

out of amaze



For parents of children with special needs in Brighton & Hove



SEN Online Info Fair

Getting the most out of IT and the internet

These days more and more information, services and resources are reached online. Come to our Amaze Info Fair on **Friday 22 November** at **The Bridge Community Centre, Moulsecoomb** to make sure you and your child aren't missing out! There'll be stalls, workshops and more.

If you're an absolute beginner, learn the basics to get online. Get top tips to keep your child safe online. Find out about the best special needs 'apps' your child could use on an iPad/tablet. Get advice about software and hardware to help children with all sorts of needs. The Mayor is coming along to 'cut the ribbon' on Amaze's new website and improved pages about disabled children's services on the council's website. And there'll be a chance to see how the city's Local Offer for SEN is taking shape.

Stalls

You can also talk to services face to face. This year we have more workshops and fewer stalls, but the key ones will be there and have information about their services and useful online resources for you and your family.

Workshops

Choose between:

1. Getting online and getting started
2. Assistive technology: what software and hardware can help?

3. E-safety: what parents need to know
4. SEN apps: a world at your fingertips
There will also be focus groups asking your opinion: one on what apps you'd like to see and one on the Local Offer. Call the helpline to book onto a workshop or focus group.

Event timetable

9.30am-1.30pm: Drop into the Amaze Information Fair anytime to browse the stalls
10am: workshops 1 and 2
11am: workshops 3 and 4
12 midday: focus groups
1.30pm: Amaze AGM to report on the year's work and to appoint new trustees. Lunch provided but you need to book for this.

Prizes and goodies

You'll get free refreshments, Kinder Egg goody bags and pamper treatments and you can **win an iPad kindly donated by Bright Interactive!**

New venue

The Bridge is at Lucraft Road, BN2 4PN, next to BACA School. You can park easily or get there by bus or train and we'll pay your travel expenses. You can just turn up on the day, but you need to book to be sure of a place at the workshops or to stay for the AGM. Call Amaze on 01273 772289 to book or get directions.

Parent carers need some care too!

We all know that caring for a child with special needs often means that your needs get forgotten. But your responses to our recent **Parent Carer Survey** make it plain that this lack of time and care for yourselves is having a serious impact on your physical and mental health. Read some of the most striking statistics from the report on page 6.



Goodbye to Portage

The Children's Society **Portage & Befriending** Service has now closed after 31 years supporting families in Brighton and Hove.

The Children's Society has changed its priorities nationally and funding Portage no longer fitted with its plans. The huge strength of feeling and support from parents and professionals locally was not enough to alter this decision and Portage & Befriending sadly closed at the end of August.

Rachael Wilson, Senior Project Worker at the Children's Society, says: "We would like to extend a warm thank you to everyone for all their support and kind words. The Children's Society has committed a small one off pot of funding to support the transition of the Portage Service to another provider."

If you are interested in contributing to this process, please email: rachel.wilson@childrenssociety.org.uk or call Rachael on 01273 749085.

And goodbye to Anne

Though we can't thank all the great professionals who have worked with our children, we want to say a fond farewell to **Anne Robson** who retired as head of the **ASC Support Service** in July. Anne was a teacher for 38 years, many of which were spent in dedicated effort to give children on the spectrum a better experience in education. Good luck Anne!

New Amaze website is live and kicking!

Our brand new, beautiful website is now live and eager for you to visit at www.amazebrighton.org.uk! It has all the same detailed advice about health, education, benefits and more in the Advice for Parents section as our old site, but loads more images, a clearer structure, lots of links and downloads and more ways for you to get in touch and interact.

All in one place

Most pages now have boxes on the right hand side that link to relevant service providers' websites or useful downloadable documents. And you can also find 'related content' that's elsewhere on our website this way too!

News and events

The very latest news and events are featured on the home page, or you can browse all our events and news at www.amazebrighton.org.uk/news-and-events. If you read something really interesting, you can share it with others. There's even a button to add an event directly to your Outlook calendar!

Staying connected

Our latest Facebook post is now visible and clickable on the homepage and you can join our closed Facebook



group via the following page: www.amazebrighton.org.uk/get-involved/join-facebook-group. And if you want to send Amaze feedback about any issue, you can do so easily via a form at: www.amazebrighton.org.uk/about-us/contacting-us

Get involved

If you want to donate or fundraise for Amaze, or perhaps you are thinking of volunteering, all the information you need is in the 'Get Involved' section. You can also share your parent story with us here too.

Please visit the site soon and let us know what you think. Or come along to our **SEN Online Info Fair on 22 November** (see front cover) and let us take you on a virtual walk through the new site and all its features.

Amex backs our work with parents of teens



We'd like to say a huge thank you to American Express for giving us £4,000 towards our transition work. The funding will help us develop our **Preparing for Adulthood** scheme, giving parents and carers one to one support as they start to plan for their child's life after school. It will enable us to recruit, train and supervise a team of volunteers who we can match with the most vulnerable families not currently

eligible for support from adult social care.

Ivan Mainprize, Vice President at American Express, said: "We applaud the valuable contribution these projects are making to hundreds of people's lives across Sussex. At American Express we believe in supporting the local communities in which we live and work." **Once again, thanks Amex!**

Pressing for change nationally

Amaze and the PaCC have written three separate letters to **Brighton and Hove's MPs** over the last eight months to lobby them to press for improvements to the draft **Children's and Families Bill** – the legislation that sets out provisions and processes to support children with special educational needs across education, health and social care. Sadly, we feel that this draft legislation still falls short of the aspirations of the original Green Paper. We also feel that the new Care Bill fails to extend the same rights and support to parent carers as other carers of adults and have asked for this to be amended.

Whilst Amaze is doing what it can to press for improvements, other national organisations and charities have much more capacity than us. So if you are concerned about this or want to know more, you might want to look at

www.ipsea.org.uk or www.edcm.org.uk

If you'd like to write to your MP, you can get ideas about what to include in our campaign letters at www.amazebrighton.org.uk/resources/amaze-literature

Much of the finer detail and guidance about how the legislation will work in practice and affect families is in the draft Code of Practice which came out on 4 October. The consultation on this is open until 9 December. You can read and respond to the draft Code of Practice at www.gov.uk/government/consultations or check out the News and Events section of our website for details.

If you would like to get involved in looking at the new Code of Practice, please book to come along to our **SEND Pathfinder Parents' Workshop on 14 November at the Brighthelm Centre** (see page 12 for more details) and make sure you join the PaCC Facebook group so we can keep you up to date. To join, just email paolo@paccbrighton.org.uk



Tudor House rated 'outstanding'

After an unannounced inspection at the end of July, Tudor House residential home has been rated as outstanding by Ofsted. Jenny Brickell, Manager of the Integrated Child Development and Disability Services, said, "Ofsted has raised inspection standards for residential homes, which makes maintaining the outstanding rating (of the last 5 years) an even bigger achievement. Clare Brunt, Tudor House manager, and her team deserve significant praise."

Have training, will travel

Amaze has teamed up with the **Grace Eyre Travel Buddy Project** to provide a training programme for parents to help their teenager to learn to travel safely. The Travel Buddy training started just before the summer holidays.

A group of parents and young people came to an information session one evening and the young people talked about the places they would like to get to – catching a bus to the youth club; walking into town;

catching a train to college and getting a bus to the London Road shops.

Ben Gardiner from Grace Eyre showed us a film about people with learning disabilities who'd learnt about road safety and how to use buses on their own, as well as a film about a person with learning disabilities dealing with bullying on a bus.

Ben gave all the young people a bright orange wallet that they can put their bus pass in which alerts the bus driver to the fact that they have a learning disability and he shared

some ideas about what can help a young person learn to get about safely.

Ben has started helping each young person and their parent with the journey they want to learn to do.

Contact Amaze if you think your son or daughter would benefit from this kind of support and you'd like to help them learn to get about safely.

For young people aged 18+, Grace Eyre are running **Travel Training courses** with available dates in **October and November**. Contact Ben Gardiner at Grace Eyre on 222053 to find out more or to book a place.



"Ben gave me some ideas that I wouldn't have thought to do myself and the exercises about road safety were very accessible"
Parent

A day in the life of an LDD Adviser

Allison Farrell, a Learning Difficulties and/or Disabilities Adviser with the Youth Employability Service, tells us what she does in a typical working day.

My team's role is to help young people who have a Statement of special educational needs to make the transition from school to further education, employment and training. I work with students with severe and complex needs at Downs View Link College and students who attend out of city special schools.



My typical working day involves attending annual reviews at schools and colleges to keep up to date with a student's needs and requirements and to discuss their longer term plans. At these reviews I meet the key people in the student's life and begin the process of gathering the relevant information to share with future college and training providers.

Whilst I am at school or college I may also observe a class to get to meet the students in an informal way and see the everyday support that they need. Where appropriate, I will see students individually for careers advice sessions. I also use that time to catch up with staff that I liaise with regularly including the office staff, teachers, teaching assistants and therapists.

I may also do a home visit to discuss options with students, parents and carers in more detail and to draw up an action plan summarising the next steps.

I usually return to the office later in the day to catch up with emails and telephone queries, update computer records and research queries and plans for people. I work closely with the other agencies that are involved with students when planning for their future, such as Transition Caseworkers, and usually make several phone calls and emails each day to a wide range of organisations.

At this time of year I am still working with the students who are just starting in their new colleges or training placements and am currently checking that they know their start dates, have suitable transport and have any equipment they need in place.

The work for next year's leavers has already started and many of them have already had college visits. I am arranging further visits for their parents and carers and I try and stay in regular contact with the various training providers and colleges to ensure that I am up to date with what they offer.

“As our service keeps in contact with students until they're 25, it's great to see how young people are doing long term.”

Also, at this time of year, I draft Moving On Plans which summarise a young person's current situation and the support they will need in their next education setting. These plans will be finalised during this term ready to be shared with colleges that they will be applying to.

This term sees the introduction of the new Education, Health and Care Plans which, over time, will replace Statements and Moving On Plans and I will be having training on what this will mean in practice for my service and the young people we work with.

It is lovely to see the students move on successfully and, as our service keeps in contact with students until they're 25, it's great to see how young people are doing long term and to offer the support of the Youth Employability Service should they need further help to get into work or training in the future.

If you have any questions, contact the LDD Team at the Youth Employability Service on 01273 294247.

'It's not on!' - Stop Hate Crime towards People with Learning Disabilities

People with learning disabilities and the professionals who work with them are invited to this conference on **Tuesday 26 November, 10am-3pm, at Hove Town Hall**. The event aims to raise awareness of an issue that can have devastating effect on people with learning disabilities living in our city. There'll be speakers who know a lot about learning disability hate crime and community safety, workshops, stalls, music and a free lunch. To book, call Anke on 01323 727872 or visit <http://its-not-on-es2.eventbrite.co.uk>. The event is free of charge, but booking is necessary.





Independent Living

Amaze has been finding out about 'Shared Lives', a local project from the council and the Grace Eyre Foundation, that is helping young people over 18 to live more independently.

Natasha Brown, from The Grace Eyre Foundation, told us how it works.

"Shared Lives means that anyone from 18 upwards (who has been assessed as needing support) can receive respite or long term care within a secure, happy, family-style environment, where the emphasis is on supporting them to learn new skills, maintain their independence and develop their interests.

"All of our carers receive training and undergo an intensive assessment process to ensure they have the right skills and outlook to provide care. This assessment also helps us to match the personalities and interests of the individual and the carer.

"Throughout the year, individuals can have a short break either over a weekend or during the week. Some of the people who use our service use this time to see what it's like and build confidence prior to living with a carer on a long term arrangement.

"There is also a relatively new type of care called 'Kinship' in which the

individual lives in a house or flat with their peers, but is still fully supported by a carer, who lives close by. Kinship is a great way for someone to be very independent but gain the kind of practical and emotional support they need to flourish in their own home.

"We usually get referrals through the Community Learning Disability or Mental Health Teams but parents can self-refer. They can also self-fund this kind of care and, with more and more people using individualised budgets, this may become the way forward."

Natasha is responsible for new carer's assessments and all new referrals and she is happy to talk to parents and their children about Shared Lives, either by phone or face to face. Call her on 01273 222025 or email nbrown@grace-eyre.org

Tips from parent carers of people living 'Shared Lives'

"Listen to what the young person wants because if it hadn't been what my daughter wanted then I don't think it would've worked."

"Build a relationship and get to know the carer and how she or he communicates. Be flexible about the fact that their way of doing things might be different."

"Accept that if you have gained in having less responsibility for your young person that also means you do have less influence. You have to accept that you have to let go, not just of the young person. ..These children are becoming adults and going out into the world with lots of other structures and lots of other professionals involved. You have to let go in all sorts of directions really, that's my experience."



Tips from a young person who has made the move away from home

"Support them by helping them do washing up and putting clothes in the washing machine and helping them put the machine on and teach them to do it and then they can do it the next time."

Our next 'Through the Next Maze' handbook will include a chapter all about housing called 'A Place to Live'. You can download this new chapter from our website in December.

Parent carers tell it like it is

A huge thank you to the 340 of you who completed our recent survey and gave us such powerful insights into your lives as parent carers. We're already using your responses to promote understanding of your role and lobby on your behalf.



The first thing to strike us is how many of you have an extra complication to your caring role. 18% of you say you have additional needs/disabilities yourself; 11% of you are caring for a child who is adopted/fostered; and 16% of you have more than one child with special needs.

Many of you are caring for your children with little help from others. Over half of you said you cared on your own with some support from a partner, relative or services. Nearly a fifth said that you care for your disabled children completely on your own, with no other help.

We asked about what kind of extra care you give. Most parents (86%) said they spent additional time with their children with special needs building their confidence or reassuring them in everyday tasks and 79% provided extra support with behavioural issues. 75% helped with personal care and 73% helped with communication. Over 65% of respondents said you spent more than 20 additional hours each week caring for your disabled child (over and above 'normal' parenting duties)

Any parent will tell you it's hard to get time away from the kids – but being a parent carer and finding suitable cover is much more complicated. Almost a quarter of you said you hadn't had a day, or even an evening off, from caring in over six months and 14% said you'd never had any time off, not even an evening. More than 75% have never received any form of respite or short break.

You also told us how being a carer takes over your lives. 60% of you said

you aren't in paid work, or have had to reduce your working hours because of your caring responsibilities. Over two thirds feel that you neglect yourselves or sometimes don't look after yourself enough and only a third ever get a good night's sleep. A quarter of parent carers (with children from 0-19) are disturbed *every* night.

Taking all that into account it's sad but not surprising that almost a fifth of you feel anxious, stressed or depressed most, or all, of the time and are on prescribed medication to help manage this. 15% of you said you would like to receive counselling and haven't been able to get this.

You said...that the adequate provision of good quality short breaks is one of the most important factors in being able to cope.

All this information helps Amaze staff better understand the impact of having a child with a disability or special need, and do our best to make sure our services are helpful. Thank you for the honest feedback about what we offer – it's great to hear that most of our services scored four or five out of five from over 90% of you. But we are also listening to where you are not as happy. We know you want Amaze staff to be able to answer the helpline phone more often when you actually ring, rather than us ringing you back and we are going to work on improving this. We will also be

planning how we can deliver more Amaze courses in the evenings or weekends, so those of you who work can attend. If you'd like to tell us about other ways Amaze can improve please do so via our website at:

www.amazebrighton.org.uk/about-us/contacting-us

These survey results also help us demonstrate to other service providers that being a parent carer can be challenging and isolating. They need to better understand the impact of having a child with a disability or special need, and involve you as carers when planning, developing or evaluating services.

You said in the survey that the adequate provision of good quality short breaks/respite is one of the most important factors in being able to cope with the added stresses and strains of having a child with special needs. Our CEO has just written to all the local political parties to ask them to protect budgets for disabled children's services, especially short breaks and counselling for carers. We believe this will actually save money in the longer run.

Amaze will continue to lobby locally about protecting services. We will put more on our website about this, including suggestions of what you can write to your local councillor.

Read the full survey results on our website at www.amazebrighton.org.uk/resources/publications/reports And if you need some ideas, read our **top tips for looking after yourself** and making the most of the support that is out there on the facing page.

Counselling at the Royal Alex

On the High Dependency Unit of The Royal Alexandra Children's Hospital there's a counselling service for **parents and carers who have a child or baby with a medical condition as the primary reason** for seeking counselling. Funded by the Rocking Horse Appeal, the service is available on Tuesdays, from 9-5, for the next two years. Counselling takes place in the hospital.

If you're interested, call Sandra Chitty on 01273 696955 ext 2501 or email sandra.chitty@bsuh.nhs.uk Alternatively you can ask a professional involved with your family to contact Sandra for you. If you are not eligible for this service, call the Amaze helpline to find out what else is out there for you.

Befrienders for you

Face 2 Face parent befrienders can support you through the worrying and confusing experience of having a child who has recently been diagnosed with special needs (or at any other difficult time). You can self-refer or be referred by any care or support professional. Call the scheme's co-ordinator, Amanda Mortensen on 07436 810608 or email amanda.mortensen@scope.org.uk for more information.

BHT's Mental Health and Wellbeing Service

Brighton Housing Trust's Mental Health and Wellbeing Service has a range of services to help you learn ways to cope with life's challenges. They run wellbeing groups with trained counsellors, life-skills workshops, women only groups provided by Threshold, and can even offer one to one support. For details visit www.bht.org.uk/services/mental-health-and-wellbeing



Top Tips for looking after you

- **Check you are getting everything you and your child could be entitled to** based on their needs by calling the Amaze helpline, or reading the information on our website and in our handbook, Through the Maze.
- **Find out if there is specific help for any issues you have.** For example did you know there is advice for carers about looking after your back if you are doing a lot of lifting? You can call the Back Care Support Service on 01273 296133
- **Carve out a bit of 'me time'** on a regular basis and don't feel guilty about it. Even ten minutes with your feet up makes a difference.
- **Look after your own diet as well as the kids.** Many of us have found exercise helps too, even if that feels like a crazy suggestion when you are overtired and overstretched!
- **Apply for a Carers Card** – the discounts focus on health and well-being. Visit www.amazebrighton.org.uk/services-and-support/the-carers-card to apply.
- **Talk to your GP** if you think your caring role might be affecting your physical and mental health.
- **Get together with other parents.** Amaze keeps a list of the local parent groups (like Pebbles, Link Up and mAScot) where you can be sure to meet people who share your experience. And don't forget the monthly coffee mornings in Moulsecoomb and Hangleton. See our website for dates. There are some good online groups for parents too if you have trouble getting out.
- **Think about having some counselling.** There are a few places parent carers can get free or low cost counselling depending on their circumstances so get advice from the helpline about which is the best fit for you.
- **Visit www.mindcharity.co.uk.** Their 'Advice and Information' section has a comprehensive directory of local mental health and wellbeing services
- **Try asking for help** sometimes. Friends and relatives often respond better if we start by asking for something simple and quite specific.
- **Do a course for parent carers.** You can share experiences, learn new skills and meet other parents. Call our helpline or go to our website to find out about courses that are run locally and see page 15 for our upcoming courses.
- **Look at Compass Card offers or activities** that (you and) your child could take part in to get them out of the house.
- **Join the Parent Carers' Council** and have a say about what matters to you. At least it will feel like you are making things better for the future!



CCAs are out of this world

Looking for a class where your child will be welcome and teachers will understand their needs? Try one of Amaze's Compass Card Activities (CCAs).

There's something for everyone – from U-Sport multi sport club which welcomes 11 to 19s with the most complex needs, to a **unique journey into space for all ages and disabilities with Otherworld**, the brain child of Same Sky and Different Planet Arts.

Otherworld, one of our latest CCAs, combines theatre, drama, storytelling and space travellers to engage the whole family. An interactive world with the latest sound and image technology, look out for Otherworld family days at Downs View School on Saturday 16 and Sunday 17 November, at Heronsdale School in Shoreham on Saturday 7 and Sunday 8 December and at the Corn Exchange in January next year.

For 11 to 19 year olds who need to run off some energy, we've re-launched our **weekly multi-sport club Fun-fit with a new Saturday morning time slot** from 11am till 12 noon at King Alfred Leisure Centre. Specially designed for young people with disabilities or special needs, Fun-fit banishes boredom with a full range of activities to suit everyone – and there are free goody bags for first timers. If your child's under 11, give Saturday Active Club, our multi-sport club for 5 to 11s on the first Saturday of the month at King Alfred, a go – it's a godsend!

For teenagers who prefer to keep their feet off the ground, we've got a **new inclusive trampolining class, High Flyers**, on Thursdays from 4.30 till 5.30pm at Moulsecoomb Community Leisure Centre. Sign up by calling 01273 622266.

Also coming early next year is a second **archery** CCA from Adventure Unlimited for 11 to 19s. We should have more news about it towards the end of 2013.

You'll find details of all 19 of our CCAs in our updated CCA guide at www.amazebrighton.org.uk – or call the Amaze helpline on 01273 772289 for a printed copy.

And Leisure Buddies make CCAs even easier

If your child struggles trying new things and is aged 11 to 19, there's help at hand for young people attending Fun-fit, U-Sport, High Flyers, archery, climbing or kayaking CCAs. Leisure Buddies – a bit like a short term leisure befriender – can help them travel to and from an activity and help coaches understand their needs. Book in advance. Call Lisa Nash for info on 01273 420580.



A little card goes a long way...

When Claire Perry goes on holiday with her daughter, the Compass Card goes too.

Compass Card parents often show the card at unexpected venues, but Claire has gone further than most in her quest to get the best possible deals – including Disney World Florida where she got a fast pass for her group, the Van Gogh Museum in Holland where the card allowed the family to skip the two hour queue and closer to home, discounts at the London Eye, Tower of London, Legoland and the London Aquarium.

"I take it everywhere!" says Claire.

Did you know?

In the last year, we gave away over 350 free tickets to Compass Card families through the e-bulletin Compass Team News (CTN). CTN hits your inbox every Thursday – so if you haven't given us an email address yet, you could be missing out! Call us now on 01273 772289.



Ladies help make-up funds for Amaze

Over 40 of our lovely lady supporters showed that they were beautiful inside and out when they raised £1000 for Amaze at the Clinique Pamper night at Boots back in June.

They indulged in an evening of pampering and sampled the latest Clinique products, while receiving beauty tips and tricks, skincare and fragrance advice from helpful Clinique staff. Due to popular demand, we will hold this event again in future.



A taste of things to come

Our first wine and cheese tasting event was a great success. Thanks to Butlers Wine Cellar and La Cave à Fromage for bringing some fantastic wines and cheeses to taste, and to Brighton College Pre Prep school for hosting the evening. We raised £3080 on the night so a final thank you to all those who joined us. Find out more about Butlers Wine Cellar or La Cave à Fromage via their web-sites at www.la-cave.co.uk or www.butlers-winecellar.co.uk/

Leaving a legacy

How your future generosity can help Amaze to keep helping families with disabled children

Amaze has been told we are to receive a very generous legacy of £30,000 from the late Mr Gordon Stewart. This is an extraordinary amount of money that will help us invest in much needed infrastructure to support our services.

Amaze receives very few legacies, even though they can make up a large proportion of most charities income. So, if you or a relative are considering putting a charity in your will, please think of Amaze.

Every single gift counts...for example just £1 generates an average £60 for families who we help to claim DLA.

As we all know, public funding of services to support disabled children and their families is under pressure. The government is making complex changes to health, social care,



education and the benefits system, all of which could have a profound effect on our families. Certainly we anticipate that there will be an increased demand for Amaze's services in the future and most likely less funding to provide them.

Every single gift counts. For example, £1000 could pay for over 30 helpline hours or benefit more than 30 families with disabled children. Just £1 generates an average of £60 for families who we help to claim DLA.

If you would like some guidance about leaving a legacy or supporting Amaze in other ways, please contact Nicky Bagilhole on 01273 234014 or email nickyb@amazebrighton.org.uk

Could you or your friends run for Amaze?

Places are still available for runners in:

- The Brighton Half Marathon - 16 Feb 2014
- The Brighton Marathon - 6 April 2014

Please spread the word and keep Amaze running!



‘A roller coaster of epic proportions’

PaCC Co-chair, Fiona England, tells us about the awesome highs and lingering lows of bringing up a son with special needs.

This year our son Dan turned 10. A decade of parenting my precious second born son. Dan has Down Syndrome, an associated severe learning disability and a sometimes moderate, sometimes severe, hearing loss. Dan attends a mainstream primary and we are thrilled by his very successful inclusion.

Dan's 10th birthday falls in the year of Brighton and Hove's 'Great Parenting Debate'. My experience of parenting daughter number one, aged 25, and daughter number two, aged 7, are otherworldly experiences in comparison to parenting Dan.

The decade has been a roller coaster of epic proportions. The highs are stultifying wows and the lows dig deep and have the tendency to linger. I can say with hand on heart that the highs, milestones reached, eye bogglingly wonderful displays of Dan's constantly emerging (and frankly awesome nature) are led by Dan. The lows are always led by the system, the battlefield, the mountain

range that you cannot, as hard as you try, scale to the top of in a straightforward way – a way that is thwarted by slip back down again delays and, once one mountain is conquered, the next looms fearfully nearby.

“The highs... are led by Dan. The lows are always led by the system.”

The cliff face culprits which many of us SEND families struggle with include ("Arggh!" we shriek) the DLA form, fathoming the Statementing process, getting decent transport, the desperation to get some respite, choosing schools, getting the correct provision. It's the steepest learning curve of my life or is it instead an immense test of my emotional stamina?

We have survived and conquered many (not all!) battles in the first 10

years and now we look to the future with an even keener eye.

For me now, an even bigger threat of an even taller mountain is looming large. I am worried. Worried for my family and worried for all of us SEND families. The fear? A four letter word – CUTS – or the threat of cuts. This fear of cuts is a serious reality. Local authorities will have to make decisions on how to spend the depleted budgets imposed by central government.

Up to now Disabled Children's Services have been fairly protected. But we live in a state of rising need and static resources. All too often, we hear from professionals "there is no money in the pot". We can thank Amaze for lobbying hard on our behalf to protect these services. But we as parent carers also need to shout loud and hard that our disabled children's and young person's services should be protected and survive the cuts. Our children need services. We need services. Let's talk to and write to our local councillors to protect what we have.

As well as protecting what we have, I would also like to see a push for a vital and clear culture shift in local authorities to identify the real needs of our children and young people, and to articulate these needs loudly and clearly to central government. Our children need more not less!



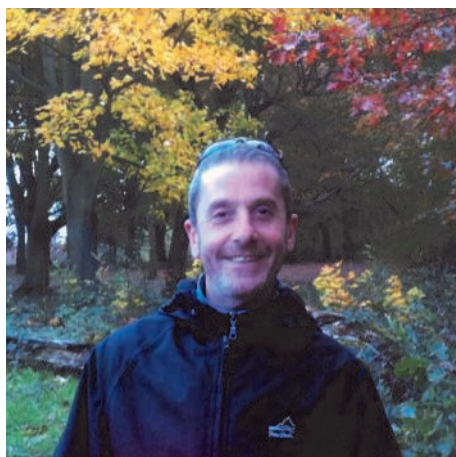
Meet Paolo Boldrini, PaCC's new Parent Participation Worker

Paolo takes the time to introduce himself, to tell you about his life so far, and his new role with the PaCC.

I was born in Italy but moved to the UK in 1990, first to London and then to Manchester to study Social Anthropology. I chose this course because of my innate curiosity about people and the experience of living among different cultures but my studies really opened my eyes to differences in attitudes and how important dialogue is between different cultures. I became interested in identities, how groups work and how individuals from different cultures relate and interact with each other.

At the same time, someone in my family reached the late stage of terminal illness. Apart from the painful realisation that I was going to lose a person very dear to me, I also experienced the emotional stress, fatigue and exhaustion of looking after someone with a challenging health need. I found good quality information hard to come by and spent years going from one specialist to another to try to find out how to make things 'better'. The situation put a huge strain on my family and made me realise that, apart from the person experiencing the 'health issue', there are also the carers who are often left isolated, worn out and exhausted.

That's what attracted me to the role of the PaCC Participation Worker at Amaze. I am passionate about the need for services to listen to, and support, the needs of carers, and I want to support as many of you to get involved with us at the Parent Carers' Council as possible.



I will be building on the incredible work that my predecessor Debbie Collins has done. She managed to enrol over 210 members in the last four years and I want to make sure more of you than ever sign up and get involved this year.

"I experienced the emotional stress, fatigue and exhaustion of looking after someone with a challenging health need."

The Amaze office is becoming my new second home and the team my new extended family. I am looking forward to meeting you all.

If you have not yet joined the PaCC but are keen to find out more please contact pacc@amazebrighton.org.uk

Thank you to Debbie Collins who has stepped down after four years in this role. She is continuing as the Amaze SEN Pathfinder Parent Lead on secondment at the Council.

A BIG Voice

The Parent Carers' Council has been very successful over the last five years.

PaCC Parent Representatives (Reps), trained and supported by Amaze, have put across the needs of disabled children and their families at over 20 different **Partnership Board meetings, panels and subgroups** in the city and the South East.

PaCC members regularly sit on **interview panels** recruiting the people who care for our children, such as occupational therapists and the Social Care Team Manager.

Teams of **Parent Ambassadors** 'audit' the different services our children receive to see how well they meet the standards set out in the Partnership Charter.

In-depth **PaCC reports** on Health, Education and Therapy Provision have led directly to service improvements.

But there's loads still to do! We've identified how we want to get even better and become an even stronger 'voice' locally. We want:

- To listen to what you are telling us are the 'hot topics' or problem areas locally
- Refocus the PaCC Steering Group to develop 'position statements' to press for improvements in these areas
- To better communicate what the PaCC is trying to do
- To better shout about our achievements
- To encourage more parent carers to join the PaCC

To find out more about what we do and how to get involved contact paolo@amazebrighton.org.uk or visit our new website at www.paccbrighton.org.uk which launches in November.

Latest news from the PaCC

The PaCC has been very busy lately...

Get Connected

We have begun hosting **PaCCConnect meetings**. These are focus groups for parents to come together at Amaze to discuss a particular service or topic, identify what works well and what doesn't and look at solutions or recommendations that we can put forward. The powerful bit is that these meetings are also attended by the relevant service manager or commissioner for that area, so they get to hear first-hand what the latest issues are. They get involved in discussions about problems or solutions there and then and take others away for consideration.

Our most recent PaCCConnect was a lively session with Lore Riedel from the Children's Disability Service social work team. The discussion focused in part on assessments and eligibility for social care. Parents also raised issues

about Direct Payments and just how much choice and control they can offer. You will be able to see the notes from this session on Amaze's website or you can email paolo@amazebrighton.org.uk to request a copy.

We are in the middle of planning the next two PaCCConnect meetings: one on wheelchairs and equipment and the other about primary health care (GPs). We'll advertise dates for these soon.

Council Scrutiny Panels

This summer, councillors from across the political parties and relevant officers at the city council have begun two detailed projects: one looking at the problem of bullying of children and young people in the city; the other about the needs of children and young people with ASC and their families. We have supported parents to give evidence at both.

A new website

You might have noticed that Amaze's website has had a makeover (see www.amazebrighton.org.uk). We are also developing a new PaCC website which you will soon be able to find at www.paccbrighton.org.uk. It will feature all our work and tell you how you can get involved. It's due to go live in November and we'd love to hear what you think.

Tell us what you like or what we can improve. Share your story about life as a parent carer or about your child. Tell us what's bothering you right now. Find out about PaCCConnect or other events and how to join.



SEN Pathfinder: latest on trying out changes to SEN

Amaze and PaCC Parent Reps are still involved in supporting the development of SEN changes as part of Brighton & Hove's participation in the SEN Pathfinder. The draft Children and Families legislation is due to come into effect in September 2014 and Regan Delf, the Head of SEN at the Council, is now responsible for rolling out the changes for families in time for then.

Key changes?

A single **Education, Health and Care Plan (EHCP)**, to replace a Statement of SEN, is being designed to offer a more holistic and child-centred look at what a child needs. More families will be given the chance to try the new EHCP from this autumn. If

you've been given this option and aren't sure – call the helpline to talk it through.

A **Local Offer** is being developed which will be a searchable website setting out what each service can provide for your child in the city. Currently schools and services are being supported to answer key questions set by parents. This should be published in December.

There should be more 'choice and control' in determining the 'purchase' of services via **Personal Budgets**. These are being trialled by 12 families in social care (short breaks) and for home-school transport arrangements. The council is also looking at how to offer Personal Budgets in more areas like continuing health care services

and other SEN provision.

EHCP plans can go up to 19 and even 25 for some young people which should help planning and **preparing for adulthood**. The aim is better opportunities for disabled young people in college, training or apprenticeships, but making this a reality is proving a challenge. Some young people over 16 already have a single EHCP – and preliminary feedback is positive.

Want to know more? Then come along to the **SEN Pathfinder Parents Workshop**, 9.30am to 2pm (lunch included) on **Thurs 14 November** at the Brighthelm Centre. To book a place, call the helpline or email debbie@amazebrighton.org.uk

Who are your PaCC Champions?

It's awards season again. The PaCC wants to recognise the great work that goes on with our children in Brighton and Hove and we need you to tell us about the outstanding people of the year.



You know who we mean. That professional or team who just made life a little bit easier for you, who put in the extra effort or battled on your behalf to improve the standard of care.

A great example of a PaCC Champion is Occupational Therapist Jane Cleaver who won an award last year in the Social Care category. Jane was nominated because **"she organised all the adaptations in my house for my son. She is kind, caring and always listens. She responds straight away to any problems I have and is very thorough. The work that she has requested for us has improved**

our standard of living and made a huge difference to my son's life and mine."

Can you think of another professional like Jane who you would like to see recognised for their great work? Or maybe it's the person who has been quietly supporting you for years and to whom you never really knew how to say thank you properly. Well now you can by making them a PaCC Champion.

You can nominate online at: www.surveygizmo.com/s3/1387141/PaCC-Champions-Nomination-Form-2013 or via the Amaze website and

help us to find the PaCC Champions for social care, health, the voluntary sector and education. Once we've received your responses, a panel of parent carer judges will review the nominations and decide the winners.

Alternatively, complete the form below and return to Paolo Boldrini by 6 November 2013. Or email your nominations directly to Paolo via: paolo@paccbrighton.org.uk.

Please take a few minutes to say thank you for the great work done by people in Brighton and Hove.

Nomination form for PaCC Champion award



Nominate someone working in any service or capacity, who you feel deserves recognition for their excellent work with a child or children with special needs.

Your PaCC Champion:

Name

Job/Team

Category: Social care ☐ Health ☐ Education ☐ Voluntary sector ☐ ? (tick appropriate box)

Use this space to tell us why you would like to nominate your PaCC Champion. You could tell us about a specific act on your behalf, the difference they have made to your family or what your life might be like without them.

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Your contact details:

Name Tel

Please return the completed form to Paolo Boldrini, Parent Carers' Council Participation Worker, c/o Amaze, FREEPOST SEA 14216, Brighton, BN1 3ZZ or email your nominations to paolo@paccbrighton.org.uk by the 6th November 2013.

Buying and cooking on a budget

Planning meals, sticking to a shopping list and making the most of the food we buy can help us all eat more healthily, for less. And research tells us that establishing good eating habits early on gives children a head start. This is all the more important, and sometimes more tricky, when you have a child with special needs. Here we share some top tips to make your money go further.



- **Cook from scratch: it nearly always saves money** compared to ready meals and takeaways. There are some great, cheap recipes on: www.agirlcalledjack.com and www.change4life.com. Children love helping weigh, mix and chop: encourage them to join in.
- **Write a meal plan together** for the week and check what you already have in the fridge and cupboards to make these recipes.
- **Write a shopping list** and take it with you! Keep children busy counting, checking items off the list or comparing prices.
- **Frozen fruit and veg** are as nutritious as fresh and usually cheaper; you only use what you need so avoid waste.
- **Tinned oily fish** like sardines and salmon can be cheaper than buying fresh fish. They are packed with heart-friendly omega-3 fats, are simple to prepare and have a long shelf life.
- **Make meat go further:** add more vegetables to curries, chilli, bolognese and stews.
- **Beans and pulses like lentils** are cheap and high in protein if you want to cut down on or cut out meat. And they count towards your '5 a day'. Dried are cheapest but cans are good value and convenient.
- **Buy and eat seasonally.** It makes sense and it's often cheaper, fresher and tastier.
- **Replace morning or afternoon**

snacks with fruit. A banana or an apple can cost about half the price of most chocolate bars or packets of crisps. The savings add up and so do the health benefits.

- **Use up leftovers** - Sunday roast makes a shepherd's pie or a curry; leftover rice makes a stir fry. For lots more ideas try www.lovefoodhatwaste.com
- **Sign up for free school meals.** If you're entitled don't miss out.
- **Basic lines** ingredients at the supermarkets can dramatically cut your food bill. Broken grains of rice are just as fluffy cooked! But avoid processed and ready meals which are more likely to be high in salt and saturated fats
- **Make use of markets and local greengrocers.** They will often sell in smaller quantities than supermarkets and can work out cheaper. Or grow your own.
- **Join a food co-op.** Find out about existing food co-ops in the city at www.bhfood.org.uk.
- **Shop online.** Your regular items are saved in a list, so you can save time

and money as you are less tempted to buy other items

- **Supermarkets reduce prices** on products that are close to their sell by date. Just be sure that you'll eat, cook or freeze your bargain before it goes off.
- **Get together with friends and family to buy in bulk:** discount websites such as www.approvedfood.co.uk offer deals on bulk purchases including food past its 'best before' but not past its 'use by' date. Remember the delivery charge is at least £5.
- **If you have an emergency** and cannot afford even basic ingredients to make a meal speak to your health visitor, social worker or the food partnership about accessing a local food bank.
- **Brighton and Hove Food Partnership** helps people learn to cook, eat a healthy diet and grow their own food. Check out www.bhfood.org.uk.

The last word: 'Never shop when you are hungry!'

More worried about how they eat?

If your worries about mealtimes are more around feeding and eating issues, Contact a Family have a useful booklet on 'Feeding and Eating'. Call for a copy on 0808 808 3555 or download it from their website at www.cafamily.org.uk. Amaze also has Triple P tip sheets on mealtimes that we can lend to you, and these cover a range of issues from picky teenagers to younger children who eat things that aren't food. The National Autistic Society has useful advice on its website about dealing with ASC and diet issues. See www.autism.org.uk



A course, of course

The results of our recent parent carer survey are a reminder to us all to find things to sustain ourselves.

Doing a course with other parent carers is one really positive step to try. What do parents say helps about a course aimed especially for parent carers?

- Information or understanding about your child's needs
- Sharing ideas and experiences with other parents and trainers who know about special needs
- New skills, strategies, tips to help your family
- A bit of time and space to make sense of the challenges we face

Amaze has courses coming up (see right) but **Seaside View** and **CAMHS** also offer some options:

- **Time Out for ASC** – if you have a child up to 10 with ASC
- **Exploring ASC** – for parents of over 10s
- **ATLAS** – if your child has ADHD and sees CAMHS
- **Mindfulness** – for your own mental wellbeing

Downs View and Hillside schools also have a programme of meetings and training sessions for their parents. The Parenting Team has details of Triple P seminars and courses across the city. Call the helpline on 01273 772289 to help you work out if there is something out there for you.

Amaze courses coming soon

This term:

Looking After You starts **Monday 4 November**. Call right now to see if there is a last minute space on this super stress-busting course that mixes talk, relaxation techniques and a bit of Pilates.

Next term:

Insiders Guide for parents of under 5s – combines practical information and skills, with time to look at how it feels to have a young one with additional needs and how to build our resilience.

Triple P Stepping Stones – positive parenting and behaviour for parents of under 12s (daytime).

Triple P Teen – positive parenting and managing behaviour for parents of over 11s (evening).



Amaze courses are **FREE** and at least one of the trainers will always be a parent carer themselves. Call the helpline to find out more. You can go on the waiting list for any course that would suit you. When we next run that course we contact everyone on the list to give them first chance to book a place.

PECS Weekend 9/10th November

This is a special event in partnership with Pyramid PECS trainers offering two days of PECS training for parents here in Brighton and at a big discount. PECS is a picture based approach to communicating that can be transformative for children with little or no verbal communication. There are only 10 spaces for the weekend and the cost is £90 per person. **Call the helpline urgently to find out if there are any places free at the last minute.**



Win tickets for "Happy Days: A new musical"

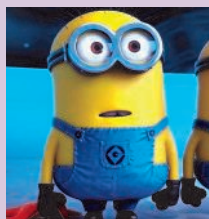
We've got a pair of tickets to give away for the happiest show in town – the Theatre Royal Brighton's 'Happy Days: A new musical'. Based on the hit TV series, Happy Days features the unforgettable Arthur 'The Fonz' Fonzarelli, the Cunningham family and all the gang – as they battle to save their beloved diner Arnold's from demolition.

Open to Compass Card families, you just need to send your name, the Compass Card holder's name, plus your address, phone number and email address (if you have one) by Friday 15 November.

We'll inform the winner by the end of November. Tickets are for the 7.45pm show, Monday 20 January. Send your entries to Amaze, at the address to the right or email compass@amazebrighton.org.uk

Despicable Me 2 at the Duke's

The next autism-friendly screening at the Duke of York's is Despicable Me 2.



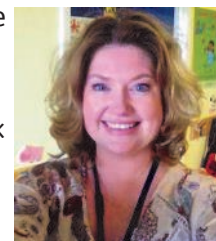
It's on Sunday 10 November and Amaze volunteers are on hand. Doors open 10.30am for free filter coffee, tea, squash and biscuits. Children pay £3, adult carers go free. There's also an autism-friendly screening of the film at the Duke's at Komedia on 2 November.

New Parent Liaison at ASCSS

Alicen Haire is the new Parent Liaison for the Autistic Spectrum Condition Support Service. A parent carer herself, she can offer any parent of a school-aged child with autism, information, support and a listening ear. She works on Tuesdays and Wednesdays and you can call her on 07578 768441. Outside these times

you can leave a message on the ASCSS office line on 01273 424963 or email alichenhaire@downspark.brighton-hove.sch.uk at any time.

Alicen is also restarting the popular ASCSS parent coffee mornings. The next one is at 9.45am on 4 Dec at Downs Park School.



Curl up with a book

Listening Books is an audiobook library service for people who struggle to read for whatever reason.

Listening to books is a fantastic way for children who struggle with reading to enjoy the same books as their peers

and, as Listening Books record educational books in-house, children can also access titles they might need for their school work. Subscriptions are available from just £20 per year.

To sign up or for more information, visit www.listening-books.org.uk or call 020 7407 9417.

Amaze helpline:

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

This Christmas the helpline will close from Tues 24 Dec to Weds 1 Jan. It reopens on Thurs 2 Jan.

Save us paper and get this newsletter earlier by email!
Just email your details to info@amazebrighton.org.uk



Amaze

Community Base
113 Queens Road
Brighton BN1 3XG

T: 01273 772289

E: info@amazebrighton.org.uk

W: www.amazebrighton.org.uk



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