

# out of amaze



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

## SEND changes start to take shape

Last November, the joint meeting of the Health and Wellbeing Board and the Children, Young People and Skills committee gave the go ahead for Brighton & Hove City Council to start consulting on proposed changes to the city's specialist nurseries, special schools and pupil referral units. The consultation opened on 5<sup>th</sup> February and will consider plans to:

- **Provide integrated health, care and education on site** in special schools and pupil referral units for children with the most complex SEND, including social, emotional and mental health problems
- **Create an inclusive nursery** where young children with complex SEND can learn alongside other children and **re-locating the Jeanne Saunders/Easthill Park nurseries** there
- **Amalgamate Hillside and Downs Park** into one school for the full range of learning difficulties for the west of the city
- **Expand Downs View** to create one school for the full range of learning difficulties for the east of the city
- **Reorganise Cedar Centre, Patcham House and Homewood College** as the city's integrated provision (based on Cedar Centre site) for children with social, emotional and mental health needs
- **Merge Brighton and Hove's Pupil Referral Unit (PRU) and the Connected Hub** to form a single PRU on fewer sites

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Nicki and her sons meet the cast of 'The Gruffalo' at the Vaudeville Theatre. Photo by Adam Bennett.

## Gruffalo gala just grrreat

The curtain went up early this year on Amaze's fundraising programme. Thanks to our new patron, best selling children's author Julia Donaldson, we were lucky enough to be a joint beneficiary (together with Childline) of a very special Gala Performance of 'The Gruffalo' on 2<sup>nd</sup> January at the Vaudeville Theatre in London's West End. The gala raised over £4000 for Amaze - a very auspicious start to 2016 we think you'll agree.

The stage adaptation brought the book's much loved animal characters vividly to life with songs, laughs and scary fun for the children and their grown-ups. And one lucky Amaze

parent, Nicki Morgan, won family tickets to the show via a Facebook competition we ran just before Christmas. Nicky and her sons got to see the show and meet Julia and the cast afterwards.

"We're big fans of Julia Donaldson and have lots of her books. The show was excellent and kept Joe and Finley's attention which is no mean feat! The highlight for us though was having a cuddle with the Gruffalo himself and then 'Grrrrr-ing' all the way home; I'm not sure what the other passengers on the train thought of us but we didn't care as we really had a fantastic day."

**INSIDE:** Top tips for EHCPs • Volunteer for Amaze • PIP face to face assessments • Our work with young people • Compass Card Activities latest and more...

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**Regan Delf, Assistant Director, Children's Services**, explains why the council is proposing these changes:

"We know parents of children with the most severe and complex needs can struggle with the number of professionals involved with their children. We want to respond to this by creating truly integrated special school and PRU provision for our children across education, health and care. This is in the spirit of Education, Health and Care Plans and means that different professionals work together even more closely as a team within and beyond the school day.

"We also want to offer more support to parents at home where children have difficulties or challenging behaviour and to offer activities after school, at weekends and in the holidays where we can. However we need to make some changes to our provision to be able to afford this.

"We are keeping at least the same

number of places in our special provision but we are proposing that we bring some of our schools together so that we can create three schools instead of the current six schools and two PRUs. We also want to move our specialist nursery onto a mainstream nursery site so children can benefit from a mainstream setting and specialist provision together.

**"We are keeping at least the same number of places in our special provision but we are proposing that we bring some of our schools together."**

We understand how important it is to avoid disruption to children as far as possible so we are proposing to bring changes in over the next four years with a personalised plan for

every child to ensure their needs continue to be fully met."

PACC members and Amaze staff helped to develop the consultation document which you can find on the council's consultation portal at [www.brighton-hove.gov.uk/spr-consultation](http://www.brighton-hove.gov.uk/spr-consultation). Parent carers and young people are also on the Governance Board which will oversee this part of the SEND review.

This consultation closes on 22nd April but there will be a long period of further consultation (about a year in total) before any final decisions are made about how things should be different. This means that you will have plenty of time to find out how these might affect your child and have your say. We will be involved in running some events, so that that you can find out more about the changes that are being proposed and to give everyone the chance to have their say. We will let you know about these very soon.

## Changes to Amaze services from April

Amaze has had some good news about future funding for our key services, but the picture is not completely 'business as usual', so we want to let you know what to expect from April onwards.

A big chunk of what Amaze offers to parent carers and young people relies on funding from Brighton and Hove City Council. Our current contracts with the council to run The Compass in Brighton and Hove and to provide the local Information, Advice and Support Service (IAS) which includes the helpline, newsletter, handbooks, website, one to one help with education and related issues, courses, the DLA project, etc. both run out at the end of March. So we have had to retender for the new contracts and

are delighted that we have been selected to continue to provide the services they cover. However, the council's budget is very stretched now, so the funding we get has to go further.

We are looking carefully at what we can offer with the new amount of funding, trying to protect frontline services to parents and young people. There will be some changes and we hope everyone will understand. To give some examples, Helpline hours may reduce, although we hope to still open on five days a week. This

newsletter may be by email/on-line rather than printing paper copies. We may offer more help over the phone and be less able to come out to support you face to face. We will help with DLA and PIP claims but there may be more of a wait or advice on how to do it yourself if you can. And we may have to reduce the number of training courses we offer.

We will publicise any changes to the IAS service when we have the final picture. We explain more about changes to The Compass on page 9.

One bit of good news is that the DfE have said they will fund Independent Support for another year and probably two. We have not had all the details yet but we are hopeful that Amaze will carry on helping parents and young people with new EHC plans and transfers in both Brighton and Hove and West Sussex until 2018.



## Kids Like Us sibs group a hit with families



We got great feedback from families of children who attended Kids Like Us, our pilot group for siblings of disabled children which launched in November. As one parent put it: "My daughter enjoyed meeting the other children who understand the pressure she often feels."

Funded by Brighton & Hove's

Mental Health Innovation Fund the group had 12 regular attendees who were able to share some of the positives of having a disabled sibling as well as explore the challenges.

"A siblings group provides an opportunity for sibs who may sometimes feel sidelined to share the things that make being a sib unique," says Ruth Sullivan, the group's facilitator. "You cannot underestimate the impact this has on feelings of isolation, wellbeing and self esteem."

The project is being evaluated as we go to press and we're part way through running a second group at Ralli Hall in Hove. We may be able to run further groups if we can get the funding so watch this space.

## Info Fair draws a crowd

We were delighted to see over 230 young people, parent carers and teachers at our Looking Ahead Info Fair at City College in November. The hall was buzzing and our workshops and taster sessions in music sampling and travel training were nice and busy too.

**"Being able to speak to specialists face to face and get advice was very useful."**

It's the first time we've actively geared an event towards young



Bethan and Pippa on the T21 stall.

people themselves and, barring a few issues with space to move around, the feedback from the event was very positive.

Turn to page 14 to find out about some of the other work Amaze has been doing with young people.

## Compass Card West Sussex launches soon

Last autumn Amaze was commissioned by West Sussex County Council to introduce the Compass scheme to West Sussex. Registrations for the new card are just about to open and Compass Card West Sussex will be launched on 8 April with a free Fun

Day at Lodge Hill outdoor activity centre near Pulborough.

Compass Card West Sussex will directly benefit Compass Card holders in Brighton and Hove too – many offers will be shared between the two areas. For more information, email [CompassWSx@amazebrighton.org.uk](mailto:CompassWSx@amazebrighton.org.uk) or call Amaze on 0300 123 9186.



Ed Gamble in full flow – Photo by Rodney Beckford

## Big shout for BIG Cheer

Our 5th BIG Cheer for Amaze completely sold out Komedia last October and raised a smashing £5,000 for our work with families of children with SEND. The now annual comedy extravaganza brought together popular TV, internet and radio fixtures Joe Wilkinson, Roisin Conaty, Ed Gamble and Simon Evans with brilliant newcomers Lloyd Griffith and Elliot Steel. Matt Richardson, one time Xtra Factor host, was our wonderful compere.

Thanks to all the comedians for treating us to such a fantastic night of entertainment and giving their time for free and to all those of you who came to see the show.

## Looking After You too!

Sometimes we all need a bit of a prod to make us think about looking after ourselves and not just our children. Amaze has been running a Looking After You course for the last few years which does just that. And now, you can find some of the tips and resources from that course online at [www.amazebrighton.org.uk/services-and-support/training-support-groups/looking-after-you](http://www.amazebrighton.org.uk/services-and-support/training-support-groups/looking-after-you). There's information about the course, a fact sheet and a couple of audio files that take you through some guided relaxation. Enjoy!





## Have chairs will travel

Last autumn half term Blatchington Mill School took 51 Year 11 students on their annual Business Studies trip to New York. Five of the students just happened to be wheelchair users. Their story is a reminder that all school trips can and should be inclusive, even if this is a challenge in practice.

The school had never taken any wheelchair users on long haul trips before, let alone five, but **Daniel Reeves, SENCO** at the school, explains how their initial concern was overcome by a determination to make it work. "People thought we were a little bit mad to be honest," says Daniel "but right from receiving the completed forms we thought, 'how can we not do it?' Our Head was fully behind the trip so our Trip Coordinators contacted our usual tour operators and luckily they were up for the challenge too. They worked closely with the airline and hotel and did a number of firsts for them such as sourcing hoists, accessible transport and ensuring that all the activities were inclusive."

Early on Daniel and the team realised that the success of the trip was going to depend upon the school and parents working really well together. "We were very honest from the start," he says. "We told them we'd never done anything like this

before and that it was going to need trust and flexibility but it helped that we already had good relationships." Staffing was crucial too. "All of the five young people use power chairs

**"It wasn't easy. It's really important people know that....but it was worth it."**

but we couldn't take these with us so we'd need personal assistants to push them. We felt it was unreasonable to ask one carer to do all the sightseeing walks and personal care tasks alone so we decided we'd need to take two support staff for each young person. This added £10,000 to the cost of the trip including the flights and accommodation but it did mean that we all felt much more confident that we could do it."

The school decided not to spread this cost across all the students travelling so instead they looked

around for different types of funding and were very lucky to get all the additional costs funded by a local philanthropist.

Daniel led the ten teaching assistants and their charges as a kind of trip within a trip, but they enjoyed exactly the same outings and activities as their non-disabled peers which helped to make the trip so life-enhancing. **Chusie Briceno-Pereira**, one of the disabled students who went, says: "It was one of the most empowering, stimulating and moving experiences of my life. I would like to thank all Blatchington Mill staff for being brave and tenacious enough to not have laughed or straight-out dismissed the prospect of taking not one, but five, wheelchair users on a trip across the globe."

But Chusie makes it clear that it wasn't all plain sailing. One day the accessible cars they'd organised to take them to a boat trip to Liberty Island didn't turn up (their non-disabled friends had taken the subway) so they tried to flag down a few of New York's famous taxis, but without success. "In the middle of the ever so glamorous Fifth Avenue, why would multiple taxi drivers emblazoned in that famous yellow, turn me down even when driving a fully accessible vehicle? And you'd imagine that a country that thinks so highly of itself would at least have decent pavements or a wheelchair friendly underground system; it doesn't and while this doesn't surprise me it does alarm me."

Daniel paints a realistic picture too. "It wasn't easy. It's really important people know that. For example, the five wheelchair users had to be up an hour earlier than the other students to give them enough time to prepare for the day, and travelling in convoy on New York's busy streets had its own challenges! Also, we often spent the entire lunch hour trying to find a Starbucks or Pret with an accessible loo then queuing up to take turns



with the regular customers, but it was worth it. We had to think outside the box and work our way out of problems, usually by asking the students what they wanted to do or were comfortable with."

Chusie enthuses about just how empowering the whole experience was for her and her friends: "It's been almost three months since our visit, and images such as the sun setting from the top of the 'Rock', the overwhelming buzz of Time Square and the nocturnal view of the old New York Highline still fill me with utter joy every time they pop into my head."

**"Was my experience glorious? It most certainly was. Would that experience change if I hadn't gotten the help that I did? It most certainly would have."**

Though she's acutely aware of how particular her experience was too: "I was lucky enough to have two professionals helping me through a city with close to little disabled access. Was my experience glorious? It most certainly was. Would that experience change if I hadn't gotten the help that I did? It most certainly would have." She sums up by quoting the Alicia Keys song: "New York is indeed a 'concrete jungle where dreams are made of' but it's not an accessible concrete jungle as of yet!"



## Top tips for Education, Health and Care Plans

Going through the EHC planning process or moving from a Statement of SEN to an EHC Plan can be challenging for parents and young people. Here's some tips that might help.

1. **Contact the Independent Support service.** Independent Supporters are specially trained to work with families going through the EHC process to ensure you know what to expect, when you need to take action and to offer you support and information when you need it. In Brighton and Hove and West Sussex the Independent Support service is provided by Amaze.
2. **Any person should be able to pick up the EHC Plan and get a detailed understanding of your child.** Make sure all the positive things about your child are included and that professionals can see how your child likes to be worked with, and get a good understanding of their needs.
3. **Include your child in as much of the process as possible.** The EHC plan is about them so it is important that their views and wishes are used.
4. **All the professionals should be using a "person-centred" approach** which puts the child/young person and their family at the centre of all decision-making. It is their responsibility to ensure that the assessment process works for you and that you are happy with the EHC Plan.
5. **Make sure you tell all the professionals who work with your child** that you are going through the EHC planning process as they may be asked to supply up to date information.
6. **Reports that are older than a year or two may need to be updated.** Even recent plans may not reflect your child's needs so you may want to ask for new assessments to be conducted.
7. **Make sure that the person writing your plan understands what you want for your child.** A good relationship with your SEN caseworker/plan co-ordinator can make the whole process easier.
8. **Outcomes are the key to a good plan so think about how you would like to describe your child in 2-3 years' time.** "Sami goes on a play date once a week", "Charlie goes to the toilet with no support", "Taylor is now eating vegetables once a day", "Tyson travels independently to college"
9. **Professionals need to write the outcomes in a SMART way** (specific, measurable, achievable, realistic, timebound) so that you can monitor them closely.
10. **When the family receives the draft EHC plan you only have 15 days to read it and request any changes if needed.** This is a good time to ask for Independent Support if you have not already done so. Once finalised you would need to go to the trouble of lodging an appeal to make changes so make sure you are happy with the draft.
11. **Don't just dust off your EHC plan for the annual Review.** It is a useful document to discuss with professionals at any time so that you can monitor the impact of provision on your child.

**Ask for an Independent Supporter! Call Amaze on 01273 772289.**

# We ♥ our volunteers

And they tell us that volunteering with Amaze is great. So why not join the team?

Amaze couldn't do the work we do without our brilliant volunteers. So when we did an anonymous survey of our volunteers before Christmas we were happy to hear that they feel valued and supported. They told us their induction and training prepared them for what they do, that we communicate with them well and that they know how their work contributes to how Amaze helps families. So we can confidently say that if you'd like to become an Amaze volunteer you should find it a good experience. We have opportunities for new people to train with us for three roles: DLA, Helpline and IAS volunteers.

## Could it be you?

How do you know if you're the kind of person we need? Top of the list is being a **good listener** who can get on with all sorts of people. Can you also make sense of reports, explain complex information and get things down in writing clearly. And would you enjoy helping someone work out what they think and support them to get that over to others? If that sounds interesting, but you're not sure you know enough, don't hold back - we give you lots of 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. So which role would suit you?

**DLA volunteers** help with Disability Living Allowance and PIP claims. If you've seen a DLA form you'll know it can be quite off-putting and that having someone to work through it with you is a huge help. Our DLA volunteers can really see the

difference they make. It involves quite long visits to work through a claim but each bit of work is completed quickly, so this role can suit people whose availability varies. DLA Volunteer training: **Wednesday 16th and 23rd March**, 9.45am to 2pm.

Our **Helpline volunteers** support Amaze's busy helpline. They pick up voicemail and email messages and make sure no-one is missed, and they respond to some calls 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 volunteers** have a varied role giving information, advice and one to one support to parents or young people as they try to sort out issues with their education, care or health. This could mean helping them prepare for a key meeting and going along with them. It can 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.

**"I think it's a really good organisation and I'm proud to be a volunteer with it."**

IAS and Helpline Volunteer training will take place in April and May, dates to be confirmed.

## A volunteer's story

Lea Berland, one of our helpline volunteers explains how and why she volunteers for Amaze.



"I first used Amaze 15 years ago when my daughter was diagnosed with cerebral palsy and I really needed emotional support. Even then I remember thinking it would be good to volunteer for Amaze at some point but it wasn't until last year, when I wasn't working, that I was finally in a position to do so.

"I chose Helpline volunteering because I need regular hours that work around my younger son and because I prefer to work alongside

someone else. My usual day is Wednesday and I'm in the helpline booth from 9.30 to 12, recording messages on the database and helping with simpler calls."

"I got useful training before I started but I've learnt most from just doing it every week. And the more you do it, the more your confidence grows."

"I really like the way that people seem open to letting you do more if you want to. For instance, a caller last week wanted information on holiday grants and I was able to go off and do the research for them and handle the call myself."

"Volunteering for Amaze makes me feel good about myself. It's not always easy for people to find the information they need and it's great to be able to help and really make a difference."

**If you are interested in volunteering for Amaze, just email [info@amazebrighton.org.uk](mailto:info@amazebrighton.org.uk) to find out more.**





L-R: Emma Lowe, James Maddox, Reza Ataie, Matthew Howson and Virginia Harvey proudly display their 2014 PaCC Champion Awards for outstanding work with parent carers.

## Worthy winners

We were delighted to present our very deserving 2014 PaCC Champions with their rather snazzy awards at the Amaze Info Fair in November and a great time was had by all.

Congratulations once again to those outstanding professionals who were recognised for giving our children an exceptional level of support and care: James Maddox, SEN Teaching Assistant at St. Andrew's CE Primary, Hove (Education); Virginia Harvey, Speech and Language Therapist – Deafness at Hove Polyclinic (Health); Emma Lowe, Outreach Services and Matthew Howson, Social Worker at Seaside View Child Development Centre (joint Social Care winners) and Reza Ataie, volunteer co-ordinator of a Dads Group, Brighton and Hove (Voluntary sector champion).

### Nominees for 2015?

No sooner is one set of awards gleaming on the mantelpiece than we are looking for your nominations for your next generation of PaCC heroes.



Matthew Howson receiving his award from Tom Bewick, Lead Councillor for Children's Services.

Did a professional in the SEND world go the extra mile for you and your child in 2015? If someone who has worked with you in the Health, Education, Social Care or Voluntary sectors has been a shining star, request a nomination form via [admin@paccbrighton.org.uk](mailto:admin@paccbrighton.org.uk) or nominate via our website at [www.paccbrighton.org.uk/what-we-do/pacc-awards](http://www.paccbrighton.org.uk/what-we-do/pacc-awards)

## PaCC's response to budget proposals

Because of reductions in central government grants, Brighton & Hove City Council has to make savings of £68m over the next four years and they have issued proposals highlighting where they think cuts could be made. PaCC appreciates the difficulties the council faces, but is concerned that any savings in their budget should not affect frontline services for families with disabled children. We have been working hard with council officers to unpick the proposed savings shown in the budget papers ([www.tinyurl.com/zaqfmus](http://www.tinyurl.com/zaqfmus)) to ensure SEND provision is protected.

Parent carers tell us there are already huge issues around the capacity of services to meet current levels of need, including specialist support in mainstream schools, unacceptably long waiting lists for CAMHS and other therapies, and a lack of direct payments to pay for respite. We have fed this back to the local authority and councillors and highlighted that we believe that investment in frontline services actually needs to increase.

Councillors, officers and PaCC agree that the city is embarking on a huge transition in the reshaping of SEND services for children and young people aged 0-25. PaCC has been broadly supportive of the proposal for the city's special schools to become more integrated with health and social care services but we have a number of concerns about the details of the redesign (yet to emerge at the time we went to press).

Continued overleaf



PaCC has also stressed that families in need must not lose services during this transition phase and frontline services must be protected.

PaCC has asked officers, and the Lead Councillor for Children's Services, Tom Bewick, to make a commitment to reinvest any funds raised from the sale of local authority special school buildings into SEND services and to fund start-up projects in much needed areas like short breaks and activities at the end of the school day and weekends.

PaCC knows there is a much higher need for services than can currently be met in the area of social care. Nationally there is a big drive towards

personalisation in social care, and the local authority is keen to identify how families can be more in control of their own budgets by increasing the use of direct payments. At PaCC's suggestion the council has already removed a proposed saving in this area of £28k.

**PaCC has also stressed that families in need must not lose services during this transition phase.**

PaCC is deeply concerned that proposed cuts to vital community and voluntary services in Brighton and

Hove, that currently play a huge role in the delivery of services from short breaks to information, advice and support, are included in the budget proposals and we will continue to ask for these to be removed. For our full position statement on the budget proposals affecting SEND services in the city, visit our website at [www.paccbrighton.org.uk](http://www.paccbrighton.org.uk).

PaCC welcome feedback from the community on all issues raised by the redesign of SEND Services in the city. Please email your views to us at [admin@paccbrighton.org.uk](mailto:admin@paccbrighton.org.uk) or come along to our PaCCConnect on 16<sup>th</sup> March (see opposite page).

## After-care at the Alex

How good is the support you get once your child comes home from the Royal Alexandra Children's Hospital (RACH)?

During the past few months PaCC and Amaze have run a consultation to find out about parent carers' experiences of the kinds of support they get at the time when their child is discharged from the hospital. This consultation was organised as part of our ongoing engagement work with the local Clinical Commissioning Group (CCG). Through this work we want to make health care services more responsive to children with disabilities and additional needs and to their families.

A large number of respondents to the consultation said their children spend a long time in the hospital and stress **just how important discharge notes and information, follow up and support are**. Whilst many parents are happy with the support received some others want the service to improve *'I just got a discharge letter and basic*



*medications...I felt a bit lost'.*

**Community nurses provide a good quality of support** but when there is limited capacity **follow-up phone calls and/or emails would really help** *"Someone to check that you and your child are doing OK"*.

Parents are asking for **a better care plan and improved communication between health and social care**

professionals. Our recommendations included the suggestion that **discharge notes should include a 24 hour number to call in case of emergencies** and also **contact for other organisations** which can provide support, for example Amaze, Face to Face and parent carers' community groups.

Our recommendations for RACH on discharge and support expand the work we did with our 2012 'Talk Health' report and its 2013 follow up. As a result, a PaCC parent rep now sits on the Disabled Children's Acute & Community Liaison Group. The group oversees the work of the hospital, and working parties have been set up on the following themes: 'rapid access' passport system; helping nonverbal children to communicate when in hospital; leaving hospital and outpatients (Level 5). Read the full reports at [www.paccbrighton.org.uk/resources/reports](http://www.paccbrighton.org.uk/resources/reports)

**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 part in SEND Review

PaCC has been very busy over the last few months with three key areas of proposed changes to SEND provision that have come out of Brighton & Hove's SEND review.

### Changes to specialist educational support services in mainstream schools

The council is planning to reorganise eight learning support services such as the autism support and sensory needs services, into a single **Educational Psychology and Learning Support Service**. They believe it will give greater flexibility and provide more support to families. However, there has been a lot of controversy around this, resulting in a petition of over 10,000 signatures, particularly the change from "specialist teachers" to "generic advisers" and a cut in the number of these posts.

Our PaCCConnect forum in November allowed parent carers to voice their concerns directly to senior officers at the council. PaCC then wrote a position statement to ensure the voice of parent carers was heard by the local authority. PaCC supports certain aspects of the re-design, including shared management and co-location, but does not support a reduction in frontline staff or any risk of loss of specialisms. PaCC also asked for more consultation with schools and nurseries.

The council has listened to ours and others' concerns. As a result, the consultation was extended to 31<sup>st</sup> January. PaCC, together with young people and school and nursery reps, joined a 'stakeholder group' to analyse the responses to the consultation. The council has also appointed an independent SEND specialist to review the proposals.

proposals to reorganise the city's special schools and special educational provision (including the PRU and Homewood College) into three new "Integrated Specialist Provision" hubs in the city. The vision is for children to access their health, care and education needs in a 'one stop shop'. This was discussed at a PaCCConnect in November and there will be another **PaCCConnect on 16<sup>th</sup> March to discuss the proposals further**. The council consultation is open until April 22<sup>nd</sup>. To have your say, visit [www.brighton-hove.gov.uk/spr-consultation](http://www.brighton-hove.gov.uk/spr-consultation).

### New way of assessing eligibility for direct payments

The council are investing in a new system for allocating direct payments. This is called FACE, and is the same system used in adult social care. PaCC and Amaze have been involved in advising and assessing the viability of FACE for children, young people and their families. Using FACE does not mean there will be any extra funds available, but the idea is that direct payments will be distributed more fairly and transparently. PaCC have consistently asked for the direct payment pot to be increased to meet unmet demand, and we requested this in our recent response to the proposed council budget for 2016/17.

The PaCC steering group continues to work hard to represent parent carers during this time of change and budget cuts. See the box on the right for details on how to share your views.



### PaCC priorities for 2016

We had a very busy stall at the Amaze Info Fair where we talked to parent carers about the issues that matter to them. We've added this feedback to the views we've gathered from our PaCC partners and our recent PaCC survey to determine what you want us to focus on for this year.

You've made it clear that **mental health** is still a top priority for parent carers so we'll be holding a **PaCCConnect on Mental Health on Weds 27<sup>th</sup> April, 9.30am to 12.30pm** at Community Base, 113 Queens Road, Brighton. You also told us that it's very important to keep open communication between parent carers and the local authority on proposed changes to SEND services. So we'll be holding a PaCCConnect on the **Proposed Integration of Special School Provision in Brighton and Hove on Weds 16<sup>th</sup> March** at Ralli Hall, on Denmark Villas in Hove.

We always want to know what matters to you as parent carers. You can do this via our website at [www.paccbrighton.org.uk/get-involved/give-us-your-views](http://www.paccbrighton.org.uk/get-involved/give-us-your-views). Or join the PaCC by emailing [admin@paccbrighton.org.uk](mailto:admin@paccbrighton.org.uk). We also have a closed Facebook group where parents can discuss issues amongst themselves too. Visit [www.facebook.com/groups/parentcarerscouncil](https://www.facebook.com/groups/parentcarerscouncil)

### Changes to special schools

Councillors voted in November for the council to work up and consult on

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





## Need a cuppa and a chat?

If you live in Portslade, Moulsecoomb or Whitehawk our monthly coffee mornings might be just what the doctor ordered.

Our regular coffee mornings offer a space for you to relax, meet other parent carers and find out more about what's available in Brighton and Hove for children with SEN and disabilities, you and your family. Parents who go to the coffee mornings have a say on what they would like each session to be and during the past three years we have included CAMHS workshops, stress busting techniques, an educational psychologist information session and a mindfulness workshop, just to name a few.

**"I'm so glad I came to the group today. I didn't realise how stressed I was... It feels so good to offload and be offered support."**

This is what a parent carer said about our **Hangleton and Knoll Parent Carer Coffee Morning** which meets every third Tuesday of the month from 9.30 to 11.30am at **St Richard's Church**, Egmont Road. The group is facilitated by Amaze, PaCC and the Hangleton & Knoll Project.

Our **Sunflower Support Group** takes place every second Tuesday of the month from 9.30 to 11.30am at **Moulsecoomb Primary School** or The Bevy Pub. The group is run by a partnership between Amaze, PaCC and the Trust for Developing Communities (TDC).

A parent who comes to our Moulsecoomb group was able to rebuild her confidence and successfully apply for a part time job: "I really think the group helped me



Our Sunflower Support Group enjoy a pottery painting session at Paint Pots in Brighton.

with my confidence, and keeping it up. Completing the successful funding bid last year [for the group summer outing] really made me believe I could do it."

And from **Thursday 25<sup>th</sup> February** we're launching a new **coffee morning** on the last Thursday of every month, from 9.30 to 11.30am at the **Whitehawk Inn**. Come and join us! To find out more about coffee mornings email Paolo on [paolo@paccbrighton.org.uk](mailto:paolo@paccbrighton.org.uk) or call 01273 234862.

Coffee mornings are supported by Brighton and Hove Community Works through funding from Brighton & Hove City Council.



### Lego Club for children on the autistic spectrum

PaCC administrator, Jo, has been regularly visiting a Lego Club for autistic children with her eight year old son, Freddy. Jo says, "Freddy absolutely loves Lego Club and talks about it all the time. He's made some great friends there and gets to do what he loves best – building Lego figures!"

The Lego Club for ASC kids takes place every fortnight on Sundays from 2.15pm to 3.45pm at the Meadowview Community Centre, Moulsecoomb. There's a minimum donation of £3 per session. The club is suitable for children aged five plus and siblings are welcome.

For more details, email [terri.oatley@yahoo.co.uk](mailto:terri.oatley@yahoo.co.uk) or follow the Lego club on Facebook at [www.facebook.com/Lego-Club-1617078528553280](https://www.facebook.com/Lego-Club-1617078528553280)



### Three cheers for Fiona!

Congratulations to PaCC Chair, Fiona England, for completing 50 miles of long-distance cold water swims by her 50<sup>th</sup> birthday in December 2015. And she raised a fantastic £4315 for Amaze in the process!

Fiona says, "The demands of

bringing up a child with Down's syndrome are at times very tough. What kept me going? Three major positives: my family, outdoor swimming and Amaze.

"Amaze helped us as a family when we were at rock bottom. Through the help of a highly skilled Amaze worker, we found a way to tackle this sense of doom and an onerous mountain of necessary paperwork. After a while, I even found the time to find a sport I love and life has eased a little bit more. Outdoor swimming helps me find some peace in this mad, bad world."



# Ask the experts

This week's experts are **Ros Cook**, Amaze's Operations Director and **Philip Warford**, Managing Director of local law firm, Renaissance Legal.

**"My daughter has always needed extra help at school and was on School Action Plus. Now I have been told she is on SEN Support. My friend's son is on SEN Support too but he doesn't have the level of needs that she does. How does this work?"**

**Ros says:**

"One of the changes to the law on special educational needs that took effect in September 2014 is that School Action and Action Plus were replaced by SEN Support.

How it works now is that if children have extra needs but these can be met by using varied teaching approaches there is no need to call it SEN at all.

"If they need extra help that is on top of, or different from, the usual range of strategies a teacher would use, then they should be on SEN Support. And if they need support that is above and beyond what a school is expected



to provide from its own resources, then they may need an Education, Health and Care Plan (EHCP).

"Some children on SEN Support will be getting a bit of help and some will get lots, up to £6000 worth in some cases. How much help they get is meant to be based on their individual needs and decided through a process called Assess, Plan, Do, Review. This starts by looking at (ASSESS-ing) the child's needs and what might help.

**"Some children on SEN Support will be getting a bit of help and some will get lots."**

Then a PLAN is made about what help to give, when, and what outcomes it should bring. Next comes the actual DO-ing. Then a REVIEW of how things are working - are those outcomes happening? This leads to the next PLAN and so on as long as the child needs extra support.

You should be involved all along, as should your child especially as they get older. And you should have some sort of review and update with school, three times a year.

So it is fine that your daughter and your friend's son are both on SEN Support. What you need to keep an eye on is whether she's happy and making progress.

**"I've been told that I need to do a Lasting Power of Attorney for my daughter who has SEN but I don't understand what I need to do. Could you help me?"**

**Philip says:**



"Just to explain for those that don't know, a Lasting Power of Attorney (LPA) is a legal document where you give authority to another person (known as an 'Attorney') to make certain decisions on your behalf.

This means that at such time as you no longer wish to make decisions for yourself, or you lack the mental capacity to do so, someone has been appointed to make decisions on your behalf. Anyone aged 18 or over, with the capacity to do so, can make an LPA.

"You say that your daughter has SEN which leads me to believe she is under the age of 18. If that's the case, she would not be able to put in place an LPA. What often happens is that when a person with SEN is coming up to transition (from childhood into adult life) LPA's are mentioned as they might then become relevant. However, an LPA may not be appropriate if a young person's mental capacity is not high enough to make an LPA.

"The alternative for someone who lacks mental capacity is for family or friends to apply to the Court of Protection

for the Court's authority to make decisions for the person who lacks capacity.

"The Court of Protection can make an order authorising a person to act on behalf of someone who lacks capacity; the person who acts is called 'the Deputy'. The Court of Protection will set out the Deputy's specific powers in any Order it makes. The powers given will depend on the needs of the person who lacks capacity.

"For more information come along to a **seminar** that we're running with Amaze on '**Court of Protection, Lasting Powers of Attorney and Mental Capacity**' on Tuesday **15<sup>th</sup> March**, 10am to 12.30pm in the Conference Room of Community Base, 113 Queens Road, Brighton BN1 3XG. Call Amaze to book."

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.

**Do you have a question you need answered? Email: [charlotte@amazebrighton.org.uk](mailto:charlotte@amazebrighton.org.uk) and we'll find an expert who can answer it in the next issue.**

## PIP: Preparation Is Paramount at face to face assessments

Personal Independence Payment (PIP) is the new benefit replacing Disability Living Allowance (DLA) for working age people and the process of claiming is very different.



It's not just about the paperwork: most young people will be required to attend a face to face meeting. The assessor will want to see how what is written on the PIP claim pack matches up with the young person they are meeting. It's important to get both parts right.

### How to tackle the claim pack

**Take nothing for granted:** PIP is never a shoe-in. We think it's easier for young people with more complex needs to secure the highest rates of PIP than DLA. However, experience tells us that you'll need to put as much time and effort into this application as any previous DLA claim.

**Do the spadework: you will need as much evidence as you can muster.** If a young person has a Statement of SEN, an EHC Plan or reports from a health professional, include these. If you have no advices, but feel a young person still has very significant extra needs, think about paying for an independent assessment. A claim without supporting evidence is likely to be unsuccessful.

**Involve your child.** Young people are often the ones who know best how their illness or disability affects them. So work together to 'tell it how it is'. Give examples. Use extra paper. Always keep a copy of the claim.

**Get help to fill them in if you can.** You can get a PIP info sheet from Amaze via our helpline and Disability Rights UK has a helpful guide at [www.disabilityrightsuk.org](http://www.disabilityrightsuk.org). If you feel really stuck Amaze may be able to offer individual help; ring 01273 772289 to find out more.

### A week before

**Start keeping a diary:** having examples of when things don't go well at your fingertips helps when you're under pressure.

**Revise and read through paperwork again, together.** The last time either of you looked at the PIP claim will have been months ago.

**Rehearse giving explanations: avoid 'yes' or 'no'.** The answer to 'Can you tell the lady what happened when you made beans on toast?' will be more revealing than a one word answer to 'Can you cook a simple meal?'

**Check who your child wants to support them at the assessment:** someone who is on their side and understands how their disability impacts their everyday life. This can be a friend or worker, but is most likely to be you.

### On the day

**Arrive in good time:** it can help to practise the journey and 'stake out' the building a few days before.

**Be aware that the healthcare professional will observe and note everything:** from whether a young person lets a door go in your face as you come into the room, to how they put their coat on. So don't be too helpful.

**Step in if your child is struggling to 'follow' what is said or the relevance of a question.** Doing this in a clear, positive way - phrasing questions more simply - will help the assessor spot how easily things can go wrong.

**Beware of assessors who ask 'closed' questions.** If a young person answers 'yes' or 'no' encourage them to say more: you or they need the opportunity to qualify any answer.

**Add to and comment on what a young person says** if you feel their own perception of their abilities is unrealistic or they are saying things just to impress.

**Agree beforehand how a young person will tell you or signal that they need to stop.** It's OK to ask for a break, if a young person needs one.

Amaze has an info sheet all about PIP. Call the Helpline on 01273 772289 to request a copy.



# Big changes to CCAs

Compass Card holders of all ages have enjoyed our Compass Card Activities (CCAs) since they were introduced six years ago, but sadly changes to our funding (mainly from Sport England) mean big changes.

Some activities will continue, but they won't be monitored by Amaze or promoted as CCAs. Others will come to an end. Otherworld will remain a CCA (see right for details).

## Activities that will go on, but not as CCAs

**U-Sport**, the multi sport session for over 11s with moderate and complex needs. Extratime intends to extend U-Sport into April and May 2016, so contact them on 01273 420580.

**Saturday Active Club.** A monthly multi-sport session for 5-11s on the first Saturday of the month at King Alfred will continue, but the 50p Compass Card discount will no longer apply.

**Travel Training with Grace Eyre.** A rolling programme of courses for over 18s with learning disabilities and one to one training for specific journeys. Call Grace Eyre on 01273 222053 for more details.

**Make Your Mark art club**, run by Sue Winter will continue to run at various venues, usually on the first Saturday of the month. Call Sue on 07400 963087 for details. The Compass Card discount of £2 will remain in place.

**Autism-friendly screenings at the Duke of York's and the Duke's at Komedia.** Prices, etc. stay the same, but Amaze won't be able to provide volunteers for the screenings at the Duke of York's from the end of March.

**Grace Eyre swimming sessions for 14s and overs** are expected to continue, but a new venue is currently being sought. Call Grace Eyre on 01273 222097.

## Activities that will end

**'Climb for a Fiver' sessions** for over 11s at High Sports in Withdean are ending. The last Beginner sessions for young people with SEND are on 27<sup>th</sup> February and 19<sup>th</sup> March and the last Para sessions are on 5<sup>th</sup> March and 16<sup>th</sup> April. You will still be able to take advantage of the High Sports Compass Card discounts – 20% for your first session after doing a CCA, or 10% as standard.

**Fun-fit Spiral**, our multi-sport session for over 11s is ending. The remaining sessions are on Sundays from 28<sup>th</sup> February until 20<sup>th</sup> March.

**Archery and Kayaking with Adventure Unlimited** will end but please check [www.aultd.org.uk](http://www.aultd.org.uk) for sessions that might suit you in the future.

**Amazing Cookery for 19-24s** with Brighton & Hove Food Partnership (BHFP) will end – but do look out for similar courses from BHFP.

**High Flyers trampolining for teenagers** is now at an end. If you're looking for an alternative, there are several trampolining classes at Southwick Leisure Centre for children and young people with additional needs. Call Southwick Leisure Centre on 01273 238111 for information.

**Street dance mini-courses for over 11s** at Marina Studios will end but we expect there to be one further course in April or May. And do check out the mainstream programme at Marina Studios on their website [www.marinastudios.co.uk](http://www.marinastudios.co.uk)



## Otherworld – come and see 'Cloud Forest'

We're pleased to say Otherworld will remain a full-blown CCA. Come along to the next run of Cloud Forest at BACA, Lewes Road, Brighton BN1 9PW from **Wednesday 11<sup>th</sup> to Sunday 13<sup>th</sup> March**. The rainforest theme with its band of explorers, scientists and rainforest guardians has been a hit with Amaze families. "This one has been my daughter's favourite so far – totally engrossed from start to finish," says one parent.

To book, call Brighton Dome on 01273 709709, visit the Box Office or visit [www.brightondome.org](http://www.brightondome.org). Tickets £4 for children, £3 for adults. Booking fee and postage charges may apply.



## Compass Card Offers?

Reductions in our funding from Sport England and the council mean you will see some changes to how Amaze runs Compass Card offers and the Compass database in Brighton and Hove. For example, we may need to reduce the frequency of our e-bulletin or reduce the size of our offers guide. However, expanding the Compass Card into West Sussex (see page 3) will mean card holders in Brighton and Hove will be able to share many of the new offers we're negotiating for West Sussex. More on this in the next issue.



Young people at our 'What's out there?' information gathering event.

# Amaze's work with young people

It's almost a year since Amaze began working directly with young people, providing information, advice and support (IAS). Here's what we've been up to.

## Finding out what young people want

In March 2015 we asked a group of 15 young people aged 16 to 23 about the kinds of information and advice they wanted and how they might want to get it at our 'What's out there?' event. Nearly all of them wanted information about going out and about, Compass card activities and meeting and making friends. Most were interested in finding out about where they might live in the future and what local services there are in the city that could help them. They also told us it would be helpful to have information about further education, voluntary work and help with getting a job and that finding out things about health issues such as contraception was also of interest.

All of the young people said they relied on their parents to get the information they needed and nearly

all of them said they would also ask their friends for advice. They all had a mobile phone and access to a computer or laptop and said that they used the internet or Youtube to find things out.

**"None of the young people had rung a helpline but just over half said they would go to a drop in."**

Interestingly, none of the young people had rung a helpline but just over half said they would go to a drop in and speak to someone if the occasion arose and nearly all of them said they would like to get advice and talk to someone in their own home. Just over half said they'd find it helpful to talk to someone at school or college or at a youth centre.

## Employing Danielle

Amaze decided it would be a good idea to have a young person to help us with our work with young people. Danielle Garratt has been a paid intern working for us for two days a week since April 2015.

## Spreading the word

Danielle has spoken to young people in schools and colleges about what Amaze offers, together with Sally, our Independent Supporter, who supports young people with their Education, Health and Care Plans. We wrote about our new service for young people for the last AHA Newsletter for young people with SEND.

## The Local Offer

Danielle gave lots of suggestions to the local authority about how they might improve the information on the Local Offer – their online listing of all the local services for disabled children and young people and their families. See the revised version now at [www.brighton-hove.gov.uk/localoffer](http://www.brighton-hove.gov.uk/localoffer).

## The Power Group

Danielle supports Sue Winter to run the Power Group, a young people's self-advocacy group that takes place once a fortnight at the Young People's Centre. The Power Group is run in association with Dawn from Speak Out too. In response to some of the issues the young people have raised the Power Group has had sessions about safe sex and contraception and about preparing for an interview and getting a job.





## Developing courses

Some of the young people in the Power Group have given their views on a Healthy Relationship course that is being planned by the YMCA and the WiSE project (What is Sexual Exploitation?). Danielle will help deliver the eight week course to Year 11 students at the Cedar Centre and once the course has been tried there, it will be available to all secondary schools in the city.

Danielle has also been working in partnership with Right Here, a local mental health charity for young people, to deliver three workshops in secondary schools, 'Coping with exam stress', 'Social media and mental health' and the '5 ways to wellbeing' sessions. Amaze thinks this work is really important knowing how many young people in the city struggle with their mental health.



Sam from The Specials meets Rachel Travers, our CEO and Caroline Lucas, MP for Brighton Pavilion, at our Info Fair.

## Information Fair

Because providing information, advice and support to young people up to the age of 25 is new to Amaze and to a lot of other services, Amaze decided to make this the focus of our annual Information Fair in November last year. For the first time we invited both parents and young people to attend 'Looking Ahead' at a venue geared specifically towards young people, City College.



Grace Eyre delivering travel training taster sessions at the Info Fair.

We were very pleased with how many people came along – some were supported by their schools or colleges and some on their own. With funding from Healthwatch Brighton and Hove, we were able to film interviews with some of the young people who attended about their information needs – we'll be producing a short film that we will share with health and social care managers and publish on the Amaze website soon.

## Our funders

This work was made possible with funding from Brighton & Hove City Council, the Doris Pacey Foundation and Healthwatch Brighton and Hove.

## Our vision for the future

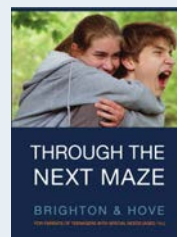
Amaze is keen to continue working directly with young people and parent carers and helping to shape and develop services for young people in Brighton and Hove. If we had the funding, we would like to recruit, train and support a team of young people who would be peer supporters for other young people with SEND.

Young people with SEND can call our helpline for information, advice and support on 01273 772289. We'll also be working hard to try to continue to bring information directly to young people in schools or other relevant locations across the city.

## Through the Next Maze - out soon!

The latest edition of Through the Next Maze, our handbook for parent carers of young people **aged 14+**, is about to be published. It's packed full of useful info and advice about preparing for adulthood including choosing further education, puberty and relationships, benefits changes, independent living, health, travel and more.

If you'd like to request a copy, email your name and address to [charlotte@amazebrighton.org.uk](mailto:charlotte@amazebrighton.org.uk). It's free to parent carers who live in Brighton and Hove or have children who go to schools or colleges in the city or £9.99 if you live out of area.



## Inclusive dance for 13-25s

Extratime and Rounded Rhythm are running an exciting new inclusive dance group for 13 to 25 year olds. There's still time to join the group which meets on Mondays, from 4.15 to 5.45pm, at Portslade Aldridge Community Academy (PACA) and prepare for a performance on Saturday 19<sup>th</sup> March.

It's aimed at disabled and non-disabled dance lovers of all abilities – no experience necessary – and trained Extratime staff and Rounded Rhythm dance teachers will provide appropriate levels of care and support so everyone can join in.

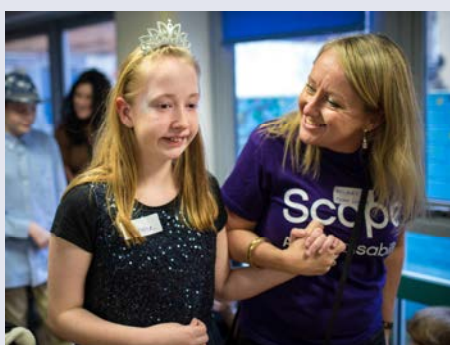
It costs £8 per session and that includes a healthy snack and transport to the venue for students coming from Downs View Link College, Downs View School, and Portslade schools. For more information visit Extratime's website at [www.extratimebrighton.org.uk](http://www.extratimebrighton.org.uk)



Young people with SEN and disabilities can call our helpline on 01273 772289 or email [helpline@amazebrighton.org.uk](mailto:helpline@amazebrighton.org.uk) for information, advice and support

## Fashion fabulous

**Scope Face 2 Face** held a fabulous family **fashion show** in January to celebrate their befriending service and the families who have used it. Gap supplied the clothes and the models were children and young people with SEND and their siblings. Face 2 Face co-ordinator, Amanda Mortensen, says, "We wanted to give children and young people a chance to do something different and be in the spotlight. Gap kindly lent us the clothes and we had a lot of fun!"



## Coming soon...

**Brighton Half Marathon - Sun 28<sup>th</sup> Feb**  
Come and cheer our team of runners in the Brighton Half Marathon. Amaze will be by the roundabout at the Palace Pier from 9 to 11.30am.

**Planning for the Future: Mental Capacity, Powers of Attorney and Court of Protection - Tues 15<sup>th</sup> March, 10am to 12.30pm.** Seminar run by Amaze and Philip Warford of Renaissance Legal at Community Base, 113 Queens Road, Brighton.

**PaCConnect on Proposed Integration of Special Schools - Weds 16<sup>th</sup> March, 9.30am to 12.30pm.** At Ralli Hall, Denmark Villas, Hove. Hear the latest information and ask questions of some of the people in charge of the proposals.

**PaCConnect on Mental Health - Weds 27<sup>th</sup> April, 9.30am to 12.30pm**  
At Community Base, 113 Queens Road Brighton.



## Our Val-ued friends

A huge thank you to the Ladies' Section of East Brighton Golf Club, and the 2015 Ladies' Captain, **Val McLeish**, who raised almost **£4,000** for Amaze last year through social events, competitions, raffles, and a Charity Day supported by all the club members and their guests.

Thanks also to Amaze patron, **Henry Normal**, who held a second night of poetry in aid of Amaze. The Joy of Frogs was a celebration of love, romance and other unrealistic expectations on



Valentines Day at Latest Bar Brighton. And thank you once again to **Fiona England**, PaCC Chair, who raised a whopping £4,315 with her 50k outdoor swimming challenge last year (see page 10 for more details).

Last but not least, we'd like to thank an anonymous donor for the £500 they gifted to Amaze. We are allocating this money towards training and supporting helpline volunteers. Thank you to all our supporters; we couldn't continue without you.

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 5pm, and Fri mornings 9.30am to 1pm



### Amaze

Community Base  
113 Queens Road  
Brighton BN1 3XG  
T: 01273 772289  
E: [info@amazebrighton.org.uk](mailto:info@amazebrighton.org.uk)  
W: [www.amazebrighton.org.uk](http://www.amazebrighton.org.uk)

