children were in bed. At one stage my husband was working during the day and as soon as he returned from home I'd go to my office to do

a couple of hours to try and keep my job. Not surprisingly this couldn't be sustained, we all got very stressed, and I had to give up work and stayed at home for three years.

Eventually I decided I wanted, for my own sanity, to do something outside of the home and volunteered as a school governor and subsequently co-founded ACCT: Asperger's Children and Carers Together, where I now work as Director. I then became involved in setting up the Sheffield Parent Carer Forum on a voluntary basis and have now signed up to be a trustee. I have loved doing this voluntary and paid work but the thorny issue of childcare has been one of my biggest challenges.

So what have been my own personal problems with accessing appropriate childcare? Most parents when they have a child look at the usual options of childcare, for example childminders, after-school and holiday clubs, perhaps a local babysitter when they get a bit older - but for me, as for many of you, this is simply not possible. I need someone who is medically trained to administer medication, including an epi-pen, someone who can deal with my child's autism and sensory difficulties, and can be available during the day should my child be absent from school! Quite a tall order as you can imagine! A childminder would have been impossible because my child would not have coped with the other children and an after-school or holiday club would have been overwhelming because of his anxiety and sensory issues. The easiest option would have been not to do anything but as well as wishing to earn money for the family I wanted to engage my

The childcare headache: A parent's story cont.

brain, wanted to be part of society, wanted to make a difference in my community and simply wanted to work! Not much to ask for, you would have thought, but the solution has been anything but simple.

In the end we employed a psychology student, trained her ourselves, had an arrangement whereby she'd go into school and help if my boy was able to attend school, but if not, stay at home with him. This way, I would get 10 precious hours per week to be able to get out of the house, attend meetings, and do my work! I've also been able to work at home via a computer and I have to say this has made me a lot happier and as a

consequence has benefited the whole family.

So how can we change the situation in Sheffield for other families facing a similar situation? I believe the DCATCH meetings have been an excellent starting point for professionals and carers alike to think laterally and try to find individual solutions for individual families. One size does not fit all, and whilst some families will be able to send their children to childminders and children's clubs - especially once we have a directory of specialists who can cope with children with additional needs - others will need tailor-made solutions similar to the type we created for my family,

possibly with the help of Direct Payments or personalised budgets. In addition, we need to ensure that providers are trained and prepared for the individuals that our children and young people are. Let's hope these initiatives are only the start of a new way of supporting families with disabled children to access appropriate childcare.

If you'd like to discuss the work of the DCATCH group or tell us about your difficulties regarding childcare, then please email me on deborahhwoodhouse@hotmail.co.uk, or post on the discussion board of the Forum website.

By Deborah Woodhouse (Trustee)

DCATCH Update

DCATCH (Disabled Children's Access to Childcare) is a 3-year programme aimed at improving the range and quality of childcare available to families with disabled children/young people.

Under this initiative, Sheffield City Council has received a one-off grant payment of just under £120,000.

A working group of officers and parents has been meeting since May 2010 to decide how this money could be used to improve childcare for disabled children in Sheffield in a sustainable way (bearing in mind that the grant is ringfenced and must be spent by April 2011!). As central government have made no commitment to continue the DCATCH funding, the group is keen to maximise this opportunity and leave a legacy that lives on beyond March 2011.



So far, the group has approved the following proposals:

- Extend the current Early Years Intervention Grant to cover the additional cost of caring for a disabled child (e.g. 1:1 support, equipment) during school holidays. This grant can be accessed by all private and voluntary childcare settings and childminders caring for children under the age of five.
- Set up a network of specialist childminders able to care for and understand the needs of

disabled children and young people, particularly in the 11+ age group. This includes training and mentoring as well as top-up payments to childminders to cover any extra costs and/or lost earnings (e.g. as a result of having to reduce group sizes). An information event for interested childminders and parents has been organised for the 18th of September (see "Dates for your diary" on the back page).

The working group is currently looking at ways of improving childcare for parents whose children, for a variety of reasons, are unable to access regular childcare settings.

Deborah Woodhouse (who also wrote the previous article) is our parent lead on this group and would be more than happy to discuss the proposals with parents and feed back their comments.

Finding your voice within a mainstream school



Dyslexia, Dyspraxia, Asperger's, ADHD, Individual Education Plan, School Action, School Action Plus, STEPS, Ryegate, Parent Partnership etc. etc. etc.!!!!

Ever feel overwhelmed by all these words, what they mean and what you should do? Ever felt like you as a parent of a child with SEN are an outsider, as though you or your child does not "fit the school system"? Ever felt silenced in meetings at school by awe or fear of teachers and SENCOs? Ever felt silenced simply because you do not know what provision you might access at your child's school? Ever felt like you are seen as a complainer or troublemaker if you have questioned your child's provision or progress? Ever heard other parents complaining of similar experiences?

Do we as families have to rely on funding and the local authority to change things?

I don't like to paint a negative picture of having a child with special educational needs – I have three children with SEN myself. I value their difference, enjoy them immensely and am seeing them making great progress. The schools have contributed to this progress. But my experience of my child being in school, and getting the best for them has been mixed and at times fraught. And these are

good schools! I have felt like a tiny, quirky fish of a parent in a shoal of other parents whom I imagine don't have to think about assessments, additional services, IEPs and attendance records. Inclusion, the buzz word - do you know how it applies to your school or your child's experiences?

DOES IT HAVE TO BE LIKE THIS? As a parent, I encourage you think about that. How else might it be? Do we as families have to rely on funding and the local authority to change things? After 6 years of assessments and IEPs with my 3 children, I began to think. I wanted support and I could see the SENCO might, too – it must be lonely being a SENCO, holding all those children and parents in mind, and trying to get busy teachers in a big school to take on board SEN and inclusive practices. I thought what

Finding your voice within a mainstream school **cont.**

if we, as parents together, developed a voice. What if we supported each other and the school? Would that make a difference?

I approached our SENCO, and asked whether or not she thought a school support group for parents of children with SEN would be a good idea. She checked with the head, and said they thought it would be great. She set up a talk on dyslexia by STEPS in the evening at school, and invited all relevant parents and junior and associate infant schools to help me get started. From there on it was simple. Loads of parents came. Loads of people had questions at the end of the talk. Loads of parents were clearly frustrated or still had issues from diagnosis and current provision. But there was also loads of energy. The Head came too – and witnessed the concern and issues that people were raising. I circulated a contact sheet and jotted down parents' ideas as they were talking on what support they would find helpful for themselves and their children.

From this meeting, a core group of parents emerged who wanted to form a SEN support group. We discussed ideas from the meeting in the pub! From these early beginnings, a more formal but open group has emerged and is still emerging! We now have some definite aims, discussed in partnership with the SENCO. The aims of the group are to provide a support network for parents, and to work with the school to develop strategies around provision for children with any special educational need. This is beyond what I had imagined happening. I never thought that such a group could take on a strategic role – but we have and the school have welcomed this.

We currently hold termly open meetings at the school with the SENCO, for anyone with an interest in SEN. They are an opportunity to meet parents, have a coffee and to hear what is happening with regards to SEN and to work in partnership with the school in developing practice. We have organised some social events too. Joint initiatives between the group and school have included

- A comprehensive SEN section of the school website, with learning resources and links
- Leaflets for children written by the SENCO in conjunction with children explaining dyslexia and Asperger's
- A review of parents' perception of IEPs conducted by the school, with some changes subsequently
- Introduction of coloured rulers to reduce visual stress within classrooms
- A central list of parents who are willing to talk to other parents about the assessment process or their child's particular condition
- Parents have run additional groups, including a keyboard skills group for up to ten children (touch typing)
- Parents sharing information on resources – including glasses for visual stress, listening programme and local tutors
- Formal link to Sheffield Parent Carer Forum
- Links with feeder infant schools, to reach more parents and raise the schools' awareness of what we are doing

Most importantly, we have found a voice that can be listened to. And the school has welcomed it – they look good too!

My top tips for getting an initiative like this off the ground:

- Approach your SENCO
- Offer them a vision of what such a group might offer the school - are they interested in raising their profile, in getting brownie points for increasing parent partnership, in increasing resources available for children with SEN, with getting added value for children?
- A neutral, informative talk on a subject worked very well to get people talking, meeting with one another and sharing good ideas
- Offer to help the school – can you as parents help out in SEN provision – extra reading, running a group, fund raising – what can you offer your SENCO and children?
- Focus on the positive ideas parents might have for practice
- Support each other – have fun!

Every school is different – and different strategies and solutions will suit different schools and their parents. It is worth thinking about though - would your school be interested in having a regular forum where parents, who know their child's needs best, can be heard? And as parents – are you interested in knowing about the school's SEN practice, and the policies and pressures informing this? Having this dialogue might be challenging for schools and parents alike, but schools working in partnership with parents at a time of economic uncertainty can find creative ways of working to increase SEN provision and inclusion.

By Emma Taylor (Trustee)

Short breaks Q & A



Throughout the Aiming High for Disabled Children Programme and the transformation of Short Breaks we have been asked a range of questions from parents and carers of disabled children and young people. This article seeks to answer some of those questions:

What is a short break?

Fundamentally a short break can be anything that provides the primary carer of a disabled child/young person a break from the additional responsibilities that this brings. Short breaks can be overnight or day care and take place in a wide variety of settings.

How much money does Sheffield City Council spend on short breaks?

During 10/11 Sheffield City Council received £2,025,000 revenue funding and a further £787,000 capital funding to support the transformation of short breaks. This is in addition to the money that is already being spent on Short Breaks in the city, which is in excess of £4,000,000 per annum.

How can I find out if I am entitled to a short break?

Short breaks are based upon an

assessment of a family's circumstances and the impact that caring for a disabled child may have. For instance, increased family stress, lack of sleep etc. At present short breaks are offered in Sheffield to any family with a child who has a diagnosis of disability with higher levels of service requiring an assessment in the form of a CAF or social work assessment.

What happens after Aiming High in April 2011?

As with many things in the public sector at the moment, local authorities are awaiting clarification from central government. The Government are undertaking their comprehensive spending review in the autumn at which point things should become clearer. The Coalition have made positive noises about prioritising investment in "respite" care but are yet to commit to what this looks like in practice.

The Government intends to legislate for short breaks in March 2011, placing a mandatory duty on local authorities to provide short breaks. In summary the draft documentation would indicate that short breaks would need to be provided to families who either would be at

significant risk of breakdown without them, or who would function more effectively if a package of short breaks were in place.

Where can I find out what is available in my area?

The best place to start is by contacting SIGN on 0114 2669476. They hold a range of information about short breaks and also about services that are available in the city for families of disabled children.

Are short breaks only provided in school holidays?

No, short breaks are provided all year round. The level of service a family receives is based upon an assessed level of need.

Are short breaks only available for disabled children or can they be accompanied by their siblings or parents?

Most short breaks are funded for disabled children, however there are also some services in place for siblings. In addition, if a disabled child is accessing a universal provision e.g. leisure centre, there is no reason that they could not be accompanied, although this is likely to incur a cost.

Can I get direct payments instead of a short break?

Yes, direct payments can be provided in place of an organised short break.

Who is providing training for Short Breaks providers?

We have commissioned a range of training which providers have access to. Amongst others this includes, first aid, manual handling, autism awareness and Team Teach (www.team-teach.co.uk). All courses are being publicised to short breaks providers.

Can I combine different short breaks?

Yes, this is possible and would depend upon the circumstances and needs of the family.

Short breaks Q & A **cont.**

My child just wants to access a mainstream club but they say they cannot take her, what do I do next?

There are a number of answers to this. Firstly anybody who provides a service of any sort either on a commercial or voluntary basis is bound by disability discrimination legislation. This states that a provider of services must make "reasonable adjustments" to accommodate the needs of disabled people. The challenge with this is the definition of "reasonable", as there are many factors affecting this, including cost of making the adjustment, health and safety and building constraints. However the first action should

always be for a provider to see if there are simple steps that can be taken to operate more inclusively.

Alternatively there may be support that Sheffield City Council Special Needs Inclusion Playcare Service can provide to a service in the form of mentoring, training etc. If you have an instance such as this please contact SNIPS on 0114 273 4017 or by email at cypdsnips@sheffield.gov.uk

Can I still access a short break grant?

Yes we are still accepting applications for short breaks grants which can provide up to £370 per family. The closing date for

applications is 31 December 2010 and money must be spent by the end of March 2011. If you would like further information please contact Catherine Calton on 0114 2398336 or catherine.calton@sheffield.gov.uk

By Chris Easton (AHDC Short Breaks Programme Officer)

OUR TEAM

Co-Chairs:

David Roe

Jayne Woodward

Treasurer:

John Vear

Trustees:

Catriona Laing

Clare Peck

Deborah Woodhouse

Emma Taylor

Helen Prescott

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We welcome articles from parents, professionals and practitioners. Please contact us to discuss possible contributions.

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We want your stories!

We know that well over 700 families in Sheffield have accessed a £370 short break grant so far. Were YOU one of them? If yes, we'd love to hear how you used our grant - where did you go, what did you do, did your family enjoy it?

Please send us your stories, photos, drawings, etc., and we will publish the best ones in our next newsletter. All published contributors will receive a £10 gift voucher.

Plus, by sharing your story you might help us persuade the Council to continue this popular scheme in the future...

Please send contributions by 3rd December 2010 to:

Sheffield Parent Carer Forum
c/o Sheffield Carers Centre
FREEPOST NEA9555
Sheffield S1 2ZZ

Email:
enquiries@sheffieldparentcarerforum.org.uk

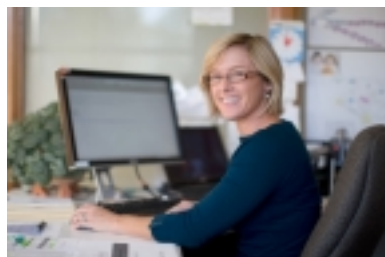
Volunteers needed

Could you spare a few hours each month to help us with some admin work? Tasks might include:

- preparing mail shots,
- updating our membership database,
- photocopying,
- helping with event organisation.

A basic level of computer literacy would be useful, but full training will be provided.

If you are interested, please call us on 0114 2521913 to have a chat.



We would also love to hear from professionals (e.g. law, PR, design, fundraising, IT...) who might be able to help us on a pro bono basis.

Get in touch

**By Post:**

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c/o Sheffield Carers Centre
7 Bells Court, Bells Square
Sheffield S1 2FY

**By phone:**

0114 252 1913

**By e-mail:**

enquiries@sheffieldparentcarerforum.org.uk

**Drop-in:**

Currently by appointment only;
please contact us to make an
appointment

**Website:**

www.sheffieldparentcarerforum.org.uk

Dates for your diary

17th September, 10am-12pm, Sheffield Carers Centre: meeting of Education sub group (see p. 6)

18th September, 9.30-11.30am, Centre in the Park, Norfolk Heritage Park: Information meeting about setting up a network of specialist childminders (see p. 11)

28th September, 9.30-11.30am, St. Mary's, Bramall Lane: Schools Forum meeting on funding review (see p. 6)

11th October, 10am-2.30pm, St. Mary's, Bramall Lane: Parent Carer Conference (see p. 2)

4th November: 7.15-9.15pm, Quaker Meeting House, 10 St. James Street: Information evening on SEN law

Further details can be found on our website. Please contact us if you'd like to attend any of the meetings listed!

Our aims

We want:

- disabled children and their families to have a better quality of life
- disabled children to be fully included in, and accepted by, their local communities
- disabled children to receive all the services, help and support they need to reach their full potential

We will work in partnership with parents, schools, the local authority, the health authority and the voluntary sector to achieve these objectives.

Specifically, we will:

- give parents of disabled children in Sheffield a strong voice in influencing local developments that affect their children
- keep parent carers informed of developments that affect their children
- provide a platform for parent carers to exchange information and support each other
- signpost parent carers to sources of advice and help

