

# out of amaze



For parents of children with special needs in Brighton & Hove



## More than the money

We wanted to know what you think of our **DLA service**, so we got a nice man from the University to ask you and you told us it's worth more than just the cash.

Dr Carl Walker, from the School of Applied Social Science at the University of Brighton, interviewed a sample group of parents who had received Amaze's support with claiming DLA. He asked them for their views on the DLA service and also about the impact that having a disabled child has on their lives.

### What you told us

Parents who took part said that our volunteers are friendly, warm, flexible and approachable. They listen and listen some more, with empathy and genuine positive regard. They make

claiming DLA, often described as a 'hideous' process, much more bearable and do-able than it would otherwise have been.

Asking 'curious questions' and 'wondering aloud' tells you 'it's right to be concerned and you know your child best', when very often other agencies had made you feel as if the problem lay with you or that your views didn't count.

Just 'letting you talk' means you can 'tell it how it really is', balancing everyday challenges with the joy your

Turn to page 2 to read more...



### Amazing award

Amaze was delighted to win the much-coveted 'Biggest Impact' award at the inaugural CVSF Sector Stars Awards 2012. The awards, organised by the Community and Voluntary Sector Forum, recognised our work in Brighton and Hove supporting some of the city's most vulnerable families.

Rachel Travers, Amaze CEO, said: "To win the award category 'Biggest Impact' is overwhelming. For the last 15 years our staff and volunteers have worked tirelessly to provide Brighton and Hove's parents and carers with the information and support they need to get the best for their children. We're so proud to be recognised for these efforts – and the impact we are making on our local community."

The panel of judges, which included Mayor, Bill Randall, and Councillor Phelim Mac Cafferty, Deputy Leader of the council, said: "Amaze were recognised for years of dedicated support to some of the city's most vulnerable people and for their staff who go above and beyond their responsibilities to ensure successful outcomes."

Thank you once again to all our staff and volunteers.

**INSIDE:** Housing • Therapies latest • More sports for teens • PIP and DLA compared • Amaze courses • SEN Strategy launch • Parent stories and more...

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child brings, rather than focusing just on the negative stuff. Also, it's a relief that our volunteers are happy to take on the writing it down and you say we are very skilled at drawing out what is out of the ordinary about your family life and catching it on paper.

**'My volunteer teased it all out...gave it language, ...could make the links that I just couldn't see by myself'**

Amaze volunteers are often a 'gateway', thinking about the needs of the whole family and signposting you to other relevant activities, services and support groups.

Getting an award of DLA for your child contributes very positively to your financial and mental health and this had a knock on effect for your child's wellbeing and the rest of the family; many of you said you couldn't have done it without help. It is a clear signal that what you do is extra and different and for good reason.

The process of claiming has an impact of its own: you have the same child but you understand their needs better and feel more able to manage.

Sometimes you have to wait longer than we would like for help and this can feel stressful. We will work harder to get better at this.

We'll leave the last word to Carl: "Parents spoke openly about loss, isolation and the relentlessness of 'living on red alert day and night', but what shone through was positivity, resilience and loving relationships."

**Read the full DLA report in the Resources section of our website under Publications/reports. If you want help with claiming DLA, call our helpline on 01273 772289. And thank you to all the parents who took part.**



## More sports for teens with LD

As you'll read on page 9, Compass Card teens will get another six Compass Card Activities this year, thanks to Sport England funding, but there's more good news on the way for young people with learning disabilities in the city.

Like Amaze, the Hove-based Grace Eyre Foundation was also awarded Sport England money; and its three year 'Sports for All in Sussex' programme will benefit young people over the age of 14, as well as adults.

The new project, which will roll out in West Sussex as well as Brighton

and Hove, starts in the spring and brings together partners including Grace Eyre, Special Olympics, Freedom Leisure, Badminton England and Outreach 3 Ways. Activities will include boccia, badminton, football, power lifting, swimming, golf and ten pin bowling.

Amaze will be working closely with Grace Eyre to ensure that Compass families benefit from the new project, as well as the exciting new programme of Compass Card Activities. Watch this space!

## New group say Mental Health Matters

Mental Health Matters is a new support group for parent carers of children and young people with mental health and wellbeing issues. It's informal, friendly, run by parents for parents and all about sharing experiences and supporting each other. The group meets regularly in Brighton and Hove but varies the times and venues to try to meet parents' availability.

If you have a child or young person who is struggling with dealing with everyday life, may or may not have a diagnosis and would like to talk to other parents in similar situations, then contact Becky Jenner on [rebeccaljenner@aol.co.uk](mailto:rebeccaljenner@aol.co.uk). Or find out more on Facebook at [www.facebook.com/MentalHealthMattersCYPPC](http://www.facebook.com/MentalHealthMattersCYPPC)



## Our SEN Fair ticks your boxes



A whopping 97% of parent carers who completed a feedback postcard at our recent SEN Info Fair told us that they found the event useful or very useful!

You told us that being able to speak to so many services and organisations (including Amaze itself!) all in one place was the best bit, closely followed by the workshops we ran on the day and the pampering for parent carers. We asked you if there was anything missing from the Fair but,

aside from making the event longer, you think we managed to cover almost everything that you wanted us to on the day.

We also used the feedback postcards to find out what you think of Amaze services and, once again, 97% of you said you find them useful or very useful. Great news! You gave us some suggestions for what we might do more of too; most popular were more workshops and groups for parent carers and more help with transition to adulthood.

This has given us plenty to think about and we'd like to say a big thank you to everyone who filled out one of our feedback postcards on the day.

You also told us about your priorities for SEN provision in the city - more about these in the next issue!



## Could you be a befriender?

Do you remember how you felt when your child was given a diagnosis of disability or additional need? Would you like to use your experience to help other parents going through this? If so, why not offer your time as a befriender?

Scope, a national disability organisation, has obtained funding to develop a Face 2 Face befriending scheme in Brighton. Face 2 Face is a one-to-one befriending service offering emotional support to parents whose children have been recently diagnosed, or at any other time a parent feels overwhelmed with issues relating to their child's disability.

Every Face 2 Face befriender is a parent too – someone whose own child has a disability. They know what it's like to cope with a new diagnosis and can offer support to help parents make positive adjustments to the news that their child has a disability. Full training and ongoing support is given to all Face 2 Face befrienders.

If you are a parent of a child who has a special need or disability, and you have some time to befriend and support other parents, call Nigel Marsh, Scope Senior Regional Response Worker, on 0808 800 3333, or email [nigel.marsh@scope.org.uk](mailto:nigel.marsh@scope.org.uk) or visit [www.scope.org.uk](http://www.scope.org.uk)

## Brighton unveils new SEN Strategy

Brighton and Hove has a new SEN strategy to shape the future for special educational needs in the city for the next five years. Parent carers got a preview at our Info Fair (see above) before it was officially launched on 30 November.

So far, everyone seems happy with the overall vision which emphasises that SEN is not only about helping children get the best they can from education, but also about how they can lead happy, healthy, independent and fulfilling lives right through to adulthood. The message is that Brighton will set its sights high, encourage good partnership (inc. with parents) and try to make sure most children can get what they need as locally as possible.

The strategy sets out five priorities that have also been met with general approval:

1. To improve outcomes and reduce disadvantage for children and

young people with SEN and disabilities

2. To improve the assessment and identification of SEN and disabilities
3. To create and ensure high quality provision for all children and young people with SEN and disabilities
4. To work proactively and collaboratively with parents, children and families
5. To improve transition arrangements post 16 and services for young people up to the age of 25

The strategy picks out two groups of children for a special focus: those with ASC and BESD. So it's all looking positive, but the proof of the pudding is what happens in practice. The next step is five new working groups, one for each priority, to look at how to move in the right direction. We're aiming for a parent rep on every group and we'll let you know as things take shape.



## A place of their own?

Explore your child's future housing options with Amaze

### Are you starting to think about where your young person might live when they are older?

Like many parents, you might be finding it difficult to imagine your child not living with you when they get older. You may be worried that no one else will be able to care for them and love them in the way that you do. Or you may be feeling that you're ready for them to leave home but are worried that there is no suitable support and provision for them.

Amaze is writing a new chapter for our 'Through the Next Maze' handbook for parents which will be ready in September. It will explain what the housing options are in Brighton and Hove for young disabled people. It will include the experience of other parents and young people who have made that move and can offer some tips about how they've gone about it.

From talking to parents whose young people have moved out, what comes across clearly is that it's important to think and start planning early for this major move. You can start discussing housing options when your child is still at school as part of their transition planning annual review meetings.

If this is something you're starting to think about and would like to find out more and get together with other parents to talk about this, Amaze is organising a **Housing meeting on Tuesday 12th March** at Community Base from 10am to 12 noon.

**Please contact the helpline on 01273 772289 to let us know you'll be coming. If your son or daughter has moved out, then we'd be really interested to hear about your experience. Contact the helpline and leave your details and Sue will get in touch with you.**

### The Lowdown on DLOs

Did you know that Sussex Police has Disability Liaison Officers (DLOs) working across the county to ensure that people with a disability get fair and equal treatment from the police?

DLOs are police officers and police community support officers who work as part of Neighbourhood Policing Teams. They are provided with additional training to engage with and offer support and advice to people who have a disability.



### What do DLOs do?

- Offer a friendly point of contact for people with a disability and give advice and support
- Make sure that disability-related hate crime is identified as such, and ensure other members of the force do the same
- Help people with a disability to find out about useful services
- Advise officers and staff about engaging people with a disability and removing barriers
- Act as a public figurehead for people with a disability and ensure that they are valued within community groups

DLOs are happy to provide help and advice if you have any questions or need support with a particular issue.

To speak to a DLO, call 101. Or you can find out more on Facebook at [www.facebook.com/BrightonHovePoliceDLO](http://www.facebook.com/BrightonHovePoliceDLO) or via [www.sussex.police.uk](http://www.sussex.police.uk)



## Bye DLA, hello PIP for rising 16s

From April 2013, the Government is introducing a new benefit for disabled adults. Personal Independence Payment (PIP) replaces Disability Living Allowance (DLA) for eligible working age people. Here we tell you how PIP will be rolled out.

**From June 2013, there will be no new claims for DLA for adults (nothing is changing with children's claims). The exception will be for some young people coming up to 16, who are already getting DLA.**

**Your child will need to claim DLA again if their DLA award ends on their birthday and they are 16 on or before 6 October 2013.** Although you miss out this time, you can look forward to claiming PIP some time before March 2018!

**Your child will need to claim PIP if they turn 16 on or after 7 October** when their existing award for DLA is coming to an end.

**You'll get a letter to tell you when and how to apply for PIP:** and you'll need to tell DWP if you intend to make a claim for PIP.

**You cannot apply for PIP until a person is 16, so there will be special rules** allowing the DLA award to run on after your child's birthday, until a decision is made on the claim. These claims will be looked at by a specific team of decision makers.

**From October 2013, anyone over 16, reporting a change in circumstances which might affect the rate of their DLA award, will be reassessed under PIP.**

**From that date, you can choose to make an application for PIP even if you have a fixed-term or indefinite award of DLA.** This would make sense where a young person is likely to be awarded a higher rate under PIP than their current DLA award.

**From October 2015 PIP will be rolled out to everyone else.** There will

be no automatic migration between the benefits. Everyone still getting DLA will, over time, be contacted and invited to claim PIP.

**Young people with indefinite or lifetime awards of DLA** will be the last to be moved on to PIP. The DWP says it does not expect to complete the reassessment of all existing DLA claimants for PIP until March 2018.

**As appointee, you need to act promptly as soon as a young person is invited to claim PIP.** If neither of you reply to the invitation to apply for PIP, their DLA award will be suspended only four weeks later. If a claim is made within four weeks after



the suspension, the DLA award will be restored until a decision is made on the PIP claim. If you do nothing, your child's DLA claim will end after eight weeks. There will only be limited appeal rights against this decision.

**Any DLA award will always end when the PIP claim is decided.** If you are refused PIP, you cannot go back to claiming DLA.

**In the next issue we'll tell you more about how decisions are made and how to make a strong claim.**

### DLA and PIP - SPOT THE DIFFERENCE!

- PIP will not be taxed, or counted as income for means-tested benefits or Tax Credits. It's not based on National Insurance contributions and can be paid both in and out of work.
- PIP has two components: a mobility component based on a young person's ability to get around, and a daily living component based on their ability to 'look after themselves'.
- If a young person is entitled to the daily living component of PIP, then someone else may be able to claim Carer's Allowance for looking after them.
- Getting the enhanced rate of the mobility component will entitle a young person to access the Motability scheme and a Blue Badge
- PIP will be a passport to disability premiums and extra Tax Credits in the current benefits system. In future, if a young person is included in their parents' Universal Credit claim, a disabled child amount will be payable in the household's Universal Credit award.
- Any household that includes someone getting PIP will be exempt from the benefit cap.

**However, while it looks similar in some respects, the PIP will use an entirely new set of criteria to decide whether someone qualifies for the benefit and if they do, the rate they will be paid. More about this next issue!**



## Link UP is 10!

Last December, Link-Up, the social group for parents and children with special needs in mainstream school, celebrated its 10 year anniversary. They had a private party at Funplex to celebrate and children of all ages, with all sorts of special needs, had tons of space to play, while their parents chatted and relaxed over a cup of tea. One family said, "The Link-Up Party was the best activity we went to over Christmas".

Link-Up was founded by a group of parents of children with SEN at Elm Grove Primary School. These parents got together to organise fun activities for their children. The activities were so successful that they decided to apply for funding so that they could organise activities for a greater number of children in mainstream schools with SEN.

Link-Up is still run entirely by parents of children with SEN. They organise activities for children with Statements or on school action plus in mainstream schools. These children often feel isolated at school, and Link-Up gives them and their families the chance to socialise and do things they might not be able to do otherwise. Link-Up's members have a really broad range of special educational needs, including Down's, ASC, speech and language difficulties, sensory needs and global developmental delay.

Over the last year, activities have included horse-riding, a trip to Drusillas, pizza making and residential trips. In January, Link-Up went ice-skating at the Royal Pavilion. Over 20 children were on the ice, some having a quick go before deciding a hot-chocolate inside was preferable, some persevering to the end!

Diana Boyd, Link Up treasurer, says, "It was lovely to see so many children and their families getting together and having fun. My son Luke, who first stepped onto the ice just a year ago at the previous Link-Up ice-skating trip, whizzed round the ice joyfully. Link-Up gave Luke the confidence to give it a go last year, and combined with some roller-blades handed down from another Link-up member, he is now a confident, happy skater."

Link-Up is currently planning a trip to Legoland, a residential weekend and more horse-riding. They are lucky to have Children in Need funding, so most activities are free for Link-Up child and carer, with a small charge for siblings.

**If you'd like to become a Link Up member, email [linkup@linkupbrighton.org](mailto:linkup@linkupbrighton.org) or call Gail on 01273 271868.**

### Other local social and support groups

**Kaleidoscope:** for parents and carers of children with physical disabilities. Call 07807 647630 (Preston Circus)

**Sweet Peas:** parent and toddler group for children with special needs. Call 07917 887526 (city centre)

**Little Darlings:** for children with special needs and their parents or carers. Call 07799 414837 (Hollingdean)

**Brighton Pebbles:** for families with disabled children aged 4-14 with any disability. Call 07766 156571 (Hollingdean)

**Parents with Teens:** Amaze group for parents of teenagers with special needs. Call 772289 (city centre)

### Groups for specific conditions:

**mASCot:** Autistic spectrum condition parent support group and online forum. Email: [info@asc-mascot.com](mailto:info@asc-mascot.com) or visit [www.asc-mascot.com](http://www.asc-mascot.com)

**Dyspraxia Foundation Sussex (East) Parent Support Group:** Meet monthly in Brighton. Contact [lucy.dcd@ntlworld.com](mailto:lucy.dcd@ntlworld.com)

**Tourette Syndrome support groups:** for parents/carers of children with Tourettes. Contact [emma@tourettes-action.org.uk](mailto:emma@tourettes-action.org.uk)

**T21 Brighton & Hove:** for children with Down's Syndrome and their families. Call Emma on 07810 567626

**Worthing KiDS Down's Syndrome Support Group:** for families with children up to 12. Call 07570 768893

If you don't see a suitable group here, call our helpline for more info. Also, see details of a new Mental Health support group on page 2.

# A day in the life of...

Kerry Bridge, participation worker for the Aiming High Advisory Group (AHA!)

I have been working for Brighton & Hove City Council for six years. I work in the Participation Team as part of the Youth Service. I first started my job volunteering for the Participation Team to help set up the Brighton and Hove Youth Council when I was 15 years old.

## What is the AHA! Group?

The AHA! Group was formed to let decision makers know what young disabled people think about growing up in Brighton and Hove. The young people meet four times a term and we discuss issues that are facing them such as independence, acoustic play equipment in parks and the new Special Educational Needs Strategy to name a few things.

## My work with the group

First of all we have a staff meeting at the beginning of each term to decide when the meetings can take place, what issues we are going to discuss with the group and who is going to lead what part of the session.

**‘At the meetings young people talk about issues that are facing them.’**

After the dates are set I book the taxis for the young people in the group through the Home to School transport team. At the meetings young people talk about issues that are facing them

such as independence, transport and provision and accessibility of



activities for young people with disabilities. After the meetings the voices of young people get recorded in Key Actions and Important Messages which gets taken to the Strategic Disability Partnership Board. Then the process happens all over again!

What I love most about my job is working with the young people and listening to what they have to say and also seeing the young people grow within themselves.

## School surprise - Pets are welcome!

Would you believe us if we told you that it's not just humans working in our schools - cats and dogs are doing their bit too! Sussex Caring Pets (SCP) is a local charity that provides animal assisted therapy in schools, hospices, care homes and hospitals. Owners and their pets are assessed for suitability and, if successful, they get to work alongside professionals, sharing their pets' love with others who need it.

Graham Bourgoing, chair of SCP, explains: 'Our therapy support dogs and cats can stimulate those who might feel isolated or not motivated to communicate with others, with their non-judgemental affection.'

SCP also works in the Cedar Centre special school, where Graham teaches maths: 'At the Cedar Centre, therapy support dogs help children talk more calmly and easily and, ideally for me, better focus on counting and maths! The sessions are very informal according to the individual's needs.'



This is where you can come in - SCP are looking for more volunteers. You and your pets have an assessment and, if successful, you can volunteer for an hour a week, a fortnight or month - whatever suits.

Graham, who volunteers with his golden retriever Lucy, recommends it: 'I can say, without hesitation, it's been a rewarding and enjoyable experience for us both!' Download the application form at [www.sussexcaringpets.org](http://www.sussexcaringpets.org) or email [info@sussexcaringpets.org](mailto:info@sussexcaringpets.org)



## More money making heroes

You don't just have to be a runner to raise money for Amaze. All sorts of activities can help to build up our funds. For example, recent events have included coffee mornings, cake baking, Christmas carols and collections.

Girls from a **Roedean School Business Studies Class** really thought out of the box and raised a fantastic £928.50 when they turned their hand to selling onesies and mobile phone covers.



And the **Grand Hotel Brighton** gave us a cheque for £1000 from their corporate fundraising pot to support the Amaze Helpline. A group of Amaze families and staff enjoyed a grand high tea as staff were presented with the cheque.

We'd like to say a huge thank you to the Roedean girls and the Grand. And if any of you out there have a good fundraising idea of your own, however modest, contact Nicky Bagilhole on 01273 234020 or email [nickyb@amazebrighton.org.uk](mailto:nickyb@amazebrighton.org.uk)



## Marathon runners get set to go

A big shout out to all those of you who right now are limbering up to run for Amaze in the Brighton Marathon on Sunday 14 April!

### All the difference

We really appreciate all the hard work and dedication our runners put into supporting the work we do with parents of disabled children. Last year, the money raised helped to fund an extra helpline session - our lifeline for parents who really need advice or just someone to talk to when things get tough. You can be assured that this year's funds will make a massive difference too.

### Want to run and haven't told us yet?

You can still run for Amaze if you have your own place in the race, or we have charity places available right up until 1 March. If you are not a runner, join us on the day to cheer and soak up the atmosphere.

## BIG CHEER 3 goes down a storm

Thank you to everyone involved in the 3rd BIG CHEER for Amaze at Theatre Royal on 7 February. Once again, the fabulous comedy line-up had us in stitches.

Compere Ray Peacock served up the heady comedy mix of Angela Barnes, John Moloney and Raymond and Mr Timpkins - all topped off with the brilliant Phill Jupitus, who, together with special guest Rowland Rivron,



Photo by Andrew Fozard  
[www.photographybyfoz.com](http://www.photographybyfoz.com)

ended the show on a hilarious musical high. The results were a lot of laughs and a lot of cash. Roll on BIG CHEER 4!



## Sporting chance for teens with special needs

Teenagers with special needs in Brighton and Hove will have more choice of physical activities than ever before, thanks to Sport England Inclusive Sport funding from the National Lottery.

The money will support six new Compass Card Activities (CCAs) over the next three years. Amaze will lead the project and work closely with Adventure Unlimited, Brighton & Hove City Council, The Crew Club, Extratime, Freedom Leisure and Sussex Central YMCA, to deliver the activities. "This new money means we can provide a range of activities for teens and go further in including young people with more complex needs" says Amaze CEO, Rachel Travers.

Most of the new activities will be launched at the Amazing Zone at Takepart Launch Day in Preston Park on Saturday 22 June.

### New activities

**U-Sport** is a monthly activities club on a Saturday which is exclusively for teens with moderate or complex needs, delivered by Extratime, The Y Club and The Crew Club. This four hour session will offer a range of sporting activities and will alternate between

the Y Club on Marmion Road, Hove and Whitehawk's Crew Club.

There will be a weekly **fitness class for teens** with mild and moderate special needs provided by Freedom Leisure. Young people with complex needs may also attend with a PA or carer.

Three new CCAs are being run by Adventure Unlimited. The first is an inclusive **climbing** class at Stanley Deason Leisure Centre for teens with mild, moderate and more complex needs. They will also run an inclusive seven week **archery** course for teens

with mild, moderate and more complex needs and an inclusive three day **kayaking** course in the school holidays for teens with mild or moderate needs.

The last new activity will be a weekly **trampolining** class from Freedom Leisure, which we expect to launch later in 2013. The six week classes will run in term time and will be for teens with mild and moderate special needs. Teens with more complex needs will be encouraged to attend with a PA or carer.

### A helping hand

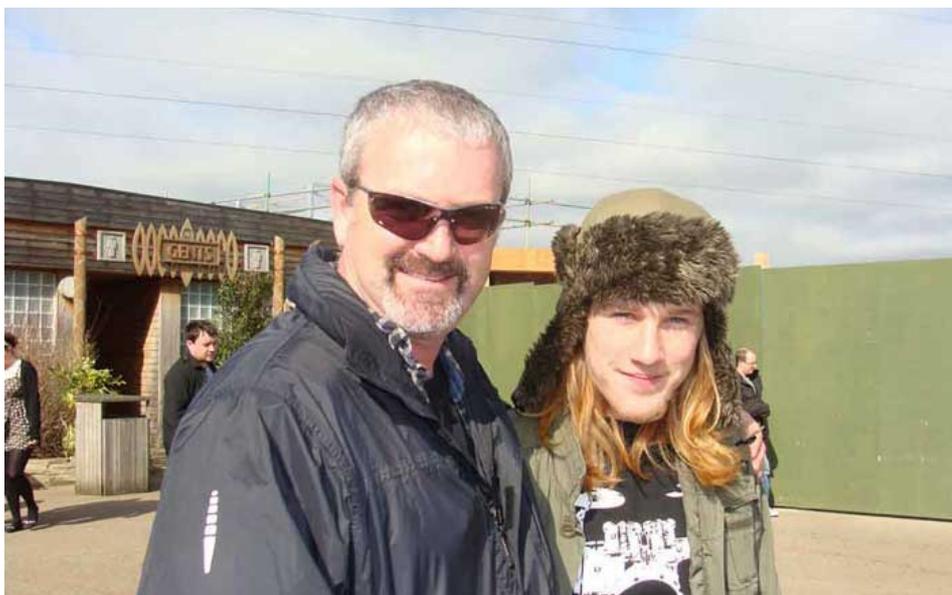
If your teen needs an extra hand to help them attend the fitness class, trampolining class, or activities provided by Adventure Unlimited, there could be some help available through specially trained staff called 'leisure brokers' provided by Extratime. These brokers will also assist some young people attending U-Sport. Brokers can attend the first few sessions with the young person and help coaches fully understand their needs.

### And that's not all...

Later this year we'll be trialling a new cooking CCA provided by Brighton & Hove Food Partnership. The first course is planned for the summer term and a second for the summer holidays. Young people will need to attend the class with a PA or carer. We'll give you more details as soon as we can.

### East Sussex concession card on its way!

Rocking Horse and East Sussex County Council are launching a new concession card for disabled children and young people in East Sussex later this year. Similar to the Compass Card, **i-go** will be available to 0 to 25 year olds with significant additional needs who live or go to school in East Sussex outside Brighton and Hove. Most families will find their child is eligible either for the **Compass Card** or the **i-go** card, but some may be eligible for both. To find out more about the Compass Card, call us on 01273 772289. To get info about the i-go card, call 0345 60 80 192.



## Our boy Bill - the journey so far

PaCC mum Sam Bayley reflects on life with her son Bill

I can't believe Bill is celebrating his 16th birthday this March and that he is sitting his GCSEs and coming to the end of his time at school. The young man I see going off to school every morning is completely different from what I had envisaged 14 years ago when our chubby, babbling little boy first got his diagnosis.

Our wonderful Bill was born a happy, big, healthy boy in 1997. He was all me and my husband Paul had hoped for. At the age of 3, Bill was finally diagnosed with Autism Spectrum Condition after months of assessments following our concerns about his delayed speech and odd behaviour. This started us on our journey into a world of autism.

Bill had a wonderful start at the Jeanne Saunders Centre, which was a fantastic grounding for us all to understand Bill's needs. We were supported by Presens, and the centre itself, which was a godsend as we were all very confused and frightened with this new situation we found ourselves in.

Bill's move to mainstream reception class wasn't as smooth as we had hoped and the different level

of understanding of Bill's needs in mainstream school became very apparent. This is where my life really changed in the fact that I realised battling, fighting, negotiating and working closely with others was going to be my new take on parenting and supporting Bill.

**“Having to guide Bill through school and life inspired me to support other families in the same situation as us.”**

In 2003 we went on an adventure of a lifetime, travelling around France in our camper van for the whole of the summer holidays. Two weeks into our adventure, up a mountain, miles from anywhere, Bill had a massive seizure. He had never had anything like this before and he was rushed to hospital for tests and was diagnosed there and then with BRE (Benign Rolandic Epilepsy). For Paul and me, it was just incomprehensible that our darling Bill had another burden to carry with him through his young life.

I was more angry with this happening than when he was diagnosed with ASC as I felt his ASC could be managed and worked on, whereas the epilepsy affected his health and to a point was out of our control. We felt that our lives had completely changed.

Over the years Bill has continued to progress with his speech and language, he manages his autism well and is doing the best he can at school. He has lots of friends and a girlfriend too! He has also been seizure-free for two years now, which is fantastic and has made a big difference to our lives.

Bill has taught us so much and has been a real inspiration to me personally. Having to guide Bill through school and life inspired me to support other families in the same situation as us. This I have done by starting the support group, mASCot. Visit [www.asc-mascot.com](http://www.asc-mascot.com) for more information. Meeting and helping other families gives me the strength to stay strong for Bill and my family.

This is Bill's story to date; it has been a bumpy road for all of us and very hard at times for us and our wonderful, supportive family. But throughout all of this Bill has been so happy; he has taken everything in his stride. Never crying or moaning when he has had treatments or assessments, he has shown a lovely strength of character for such a young man, which I know will stay with him into adulthood.

**But most of all, our Bill has never stopped smiling and making us proud.**



# What's happening with the SEN Pathfinder?

First the big news – the government has decided to extend the Pathfinder until September 2014 when the new law will take effect.

This gives more time to build the learning from the Pathfinder into the new regulations and Code of Practice that will put the legislation into practice. See the box to the right to make sense of the timetable for changing the SEN system.

Meanwhile all the parts of Pathfinder locally are making progress, but the one that has moved on most since the last newsletter is **Single Plans** (or Education Health and Care Plans). Lalli Howell is working on this and gives us an update:

“We now have 46 families trying out a new style plan. We’ve been working with them to personalise the current system to better match their needs. We spent some time in December analysing all the areas that parents and schools had highlighted as needing some change or greater flexibility and used this to draft a new document for planning and review that is much more child and family centred than a Statement of SEN. We will be trialling this further with families in the coming weeks. We now need to think more about assessment and how this might give us the best possible picture of a child’s needs, to help us all make good decisions about what provision is needed.



“We appreciate that some families need greater support than has historically been on offer. We have trained up some volunteers from a range of backgrounds to act as key workers and we’re testing out the impact a key worker can have with a small number of families as they develop their Single Plan. We’ve worked closely with the Seaside View keyworking service, Amaze and the SEN team in setting this up.

“We now want to focus on Single Plans for young people age 16 to 25, as the new legislation is likely to extend the age range for which the Local Authority is responsible. We have lots of work to do with FE colleges, other providers of services for those with SEN and disability post 16/19, and employers.

“Lots to do and it’s exciting stuff! We appreciate the input from parents and look forward to working with more of you in 2013.”

## SEN PATHFINDER - TIMELINE FOR CHANGE

**4th Feb 2013** – Children and Families Bill went to Parliament to start the stages of debate to become law

**Spring/early summer 2013** - draft Regulations and outline Code of Practice published

**Spring 2014** – Royal Assent i.e. the legislation is passed and becomes law

**September 2014** – the new law takes effect. Children with existing Statements of SEN will gradually switch over to EHC plans over the next 2 or 3 years.

This is the timetable if all goes as planned, which is looking quite likely now. Don’t forget the current system stays in force until September 2014.

For more about the Children and Families Bill, visit: <http://services.parliament.uk/bills/2012-13/childrenandfamilies.html>



## Extratime for bargain-hunting?

Extratime is opening a charity shop on Boundary Road in Portslade. If you fancy a spot of shopping, why not pop along and bag some pre-loved bargains while at the same time supporting their brilliant work to provide fully-inclusive after school and holiday clubs for children with and without disabilities.

## Hints and tips on challenging behaviour

The Challenging Behaviour Foundation has a lot of helpful factsheets for parents of children and young people with severe learning disabilities and challenging behaviour. Download them from [www.challengingbehaviour.org.uk](http://www.challengingbehaviour.org.uk) or contact their Family Support Line: 0845 602 7885. Factsheets include topics such as: Understanding challenging behaviour; Self-injurious behaviour and Difficult sexual behaviour.

## It's good to 'Talk Health'

Since the launch of the 'Talk Health' report last summer, PaCC has presented the report to the city's Health and Wellbeing Overview and Scrutiny committee (HWOSC). The councillors on that group were impressed by the recommendations made and have championed 'Talk Health', calling all the services reviewed within it to report their responses back to them.

Over the last few months we have also met with service managers from

CAMHS, managers from the children's hospital (RACH), therapy leads from Seaside View and the commissioners from the Clinical Commissioning Group, who in turn have presented the report to the city's GPs.

They have all listened to the recommendations made and agreed to start making changes in the way that services are being delivered. Over the next few months we will update you in more detail about each of the areas as

### Key recommendations from 'Talk Health':

- Improved parent participation
- Improved resources particularly in the community
- Improved communication and transparency between services and families

your recommendations begin to be rolled out.

Join us at 10am on **20 March** at the **Brighthelm Centre** to hear what changes have been made since 'Talk Health'. Call Amaze on 772289 to book.

## Speech and Language listens to parents

Last summer, the Speech and Language Therapy (SLT) service contacted an anonymous sample of parent carers of the children they work with in mainstream schools, special schools and units.

They wanted to evaluate parents' views about the quality of information and contact they had received from SLT. 28% of parent carers responded from special schools and units, and 17% from mainstream.

**Information?** A large number of mainstream parents confirmed they had received written information about the SLT Service. This was less so with special schools and units where only new children are given a leaflet. Where parents had received written info, they said it was presented in a way they could understand.

Most parents knew that they could contact their SLT through their child's school. However, a proportion of parents did not know contact details for their child's SLT. Also of concern is the fact that more than half of the parents from special schools and units said information provided had not helped them to support their child's needs outside school.

**Advice and contact?** Though the majority of parents felt they had received written and/or verbal advice about their child's SLT needs, a significant minority didn't, which is of concern. Many parents commented that they would like to meet SLTs to discuss their child's progress or ideas for helping them outside school and that SLTs needed to initiate this contact more.



**Understanding?** The majority of parents understood how the SLT service works in their child's school and felt that the SLT had a good level of knowledge and understanding. Most parents also understood the role of the school staff in supporting the SLT plan. However, some wanted more direct therapy and one to one sessions with the therapist. Nevertheless, most

parents believed that their children's SLT needs were being supported appropriately by the school. Fewer parents felt involved in decisions about their children's speech and language therapy.

**What next?** As a result of the survey, SLT plan to implement the following actions:

1. **Discuss the outcome of survey with the SLT team and PaCC**, and plan strategies for increasing parent carer liaison
2. **Improve communication between parent carers and SLT:** offer contact in school holidays if requested; send flyer at end of term with SLT contact details and ensure schools display SLT contacts details in Reception; provide 'open' days in special schools and units during term time for parent carers to meet with SLT; ensure parent carers get written updates when there is a significant change in their child's SLT targets
3. **Arrange a parent focus group facilitated by PaCC** to discuss how to improve communication with parents
4. **Share outcome with head teachers of special schools and discuss allocation of SLT time** and balance between therapy and parent/carer liaison

## More news on Therapies

PaCC's 2008 report, 'More Therapies in the Community', highlighted a lack of therapy provision for children with special needs locally. Following on from that, the Integrated Children's Disability Service commissioned an independent review of therapy services in the city which recommended some key service developments.

These have been adapted by the therapy managers at Seaside View and used to change and develop the service to reflect parents' concerns. Below is a summary of the changes that have been taking place and some plans for the future.

### Data collection

The three therapy services - Speech and Language (SLT), Physiotherapy and Occupational Therapy (OT) - are in the process of getting an IT system that will enable them to share information. In the meantime they are collating information such as reports in children's files. Children with complex needs in a mainstream school will have a health plan.

### Info and communication

All the therapy services now produce parent-friendly information leaflets, designed with guidance from PaCC.

SLT leaflets are available in children's centres and GP surgeries and all families referred to the service get a leaflet in the post. Flyers and information leaflets from the OT service are also posted to each child referred. And each time a physiotherapist sees your child in school, a summary of the visit will go home with the child.

It has also been proposed that therapists will update families who are receiving therapy in school at least termly and/or if there is a significant change in treatment. This is in response to parents saying that a report once a year with the annual review is not enough.

### Waiting times

Therapy services are trying to reduce their waiting lists but there is still some time between referral and the appointment. Waiting times will be stated in referral letters.

At the time of writing, SLT waiting times are 5 weeks for the initial assessment and 8 for treatment.

Physiotherapy have reduced waiting times to 12 weeks for non-urgent referrals, and see urgent and semi-urgent referrals within 4 and 8 weeks respectively. However, this does mean that they are holding large caseloads.

OT are able to see pre-schoolers and children with complex needs within 12 to 18 weeks. For other children, the waiting time is currently 9-12 months, but they are aiming to reduce this to 6 months by end of March 2013, and to 18 weeks by September 2013.

### Skill mix and training

The physiotherapy service has recruited a technical instructor and administrator which will free up the physiotherapists' time.

All therapies are focusing on training up assistants in schools to deliver programmes in schools. It has been agreed that the principle of training parents alongside TAs in schools is a good idea and the practicalities of this will be developed over the next year.

### Eligibility and access

The criteria for getting direct therapy have been outlined as follows:

- to provide a period of further or



- ongoing assessment for a child
- to introduce and demonstrate a series of specific activities to a parent/carer or school staff
- to provide a period of intervention that requires the specialist skills or techniques of a therapist or therapy assistant to achieve the outcome. These may be carried out in a group or individually.

The SLT service will accept referrals from parents and all therapies accept referrals via the Seaside View referrals panel.

### Parent participation

We have two parent reps from the PaCC Steering Group who sit on the Quality and Standards group but, as a result of the questionnaire sent out to special schools, the therapy services would like to get a group of parents together from special and mainstream schools to look at improving communication between families and the therapy services.

If you are interested in joining this group then please contact PaCC via [tim@paccbrighton.org.uk](mailto:tim@paccbrighton.org.uk) or the Amaze helpline on 01273 772289.

# Amaze workshops and courses

Amaze aims to offer parents courses and workshops that cover the topics you want to know about, in a friendly atmosphere and alongside other parents who share your experience. Most are delivered with parent trainers to keep it real.

- **Insiders Guides - see below for more about IG and the next course**
- **Triple P - all about behaviour and parenting positively**
- **Looking After You - to keep stress at bay**
- **One day workshops on benefit changes, bullying, tricky meetings or from outside experts like the one coming up in March (details below).**

How often we run courses depends on the funding we can find for this, so we can't always plan far ahead. But if you call the helpline and ask to go on our waiting lists, we'll make sure you get first chance to book when we do run that course. And looking at those waiting lists helps us work out which courses to run if we can't do them all. So call and tell us what you want.

**Read more about the courses and workshops we have coming up next:**

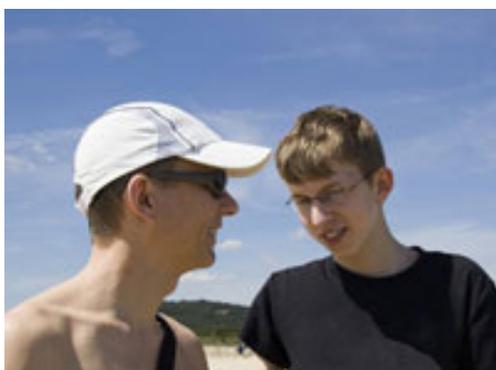
## Can your child "see" what they see?

A workshop about visual processing difficulties  
Tues 26th March, 10am to 12 noon, Community Base

Many children have problems with visual processing even though their eyes seem to work fine. Janet Harwood, a teacher for the visually impaired, will explain what cerebral visual impairment (or visual processing difficulties) means and why it often gets missed. She will look at how we can tell if this affects our children and what can be done to help them.

Janet says "Many, many people have this condition but have no clinical diagnosis of visual impairment. It covers a huge spectrum from children with profound and multiple learning disabilities to children who may be cognitively able but are failing because their issues go unrecognised and consequently their needs are not being met, or may even be attributed to other disorders."

Unsure if this workshop is for you? Some of the children more likely to be affected include: children born prematurely; children with cerebral palsy; those who have had lack of blood supply/oxygen to the brain, head injury, meningitis, encephalitis, hydrocephalus or neonatal low blood sugar; children with congenital anomalies. It can also be linked to other conditions such as ASD, but sometimes there is no obvious reason.



## Insiders Guide for Parents of Teens starts 17<sup>th</sup> April

Insiders Guide courses are special because they offer a mix of useful knowledge with a chance to check out where we are in our journey as parent carers, and get together with parents at a similar stage. The next one we are offering is the teens course, which is for parents of young people aged 13 plus with more significant needs. It covers things like planning ahead, puberty and relationships and building our own resilience as parent carers.

The course is free and takes place at Community Base for six Wednesday mornings, starting on Weds 17<sup>th</sup> April. It will be run by Claire, a parent of a teenager with learning disabilities and Sue who brings her knowledge as an Amaze worker.

**To book onto or enquire about any of our courses, call the helpline on 01273 772289**



## The Swedish Kinder Care

Angie Hart, parent carer and resilience specialist, tells us about the SEN system in Sweden and how it can inspire us to aim higher for our kids.

When Birgitta, the headteacher of the Swedish special school, first told me about their service, I didn't think I'd heard right, "Our school is open from 7am-5pm, five days a week. Apart from the weekend, Christmas is the only other day we are closed."

She went on, 'Parents can have overnight respite care a day a month, or every two weeks, or even more. The county even offers a qualified person to come and look after the children if the parents want some time on their own. The parents must apply for this at the municipality office.'

'We do everything we can to support children to stay at home with their parents. The school day is 9-4, but the doors are open all day so that parents can drop their kids off and go to work or just have some time out.'

You're probably thinking that Birgitta is the head of a private outfit for rich parents. But no, she runs a well-resourced state school and nursery for children with special needs in Sweden.

Anette, a preschool university lecturer from Mälardalen University, who accompanied me, could hardly believe that I didn't know this about Sweden already. It seems that nobody told me because they took the system for granted.

**'They have an enormously difficult job. We have to support them in whichever way we can.'**

As the head teacher talked, the past 17 years of my life flashed past me. I'd always thought we were lucky to live

in Brighton because there was some sensible provision. But still fragments of the juggling flashed back - waiting for a letter from Cherish playscheme one summer, frantically hoping we'd been allocated even a 10-3pm slot, two days a week, because I had a work meeting I couldn't move. Or feeling overjoyed when Extratime afterschool club started up, only to despair at trying to sort childcare between times when my daughter's special school suddenly announced a move to finish the school day at 2pm.

'How do you work out what children and parents are entitled to by way of support?' I asked Birgitta, wide eyed. Now I'd have her, surely there is some conflict there! 'According to what the parents want,' came the astonishing response, 'They have an enormously difficult job. We have to support them in whatever way we can.'

Thinking about what Birgitta said may lead you to plan your emigration. But before you pack your case and try to bribe the kids to come too, let's remember how cold it gets in Sweden. Perhaps instead we should just get a bit more challenging of our own lot in dear Blighty? Amaze and others do a good job of lobbying, but lets summon up some energy to seriously agitate - send David Cameron and colleagues to Sweden for example - if only we weren't too knackered trying to juggle everything, eh?

Just knowing this kind of service exists has its own power too. Keep it in mind when you are trying to negotiate for services for your child, and you may just start to feel less like you are asking for the world.

### Want more information on childcare?

Amaze produces two useful factsheets: 'Childcare Questions' gives you hints on what you need to look for and 'Choosing Childcare' tells you about the kinds of care that are available locally. The Family Information Service (FIS) also produce a great booklet called 'Childcare Choices' with a section all about special needs. FIS can also give you extra support with finding the right childcare if you need it. Call FIS on 01273 293545.



### The Right Stuffers

It takes a lot of people to get this newsletter through your letterbox. Top of the list are an amazing group of volunteers who help stuff them into 3500 envelopes every issue.

We thought it was high time to say a huge thank you to Jill, Sue, Christine, Janet and Ann, for making such light work of such a heavy task.

It would really help to ease their load if those of you who no longer want the newsletter could let us know. Likewise, if you'd be happy to get it by email, you could help us to save some money on our postage - plus you'd get it a bit earlier.

Just call the helpline or email [charlotte@amazebrighton.org.uk](mailto:charlotte@amazebrighton.org.uk)

### De-stress at carers' workshop

Two senior practitioners from Brighton Alexander Technique College are running the third Alexander Technique Carers' Workshop at Community Base, 113 Queens Road, Brighton BN1 3XG on Friday 15 March from 10am till 12 noon. These popular sessions really get to the root of stress and back problems and are available to Compass Card parents and Carers' Card holders for just £5.

Book in advance by calling Francesca Aldridge on 01273 206859/ 07941 451632, or email [francesca.aldridge@which.net](mailto:francesca.aldridge@which.net)

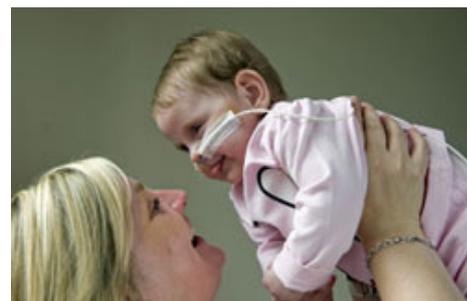


## Want to be Amaze's next top models?

A picture paints a thousand words they say and we agree! Nothing helps convey the extraordinary normality of caring for a child with special needs better than a brilliant picture and we need lots of them to help bring to life our publications and new website.

We're lining up a great local photographer and want to find families who would be happy to have their photos taken for use on our website, annual report, newsletter, etc. In exchange you'll get a lovely set of professional digital images free, together with a framed copy of the best one to adorn your walls.

A group of families modelled for us a few years back and their gorgeous



Natasha and Scarlett had this lovely photo taken by Bob Griffin in our last photo shoot.

photos have really helped us to communicate what we do to other parents in need as well as to professionals who might fund us.

**If you are interested or just want to find out more, call our helpline or email [charlotte@amazebrighton.org.uk](mailto:charlotte@amazebrighton.org.uk)**

## Amaze helpline:

For information, advice and support, call 01273 772289 Mon to Thurs, 9.30am to 12 noon, *plus* Mon afternoon 12 to 5pm and Thurs eve 5.30 to 8pm *term-time only*.



### Amaze

Community Base  
113 Queens Road  
Brighton BN1 3XG  
T: 01273 772289  
E: [info@amazebrighton.org.uk](mailto:info@amazebrighton.org.uk)  
W: [www.amazebrighton.org.uk](http://www.amazebrighton.org.uk)

### Want this newsletter by email?

Then email your details to [info@amazebrighton.org.uk](mailto:info@amazebrighton.org.uk)

Some articles in this newsletter represent the personal views of the contributor, rather than Amaze as an organisation. Amaze wishes to advertise all of the events and services listed because we think they may be of interest to parents. However this is not the same as recommending these to you. It is assumed you will make your own decision about whether they suit you and your family.

