



Looking ahead

Amaze Information Fair for **young people with SEND and their parent carers.**

Friday 27th November, 9.30am to 1.30pm at
City College, Pelham Street, Brighton BN1 4FA

If you're aged 13-25 (or the parent carer of a child at secondary school or beyond) come along to our 'Looking ahead' Info Fair and find out all about what's on offer locally for young people with special educational needs and disabilities. You'll be able to speak to representatives from SEND services, take part in free workshops and fun activities and meet up with other people like you.

Stalls and more

There'll be over **30 stalls** from a range of services, support groups and organisations including the **SEN team**, the **Youth Employability Service**, **Supported Employment**, leisure providers and even the **Heart Venture dating service** for young people over

18 with additional needs who are looking for romance.

Representatives from **local colleges** (not just City College) will be on hand to talk about their courses and the kind of SEND support they can offer and there'll be people from adult social care who can explain what kind of support is available for young people and who is eligible. You'll also be able to speak to the Parent Carers' Council (PaCC) and Amaze and find out all about our new Information, Advice and Support Service for young people aged 16-25.

Workshops and treats

We will be running **three free workshops** on the day; 'Safe in the City' and 'Teens and Sleep' which are suitable for young people and their carers and 'Who Cares About the Care Act?' which is run by PaCC and aimed more at parent carers. And we'll have a **pamper zone** where you can enjoy a free massage or nail treatment.

Young people will also be able to try a **music sampling drop in session** run by Carousel or some **independent travel role playing**, courtesy of Grace Eyre. A Brighton & Hove bus will be parked in the City College car park and young people can practise everyday travel situations and find out more about Grace Eyre's independent travel training.

And if all that isn't enough, we'll round off the day with Amaze's annual general meeting (AGM), where we report on our year's work, appoint Trustees and share lunch.

How to book

If you want to do one of the free workshops or stay for lunch at the AGM, you'll need to let us know. Call the helpline on 01273 772289 or email info@amazebrighton.org.uk Otherwise, just turn up! And don't be put off by travel expenses - we will refund your bus, train or car park costs. Just show your tickets or receipts to the Amaze staff on the door. We look forward to seeing you there!

INSIDE: New Amaze siblings group • Bullying advice • Home to school transport latest • Courses and workshops • Compass Card Activities and more...

Health and Wellbeing strategy shapes up

Brighton and Hove's Health and Wellbeing Board (HWB) are working on a new joint strategy setting out their priorities for improving the health and wellbeing of the city's population by 2020.

The five priorities are:

1. Reducing inequalities across Brighton and Hove
2. **Safe, healthy, happy children, young people (CYP) and families**
3. Giving every person the chance of living and aging well
4. Developing healthy and sustainable communities and neighbourhoods
5. Providing better care through integrated services

Amaze staff and PaCC Parent Reps have been giving their ideas and views on the work set out under Priority 2 (highlighted), in particular to provide children and young people with SEND and their families with

high quality, integrated support and to improve the emotional and mental health and wellbeing of children and young people.

The Health and Wellbeing Strategy is setting out a vision - more detailed commissioning and work plans will follow. We'll publish links to these on our website once they are finalised. One such detailed plan is the local CCG or Clinical Commissioning Group's 'Transformation Plan for Children & Young People's Mental Health and Wellbeing' which sets out plans for improving services and support in this area. The CCG has incorporated a lot of the feedback which PaCC provided including:

- Providing more services for children in their own community (not just clinical settings)
- Involving more children and their parents in the design of services
- Improving information about services – having clearer eligibility criteria, etc.
- Reducing barriers to accessing services
- Supporting more young people at transition as they prepare for adulthood
- Having more mental health workers in schools
- Having more outreach counselling
- Improving access to psychological therapies
- Having a health promotion post to support parents and carers

Thanks to everyone who feeds back to the city's consultations – it's great to hear that our input is being listened to.

Amaze plans to be a better listener



At Amaze we regularly ask our users for feedback on the services they have received to make sure we're providing you with what you want and need. This is often hugely complimentary with many of our parents taking the time to send wonderful thank you messages (and even sometimes chocolates) – which are never expected but always much appreciated!

But it's not just nice to get good

feedback - it's a crucial way for us to demonstrate our value to funders and learn where we need to improve.

Recently you've told us:

- 97% of you were very pleased with the help you had with DLA and PIP forms
- 94% said you were very pleased with the individual help you had from our Information Advice and Support team
- 96% of parents who have received Independent Support said this had a positive impact for them

But many of you have also told us that you wish you could get through to the Helpline more easily - you don't want to have to leave a message and wait for someone to call you back. So we've been working hard to improve this. We have introduced:

- **Longer opening hours** – the Helpline is now open from 9.30am to 5pm Mon-Thurs and 9.30am-1pm on Fridays
- **A call back facility** if you need an evening call back
- **A new case recording system**
- **New helpline volunteers** to take messages and handle more straight forward admin calls

Hopefully you'll notice an improvement in our response times when you next ring.

We've also used your feedback to inform our new **Strategic Plan** which sets out what we want Amaze to do over the next three years. Read it at www.amazebrighton.org.uk/about-us/impact. You can tell us what you think of our services or our new strategy, on the feedback form at www.amazebrighton.org.uk/about-us/contacting-us/

Best-selling author gets behind Amaze

We are delighted to announce that Amaze has a new patron – the much loved and universally renowned children’s author, **Julia Donaldson**, Children’s Laureate 2012-13 and writer of a whole host of picture book classics including **The Gruffalo**, Room on the Broom, The Snail and the Whale and The Singing Mermaid. Julia heard about Amaze from a good friend who has been one of our trustees for many years. She says, “Since moving back to the area, I was keen to support a local charity that works with children and families and I



Julia Donaldson, renowned author of best-selling children’s books like The Gruffalo.

was impressed with all the things Amaze does to help families with children with additional needs.”

Julia will be working with our **fundraising** team to see how she can help to promote our work to a wider audience.

Wellesley Golf Day goes with a swing



The winning team: Richard Rochford - Wellesley Wealth Advisory; Ian Powell - BTMK Solicitors LLP; Paul Hearmon - Right of Light Consulting Ltd and Chris Fleming - inTAX LLP.

On Wednesday 15th July the fifth Annual Golf Day from **Wellesley Wealth Advisory** chartered financial planners took place at the Dyke Golf Course.

The event which was organised jointly with Amaze, sold out and raised a fantastic **£7,416** to be split between Amaze and the Wellesley Charitable Foundation.

There was a great atmosphere as teams from local companies and Wellesley clients enjoyed a competitive 18 hole golf game followed by a lovely lunch, fundraising raffle and auction. Amaze is proud of our partnership with Wellesley Wealth Advisory who also sponsor this newsletter. Thank you to everyone who attended the golf day, to all the prize donors and our generous sponsors including our gold sponsor Wilson Sandford.

New Amaze ADHD course and sibs group

This winter Amaze is launching two new projects - an **Insiders’ Guide course for parents of children and young people with ADHD** and a

regular social group for brothers and sisters of children with SEND. The **siblings group** launches on Tuesday 10th November in Hollingdean and the pilot ADHD course will start on Friday 13th November in Hove.

Parent carer writers get published

Paperweights is a brilliant new collection of highly personal writing by local parents and carers of disabled children. It is the result of a six month **therapeutic writing** course funded by Scope Face 2 Face and led by Kate Ogden, Extratime’s coordinator (who also has an MA in creative writing). It is available for £5 from Waterstones on North St.

Future creative writing courses may be available if funding can be secured. For more details, email amanda.mortensen@scope.org.uk



Volunteering for Amaze makes you happier

Edward Hartfield, an Amaze volunteer, has made it onto a list which celebrates the 28 happiest people in Brighton and Hove.

Edward, who helps out at our autism friendly cinema screenings and fundraising events like the Brighton Marathon, joins dog wardens, nurses, teachers and bloggers on the Happy List for the warmth, kindness and good cheer they spread to others. Find out more at www.actionforhappiness.org



Could you spare some time to help out at our fundraising events or other activities? If so, we'd love to hear from you. Just send an email to nickyb@amazebrighton.org.uk or call 01273 234014 to find out more.

Read all about our new Siblings group on page 6 and our new IG ADHD course on the back page.

Needs of partially deaf children 'overlooked' in school



An estimated **20,000 school-aged children** in the UK suffer from **mild to moderate hearing difficulties** and, according to recent research commissioned by the National Deaf Children's Society (NDCS), almost half of these may be falling behind in school. The research, which used online questionnaires and interviews to gather the viewpoints of parents and professionals found that partial deafness "had a major impact" on children in school.

The reasons

The large majority of the respondents to the survey (86%) had children in

mainstream schools and 69% of these parents said that **poor acoustics, background noise and difficulty understanding speech at a distance** were major challenges for their child at school. A third of parents felt that a **lack of awareness among teaching staff** was to blame for their difficulties.

Susan Daniels, chief executive of the NDCS said: "Mild and moderate deafness can often be overlooked because of a perception that it is not a serious condition or that children are 'coping' at school. But often these children are nodding their way through life without really understanding what is being said and missing out on vital early development."

Nearly half of parents said their child's partial deafness was having an impact on their participation in assembly, outdoor activities and group work, and 41% believed it had an impact on their child's participation in class. Tellingly, 60%

of parents felt that they wanted more educational support for their child.

What can be done?

The NDCS has called on government to ensure that:

- Young people and parents are given access to **more information** about the potential impact of mild and moderate hearing loss and the support available.
- There is **more training for teachers** to give them greater awareness of hearing loss and how to minimise its effects in class.
- Local authority services have **enough resources to provide necessary support**.

If you have concerns about how your child's mild to moderate hearing loss affects them at school, speak first to the school's SENCO or your child's audiologist. If your child doesn't yet have a diagnosis, but you are worried about their hearing, speak to your GP.

To read the full report visit www.ndcs.org.uk/family_support/audiology/types_and_causes_of_deafness/mild_and_moderate.html

The local view

We were interested to find out how local parents felt their child's mild to moderate hearing loss affected their progress in school so we got **Heather Fletcher**, an **Amaze Independent Supporter** who is also a support worker at NDCS, to ask some of the families she works with for their views. Here are two experiences:

Julie's* story

"Sensory Support first got involved with our family when my son was 21 months and he was fitted with bi-lateral hearing aids. We had regular home visits which we found tremendously helpful ...Once



my son went to school the support transferred there and we were no longer in the loop, which we found disconcerting.

"For the first two years of school I was not informed either prior to a visit nor did I receive any feedback. This did not give me the opportunity to bring my own queries or concerns and did not give me any vision as to what was happening. I am not sure whether this was due to lack of communication from the school or from Sensory Support. During Year 2 this did improve somewhat and I started to receive reports and was personally informed of the change of radio aids to wireless. Overall our

experience with Sensory Support has been positive."

Sarah's* story

"My Teacher of the Deaf (TOD) has been very proactive in working with my daughter's educational setting by delivering deaf awareness training to all staff who work with her. We also had concerns about our daughter starting school and the reactions from other children in relation to her deafness, and the TOD has arranged to visit the class and educate the other children which is great."



* All names have been changed to protect anonymity



Let's talk about bullying

The idea of our child being bullied is so upsetting it can be hard to know how best to talk about it with them. And when it comes to cyberbullying we may not be sure we even speak the right language. Here are some tips that might help.

If you think your child is being bullied you want to get them to talk about it and find out more. But some children will clam up if you start asking direct questions. Or they may not know that what is happening to them is wrong and could be called bullying.

Try using questions that get your child talking about their day, especially the less structured times. What did you do at break time? Who were you with? Was that fun? Would you have liked to play or do anything different? Tell me something good that happened to you today. Anything not so great about today? Things may emerge bit by bit. Don't rush them or make it an interrogation.

Some children don't use words or have trouble talking about feelings. You could draw pictures together of their day or act out little scenes with toys. Get happy, sad and angry faces that they can use to say how they feel without having to talk. Or use a thumbs up, thumbs level, thumbs down code.

Some children may find it easier to write things down for you to read rather than say it out loud; try a diary, or a worries box, but be clear about this being shared and different from a private diary. Would an older child prefer to say things in a text or email?

If your child tells you they are being bullied **do all you can to react in a concerned but calm way.** It's important not to brush off what they say or minimise it. But equally if you seem really angry or upset they may not tell you everything.

Praise them for telling you something has happened that worried or upset them. Take them seriously but don't jump to conclusions. We all know our children can misread a situation sometimes. They may think someone is their friend when actually they're being mean, but they can also think someone is bullying them when they just did not want to play their way that day.

Gently tease out more detail. You need to strike a balance between listening to your child's feelings and helping with those, and finding out more factual information about what happened, where and who was involved. You're going to want that information if you are going to talk to the school so when you have found out more **make notes for yourself** rather than relying on your memory.

Talking about **cyberbullying is not so different.** Step one is to **make sure you are part of your child's life online** in the same way as you are the rest of their life. Make a habit of getting them to tell you about what they enjoy online. Can they show you or teach you things? **Make sure you are not only making negative comments** about their use of games, phones and devices as this increases the risk that they won't tell you if things go wrong for them there. **Look at privacy settings together.** Make sure they know how to block or unfollow someone. This should help them feel able to tell you if they experience cyberbullying at any level so you can deal with it together.

Need further help and advice on bullying?

- Sign up for the **Anti-Bullying Alliance workshop on bullying** hosted by Amaze on **20th November**. See www.eventbrite.com/event/17427127006
- Speak to the Amaze helpline on 01273 772289 for advice
- Ask us to send you our 'Bullied at school' factsheet and Brighton & Hove City Council's parent leaflet 'Safe from bullying'
- Look at some of the great resources for parents and children online via www.anti-bullyingalliance.org.uk/send-resources/resources-for-parents



Spotlight on siblings

As Amaze launches a regular new group for siblings, we look at what's out there locally for sisters and brothers of children with SEN and disabilities.

We all know that looking after a disabled child can mean that their brothers and sisters get less attention. Add to that the extra caring responsibilities that can come with being the sibling of disabled child and it's easy to see just how different our other children's experiences of family life may be from that of their friends (the quotes on page 8 bring this vividly to life) - and just how much they might benefit from something that's just for them.

Kids Like Us

With this in mind, Amaze is launching a new group **for brothers and sisters of disabled children aged 8-13** called 'Kids Like Us'. This pilot project will offer siblings the time and space to think about things that affect them, and have fun and play games with other children who share similar experiences. The first group begins on **Tuesday 10th November**, 4pm to 6pm at **Hollingdean Community Centre**. To find out more or register

your interest contact Ruth Sullivan on info@amazebrighton.org.uk or call our helpline. Places are limited so call soon. Thankfully Amaze isn't the first or the only group in the city to focus on the needs of siblings.

Local sibling support

Autism Sussex run a monthly **Saturday group for 8-16 year olds** who have a brother or sister with ASC. There are lots of fun activities like music, drama, cookery and games but the group also gives them the chance to learn more about autism, including strategies to deal with any behaviours, and get support from their specialist team. All sessions must be booked in advance and cost £5. Call 0345 450 0060.

Brighton Pebbles, the local social group for families of children with SEN

and disabilities, has developed **events just for siblings**, including a yearly camping trip. They work to give siblings the chance to meet others in the same boat and just have fun without fear of judgement. To find out more call 07506 105265 or visit www.brightonpebbles.org.uk.

Though they don't offer a group specifically for siblings, **Link-UP** organises social activities for children with SEND in mainstream schools and their families. Through fun days out and workshops, siblings can have the chance to meet other children like them in an informal way. Call Link-UP on 07969 306607.

Young people who carry out a significant caring role for anyone in their family can get support from the **Young Carers** project at the Carers Centre. You can call them for advice and support or join one of their **Young Carers' groups** for 8-12s or teens. The groups are mostly about having fun, but some offer support on specific issues too. Call 01273 746222 or email info@thecarerscentre.org.

Downs Junior School runs a weekly SIBS group for children. Though it's the only school group in the city we know of so far, there's no reason why others couldn't follow suit. If you want to set one up, perhaps you could speak to the SENCO or inclusion co-ordinator at your child's school. The SIBS website (see below) has resources that can advise them or you on how to do this.

Sibs

Finally, **Sibs** is a brilliant national charity that gives all sorts of advice, information and practical support to siblings of disabled people and their parents. Visit www.sibs.org.uk.

Kids Like Us sibling support group for 8-13s starts **Tuesday 10th November**, 4-6pm, at **Hollingdean Community Centre**. Email info@amazebrighton.org.uk to join!



PaCC moves on Home to school Transport

It's been an anxious summer for parent carers regarding changes to home to school transport. Councils across the country have been cutting this service, and PaCC has worked hard to ensure that parent carers' voices are heard in Brighton and Hove. We organised a very well attended PaCConnect focus group in July where parent carers spoke collectively and freely to council officers about the changed policy. A heated but useful discussion ensued, demonstrating just how important this service is to families.

What we talked about

Parent carers were pleased to hear officers describe their work with schools to support independent travel training and how this can be positive for young people, but they made the point that independent travel is only relevant for a minority of children with SEND. Parent carers also expressed concerns that the assessing panel are all 'council in-house' and as such lack neutrality, and they called for greater transparency about eligibility. They also brought up some of the issues they'd faced trying to communicate with the local authority. Minutes of the meeting can be read at www.paccbrighton.org.uk/what-we-do/pacc-connect-events/

What happened next

PaCC followed up on all these issues at a meeting with senior officers from the local authority, who listened to our ongoing concerns, and provided some statistics we had requested.

The local authority agreed to:

- Maintain transport for appealed cases until the appeal is resolved
- Use feedback to improve the application form
- Ensure their statutory duty is met
- Issue draft criteria for pre-school and post-16 transport regarding equalities issues

At the beginning of September 2015, 348 taxis had been agreed, and 20 out of 24 appeals had been successful.

The work isn't over, but we feel good progress has been made and our voices have been heard.

The local authority does not have a statutory duty to provide home to school transport for pre-schoolers and post-16s. However, PaCC raised equality issues for these groups, and the council positively acknowledged that these should be scrutinised. They are updating the post-16 transport policy to include more detail about eligibility criteria. Parents who wish to appeal can submit supplementary information in line with this update. For more information, contact the home to school transport office.

This has been a very worrying time



Secondary schooler, Dan, ready for his school transport.

for parent carers and several families have been directly affected by the changes. The work isn't over, but we feel good progress has been made, and our voices have been heard.

The future

The next steps for PaCC, following your feedback, are to work with the Home to School Transport Team to ensure clear and timely communication about transport before the start of each school year and to monitor the Independent Travel initiative, so please do feedback your experiences if this applies to you. Just email admin@paccbrighton.org.uk or call 01273 234862.

Make your views count. Join the PaCC by emailing admin@paccbrighton.org.uk or tell us what is concerning you at www.paccbrighton.org.uk/get-involved/give-us-your-views



Send us your snaps!

We need lovely pictures of you and your children...

...For the 2016 PaCC Calendar

Our award winning PaCC Calendar for 2016 will have the theme of 'My Best Friend' and we are looking for **12 snapshots** of your child and their best friend - be it a **sibling, neighbour, close family member, school buddy, support worker, a pet or even a cuddly toy!**

All we need is a good quality photo of the best friends together (ideally in a jpg format) and a few words telling us what makes their friendship precious or describing special moments they have shared. We'd also like you to tell us a little bit about your child - what they like to do, their hobbies and interests, and their medical condition or disability if you're happy to share that with us. Just email the photo and words under the heading 'PaCC 2016 Calendar' by **Friday 6th Nov** to admin@paccbrighton.org.uk

...For our image bank

A picture really does tell a thousand words so we'd love to have more of them to use in this newsletter, our leaflets and on our website. If you have any lovely images of you, your child or your family that you'd be happy for us to use, just email them to us under the heading 'PaCC Image Bank'.

NB: By submitting your child's photo we will consider you are giving consent on behalf of your child, their best friend, and anyone else featured to appear in PaCC publicity materials.

Brothers and sisters tell it like it is

It's great news that Amaze is introducing a new group for siblings (see page 6). Those of you juggling to balance the needs of all your children and young people will be aware of the impact on family life for siblings. So we asked some brothers and sisters, "What's family life like for you?"

"Sometimes it makes life more enjoyable because she does funny stuff that makes me laugh."

"It's difficult when he cries and hits."

"It's different cause I don't get to see my baby brother when he goes to London hospital and I don't get to see my Mum too. We used to do more fun things before (he) was born, but now he is ill a lot and we can't."

"She destroys my stuff but she is still my sister and I love her anyway. She can be kind when you're feeling sad, and will notice and come and give you a hug and stroke your face. Having her as a sister makes life more interesting and exciting."

"It's tricky because we always have to set good examples to him for behaviour, so we aren't allowed to get into fights."

"It's so much fun to play with her when she has lots of energy, and she's got some cool electronic toys!"

"It's hard for Mummy because he needs looking after all the time, and she's also got to look after us at the same time."

"We get to skip queues and go on fun trips and sometimes we don't have to pay!"

"When he is in hospital, and he's very poorly, I worry because I don't know what's going on and he might die."

"A charity paid for us to have a Centerparcs holiday. It was because we had had a very difficult year. We felt very lucky and our friends were jealous!"

"Once some boys in the park laughed. They were laughing and saying 'look at his face'. I didn't tell Mum."

"I don't get enough time with Mum."

"Sometimes my friends say they wish they had a brother like mine, because he's super cute, and I think 'you wouldn't, because of all the hospital' and then I feel guilty and upset because I can't stop him from having to have all the operations."

"I don't tell my friends when he is poorly because they might make too much fuss, and that just reminds me about it all over again, and I get angry with them and start shouting."

"I don't think any of my friends have sisters or brothers with disabilities. I feel different."

"We love him the way he is and wouldn't have him any other way."



Your feedback sets our agenda

Our PaCC Members' Survey results make mental health, school support, therapies and transition our top priorities

This summer, we asked **PaCC members** to complete a **survey** so that you could tell us what we should be doing. Thank you to those who completed it. Pleasingly, parent carers scored PaCC nearly 8/10 when asked how well PaCC represents their views.

We asked you to choose priorities for the coming year and top of the bill was **mental health**. Our PaCC reps for mental health will continue their hard work representing parent carers at board level, using information from recent PaCCconnects and surveys.

Other priority areas of concern were

transition and links with adult services, support provided at schools and therapies. In terms of transition, you want services to "communicate better and more" for older children.

Communication is something that we at the PaCC can improve upon too. "It would be great if the Facebook page had more members and became a more dynamic forum" said one member. We know the PaCC website needs updating so this is one of our priorities and a membership card was also a popular idea.



Information about the profile of our membership emphasised the need to reach out more to minority groups, as well as younger parents and we have gained helpful insights and ideas about areas for future work. Above all we were delighted that responses were overwhelmingly constructive; some were simply positive: "Well done all, thank you".

The full report can be read at www.paccbrighton.org.uk/what-we-do/representing-parent-carers/

And the winners are...

After careful consideration of your many nominations for individuals or groups who gave you outstanding support last year, we're delighted to announce our **PaCC Champions 2014!**

Education: James Maddox
Special Educational Needs
Teaching Assistant, St.

Andrew's CE Primary, Hove

"Mr. Maddox works so hard to get the best from Ferris and empower him to achieve his potential, whether it is helping him to concentrate in a busy environment and pushing him to work when he is so clearly daydreaming, or being innovative in making up games/rewards to focus him and generally making school fun."

Health: Virginia Harvey
Speech and Language Therapist
- Deafness, Hove Polyclinic

"Virginia has worked with us as parents around our daughter's complex speech and language/communication needs, advising and guiding us. She

has also worked with our daughter's other services for consistency around her communication."

Social Care: Emma Lowe,
Outreach Services and Matthew
Howson, Social Worker, Seaside
View Child Development Centre

"Emma has been taking our severely autistic son, Merlin, out on outreach sessions for six years now, after losing his older sister very suddenly. She's become his 'best friend' and has changed our lives for the better. She takes him horse riding and swimming every week. She is amazing!"

"Matthew has been a great social worker and has made a big difference in our family situation, always on time, available on the phone and very helpful when needed."

Voluntary Sector: Reza Ataie
volunteer co-ordinator of Dads
Group, Brighton and Hove

"Reza has kept going with this despite the difficulties of supporting dads and male carers. This is a very hard group to support: dads usually go out to work and are not as tuned in to the support available or social networks as women. Men are always less likely to communicate when they need help, men are unlikely to join in groups dominated by women."

We'll be presenting each of the winners with a special certificate soon!

2015 nominations?

Help us identify a professional, a team or an organisation in the Social Care, Health, Education or Voluntary Sector who has gone that extra mile for you and your child during the past 12 months. You can **nominate online** at www.surveygizmo.com/s3/2325117/PaCC-Champions-Nomination-Form-2015 **until Friday 18th December.**



Have a cuppa and a chat with PaCC

at the Amaze Info Fair

We very much look forward to seeing you for a cuppa at the Amaze Info Fair on 27th November, which is all about 13-25 year olds and their parent carers. We want to hear your concerns, suggestions and feedback and find out what you'd like us to focus on. We are especially interested to meet anybody who would like to play a more active role in PaCC, and we can explain more about the opportunities available. We look forward to meeting your young people too, as this year's event is actively inviting them to take part.

So grab a cuppa and come and find us - we've nabbed the best spot by the tea and coffee stall!

On yer bike!

This summer, PaCC mum, Pippa, and her son Leo, visited the **We Cycle Too** track at Brooklands Pleasure Park in Worthing and had a great time. "We tried out the tandem trike, which Leo loved, and he also had a go on his own trike which had a pulling/steering handle."



We Cycle Too have a range of bikes and trikes, including an electric one, and friends and family can take along their own bikes too so it's a great day out for the whole family. For bookings, call 01903 765716, text 07974 818313 or email lynnebrooklands@gmail.com

How primary care can better support you

As you are probably aware, the way **health care services** are organised and how you can access them is changing fast. Previous health consultations by PaCC have revealed that parent carers living in Brighton and Hove tend to neglect their own health as result of their caring role and are more likely to suffer more from isolation and poor mental health and wellbeing. Because of this it's very important that the voices of parent carers are heard during this period of transformation and that any health care changes take your needs into account.



During June and July we ran a **consultation** on how you would like to access primary care and receive support from it (by primary care we mean your first point of contact in the health service, usually your GP). You said that better primary care for

parent carers meant a **more flexible booking system** and **longer appointments with your GP** so you have time to discuss whatever issues are having an impact on you and give you a **chance to talk about your mental health**. You felt primary care could provide **more counselling**.

"To talk about my mental health I need more time, the issues are quite complex."

You said that primary care could provide **information** or **opportunities for physical activities** and help with a healthy diet. You also suggested that primary care might provide **support through workshops and groups**.

Recommendations from our online questionnaire are being collated into a guide to be used by GPs who will be working together in 'clusters' in future so that you have more choice of support available. Read the full 'Transforming Primary Care' report and check the 'GPs cluster map' on our website at www.paccbrighton.org.uk/resources/reports

SEND Review latest

In line with the Children and Families Act, Brighton & Hove's senior managers continue to develop plans for integrated provision of education, health and social care, as part of a citywide SEND Review.

At the SEND Review Governance Board, PaCC Reps Fiona England and Diana Boyd have stressed that focus groups with parent carers must remain an ongoing part of the review process and PaCC will continue to work closely

with the local authority as more concrete details of changes emerge.

The next important date for the SEND review is **10th November** when Regan Delf, Assistant Director (Children's and Adult Services), will present a further Integrated Services paper to a Joint Committee. Once recommendations are agreed, a formal six week consultation period will take place - we'll make sure you know about this as soon as we do.

Ask the experts

This week's experts are **Philip Warford**, Managing Director of local law firm, Renaissance Legal, and **Lizzie Batten**, manager of our DLA work.

"Can we leave our home to our son?"

Philip says:

"Leaving the family home to a child is naturally what most parents want to do, but when that child has SEN or a disability, doing so might not be quite so straightforward. For example, leaving your child the house may impact their benefits, or indeed it may cause practical problems for them to live in the house unassisted. Some of the issues that you need to consider are:

- Does your child have the capacity to be a home owner?
- Is your child able to live in the home by themselves when you are not there to care for them? If not, what care package can be set up to care for them?
- Are they vulnerable? If so, is it better that they are not left living in a home without support?
- Who is going to pay the insurance and service bills, and where will money come from to pay these?
- What happens if anything breaks down? Are they, or the care team, able to deal with it?
- Are there better options to make sure that your child is protected, like assisted living or shared housing?
- What effect will this have on your child's benefits now and in the future?

"If you are thinking of leaving your house to your child, taking a long-term view is sensible. This means finding a solution that will ensure things are workable in the future, particularly as the personal circumstances of a child with SEN or other disabilities may change over time. One option is to create a Trust and to put the property in it. Doing this helps avoid some of the issues of ownership and, crucially, provides flexibility for change. However, if you are thinking of placing your home in Trust then you would also need to put cash in the Trust to pay for things like insurance and bills."

"If you want any more advice around this issue, why not come along to the **Wills and Trusts workshop** I'm running with Amaze on **Thursday 12th November.**"

For individual legal advice call Renaissance Legal on 0845 505 60 50 or visit www.renaissancelegal.co.uk NB: If you show your Compass Card, you can get a 10% discount on fees at Renaissance Legal.



"My son took his first steps at 28 months, but at three is still tottering. Another parent has suggested claiming the mobility part of DLA. Would he be eligible?"

Lizzie says:

"Some children aged three who are up on their feet can claim the higher rate of the mobility component but to do so, the DWP has to agree that your child is 'virtually unable to walk' - a really odd term. In reality, what this means is that an eligible child will not be able to walk a reasonable distance outdoors. At three, most children can walk for quite a long time and run about freely, so as far as the DWP is concerned, a longer or 'reasonable distance' may be as short as 100 metres.

"The DWP takes into account how safely and steadily, how quickly and how far a child can walk, so to make a successful claim you need to explain in detail exactly what your child can and can't do and how you both manage. So count and measure and give them as much detail as possible. Here are some examples of the kind of details about mobility that might help the DWP recognise your child needs the higher rate:

- Walking is not automatic for your child like it is for other children - taking steps requires a great deal of concentration and physical effort
- Your child may be able to take about 30 steps independently, with lots of encouragement, but then they lose their balance through distraction or tiredness.
- Indoors your child prefers to crawl and they'll drop to the ground and do this on the pavement as well.
- You can't carry your child because they haven't the strength to wrap their legs around you and tend to fall away.
- You use a double buggy so their ventilator and suction equipment can take up the spare seat. Or you can't use the double buggy because your child will hit their sister or pull her hair if they can reach.
- Without a car, you'd be marooned at home

"Be sure to include as much evidence as you can to support what you say, keep practitioners and consultants in the loop, send them a copy and keep one for yourself. Then post your claim by special delivery. Good luck!"



Email: charlotte@amazebrighton.org.uk if you have a question for an expert and we'll try to answer it in the next issue.

What having an Independent Supporter meant to me

Melissa Chivers was a student at PACA Sixth Form last term when her Statement was transferred to an Education, Health and Care (EHC) plan. Now studying at Northbrook College, we asked Melissa to tell us what it was like to work with Sally, an Independent Supporter for young people from Amaze.



Melissa Chivers got support with the EHC Planning process from Sally, Amaze's Independent Supporter for young people.

At the beginning of the EHC planning process, you had to fill in a form about your views. How did Sally help you to say what was important to you?

"Sally made sure that I had a clear understanding of what was really important to me, since it is really hard talking about yourself. So she laid it out differently and had white paper so everything I said wouldn't be written on the EHCP because as you fill it in, you think of it in so much more detail and can always go back at the end and change it."

Did you go to the transfer meeting at school? What was it like?

"Yes I did go to the transfer meeting at school. It was very

good because I had the chance to hear other people's opinions on me and had a clear version of what people thought was best for me and what was best for myself. Sally was very helpful - she made things so much clearer and was explaining 'what was what' since a lot of information is said in the meeting."

A few weeks after the meeting, you got the draft EHC plan. What happened then?

"When I received my draft EHC plan I saw other opinions about me in there that I could edit a little bit since I felt that things weren't informed correctly. Because with the EHC plan it's about you and you want to make sure it is perfect for wherever it may go in future."

"I am really happy with what's in my EHC plan because I've had a chance to voice my opinion and feelings into it."

Are you happy with what's in your EHC plan?

"I am really happy with what's in my EHC plan because I've had a chance to voice my opinion and feelings into it. And it feels much better knowing what's going into it."

Would you recommend the Independent Support Service for other young people when they are getting an EHC Plan?

"Yes. I'd definitely recommend it. It's a long process and it's much better having support than not having it. I'd regret it if I didn't have any help because I've added so many things into my EHC plan that I thought I wasn't able to do."

Want Independent Support to help with EHC planning?

Young people with **special educational needs or disabilities aged 16-25** who want help with EHC planning or with transferring from a Statement to an EHC plan can get help from our Independent Support service. They can call **01273 772289** or email helpline@amazebrighton.org.uk or get a carer to contact us on their behalf. And don't forget that parent carers can get Independent Support too!

What the Care Act means for young people with support needs

Last year two new acts were passed that affect disabled young people preparing for adulthood. The Children and Families Act (Part 3) focuses on special educational needs and disability, and the Care Act (Part 1) focuses on the care **and support of adults**. We've shared quite a bit about the changes brought by the Children and Families Act including how EHC plans have replaced Statements and can go up to age 25 in some cases. But we've not told you as much about the Care Act, which focuses on the care and support of adults. So what do you need to know?

The Care Act deals with adult social care for anyone over 18. This means there are a group of young people aged 18-25 who are entitled to support through both pieces of legislation. The two Acts have the same emphasis on outcomes, personalisation and services working together. They both cover the planning that should happen for a young person to prepare for adulthood and move to adult social care if they need this.

The Care Act introduced a duty on local authorities to carry out **Child's Needs Assessments (CNA) for young people** who are likely to have needs for care and support from 18. The purpose of a CNA is to find out what adult social care a young person might be eligible for once they reach 18 so they can make informed choices about their future. There's no fixed date when this assessment should take place, but the conversation about whether they need a CNA should begin in the Year 9 review of their EHC plan and carry on at future annual reviews.

The CNA should take place when it will be of "significant benefit" to

planning with the young person; certainly in good time before they turn 18 and can fit alongside their EHC plan. You can ask for a CNA but the local authority can say no if they think your child will not need adult social care support or you are asking too early for a CNA to be useful.

The purpose of a CNA is to find out what adult social care a young person might be eligible for once they reach 18.

The assessment should include person-centred information about a young person's needs and aspirations, with short and medium term outcomes which can be used as the basis for discussion with the young person, their family, and a professional from adult services about the support that may be available to them. It should include an **"indicative personal budget"** – this means the amount of money that the young person is likely to need to pay for their support needs – so that the young person and their family are able to plan what their future support might look like.

If a young person is getting social care support via children's services the Care Act requires this support to continue until adult care and support is in place, or the assessment clearly decides that adult care and support is not needed.

If you or your young person need advice and support about organising support from adult social care, call our helpline on 01273 772289.

Make friends with Grace Eyre

Grace Eyre Friendship Group is a **social group for adults with learning disabilities** aged 18-25.

The Friendship Group supports individuals and their carers to participate in more activities and events and to get out and about more. They have regular weekly meet ups on alternate Wednesdays and Fridays, distribute a monthly calendar of activities, and help to link volunteers and people with similar interests. To find out more, contact Jacqueline Sethi at GEfriendship@grace-eyre.org or call 07436 093120.



Insiders' Guide course for parents of teens

Don't miss our friendly and supportive course for parents of teens and above. It covers things like dealing with professionals, planning ahead, handling meetings, puberty and relationships. We also look at how it feels to have a child with SEND and how to build our own resilience.

"This has been a really enriching and valuable experience."

The course will be **early in 2016** so call our helpline and ask to go on the waiting list - we'll contact you as soon as we have a date. Call 01273 772289 or email info@amazebrighton.org.uk

Our sea swimming stars

This year, we've been really lucky to benefit from the extraordinary efforts of two amazing sea swimmers who have gone through hell and high water for Amaze and the families we work with.



Fiona England

To celebrate turning 50 in December of this year, Fiona England, Amaze mum and Chair of the Parent Carers' Council, has decided to complete a 50 50 Outdoor Swimming Challenge to raise funds for Amaze. A regular sea swimmer, Fiona is swimming a challenging 50k in a variety of outdoor locations including a river, a lake, outdoor lidos and of course, the sea. To track Fiona's progress or sponsor her please log on to www.justgiving.com/Fiona-England1. Good Luck Fiona!

Simon Cooke

In the early hours of May 26th this year, Simon Cooke set out on an extraordinary challenge to break a world record for the earliest, coldest ever cross channel swim in aid of Amaze. The sea was unusually cold for the time of year, and the low temperatures made the challenge

much more risky than anticipated. Tracked by many, Simon got off to a great start and did four and a half hours of swimming before his coach and medic, Fiona Southwell, made the difficult decision to pull him out of the water. His body temperature had fallen dangerously low from swimming through pockets of water as cold as eight degrees celsius.

Since having to cut his challenge short, Simon has received so many consoling messages from friends and supporters who all agree he's a hero anyway. His press coverage was extensive and his swim **raised over £11,700** - a huge heart-warming success for both Simon and Amaze. Thank you Simon - you're our champion!



Calling all runners! We have places available for the all the big running races (Brighton Brooks 10k, Brighton Half and Brighton Marathon). Please get in touch if you would like to help keep Amaze running. Call 01273 234014.



Poems and wine work wonders for Amaze

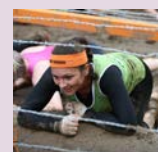
Sporting challenges are not the only events that raise funds for Amaze.

In September, **Ridgeview Vineyard** in Ditchling hosted a **tour and wine tasting** which raised over **£4,000** for us. Guests enjoyed an autumnal tour followed by a tasting, canapés and an auction in their wonderful new tasting room designed and built by Nutshell Construction (who kindly sponsored the vintage red bus that ferried guests there and back). Thanks to guests, prize donors and staff at Ridgeview and Nutshell.

And we'd like to say a huge thank you to **Amaze patron, Henry Normal**, who raised **£1000** for Amaze from his **sell out poetry night** at Komedia on 9th September. **'Photos with My Son'** was a funny, moving and inspirational account of Henry's life with his autistic son Johnny and the audience absolutely loved it. Look out for more poetry nights to come.

Tough mudders and daughters

Thank you to **Jenny Guisquet** who's done a number of tough challenges for Amaze this year including Tough Mudder and raised a whopping **£727.43!** And a big well done to mother and daughter **Carmen and Elsa Appich**



who completed their London to Brighton bike ride on 6th September. Thanks so much for all your hard work.

Get active this winter

Break the winter gloom with Amaze's fabulous programme of Compass Card Activities (CCAs)



CCAs are Amaze-supported activities where you can be sure your child's needs will be understood. For full information, take a look at the Compass Card app, view our CCA guide at www.amazebrighton.org.uk or keep up to date with the Amaze e-bulletin, Compass Team News – but in the meantime, here are a few highlights.

Multi sport club for 11-19s.

Fun-fit Spiral has a brand new venue at the Old Boat Corner on Carden Hill and runs on Sundays in term time from 2.30 to 4.30pm. This established multi sport session welcomes siblings and friends too and it's a great place to run off steam and make connections.

Street dance for 11-19s.

What could be cooler than learning some slick dance moves with the city's

award-winning Streetfunk team? The next course is from 10am to 12 noon on 21st December and 10am to 1pm on 22nd December (with showcase for families in the last hour). Call Marina Studios on 01273 253679 to book.

Swimming for over 14s with learning disabilities.

This new class is for young people who want to learn to swim, as well as improvers - and if they have a competitive streak, there's a pathway to the city's Special Olympics team. It's on every Thursday evening 6 to 7pm at Brighton Swimming Centre on Eastern Road. Call Jon Hart on 01273 222097 or 07848 456214 to book. First two sessions free for Compass Card holders.

Cookery for 19-24s.

Brighton & Hove Food Partnership (BHFP) is repeating its popular, free cookery course early next year and booking opens on 23rd November. The course is from 5.30 to 7.30pm on Tuesday 12th January to 9th February 2016. It's only once a year, so don't miss it!

Try This! and claim your free sports goody bag

If you want to try out **disability-friendly sports** for free, catch up on the latest Compass Card Activities and get a free sports goody bag into the bargain, don't miss Try This! on Saturday 7th November at King Alfred Leisure Centre.

Suitable for children and young people with additional needs of all ages and their family and friends, the event is from 10am till 12 noon and

Amaze will be on hand to provide leisure advice and information. Try This! is a collaboration between Amaze, the council's Active for Life Team, Freedom Leisure and local sports providers. Come and try multi sport, boccia and new age kurling with Saturday Active Club, cricket with Sussex County Cricket and basketball with Spiral Sussex. Just turn up on the day. Call the Amaze helpline for more info or check the Amaze e-bulletin, Compass Team News.

App-ily ever after?

Almost 400 people have downloaded the new Compass Card app onto their iPhone or Android smart phone and have access to the very latest information on Compass Card Activities (CCAs) and Compass Card offers. The news function on the latest version is now fully operational too, so you can get updates on the move.

Search 'Compass Card' in the App Store or on Google Play to download the free app – and if it's already on your 'phone, make sure you've updated to the latest version. "I've downloaded the Compass Card app – genius!" says one Amaze family.



Catch the jungle beat

Otherworld is back with a steamy, tropical feel as the **immersive theatre project's** theme turns to the jungle. A Compass Card Activity packed with surprises and delivered by an artistic collaboration between Same Sky and Different Planet Arts, Otherworld Project Coordinator, Ari Hadjilias, promises the new rainforest environment will keep families spellbound. "Our jungle theme is a whole new world for families, with a journey that changes every time – come and explore!"

The next Otherworld show run is in Worthing from Wednesday 25th to Sunday 29th November. Look out for details on the Compass Card app or via the Amaze e-bulletin, Compass Team News.



Amaze courses - coming soon

Planning for the Future: Wills and Trusts - Thurs 12th November, 10am to 12.30pm at Community Base with Phil Warford of Renaissance Legal

Anti-bullying workshop for parents- Fri 20th November, 10am to 2pm at Community Base. Tips for parents who are concerned about bullying at school.

Amaze Info Fair - Fri 27th November includes three bookable workshops on sleep, the Carers Act and safety – see front page for more detail.

How to claim PIP - Wed 2nd December, 10am to 12.30pm at Community Base. Lizzie explains how to claim PIP, the benefit that replaces DLA at 16+.

Insiders Guide courses offer a mix of useful knowledge with a chance to check out where we are in our journey as parent carers. This winter and spring we have an **IG for Parents of Teens**, one for **Parents of Under 5s** and a **NEW** course for **Parents of children with ADHD** – see right.

Triple P courses are all about behaviour and parenting positively. Stepping Stones starts January for parents of under 12s. Teens for parents of 11 plus will be later in the spring.

To find out more about any of these courses or to book, email info@amazebrighton.org.uk or call 01273 772289.

New Insiders' Guide course for parents of children with ADHD

Parents say it really helps when they meet up together, share tips and learn more about ways to manage tricky situations. Thanks to funds from the Community University Partnership Programme at the University of Brighton, we want to create a brand new Insiders' Guide **support course for parent carers of children with ADHD**. We will be working with parents, Community CAMHS and the University to design, test and evaluate the new course. Now we need your help

If you have a child aged between 8 and 16 years whose main diagnosis is ADHD, could you take part in the very first course and test the materials? You'll give us your views about what worked well and not so well.



The course will run over six Friday mornings, from 9.30am to 12.30pm, starting on **Friday 13th November** at Ralli Hall Community Centre, 81 Denmark Villas, Hove BN3 3TH. Travel costs are covered.

If you would like to know more or want to book a place, contact Amaze on 01273 772289 or email helpline@amazebrighton.org.uk

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 5pm, and Fri mornings 9.30am to 1pm. *NB: This Christmas, the helpline will close from 24th Dec to 3rd Jan and reopen on Mon 4th Jan 2016.*



Amaze

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