

# out of amaze



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



## Make a splash with our 100m water slide

Amaze is bringing a giant 100m water slide to Wild Park in Brighton on Saturday 15<sup>th</sup> July 2017.

Come with friends and family to slide or just enjoy the fun-filled atmosphere. **Heart FM** will be pumping out tunes, there'll be a bouncy castle, a fire engine and other entertainment for younger kids, and **SAMA** will be running **superhero sumo wrestling** and **karate or kick boxing tasters**. Refreshments and ice-creams will be available at **J's Café & Deli**.

At the time of going to print, you can still buy tickets online at [www.yotickets.com](http://www.yotickets.com). It costs £12 per

slide, which includes a minimum donation of £5 to Amaze. Any remaining tickets will be sold on the day. Riders can be any age from 7 to 107 and can ride by themselves or accompanied. There's more info at [www.facebook.com/AmazeBrighton](http://www.facebook.com/AmazeBrighton)

We are really excited to be bringing a giant water slide to Brighton and we hope to do it again next year.

Thanks to Heart FM, J's Café & Deli and Brighton & Hove City Council for making it possible.

**INSIDE:** SEND Hubs • Mainstream inclusion • Mental health changes • Summer play schemes • Disability Pride • PIP guidance • Compass summer and more...

## Big Lottery win for young people

Amaze is delighted to have been awarded £198,734 from the **Big Lottery Fund's Reaching Communities** grant scheme to fund our 'Amazing Futures Project' with young people with SEND aged 14-25.

Over the next three years, we'll be developing our direct work with young people alongside our work with parent carers, making sure that the views and aspirations of young people with SEND are embedded in all that we do.



The 'Amazing Futures' project is about improving the support available for young people during the transition to adulthood and will include a range of activities such as recruiting young people to provide peer support, developing information and resources specifically for young people, and offering group activities, workshops and training courses to both young people and parent carers.

We're also very grateful to **Newman's Own Foundation**, **NatWest Skills and Opportunities Fund**, **Sussex Community Foundation** and the **Insurance Industry Charitable Foundation** for funding towards the first year. Read more about the project on page 4.

# Special school hubs get go ahead

Some significant decisions have recently been made to take forward the plans to redesign the city's special schools and Pupil Referral Units.

It was with a heavy heart that councillors made the final decision to close Patcham House school in August 2018. They recognised the very good work undertaken by the school staff over many years, but it is felt that the school has become too small, needing considerable financial subsidy, making it unsustainable in the future.

Following the recent consultation, the proposals to make changes to our special schools and PRUs to create three hubs were approved at committee on Monday 19<sup>th</sup> June. These changes are likely to take place over a two-year period from September 2018, once the final stages of the legal process are dealt with. The hubs will bring together education, health and care services

for pupils with SEND, and offer better support for children and families.

**These changes are likely to take place over a two-year period from September 2018, once the final stages of the legal process are dealt with.**

The local authority intends to support children and families through this time of change, to minimise any disruption. And parent carers can of course contact Amaze for support too.

## ICAN on the move

From September, the specialist ICAN speech and language nursery class based at Carden Primary School is changing to an **outreach service**, as part of the Brighton and Hove Inclusion Support Service (BHISS). It will continue to provide specialist support for children with severe developmental speech and language difficulties but will do so in their local nursery or education setting. This is a temporary arrangement, for a year or so, to give the local authority the chance to review how they provide support to nursery-aged children with speech and language difficulties.

BHISS specialists will visit 16-20 children with significant speech and language difficulties in their nursery or education setting for the year before they start school - the aim is to boost the child's language so that they are ready to join a mainstream reception class, wherever possible.

Staff within the child's nursery or setting will get advice, support and training from the specialist team to deliver a targeted programme of support, either one to one or in small groups, including Makaton.

## New Community Wellbeing Service for children and young people's mental health

From the 1<sup>st</sup> June, there's a new single point of access for all non-urgent mental health referrals for children and young people in the city.

Parent carers, professionals and young people can contact the central triage hub of the new **Community Wellbeing Service** which will conduct routine assessments and decide upon appropriate support. The Triage team is available Mon-Fri, 9am-1pm on 0300 002 0060.

Children with mild to moderate mental health issues (such as mild

depression, anxiety or low self-esteem) will stay within the Community Wellbeing Service for short term interventions such as counselling or CBT. Or these children could get similar support via a primary mental health worker from their **School Wellbeing Service**.

Children with moderate to severe mental health needs including self-harming, depression and post-traumatic stress disorder will be referred to specialist CAMHS for more sustained treatment by psychiatrists, psychologists, nurses and therapists.

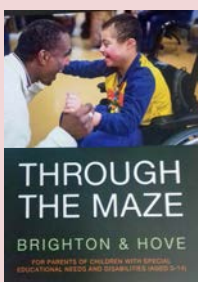
There will be close working links between the Community and School Wellbeing Services, as well as specialist CAMHS, to ensure a smooth transition from one service to the other should this be in the child or young person's interest.

There's lots of helpful information about mental health services and support for people up to 25 in Brighton and Hove on the new Find, Get, Give website at [www.findgetgive.com](http://www.findgetgive.com). If you have visited a service, you can leave them a review and a star rating. You can also access help and advice pages to find books, podcasts, apps and other handy tools that can help with wellbeing.

## Through the Maze handbook out now

Amaze has just published the latest edition of our handbook for parent carers, *Through the Maze*.

The book helps parent carers to navigate the particular journey of caring for children up to 14 with additional needs. There are chapters on diagnosis, health, education, social care, looking after yourself and more.



You can get a free copy if your child has a special

educational need or disability and you live in Brighton and Hove, or your child goes to school or pre-school in Brighton and Hove. Call the helpline to request a copy on 01273 772289.

## Make some noise for Amaze!

Amaze is delighted to have been selected as one of Global's Make Some Noise charities for the year. This will include a year of fundraising and promotion on their many radio stations including Heart Sussex and Surrey – culminating in a UK-wide Global's Make Some Noise Day on Friday 6<sup>th</sup> October 2017.

The campaign will raise much needed funds for Amaze and other local organisations that support children with SEND – Extratime, Brighton Pebbles, T21 Brighton & Hove, mAScot, Barnados LinkPlus and Sweetpeas.



## Amaze gets friendly with new Face 2 Face service

Amaze is running a new project offering emotional support to parents through befriending.

**Amaze Face 2 Face Befriending** is a peer support service offering families support around the time of diagnosis or new challenges. The project is delivered by a team of 20 volunteers, all parents of children with additional needs, who have received intensive training. The service was part of national charity Scope and has now been taken over by Amaze, complementing its existing services.

Befriending can prove to be a lifeline for parents during challenging times. "When my son, Billy, 6, was diagnosed with autism my first thoughts were how will I cope, how will I stay strong, how am I going to do this?" says Amanda Stockford, who now co-runs the monthly autism group. "My befriender was there for me as another mother who had already been on this journey and to let me know it would be alright, I would cope, and there was light at the end of the tunnel. Without her my son's world could have been a very different place. Because of her, we face the future together strong and with hope."

As well as **one-to-one support**, which is offered for up to six months, Face 2 Face also runs groups. These include a **dads group** (monthly on the last Thursday of the month) and a **weekend club for under 7s with autism** or going through ASC assessments (on the second Saturday of the month). Face 2 Face also supports an **under fives PRESENS group** (preschool special educational support) every term-time Monday.

If you'd like get support from a befriender or attend one of our groups call the Amaze helpline on 01273 772289. If you'd like to become a befriender, we're running a **training course** over eight weeks, starting in October. For more information, email [amandam@amazebrighton.org.uk](mailto:amandam@amazebrighton.org.uk)

We'll be putting on a **Fashion Show** on **Sat 18<sup>th</sup> November** at Downs View Link College. If your child would like to have fun on the catwalk email Amanda (above). We're also looking for volunteers to help on the day.

Finally, we are putting together a team for the **Color Run** on Sat 23<sup>rd</sup> September. Read more on page 14.



# Amazing Futures

Amaze's new peer supporter project will help build brighter futures for young people with SEND

Winning Big Lottery and other funding means we'll be doing lots of brilliant work with young people over the next three years.

## Interns and assistants

We'll be offering a part-time paid internship to a young person during each year of the project and we've just appointed Danny Knight as this year's intern. Danny currently does care work but he has a passion for outdoor education and has worked in American summer camps. He's dyslexic and really looking forward to having "the opportunity to support young people who face similar challenges to myself".

Danny takes over from our previous intern, Danielle Garratt, who was instrumental in helping us to develop our young people's work and who contributed to the success of our bid. We're very glad she'll continue to be involved in the project as a volunteer.

We've also appointed a new part-time Communications and Editorial Assistant, Rose Fenge. Rose will work closely with the project coordinator, Sue Winter, and the project intern to develop accessible information for young people with SEND and promote the project in print and online media.

## Peer support

We're training a team of young people (18+) with and without SEND to be volunteer peer supporters for other young people with additional needs aged 14 to 25. So far, we've had some 'just for fun' sessions, which the volunteers helped to plan and run, to help us get to know one another and see how we might match young people with the right supporter.

Some of the girls and young women who came to these initial sessions found it a bit overwhelming, so we've decided to set up and run separate girls' and young women's sessions too. These will happen once a month on a Tuesday, early evening.

And we'll continue running the free sessions over the summer holidays on Thursdays from 10am– 1pm in the Conference Room, Community Base, 113 Queens Road, Brighton BN1 3XG.

- **27<sup>th</sup> July, 10<sup>th</sup> and 24<sup>th</sup> August**  
For any young person aged 14+ with SEND
- **3<sup>rd</sup>, 17<sup>th</sup> and 31<sup>st</sup> August**  
For girls and young women aged 14+ with SEND

To register or book a free place, contact Sue Winter (see box below).

## Groups for young people

Amaze has set up a **young people's advisory group** to help develop and plan our priorities for the project. The young people involved chose the project's name - Amazing Futures. They've also helped us to develop the Compass Card website. Any young person with SEND aged 16+ can be involved in the advisory group.

We're continuing to run the **Power Group**, a self-advocacy group for young people aged 16-25 with learning disabilities. We do this in partnership with Speak Out, the



advocacy organisation for adults with learning disabilities in the city. A small group of young people meet at the Young People's Centre once a fortnight to talk about anything they want to. Sometimes we invite guests to come and speak about subjects that have come up in the group. Young people interested in joining the Power Group should contact either Sue at Amaze or Dawn at Speak Out [dawnthorpe@bhspeakout.org.uk](mailto:dawnthorpe@bhspeakout.org.uk)

## And there's more

We'll be working in partnership with YMCA's Right Here Project to adapt some of the courses they run for secondary schools promoting positive mental health. Once adapted, we hope to offer them in some of the special secondary schools in Brighton.

Finally, the Amazing Futures project will be part of the Disability Pride Event on Sunday 9<sup>th</sup> July – read more about this on the back page.



## Interested in Amazing Futures Peer Support?

If you're 18+ with or without SEND and would like to join our team of Peer Supporter volunteers, or if you're 14 to 25 with SEND and would like to have a Peer Supporter, please contact Sue Winter on 07483 111648 or email [sue@amazebrighton.org.uk](mailto:sue@amazebrighton.org.uk)



The Amaze team celebrating 20 years of supporting families at our staff away day in June.

## Celebrating 20 years supporting families

Amaze turns 20 this year and we'd love you to help us celebrate this significant birthday and the difference we've made to the lives of families in Brighton and Hove.

Back in 1997 Amaze was launched to provide information, advice and support for families with disabled children, bringing together two existing parent-led projects, the Network of Parents and the Parent Link Project. At the time, local parent carers described feeling "lost in a maze" when their child was diagnosed with an additional need and they campaigned to improve the information and support available to them.

Lizzie Batten, Amaze's DLA Project Manager, was there at the start and remembers just how far we've come since then:

"There was a real lack of information. Hardly any organisations had websites, social media didn't exist and most parents didn't even have access to the internet at home. So there was no way for parent carers to find each other and get together, and we missed out on all those brilliant tips that parents

often share with each other.

"And when you did get information, it was often no help. Professionals seemed to speak in a mysterious way, using words you didn't understand.

"I remember thinking that if I was finding it so difficult to get the right help for my daughter, how on earth would someone who was less fierce and less resourceful than me do it!"

**"Young people whose parents we have supported over the last 20 years are now keen and able to start helping others."**

20 years on, Amaze has supported a whole **generation of children and their families** with an ever-expanding range of services, developed according to what parents told us they

needed: a helpline, publications, help with DLA claims, more chances to have fun via the Compass Card, parent training courses, and more. Over the years we have had tremendous support from our statutory partners and funders, and many hundreds of parents and professionals have contributed their expertise to our work.

Our latest **Amazing Futures** Project (opposite) is the most powerful and direct embodiment of all this work, as some of the young people whose parents we have supported over the last 20 years are now keen and able to start helping others. Eight of the young people we have recently trained as Peer Supporters have a special educational need or disability themselves, and their parent carers feel their participation in the project is a direct result of Amaze's help over the years; they have been able to build their own and their child's resilience, leading them to now feel able to volunteer their time to help other young people with disabilities.

We are calling the impact of this 20 years' work '**Generation Amaze**', and we are looking for new funders (especially local businesses) to join us as sponsors to **help fund the next generation of Amaze families**. If you have any contacts with local businesses who you think might be interested please contact [nickyb@amazebrighton.org.uk](mailto:nickyb@amazebrighton.org.uk).

We'll be celebrating Generation Amaze and Amazing Futures at lots of events in the coming months including a giant water slide and fashion show, with a final celebration event at the Duke of Yorks on 4<sup>th</sup> December. Read more about the birthday events on page 14 and in forthcoming issues and help us to celebrate 20 amazing years.







## Everything you need for summer fun

The Compass Team at Amaze will be working hard this summer to bring you plenty of ideas and information about fun things you can do over the long summer break.

### The Compass Team blog

You'll find the latest Compass Team blog at [www.compasscard.org.uk](http://www.compasscard.org.uk) and we'll be focusing on keeping children and young people entertained, come rain or shine, during the holidays. You'll also be able to add your own ideas and get top tips from other families too.

### New 'Fun stuff' leisure guide

We'll have our brand new Fun Stuff leisure guide available in time for the

summer holidays. It's packed with well over 100 individual leisure listings and it covers social and support groups, youth clubs, soft play and farms and sports from kayaking and surfing to table tennis, swimming, tenpin bowling and gyms. It's in a handy A5 format with an easy to follow index and you can download it from the Resources page at [www.compasscard.org.uk](http://www.compasscard.org.uk), pick it up from Disability Pride on New Street in Brighton on Sunday 9<sup>th</sup> July or call the Amaze helpline on 01273 772289 and ask for a copy to be posted to you.

### Compass Card offers

There are well over 150 Compass Card offers at around 250 locations across Brighton and Hove, West Sussex and beyond, so make sure you've got the Compass Card app to hand when you're out and about. Just go to the App Store or Google Play, search 'compass card' and download the Brighton and Hove version. If you don't have an iPhone or an Android smartphone, you'll find everything you need on the Offers page at [www.compasscard.org.uk](http://www.compasscard.org.uk)

## Help us shape a Compass Card future

**How do you rate the Compass Card?  
What are your favourite Compass Card offers and what new offers would you like to see?**

We'd love to hear your views and we've now extended the deadline for our short Compass Card Brighton and Hove survey until 14 July 2017, so there's still time! There's a survey for young people, as well as one for parent carers and if you provide your contact details, we'll enter you in

our draw for £50 worth of Love2shop vouchers.

You can find both surveys online at [www.compasscard.org.uk/news-and-events](http://www.compasscard.org.uk/news-and-events). Or you can call the helpline on 01273 772289 or email [compass@amazebrighton.org.uk](mailto:compass@amazebrighton.org.uk) to request paper copies.



**Tell us what you think of the Compass Card by 14 July and you could win £50 of Love2Shop vouchers**



## Away for a day

Our annual PaCC Away Day is a chance to get together to review what we've done over the last year and plan for the year ahead. We covered a lot of ground!

### Communicating with PaCC members

We all agreed on the importance of maintaining regular contact with our members. With this in mind, we plan to have more regular updates about what we've been up to on our Facebook page. Please join our page (see box for details of how to join). We will also continue to keep you informed of the latest news through our website, the Amaze e-bulletin and of course this newsletter.

### More mainstream

Based on feedback we've had from parent carers, we agreed it's vital for PaCC to have more contact with school SENCOs, and we started this process with our recent PaCConnect on Inclusion in Mainstream schools (see page 9). We are aware of the gap in

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support for parent carers who don't have an EHCP (Education, Health and Care Plan) but do have a child with additional needs. This is now high on our agenda and will be part of future planning.

### Celebrating successes

We've had an amazing impact over the past year. For example, we influenced councillors to invest £150k in the Direct Payments budget and got a commitment from the council that the number of overnight residential places at Drove Rd and Tudor House will not decrease. We also got closely involved in shaping better mental health provision for SEND children and improved support at the Royal Alex, to name but a few.

### SEND review of special schools and PRUs

PaCC reps have been involved in the proposals to reorganise the city's special schools and PRUs to keep families' needs central to the discussions - our local politicians voted unanimously in favour of the plans in June. PaCC wrote a position statement on the plans and set out a list of recommendations for the local authority and the executive heads and their management teams to evaluate the success of the changes. You can read our Position Statement at [www.paccbrighton.org.uk/what-we-do/pacc-position-statements](http://www.paccbrighton.org.uk/what-we-do/pacc-position-statements).

We will continue to work closely with the local authority and other services that support our children to make sure our voices are heard. And we'll keep you informed about our work, including an update from the Children's Disability Team on how the £150k investment into Direct Payments is being used.

**Make your views count. Join the PaCC by emailing [admin@paccbrighton.org.uk](mailto:admin@paccbrighton.org.uk) or tell us what is concerning you at [www.paccbrighton.org.uk/get-involved/give-us-your-views](http://www.paccbrighton.org.uk/get-involved/give-us-your-views)**  
**You can also join our closed Facebook group at [www.facebook.com/groups/parentcarerscouncil](http://www.facebook.com/groups/parentcarerscouncil)**





## New dawn for mental health services

Services for children's mental and emotional health have been a key issue for us over the years. PaCC has worked hard to make sure parents' concerns about accessing mental health support for their kids moved to the top of the local agenda. Positive and persistent work by PaCC parent reps, particularly Helen on the Child and Adolescent Mental Health and Emotional Wellbeing Partnership Group, have had an impact so we are happy to report some real change.



Children and young people who need help with their mental health and wellbeing can now access a new service previously just for adults. **Brighton and Hove Community Wellbeing Service** will introduce a single point of access for all mental health referrals, so those in need can access appropriate support as quickly as possible. The hope is that referral times will dramatically reduce because previously separate services will now work in partnership. This will also be a chance for children and young people's services to tap into the expertise and processes already in place through adult provision. Alongside this new service the mental health support available through schools is being strengthened. And there are changes to how the specialist CAMHS service based at Aldrington House will work too. There's more detail about the new service and how to reach it on page 2 of this newsletter.

## Your health - your views

During the past few months PaCC and Amaze have been asking parent carers for their views and experiences on some diverse health issues: making healthcare complaints, food poverty and active living.



In terms of complaining or giving feedback about health care, parents told us that it does really help to have a person or organisation that can help with giving feedback about health care but that it is still a difficult and time-consuming process. Parents said they were often too tired to have *"the energy to sit down and put it all in writing"*. **Parent carers told us that they would like systems that are clear and responsive to their suggestions and complaints.**

Parent carers don't want to be seen as a burden or as a troublemaker and they're scared of the repercussions on their children's care if they make a complaint or raise a concern. **An effective, independent system that doesn't penalise future relationships between parent carers and professionals would be a real benefit.**

Voluntary sector organisations and in particular Amaze Helpline staff are hugely important for helping parent carers find out more about the different systems and how to navigate them. **Ongoing financial support for voluntary sector organisations is therefore paramount.**

From our consultation around food poverty and active living, we found out that **17 per cent of families are skipping meals or don't have enough**

**to eat as a result of economic hardship.** One parent confessed *'I do occasionally miss a few meals to make sure my family are eating healthy'*. This consultation highlighted the fact that **changes in the benefits system, rising living costs and stagnant wages mean a staggering 33 per cent of families with disabled children are experiencing food poverty.**

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Economic issues also underpin parent carers' feedback about active living. Many parents told us they needed **more affordable local activities.** The report highlighted the extra barriers that families with children with additional needs face, for example activities that are not 'additional-needs' friendly'. Amaze's Compass Card has reduced many of those barriers for local families, and more recently the city's Carers' Card has made some health and wellbeing activities more affordable but **more can still be done to ensure that the whole family can enjoy an active life.**

Recommendations from both reports were passed on to the local Clinical Commissioning Group (CCG) and we will follow up any outcomes. You can read the full reports at <http://paccbrighton.org.uk/resources/reports/>



## PaCConnect shines light on inclusion in mainstream schools

In April, PaCC hosted a well-attended PaCConnect forum, looking at what works and what doesn't around inclusion of children with SEND in mainstream school.

SENCOS from two secondary schools came to the meeting, as well as Councillor Vanessa Brown, representatives from the local authority, Amaze and Extratime (see Anna Czepil's piece on page 12). But the event was all about listening to parent carers, and capturing their views on how to improve mainstream inclusion for children with SEND. These are being condensed into a report to be shared with heads and SENCOS across the city.

Topics included access to trips and extra-curricular activities, behaviour management, communication between school and parent carers, and accessing your local school. PaCC encouraged parent carers to share examples of what's working well, since we think sharing good practice is key to helping schools up their game. If one school can do it, then others can too.

illegal part-time timetables and informal exclusions. Others reported that during the admissions process, secondary schools had mixed attitudes towards welcoming their child with special needs.

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are cost-free and can have  
a big impact on families.

Parent carers talked a lot about how they can feel blamed for their child's difficulties, which increases the stress of caring for a child with SEND. Respect and compassion are cost-free and can have a big impact on families. The SENCOs and parent carers agreed that if parent carers are viewed as valued partners, this benefits the child with SEND.

It was great to hear examples of good inclusive practices from the



SENCOs who attended. Patcham High and Blatchington Mill secondary school SENCOs both talked passionately about the importance of all children being equal members of their school community. Differentiation of all aspects of the day are considered and early planning is a core principle to include children on school trips, etc.

PaCC is keen that a set of inclusive core principles is developed and then prioritised by all schools in Brighton and Hove. These principles, combined with strong school to school support focused on good practice, will lead to improved inclusion for the SEND Community. PaCC will update you on progress in forthcoming newsletters.

Sharing good practice is key to helping schools up their game.

Parents gave examples of good practice, such as flexibility in school to help children with anxiety, and having a consistent and creative individual needs assistant. Having the child at the centre of provision – whether that be individual behaviour plans, differentiation (adapting to individual needs) in class or flexibility over uniform – was seen as vital for proper inclusion.

Equally, there were examples of less positive experiences. Parent carers spoke of the stress caused by

## PaCC Awards and PaCC Calendar

The PaCC Awards are our way of thanking professionals who have provided outstanding support to our parent carers and their children. They are also a great way to highlight how vital these services are.

If someone in the Health, Education, Social Care or the Voluntary Sector has gone out of their way to help you and your child this year, then what better way to thank them than by nominating them for the PaCC Awards 2017? You can do this at [www.paccbrighton.org.uk/get-involved/nominate-pacc-champions](http://www.paccbrighton.org.uk/get-involved/nominate-pacc-champions) you can email [admin@paccbrighton.org.uk](mailto:admin@paccbrighton.org.uk) to request a nomination form.

## Funding for the PaCC Calendar

The much loved PaCC calendar is in need of funding!  
If you know anyone who might be willing to sponsor  
the PaCC calendar for 2018, please email  
[admin@paccbrighton.org.uk](mailto:admin@paccbrighton.org.uk)





## Introducing our new Steering Group members

Hello, we are Anna and Ali, the newest members of the PaCC Steering Group. We both have children who are deaf, and we became aware of PaCC as a result of campaigning for the needs of deaf children during the SEND review last year. It's a real privilege to be part of this group.



Anna Jenkins

We sit as parent reps on CHSWG (Children's Hearing Services Working Group), representing the voice of parent carers of deaf children. CHSWG is a local multi-agency group including new-born screening services, audiology, paediatricians, health visitors, the sensory needs team, speech and language therapy, the National Deaf Children's Society, family support worker, and the community audiology service.

We meet every three months to look at provision for deaf children in health, education and social care, with the aim of developing the range of services used to make them more effective and family friendly.



Alison Davies

If you are interested in joining the PaCC Steering Group email [admin@paccbrighton.org.uk](mailto:admin@paccbrighton.org.uk). For more information on CHSWG you can email [davis.alison@virginmedia.com](mailto:davis.alison@virginmedia.com)

## Don't be shy... join the PaCC!

**We have over 300 PaCC members – can you join us?**

PaCC are here to make sure your voice is heard as a parent carer. Our members are a huge part of that process. If you want to take part or just hear what's going on, you can join PaCC at:

[www.paccbrighton.org.uk/get-involved/join-the-pacc](http://www.paccbrighton.org.uk/get-involved/join-the-pacc), or you can email [admin@paccbrighton.org.uk](mailto:admin@paccbrighton.org.uk) with your details.

Our Facebook page is regularly updated with news, meeting dates, etc. Join our facebook page here; [www.facebook.com/groups/parentcarerscouncil/](https://www.facebook.com/groups/parentcarerscouncil/)



## Extratime – child care champs

Extratime is one of seven PaCC partner organisations who provide services and support for children with SEND and their families. Their fully inclusive **after-school and holiday clubs** offer a range of activities, well trained staff and one to one support if necessary.

This year, Extratime have been very proud to be a **charity partner of Brighton and Hove Albion** for the 2016/17 football season. The partnership has helped the charity raise much needed funds to support their work, and also given Extratime families and staff the chance to be part of what has proved to be a most exciting year for the football club, as they won promotion to the Premiership.



Extratime's after school and holiday clubs take place at six locations across Brighton and Hove and Shoreham. The school age schemes are for children with and without SEND, the youth schemes are specifically for 13-25s with additional needs.

Read all about Extratime's summer schemes opposite or visit [www.extratimebrighton.org.uk](http://www.extratimebrighton.org.uk) for more information or to book.

PaCC's pull-out supplement is funded by the Department of Education through Contact a Family.







## Sorted for summer?

Not worked out what to do with your children over the summer holidays yet? Don't panic! Our annual lowdown of inclusive summer schemes and activities can help you plan the break you need and keep them entertained.

### Inclusive schemes

#### Extratime (primary school age)

Mon 31<sup>st</sup> July to Fri 25<sup>th</sup> August at Downs View School, Woodingdean and Hillside School, Portslade. 8.45am to either 3.30pm (£21) or 5.30pm (£24.50). Fully inclusive play scheme offering one-to-one support if required. Children with and without additional needs take part in games, activities, trips and more. Email [hello@extratimebrighton.org.uk](mailto:hello@extratimebrighton.org.uk) or call 01273 420580 to book.

### Special schemes

#### Cherish (16-25s) Tues to Fri, 1<sup>st</sup> to 25<sup>th</sup>

Aug, 10am to 4pm. Mini-bus based days out for young people with learning disabilities. One to one support. 16 to 18 year olds pay £17 per day, 19-25 year olds pay £45 (Individual Budget) or £25 (DLA only rate) Call 01273 295171/ 295530. Booking forms available from 3rd July.

#### Extratime Youth Scheme (11-19s)

Mon 31<sup>st</sup> July to Fri 25<sup>th</sup> August,

8.45am to 5.30pm (£25.50) at Portslade Village Centre and Woodingdean Youth Centre. Activities for young people with disabilities, with one-to-one support if required. Both venues have wheelchair access and a hoist/changing bed. Email [hello@extratimebrighton.org.uk](mailto:hello@extratimebrighton.org.uk) or call 01273 420580 or email to book.

### Parent led social groups

Local social groups for kids with additional needs continue over the summer and many of them organise holiday outings or activities. If you

attend groups like **Brighton Pebbles**, **Mascot**, **Kaleidoscope** or **T21** it's worth finding out what they are doing over the summer. You can call the Amaze helpline to get details of local parent support groups or visit [www.amazebrighton.org.uk/services-and-support/parent-support-groups](http://www.amazebrighton.org.uk/services-and-support/parent-support-groups)

### Further information

Amaze has a brand new '**Fun Stuff**' guide that lists oodles of local leisure activities and our '**Choosing leisure**' factsheet gives advice and tips on how to choose and settle your child into an activity. You can download them at [www.amazebrighton.org.uk/resources/publications/fact-sheets](http://www.amazebrighton.org.uk/resources/publications/fact-sheets). And don't forget to check out the latest leisure offers attached to **Compass Card Brighton and Hove**. Visit [www.compasscard.org.uk](http://www.compasscard.org.uk).

The council's colourful '**Summer Fun**' booklet has loads of ideas for things to do in the summer for kids. You should have had one in your children's book bag or you can find a copy in your local library or leisure centre. Also, the **Local Offer**, Brighton & Hove's online directory of services for children and young people with SEND, has information about leisure activities and schemes. Visit [www.brighton-hove.gov.uk/localoffer](http://www.brighton-hove.gov.uk/localoffer)

**If you have any questions about leisure or childcare, call our helpline on 01273 772289.**

### Whoopsadaisy's summer open week for under fives

Whoopsadaisy, the Brighton-based conductive education charity, is holding an **open week from 7<sup>th</sup> – 11<sup>th</sup> August** at their Preston Park pavilion, for families with **children under five** who are concerned about a delay in their children's physical development, or who already have a diagnosis linked to cerebral palsy or other motor disorders. Families can see how Whoopsadaisy works and have an assessment done to see if their child could benefit from the charity's free conductive education parent and child sessions that aim to help children become as independent as possible before they start school. To arrange a visit, call Whoopsadaisy on 07533 956149.

## What inclusion means to us

Inspired by the recent PaCConnect on mainstream inclusion, Anna Czepil, Head of SEN at the council, gives her take on what successful inclusion looks like in practice.



“Every parent wants their child to have an enjoyable and fulfilling experience at school, so that they have a great start in life and can make the journey towards adulthood with happy and fun memories along the way. As a local authority we want this for all children and young people in Brighton and Hove. We also believe that, wherever possible, children and young people are best placed in their local community school.

“We don’t just mean that pupils with SEN should, wherever possible, be educated in a mainstream school, but also that they should join their peers in the full curriculum and life of the school. Also, while separate provision may be necessary for specific purposes sometimes, children and young people with SEN should generally take part in mainstream lessons rather than being isolated in separate areas.

“For parents who want to see their child educated in mainstream, the key message I took from the PaCConnect is for parents and schools to have open and transparent communication about what is and what isn’t working. Parents have good advice for teachers about what strategies work for their child, to allay anxiety for example and make them more comfortable in the school environment.

“As a society we need to learn to recognise, accept and work inclusively with children who may behave and learn differently, rather than giving those children the often unmanageable task of conforming to what society sees as typical behaviour. At the PaCConnect, for example, we heard about a child with autism who was struggling to keep their shoes on or wear the school uniform because of their sensory issues. Not complying with the school uniform policy can land pupils in trouble, but when we look at the reason behind this and accept that following these rules will have a detrimental effect on that child’s learning, we soon realise how important making allowances can be.

“The inclusion model supports and addresses the individual needs of each child. And it doesn’t just benefit students with SEND - it creates an environment in which every student has the opportunity to flourish.”

**Read more about the PaCConnect on mainstream inclusion on page 9.**



## Play dates at The Alex

The Alex’s new Stay and Play session is all about making hospital less scary for kids with SEND. Pippa Hodge, PaCC Steering Group member, reports.

“It was certainly no ordinary Saturday on Level 5 at The Alex! Hospital visitors could see children in mini hospital scrubs attending to their teddies in a hospital bed (the teddies came free in a goody bag) or zooming around in the mini electric cars that children can use to drive themselves down to the Operating Theatre on Level 7. More surprises followed, with the arrival of the wonderful Pentacle drumming group, a magician, and the resident ‘Chuckle Doctor’.

“This was the first Stay & Play session for 4-8 year olds at the Royal Alexandra Children’s Hospital. It was co-created by Sallie Moller and Hannah Beacock from the Perioperative Team, Katy Weaver, Play Therapist, and myself, who all share a passion for helping make the experience of being in hospital less worrying for children and their parents.

“Our idea was to bring children with additional needs together with hospital staff and lay on some fun so that they can feel more relaxed and have a positive experience to build on. Staff have a chance to interact with children, getting to know them when they are well, and it gives children a chance to build up trust and familiarity with staff. Parent carers can chat and share handling tips with staff members, and brothers and sisters also get to join in the fun, because we know that when a child has more complex needs, the whole family end up sharing the experience.

“The April event was the first of four planned sessions, funded by Rockinghorse, with future sessions being planned for older children later this year. So watch this space!”



# Getting around and about PIP

The government has introduced new PIP descriptors for 'going out' that exclude most claimants with mental health conditions. What you write on the claim pack and say at assessment is now more important than ever.

To a great extent, these new rules\* have gone under the radar as the government brought them in by amending existing regulations, which does not require any debate or vote in parliament. We think it's worth explaining the new rules.

## What's new?

The phrase 'for reasons *other than* overwhelming psychological distress' has been added to three of the PIP descriptors relating to planning and undertaking journeys. Descriptors are phrases the DWP use to capture the key skills and help you need to carry out an activity.

## What does this mean?

The DWP should award points for the descriptor that best fits a claimant's circumstances most of the time. In practice, **if the DWP decides the problem is simply that a claimant is too anxious to go out unless they have someone with them, they are unlikely to be awarded more than 4 points**, not the 8 or more they need to get an award of the mobility component.

## Make what you say count

So it's vital you leave no room for doubt. Where 'anxiety' or 'overwhelming psychological distress' is an expression of an underlying condition like autism, a learning disability or sensory issues, you need to make this clear. Lots of things can make people feel anxious but what's the underlying problem for your young person?



Explain in detail and give examples if they need support to:

- plan the different elements of a journey, book tickets, manage their time, read a map, timetable or written directions
- know who to approach if they need help or get lost
- hold onto spoken directions long enough to follow them
- problem solve when they need a plan B
- rehearse familiar local journeys over and over again

*"Directions and maps are no use to Karen: she can't visualise herself on the route."*

Explain in detail and give examples if your son or daughter is unable to reliably assess risk and:

- cannot judge the speed and distance of moving traffic
- anticipate consequences
- behaves as if they are invincible

*"Joe can be very daring when he crosses the road, often frightening the driver of the oncoming vehicle"*

*with his timing. He believes it is their job to get out of his way, rather than vice versa."*

Explain how being amongst other people outdoors has its own challenges and your son or daughter needs your advice and presence to:

- negotiate noisy crowded spaces
- speak when they need to
- resist making remarks that draw negative attention
- remain calm
- stay safe from bullying, sexual or financial exploitation

Give examples if you have to physically intervene when things go wrong:

*"Asher always makes the same choice, so he never needs any time. His younger brother was taking longer than Asher could tolerate to decide what to buy so Asher shouted and hit him several times. I had to drag him off and out of the store: all the time Asher was hyperventilating, lashing out and in a panic. He was completely unreachable."*

## Make a strong case

Be specific and give examples about what can go wrong and why a young person cannot plan or undertake a journey on their own. Connect what happens to their difficulties with processing, social communication or problem solving. Always include supporting evidence to back up what you say.

*"Isaac has ASC. He thinks we know what he thinks. If he gets lost he expects us to know where he is and gets cross if we do not."*

\*The new regulations do not apply to decisions made before 16 March 2017.

Read more information about the scoring system for PIP at [www.disabilityrightsuk.org](http://www.disabilityrightsuk.org)



## 20/20 vision for funding the next 'Generation Amaze'

Amaze has an ambitious plan to raise an extra £20,000 of new income in our 20<sup>th</sup> birthday year

We'll use the 20k raised to help us reach the next generation of families who need support from Amaze.

We're looking for **20 local companies** to join forces with Amaze in a mutually beneficial partnership for one year. Please can your company help or do you know anyone who can?

Or perhaps you're part of a community group, professional society, sports club or other

organisation that might be able to offer us some birthday funding.

Individuals can do their bit by running for Amaze. This year we need runners for the **Brighton Color Run**, the **Brighton Brooks 10K**, Brighton **Half Marathon** and Brighton **Marathon**

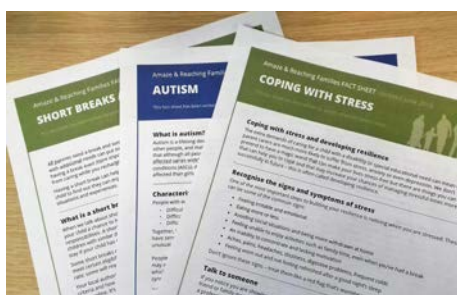
Or you can come along to support our celebration events taking part throughout the year - see our full fundraising calendar to the right.

## Fact sheets a big hit with parents

Last summer, Amaze launched a range of 40 fact sheets as part of a joint project with West Sussex parent carer charity, Reaching Families. We're delighted to say that **over 4,500 fact sheets have been downloaded** from our two websites since then.

The fact sheets cover a range of topics from advice about specific conditions such as autism and ADHD to claiming DLA and handling meetings and living without a diagnosis.

There are several education-related fact sheets that might make useful holiday reading: 'Starting secondary school', 'SEN Support' and 'EHCPs'. Just visit our website to download at [www.amazebrighton.org.uk/resources/publications/fact-sheets](http://www.amazebrighton.org.uk/resources/publications/fact-sheets)



## Fundraising and events calendar

### 2017

**9<sup>th</sup> July - Disability Pride**

at Brighton New Rd and Pavilion Gardens

**15<sup>th</sup> July - Amazing 100 Metre Water Slide**

at Wild Park, Brighton (see our cover story)

**22<sup>nd</sup> September - Wine Tasting**

with Henry Butler, at Hanover Community Centre, Brighton

**23<sup>rd</sup> September - Brighton Colour Run**

for Amaze Face 2 Face Befriending Service

**18<sup>th</sup> November - Disability Fashion Show**

at Downs View Link College, Brighton

**19<sup>th</sup> November - Brighton Brooks 10K Race**

**4<sup>th</sup> Dec - Amaze 20th Birthday Celebration**, at Duke of Yorks, Preston Circus.

### 2018

**25<sup>th</sup> February 2018 - Brighton Half Marathon**

**15<sup>th</sup> April 2018 - Brighton Marathon**

For full details of these events, visit our website or call Nicky B on 01273 234014 or email her on [nickyb@amazebrighton.org.uk](mailto:nickyb@amazebrighton.org.uk)



# Ask an expert

Philip Warford of Renaissance Legal and Karen Milton, Senior Specialist Occupational Therapist, answer your questions.

**"My partner and I are ready to make our wills and are considering putting in place a Trust to protect our son, who is disabled. What should we think about before visiting a lawyer?"**

## Philip says:

"There are some key areas that we encourage people to have a think about at home, prior to attending their first meeting with a lawyer. However, please don't get bogged down by making decisions as the lawyer should discuss all of the options available during the first get together and once you're armed with all the information you can make decisions from there. Here are the top five things to think about before the meeting:



- **Funeral Wishes** - It might seem difficult but it's important to consider if you'd prefer to be buried or cremated. This is a personal choice but something that will need to be included in your Will so your friends and family are aware of your wishes.
- **Guardians of children under 18** - This is a decision that a lot of people struggle with, which is completely understandable. Considering who you would like to care for your children is a big decision to make and requires careful thought especially if one of your children is disabled or has additional needs.
- **Executors** - Who would you like to administer your estate? These are the people in charge of ensuring that your wishes are carried out.
- **Trustees** - Who would you like to deal with the Trust that you will need to set up to look after the finances for your child? Trustees make important decisions in relation to how the money held in the Trust will be dealt with to benefit your child, so this needs some very careful consideration.
- **What happens if you all die?** - This is always the 'sucker punch', but you need to have a think about who you would like to benefit if you, your partner and son all die, say, in an accident together.

For more information about Wills and Trusts please come along to our next **Wills & Trusts seminar** in December. More details in the next issue.

For individual legal advice call Renaissance Legal on 01273 610611 or visit [www.renaissancelegal.co.uk](http://www.renaissancelegal.co.uk) NB: Compass Card holders get a 10% discount on fees.

**"My friend's son is autistic and has just started doing something called the 'Just Right' programme at school and home. Could this also help my daughter who has some sensory processing issues?"**

**Karen Milton says:** "The 'Just Right' programme uses colour zones to help children understand and communicate how they are feeling and what makes them feel 'just right', when they're calm and alert and able to respond to whatever is happening in their environment. It has been developed here in Brighton and Hove by the Occupational Therapy Team, BHISS (Brighton and Hove Inclusion Support Service), CAMHS Learning Disability and specific teachers within the special schools.



"The 'Just Right' approach is built round a **scaling system, with four key colour zones** – blue, green, orange, red – **each of which relates to a different sensory or emotional state**. It all starts with identifying the green or 'just right' zone. Information is gathered from parents, the child, teachers and specialists who work with them to find out what 'just right' feels like to them and what can be done to help keep them feeling like that, ready and able to learn, as much as possible. This might be making sure they have the same seat every day or that they get a short burst of exercise to either calm them (orange) or wake them up if they're slumping into the blue zone.

"The key to the approach is recognising triggers. Children often describe themselves as feeling 'fizzy' or a bit agitated in the orange zone, for example – the aim is for the child and teacher to recognise when this happens and employ a strategy to prevent them hitting the red zone, where their behaviour and feelings might become much harder to handle.

"The brilliant thing about 'Just Right' is that it is absolutely **tailored to the individual child**. Each child will have an entirely different set of circumstances that keep them feeling 'just right' and an entirely different set of triggers. And they don't even need to stick to the given colours – they can choose their own! 'Just Right' helps children and young people to develop insight and knowledge about themselves, as well as their own programme and strategies. Parents and carers can use that same bank of tools and strategies too, which gives a consistent approach across children's lives.

"Speak to your school SENCO about whether the 'just right' approach might help your daughter. It's used in special and mainstream schools, as part of specialist support from BHISS or Seaside View. BHISS also offers termly training for teachers and other school staff and runs 'Just Right' coffee mornings for parents of children with autism, and a 'parent pack' all about the approach is currently in development which will be available soon.

## Amaze courses and workshops

We have some bite size sessions on key SEND issues coming up this summer and autumn. These are free and led by Amaze IAS and Independent Support workers.



**Preparing for the Future at the Year 9 Annual Review** - 10am to 12 noon, 12<sup>th</sup> July, 20<sup>th</sup> Sept and 5<sup>th</sup> Oct plus 7-9pm on 5<sup>th</sup> Oct

This vital session will help you think ahead about how the Y9 review should kick off plans for transition to adulthood. They all take place in the Amaze Meeting Room at Community Base (see address bottom right).

**Getting the best from your child's EHCP** - 9.30am to 12.30pm, 3<sup>rd</sup> Oct.

This is for any parent expecting to go through the EHCP process soon, either as a transfer from a Statement or to get their first Plan. It will guide you through the process. It will take place in the 5<sup>th</sup> floor Conference Room at Community Base.

## Longer courses

**Triple P Stepping Stones** - the autumn course is already full but we will run another early in 2018. Also coming in the autumn and spring - a **Wills and Trusts session** and **Insiders' Guide** courses for parents of **teens**, children with **autism** and children with **anxiety**. Register your interest now so you get the dates as soon as we are taking bookings.

To book or register your interest email [info@amazebrighton.org.uk](mailto:info@amazebrighton.org.uk) or leave a message on the helpline 01273 772289.

## Disability Pride comes to town

Brighton and Hove hosts England's first ever Disability Pride on **Sunday 9<sup>th</sup> July 2017**.

This much-anticipated event will be a positive celebration of and for people with all types of disabilities. It's completely free and will take place on New Road, Brighton (by the Theatre Royal) between **2 and 7pm**. There'll be a stage showcasing fantastic bands, singers and speakers with confirmed names that include Unified Rhythm and Daniel Wakeford from The Undateables.

**Amaze and PaCC will be there** too with a stall where you can pick up our latest information. We'd love to see lots of our families there and invite you to bring a picnic and join people from Amaze, PaCC and other organisations like mASCot, T21, Pebbles, and Extratime between



**1pm and 4pm on the lawns at Pavilion Gardens**, where you'll be able to soak up the atmosphere of Disability Pride from a slight distance. There will be two disabled toilets and one Changing Spaces toilet facility on New Road.

To find out more about the event visit [www.disabilitypride.org.uk](http://www.disabilitypride.org.uk) or find them on Facebook under Disability Pride Brighton.

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](http://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. Monday to Friday, 9.30am to 2pm, Wednesday to 4pm



### Amaze

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