

# out of amaze



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

## Amazing park events

This June, Amaze would love to see you in Preston Park for **two special events** for you and your family.

## TAKEPART Launch

The Amaze Team will be giving sports and leisure advice at the **TAKEPART Sports & Physical Activity Festival Launch** from 12 noon till 5pm on **Saturday 20<sup>th</sup> June** in Preston Park – so come and see us in the Amazing Zone next to the basketball courts. We can tell you all about our Compass Card Activities and the full range of Compass Card offers, suggest what might work for you or your Compass Card holder and signpost you to all the sports, dance and physical activities you can try or watch on the day – including disability-friendly Amazing Activities. Read more on page 13.



## Compass Challenge family walk and picnic

We'd like to invite Amaze families and friends to the first ever Compass Challenge **sponsored family walk and picnic** on **Sunday 28<sup>th</sup> June**, also in Preston Park. After the inclusive, wheelchair-friendly challenge we'll meet for a picnic, with soft drinks, music and entertainment provided by Amaze. See the **back page** for **more details**.



## Amaze launches Information, Advice and Support to young people

Amaze is delighted to announce that we are extending our support to young people. We are now offering Information, Advice and Support (IAS) services directly to young people with special educational needs and disabilities from 16 up to their 25<sup>th</sup> birthday. Young people got the right to IAS as part of the SEND reforms in the Children and Families Act last year and Brighton and Hove City Council have agreed to support Amaze to provide this locally.

We can help young people with things like getting the right support from school or college, training, health services or social care. Of course, young people will probably still rely on their parents to help them make important decisions about their

future, but our new service means that young people can access information and support with their parents or by themselves if they'd prefer that.

We offer impartial advice. This means we won't tell a young person what to do - we'll provide information so they can make their own choices. To get support, young people can call our helpline on 01273 772289 or email [youngpeople@amazebrighton.org.uk](mailto:youngpeople@amazebrighton.org.uk)

This new service will work alongside our Independent Support service for young people getting EHC Plans. We will develop what we offer based on what young people say they want and how they'd like to get information and support. See page 4 to find out more.

**INSIDE:** Transport to school changes • New sibling group • Young people's page • Ask an expert • PaCC Home adaptations forum • DLA tips • and more...

## SEND Review makes progress

Since February's meeting to agree key priorities, work on the SEND Review has made steady progress.

A **conference/workshop** was held on 13<sup>th</sup> March to consider examples of integrated provision (where education, health and care services are provided from the same location) from other parts of the country. Attendees heard from staff working in Walnuts School and Walnuts Care, Milton Keynes; The SABDEN Federation, East Sussex and Swiss Cottage School, Camden.

The event was very well attended by **professionals** from Brighton and Hove's special and mainstream schools along with staff from health and social care. Four **PACC parent reps** attended the workshop and have fed

back to the local authority and **Amaze** and student representatives were also there.

Following this, the council is now working on more detailed proposals for the three areas of integrated provision - Early Years, Special Educational Needs and Disability (SEND) and Social, Emotional and Mental Health (SEMH) Needs. Rachel Travers, who attended the conference on behalf of Amaze, said, "The conference was a really useful opportunity to hear how integrated provision is organised elsewhere in the country and consider how such services might operate here".

The council are also continuing to investigate:

- Potential use of a Resource Allocation System to provide greater clarity and fairness in the allocation of social care support.
- Proposals for the re-alignment of school support services to improve support (and training) to parents and their families.
- Further development of joint commissioning for health and other services.

There'll be another chance to join the consultation on integrated provision in the summer.

The PaCC is looking forward to working alongside the local authority throughout the next stages of the SEND Review. The PaCC has requested focus groups for parent carers so the wider SEND community is given a full opportunity for feedback during these next crucial stages.

## Brighton & Hove launch Autism Aware Award for local schools

Brighton & Hove City Council have announced a **collaboration with West Sussex** to introduce an Autism Aware Award scheme for schools in Brighton and Hove. The scheme was initiated in 2005 by the West Sussex Social Communication team and has been very well received and evaluated by around 30 schools there.

*"This Award is one of our favourite schemes - it really showcases and formalises the work we do with all of our young people, but especially those on the spectrum. We are proud of it because it is a whole school achievement and we have learned a lot and made some great supportive relationships with colleagues in other schools along the way."*  
**SENCOs from West Sussex secondary school.**

Downs View School and the Autistic Spectrum Condition Support Service are planning to run the first Autism Aware Award scheme from September 2015. There will be an initial information session for interested schools in October at Downs View.

**"Hopefully in the summer term of 2016 we will have our first schools with the Autism Awareness Award"**

The award is for the school, who will commit to a series of eight training sessions in the spring term covering topics such as Psychological Theories and Thinking Styles, Sensory Processing Difficulties in Young People with ASC, and Socialisation

and Peer Awareness. There'll be homework after each session for the schools to do and plenty of opportunities to work with the tutors.

Each school has to produce a portfolio, which pulls together lots of evidence to support them achieving the award, which is then internally and externally checked. Mary MacPhail, ASCSS Interim Head of Service, says, "Hopefully in the summer term of 2016 we will have our first schools with the Autism Awareness Award".

For more details contact the ASCSS on 07578 768441 or email [lisa@bourne@downspark.brighton-hove.sch.uk](mailto:lisa@bourne@downspark.brighton-hove.sch.uk)

*"This award makes me feel safe because I know that the school care about me being here."*

**Year 6 girl with autism, West Sussex**



## New Amaze group for siblings



Amaze is really pleased to have won some funding from the Brighton & Hove Clinical Commissioning Group and City Council Mental Wellbeing Innovation Fund to set up a **siblings support group** from this September. The group will be aimed at supporting **children aged 8-13** who have disabled brothers or sisters.

We are just at the planning stages but we'd love to get the views of siblings about what they might like. What sort of things would they like their group to do? Where should we hold it? How often?

If you're the parent of a sibling who would like to get involved in the development of the group contact

[rachel@amazebrighton.org.uk](mailto:rachel@amazebrighton.org.uk).

We are also keen to hear from older or adult siblings of disabled children who might be up for getting involved in supporting the group. Maybe you would like to gain work experience in this area and be willing to come along and talk to the new group? Let us know.

There are **other sibling groups** in the city - some schools provide them and there is one run by the Carers' Centre for siblings who undertake a caring role for their disabled sibling. Brighton Pebbles organises trips and two holidays each year for siblings with their families. Contact Pebbles on 07506 105265 for more information.

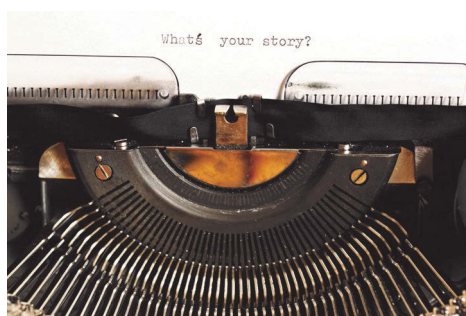
The Keyworking Team is also setting up a new siblings group at Seaside View which will focus on younger children aged 5-10 whose family has a keyworker. We will put more information about this and Amaze's sibling group on our website and Facebook as they develop.



### Free counselling for parent carers

Amaze can now refer parent carers for counselling through a new partnership with **Relate**. Relate has **expert counsellors** who understand the impact parenting a child with additional needs can have on **families and relationships** and we can make one or two referrals to them each month for free counselling.

**You don't have to be a couple** to take this up, just a parent carer who would like space to explore things safely and confidentially. Contact the Amaze helpline or email [info@amazebrighton.org.uk](mailto:info@amazebrighton.org.uk) to discuss if this could be right for you.



### Tell us your story

Nothing helps people understand what it's like to bring up a child with additional needs better than real life stories. And these same stories help convince funders just how vital it is to keep supporting charities like Amaze.

**Could you tell us your story?** Who are you and your child? What is life like for you every day? Why did you first turn to Amaze? Did we help? And if so, how?

We'll use your stories to bring our literature to life and to make funders see just what kind of impact our work has. And of course we'll change names to protect your anonymity (if you want this) and send you a copy to check before we ever use anything.

### Why did you first turn to Amaze? Did we help? And if so, how?

So, write us a few paragraphs (or more) telling your story and email it to [charlotte@amazebrighton.org.uk](mailto:charlotte@amazebrighton.org.uk). And if writing is not your thing, just send Charlotte your contact details and she'll get in touch to hear your story and write it for you.



### Coffee in Whitehawk?

We're about to start running coffee mornings for parent carers in Whitehawk. We already run them in Moulsecoomb and Hangleton & Knoll and parents there tell us they really enjoy getting together with other parents in the same boat, and meeting people who run services like CAMHS or the ASCSS. We'll have a venue and dates soon. So contact [info@amazebrighton.org.uk](mailto:info@amazebrighton.org.uk) or call the helpline on 01273 773389 if you're interested.



## What young people want

Now that Amaze is offering **Information, Advice and Support directly to young people**, we wanted to find out what kind of information they'd find helpful and where and how they'd like to get it. So we invited a group of young people to our 'What's out there for you' event in March.

15 young people came along and

filled in a questionnaire telling us what kind of information most matters to them. All 15 said they wanted to know about Compass Card Activities and offers. Many wanted information about meeting other people and going out, about where they might live in the future and local services that might be able to help and support them. They also told us

they wanted information about their education, college courses, finding voluntary work and getting a job. Some wanted to find out about things like getting contraception. And some wanted information about travelling around the city and what benefits they might be entitled to.

We also got the group to have a look at the Amaze website. This was designed for parents, not young people, so we knew they'd have lots of helpful suggestions about what they might like a website for them to look like. They told us they'd like less words, more animation, YouTube clips and pictures, and the sense that it was clearly aimed at them. All the young people who took part were given £20 gift vouchers for helping Amaze.

The young people were filmed interviewing one another about what they enjoy and what they want to know about on the day. Once the film has been edited, we'll put it on the Amaze website. We then hope to put their suggestions into action, if we can get the funding.

## Meerkats, cookery and the Isle of Wight

Brandon, Amber and Jasmine tell us what they enjoyed most about National Citizen Service

In our last newsletter, we mentioned the National Citizen Service (NCS) and their **community volunteering and activity programme for young people**. Brandon, Jasmine and Amber took the offer up earlier this year and graduated from the programme in April.

### What did they think about NCS?

Brandon said: "I really enjoyed meeting all my group (the Meerkats). I loved the trip to the Isle of Wight

and the activities. I had a great time. It was really good to work in a group and participate."

Jasmine said: "I really enjoyed the cookery day and the day we explored Brighton."

Amber said: "I loved going on the big swing when we went to the Isle of Wight."

Brandon's Mum, Liliana, said: "NCS was a great opportunity for Brandon to meet new people, be part of a group, create something and give back to the community. Brandon was



Brandon, Amber and Jasmine's graduate the programme with Haitch Zaida from NCS.

looking forward to every weekend to be there, to plan and put his opinions and be heard."

If you are interested in the NCS summer programme, contact Haitch Zaida on 07876 898035 or visit [www.ncsthechallenge.org](http://www.ncsthechallenge.org) for more information.



# Meet our new intern

Danielle Garratt tells us about her new role at Amaze and what she's done so far



"My name is Danielle. I am 21 years old and I have just started working for Amaze as a paid intern for two days a week to help them develop their young people's Information, Advice and Support Service.

"I have a visual impairment. I love drawing and making things. I volunteer at Make Your Mark which is a group for young people who have a disability and who like doing arts and crafts and I am also a part of the Power Group, Amaze and Speak Out's young people's self-advocacy group which gives young people with learning disabilities a chance to talk about whatever we want to talk about.

"The first thing I did in my new role was to take part in an Amaze event with other young people to help find out what kind of information and advice we want and how we would like to get it. You can read a bit more about this in the article on the opposite page. In my first week working at Amaze I went to Kings House and met Graham Read, Head of the Special Educational Needs (SEN) team. We talked about how Amaze will

help the council improve the information on their website in the Local Offer.

"Graham explained to me that the Local Offer should have all the information about services and support for all children and young people with special educational needs and disabilities. They want this information to be more accessible to

**"In my first week at Amaze I went to Kings House and met Graham Reed, Head of the Special Educational Needs (SEN) team."**

parents and young people. I am going to help Amaze with this work. I have been looking at the Local Offer and making suggestions about what information needs updating.

"On the 2<sup>nd</sup> April, which was World Autism Awareness Day, I helped on the Amaze stall at Brighton Open Market talking to people about the support Amaze offers and letting them know that we now offer information, advice and support directly to young people."

"Helping out at the Autism Awareness Day was great as I got to find out lots of things about autism services in Brighton. I'm going to Sussex Downs College in a couple of weeks to talk to young people about the Power Group. I'm really looking forward to this as I went to Sussex Downs and it'll be great to see some of my tutors."



## Art Workshops for young people with SEND

Mymarc runs Make Your Mark monthly art workshops for young people with SEND aged 16-25. Usually on the first Saturday of the month, Make Your Mark is a Compass Card Activity so young people registered on the Compass pay a discounted rate of £15 for the three hour workshop.

Thanks to funding from Brighton and Hove's Health and Wellbeing Innovation Fund, MyMarc ran a volunteer training course, with 10 participants and 10 young people from Downs View Link College taking part in five art workshops. The work they did was shown at the Link College's Open House Art Lab exhibition as part of the Brighton Festival in May.

Mymarc will be offering FREE art workshops over the summer holidays, thanks to funding from the young people's engagement worker for Brighton & Hove Museum and Art Gallery. The dates are Saturday 25<sup>th</sup> July, and Saturday 1<sup>st</sup>, 8<sup>th</sup>, 15<sup>th</sup> and 22<sup>nd</sup> August from 10am to 1pm. Places are limited so to avoid disappointment please book early. You can email Sue Winter on [sue.winter@icloud.com](mailto:sue.winter@icloud.com) or call her on 07400 963087. Young people who need one to one support can come with support workers.

**If you'd like to join the Power Group for young people with learning disabilities aged 16 to 25, call Sue on 01273 772289 or email [youngpeople@amazebrighton.org.uk](mailto:youngpeople@amazebrighton.org.uk)**

Mymarc is a Community Interest Company (that means that all the profits go back into the organisation). It was set up last year by Amaze's Transition Development Worker, Sue Winter and Claire Peligry (parent to Heloise).

# Tips for showing them how you care

When your child has additional needs most parenting advice can seem out of step with your experience so we tend to learn what works as we go along. This means it can be hard to explain just what we do and why on a **DLA claim form**. Here are some pointers to help you notice what's extra and different about your child's development and how much you do to help.



**Does picking up new skills seem effortless for other children but very hard work for yours?** It may not be enough for your child to watch and listen and have a go a few times to get something right. Every new task may require lots of repetition, over days, weeks or months. A new skill will be forgotten unless it's practised and your child may need to go back to basics regularly and relearn the same information. All this takes a lot of time and patience so make sure you include examples on your DLA form.

**Does your child habitually forget what you tell them, what they are supposed to be doing, or where they've got to in a task and have to go back to the beginning and start again?** If you find you have to say the same things over and over again and encourage your child to feel OK about asking other people for help when they can't remember, put this in your claim. Or perhaps you've shown your child how to make lists, use notes or handouts and you do this at home to instill the good habits your child may need to rely on until they become second nature. All these are important examples of the extra help you are giving them.

**Does your child get in a muddle learning to do things in the right order,** so activities that require some planning and organisation need to be broken down and simplified? Whether it's getting dressed or wrapping a present, if you are still teaching your child how to tackle tasks their friends can do for themselves, give examples and write this

on the claim pack. Maybe you are getting them to do the last or next easiest part of the job, while you tackle the harder parts? Or you show them how to get started and talk through what to do next? If everyday routines, like cleaning teeth get forgotten if you aren't checking, include this too.

**While other children are keen to be independent, does your child seem happy for you to do everything for them?** Perhaps it takes a lot of persistence just to catch and hold your child's attention or encourage them to watch and copy as you demonstrate washing their face or how to hold their knife and fork? Or maybe you are helping your child hand on hand, or hand under hand to try together? Make a point of mentioning this in the claim.

**Even very young children can entertain themselves** but some children can't reach for toys or explore their environment without help. Others need placing 'in the centre of the action' otherwise they get left behind or left out. If you are playing out story lines with Thomas the Tank and his friends while your boy wants to line them up, you are helping to extend and develop their play and you should mention this.

**The playground feels like a battleground.** Most children have the capacity to join in, make friends and play without involving grown-ups. Playing co-operatively is where children learn a lot about negotiation, compromise, sharing and taking turns. If you are on alert, relentlessly making things better or sorting out problems, while other parents relax, you must be doing something extra and different. If you need to explain or adapt the rules so the game is fair to everyone, or intervene when your child is being overly boisterous and fails to notice they've hurt or upset another child, if your child needs support to manage anger or disappointment if the game doesn't go their way, write it all down.

**If any of these examples ring true for your child, include them in the DLA claim pack where it asks about your child's developmental needs. Or call our helpline on 01273 772289 for advice to help you complete your claim.**





## How PaCC represents your views

The Parent Carers' Council gives a voice to parent carers by representing your views at various meetings across our city.

Trained PaCC Parent Representatives sit on about 25 different decision-making strategic boards, groups and subgroups alongside local professionals from health, social care and education services. We regularly attend meetings with Brighton & Hove City Council, the local NHS and Clinical Commissioning Group (CCG), as well as regional and national meetings with other parent carer forums. We do this because we believe that parent carers' concerns, opinions and suggestions need to be central to planning services and provision.

This kind of working relationship is called 'co-production,' which means delivering public services based upon an equal and reciprocal relationship between professionals and the people who use their services. That's you and your families! The idea is to achieve better results and an improvement in the way services work by valuing and

drawing upon everyone's expertise and knowledge. And that should include the 'coal face' perspective that parent carers bring.

In the last newsletter, for example, we talked about the Special Educational Needs & Disabilities (SEND) Review that was underway in our city. We told you about our two parent representatives - Fiona and Diana - who attend and contribute to key meetings, where the entire SEND service is being looked at, to explore how to make services more effective in a time of scarce resources and cuts. After their meetings, Fiona and Diana report back their findings to the PaCC Steering Group and help us share that information with other parents whilst

continuing to promote the parent carer viewpoint.

An encouraging development that's emerging from this 'co-productive' approach is the formation of small working groups, where Parent Reps

*"Working as a PaCC rep can be challenging, but it's almost always interesting. Sometimes it feels like one step forward, two steps back – particularly in the current climate of council cuts - but at other times I really feel I'm making a difference."*

**Diana**

sit alongside the professionals and help devise changes and improvements to the current service. Our recent Home Adaptation PaCC Forum is an excellent example of this in action (see overleaf).

Though all this 'co-production' may sound rather official and daunting, we want to stress that we are all parent carers – just like you. We are passionate about using our collective voice to preserve and improve the vital services that we, as families, need for our children, at a time when there is increasing budgetary pressure. If you are passionate, and would like to actively contribute, we'd love to hear from you. As parents and carers, you're already expertly qualified!

You can see the full list of the meetings we attend on our website at [www.paccbrighton.org.uk/what-we-do/representing-parent-carers](http://www.paccbrighton.org.uk/what-we-do/representing-parent-carers)

**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)**



# PaCC's home adaptations forum

Our latest forum brought parent carers together with professionals from the council's Housing Adaptations Team to discuss some of the issues involved in adapting your home.



For some of our families, the changing needs of a child with disabilities as she or he gets older begins to be incompatible with some of the practical aspects of our home, and adaptation may be required. This might be relatively minor additions such as a shower chair or grab rails, through to a major home reconfiguration, funded by a Disabled Facilities Grant via the local authority. On Wednesday 18<sup>th</sup> March PaCC's regular forum, PaCCConnect, explored some of the **key issues around home adaptations**.

**"I'm really pleased I attended the adaptations meeting... these connections are essential, communication is the key to resolving so much. I really like that it was incredibly well organised and structured - the positive effect this has cannot be underestimated. Thank you!"**

**Susanne, parent carer of a 9 year old**

A group of parent carers were able to talk about their experiences and difficulties in making their home function better for their child. They were joined by Sarah Routledge,

Senior Occupational Therapist (OT) at Seaside View, Alex Dickie, Housing Adaptations Technical Team Leader at Brighton & Hove City Council and Jenny Brickell, Integrated Child Development and Disability Services Head at Seaside View Child Development Centre, who participated as an observer.

**"We're grateful to PaCC for giving the Social Care Occupational Therapy Service and Housing Adaptations Team Manager the opportunity to meet with a group of parents and carers. It was very valuable to hear their views. As a result we now have an action plan to take forward to improve the Home Adaptation experience."**

**Sarah Routledge, Senior Occupational Therapist, Seaside View Child Development Centre**

The forum was very frank and informative. The professionals explained how the local process works, and their role within it, and parents were able to direct their specific questions and get immediate feedback. For example, one mum said that she felt that only the needs of her disabled child were considered, instead of those of the whole family. And Sarah Routledge explained that the OT does advocate for the whole family, taking into account the impact on parents and siblings. However, she admitted that typical Brighton housing stock often limits options. As a direct result of our forum the OT adaptations team agreed to:

- produce an Information Pack to give to parents and carers at the start of the adaptations process
- amend the social care OT information leaflet to be clearer about the role of the social care OT and make sure it's accessible in the council's Local Offer
- consider producing a poster or booklet to explain the social care OT role and equipment and adaptations process

PaCC will work with the **social care occupational therapy team** to ensure the information is useful and parent-friendly. You can read the minutes from the forum, and get links to lots of important information at [www.paccbrighton.org.uk/what-we-do/pacc-connect-events](http://www.paccbrighton.org.uk/what-we-do/pacc-connect-events)





## Latest on the Home to School Transport Policy

As many of you will know, Brighton & Hove City Council has recently revised its Home to School Transport policy. Here we look at some of the key changes in the new policy and PaCC's response to these changes.

### Consultation

February's consultation on the new Home to School Transport Policy received an incredible 149 responses, demonstrating the importance of this issue to families of children and young people with additional needs. Many parents, while supporting the aspiration of independent travel, expressed concern about how this could be implemented for their children, many of whom are very vulnerable. The expectation of parents taking their children to school was another area of concern.

PaCC responded to the consultation (see [www.paccbrighton.org.uk/resources/reports](http://www.paccbrighton.org.uk/resources/reports)) as did other organisations including Amaze, MASCoT and the DfE. And Diana Boyd from PaCC and Rachel Travers from Amaze met with council officers to discuss some of your key issues. The council also published a response to the consultation, in which it says they "recognise that the quality of travel from home to school makes an important contribution to the quality of the school day".

Some welcome changes to the policy include removing reference to using DLA to fund home to school transport, and adding a sentence about taking into account whether other children of the same age normally walk to school when assessing parents' ability to accompany their children.

### The new policy

The new Home to School Transport Policy has now been finalised, and there are big changes to the way home to school transport is to be

assessed and provided. You can read the full policy and the council's response to the consultation here:

[www.brighton-hove.gov.uk/content/children-and-education/schools/school-transport](http://www.brighton-hove.gov.uk/content/children-and-education/schools/school-transport)

Encouraging and planning for independent travel remains a strong focus of the policy, and the council is already working with schools to identify which students should be able to travel independently in the future, and the training they'll need to help them do this. Parents also need to be aware, when choosing a school, that the council will only provide transport if they choose the 'nearest suitable school' named by the local authority. Call Amaze for advice if you think this may be an issue for you.

Parents must also now reapply for transport each year, usually alongside the annual review. All families who currently get home to school transport should already have already applied for transport for next year (deadline 12<sup>th</sup> May). If you have not completed the application form, and think your child needs transport to school, contact the Home to School Transport Team on 01273 293501.

Parents can appeal the council's decision, and it explains how to do this in the policy. If you need support with the application form or appealing, you can contact Amaze on



01273 772289. More information can also be found on the IPSEA website at [www.ipsea.org.uk/what-you-need-to-know/home-to-school-college-transport](http://www.ipsea.org.uk/what-you-need-to-know/home-to-school-college-transport)

### PaCC's response

PaCC recognises that these changes may cause alarm for a number of our families, and we continue to work hard to raise your concerns with the council. In line with our collaborative ethos, we are running a PaCC Connect Forum on June 25<sup>th</sup> (see below) to bring parents and carers together with council officers, so that we can all understand the new policy, and address specific areas of concern. Do join us and share your views.

### PaCConnect on Home to School Transport

Thursday 25<sup>th</sup> June, 10am to 12.30pm

Come and join us on Thursday 25<sup>th</sup> June in the 5<sup>th</sup> floor Conference Room at Community Base, Queen's Road, Brighton to discuss all your concerns about changes to home to school transport. Coffee from 9.30am for a 10am start. Email [admin@paccbrighton.org.uk](mailto:admin@paccbrighton.org.uk) to let us know you are coming.



## Having your say on GPs and health checks

Over the past few months at PaCC we have been busy finding out what you think about GPs and the health checks that are offered to anyone aged between 40 and 74.

### GPs

Previous consultations have highlighted the need for better understanding from GPs about the particular experience of caring for a child with additional needs. Parent carers weren't happy about having to call at 8.30am for appointments when most are on their way to school at that time. Collated responses from our latest online questionnaire recommended that GPs offer a choice of phone or online booking systems and also that surgery staff get more training in understanding the 'parent carer journey'. As one satisfied parent carer commented "My surgery is aware of my son's autism and if my own GP has no appointment he will always call back".

### Health checks

The Clinical Commissioning Group (CCG) aims to improve health checks and make them more accessible. PaCC ran an online questionnaire to get parent carers' views about health checks and 92% of respondents said they would go for a health check if their GP surgery invited them. Parent carers would like to find out about health checks through their GPs, but they'd also like to have the choice to have one at home, at community centres or relevant events.

All suggestions and ideas have been fed back to the local CCG as part of our ongoing engagement. You can read the full reports on our website at [www.paccbrighton.org.uk/](http://www.paccbrighton.org.uk/)

## Best friends needed for PaCC calendar 2016

The theme for our very popular, and award winning PaCC Calendar for 2016 will be 'My Best Friend'. And we are looking for 12 stories to bring our calendar to life in a fun and vibrant way.

PaCC would love to hear from you with a few words about your child or young person's best friend. This could be anyone; a sibling, neighbour, other close family member, school buddy, support worker, etc.

You just need to send us a good quality digital image (a JPG) of your child and their best friend, together with a few words about what makes their friendship precious or maybe a brief description of some special moments they've spent together. You can also tell us a little bit about your

# 2015



Hayley Jones' award winning Brighton Eye photo on this year's PaCC calendar.

child or young person - what they like to do, hobbies, interests, etc. - and their medical condition or disability, if you are happy to share this with us.

Just send your details to [admin@paccbrighton.org.uk](mailto:admin@paccbrighton.org.uk) and title your email "PaCC 2016 Calendar."



## Celebrating Parent Carers National Carers Week - 8<sup>th</sup>-14<sup>th</sup> June

Caught up in the hectic day to day business of being a parent carer, you may well not know that National Carers' Week is nearly upon us.

If you want to know what's happening in Brighton and Hove for Carers' Week, visit the Carers' Centre website at [www.thecarerscentre.org](http://www.thecarerscentre.org).

We will be making sure we put our feet up at some point during Carers' Week to have a cuppa and cake (it may even be a cheeky glass of wine!)

We would like to recognise our parent carers and all that you do for our precious children. So PaCC will randomly select five PaCC members to receive a surprise gift through the post from us - will it be you?

## Coming soon!

### PaCCConnect Forum on Home to School Transport

Thursday 25<sup>th</sup> June, 10am to 12.30pm at Community Base

To find out more or come along, email [admin@paccbrighton.org.uk](mailto:admin@paccbrighton.org.uk)

### Results of PaCC Members Survey

Thanks to everyone who completed the PaCC Members Survey in March. We've received 47 responses and will report on the results in the next newsletter.

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

**contact a family**  
for families with disabled children

 Department for Education



## Our Brighton Marathon marvels

Thank you and congratulations to our Brighton Marathon runners; Paul Bentley, Julius Brinkworth, John Prebble and Dave Wilkins and Mini Mile Runner, Elodie Nevitt and Joshua Bateup. Together they have raised over £3,500 for Amaze.



Clockwise from top left: Beth and Leo; Elodie Nevitt; Dave Wilkins; John Prebble and Paul Bentley

## Calling all cyclists

**Fancy getting on your bike for Amaze or know a keen cyclist who might?**

Amaze has places in the annual Do It For Charity London to Brighton Cycle Ride on Sunday 6<sup>th</sup> September 2015. You could join two thousand fellow cyclists on the 54 mile route which kicks off in South London then travels through Mitcham, Carshalton, Chipstead, Banstead and Haywards Heath before ending up in our very own seaside hotspot, Brighton. Get full details at [www.doitforcharity.com](http://www.doitforcharity.com) or contact Nicky B on 01273 234014



or [nickyb@amazebrighton.org.uk](mailto:nickyb@amazebrighton.org.uk) for more information.

And if cycling is not your thing, perhaps you could support us at one of the other events in our fundraising calendar (right).

## Golf event tees off soon

We're getting excited about our forthcoming **charity golf day** with Wellesley Wealth Advisory (sponsors of our newsletter) on **15th July**. Guest speaker Simon Fanshawe OBE, writer, broadcaster and local celebrity, will join us at the Dyke Golf Club, Brighton.

A few spaces are still available to play golf at £200 per team or £50 per

person, which includes breakfast, shot gun start, 18 hole golfers challenge and a lovely lunch with auction and raffle. Thank you to all our generous sponsors and prize donors. You can still support Amaze by sponsoring a hole for £100 or donating a prize. Contact Maria Tyrrell at Wellesley ([maria.tyrrell@sjpp.co.uk](mailto:maria.tyrrell@sjpp.co.uk)) or [nickyb@amazebrighton.org.uk](mailto:nickyb@amazebrighton.org.uk)

## Fundraising calendar

**Sunday 28<sup>th</sup> June**

**Amaze Compass sponsored walk and family picnic**

Preston Park, Brighton

**Wed 15<sup>th</sup> July**

**Amaze and Wellesley Golf Day**

Dyke Golf Club Brighton

**Sunday 6<sup>th</sup> September**

**London to Brighton Cycle Ride**

Clapham Common start

**Thursday 17<sup>th</sup> September**

**Wine Tour and Tasting**

Ridgeview Wine Estate, Ditching

**Thursday 22<sup>nd</sup> October**

**BIG CHEER for Amaze**

Komedia Brighton

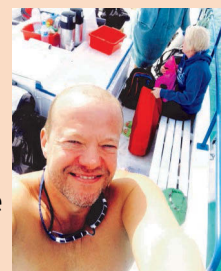
**Sunday 15<sup>th</sup> November**

**Brooks 10K Race**

Brighton

## Simon's Channel challenge

As we go to print, brave Simon Cooke is waiting to attempt the earliest and coldest ever Cross Channel Swim for Amaze. Follow his progress via our website and look out for him on the local news. In the next edition we hope to celebrate a new world record. Please help him reach his fundraising target and donate £5 by texting 'SCWR55 £5' to 70070 or via his Just Giving page at [www.justgiving.com/Simon-CookeWorldRecord](http://www.justgiving.com/Simon-CookeWorldRecord). Good Luck Simon and thank you for all your efforts on behalf of Amaze!





# Get set for summer

Here's our regular round up of holiday schemes and activities to keep your kids entertained this summer.

## Special schemes

**Cherish (16-25s)** Tues to Fri, 4<sup>th</sup> to 28<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 (£12 concessions) per day, 19-25 year olds pay £45 (Individual Budget) or £25 (DLA only rate) Call 01273 295171/ 295530.

## Extratime (11-19s)

Mon 27<sup>th</sup> July to Fri 21<sup>st</sup> August at Crew Club, Whitehawk and Hove YMCA, Marmion Road. 8.45am to 5.30pm (£23). Youth schemes for young people with disabilities, offering one-to-one support if required. Call 01273 420580 or visit Extratime's website at [www.extratimebrighton.org.uk](http://www.extratimebrighton.org.uk) to book.

## Whoopsadaisy Holiday Club for children with physical disabilities

Monday 17<sup>th</sup> to Friday 28<sup>th</sup> August  
These fun active sessions (for 5-12s) focus on improving existing physical skills and developing new ones and

usually have a theme. They are based at the Whoopsadaisy Pavilion in Preston Park and the suggested donation is usually £30 per day from 10am to 3pm. Call Whoopsadaisy on 01273 554178 and 07588 555761 or email [info@whoopsadaisy.org](mailto:info@whoopsadaisy.org)

## Inclusive schemes

### BHIP Holiday Play Scheme (3-11s)

27<sup>th</sup> July to 7<sup>th</sup> August at West Blatchington Primary School, Hove. Inclusive play scheme for children with and without disability/special needs. Short day from 8.30am to 4pm or 10.30 to 6pm costs £21. Full day from 8.30am to 6pm costs £23. To book, call 07821 541765, 01273 295533, email [info@bhip.org.uk](mailto:info@bhip.org.uk) or visit [www.bhip.org.uk](http://www.bhip.org.uk)

### Extratime (5 years+)

Mon 27<sup>th</sup> July to Fri 21<sup>st</sup> August at Ash Cottage, Woodingdean and Hillside School, Portslade. 8.45am to either 3.30pm (£19) or 5.30pm (£21). Fully inclusive play scheme offering one-to-one support if required. Also at St

Luke's Infant School (5-11s). A long day here costs £22. You can visit [www.extratimebrighton.org.uk](http://www.extratimebrighton.org.uk) or call 01273 420580 to book.

All special and inclusive play schemes book up quickly, so we'd advise you to contact them early to secure a place.

## Parent led social groups

Most parent-led groups for kids with special needs will continue, at least in some form, over the holidays and many of them organise activities. If you attend groups like **Brighton Pebbles**, **Link UP**, **Kaleidoscope** or **T21** it's worth finding out what they are doing over the summer. You can call the Amaze helpline to get the contact details of these and other groups or visit [www.amazebrighton.org.uk/services-and-support/parent-support-groups/](http://www.amazebrighton.org.uk/services-and-support/parent-support-groups/)

## Fun things factsheet

Our 'Fun things to do' factsheet is full of up to date information about local leisure activities - download the latest version from our website from mid June or call the helpline for a copy.

'Summer Fun', the Family Information Service's annual booklet lists loads of mainstream and more specialised activities across the city throughout the summer. You should get one via your child's primary school, or you can see one in your local library, children's centre or other community venues. Or you can download it from the council's website at [www.brighton-hove.gov.uk](http://www.brighton-hove.gov.uk). Finally, you could do your own research on websites like [www.childfriendlybrighton.co.uk](http://www.childfriendlybrighton.co.uk) or [www.kidsinbrighton.co.uk](http://www.kidsinbrighton.co.uk)

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





## Come and see us at TAKEPART

TAKEPART Sports & Physical Activity Launch Festival on 20th June is the perfect opportunity to try out all those activities you've been curious about and find out more about the hundreds of local clubs and organisations that can get you up and running in your chosen activity.

The Amaze Team will be armed with brand new Compass Card guides and our very latest round town leisure guide, Fun Things to do for All Ages. And our leisure experts will be able to give you plenty of information about clubs, sports, leisure deals and much more, to help you and your family make the most of our lovely city in the coming months.

Look out for Amazing Activities around the park on the day. They are disability-friendly sports and physical activities and include All Ability Bikes in the Bike Zone, Sports For All Table Tennis from Grace Eyre in the Ping Zone, Sound Tennis, an inclusive obstacle course with Active 8, wheelchair football and wheelchair basketball with Albion in the Community and Brighton Ultimate Frisbee.

Amazing Activities continue throughout the full two week festival. Look out for the Best of Health event for adults with learning disabilities on Thursday 25 June at King Alfred and the brand new 'Compass Challenge', Amaze's sponsored walk and family picnic on Sunday 28 June (see the back page). TAKEPART Sports & Physical Activity Festival runs until Sunday 5 July and culminates with the Paddle Round the Pier event with its fully inclusive Access Beach (book inclusive watersports tasters by emailing [access@paddleroundthepier.com](mailto:access@paddleroundthepier.com), or call 01273 295192 or 07717 303259).

Look out for festival leaflets round town. You can also visit [www.brighton-hove.gov.uk/takepart](http://www.brighton-hove.gov.uk/takepart) to check out the festival online.

### Have you got yours?

We've got brand new Compass Card guides and a fully updated Fun Things to do for All Ages fact sheet and we'll be giving them away at the Amaze stall at TAKEPART on Saturday 20 June. If you can't come and see us on the day, visit [www.amazebrighton.org.uk](http://www.amazebrighton.org.uk) and click on the Compass Card link to download your copies from mid-June, or call the Amaze helpline on 01273 772289 and ask them to send you copies through the post.

## Otherworld splash down

Otherworld's 2015 theme, Beneath the Waves, has been wowing participants, with many shows selling out.

A stunning sensory immersive theatre experience for all disabled children and their families, Otherworld's next show is at Chailey School, North Chailey, from Wednesday 10<sup>th</sup> to Sunday 14<sup>th</sup> June and St. John's School in Seaford from Wednesday 8<sup>th</sup> to Saturday 11<sup>th</sup> July. Don't miss!

For more information, visit Same Sky at [www.samesky.co.uk](http://www.samesky.co.uk) or call the Amaze helpline on 01273 772289.



### Get the app!

If you haven't downloaded the new Compass Card app to your iPhone or Android smart 'phone yet, there's never been a better time to do it!

We've been working with local app company, Dabapps, to continue to improve the app and from the beginning of June we'll be using the app's news feed. There will now be an alert to tell you when there's news you haven't seen yet and you can check for news snippets, leisure information and more.

We've also dealt with glitchy web links in the app, improved the search filter and added a welcome screen for people who are new to the app.

To install the Compass Card app, just search 'compass card' in the Apple appstore or in Google Play.



## Park or pub, Dad?

Whichever you prefer, there's a Dads' group for you.

We all know that parent groups can sometimes feel like Mums-only zones. The local council and Scope recognised this and set up two groups where **dads or male carers of kids with SEND** can meet up with other blokes in a similar situation.

There's a regular **pizza night** at the Stoneham pub in Hove, which takes place on the **last Thursday of every month** from 7pm. And a monthly **dads' running group** that meets at 9am on the **second Saturday of every month**, alternating between Preston Park and Hove Park.

Both groups are friendly and informal and the pizza nights sometimes invite people from local services to tell you what's out there. To join either group, email [reza.ataie@scope.org.uk](mailto:reza.ataie@scope.org.uk) or [david.higgins@brighton-hove.gov.uk](mailto:david.higgins@brighton-hove.gov.uk) or call 01273 265825.

## Or prefer a sing song?

Mums and dads can boost their spirits at the new Feel Good choir for parent carers. Join other mums, dads and carers of kids with additional needs on Wednesdays (usually fortnightly) from 8pm to 9.30pm at the Brighthelm Centre Roof Room. The choir is led by the brilliant Juliet Russell of Vocal Explosion. **Next date 17th June.** Contact Amanda on 07917 887526 for more information or email [amanda.mortensen@scope.org.uk](mailto:amanda.mortensen@scope.org.uk)



## Learning to travel independently

Children and young people at the Cedar Centre are undergoing a programme of training to help them learn to travel independently. Lalli Howell, Cedar Centre Head, tells us how it works.

"At Cedar Centre, Independent Travel Training is embedded into the school curriculum for pupils in KS3 and 4. We also have two pupils in the primary stage who are travelling independently to school.

"All the travel training tutors talk to parents and, depending on the individual needs of the child or young person, we offer group or bespoke programmes. It's all about working together to support young people on their journey to becoming an independent traveller.

"A child or young person may do various types of travel training: from bus practice with a tutor, or travelling with a buddy who's already an independent traveller, to learning to use a bike, or walking to school.

"We also support the practical travel training with lessons about protective behaviours. These teach children and young people how to be safe when out in the community.

**"I would never go back on taxis. I prefer buses and it makes me feel grown up."**

"One of our Year 10 students with autism sums up how it worked for him: 'When I first went on the bus it made me feel very happy and grown up. I started to go with two buddies, but now I go on my own. I would never go back on taxis. I prefer buses and it makes me feel grown up.'"

## Want to get on your bike? Get a free tandem for the summer!

Charlotte's Tandems is a national charity that hires out tandems and tag-alongs for free for use by disabled children and adults. So if you fancy giving it a go and riding two-up, here's your chance. The charity usually hires out the bikes for two months at a time. For more info, email [charlottes.tandems@gmail.com](mailto:charlottes.tandems@gmail.com) or visit [www.charlottestandems.co.uk](http://www.charlottestandems.co.uk)



# Any questions? Ask the experts

From education to benefits, to writing a will, our new feature gets the experts to answer your burning questions about caring for a child with additional needs. This week's experts are **Philip Warford**, Managing Director of local law firm, Renaissance Legal, and **Ros Cook**, manager of our Information, Advice and Support Service.

**'I've heard it's a good idea to set up a trust but what if I haven't got anyone I could think of to be a Trustee?'**

**Philip says:**



"Who you choose to appoint as Trustees is key to ensuring that the Trust can run smoothly and provide the appropriate protection for your disabled or vulnerable child as the main

beneficiary. Trustees can be family members, friends, professionals, or a combination of these.

"We usually start by suggesting that you consider family or friends as Trustees as they know your child so have an understanding of your child's preferences and personal needs. Furthermore they tend to act without charge. A Trustee can also be a trust beneficiary, but care needs to be taken to avoid any conflict between the personal financial interest and their duties and responsibilities as a Trustee.

"If you don't want to place the responsibility and commitment on family or friends, or you do not know

anyone suitable to be a Trustee, you may prefer to choose a professional entity to act as Trustee such as a solicitor, accountant or a professional Trust Company. Many professional firms and banks undertake this service, however charges do vary. It may be a set fee or an annual percentage charge based on the value of the Trust fund.

"You could also consider having Mencap Trust Company as the Trustee. Mencap Trust Company is a not-for-profit organisation which provides discretionary trust services to people with disabilities and their families.

"Choosing the right Trustees is very important; look at all your options carefully to ensure those you choose will always act in the best interest of your child."

Philip Warford runs joint workshops with Amaze on legal issues for parent carers. Check out our website events listing for the next one. For individual legal advice call Renaissance Legal on 0845 505 60 50 or visit [www.renaissancelegal.co.uk](http://www.renaissancelegal.co.uk) NB: If you show your Compass Card, you can get a 10% discount on fees at Renaissance Legal.

**"My son Billy started school last September. Seaside View have told us he has global delay. His teacher is lovely and he's getting quite a bit of extra help, but school is really hard for him. My mum says he should have a Statement. His teacher said she'd ask the SENCO. Can you give me some advice?"**

**Ros says:**



"To clear one thing up straight away, Statements are being phased out and replaced by Education, Health and Care (EHC) plans. More about this later. First let's think about Billy's situation. It sounds like some bits of starting school have gone OK. You're happy with his teacher and he's getting support. So it may be a little early to be thinking about an EHC plan.

"Most children with special educational needs go to their local school and get help called 'SEN support'. This can be a mix of special attention from their teacher, different activities or equipment, group work, one to one help from a classroom assistant - a whole variety in fact. The specifics of what they do with Billy should be planned and reviewed by the school with your input.

"Given that you're worried, it makes sense to ask for a meeting with the SENCO to go over this. The help Billy

gets should be based on his needs and the next steps for him in his learning and development (often called outcomes) should be written down. The school can ask others for advice too; an educational psychologist, for example. Call our helpline if you want help to plan what to say and ask at the meeting.

"But what about an EHC plan? These are for children who need help and support that's beyond what a school can do from their normal resources. If Billy is not making progress or flourishing at school despite getting well-planned help, or if he needs a really high level of support all through the school day, that's when an EHC plan may be useful. You or the school can ask the local authority to consider assessing him for one, so talk that over with the SENCO. If you do go for one, you can ask Amaze about support for you during the process from our Independent Support service. Just call the helpline on 01273 772289."

**Email: [charlotte@amazebrighton.org.uk](mailto:charlotte@amazebrighton.org.uk) if you have a question for an expert and we'll share the answer with other parent carers in the next issue.**

## Amaze autumn courses

**Looking After You** is our super stress-busting course that mixes a space to talk, with practical relaxation techniques. The course starting **6<sup>th</sup> October** is for parents of younger children, especially little ones with health needs.

**Planning for the Future** – Wills and Trusts – Thursday **12<sup>th</sup> November** Workshop with Phil Warford of Renaissance Legal.

**Amaze Info Fair** – Friday **27<sup>th</sup> November**  
A date for the diary, more details in next newsletter.

**Insiders Guide** courses offer a mix of useful knowledge with a chance to check out where we are in our journey and get together with parents carers at a similar stage. This autumn we'll have an IG for Parents of Teens and one for Parents of Under 5s.

**Triple P Stepping Stones** – a course all about behaviour and parenting positively for parents of under 12s. No dates as yet, but we'll keep you posted.

Email [info@amazebrighton.org.uk](mailto:info@amazebrighton.org.uk) or call 01273 772289 for more information or to book.

## What do you think of our handbook?

We want know what you think of our handbook, *Through the Maze* – the one for parent carers of children with SEN and disabilities up to 14.



We've created a short online survey about the book which you can access from our home page or at:

<http://tinyurl.com/nsbqvbc>

It only takes 4 minutes to complete and your feedback will really help us to secure funding and plan the content for the next edition. Thanks in advance!



## Do the Compass Challenge walk with us

**Sunday 28<sup>th</sup> June 2015, Preston Park, Brighton**  
**Challenge: 11am – 12.30pm Picnic: 12.30pm**

As we announced on the cover, we're running a brand new event this June, the Compass Challenge sponsored **family walk and picnic** in aid of Amaze. In partnership with Brighton & Hove's Healthwalks (and part of TAKEPART), The Compass Challenge is a circular walk round Preston Park which also includes **four mystery challenges** at the four points of the compass.

It's a **gentle route**; each of the challenges has been designed with children and young people with special educational needs and

disabilities in mind and it's suitable for wheelchair users. Once the walk's over, we'll meet for a picnic – you bring your own food and Amaze will supply soft drinks and entertainment.

We ask that people walk in teams (minimum 2 people, maximum 6) and that all children are accompanied by an adult. It costs **£5 per person** to sign up and then you raise whatever you can for Amaze.

We can't wait to get together with all our families on what promises to be a lovely day. Contact Nicky B for an information pack on 01273 234014 or [nickyb@amazebrighton.org.uk](mailto:nickyb@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](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  
Mon to Thurs, 9.30am to 12 noon, *plus* Tues afternoon 12 to 5pm and Thurs eve 5.30 to 8pm *term-time only*.



### Amaze

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W: [www.amazebrighton.org.uk](http://www.amazebrighton.org.uk)

