

## Ready, Steady, SEND

Amaze Information Fair on **Friday 25<sup>th</sup> November** at the Brighthelm Centre, 9.30am to 1.30pm

This year's Amaze Information Fair is a feast of information **for parents of children aged 0 to 11 with special educational needs or disabilities (SEND)**. If you have a young child and you are just getting to grips with the world of SEND, this is a golden opportunity to find out about services and activities for your child now and in the future. And if you're bit further along the road, you will appreciate the chance to have a face to face chat with useful people and groups.

There will be **30 plus stalls** from a range of services and organisations including Seaside View, the SEN team, the new Educational Psychology and Learning Support Service, short breaks and leisure providers, health information and much more. You'll also find parent support groups, PaCC and Amaze.

### Meets and treats

We make sure you're looked after. There'll be free refreshments and pampering again this year. We also have a special visitor - our new patron, children's author **Julia Donaldson**. You'll be able to buy Julia's books and have them signed by the author herself to help raise funds for Amaze. And if you need to bring your little ones with you, we have a room where you can both take a break from the bustle of the main hall with toys and a fun art activity.

### Workshops and more

We're running two workshops: 'Getting the right SEN support at nursery or school' with Liam from Amaze and the Independent Support team and 'Promoting positive behaviour' with Tracey Williams, from the Educational Psychology service. To be guaranteed a place, you'll need to book first (see below).

### Event timetable

**9.30am-1.30pm:** Drop into the Info Fair anytime to browse the stalls  
**From 10am:** Book signing with Julia Donaldson  
**10am:** 'Getting the right SEN support'  
**11.15am:** 'Promoting positive behaviour'  
**12.30pm:** PaCC Champion awards  
**1.30pm:** Amaze AGM to report on the year's work and to appoint new trustees. Lunch provided but you need to book for this.

### Getting there

The Info Fair is at the Brighthelm Centre, North Road, BN1 1YD. Lots of buses stop nearby at Churchill Square and Brighton Station is five minutes' walk away. And there are lots of car parks nearby. You can just turn up on the day, but if you want to attend a workshop or stay for the AGM you'll need to book. Just call the helpline on 01273 772289 or you can email [info@amazebrighton.org.uk](mailto:info@amazebrighton.org.uk)



### #IAM WHOLE

Young people from Brighton and Hove (including Amaze's intern, Danielle) joined Jordan from Rizzle Kicks to launch an **anti-stigma campaign on mental health** at the i360 on October 5<sup>th</sup>. Sadly it will be no surprise to Amaze parents and young people to hear that research for the campaign found that a third of young people with mental health difficulties say they experience stigma including social exclusion and verbal abuse. The #IAM WHOLE campaign aims to shift the stigma and reject negative language around mental health difficulties. Watch the campaign video and Jordan's song "Whole" on YouTube to add your voice to the campaign.

### Praise for Brighton

The Ofsted and CQC inspection of how Brighton and Hove is getting on with the **SEND reforms** praised the progress so far by the city council, local NHS and partners. They also identified some areas that need more work. The inspectors were keen to hear from parents and young people. Amaze and PaCC took part to help give a full and balanced picture of SEND services in the city, and were pleased to be identified as amongst the city's strengths. Read more about the inspection on page 7.

## Third outstanding Ofsted for Downs View

**Downs View School & Downs View Link College achieved a third 'outstanding' Ofsted judgement following their inspection in May this year.** The school and college were praised for their work across the age range, the extent to which learning is personalised and the exceptional progress all the pupils make. Ofsted also said that the support given to parents, carers and families overall was a strength.

Headteacher, Adrian Carver, says "We are delighted with the results of the inspection. We work very hard to ensure that the diverse and complex needs of our pupils are assessed effectively and appropriate strategies and techniques put in place to maximise every child or young person's abilities. And we are always seeking to develop innovative approaches to ensure all pupils make



outstanding progress." For further information about Downs View, visit [www.downsview.brighton-hove.sch.uk](http://www.downsview.brighton-hove.sch.uk)

## New home for SEND support

The city's reorganisation of Educational Psychology and Learning Support Services has taken shape this term with a new integrated service in a new home.

The city's new Integrated Support Service (watch out for a possible new name as we've heard this is temporary) is based at Brighton & Hove Music & Arts in Carden Primary School.

From now on, Educational Psychology, Community CAMHS and learning support services will be working together from this site. The new integrated learning support service encompasses and replaces the old Autistic Spectrum Condition Support Service, the Sensory Needs Service, Language and Literacy Support Services, PRESENS' offsite team and the Behaviour and Inclusive Learning Team (BILT).

The Integrated Support Service will work with education settings to support access and inclusion. The aim is to build a more unified service for the future for children and young people aged 0- 25 with additional needs. They are in the process of developing a unified 'single point of access' referral system but, until that's ready, referrals should come via the forms and systems that have been used up to now. Your school should know how to do this.

This new service has a new Head, Mohammed Bham. Mo says, "I am proud to be leading the newly formed Integrated Support Service for the city. We have talented, creative and specialist staff providing a prevention and early intervention service to improve the education, learning, and social emotional and mental health of all children and young people with additional needs".

Mo told us about his vision: "I want us all in Brighton and Hove to inherit

the future that we create, based on beliefs about the transforming power of education, the importance of a holistic, caring and respectful view of children and young people, so that families can enjoy productive and satisfying relationships."

**"I want us all in Brighton and Hove to inherit the future that we create."**

Contact details for the new service are: Brighton & Hove Integrated Support Service, c/o Brighton & Hove Music & Arts at Carden Primary School, County Oak Avenue, Brighton BN1 8DJ. Tel: 01273 293481.

### New Head of SEN for the city

Anna Czepil is the new Head of SEN for Brighton & Hove City Council. She's worked in local government for 12 years, for the most part in Children's Services at East Sussex County Council. Most recently she was the SEND Joint Commissioner, working across education, health and care and she led on their Local Offer, working closely with East Sussex Parent and Carers' Council to ensure the voice of the family was heard at a strategic and operational level.

Anna says, "Having lived in Brighton for 15 years it is great to now be working for my local community. It's a big challenge getting the right balance between meeting the needs of the individual child, striving for equity for our children and young people and getting the best value and quality provision within the constraints of a tight public purse. Still, it is the reason I get up in the morning. I love the job because I have a great team around me and we can make all the difference to our children's lives."



## More facts at your fingertips

Did you know that Amaze now has 40 info-packed fact sheets all about the issues that matter to you? And that you can download them all for free on our website?

Some of the fact sheets are about specific conditions like autism, ADHD or Down's syndrome and tell you about the kinds of services that can help locally and where to go for more information. Others deal with issues that parent carers have told us they find particularly hard, such as living without a diagnosis, handling challenging behaviour, getting their child to sleep or preparing for adulthood.

There's another set that offer tips on making sure you get the right services and support for your child. You can get advice on managing meetings, claiming DLA and PIP; short breaks and respite and choosing leisure activities.

We're especially pleased that we've created some brand new fact sheets all about recent changes to SEND services. Our 'SEN support' and 'EHC Plans' fact sheets tell you all about



the ways children with additional needs may be supported in school and how to go about making sure your child is getting the right support.

We created the fact sheets in partnership with West Sussex charity, Reaching Families, which shares many of our aims and values and it was all thanks to the RAISE Challenge Fund which gave us £12k to research, write and produce the fact sheets together with parent carers. Different versions are available for use in both Brighton and Hove and West Sussex.

**Download the 40 fact sheets from our website at**  
[www.amazebrighton.org.uk/resources/publications/fact-sheets](http://www.amazebrighton.org.uk/resources/publications/fact-sheets)

## Amaze awarded PQASSO Mark

We're proud to announce that Amaze has just been awarded the PQASSO Quality Mark (at Level 2) by the National Council for Voluntary Organisations. The PQASSO Quality Mark is a nationally recognised award offering external checking and reassurance about the quality and credibility of small charitable organisations.

Charities are under increasing pressure to demonstrate they offer good value for money and achieve

positive outcomes and results for the people they are trying to help, but also that they have good systems for things like finance, governance and staff development.

"I see on a day to day basis how dedicated the Amaze staff and volunteers are so it's wonderful to have external recognition of the quality of work we do," says Amaze CEO, Rachel Travers.



## Last post for newsletter

We're very sad to say that, unless we get some additional funding, this is the last time you'll be getting a copy of this newsletter by post. Though print costs are reasonable, the cost of printing *and* posting out individual copies to over 1700 families has become too great in this time of reduced budgets.

We'll continue to send **paper copies to special schools**, enough for them to send one home to every family. We'll also send **reference copies to mainstream schools**, libraries, children's centres and nurseries, etc. And of course, you'll be able to get a **digital copy straight to your email inbox** (hopefully a bit sooner than you'd get the printed version).

If we already have your email address, you don't need to do anything - we'll automatically switch your paper copy for a digital version. If you don't remember giving us an email address, or if it has changed recently, then please email: [info@amazebrighton.org.uk](mailto:info@amazebrighton.org.uk) putting 'Newsletter' in the subject line of the email. We'll make sure you're on the mailing list for future issues. The next edition is out in February 2017 so look out for it in your inbox.

And if you know of any business or person who might be able to help with print or postal costs, do get in touch!





The Royal Alex's new SEA LIFE-themed sensory room in collaboration with Merlin Entertainment

## Making hospital easier

Find out what the Alex has been doing to improve our children's experience of hospital

Whether it be a routine blood test or weeks in hospital with an infection, hospital visits can be among the most stressful and challenging times for parents of disabled children. We are lucky to have a children's hospital in the city and the Royal Alexandra Children's Hospital was recently awarded 'outstanding' by the CQC. You may remember in 2012 the Parent Carers' Council produced a 'Talk Health' report in which parents fed back on their experience of health services. The Alex has acted on many of the recommendations in that report, for example by prioritising children with special needs at the hospital and increasing parent participation.

The team at the Alex has been focusing on improving the experience of disabled children with the principle, 'if we get it right for disabled children we get it right for all'. "We genuinely try to offer a patient-centred, holistic service to all our children and families and work with parents to offer individualised

care," says Lorraine Tinker, Directorate Lead Nurse, Children's Services at the Royal Alexandra Children's Hospital.

The hospital has worked to create a welcoming environment and, with Rockinghorse funding, has built a sensory garden and sensory

equipment in one of the assessment rooms in A&E as well as a new SEA LIFE themed sensory room, in collaboration with Merlin Entertainment.

There is also now an on-site paediatric mental health liaison team who can do rapid assessments.

There is also now an on-site paediatric mental health liaison team who can do rapid assessments and facilitate a rapid discharge, where previously children and young people could be waiting days for CAMHS assessments.

The hope is that the whole hospital experience will feel less overwhelming for our children and young people.



Sensory garden funded by Rockinghorse.

### What is the Alex doing to make stays or visits easier?

- The hospital can create Makaton timelines to support children and young people's understanding of their day in hospital and help them make choices
- You can use your Blue Badge to go in the 'exit' therefore having a priority in the car park queue
- You can book a signer for any appointment and arrange one as soon as possible for an unplanned admission
- There is a new 20 minute bay outside the car park to allow drop off and unloading of equipment
- Parents can contact the play specialists before a planned visit, and can visit and explore the department and equipment beforehand
- The hospital is currently trialling Safespace beds and the Mahlstrom extending cotbed. If your child requires close supervision to stay safe at night, the hospital will support you with this
- The hospital offers a team of musicians, massage and reiki therapists, who are sensitive to the needs of your disabled child

# Unfair DLA hospital rules scrapped

Following a successful campaign by parents and disabilities rights organisations and a landmark judgement by the Supreme Court in 2015, the government has recently scrapped the rules that stopped payment of DLA or PIP for children who have long stays in hospital.

Previously, once a child had been in hospital for 84 days (or 28 days if aged 16 to 18) their DLA payments were suspended. What's more, where a first claim for DLA was made for child in hospital, payments would not start until the child was discharged home. Similar rules applied to PIP.

The thinking was that when your child is in hospital, the NHS is responsible and paying for their care. So if a child was getting DLA as well, the same care would be paid for twice over. The reality, of course, is that most of us have found ourselves actively involved in our child's treatment and spending at least as much, if not more, time caring for a child who is in hospital rather than at home. Taking time off work, travelling back and forth and 'living' in a hospital creates financial hardship. Following a campaign led by the Mathieson family and disability rights campaigners, the Supreme Court found the DWP policy of suspending welfare payments was a breach of human rights.

## What are the new rules?

Now, as long as your child is under 18 when they go into hospital, they will continue to be paid DLA or PIP, no matter how long their stay. You can make a first claim for DLA or PIP when your child is in hospital and, as long as your child has had eligible needs for at least 3 months, payments will now start immediately. This is important for babies with complex needs.

**Now, as long as your child is under 18 when they go into hospital, they will continue to be paid DLA or PIP no matter how long their stay.**

When a young person getting DLA turns 16, they are normally invited to claim PIP. But if they are in hospital at that time, their DLA award should be extended and payments should continue: they will not be invited to claim PIP until they have returned home.

Young people who turn 18 whilst in hospital will also continue to be paid DLA or PIP: they continue to be exempt from the 'adult' hospital inpatient rules so long as they were under 18 when their stay in hospital began.



The Mathieson family, pictured after their Supreme Court victory, were supported in their campaign by Contact a Family and The Children's Trust.

Hospital rules about payments remain unchanged for everyone aged 18 or over. This means that if your son or daughter is 18 or over when they go into hospital, their DLA or PIP payments will be suspended once they have spent 28 days in hospital and re-instated once they are back home. Anyone making a first claim for PIP will need to wait until they are discharged home before payments can start.

## What about other benefits in hospital?

**Child tax credits** are not affected, in the same way that they continue to be paid if a child is away at residential school. However, as Universal Credit is rolled out, new rules will mean that payments for a dependent child stop if they are away from home for six months or more and this includes hospital stays.

**Child benefit** is paid for the first 12 weeks. After 12 weeks, you can continue to get child benefit if you are regularly spending money on your child's behalf, for example on clothing, pocket money, internet and TV access. As long as you get child benefit, you will continue to get any child dependant's addition that may still be payable with other benefits.

**Carer's Allowance** for a child under 18, should not be affected as long as you continue to provide at least 35 hours of care a week. Even if it isn't always possible to do this, you may still be able to claim Carer's Allowance for up to 12 weeks, so it's worth checking this out.

# Ask an expert

Ros Cook, Services Director for Amaze, and Philip Warford of Renaissance Legal answer your questions

**"Everyone says you should notice your child being good and not pick up on their bad behaviour all the time, but I think that's really hard to do. Can you give me any advice about how to do it?"**

**Ros says:**

"Yes it's easy to say, but harder to do. After all there are some bits of behaviour you can't let go. But it is sound advice.



Most children are interested in getting and keeping our attention. If we want to see more good behaviour, we need to make sure this gets just as much attention as the stuff we don't like. And you need to make a

deliberate effort for this to happen because it's easy as busy parents to let them get on with it when they're no trouble!

So step one is to spot when they do the right thing and let them know you have noticed. Use descriptive praise where you tell them what it is they are doing right. Instead of saying "well done" or "good girl", spell it out. Try saying "you're playing all by yourself – that's great" or "thank you for clearing your plate off the table".

If their behaviour is a bit tricky at the moment you may have to be alert to catch them whilst they're still being good. You might say "well done – you are trying to pull your socks on"

before they get frustrated and cross. Or spot when they might have behaved less well, but managed not to: "you stayed really calm when your sister took the biscuit. That was brilliant."

For some children you need to keep the words even simpler for them to understand. Add signs and use short phrases but still describe what they're doing right, like "good sitting". In some situations praise out loud would be embarrassing so show approval with a thumbs up, wink or high five. If your child is not very motivated by praise and attention alone, back it up with a quick and simple reward to make sure they get the message.

Challenge yourself. Keep an eye on how often you say "no", "don't", "stop" and see if you can give at least as many bits of praise. You could be surprised by how much impact this has.

**"I need to set up a Trust for my daughter who has a learning disability, I've heard about a Discretionary Trust and a Disabled Person's Trust but which one do I need?"**

**Philip says:**

"A Trust is the best way of financially providing for a disabled or vulnerable person throughout their lifetime. The two most common types of Trusts used to provide for a disabled or vulnerable person are Discretionary Trusts and Disabled Person's Trusts (DPT).



"A Discretionary Trust involves the Trustees having full discretion to use the assets to meet the needs of any beneficiaries at any time. With this type of Trust there must be more than one beneficiary. None of the beneficiaries have any fixed entitlement to receive any assets from the Trust. This means that the Trust cannot be taken into account when assessing

entitlement to means-tested benefits or Local Authority funding. Although a Discretionary Trust is very useful, the tax treatment is not favourable and needs to be considered.

"A DPT is a Trust set up specifically to benefit a 'disabled person' and is largely similar to a Discretionary Trust. As with the Discretionary Trust, the Trustees have full discretion on how to administer the Trust.

"The main advantage of a DPT over a Discretionary Trust is the favourable tax treatment it receives for Inheritance Tax, Income Tax and Capital Gains Tax.

"Which type of Trust is more appropriate depends entirely on yours and your daughter's circumstances, for example: your daughter's age; the nature and the long-term prognosis of

her disability; any benefits and funding received; the needs of other family members and the value of your assets. What you first need to determine is if your daughter meets the criteria for a DPT.

"A Discretionary Trust is usually more suitable where the tax implications are limited. A DPT is used when tax is likely to be a significant problem and there is not a great need to provide for others. By carefully considering all of the factors, you will be able to put in place the right type of Trust which can provide the long term financial support for your daughter."

For individual legal advice call Renaissance Legal on 0845 505 60 50 or visit [www.renaissancelegal.co.uk](http://www.renaissancelegal.co.uk) NB: Compass Card holders get a 10% discount on fees.

**Come along to Philip's free Wills and Trusts workshop on Tues 29<sup>th</sup> November, 10am to 12 noon at Community Base or visit Renaissance Legal's stand at the Amaze Info Fair on Friday 25<sup>th</sup> November (see front cover).**





## Have your say on social care

Find out how PaCC is working to make social care a top priority in SEND planning and how you can share your views with the people who plan services.

As parent carers we know how vital it is to get a break from caring so that we can cope with the extra demands of bringing up a child with special educational needs or disabilities.

PaCC always stresses the importance of social care when writing our position statement on Brighton and Hove's budget. Our Steering Group has been explaining to senior managers that the reality of short breaks for many families falls far short of the guidance given by the Care Act and the Council for Disabled Children. The guidance says, for example, that short breaks ought to mean access to the community for children and young people, as well as equitable access to work for parents and carers.

We are pleased to see that the local authority remains committed to making social care a key priority of the ongoing SEND Review and that managers are looking at what a 'core

offer' for families might mean in terms of short breaks or direct payments. They are also committed to updating any relevant information on the Local Offer, the council's online listing of what's available locally for children and young people with SEND and their families.

With the proposed changes to special schools and creation of integrated hubs, there is the potential for different ways of offering social care support, for example through extended school days. PaCC is keen that parents are involved in co-producing any such developments so that they are not only cost-effective, but work really well for families.

As part of our ongoing discussions with the council, we'll be holding a PaCCConnect on Social Care on 16<sup>th</sup> November (see below). Come along to share your views on current services and possible developments in social care.

## Ofsted response

The Ofsted/CQC report which was published on 14<sup>th</sup> July gave an overall thumbs up to its snapshot view of how Brighton and Hove manages its SEND services. Ofsted and CQC inspectors produced the joint report after visiting the city council, CCG and some of the city's schools and children's centres. Parent reps from PaCC were involved with some of the discussions, as were some children and young people with SEND and their parent carers. The subsequent report highlighted several strengths including the support that families receive from Amaze and PaCC.

**Although the positive feedback is welcome, the report does not fully reflect the experiences of all families in the city.**

In the short time that PaCC had with Ofsted, we worked to show that there are still many areas in need of development and attention. PaCC is keen to emphasise that although the positive feedback is welcome, the report does not fully reflect the experiences of all families in the city.

Since the inspection, PaCC has fed back to senior managers that the broader view of parent carers obtained at SEND review consultations, SEND Partnership Board meetings and PaCCConnects, must be taken into account.

We'll continue to work with senior officers of the council and the CCG to ensure that the parent carers' voice is heard. Read the full report at [www.amazebrighton.org.uk/amaze\\_news/ofsted-cqcs-inspection-report/](http://www.amazebrighton.org.uk/amaze_news/ofsted-cqcs-inspection-report/)

## PaCCConnect on Social Care

**Wednesday 16<sup>th</sup> November**

**9.30am (for tea and coffee), 10am start to 12 noon**

5th Floor Conference Room, Community Base, 113 Queens Road, Brighton BN1 3XG

Come along and give us your views on social care issues for families of children and young people with SEND. We want to hear about your experiences and any ideas you may have about how Brighton and Hove can develop better social care for the SEND community. And if you can't make the meeting, then email us your views.

If you would like to attend, please email: [admin@paccbrighton.org.uk](mailto:admin@paccbrighton.org.uk) or call 01273 234862.





## A Knock-out day out

On 9th August a group of parent carers and their children from the Moulsecoomb Sunflower Support Group and Whitehawk coffee morning travelled on a Big Lemon coach to Knockhatch Adventure Park near

Eastbourne. There were 53 of us on the trip and we were lucky to have some glorious weather and a huge amount of fun. The trip was made possible thanks to funding from East Brighton Trust, amongst others.

If you didn't already know, we run monthly coffee mornings in Moulsecoomb, Whitehawk and Hangleton & Knoll where parent carers can get together, support each other, feel less isolated and find out what services are available in Brighton and Hove. Here are details:

- **Whitehawk Group** - last Thursday of the month, 9.30 to 11.30am at Whitehawk Inn, Whitehawk Road
- **Moulsecoomb Sunflower Group** - second Tuesday of the month, 9.30 to 11.30 at Moulsecoomb Primary School
- **Hangleton & Knoll Group** - last Tuesday of the month from 9.30 to 11.30am at St Richard's Church, Egmont Road, Hove

If you would like to come along you can just turn up, or to find out more call 01273 234862 or email [paolo@paccbrighton.org.uk](mailto:paolo@paccbrighton.org.uk).

## PaCC and the Alex join forces

As part of ongoing work to improve the hospital experiences of children and young people with SEND, PaCC has been working with the Alex on what happens when a child or young person is ready to leave hospital after an in-patient stay. Sometimes the discharge process is relatively straightforward, with no change to current medication or community-based follow-up. At other times, there is a lot to be discussed and extensive follow-up may be needed.

Historically, the approach to discharge has been broadly similar, but we are hoping to introduce some changes so that **straightforward discharges can be processed more swiftly**, whereas more complex discharges will be flagged up, to ensure that necessary clinical

information and support is provided.

**More time to discuss worries** means children and parents can leave feeling more confident and knowing exactly what follow up action will be taking place. We also hope to **reduce waiting time for take home meds**. We hope to pilot these changes in the coming months, so please do feedback your experiences to ward staff or to PaCC ([admin@paccbrighton.org.uk](mailto:admin@paccbrighton.org.uk) "Alex Hospital Discharge Feedback")

PaCC is also working with the Perioperative Care team, to find simple ways to help children and young people (and parent carers) to be less anxious about having procedures involving anaesthetics or sedation. For example, we hope to introduce an album of images of the ward, operating room, staff and



equipment. Parents will be able to photograph these during their 'pre-op appointment' so they can show them to their children and better prepare them for the operation. Previous feedback from families is the basis for the ideas being explored, especially if it's the first time parents or children have had to deal with a procedure that involves going into an operating room. We're also aiming to have an open day where families can come to the Alex and learn more about the experience of having an operation there. It'll be in February, so watch this space!





## Transport still a sticking point

The start of this school year was once again difficult for many families due to delays in getting information about home to school transport, despite PaCC having raised this as a big issue over the last few years.

PaCC has identified that one cause of late information is communication between the SEN Team and the Home to School Transport team at the council. We also think the annual application process is time-consuming for both families and the local authority and unnecessary for many children. The local authority also highlights the failure to return child information forms as a cause of delay. They have written to parents to say that their child's transport will be suspended if they do not return the form within two weeks.

PaCC has constructive ideas about improving the timescales and has started to work with the local authority to streamline the process.

PaCC is concerned that the new home to school transport policy for children aged 5-16 is not working well. There have been 32 appeals during the last 18 months, most of which were successful, which suggests that many families have been refused transport in error.

PaCC asked the Transport team whether this has led to any changes in the process this year. Richard Barker, Head of Home to School Transport, commented that "the council are carefully reflecting on the year of implementation, reviewing the policies and considering what else is required to address the budget pressures of the service in the context of the wider pressures on local authority funding."

PaCC is concerned that transport may have been withdrawn during appeals, despite senior officers having previously agreed that it

would continue until the appeal is finished.

On a positive note, some families report that independent travel training has been successful for their young people. However, there is no funding allocated for training this year and help in this area will be considered on a case-by-case basis.

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Transport is no longer provided for pre-school under the new policy. PaCC has raised concerns over access to ICAN and PRESENS facilities; these providers have told us some families have struggled to take up a place due to lack of transport. The local authority has said accessibility of pre-school provision is being considered. Further changes are also afoot for post-16 transport, including introducing a charge from September 2017. Other local authorities have already brought in charging for post-16 transport. PaCC is very clear that these measures for both pre-school and post-16 raise major equalities issues, which must be addressed by the local authority.

### Oliver

Oliver has Sturge Weber Syndrome which is a rare neurological condition. He has associated epilepsy, glaucoma in both eyes, delayed development, right sided hemiplegia and an extensive port wine stain birthmark.

This is Oliver with his best buddy Pooh Bear at Coram's Fields before a procedure at Great Ormond Street Hospital. Pooh Bear goes everywhere with Oliver including numerous hospital visits, but has to have his eyes covered on the swings as he gets scared!



## PaCC Calendar 2017

Our 'Best Friends'-themed 2016 PaCC Calendar was a great success. It was full of fabulous pictures and stories about our PaCC members' children and their friends and this year's theme promises to be just as great.

The 2017 PaCC Calendar will be all about **Activities and Hobbies**. What does your child love doing? How do they have fun? What do they find really interesting?

We are looking for pictures and stories about your children's favourite pastime, whether it's horse-riding, drawing, dancing, trampolining, trainspotting, Lego, Minecraft or anything else!

**What does your child love doing? How do they have fun?**

You should email pictures and a brief paragraph about your child's hobby to [admin@paccbrighton.org.uk](mailto:admin@paccbrighton.org.uk) and your child could be featured in our next year's calendar!

Entries will be used on a first come first served basis. **Closing date is Friday 4<sup>th</sup> November.**

**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)**



## Local groups good for your mental health

In May, a group of parent carers took part in an Amaze and PaCC consultation on how local community and voluntary organisations help parent carers' mental health and wellbeing.



The survey shone a light on the invaluable support of local groups and organisations such as Brighton Pebbles, Extratime, Barnardos Link Plus, Face to Face, T21 and mASCot. The kinds of things they do to support wellbeing is wonderfully varied: from family outings, short breaks, home support and befriending services, to monthly lunches, gardening and even exercise boot camps.

A parent carer from Brighton Pebbles summarised what the group does for her mental health: "Just being part of a supportive group and going out in a group to day trips and activities is incredibly helpful as you aren't alone when your child kicks off and everyone helps each other. It helps to build up confidence and self-esteem and helps with the 'can do' attitude". The survey also highlighted the positive impact on wellbeing of having discounted leisure activities via the Compass Card and getting one to one support with DLA applications from Amaze.

The consultation asked parent carers to say how they thought professionals might be made more aware of just what was out there for families of kids with SEND. They suggested that professionals should

keep leaflets about the kinds of organisations that can help to hand out to parents; that the Local Offer should be comprehensive and up to date; and that we needed to see a more 'joined-up' approach between adult and child mental health services.

We also asked people to identify any gaps in mental health provision and whether they might be met by community and voluntary organisations. They told us that siblings really needed more support and that parent carers needed more short breaks from caring to help them keep going. More free counselling and assistance with childcare to attend counselling sessions was also considered a priority - as was a more continuous, ongoing approach to mental health - time limited blocks of sessions weren't always helpful.

Respondents said that community and voluntary sector organisations were well placed to offer more support with mental health, but that they would need ongoing, secure statutory funding to enable them to do this.

We've passed on the recommendations and suggestions from the consultation to the local Clinical Commissioning Group (CCG). We hope they will contribute to a better provision of wellbeing services in Brighton & Hove and make professionals more aware of what's available in the city. Read the full report at [www.paccbrighton.org.uk/resources/reports](http://www.paccbrighton.org.uk/resources/reports)



## Free drinks, pizza and other dads

Sometimes the best therapy is to meet up with other parents who have kids with SEND and have a chat. Dads don't always get the chance to do this. That's why a group was set up to give dads with SEND kids a place to relax and meet other dads going through the same things.

The group started in January 2014 with just four dads, and its numbers have steadily risen since. The meetings are on the last Thursday of each month from 7.30 to 9.30pm at The Function Room, Stoneham Pub, Portland Road, Hove. Email Reza at [drmra@hotmail.com](mailto:drmra@hotmail.com) for more details.

## Nominate your heroes!

Every year we ask our PaCC members to nominate professionals who have gone the extra mile to help children with SEND. If you'd like to tell us about a team or a person from the Education, Health, Voluntary or Social Care sector who has given exceptional support to you or your child, you can nominate online at: [www.tinyurl.com/paccchampions2016](http://www.tinyurl.com/paccchampions2016). Or email [admin@paccbrighton.org.uk](mailto:admin@paccbrighton.org.uk) to ask for a nomination form. **The closing date for voting is 30<sup>th</sup> October.** The awards ceremony will take place at Amaze's Info Fair on 25<sup>th</sup> November.







# Make the most of childcare funding

We know that it's sometimes much harder for parent carers to get the right care to enable them to return to work, but when you do, make sure you don't miss out on all the financial help you are entitled to.

## Free childcare for two year olds with SEND

Two year olds with SEND are entitled to up to 15 hours a week of free childcare, or 570 hours spread across the year. Your child will be eligible if they have an Education, Health and Care (EHC) plan or Statement of SEN, and/or if they get Disability Living Allowance. Once your child is eligible, they stay eligible, even if your circumstances change.

Your child will be entitled to the free childcare from the term after their second birthday. You can check if your child is eligible for a place from the beginning of the term when your child turns two. To apply, go to [www.brighton-hove.gov.uk/twos](http://www.brighton-hove.gov.uk/twos) and complete the 'two year old application form'. You'll also need to send evidence to accompany your claim to the Family Information Service (FIS). Details of how to do this are on the page.

## Childcare Inclusion Funding

Childcare inclusion funding is available to support disabled children or those with special educational needs to attend Ofsted registered childcare and childcare run by schools. The fund is intended to provide for changes to the childcare provision which will make it possible for the child to access the service. This might mean changes to the building, specialist equipment, training or an additional member of staff.

There are maximum amounts payable for inclusion funding, and the amounts are different depending on whether or not you are working. Applications must be made jointly by the childcare provider and parent or carer. You can make an application any time in the year.

## 30 hours in 2017?

The government has announced that it will be doubling free childcare for families of three and four year olds from September 2017 to 30 hours. Not everyone is eligible, however - the extra 15 hours will only be available to households where both parents are working (or one parent is working in lone parent families) and earning the equivalent of at least 16 hours per week at the National Minimum Wage. There are exceptions for families with a child who gets DLA.

In two-parent families, it will be available where one parent is employed and the other has caring responsibilities for which they receive Carers Allowance, or where one parent is employed and the other is disabled or incapacitated. Parents on zero hours contracts and those who are self-employed are also eligible.

Amaze has taken part in a recent government consultation on this extended childcare entitlement, stressing that without a commitment to additional funding, such as an extension of the Childcare Inclusion Grant, many parent carers may not feel confident that their child will get the necessary support to take up the additional hours.

From spring 2017, you can check whether your child is eligible via a government website. You will need to reconfirm your eligibility for the extra hours every three months. There is a grace period if your circumstances change so your child will not lose their additional hours immediately.

Ofsted-registered nurseries, childminders, etc., can choose to offer the extended entitlement as it rolls out, but it remains to be seen how many will feel able to increase the number of places they offer.

To find out more about current or new childcare entitlements contact FIS on 01273 293545 or email [familyinfo@brighton-hove.gov.uk](mailto:familyinfo@brighton-hove.gov.uk)



## My summer with NCS

Our young person's intern, Danielle, tells us all about her summer doing National Citizen Service.

This summer I did NCS, a four-week programme for young people that offers a once in a lifetime opportunity to make friends, experience new challenges and make your mark on the community.

We had three sessions before the programme to prepare and get to know each other: a trip to try out bouldering; a meeting at Brighton Racecourse so our parents and carers could find out what we'd be doing; and a session at BACA where we got put into the teams we'd be with for the rest of the summer. We played some games to help us learn each other's names and then sat down together to write a group agreement of what people couldn't do while we were away.

In August, we went to Shropshire for our week long residential holiday. We had to meet at the Amex stadium at 7am. I felt excited but really nervous at the same time as I didn't really know anyone there.

We were staying in a big, old mansion and I shared a room with

seven other girls. As soon as we'd settled, we had to get into our groups and do team building exercises. My group was the smallest but I think this meant we had a closer bond.

My favourite activities in Shropshire were the zip wire and shelter building. The zip wire had a rope ladder, which was a real struggle to get up with my physical difficulties, but I made it!

My least favourites were abseiling and the blind trail. We were meant to be blindfolded and follow an obstacle course, but I felt really uncomfortable with this because of my visual impairment, so I opted out. It was fine

to do this. I opted out of abseiling too but I did try that first.

After a brief weekend at home to wash our stuff, it was time for the second week away at Sussex University. We stayed in the halls of residence where I had my own room. Each morning we had to make our own lunch to take to all day sessions with our team at BACA. All the activities were about presentation skills and starting to come up with ideas for your project. My favourite thing about this week was going to an Albion football match. I wasn't so keen on the walk between the University and BACA each day though.

The third week was spent at Brighton Youth Centre planning our final project. We chose Stopover, a charity for young women who are homeless or at risk of homelessness and need a safe place to live. We went to visit them and they told us they needed their overgrown garden tidying up so for the rest of that week we worked on a presentation about the project that we showed staff at the Amex at the end of the week. We also had to get donated flowers and gravel for the garden.

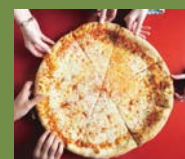
The final week was about putting everything together and working as a team to get it done. This was a very big task as the garden was a huge mess but by the end it had been transformed and we celebrated by going to McDonald's to have lunch for the last time.

**To find out more about NCS, visit [www.ncsyes.co.uk](http://www.ncsyes.co.uk)**

### New group for young people at Amaze!

Amaze is setting up a new young people's group to help us develop our work. It'll be a chance to get together, make new friends and tell us how we can make Amaze work well for you.

The first 'getting to know each other' session will be on **Weds 23<sup>rd</sup> November from 4-7pm at Amaze**, Community Base, 113 Queen's Road, Brighton. We'll play some games and share some pizzas. Any young person aged 16 to 25 who would like to be part of this group should email [sue@amazebrighton.org.uk](mailto:sue@amazebrighton.org.uk) or call Sue on 07483 111648.







Light and Shade, one of Will's illustrations for Croome Park

## William's winning illustrations

Congratulations to William Hanekom – a local young artist who has won a National Trust Commission to create a series of 12 illustrations inspired by sensory 'moments' experienced at Croome Park in Worcester.

Will, who attends monthly Mymarc art workshops run by Amaze's Sue Winter, heard about the commission through Outside In, a project based at the Pallant House Gallery in Chichester. Children with disabilities from four schools helped choose the winner and Will's drawings will be used to illustrate three maps which, together with a new sensory trail, will help everyone to get more engaged with the landscape at Croome Park. Find out more at [www.nationaltrust.org.uk/croome](http://www.nationaltrust.org.uk/croome)

## Brandon got the job!

Remember in our last issue we told you about Brandon who was doing an internship at Brighton Register Office? Well, we're delighted to report that Brandon has been offered a part-time job there. Well done Brandon!

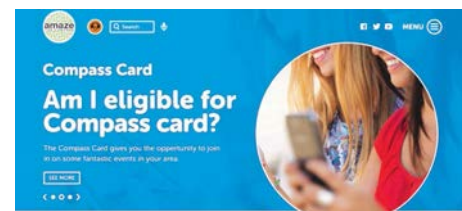


# New Compass website goes online soon!

We're about to launch a brand new website for the Compass! The new website has a completely different look and feel and there's a searchable list of all our Compass Card offers in Brighton and Hove, West Sussex and further afield. And that's just the start – there's also a leisure blog, a speak to search function which means you can use your voice to search for stuff (a bit like Siri on the iPhone or OK Google on Android smartphones), information about the Compass database and how to apply for a card and lots more.

You can find the new website here – [www.compasscard.org.uk](http://www.compasscard.org.uk) from 15<sup>th</sup> November and we'd love to know what you think. There's a feedback form on the site if you want to tell us your first impressions, or you can email us at [compass@amazebrighton.org.uk](mailto:compass@amazebrighton.org.uk)

Big thanks to the young people from Amaze's Young People's Advisory



### Latest Offers & News



Group, young people at M8s in Worthing and parent carers in Brighton and Hove and West Sussex for their help in telling us what they wanted from the new website. We're also grateful to two local companies for their help: our website developer, Madison Solutions in Portslade and our app company in Brighton, Dabapps.

If you're a regular visitor to the Amaze website, you can find the new site easily by just clicking on the Compass link on the home page.

## Latest offers!

We've added dozens of offers to Compass Card Brighton and Hove in the last six months and there are now well over a hundred deals. You can now take advantage of offers in Surrey, Hampshire, East Sussex, West Sussex and beyond.

Our most recent addition to Compass Card Brighton and Hove is **Brighton & Hove Bus and Coach Company**. The company now gives young people over 18 who aren't

studying and who don't qualify for a Disabled Person's Bus Pass, discounts of around a third on bus travel around the city.

The discount is also available to Carers' Card holders in Brighton and Hove. So if you haven't applied for a Carers' Card yet, now's the time. If your child is a Compass Card holder, you automatically qualify. Just call 01273 295153 with your card to hand.



## Compass West Sussex gets national attention

The Compass Card and database in Brighton and Hove have regularly been recognised as a national model of best practice, but the new project in West Sussex is also attracting national attention. In July, the Department of Education produced a policy paper, 'Putting children first: delivering our vision for excellent children's social care' and Compass West Sussex was included as a Case Study. Not bad for a project that launched just a few months ago!



## Oar-inspiring stuff

Amaze was delighted to be chosen as one of the beneficiary charities for this year's **Paddle Round the Pier**, the free beach and watersports festival that took place on the first weekend of July at Hove Lawns.

It was touch and go with the weather, but the fleet of creative sailing contraptions took to the sea with gusto anyway. Amongst them was the Avtrade Team (pictured below) who battled the waves in the famous paddle races and raised over £650 for Amaze. Thanks Avtrade!



Avtrade raised over £650 for Amaze.



The Mayor visits Amaze's stall.

And thanks to students from Robert Woodard Academy who helped with fundraising ideas for the event.

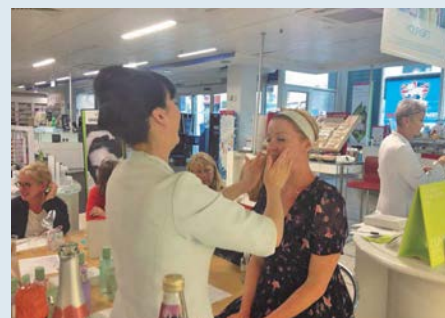
Amaze had a tent and stall to raise awareness of our work and we drew in lots of local children with a 'hook a duck' game. We even had a visit from The Mayor, councillor Pete West. It was great to see lots of you there too.

Thank you to David Samuel and the Paddle Round the Pier team who work so hard. They raised a whopping **£7,000 for Amaze** – a truly 'oar'-inspiring amount.

## Superstar funders

It was a very busy summer in terms of fundraising. Here's a few highlights.

On 9<sup>th</sup> June, we held our annual **Clinique Pampers night** at Boots Brighton. 30 women came along and proved they were beautiful inside and out by raising £400.



On 14<sup>th</sup> June, Clare Smith and the Ladies of The Dyke Golf Club raised £1,500 at their **royal themed Captains' Day** to help celebrate the Queen's birthday.



On 2<sup>nd</sup> and 3<sup>rd</sup> July and 27<sup>th</sup> August Local hero Simone Gibson completed her **South Coast Action Challenge**,

walking 54km on the South Downs Way over 10 hours. Well done Simone and thanks so much for raising over £250 for Amaze.



## Can you support Amaze and our work with families?

Right now we're especially looking for local companies to partner with and for runners for Brighton 10K, Half Marathon and Marathon. Call Nicky B on 01273 234014 or email: [nickyb@amazebrighton.org.uk](mailto:nickyb@amazebrighton.org.uk)





## Could it be you?

Amaze is looking for volunteers for our **Information, Advice and Support Service**. Find out what kinds of volunteers we need and whether it's right for you.

Volunteers are a key part of the Amaze team and help us give the best service we can to families. We're currently looking for new people interested in being Information, Advice and Support (IAS) volunteers. It is really interesting and challenging work. We only run IAS Volunteer training once a year, so act now if you're interested - the training starts soon.

### What?

**IAS Helpline Volunteers** support Amaze's busy helpline, working alongside the helpline advisor. They pick up voicemail and email messages, make sure they are recorded and reach the right person. They can respond to simple enquiries too. It's a good role for someone who can commit to a fixed slot each week and is happy with phones and computers as well as people.

**IAS Individual Support Volunteers** have a varied role giving information, advice and support one to one with parents (sometimes alongside their child/young person) as they try to

sort out services and support. This could mean helping them prepare for a key meeting or even going along with them. It might be quick and simple but often you build a longer relationship. This is a role that needs a bit of flexibility about when you are available.

### Who?

Our volunteers come from all walks of life, but parents carers are especially welcome. The essential thing for both

roles is to be a good listener who can get alongside people. You'd ideally be quick to pick up information and able to get things down in writing clearly. The Individual Support Volunteers would be the kind of people who enjoy helping someone work out what they think and support them to get that over to others.

### How?

If you're interested, but you're not sure you know enough, don't hold back because we will provide training and support. In practical terms, you need to be available during the school day as that's when most people want our help, and able to commit fairly long term after your training.

### When?

All IAS Volunteers do the same initial training course. The **next course** runs on Monday mornings on **7<sup>th</sup>, 14<sup>th</sup>, 21<sup>st</sup> November and 5<sup>th</sup> December**. You can choose between the helpline and individual support roles later. Email [gillian@amazebrighton.org.uk](mailto:gillian@amazebrighton.org.uk) now if you want to find out more.

Amaze uses volunteers in a variety of ways. If IAS volunteering is not for you, but you want to know about other ways you could help and support our work have a look on our website [www.amazebrighton.org.uk/get-involved/volunteer](http://www.amazebrighton.org.uk/get-involved/volunteer)

### Cherie's story

"I absolutely love it!", says Cherie, who has been an IAS Helpline Volunteer for Amaze for the last 18 months.

"My daughter has moderate learning difficulties and Amaze has been helping us for many years. When I read about volunteering in one of these newsletters, I jumped at the chance to give something back.

"Not only have I met some lovely work colleagues and lifelong friends, but I've also found out loads of things that will help my daughter well into her adult years. Volunteering at Amaze also given me the confidence to start at university next year to explore a career in social work."



Cherie in action on the Helpline.

## Coming soon

We're running a number of different courses, workshops and groups over this term and next.

### This term:

#### Insiders' Guide for parents of children with ADHD - Thurs 3<sup>rd</sup> Nov

at Hangleton Community Centre. Contact us now for last minute spaces. Run over six mornings, this course is designed to help with the practical and emotional challenges of parenting a child with ADHD.

#### Wills and Trusts – Planning for the Future - Tues 29<sup>th</sup> Nov, 10am to 12 noon at Community Base.

A friendly workshop run by Phil Warford from Renaissance Legal that explains how best to write a will or set up a trust for your child.

#### Info Fair workshops - Fri 25<sup>th</sup> Nov.

We're running two free workshops at the Amaze Info Fair. See front page for more details.

### Next term:

**Kids Like Us siblings group** for brothers and sisters of children with SEND. Time out to think and have fun with other children who share that experience. For 8 -13 year olds. Call now to register your interest.

**Insiders Guide for Parents of Teens** will be running early in the new year. Call now to get on the waiting list for this popular course.

#### Mental Capacity/Power of Attorney/ Court of Protection

Another useful session with Phil Warford finding out how and when as parents we can act on behalf of someone who may not be able to make decisions for themselves.

Call the Helpline on 01273 772289 or email [info@amazebrighton.org.uk](mailto:info@amazebrighton.org.uk) to book or to find out more about any of these events.

## Perfect poems for parent carers

Our Patron, Henry Normal, has just released a new collection of poetry, *Staring Directly at the Eclipse*, which features poems from his acclaimed BBC Radio 4 program, A Normal Family, together with new and selected poetry from his performance work. The collection covers big subjects like "death, loneliness, loss, human frailty and other classic conversation stoppers", all in Henry's trademark humour.

### For Amaze families, the poems about autism are particularly moving...

Although best known as a writer and producer of award-winning films and TV shows such as *The Royle Family*, *Gavin and Stacey*, *Alan Partridge* and *Philomena*, poetry is Henry's first love

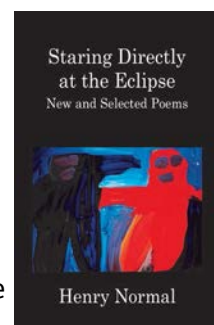
and this is his first collection for over 20 years.

For Amaze families, the poems about autism are particularly moving and inspiring. Some of you may already have heard them first hand at his popular poetry nights in aid of our charity.

We'd like to congratulate Henry on the release of his new book which you can order from Amazon at

[www.amazon.co.uk/Staring-Directly-Eclipse-Henry-Normal/dp/1910170402](http://www.amazon.co.uk/Staring-Directly-Eclipse-Henry-Normal/dp/1910170402)

If you'd like to see a bit of Henry's poetry night for Amaze, Photos with My Son, visit [www.youtube.com/watch?v=zvhuzbIm5GM](http://www.youtube.com/watch?v=zvhuzbIm5GM)



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

