

out of amaze



For parents of children with special educational needs and disabilities in Brighton & Hove

Help at hand with EHC Plans

Good news! Amaze can now offer Independent Support to families in Brighton and Hove and in West Sussex as you go through the new Education, Health and Care (EHC) assessment process.

Five of our Brighton and Hove team have qualified as **Independent Supporters** in addition to their other duties and have already supported over 40 families. What's more, as young people with Learning Difficulty Assessments are also entitled to request an **EHC plan** we now have a dedicated **Young Person's Independent Supporter** too. She can support anyone aged 16-25 who is going through the EHC process. In West Sussex we have nine Independent Supporters.

Since 1st September 2014, EHC plans have been replacing Statements of special educational needs as part of the Children and Families Act 2014 and all local authorities have developed schedules to transfer specific year groups from Statements to EHC plans over the next three years. There are significant differences between the two systems; EHC assessments consider health and social care needs as well as education and they focus on building a positive profile of the child/young person and identifying clear outcomes for them.

Independent Supporters work with parent carers and young people during the **20 week period of assessment** which may lead to a new Plan or the 14 weeks for a Statement to be transferred to a Plan. The type of support on offer will differ for each family but may include things like

explaining the stages of the process, helping to identify outcomes, attending meetings or reading the draft plan with them.

Independent Support is available to all parent carers and young people but the level of service will differ according to what you need – some families may just need to talk through ideas whilst others may need ongoing, intensive support. A young person may choose to work separately with their own Independent Supporter but, as a service, we will always encourage families to settle on a Plan which



parents and young people have all agreed on.

If you've requested a new EHC plan or been told when your Statement is being transferred, we can offer you Independent Support.

Brighton and Hove parents or young people should call 01273 772289 or email helpline@amazebrighton.org.uk West Sussex parents or young people can call us on 0300 123 9186 or email independentsupportWSx@amazebrighton.org.uk

Compass Card comes of age



The Compass Card is now open to **young people with disabilities or special**

educational needs **up till their 25th birthday**. At the start of December last year, Amaze invited young people over the age of 20 who'd previously had a card to apply again. Now we're

launching the card to **all young people aged 20 to 24 who have significant additional needs**, whether they've had a card before or not.

It's great news for young people in the city who want to get out and do things and save money too. For example, they'll be able to swim for free at King Alfred, Prince Regent and St. Luke's pools, use eight local gyms free of charge once they've paid for an induction and borrow CDs, DVDs and audio books for free in the city's libraries. **Read more on page 4...**

INSIDE: SEND Review • Compass Card app • New PaCC pull-out • Transport special • Young people's page • Courses • and much more...

Brighton & Hove budget latest

Brighton and Hove City Council's current annual budget is around £225m but due to year on year cuts in central government grants they are anticipating a budget gap of between £20-25m next year (£100m over the next five years).

Like other councils across the UK, Brighton & Hove has a tough job working out how it can make savings across all the services it provides – many of which are essential and which they have a duty to provide. Papers detailing the budget proposals can be found in the Council and Democracy section of the Brighton & Hove website or via this shortened link: www.tinyurl.com/kb6x8jm

The proposals include **£1m worth of savings to be made across SEND services** (on page 75 of the report) and a **£500k savings target for home to school transport** (on page 73).

Members of the Parent Carers' Council and staff from Amaze have met senior council officers to discuss their concerns about the proposed cuts and the possible disproportionate impact they may have on disabled children and their families.

Regan Delf, Assistant Director for SEND, assured us, saying: "The proposals have been carefully

designed to protect front line services to children and families. As a consequence we do not anticipate any significant impact on or reduction of overall support or services to families with SEND from these savings proposals."

She added: "The recommendations from the SEND Review (see opposite) are aiming to improve services for families and families should notice significant improvements in a number of areas in the future."

"We do not anticipate any significant impact on or reduction of overall support or services to families with SEND from these savings proposals."

Regan Delf, Assistant Director for SEND

However we know families will be worried about these proposals and will want to understand more, particularly as it feels that, as demand increases, some services are stretched beyond capacity. The PaCC are writing to local councillors asking them to protect SEND budgets.

Families are also concerned about the £500,000 savings target for home to school transport and the council's new Home to School Transport Policy. (read it at www.consult.brighton-hove.gov.uk/public/bhcc and respond by 27th February). The council hopes **more secondary-age children with SEND will be supported to travel to school independently** and there are some funds for independent travel training. It also hopes that some families who receive the mobility component of DLA can use this to transport their child to school. Both Amaze and the PaCC have submitted detailed responses to the transport consultation as we think the policy regarding use of DLA may be open to challenge. We'll update you on how the policy is being implemented in the next newsletter.

Other children's services such as some Children's Centres and the Play Bus are also facing cuts. **Final decisions will be made by full council on the 26th February**, the day this newsletter goes out, so some of the above proposals may change. We'll make sure the final proposals are available on the Amaze website and Facebook page as soon as possible, so visit www.amazebrighton.org.uk/news-and-events, like our [Facebook page](#) or join our [Facebook group](#).

New legislation for young offenders with SEND

The SEND reforms introduced as part of the new Children and Families Act include new legal requirements for supporting children and young people with SEND when they are detained in youth custody. They will come into force on 1st April 2015.

They have four key aims: to make sure there is one local authority responsible for a child or young person's special educational provision while they are in both the community and in custody; to

ensure a child or young person continues to have appropriate special educational provision when in custody; to help children and young people resettlement when they return to their communities by identifying their needs and ensuring that provision continues and to make the best use of the time they spend in detention so that an assessment can get under way and support can be put in place immediately on release.



The Council for Disabled Children has produced a fact sheet about the reforms. You can download it at www.councilfordisabledchildren.org.uk/resources/cdcs-resources

SEND Review unveils key priorities

Since June 2014 the council has been carrying out reviews of the city's services for children and young people with SEND and behavioural, emotional and social difficulties (BESD). This has involved wide consultations with families, children and young people and professionals who work with us.

Regan Delf, Assistant Director of Children's Services, presented a report setting out the findings of both reviews and some proposals for action to a joint meeting of the Health and Wellbeing Board and the Children's Committee on the 3rd February where they received unanimous support from all political parties and other members.

Pinaki Ghoshal, Director of Children's Services, said, "It's a key moment in the development of services for children with special needs and disabilities."

"It's a key moment in the development of services for children with special needs and disabilities."

Pinaki Ghoshal, Director of Children's Services

Coming soon

Some of the recommendations may be put in place quicker than others, for instance:

- **To combine the city's SEN support services** (such as literacy, sensory needs and ASC support) **into one 'communication and support service'**. This new service may be located on the same site as relevant health professionals like speech or occupational therapists
- **Extend the remit of SEN and disability services to offer more home support to parents**, including opening up training to parents alongside professionals and for that training to be co-produced with parents and children with SEND where possible

- To develop a **clear and transparent system for how families are assessed and receive respite/short breaks**, and ensure this is done fairly
- To provide those families with **more choice and control about what short breaks services they access** and how they access them

Further in the future

Some recommendations that were agreed will take a bit longer to plan. These focus on the development of integrated provision in three areas: **Early Years, school to college age** (from 5-19+) and **children with BESD** (including those with emotional and mental health problems).

The council will be exploring how it can extend current provision to be more inclusive, with extended day/ respite and possible residential facilities, with relevant health and care services jointly located on the same site. This will include looking at how it can make the transition to adulthood much smoother and create more vocational options for young adults.

Regan Delf says, "We are really ambitious about the changes we want to make, so that we create more holistic provision, with children and families at the heart of what we do."

The council is committed to continuing to work with parent carers and partners like Amaze to consider in more detail what this integrated provision might look like, so we'll keep you up to date and let you know how you can be involved. There are already two PaCC Reps on the Review's Governance Board which will continue to meet to oversee the next stages of the review.

Please 'like' the Amaze Facebook page or join the PaCC Facebook group to stay in touch on the SEND/BESD Review before our next newsletter is due out in June.



Amaze up to standard on safeguarding

We are delighted that Amaze got the **Simple Quality Protects bronze award** in November. This recognises that we are a safely run organisation that pays attention to safeguarding children and young people.

Amaze takes safeguarding very seriously as we all know how vital this is for children with SEN and disabilities. You can read our Safe-guarding Policy on the Amaze website or ask us for a copy. Our lead person for Safeguarding and Child Protection is Ros Cook and the deputy is Liam Ryan. Both can be contacted at the Amaze office. Next stop – the SQP silver award!

Autism awareness week and ASC conference

The local authority is holding a week of activities to promote understanding and good practice **for people who work with children and young people with ASC and their parents**.

The week kicks off with 'Improving Outcomes for Children and Young People with Autistic Spectrum Condition' on **Mon 16th March** at the AMEX Stadium, a conference with first class speakers and workshops. The council hopes to bring together people who work in education, health, social care and the voluntary sector with parents of children and young people with ASC. Amaze is distributing the tickets allocated for parents so call the Helpline on 01273 772289 if you're interested in attending.

Compass Card comes of age

It's official. The Compass Card isn't just for 0-19s with additional needs; it's now for 20-24 year olds too.

So, with the exception of some age-specific offers and activities, older young people can take advantage of dozens of Compass Card offers and activities – from discounted tickets for specific shows at the city's key entertainment venues, to a spin on the Brighton Wheel, or 10% discount on Brighton & Hove Radio Cabs fares.

Will I be eligible?

Usually, the young person will be eligible for DLA (Disability Living Allowance) or PIP (Personal Independence Payment). Or they'll have a statement of SEN or an EHC Plan, or Moving on Plan.

How do I apply?

Young people aged 16 to 24 can apply

for their own card, or a carer can apply for them. There's a special Compass Registration Form for young people (18+), so make sure you've got the right one. The registration form is online at www.amazebrighton.org.uk/services-and-support/the-compass-card/apply-for-a-compass-card or you can call the Amaze helpline on 01273 772289 and ask for a hard copy.

How soon will I get my new Compass Card?

The usual turnaround time is three weeks, but because lots of people will be applying at the same time, you'll need to bear with us on this one. While there's such a big demand, we expect to process new applications within six weeks – so hold tight!



How can I find out about the offers and activities?

You'll be sent a copy of our Compass Card offer guide and our Compass Card Activity guide, together with update sheets, when we send your Compass Card to you.

You can also see the guides and updates at www.amazebrighton.org.uk/services-and-support/the-compass-card/compass-card-offers/ – or you could download our Compass Card app to your smart 'phone (see below).



Discover our Compass Card app

Our Compass Card app is still in its testing phase, but it's up and running and we want to hear your feedback!

Developed free for us by local company Dabapps, the app is **available free** on android smart phones and iphones. All our offers and activities are there and you can search for leisure activities you're interested in, and link to GPS so you can see exactly where things are happening. Even if apps are not your thing, it could be a useful way of getting your son or daughter to choose a Compass Card Activity or find out more about Compass Card offers.

You'll find the app by searching 'Compass Card' in Google Play and on the iPhone App Store. It's free to download and quick to install. Please send any comments on the new app – good and bad – to compass@amazebrighton.org.uk

New offers!

To celebrate our age range extension, we've recently added four new Compass Card offers and a new Compass Card Activity (CCA):

- 15% discount for over 16s at Boulder Brighton in Portslade

- 10% discount on meals at the Lord Nelson Inn on Trafalgar Street
- 10% discount on drinks behind the bar at the World's End pub on London Road
- 10% discount at The Parlour café at Brighton Marina
- A new Travel Training CCA for over 16s from Grace Eyre which includes a rolling programme of six week courses and one to one training for particular journeys. For more info, call the Amaze helpline on 01273 772289 or Grace Eyre on 01273 222053.

You can search for leisure activities you're interested in, and link to GPS so you can see exactly where things are happening.



What the Compass Card means to you

Back in the summer, Amaze asked Shoreham-based consultants, JB Eventus, to assess the impact of the Compass Card on the lives of Amaze families. The resulting independent evaluation, published at the end of November, shows our unique card for disabled children and young people is about much more than affordable leisure.

Compass Card parents took part in focus groups and one to one interviews and completed a detailed online questionnaire. A big thank you to everyone who contributed; we really couldn't have done it without you.

"We were overwhelmed by your personal stories" says Amaze CEO, Rachel Travers. "You told us about the financial benefits of the card, which we expected - but you also told us about **far-reaching social benefits** - about feeling part of the community, about **improved health and wellbeing** and about greater choice and opportunities for your children."

As one parent said: "I can't stress how much it's improved our quality of life...It's given us one." Another described it as "a gateway to normality". According to the survey results, 99% of families said the Compass Card had made leisure more affordable, 98% said they felt more

confident going out as a family, 80% said they found Compass Card venues more welcoming and 79% said the Compass Card allowed them to go out more as a family.

"I can't stress how much it's improved our quality of life... It's given us one."

Many families highlighted the social benefits of the Compass Card. 83% felt it had improved their quality of life, 72% felt it had helped reduce stress and 71% said it had improved the general health and wellbeing of the family.

"As a family we are so thankful for the Compass Card, it has been a real game changer. Apart from the range of activities our son can now enjoy there are many knock-on benefits for the rest of the family, such as generally feeling more positive and integrated," commented one parent. Another said: "My son needs to have physical activities where he can be supported and feel safe and understood. He has been delighted when we have been able to join clubs and activities and he doesn't feel misunderstood, which is very important to us."

72% [of families] felt it had helped reduce stress.

The report estimates the Compass Card brings the average family savings of around £677 a year. Taking these savings and the wider economic benefits of improved health and wellbeing into account, consultants at JB Eventus estimate the Compass Card brings over £1m per year in social and economic benefits for the city - that's a whopping **£11.88 of value for every £1 spent** on the scheme.

"We're very grateful for the council's core funding for the Compass Card. This report highlights the extensive impact that their investment has for local families," says Rachel Travers.

The Compass Card has been **funded by Brighton and Hove City Council** since its introduction in 2003. More recently, funding from Sport England has allowed Amaze to extend our range of Compass Card Activities with partners like Adventure Unlimited and Spiral Sussex.

You can see both the summary and full versions of the JB Eventus report, "Opening up our World", online at www.amazebrighton.org.uk/resources/publications/reports



Be our volunteer!

Amaze is looking for volunteers to help us give parents the information, advice and support they need. Could it be you?

Do friends say you are a good listener? Are you warm and able to get alongside people? Can you also make sense of reports, explain complex information and get things down in writing clearly because sometimes that's exactly the help a parent needs. Or you might be required to help someone get their views across and be heard. Being an **Amaze volunteer** is interesting and challenging work but we offer our volunteers **thorough training and regular support**. In practical terms you need to be available during the school day as that's when most parents want our help, and able to commit fairly long term after your training. We are looking for people to join **two teams** of volunteers. Training courses start soon for both.

DLA Volunteers help with Disability Living Allowance and PIP claims. If you've seen a DLA form you'll know it can be quite off-putting; someone to work through it with you is a huge help. This role is very rewarding. You will see the difference you make. It involves quite long visits to parents to do their claim but each bit of work is completed quickly, so this role can suit people whose availability varies. DLA Volunteer training will run on Wednesdays, from 10am to 2pm on **15th, 22nd and 29th April at Amaze**.

"I wouldn't have been able to do the DLA forms without her. They're massive and I'm not good at spelling and writing."

IAS Volunteers have a varied role giving information, advice and support. Once you've done the initial training you can choose to specialise. Some of this team support our Helpline - this will suit you if you want to commit to a fixed day and time each week. Others give one to one help to parents as they try to sort out services and support for their child. Sometimes this is quick and simple but often you build a longer relationship. You can concentrate on helping with education issues or health and social care or perhaps focus on the older age group and help parents and young people preparing for adulthood. If this all sounds rather 'expert' we promise the training will equip you with the knowledge you need. IAS Volunteer **initial training** is on Thursday mornings **12th, 19th and 26th March, 16th and 23rd April**.

If you're interested in volunteering, call 01273 772289 or email info@amazebrighton.org.uk now to find out more.

Amaze courses BOOK NOW!

Insiders Guide for Parents of Teens starts **Friday 17th April** in Community Base. Over six Friday mornings it will explore the next stage in our journey with a disabled child, and the new challenges as they **move towards adulthood**. It looks at things that may feel tricky like their social lives and relationships, giving practical information and ideas, and at how we stay resilient after years of being a parent carer. It's for parents of teens who will continue to need lots of support as they get older.



COMING SOON...

Looking After You - We are planning two LAY courses this year with a special twist. The first one starts on **Wed 15th April** and gives an extra welcome to **older carers** who might be grandparents or mums and dads of older children with SEND. The other will be for **parents of babies and younger children** with disabilities or health issues. Looking After You has six weekly sessions that address your stress with space to talk, learn practical relaxation techniques and some bite-size Pilates.

Triple P - we hope to run Triple P courses later this year if we have funding - check our website. Triple P courses last eight weeks and focus on behaviour and how to use positive parenting approaches.

To find out more or book any Amaze course, call us on **01273 772289** or email info@amazebrighton.org.uk



Meet the Parents

Welcome to our new look pull out PaCC pages. The Parent Carers' Council is taking over this four-page spot in every Amaze newsletter and we plan to make the pages more personal.

If you haven't read about the Parent Carers' Council in past newsletters we hope this new format and more views from parents will appeal to you and we hope you'll consider joining us!

The Parent Carers' Council or PaCC is just a group of mums, dads and carers like yourselves who get together to try and help improve the services and support available for their families in Brighton and Hove.

The PaCC represents families with children or young people with any condition - learning disabilities, physical disabilities, complex health or mental health needs - and your involvement could be as little or as much as you feel is right. For example, you might just want to go on our e-mailing list or come to PaCC Connect events that mean something to you. Or if you feel like getting more involved you could join the PaCC Steering Group. You might then be trained as a parent representative to

sit alongside professionals from the local authority at meetings where services and policies are formed.

Whatever your involvement, it counts! Every parent carer who joins the PaCC helps to ensure that our voices are heard when decisions are made that directly affect our children.

PaCC has a steering committee that meets every two months, and this is co-chaired by Jill Weeks and Fiona England. This issue introduces three members of our fantastic steering group, who tell you about the kind of things they do to help PaCC help shape local services. Pippa Hodge (right) tells you about her role as a parent rep, and Jade Duffil and Lisa Russell talk about their contribution to the recent PaCC Connect event about the review of SEND services in the city. Turn to page 10 to meet Jade and Lisa. To join the PaCC, email us on admin@paccbrighton.org.uk

Being a PaCC steering group member

Pippa explains why she joined the PaCC and what she does to help.

"I heard about PaCC through Amaze. I signed up a couple of years ago because I



wanted to be a voice in my local parent carer chorus and find out what was going on.

"I'm a divorced mum of three and my youngest has Trisomy 21 and lots of complications, so I was tapping into lots of the local provision. Like others, I've had great, good, average and poor experiences, and so rather than feeling frustrated and doing nothing, I decided to get stuck in.

"Last year I joined the PaCC Steering Group and I now attend meetings every couple of months, support PaCC Connect events, and go to other meetings where I have some particular knowledge or experience or where I can highlight issues or suggest improvements. My personal areas of interest are wheelchair services, services for children with complex needs, and continence.

"I love that the members of the Steering Group come from all walks of life so that we reflect the diversity of our fantastic city. Everybody has something to contribute and we work in a way that respects that we all have a demanding 'day job' as parent carers. Being connected with others who are committed and passionate about bringing positive change helps me feel part of a broader group who are on a shared mission."



Helping to steer through transport changes

As many families know, home to school transport can be vital for ensuring a successful start to the school day. PaCC has been working hard to make sure parent carers' views are heard as decisions are made on potential changes to this core service.



Some will remember that changes to the contract with transport providers two years ago led to major upheavals for young people just prior to their return to school in September 2012. The transport contracts are due to be re-tendered again soon and PaCC's involvement in the decision making process and your responses to a recent transport survey should make this a better process this time round. The disruption caused by the last transport contract change triggered a PaCC-led focus group with parent carers, where council officers were invited to hear our experiences. Since then, PaCC members, Diana Boyd and Reza Ataie, with support from Amaze CEO, Rachel Travers, have attended many council meetings to explain the importance of home to school transport for parent carers and to suggest ideas about how it might best be delivered. We've also been involved in discussions about developing more independent travel training.

Steve Dillow, who is leading the re-tendering process this time round, has been very pleased to get the

parent perspective: "We'd like to thank parent carers for their response to the 'Home to school transport for pupils with special education needs' survey. It's been a valuable exercise to understand how the service is currently working for parent carers and children.

"Communication, **understanding children's needs** and **training** were common themes in responses. We'll need to have further discussions with parent reps and transport providers to

address some of these issues.

However, the feedback will be used to improve the specification for the re-tendering of the service. Areas that will be included are:

- **Notifying parents/carers** if the transport operator will be more than 15 minutes late
- **Keeping the same driver and vehicle passenger assistant (VPA)** where possible
- **Service reviews** with transport operators and parent/carer representatives
- **Guidelines on vehicle seating** configuration
- **Vehicles to be clean** and odour free
- **Radio usage not to cause alarm** or distress to children
- **Driver and VPA details to be available to parents/carers** one week before the service starts
- **Opportunity for parents/carers and children to meet drivers and VPAs** before the service starts

Sarah's transport story

"My son is 11 and his journey to school is just over a mile. Because it is such a short journey the taxi company couldn't find a driver who wanted to do the route regularly and we were getting different drivers daily. This was really awful because they didn't understand when my son refused to leave the car or that he needed constant positive chat to get him to cooperate fully in the transition from home to school. I had to discuss his behavioural issues afresh with every new driver. I was very worried about health and safety and my children were arriving at school very stressed."

"I told Katy at the transport office that I might as well be getting two buses and carrying him like I used to. She understood and was able to allocate us a regular driver who works for the local authority. We've quickly built a very good relationship with him and, more than that, we now have the chance to practice positive behaviour and routines for the morning which is good for everyone. The Transport team has really helped us. We still have stressful days but these are less regular and no longer a routine start to the day."





"There are operational reasons why some suggestions cannot be incorporated but we'll continue to work with parent representatives to address issues that are raised. We've accepted an offer from a PaCC rep to sit on the evaluation panel for the forthcoming tender."

It's great news that parent carer views have been listened to and will lead to changes in the new contracts and the PaCC welcomes being asked to be part of the process to find a suitable transport provider.

Beyond this, however, there is continuing pressure on the local authority to make financial savings and worryingly it has announced it needs to make £500,000 savings on home to school transport budgets (see page 2 for full budget story).

We can all help the Home School Transport Team make savings by letting them know whenever our child

Paula's transport story

"When my autistic son started at the Carden speech and language unit in Year 2, he was eligible for home to school transport. His anxiety could cause extreme behaviour but with patience and practice he managed it - all down to the relationship he'd developed with the driver and escort."

"When the home to school contracts changed in 2012, this was very difficult for us, and several times he almost refused to get on the bus. The driver became impatient, sometimes coming to the door, and adding to the pressure. My son doesn't respond well to tension, and there was always a risk that the behavioural issues would then come out on the bus. Sometimes they did. I spoke to the transport operator, and she suggested that, since the arrival time of the minibus was variable, the escort could text me five minutes before the minibus arrived. This worked incredibly well, and ensured that he was mentally prepared, and able to get on the minibus stress free and ready for the day."



will not need transport, for example, when they are ill or have a hospital appointment. It is also essential that we let the team know of any change to wheelchair use at least 6 weeks in advance, to ensure an appropriate vehicle is available.

If you haven't already commented on the council's proposed transport policy, you may just have time. Visit www.consult.brighton-hove.gov.uk/public/bhcc and select 'Home to School Transport Policy Consultation 2015' from the list. **Be quick - the survey closes on Friday 27th February!**

Sharing medical records

PaCC helps the local CCG get the parent carer perspective

In September last year, as part of our ongoing work with the local Clinical Commissioning Group, we asked your views, via an online questionnaire, on local plans to share patient records to support better patient care.

Feedback from the consultation acknowledged that sharing records should help bring about more joined up care and improve communication between parent carers and care professionals. However, parents who responded raised concerns about the quality and security of shared patient information. You can find the full report at www.paccbrighton.org.uk/resources/reports/

Becky Gayler, Clinical Informatics Project Manager with the local CCG, is collating feedback from parent carers

and other groups so that any future initiative around record sharing takes into account their views. Options being considered include a 'Summary Care Record', where core health information is made available to emergency services, transferring information electronically between services to improve the timeliness and quality of information and electronic clinical correspondence between GPs and hospital services. Your feedback will also help shape how detailed records and care plans will be shared between integrated services and how you can order medication, book



appointments and access your own GP records online.

In response to the consultation, the CCG is setting up an "Information Sharing Patient Reference Group" to look at how we can improve communications about record sharing so that people understand their choices and know where to get help.

For more information about record sharing search for 'Informatics Programme Update' on www.brightonandhoveccg.nhs.uk.



Working on the SEND Review

Ever wondered what PaCC members actually do? Here Jade Duffill and Lisa Russell talk about their roles as PaCC reps for the recent PaCConnect forum on the SEND Review.

Jade

"PaCC recently hosted a PaCConnect event all about the SEND review and I helped out. PaCConnects are a chance for parents and carers to meet up with professionals from the local authority to discuss issues in a kind of informal workshop. There were 30 parent carers at the event together with people from the SEND team like Regan Delf, Jacqueline Coe and Bob Wall.

"Regan introduced the key themes of the review and we then split into four smaller groups for further discussion. My role was to 'facilitate' one of these groups, which basically meant I helped parent carers to voice their opinions in a friendly, comfortable and confidential space with like minded people.

"I had a fantastic and lively bunch of parent carers with a wealth of different knowledge and experience. It was really interesting to connect parents at the start of their journey with others who were towards the end of the educational phase and preparing for adulthood. Ideas were flying around fast and furious and I felt it was essential to capture them all. I couldn't have done this without the speedy note taking of Lisa Russell.

"It was a nervous but exciting experience. I have a genuine interest in meeting new people and, dare I say it, I love a good natter! It was great to meet new people with similar experiences and for such an important reason."

Lisa



"I spent an afternoon working at the PaCC office recently, collating and summarising parents' feedback from the PaCC Connect meeting on the SEND review. Our parents have some amazing ideas to get our local authority working more efficiently for our children and young people.

"There was a lot of information to get through, reading and grouping together what parents want from the review and ideas for reform but, with the tea and biscuits always on standby, it was a happy few hours typing up notes and marvelling at how strange it was to be working in an office again after an eight year break.

"It's great to have this dedicated office space free from the distractions of home (cleaning, 'Come Dine with Me', etc). We all have busy lives with our children, sometimes balancing jobs, businesses and other voluntary work too, so it's great that we have our own place to meet and work together as a team."

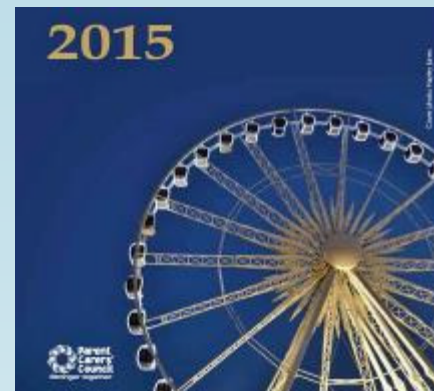
What next?

The council has now agreed the key recommendations for the SEND Review (see page 3) and it wants to ensure that families are involved as these are developed. Join the PaCC so we can keep you updated!



PaCC's calendar

Every year we produce a PaCC calendar to distribute to members and professionals across the city. The Steering Group comes up with the concept, works with designers and printers and organises a big mailout.



This year's theme was **our children as artists** and each month features a photo of a child or young person and a sample of their artwork. The front cover shot of the Brighton Eye was taken by Photographic Student, Hayley Jones, who's studying A Level photography. Our design team paid Hayley the ultimate compliment, calling it 'an excellent shot'.

We've already had lots of great comments about the 2015 Calendar. Work on the 2016 one will begin in April - **this year's theme is 'Siblings'**. We'll be asking members and partner organisations for contributions to the 2016 Calendar after Easter.

Coming soon!

PaCConnect on Housing Adaptations

Do you need adaptations to your housing because of your child's disability or have you in the past? If so, this forum will give you the chance to **talk to some key council staff** that deal with applications for adaptations. The forum will take place at Community Base, Queens Road, Brighton on **Wednesday 18th March** from 9.30am to 12.30pm.

To find out more or come along, email admin@paccbrighton.org.uk

A Day in the Life...

of a Link Plus Home Support Worker

Anne, a Home Support Worker for Brighton & Hove Link Plus, tells us how she helps support a local family.

"My motto is 'Be prepared and ready for anything!' says Anne, "as you never know what you will be doing or where you might end up going."

Anne has been supporting Vicky and Terry and their 7 children (Leon aged 15, William aged 13, Alfie aged 11, Sharna aged 10, Leah aged 8, Rosie aged 2 and Kayleigh, 10 months) since 2001. She has over 20 years nursing experience as a paediatric nurse, a general and a district nurse though she is no longer registered.

Leon was about 14 months old and his brother William just 2 weeks when she first worked with the family. Leon was born with congenital heart disease, cerebral palsy and complex epilepsy. In the early days, Anne helped for a few hours a week via SSSH (the Specialist Sitting Service which transferred to Link Plus in 2009). Now Anne **supports the whole family as and where required**. Home support is very flexible and usually made by mutual agreement between the parents and their Home Support Worker.

"I might be needed to sit at the hospital, to help attend a medical appointment, or to support the whole family so they can all go out together. I might take the children out, maybe to the park or to soft play. Or I might stay at home so that Vicky and Terry can take the other children out, or I could look after the children so that Vicky can get other things done.

"No day is the same," says Anne, "Of course there are the usual routines. I may be asked to help with school runs or meal times, for example, but in between those times

in Anne and Vicky's words 'anything goes!'

"I enjoy the variety of my work as it keeps me young and active; I'm always equipped and ready for the unexpected to happen. In the boot of the car I have extra clothes, snacks, drinks, games and toys, which might be needed to cheer up or to occupy children while they wait. I've become adept at inventing quiz games, doing art and craft, dancing, imaginary play, dressing up and supporting the children with their various clubs and different hobbies such as swimming and football."

They accept Anne as a member of their family and see her as part of the furniture.

Anne has been a constant part of all the children's lives and **her role has changed and evolved with them** as they have grown up and become more independent. Although they are aware she works for Link Plus, they accept Anne as a member of their



family and see her as part of the furniture.

Vicky agrees that Anne is far more than a worker – more like an integral part of their family. "She's an extra pair of hands when things get busy, a sounding board and someone to get advice from. All the children love Anne and look forward to her coming".

You may be eligible for the Home Support Service if your child has a severe learning and/or physical disability or if they have moderate learning difficulties, very challenging behaviour or complex health needs. To request support, you should contact the Seaside View Child Development Centre on 01273 265825 and ask for an assessment.

Barnardo's Brighton & Hove Link Plus also provides Family Link where a child goes to an approved foster carer for an overnight break or for day care.

For further information about Link Plus Short Breaks or Home Support please telephone 01273 295179.

Thank you to Anne, Vicky and Terry for giving their consent for this article to be published.

Otherworld's big splash

Our amazing Compass Card Activity, Otherworld, is back with a big splash and a new theme, 'Beneath the Waves'. This beautiful, **sensory, immersive theatre** experience for all disabled children and their families, was given **rave reviews** by our families last year. Project Coordinator, Ariane Hadjilias, says, "The new show builds on our experience and is more colourful, more vibrant, more reactive and more varied – a really magical experience."

'Beneath the Waves' is at Heronsdale School, Shoreham, from 11th to 15th March and at the Corn Exchange in Brighton from 15th to 18th April. For more info, visit www.samesky.co.uk or call the Amaze helpline on 01273 772289.



What's out there for young people?



Amaze is looking for **young people with special educational needs and disabilities aged between 16 and 25** to get involved in a project looking at what's out there for them. This means being part of a group who will find out what fun things there are to do, or how and where young people can get help and support. They will also help us find out what's missing for young people and make suggestions about how things can be improved. It will take place over a weekend **in March**. We will let you know the date.

The group will also work with some young people who are doing their **National Citizen Service** (see opposite). This means they'll get the chance to see what it involves and see if they might want to sign up for their summer project. Plus **the young people involved will get a voucher** to spend in any shop for helping us.

To find out more, contact sue@amazebrighton.org.uk or call the Helpline on 01273 772289 and Sue will get back to you.

Oska needs your films

The Oska Bright Film Festival 2015 is looking for **short films made by people with learning disabilities**.

Deadline for entries is 30th April 2015 and the Festival takes place this November, in Brighton. Visit www.carousel.org.uk for information on how to enter and view an accessible guide to film-making.



Holiday fun with NCS

Is your son or daughter aged between 15 to 25? Are they up for an adventure? Do they get bored in the holidays and would they like to make new friends?

The National Citizen Service (NCS) might be just what they're looking for. It takes place over the **spring, summer and autumn holidays**.

For a week, they'll live away from home at an outdoor activity centre and experience how it feels to be a bit more independent. They'll make friends with other young people taking part and they'll get all the support they need to try lots of exciting activities like kayaking, high ropes and abseiling.

When they get home there's a variety of workshops and activities aimed at helping them develop new skills and confidence including working on a project together in the local community. And once the project's finished, they'll **graduate in a ceremony at the Amex Stadium**.

It costs £50 but that covers everything including the residential costs and activities. If you can't afford to pay, there's a full bursary - the NCS doesn't want the cost to stop young people taking part.

Tell your son or daughter about the NCS summer programme. If they are interested, call Haitch Zeida on 07876 898035. Or, if you'd like find out more first, Amaze is hosting an information session on **Tuesday 17th March** from 4.15 - 5.15pm. Young people can come with their parents or carers and ask the people who run the project any questions they may have. Contact Amaze to book a place on 01273 772289 or email: info@amazebrighton.org.uk

Tell us what they want, what they really, really want ... to see on this page

We want to create **a page that is just for young people** in this newsletter. To make sure we do this right, we'd really like to find out what sorts of things young people might like to read about and how they'd like their page to look and feel. If your son or daughter have any ideas or suggestions, please email them to sue@amazebrighton.org.uk

Help with EHC Plans for Young People

Have you heard about Education, Health and Care or EHC Plans? They're a new way of planning support and Amaze can help young people with theirs



Lots of young people have a Statement of special educational needs, a Learning Difficulty Assessment (LDA) or Moving on Plan which lists the support they need at school or college. These are being replaced by Education, Health and Care (EHC) plans. These **new plans give young people the chance to say**

what they want for their future and what works for them. They might want to talk about their health, education and social care now and in the future.

- If a young person has a Statement the local authority may already be planning to transfer them to an EHC Plan
- If a young person has an LDA or a Moving on Plan they can ask for an EHC Plan
- If a young person has special educational needs but does not have a Statement or an LDA and they are aged 16-25 they can ask for an EHC Plan

Would you like more information about EHC Plans?

Sally Cristin is our new Independent Supporter for young people in Brighton and Hove. She can help them to:

- Ask for an Education, Health and Care assessment
- Understand what the EHC plan means for them
- Get the information they need
- Write down what they want to do
- Go with them to meetings about the plan
- Make sure the professionals know what they want

How can a young person get help?

Email sally@amazebrighton.org.uk or call or text 07483 111651.



Young people power

The Power Group is for young people with learning disabilities aged 16-25. It's somewhere to talk about what's going on for you with other young people. We meet once a fortnight on **Wednesdays** from 4 to 6pm at the **Young People's Centre**, 69 Ship Street,

Brighton BN1 1AE. Sue Winter from Amaze and Dawn Thorpe from Speak Out are there to make sure everyone feels welcome and safe. If you'd like to be part of the group, please let us know. You can contact Sue at Amaze on 01273 772289 or email sue@amazebrighton.org.uk or contact Dawn at Speak Out on 01273 421921 or info@bhspeakout.org.uk.



Money making marvels

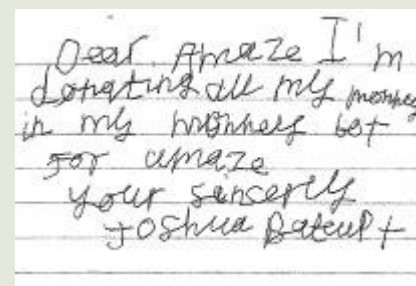
We often tell you (see the back page) about supporters who complete feats of extraordinary endurance or sporting skill in aid of Amaze's work with parent carers. But the quieter ones, the people who use whatever skills they have to raise funds, mean just as much to us.

For example, **Dorothy Stringer Business Club** (pictured above) used their entrepreneurial skills to raise **£651 for Amaze** selling Valentine's Day roses and second-hand school uniform last year.



In November 2014, a unique exhibition of 7 year old **Sophie Buckley's selfie photos** raised **£270 for Amaze**. And 11 year old **Joshua Bateup**

donated all his pocket money and his good friend **Lucy Harding** raised **£108 for Amaze** from loom band sales and the ice bucket challenge. If you think there is anything you could do, however small, to **help us help more parents of disabled children** and children with SEN in Brighton and Hove, just email nickyb@amazebrighton.org.uk



Thanks Joshua!

Welcome to Wellesley

Like most valuable things, our newsletter is quite costly to produce, so we're delighted to introduce our new newsletter sponsor, Wellesley Charitable Foundation, who will be helping fund 'Out of Amaze' for six issues.

Wellesley Charitable Foundation, the charitable arm of Wellesley Wealth Advisory, Sussex-based financial advisers, was founded in September 2012 to **help ill or disadvantaged children and their families** in Sussex and the surrounding counties. Wellesley Wealth Advisory was introduced to Amaze in 2012 by one of our trustees, Karen Smith. Wellesley (a Principal Partner Practice of St James's Place Wealth Management) in turn introduced us to St. James's Place Foundation who made a donation of £10,000 in 2013 to fund two editions of our 'Through the Maze' handbook.

Tony Hannigan, Managing Director of Wellesley, commented at the time: "We are passionate about supporting local families with disabled children and fully endorse the service that Amaze provides in signposting the support available to families, particularly in the current legislative and economic climate."

Our relationship with Wellesley Charitable Foundation has since developed and we were invited to attend their trustees meeting in August 2014 where the trustees agreed to help fund 'Out of Amaze'. We also decided to work together on fundraising initiatives, the first being a **joint charity golf day** which is being held at The Dyke Golf Club in Brighton on **Wednesday 15th July**.

The golf day will include coffee and bacon rolls, 18 holes with a shotgun start and a golfers' lunch. Places are available at **£200 per team or £50 per person** and sponsorship packages are



Tony Hannigan, Managing Director, Wellesley Wealth Advisory; Amanda Mortensen and Tim Lavender (co-chairs of the PaCC) and Rachel Travers, Chief Executive, Amaze.

also available from £100. If you'd like to support this event, either by event sponsorship, the donation of an auction prize, or by playing on the day, please contact Maria Tyrrell at Wellesley (maria.tyrrell@sjpp.co.uk) or nickyb@amazebrighton.org.uk for more information.

Wellesley is also interested in funding other organisations or groups that work to support disadvantaged children and young people in Sussex and the surrounding area. If you are a charity or know a charity that fits the bill, please tell them to contact Wellesley for a grant application form. Applications for funding are generally considered by the trustees on a quarterly basis. If you require urgent funding, please specify this and your application will be reviewed immediately.

You can contact the trustees of Wellesley Charitable Foundation at Wellesley House, 50 Victoria Road, Burgess Hill, West Sussex, RH15 9LH.



Comedian Joe Wilkinson ran the 10K and the Half Marathon for Amaze.

Wonder runners

A massive thank you to all of the runners who took part in Brighton **Brooks 10K race** in November 2014 and the **Brighton Half Marathon** earlier this month!

And thanks to all the many people like Stella Barclay aged 7 (pictured) who came along to support our runners on the day.



Try something new?

Some amazing supporters have found unusual ways to fundraise for us lately. For example, Dave, Paul, Richard, Euan and James took part in the Tough Mudder Obstacle Race (pictured below) in October of last year and raised £2023.62.



Do you want to get involved in something similar? If so, **call the Fundraising team** on 01273 234014 and we can support you or email nickyb@amazebrighton.org.uk

Find out more at www.wellesleycharitablefoundation.co.uk

Connecting single parents

Joanna Gurr, director of SPIN, the Single Parent Information Network, explains how SPIN can help support single parents in Brighton and Hove

"I became a single parent two weeks before my youngest son was born. My oldest son has had health issues since he was a baby and there have been lots of hospital appointments, operations, emergency admissions and days off school. Being a single parent is challenging at any time but if one or more of your children have additional needs, single parents can experience a much greater overload mentally and physically.

"After the breakup of my relationship I was left exhausted with debts and a deep depression. I struggled to find services that met my family's specific needs so I started SPIN in 2005 after realising that Brighton and Hove just didn't have the specialist support we needed. From the start, I've been

keen to include men and single parents with sole or shared care of their kids.

"Over the last few years whilst bringing up my sons alone and without financial support from their father, I've run projects and events and built up a membership slowly. As I now have to work fulltime, **SPIN is a free online meeting place** that allows single parents to get to know each other and choose to meet locally, either at a group event (camping in the summer, Mothers Day lunch, etc.) or just two people at short notice in the park with their children to 'get out of the house'.



"Our members are very supportive, often posting their frustrations and receiving advice and offers of help. Messages include stuff for free or for sale. We also have SPIN-offs such as a self-employed group, and single parents of teenagers.

"I send out regular emails with information about things like free tickets or discounts or funding opportunities. I even promote our members' businesses. To find out more, email SPIN@live.co.uk

"Come and join SPIN! We look forward to meeting you."

To join SPIN visit www.groupspaces.com/SPINBRIGHTON or find them on Facebook at www.facebook.com/SPINBrighton



Ask an expert

This issue, Philip Warford from local law firm, Renaissance Legal, answers a query about making a will.

I've been advised to write a 'Letter of Wishes' to go with my Will. What does that mean?

"If you've made a Will you usually only need to write a Letter of Wishes if you have set up a Disabled Person's Trust or Discretionary Trust in it.

"A Letter of Wishes is **your personal guidance to the Trustees**. It explains to them your reasons for setting up the Trust and gives them directions on how you wish the Trust assets to be used for your disabled child. It's your opportunity to put down in writing all of the factors you would like the Trustees to consider

and how you would like them to make decisions. This could also include guidance on more formal matters such as the type of investments to be used but, most importantly, it should include the more personal details about your child's medical needs, accommodation, schooling, likes, dislikes and your aspirations for your child's future.

"The Letter of Wishes should also say how the assets should be distributed in the event of the death of your child before all of the assets are used – for example maybe the assets will pass to other family

members or to your favourite charity.

"As your wishes and the needs of your child can change after your Will has been made, the Letter of Wishes should be updated on a regular basis. This will ensure it always reflects your current wishes. Place your updated Letter of Wishes in store with your Will. You can usually update your Letter of Wishes without incurring professional fees.

"The Letter of Wishes stays as a separate document to your Will and although the Letter of Wishes is not legally binding, Trustees will always follow it if it's current and applicable to your child's circumstances when you die."

Philip Warford runs joint workshops with Amaze on legal issues for parent carers. Check out our website events listing for the next one. For individual legal advice call Renaissance Legal on 0845 505 60 50 or visit www.renaissancelegal.co.uk



Sponsor Simon's record-breaking swim for Amaze!

In May, Simon Cooke will attempt to create a **world record** for the **earliest and coldest ever cross channel swim** and he's doing it all **for Amaze**. We found out how his training is going and how we can all sponsor him.

"I'm doing 3-6 hour swims in the pool every Saturday, with a feeding break every 30 minutes. I also do 3-4 hours during the week and swim in the sea at 7am most mornings to get me acclimatised to the cold. Before Christmas I did a 3 hour sea swim in 9 degrees. I'm also piling on the pounds - turning into a seal - to keep me warm in that chilly Channel.

"My Channel window is now confirmed for the **week of 16th May** (the earliest ever attempted) and Andy King, the pilot of the boat who's guiding me across, is raring to go. Also in the crew are my trainer, Fiona Southwell, who's completed the Channel herself, a doctor who'll be standing by with a defibrillator, just in case I go into cardiac arrest and a couple of friends for support."

"It should take me 12-13 hours to complete and hypothermia is my biggest enemy. But knowing all this hard work is going to such a great charity will keep me warm in my coldest hour!"

Simon hopes to **raise £20,000 for Amaze** and he's set up a Just Giving page to help him do this. Please sponsor him at www.justgiving.com/Simon-CookeWorldRecord and follow his progress on our Facebook page.

More fun for pre-schoolers and their parents

Stuck for things to do with your pre-school children? Like to meet other parents? If so, there are two groups that might be just what you need.

PRESENS (the council's pre-school special educational needs service) and **Face2Face** (Scope's local befriending service) are running **social afternoons** for parents and their children who attend onsite PRESENS or who are supported by PRESENS at nursery.

The group runs from 12.30-2.30pm every Monday during term-time at The Jeanne Saunders Centre, Palmeira Avenue, Hove. It gives parents and children the chance to get together with other families and use PRESENS' **brilliant play facilities**. If you'd like to go along or just find out more, call 01273 294944 or email

amanda.mortensen@scope.org.uk



Sweet Peas is a regular group for parent carers and **children with special needs** that meets every Friday from 12-2.30pm at the Turner Children's Centre on Ivory Place in Brighton. They mainly cater for pre-school children but older children and siblings of any age are very welcome. Sweet Peas now also includes **special music sessions** with **Rhythmix**, a fantastic local charity that promotes musical inclusion. If you'd like to go along, just call Kerry on 07875 377961.

We'd like to thank **Wellesley Charitable Foundation**, the charitable arm of Wellesley Wealth Advisory, Sussex-based financial advisers, for its contribution towards the costs of producing this newsletter.

Wellesley Charitable Foundation helps ill or disadvantaged children and their families in Sussex and the surrounding counties. For more information, visit www.wellesleycharitablefoundation.co.uk



We'd also like to thank Brighton & Hove City Council for its vital funding of our information products.



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*.



Amaze

Community Base
113 Queens Road
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