



Newsletter

For parents and carers of children and young people with disabilities and/or special educational needs in Sheffield

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Spring 2014 Issue 9 FREE!

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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

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By e-mail:

enquiries@sheffieldparentcarerforum.org.uk

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www.sheffieldparentcarerforum.org.uk

Drop-in:

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



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- Full page £100
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- ¼ page £25

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

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Welcome to our Spring Newsletter!



A very warm welcome to our spring newsletter! As we go to print, we are organising our "Countdown to the SEN Reforms" information day at St Mary's on the 14th March. This event is to provide information to parent carers about the biggest overhaul in 30 years of the special educational needs system, taking place from September 2014. There is still a great deal about the reforms to be confirmed; the pathfinders in other local authority areas are reporting many challenges, not least the timescales within which all these changes are supposed to be happening.

But the reforms will happen and parent carers need to be aware of the changes which will affect ALL youngsters with additional needs. The "local offer" should provide clear information about what services are available in the area and how to access them. Certainly that should be very beneficial to parent carers and there is a great deal of work going on with the reforms – co-production is a key theme – and we will continue to work on behalf of our members and children, and provide updates as the position becomes clearer! Read more about what will happen from page 18.

Also inside this edition: an update on the campaign against restrictions to disability

travel passes; the importance of travel insurance if your child falls ill on holiday; and "Ask The Lawyer" features the legal position regarding post-16 specialist provision.

If you have a child or young person aged 0-25 with a disability or additional needs, we need to hear from you! We know that having a child or young adult with additional needs can be difficult, but we want to 'take the pulse' of parent carers in the City in our State of Sheffield survey. This will be our most comprehensive survey yet. Details on how to take part are on page 5, and we will use the results to lobby for better services and to protect existing ones. Whilst we try to establish the scale and impact of the new budget cuts on our local services, your opinions are needed more than ever!

Although we may not be able to predict the future for our children and we know there are many challenges ahead, what we do know for sure is that as parent carers we are all stronger together – we support, learn from and guide each other. We will shortly be welcoming our 1,000th member to the Forum – and this is very much something to celebrate!

Best wishes

Jayne Woodward, Co-Chair



Christmas film is a hit with kids

Taking your disabled child to the movies can be fraught with difficulty – especially if they like to dance in the aisle, provide a running commentary, or leave half way through the film.

“My son was happy, which made me happy as well. Everything was nice.”

At our recent private screening at the Showroom Cinema, all of these things happened, and none of them were a problem.

Despite the rather early start (9.30am on a Saturday morning!), over 200 parents and children joined us for mince pies and biscuits in the Showroom Café, before settling down to enjoy a relaxed screening of The Polar Express.

The film was shown with reduced sound levels, dimmed lights and without trailers, to accommodate those with sensory issues.

“Really good to have no trailers so no waiting, and to know others understand and didn't have to worry about my child's behaviour.”

The feedback was so overwhelmingly positive that we will make it a priority to organise another screening this year.

“We really hope you do it again next year... It was our first successful trip to the cinema... Thank you!!”

The Sheffield Showroom, Cineworld and Vue all run monthly autism-friendly screenings, which usually take place on Sunday mornings.

Showroom: 0114 275 7727

Cineworld: 0114 242 1238

Vue Cinema: 0871 224 0240
(ignore voice, press 0)

Take part in our survey and protect vital services!

If you live in Sheffield and care for a child or young person (aged 0-25) with a disability or additional needs, we need your views.

We want to know if you are getting enough support; whether you are managing to combine paid work and caring; and how happy you are with your child's education, childcare, respite, health care and therapy services.

The questions we are asking are based on hundred of conversations we have had with other parents over the years. Your answers will help us gather data on a range of issues, and enable us to speak with a strong voice on your behalf.

As Sheffield City Council is gearing up to implement yet another round of budget cuts (see page 9), it is vital that we can show which services are a real lifeline for families – and which ones are so overstretched that nobody should even think about cutting their budgets!

Please take part!

Go to: www.surveymonkey.com/s/StateofSheffield2014

No internet access?

Call us on **0300 321 4721** to request a hardcopy

Closing date

30 April 2014

Prize draw for completed surveys...

Win £50, £30 or £20!

Forum membership extended to parents of young adults

At our Annual General Meeting (AGM) in November 2013, the trustees voted to extend membership of the Forum to parents of young adults with disabilities up to the age of 25. This brings us in line with new legislation intended to establish a 0-25 special needs system (see pages 18 and 19).

Jayne Woodward, Co-chair of the Parent Carer Forum, said: “Most of our trustees are

carers of children and teenagers, so we're on a steep learning curve when it comes to understanding adult services! However, this is something we'll all have to face sooner or later. We're pleased that we already have good links with other organisations who represent carers of disabled adults, such as Carers in Sheffield and the FLASH group at Mencap, and we hope to work even more closely with them in the future.”

Forum membership approaches 1,000

Membership applications have been coming in thick and fast recently, with around five new families joining every week. We now have over 930 members, which makes us one of the biggest parent carer forums in the country. If you're not yet a member, please fill in the form at the back of this newsletter and help us reach 1,000 members this year!



Do you tweet?

We didn't, until recently. Maybe it's a generation thing, but many of us don't really "get" Twitter. Luckily, our media-savvy trustee Deborah Woodhouse has taken pity on our dormant Twitter account and started tweeting on our behalf – gaining over 250 followers in just a few months. If, unlike us, you are young and hip (or just more clued up!), you can follow her **@ShefParentForum**

Let us come to you!

Our "schools roadshow" programme is now in its third year, and still going strong. Dozens of schools all over Sheffield have had visits from our outreach volunteers Joanne and Laura, who usually turn up laden with biscuits, grapes and various goodies – as well as lots of useful information. At some schools, our visit even sparked a new SEN parents' group where none had existed before.

Parents who attended our outreach visits said that they were "very informative", "helpful", "reassuring" and a "great opportunity to meet parents going through similar things".

Would you like us to come to your school? Then please encourage your school's SENCO to contact us, or just get in touch and tell us who we need to speak to.

Free legal advice sessions

Last year, we ran three legal advice sessions for parent carers, generously supported by local law firm Irwin Mitchell Solicitors. The parents who attended the sessions said they had been "very helpful" and "enlightening", that they had clarified their thinking and given them new avenues to explore.

We are delighted to be offering these sessions again this year. Solicitors from Irwin Mitchell will be available to offer advice on a wide range of personal law matters, including wills, power of attorney, setting up trusts, special educational needs (SEN) processes and provision, appeals against benefits decisions, and more.

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

Thursday 10th April, 10am-12pm

Monday 12th May, 12-2pm

Wednesday 11th June, 10am-12pm

Tuesday 15th July, 12-2pm

Booking is essential; please contact our office on **0300 321 4721** or email **enquiries@sheffieldparentcarerforum.org.uk** to book your 30-minute slot.



New! Coffee mornings at St Mary's

Whenever we ask parents to rate our events and meetings, they invariably tell us how much they enjoyed talking to other parents going through similar things. So we thought we'd run a few coffee mornings to see whether any of you fancied getting together just to chat - without the constraints of minutes, speakers and agendas.

When? Every second Thursday of the month, 10.30am – 12 noon (next meetings 10 April, 8 May, 12 June, 10 July). Pop in for a few minutes, or stay for the whole session!

Where? St Mary's Community Centre.



Who can attend? We welcome all parent carers, whatever their children's needs, whether diagnosed or undiagnosed, mild or severe. Pre-schoolers and home-educated children welcome (please bring some toys).

New parent carer reps recruited

Every year, our volunteers attend dozens of council meetings to represent the views of parent carers. Our reps are usually the lowest-paid people around the table, but they do an incredible job - reading briefing papers, gathering and representing parents' views, giving feedback ...

As parents of disabled children, however, they have caring responsibilities which limit the amount of time they can contribute. When officers asked us to join five new groups tasked with implementing the SEN reforms in Sheffield (see page 18), we knew it was time for a recruitment drive.

A mail shot to our members elicited a fantastic response - over 20 parents volunteered! – and led to the recruitment of eight new parent representatives. These new volunteers will be trained and mentored by our "old hands", to help them get to grips with their new role.

Meet our parent reps!

They would love to talk to you about your views and experiences. You can chat to them at our subgroup meetings and quarterly open meetings – please see pages 22 and 23 for dates.



Working Together training

Getting relationships with parent carers off to a good start.



Our Working Together training continues to receive enthusiastic reviews from participants. In the last 18 months, we trained more than 100 education, health, social care and third sector professionals in how to engage with parents and carers of children with special needs and deliver services in a way that takes the needs of the entire family into account.

Developed and delivered by a team of parent trainers, Working Together provides a unique insight into the often challenging realities of caring for a child with a disability. The training draws on lots of practical exercises, as well as real-life case studies to explore the stresses and strains that parents experience on a daily basis. A particular strong point that many of our past participants have highlighted is our trainers' ability to create an environment where sensitive issues can be discussed openly and without fear of being judged.

“A fantastic opportunity to be able to meet parents in this kind of forum. Really thought-provoking and helpful! Excellent!” - Participant.

Open courses run three times a year and are suitable for professionals who work with children with special needs and their families and carers, as well as for individuals and organisations interested in exploring a fresh perspective on issues of disability and equality.

Limited spaces are still available for our next open session on 30 April, from 9.30am to 1pm, at St Mary's Conference Centre, Bramall Lane. For more upcoming dates and information on how to book a tailor-made training session for your organisation, please visit our website or contact us on **0300 321 4721** or email training@sheffieldparentcarerforum.org.uk.

Services for disabled children hit by budget cuts



Services for disabled children in Sheffield have been fairly protected from the government's austerity programme – until now. When faced with another significant reduction in central government funding for 2014/15, councillors decided that they could no longer afford to exempt any service areas.

This year's budget includes cuts totalling around £1.5m to services for children and young people with special educational needs (SEN) and/or disabilities. The following services are affected:

Post-16 Placements (£390k saving)

Savings will be made by reducing the cost of SEN and post-16 learning disability placements. This will be done by “taking a holistic and multi-agency approach to individual needs which supports young people to access opportunities on a bespoke basis”. By increasing in-city provision for post-16 special educational needs, the council hopes to enable some young people currently in more costly out-of-city provision to return to Sheffield.

Short Breaks and Respite Care (£350k saving)

Savings will be made by “reducing the cost of external placements through increased local provision”. A consultation into the Respite and Short Breaks Service will be held in early April (details will be published on our website).

Educational Psychology (£300k saving)

The savings will be achieved by charging schools for the non-statutory elements of the service. The council will continue to provide statutory educational psychology services free of charge.

SEN Services (included in £300k saving)

£300,000 will be saved from the budget for Inclusion and Targeted Services, which includes services for children with SEN.

SEN Transport (£200k saving)

The council wants to save money by encouraging independent travel where appropriate, and by reviewing the use of escorts and the use of discretionary travel.

Special Needs Inclusion Playcare Service (SNIPS) (£100k saving)

Savings will be achieved by a reduction in management.

Early Years Inclusion Team (£80k saving)

Savings will be made by reshaping the Early Years Inclusion Team and integrating it within the wider Early Years service.

We are extremely concerned about the scale of these cuts - particularly in relation to the SEN reforms to be introduced later this year, which will have major capacity implications.

We are currently trying to establish what the impact on frontline services will be, and are working on a response.

Please help us demonstrate the need for these vital services by taking part in our survey! (see page 5)

Information for parents of young people aged 16+

The Sharing Caring Project at Mencap is running several information sessions about the legal aspects of caring, as well as a number of transition clinics. The information sessions are aimed at all family carers of people with a learning disability and/or autism aged 16 and over, while the transition clinics are specifically for parents of young people approaching adulthood.

Wills and Trusts

1 May, 6.30 - 8.30pm AND 18 June, 10.30am - 12.30pm

Young adults may be required to pay a personal contribution towards social care services they receive, depending on their income and savings. It can therefore be a good idea for parents to make a will and set up a discretionary trust for their young person. This enables parents, grandparents and other family members to leave money to the young person without affecting their entitlement to state support. This session will cover discretionary trusts, choosing trustees, safeguarding income, legal obligations and more.

Deputyship and the Court of Protection

30 April OR 16 May, 10.30am - 12.30pm (date to be confirmed)

A deputy is someone appointed by the Court of Protection to manage the financial affairs or welfare of a person who is unable to do so on their own. Find out how to apply for deputyship for your young person, and what this role entails.



Mental Capacity Act

8 May, 12.15 - 2.15pm OR 6-8pm (time to be confirmed)

The Mental Capacity Act affects decision-making for all people over 16 years who are unable to make some or all decisions for themselves. For example, where the person should live, what services they need, consent to medical treatment, etc. Find out how Mental Capacity Act relates to people with learning disabilities and/or autism and their carers, who can take decisions, when and how.

Transition Clinics

These clinics are aimed at parents of young people with learning disabilities/autism who are approaching transition to adult services (aged 16+). There will be four sessions during the summer term: two in the evening (3 April and 5 June, both 6.30-9pm) and two during the day (9 April and 4 June, both 10am-1pm).

All sessions will take place at Sheffield Mencap & Gateway, Norfolk Lodge, Park Grange Road. For more information and to book your place, please contact the Sharing Caring Project on **0114 275 8879** or email **scpoffice@sheffieldmencap.org.uk**

Special needs toddler groups close in droves

The number of 'Ready Steady Go' groups for pre-schoolers with additional needs has shrunk to just one in the whole of Sheffield - down from over twenty in 2011.

Run as weekly 'play and stay' sessions, the groups were set up to enable parents with concerns about their child's development to talk to other parents and get advice from a range of professionals, such as Speech and Language Therapists, Portage workers and Health Visitors.

Most of the groups were run by Children's Centres, and the managers we spoke to blamed a reduction in Council funding for the closures.

Council officers, however, told us that the funding for the groups came from a time-limited government grant (DCATCH); it was only intended to cover the set-up costs and to help the groups become self-sustaining in the long term.

The one remaining group is based at Darnall Children's Centre.

No radical changes to post-16 provision

In last year's spring newsletter, we reported that Sheffield City Council was planning to move towards a four-day week for ALL students in specialist post-16 education (i.e. both at special schools and on specialist college courses), possibly supplemented by some employment-related or leisure activity on the fifth day. This move was intended to address historic inequities between providers, and to enable the council to meet increasing demand from a static budget.

We have now been informed that there will be no abrupt changes to post-16 provision. Instead, the intention now is to taper out the time students spend in special school sixth forms, whilst simultaneously increasing their participation in enrichment activities. This will be done via an individual timetable for each student.

In addition, the Council has given extra funding to the Sheffield College to increase provision for students on their Practical Skills courses from three to four days a week.

Two bridging programmes for school leavers from Talbot, Heritage Park and Holgate Meadows special schools (My Learning My Way and New Routes) have also had a funding increase to allow them to take on more students.

Need help planning your child's post-16 provision? The LDD Team at Sheffield Futures can advise you. Contact them on **0114 201 2800**.



Changes to SIGN and Parent Partnership

In January 2014, local charity Sheffield Information Link, which used to provide Sheffield's family information service and its disability arm SIGN, closed after 26 years.

The disability information service (no longer called SIGN) is now being provided by the Sheffield Parent Partnership Service. Parent Partnership already runs the "Parents as Carers" service, which was set up in 2012 to plug the gap that was left when the Sheffield Carers Centre stopped being funded to support parent carers - particularly around health and social care services, and disability grants and benefits.

By integrating these additional functions, Parent Partnership can now provide information, advice and support on a wide range of topics, covering education, health and social care, and access to disability benefits and funding.

The SIGN telephone number remains operational, but has been diverted to the council's central Family Information Service (0114 273 4567). This service will deal with all initial disability-related enquiries; parents

who require support and guidance can ask to be transferred to the Parent Partnership Service. Parent Partnership now employs two former SIGN workers, alongside existing staff experienced in special educational needs and disability.

The AskSid family information directory and most of the SIGN resources have been rebranded and incorporated into the Council website (www.sheffielddirectory.org.uk). This is likely to be a temporary solution, as most of this information should be incorporated into the new "local offer" website due to be launched in September (see pages 18 and 19).

By expanding the remit of the Parent Partnership Service in this way, the council is anticipating what is likely to become a statutory requirement when the SEN reforms are implemented in September: a new duty on local authorities to provide an impartial information, advice and support service for parent carers which covers education, health and social care across the whole 0-25 age range.

What's changed at Parent Partnership?

Extended remit: Parent Partnership no longer covers just education. They can now also help you to access health and social care services, benefits and funding, information about specific disabilities, and local leisure activities.

New telephone number: 0114 273 6009

New address: Parent Partnership Service, Floor 4, Redvers House, Sheffield S1 2JQ

Email: ed-parent.partnership@sheffield.gov.uk or disabilityinformationservice@sheffield.gov.uk

Campaign prompts rethink on cuts to travel passes

A campaign against cuts to disability travel passes has had an impact in Sheffield.

At Sheffield City Council's budget meeting on 7 March 2014, councillors promised to look into exempting disabled children travelling to school from planned cuts to local travel concessions.

Originally, South Yorkshire Integrated Transport Authority had announced that the following restrictions would apply to ALL disability pass holders from 31 March:

- Disability travel passes no longer valid for bus/tram journeys before 9.30am and after 11pm on weekdays
- "With Carer" travel passes no longer valid for bus/tram journeys before 9.30am and after 11pm on weekdays

- No more free train travel for disabled pass holders on train services within South Yorkshire, and between South and West Yorkshire, at any time

The announcement is a big success for parents in Sheffield who had campaigned against the restrictions.

The Sheffield Parent Carer Forum had written to councillors to argue that the cuts were not just unfair, but a false economy. This is because they would make it harder for young people with disabilities to become independent travellers, and for parents to take their disabled children to school using public transport - resulting in increased demand for SEN Transport, at major expense to the council.

We hope that the exemption will also apply to the use of the "With Carer" pass when used to escort a disabled child or young person to school or college - but this has yet to be confirmed.

Top tips from parents:

Renewing your child's mobility travel pass

- DON'T use the link "Renew or replace your mobility pass" on the Travel South Yorkshire website - even though it looks like it's working, nothing ever happens.
- There is no renewal form; you need to download the application form from the council website: www.sheffield.gov.uk/caresupport/adult/support-available/travel-pass/mobility-bus-pass.html
- Take/send the completed form back to Howden House, with the required evidence.
- You will get an authorisation letter by post within 28 days. Take this to one of the South

Yorkshire Passenger Transport Executive Travel Centres. You will also need to take:

- additional medical evidence for certain conditions, such as epilepsy (if in doubt, take everything!)
- proof of address, age and identification of the pass holder (if applying for a new pass)
- your child, if their photograph needs to be updated (travel centre staff can take a picture using a web camera)
- You should receive your pass by post within a few days.



Angela Sandhal

No Parking at Sheffield Children's Hospital



In addition, the hospital has set up a park and ride scheme with discounted parking rates for patients and their families at the Q-Park Castlegate site near Ponds Forge, with a free shuttle bus to the main hospital site on the hour.

To obtain the discount, visit the hospital's main reception desk and show your appointment letter. You will be given a discount voucher to use when paying at Q-Park.

For more information on the Q-Park Castlegate Park and Ride scheme and other forms of public transport visit www.sheffieldchildrens.nhs.uk/parking. If you have any special requirements, please contact Linda Towers, Patient Advice and Liaison Service Co-ordinator, on **0114 271 7594**.

For approximately the next 12 months, there will be no car parking available at the main Children's Hospital site due to major hospital and car park construction work.

Car access is limited to drop off and pick up only. Visitors to the hospital are asked to use park and ride schemes as well as other forms of public transport.

New nurses at Ryegate

Years of lobbying from parents have finally paid off! We are delighted to report that two new specialist nursing posts have recently been created at the Ryegate Children's Centre: Jane Mitchell specialises in learning disabilities and complex disabilities, while Jackie Gilmore works with children who have a diagnosis of autism or Asperger's. Both work with children who are under the care of a Neurodisability consultant.

The nurses offer parent workshops and home visits for children who have been newly diagnosed, or who have been referred to them by a member of the Neurodisability team. They also run nurse-led clinics for children who are due a review, unless parents prefer to see a consultant. Clinics take place at Ryegate as well as several special schools; Jane



Jane Mitchell

covers Talbot, Seven Hills, Woolley Wood and Norfolk Park, while Jackie runs clinics at Bents Green, the Rowan School and Mossbrook.

Clinic appointments last 30 minutes, but parents are given a phone number to call if they need further advice and support.



Jacqueline Gilmore

Question: Specialist college courses for post-16 students with learning difficulties or disabilities (e.g. Foundation Learning or Practical Skills courses) are usually limited to three or four days of provision per week. Since many of these students are unable to access opportunities for independent study without support, they effectively get fewer hours of education than their non-disabled peers. **Is this legal?**

Answer: Post-16 education is funded by the Education Funding Agency (EFA) and for places to attract full-time funding, they must comprise of at least 540 hours of study per year. This is based on a 30-week academic year and equates to 18 hours of study per week. The EFA provides additional funding for High Needs Students amounting to £6,000 per student for a specified number of places. Local authorities are also given a top-up fund to meet any additional costs of students with high needs.

Whether appropriate education or training is full-time or part-time will depend on what is suitable for the individual student, and this may or may not amount to three or four days of provision per week. What is clear, however, is that local authorities are provided with additional funding to support high needs students, and they will be expected to exercise their functions and spend the top-up fund to provide a higher degree of full-time education or training for high needs students where this is appropriate.

The starting point is to ask the Local Authority to do a Learning Difficulty Assessment (LDA) (sometimes referred to as an assessment under section 139A of the Learning and Skills Act 2000), and to ensure that the document

produced conforms with the guidance issued by the Department for Education.

The guidance document can be found on the Department for Education's website at www.gov.uk/government/publications/learning-difficulty-assessments.

One of the key objectives of an LDA is that it "should have a specific focus on the learning programme that is required to enable the young person to progress towards greater independence and where appropriate employment". If that cannot be achieved within 18 hours a week, then the Local Authority should consider increasing the number of hours by topping up funding. The other option is for the young person to apply for a social care personal budget and use this budget to supplement educational provision by purchasing services from a day centre, which have a social care and education aspect.

To conclude, it is a concern if a Local Authority were to take the approach of only commissioning three or four days of educational provision each week for young learners with a learning difficulty without exception when this is not sufficient to meet the needs of the young person or the objections in the LDA, and especially if there is no other provision in place for the rest of the time. It may be appropriate to take legal advice if the matter cannot be resolved through the Local Authority's complaints or appeal procedure.

Answer provided by Angela Sandhal, solicitor, Public Law Department, Irwin Mitchell LLP

Introducing our brand new feature! In this section, we want to celebrate your children's successes – from the small steps that perhaps only you noticed, to the big achievements that everybody can see. So, get snapping, get writing, and tell us what your wonderful children have been up to ...



Andrew is nine years old and goes to Mossbrook special school. His favourite activities include cleaning (particularly hoovering), swimming, playing with Lego, dancing with disco lights, and watching Zingzillas and Mr Tumble on iPlayer. One of Andrew's favourite places is sitting on his Dad's shoulders (when Andrew decides that he really doesn't want to walk - and he's heavy!).

Andrew has Down's Syndrome and is in remission from West Syndrome (infantile epilepsy), which means his development has been delayed and he is completely non-verbal. His sister Maria (7), who is a real chatterbox, likes to reassure those who haven't met her brother before: "Please don't worry, Andrew is just a 'Children in Need'".

Andrew has only recently started signing more spontaneously using Makaton. It is great to see the expression of relief and happiness on Andrew's face when he realises that he can ask for an ice cream for example, by signing. He also enjoys using PECS both at school and at home. This helps Andrew to deal with the feelings of frustration which



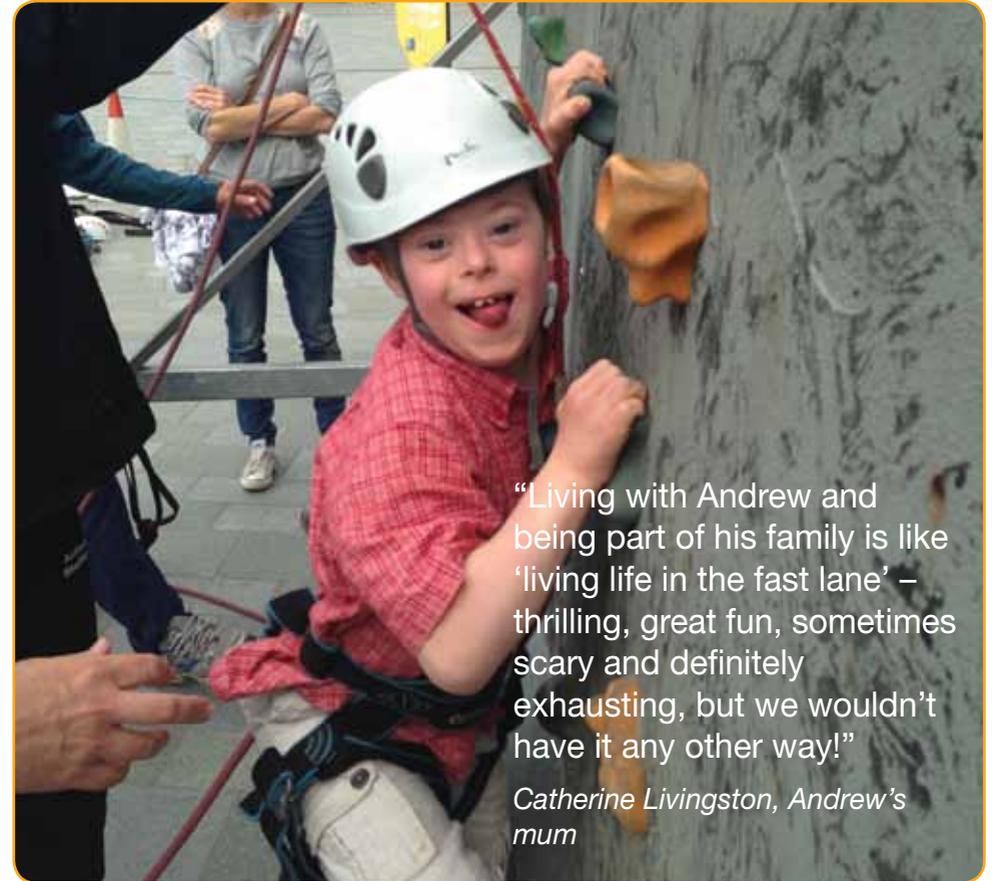
Star of this issue:
**Andrew
Livingston**

he often experiences as a result of not being able to talk.

The picture above is Andrew at his First Holy Communion. Leading up to the big day, Andrew and a friend had been attending "special" Holy Communion preparation classes at St Vincent's RC Church in Crookes.

Andrew's mum, who ran the classes herself, writes: "We enjoyed telling the children that Jesus loves us and wants us to celebrate with him, and they enjoyed many a party with balloons and cake (we had to blow out the candles every week). I will not deny that there were many challenging moments (at times I was the only person in the room). I discovered that bribes of satsumas were key to maintaining Andrew's interest!"

However, Andrew was definitely interested in the classes and showed some understanding. Every week, he would help to



"Living with Andrew and being part of his family is like 'living life in the fast lane' – thrilling, great fun, sometimes scary and definitely exhausting, but we wouldn't have it any other way!"

Catherine Livingston, Andrew's mum

put a cloth and a crucifix on a small table and sit with his hands joined in prayer, if only for a few seconds.

Finally, after many weeks of preparation classes, Andrew made his first Holy Communion together with his friends. We were so proud of him and it is clear from the photo that Andrew (what a smart boy!) was very happy on the day. Afterwards we went back home and had a big party with a bouncy castle in the back garden. It really was a day to celebrate. The Lord was smiling his broadest smile on us that day".

When out in town one day, Andrew discovered that a climbing wall had been erected in Tudor Square. Completely skipping the queue, Andrew made his way under the barrier to the base of the wall and before he knew it (with mum's permission) someone had put a helmet on him and he was being rigged up to go up the wall. He didn't go very far up, but the joyous expression on his face says it all! Andrew's mum is now looking into climbing as a new hobby for Andrew...





In September 2014, the special needs system will undergo the biggest overhaul in 30 years. Since the legislative framework is yet to be finalised, we can only give you a brief overview at this stage. More detail will be included in our autumn newsletter.

Education Health and Care Plans

Statements of SEN and Learning Difficulty Assessments (LDAs) will be replaced with Education Health and Care (EHC) plans. Unlike statements, which lapse when a young person leaves school or turns 19, EHC plans will remain in place when a young person goes to college or starts an apprenticeship, and they can go up to age 25. This should help to make the transition to adulthood less of a “cliff-edge”.

EHC plans will be more holistic than statements and cover health and social care as well as education. However, they will still only be available to children and young people with significant **educational** needs.

This is because the legal thresholds for triggering an assessment and issuing an EHC plan will be the same as for statements; namely, that the child has special educational needs which cannot be met from the resources “normally available” to mainstream settings. However, recent national changes to the school funding system mean that what is “normally available” is now defined as special educational provision costing up to £6,000 per year. In Sheffield, this financial threshold will be one of the criteria used to determine whether an EHC plan is required; however, it will NOT be the only one, and pupils needing less expensive provision may also qualify.

The government has said that it expects the “overwhelming majority” of children and young people who currently have a statement/LDA to move to an EHC plan. Transitional arrangements have yet to be finalised; however, it looks likely that this will be a gradual process, with groups of children transferring from statements to EHC plans when they reach a

key transition stage. We expect that the transfer will be done as part of the annual review, and without a reassessment.

The new legislation will ring in some major cultural changes. By placing a strong emphasis on involving children, young people and their parents as equal partners in the assessment process, it has the potential to turn what is often a faceless paper exercise into a genuine collaboration. A new focus on “outcomes” means that it will no longer be acceptable to just allocate x hours of provision, and leave it at that. Instead, schools and service providers will need to show how they are supporting the child or young person towards achieving meaningful long-term and short-term goals.

School Action, School Action Plus and IEPs to be scrapped

School Action and School Action Plus will be replaced with a single SEN category. At the time of writing, very little information was available as to which pupils would be included in this category.

The guidance on IEPs (Individual Education Plans) has been removed from the Code of Practice and replaced by a “cycle” approach of assess/plan/do/review. Although schools will still have to record what they are doing and the impact this is having, they will no longer need to follow a standardised national system.

Improved information through a “local offer”

From September 2014, every local authority will have to publish a “local offer” – a website with information about the range of support and services available for children and young people (aged 0-25) with special educational needs and/or disabilities in the area. Importantly,

this must include information about eligibility criteria and referral routes. Schools and service providers will also have to set out their own “offers” for this group of youngsters.

The local offer has two purposes: to make it easier for families to find the information they require, and to make provision more responsive to local need. This will be achieved through a new duty on local authorities to publish, and respond to, comments on their local offer.

How the Forum is involved

At the start of the year, we held two consultation workshops to find out what parents thought of the EHC plan template developed by council officers. The feedback was mixed; while parents liked the person-centred elements – such as the one-page profile with key information about the child – they also expressed concerns that a potential lack of detail could affect the enforceability of the plan.

We also worked with the council to organise a consultation on the local offer. Parents told us how they wanted the local offer website to be structured; the kind of features it should include; and what sort of information schools and services should be required to provide. They emphasized that written information could never be a substitute for face-to-face advice.

Our parent representatives, who sit on several local authority groups tasked with implementing the reforms in Sheffield, keep highlighting this feedback to ensure the views of parents are taken into account. For progress updates, please keep checking our website, or come to our Education subgroup meetings (see page 22 and 23 for dates).

Sheffield Family Support Group

The Sheffield Family Support Group is a small community group that organises fun social swimming sessions for children and young people (0-19 years) with a learning disability, and their families and friends.

Only members of the group are in the pool for these sessions, which take place in the leisure pool at Hillsborough Leisure Centre once a month. We alternate between Saturday and Sunday nights to give as many people as possible the chance to take part in this activity. The pool session lasts for an hour, and swimmers can use the waterslides and experience the thrill of the waves. After swimming, there is the option of staying for a children's party with buffet food including pizza slices, sandwiches and potato wedges.

The group has been fortunate in receiving funding from the South Yorkshire Community Foundation for 2013/14, and are hoping to be successful in applying for funding again this year.

The children really enjoy the swimming and eating with their friends at the party afterwards. Parents and carers value the family time, but also enjoy the opportunity to socialise with, and get support from, other parents and carers. Siblings enjoy meeting each other for social time and support.

The group has had a stable membership of around 25 families for a number of years, but many of our children are now young adults who are moving on and we would really like to welcome new members with younger children. In the past we have organised other activities such as day trips in the school holidays, drum and dance workshops, theatre trips and Christmas parties, and



would love to do so again if there is enough interest. We are also developing a website and a Facebook page.

Come along to our next session!

Where: Hillsborough Leisure Centre, Beulah Road, Sheffield S6 2AN

When: Saturday 5th April 2014, 6.30-7.30pm (swimming session), and 7.45-8.30pm (party session). Most people arrive around 6.15pm to allow time to book in and get changed.

Cost: £5 per child for a swim only, and £6 per child for a swim and food. Parents and carers swim for free.

More information: Contact Tana Holmes on **0790 6620383** or email **tana.holmes20@googlemail.com**

It will never happen.
But it did.



James, with Mont Blanc in the background

Last year on a family holiday in France, our son James had one of his infrequent but serious epileptic seizures.

We drove him to the local hospital where he received excellent emergency treatment; but because he was still fitting and his breathing was affected, he and I were transferred by helicopter and ambulance to the children's hospital in Lyon. James was admitted to intensive care where he stayed for a week, before we were flown home in an air ambulance.

The whole experience was very traumatic but thankfully, because we had travel insurance that covered James' condition, it didn't bankrupt us as well. I don't know the total cost of our claim, but the helicopter bill was for €2,300. Goodness knows what the air ambulance cost!

We used the annual family travel insurance policy that came with our bank account.

Getting additional cover for James was relatively straightforward. I had to disclose all his existing medical conditions, have a telephone conversation with the insurance company's medical advisor, and pay a small additional premium.

We also had James' European Health Insurance Card (EHIC) with us. EHIC entitles you to state healthcare at a reduced cost or sometimes for free. It provides cover for emergency and routine treatment, including treatment of pre-existing medical conditions, in all European Economic Area (EEA) countries, including Switzerland. NB EHIC is NOT an alternative to travel insurance! It will not cover any private medical healthcare (including ambulances) or the cost of returning home. For more information, please visit: www.nhs.uk/NHSEngland/Healthcareabroad/EHIC/Pages/about-the-ehic.aspx

The good news. James recovered well from his ordeal and amazingly, the insurance company agreed to reinsure him. So this summer we will return to France for an uneventful and enjoyable family holiday because lightning never strikes twice!?

By Anne Snowdon

Travel Insurance Tips:

- If you are part of a local support group or a social network, ask other parents if they can recommend any insurance companies; recommendations from people in a similar position can be invaluable.

Continues on the next page...

Travel Insurance Tips:

Continued

- All existing medical conditions must be disclosed and accepted by insurance underwriters for you to be fully covered.
- All members of your party should be covered under one policy.
- You need an EHIC for every member of your family.
- EHICs are FREE; do not be scammed into paying for one.

Family Fund Travel Insurance

The Family Fund has teamed up with Holiday Direct Insurance to offer affordable holiday cover for families caring for a disabled or seriously ill child aged up to 18 years old (or 23 if they are in full-time education at the time of travel). Advantages of the policy include automatic cover for all immediate family, including grandparents and carers, and no requirement for medical screening for existing medical conditions. Cover starts from £23.76 per family, per trip. For more information, please visit www.familyfund.org.uk/travelinsurance

National disability charities

National disability charities often have commercial relationships with travel insurance companies which might be worth looking at, e.g.:

- National Autistic Society: www.autism.org.uk (search for "travel insurance")
- Epilepsy Action: www.epilepsy.org.uk/info/travel-insurance

Dates for your diary

April

Thursday 10 April, 10am-12noon

Legal advice drop-in

See page 6 for more information and how to book.

Thursday 10 April, 10.30am-12noon

Coffee morning

See page 7 for more information.

Friday 11 April, 10am-12noon

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 - particularly the implementation of the SEN reforms - in Sheffield. This is a friendly and informal group, and new members are very welcome!

Wednesday 30 April, 9.30am-1pm

Working Together training

Open training session for professionals who work with children with special needs and their families. See page 8 for details.

May

Friday 2 May, 10am-12noon

Health subgroup meeting

This meeting will be attended by senior staff from the Child and Adolescent Mental Health Service (CAMHS). We want to talk to them about getting parents involved shaping in the service, and about improving support for parents of CAMHS patients.

May cont.

Thursday 8 May, 10.30am-12noon

Coffee morning

See page 7 for more information.

Monday 12 May, 12-2pm

Legal advice drop-in

See page 6 for more information and how to book.

Friday 16 May, 10am-12noon

Meeting about SEN transport

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

June

Friday 6 June, 10am-12noon

Quarterly open meeting

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

Wednesday 11 June, 10am-12noon

Legal advice drop-in

See page 6 for more information and how to book.

Thursday 12 June, 10.30am-12noon

Coffee morning

See page 7 for more information.

June cont.

Friday 20 June, 10am-12noon

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 - particularly the implementation of the SEN reforms - in Sheffield. This is a friendly and informal group, and new members are very welcome!

July

Thursday 10 July, 10.30am-12noon

Coffee morning

See page 7 for more information.

Tuesday 15 July, 12-2pm

Legal advice drop-in

See page 6 for more information and how to book.

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

To ensure we have a big enough room, it would really help us if you could let us know in advance if you are planning to come along to any of these meetings (please see inside front cover for contact details).

For more event information, please visit our website: www.sheffieldparentcarerforum.org.uk/calendar

Useful Contacts

ADHD Project Provides information, support and training for families with a child with ADHD	0114 321 1705	katy.greaves@family-action.org.uk
Autism Service* Supports mainstream schools to meet the needs of pupils with autism and related conditions	0114 235 8056 (helpline) 0114 273 6412 (office)	moira.bolan@sheffield.gov.uk
Children with Disabilities Team* Social work team for children and young people with disabilities. First point of contact for requests/referrals for short breaks services	0114 273 5368	
Contact-a-Family National charity which provides information and advice on any aspect of caring for a disabled child, including education and benefits	0808 808 3555	helpline@cafamily.org.uk
Direct Payments Team* Provides support, advice and 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 and in settings	0114 273 6411	elizabeth.hodkin@sheffield.gov.uk cathy.wigg@sheffield.gov.uk
Educational Psychology Service* Works with families and staff in educational settings to support the education and development of children and young people	0114 250 6800	mary.collins@sheffield.gov.uk
Hearing Impaired Service* Works with children who are hearing impaired	0114 273 6410	caroline.chettleburgh@sheffield.gov.uk
Independent Travel Training* Trains young people with disabilities/learning difficulties to use public transport to get to school, college and work placements	0114 205 3542	jill.siddall@sheffield.gov.uk
IPSEA National charity providing free legally-based advice on educational issues for parents of children with SEN	0800 018 4016	Email information service via www.ipsea.org.uk
Portage Home Visiting Service* Home-visiting educational service for children under three with additional support needs and their families	0114 273 6411	debbie.marshall@sheffield.gov.uk
Ryegate Children's Centre Assessment, diagnosis and therapy for children and young people with developmental and neurological problems	0114 271 7651	

School to School Support (formerly Learning Support Service) Run by Talbot Specialist School, this service supports schools and parents to improve inclusion and attainment of pupils with SEN and disabilities	0114 2930932	edlss@sheffield.gov.uk
SEN Assessment and Placement Team* Deals with statutory assessments, statements of SEN, annual reviews, SEN transport and specialist placements	0114 273 6394	ed-sensupportteam@sheffield.gov.uk
Sheffield Children's Hospital	0114 271 7000	sheffield.childrenshospital@sch.nhs.uk
Sheffield Futures Learning Difficulties and Disabilities (LDD) Team Supports young people with learning difficulties and disabilities to make the transition into further education and employment	0114 201 2800	enquiries@sheffieldfutures.org.uk
Sheffield Parent Partnership Service* Provides information, guidance and support for parents of children with SEN and/or disabilities including education, the SEN processes, leisure, benefits and funding	0114 273 6009	ed-parent.partnership@sheffield.gov.uk or disabilityinformationservice@sheffield.gov.uk
Sibling support group Support group for children who have a brother or sister with a disability.	0114 233 2908	philip.hazlehurst@burtonstreet.org.uk
Special Needs Inclusion Playcare Service (SNIPS)* Provides training, grants and mentoring support to help clubs include disabled children aged 5-18	0114 273 4017	amanda.hill@sheffield.gov.uk
Social Care Transition Team* Team of social workers who offer a transition planning service for young disabled people leaving full-time education	0114 273 5368	katarina.bajin-stone@sheffield.gov.uk
Transport Services* Provides transport services including home-to-school transport for pupils with SEN	0114 203 7570	transportservices@sheffield.gov.uk
Vision Support Service Supports children with a visual impairment and their families	0114 294 1201	marion.broadhurst@sheffield.gov.uk
Within Reach Provides sport and physical activity for disabled people of all ages	0114 273 4266	alex.wilson@sheffield.gov.uk

* Part of Sheffield City Council



Principle Support Ltd

Short Breaks and Community Based Activities

For young Adults with Learning Disabilities



Tideswell Court, 4 Tideswell Court, Sheffield S5 6JJ

We are situated in a quiet residential area in the north of the city, in Longley Sheffield. Tideswell Court is registered with the Care Quality Commission and can accommodate three service-users for overnight stays at any one time.

The house is within easy reach of the town centre and there is easy access to a number of historical areas of interest, leisure and recreational facilities.

Short Breaks

We offer short breaks in a homely environment where you can continue to develop your skills and abilities.

Support is organised to suit individuals whether it is an overnight stay, weekend, a few days or regular visits.

Support is always available
24 hours a day



Community Based Activities

During your stay at Tideswell we are able to offer a wide range of indoor and outdoor activities...

- **Crafts** - Farming and Gardening
- **Life Skills** - Cooking, Baking, Shopping, Budgeting, Travelling
- **Leisure and Social** - Ice-skating, Swimming, Crazy Golf, Walking, Ten-pin Bowling
- **Day Trips** - Museums, Galleries, Historic sites and more...

For further information contact us

Principle Support
Head Office, 9 Orgreave Road, Khepera Business Centre
Sheffield S13 9LQ

Telephone: **0114 213 1750**

Fax: **0114 238 1870**

Email: info@principlesupportltd.co.uk

Website: www.principlesupportltd.co.uk

The Sheffield Parent Carer Forum accepts no responsibility for advertisements placed in this newsletter. We urge families to check that providers comply with safeguarding and health and safety requirements before using their services.

Sheffield Parent Carer Forum Application for Full Membership

Full membership is FREE and open to all parents and carers of disabled children and young people (0 - 25) who live in Sheffield or access services in Sheffield.

About you

First name Surname

Street and house number

Town/city Postcode

Email address (please print)

Home phone Mobile

Your ethnic group (optional)

About your disabled child/children

Child 1

Date of birth

Main disability

Other disabilities

School (name)

Child 2

Date of birth

Main disability

Other disabilities

School (name)

Child 3

Date of birth

Main disability

Other disabilities

School (name)

Please tick as appropriate :

Please add me to your email list.

Please add me to your text messaging list.

Please add me to your postal mailing list.

I am happy to take part in consultations:

by phone by email

by post by SMS

I am interested in volunteering with the Parent Carer Forum.

Signature

Date

Please note: By signing this form you consent to the Sheffield Parent Carer Forum storing your information. We will not pass any of your details on to any third parties. Members of our postal mailing list will receive a regular newsletter. Members of our email list and text messaging list will receive news updates and events information. You are free to opt out of this service at any time.

Tear along here

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

2



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

Fold along here



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