

# out of amaze



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



## Face 2 Face Fashion Show gives kids a chance to shine

Sat 18<sup>th</sup> November, 2 to 4pm at Downs View Link College

Amaze is holding a very special fashion show later this month in partnership with GAP, whose local Brighton children's branch are providing clothes for the show.

The Face 2 Face Fashion show is all about enabling our children to be part of something a bit different, and giving them an opportunity they may not have had before. The last one was a great success and this one promises to be even better. Suggested entry is £2 with funds raised going to Amaze's Face 2 Face Befriending service.

The fashion show is at Downs View Link College, on the Varndean College

site on Surrenden Road. Your child and their siblings can get involved on the catwalk or backstage, or you can just come along to watch. Guy Lloyd from Juice FM is our compère and refreshments and sensory goodies will be provided on the day.

Contact Amanda Mortensen, Face 2 Face Coordinator, on 07917 887526 or [amandam@amazebrighton.org.uk](mailto:amandam@amazebrighton.org.uk) as soon as possible if your child or children would like to be involved. We need their dress size and to know about anything we need to consider to enable them to take part. We're keen to overcome any barriers to be as inclusive as possible.

**INSIDE:** SEND Hubs latest • Universal Credit • Peer supporters • PaCC view on home to school transport • Amaze workshops • Our Amazing Lizzie and more...

## Anyone for cake?

As part of our 20<sup>th</sup> birthday celebrations, we'd love you to join us for cake and a cuppa at our Annual General Meeting (AGM) on **Friday 24<sup>th</sup> November, 11am-12.30pm** at Komedia, 44-47 Gardner Street, Brighton, BN1 1UN.

As we're such cake lovers here at Amaze, we're holding a **Bake Off competition** on the day. Cakes will be judged on taste and appearance, with prizes for the best, then we'll share them with whoever comes along!



We'll also celebrate the outstanding contributions of our DLA Project Manager, **Lizzie Batten**, and Chair of Trustees, **Hugh Clench**, who've been with Amaze since its outset. We'd love to see families or volunteers who've been helped by Lizzie over the years.

The AGM will also launch our new '**Generation Amaze**' campaign which highlights the impact Amaze has had on the lives of families with disabled children over the last 20 years, and aims to raise new funds to support the next generation. Finally, we'll be hosting the annual **PaCC Awards** that recognise outstanding work by local SEND professionals (more on page 8).

Email [info@amazebrighton.org.uk](mailto:info@amazebrighton.org.uk) or call 01273 234020 to let us know you're coming, or if you'll be entering a cake in the Bake Off.

## Full steam ahead for SEND Hubs

Special schools merge for new all-round service.

On 18<sup>th</sup> September, the council's Children, Young People and Skills Committee formally approved plans to create three new integrated special education hubs in the city, in place of our current six special schools and two pupil referral units. This ground-breaking decision comes after a long period of consultation and planning.

**Cedar Centre and Downs View School** will be merged to become the new hub for children with complex needs and learning difficulties in the east of the city. The parallel hub in the west will be formed by bringing together **Downs Park and Hillside**. The third hub, created from the two pupil referral units and Homewood College, will meet the needs of pupils with social, emotional and mental health (SEMH) difficulties across the city.

This hub is going to use more than one site.

£7.5m has been allocated to the project, to build new accommodation and upgrade current facilities, so that the hubs can help deliver the top quality integrated provision that the city needs. The council wants the new hubs to offer a wide range of services for children and their families, including health and therapy, after school activities and family support.

It will take some time to make these changes - there will be no sudden moves for children - and parent carers and children will have the chance to contribute their ideas to help create the new hubs. We'll keep you posted about any chances to give your feedback via this newsletter, our website and the PaCC website.

## Grants available for families in need

The **Family Fund** is actively seeking applications for grants from Brighton and Hove families.

If you have a child with a **severe disability or a serious or life threatening illness**, you can apply for anything that relates to their needs. This might be furniture, kitchen appliances, sensory toys, computers or tablets, a holiday, or maybe something to help with college for older kids. And you can apply more than once.

You must be on a low income and able to provide evidence of this, and your child must be aged 17 or under. For full details and to apply, visit [www.familyfund.org.uk](http://www.familyfund.org.uk)

Amaze can't help with applications but the forms are straightforward and there's a brochure to help you apply.

## Amaze expands into East Sussex

Amaze is delighted to announce that we're extending our **Special Educational Needs Information, Advice and Support Service (SENDIASS)** into East Sussex, to run alongside our Independent Support work in the county. Amaze East Sussex SENDIASS will offer:

- Developments to the Amaze website and its resources so East Sussex families can find things out for themselves
- A dedicated East Sussex telephone and email helpline for more tailored information
- One-to-one advice for more complex issues

We are being funded by East Sussex County Council to provide an impartial service to parents and young people living or going to school in the county - replacing the

previous council-run 'SEN and Disability Advice Service'.

Just like in Brighton, East Sussex SENDIASS will support families to be well informed about special education and disability services and have a strong voice in decisions that affect them. We aim to help parents, carers and young people build good partnerships with services and professionals, and we can help families to find solutions when they are unhappy with how things are going.

### Helpline changes

Expanding into East Sussex has meant a few changes to our helpline service. Now when you call, you'll be asked to choose from four options: one for people who live in Brighton and Hove,



one for East Sussex, one for people calling about the Compass in West Sussex, and one for Independent Support in West Sussex.

Our helpline opening hours have changed a bit too. We're now **open from 9.30am to 2.30pm every day** for both Brighton and East Sussex. We can call you back outside these hours or you can email: [helpline@amazebrighton.org.uk](mailto:helpline@amazebrighton.org.uk) for the Brighton helpline or [eastsussex@amazebrighton.org.uk](mailto:eastsussex@amazebrighton.org.uk) for East Sussex SENDIASS.

**Call the Amaze SENDIASS Helpline on 01273 772289 and choose the 'Brighton and Hove' or 'East Sussex' option.**





## Rainbow runners

Thank you to our 30 amazing 'Color Runners' who ran a joy-filled 5k on 23<sup>rd</sup> September to help raise funds for our Face 2 Face Befriending Service.

Amanda, Livvy, Daisy and Grace Mortensen, Ann Blackburn, Clodagh Warde, Janette, Ella and Amber Ackroyd, Elizabeth and Charlize Wood, Jodie and Zoe Spearman, Jhuma and Sami Sharma, Julie and Jacob Stokes, Laura Boyd, Lauren Cook, Melissa Kelly, Merav and Roni Devere, Ros Cook, Sarah and Chloe Smith, Christine Chisholm, Sue, Amelia and Yoko Shaw, Susanna and Sophia Nicholls.

You can still sponsor them and support Amaze Face 2 Face which

gives emotional support to parent carers at challenging times like diagnosis. Just follow this link: [www.justgiving.com/fundraising/nicky-bagilholt2](http://www.justgiving.com/fundraising/nicky-bagilholt2)

And, if their story inspires you, we are recruiting now for runners in the following races:

- 19<sup>th</sup> November - Brighton 10k Race
- 25<sup>th</sup> February - Brighton Half Marathon
- 15<sup>th</sup> April - Brighton Marathon

For further information, call Nicky B on 01273 234014 or email: [nickyb@amazebrighton.org.uk](mailto:nickyb@amazebrighton.org.uk)

## Pride in our city

Ann and Ros from Amaze joined crowds of people enjoying glorious sunshine at England's first ever **Disability Pride** in Brighton in July.

"It was a wonderful day," says Ros. "Honestly, I have never seen so many disabled people of all ages together in one street. It felt like laying claim to the centre of our city."

The PaCC picnic was a special part of the event too. You can read more



about this on page 8. Look out for Disability Pride next summer too.

## Early Language Support on move

This year, support for pre-school children with severe speech, language and communication difficulties became an outreach only service: the new **Early Language Support Team** works with your child in their own nursery or pre-school rather than at the old ICAN nursery based at Carden Primary.

The Early Language Support Team is made up of a specialist teacher, a specialist practitioner, a specialist speech and language therapist and an educational psychologist. From November they'll be able to support 20 children in their last year before starting school who are experiencing severe and persistent speech and/or language difficulties. Children are usually referred to the service via a speech and language therapist - after an assessment at the Seaside View Child Development Centre.

Claire Edwards, who manages the team, says they've made a good start. "We've begun to work with the children, met them at home and in their nurseries, and devised an individual plan for each child which will be delivered by their key person at their nursery."

The team have also begun advising on things like adapting the home and nursery environment to improve communication; providing visual supports for language; setting up and supporting language groups; strategies parents can use in the home; and Makaton training for nursery staff and parents.

If any parent or carer would like to attend a **Makaton training course** to support their child's talking, email: [Stephanie.parker@brighton-hove.gov.uk](mailto:Stephanie.parker@brighton-hove.gov.uk). Your child does not have to be getting support from the service or seeing a Speech and Language Therapist to attend.

# Our Amazing Lizzie

Amaze's 20<sup>th</sup> birthday marks another major milestone: two decades of extraordinary support for families from our DLA project manager, Lizzie Batten.

Lizzie's ceaseless capacity to care, her energy, charisma and ability to convince people just how important this work is, have been a driving force in Amaze's development over the last 20 years.

## Founding member

Lizzie was part of Amaze before it even was Amaze, as our Chair and Trustee, Hugh Clench, remembers: "I first met Lizzie in 1988 when I was working as an educational psychologist in East Sussex. She joined a parent support group I ran, which led to the establishment of the Network of Parents, that later combined with the East Sussex Parent Link Project to create Amaze in 1997."

In these early days, as one of only three staff, Lizzie would turn her hand to anything that would help parents. She covered the helpline, gave one-to-one support, created the newsletter and wrote huge chunks of all our handbooks and our first set of factsheets. She also made our first events happen, negotiated some of the first deals on the Compass Card and spotted the need for us offer advice on transition to adulthood. Perhaps most significantly, she saw how hard claiming Disability Living Allowance (DLA) was for parents and how many families were missing out. She was convinced Amaze could help, so she ran a DLA pilot project to prove this and worked tirelessly to secure the funding we needed.

Hugh points to Lizzie's strong personality as one of the crucial factors in the project's success:

"She wasn't the easiest parent I worked with (!) but her determination

not to accept the status quo has led to the huge success of Amaze, in particular the DLA project, which now brings an average £3m in additional income to local families with disabled children every year."

**"Filling out the DLA paperwork is one of the most depressing tasks a parent has to do. Having Lizzie's help makes the situation bearable and also quicker."**

## Parents' champion

The DLA project is, of course, how most parents know Lizzie. And we know just how much her support means to you from the constant stream of thank you cards (and chocs) that pop through our letterbox most weeks, and the evaluation forms you kindly fill in after you've had our support. We could honestly fill pages with quotes about your appreciation of Lizzie's work, but this one is typical: "Lizzie was excellent. She gave me support to challenge some of the medical reports that I thought were inaccurate but felt I didn't have the power to do anything about it."

## Chief talent spotter

Another of Lizzie's special gifts is the ability to spot parents who, with a bit of recognition and encouragement, could be persuaded to come forward and be part of a community of mutual support. She draws people in to contribute their experiences to a factsheet or a funding bid, to become



a parent rep, a trustee or train as a volunteer.

**Debby Norris**, Amaze's Treasurer, remembers her first meeting with Lizzie and what a huge impact it had: "None of the local professionals wanted to support a DLA claim for my daughter so I called Lizzie to let her know I couldn't get the documents we needed for the claim. Her sigh in reply was so powerful. She didn't let it lie. She came to see me that Friday, squeezing me in round another appointment. It was Good Friday! When she arrived I had coffee and bacon sandwiches ready but I just plonked hers by all the paperwork and carried on with my cleaning. I remember that moment so clearly. She just stared at me until I turned and looked at her and she calmly said, 'I'm not eating unless you do'.

"She made me feel as if I mattered, and gave me a focus when I was feeling so powerless, lost and depressed. It started a friendship that has led me to work with Amaze ever since so that others will have the same support I did and never feel alone."

**Fiona England**, Chair of the Parent Carers' Council (PaCC), had a similar experience of Lizzie's unique brand of empathy and straight-talking and says it's a big part of why she's now involved in PaCC. "I was in a terrible state when Lizzie started to help us with my son's DLA and a long-winded



Direct Payments saga. It had all just got too much and I think I'd kind of given up. She came to visit and I knew she cared but she also gave me this look - a kind of no-nonsense, 'you're-just-going-to-have-to-carry-on-because-what-else-can-you-do' look, which was exactly what I needed and it got me out of the fog. Her support was fantastic and it 100 per cent led to me to getting involved with PaCC."

**Debbie Collins**, Sussex Independent Support (IS) Coordinator, started out as a DLA volunteer after Lizzie helped with her daughter Zoe's DLA claim but she has continued to get help too.

"I did Lizzie's first ever DLA volunteer training course and because I had a medical background she sent me out to do all the medical ones. Being a DLA volunteer gave me the confidence to get involved more with Amaze and then PaCC. I became PaCC Chair in 2009 and now I coordinate IS across West and East Sussex - I'm doing for others what Lizzie did for me."



### One in a million

Everyone that knows Lizzie agrees she is extraordinarily good at making stuff happen for families with disabled children - if only we could agree on what makes her so successful.

Debbie Collins thinks it's her enthusiasm and tenacity, "She's like a dog with a bone"; Debby Norris points to "her total honesty and passion."

Hugh Clench, who has known her longest, thinks it's her "dedication, commitment and unfailing empathy and sympathy for parent carers, especially those who are economically disadvantaged, hard to reach, who have special needs themselves, or who are simply ground down by the stress of having a disabled child."

Whatever it is, we wish every SEND community had a Lizzie but we're eternally grateful she's ours. Amaze CEO, Rachel Travers, sums up for all of us: "The impact Lizzie has had for families with disabled children is immense. She has been at the heart of Amaze for a generation and I'd like to say an enormous thank you to her on behalf of us all."

**"Your relentless care, even when I'm flagging with all we had to get our heads round. We can't thank you enough. Lost for words."**

## Help us shape the next 20 years at Amaze

As well as looking back over the past 20 years, it is a critical time for Amaze to be considering our future too. Every few years Amaze reviews its strategy and checks to make sure we are meeting the needs of children and young people with SEND and their parent carers and wider families as best we can, given our funding levels.

**We would really like to hear what you think**, so please take two minutes to answer these very quick questions below. Cut out the completed form and send it to FREEPOST SEA 14216, Brighton, BN1 3ZZ.

### 1. What are the best things about Amaze's services?

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### 2. Looking to the future, what could Amaze do more of, less of, or differently?

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### 3. Are you (tick) a: ☐ child (under 16)

- ☐ young person (16+)
- ☐ a parent/carers
- ☐ another relative
- ☐ a professional
- ☐ Amaze staff/volunteer

### 4. Are you from: ☐ Brighton & Hove

- ☐ East Sussex
- ☐ West Sussex

You can also complete the survey online at [www.surveygizmo.com/s3/3852867/Amaze-Strategy-Review-Survey](http://www.surveygizmo.com/s3/3852867/Amaze-Strategy-Review-Survey)

# Spotlight on our Peer Supporters

Meet some of our fantastic Amazing Futures volunteers and find out about the world they'd like to live in.

In July, we told you that our Amazing Futures Project would be training up young people with and without SEND to be volunteer peer supporters for other young people with additional needs. We now have a great team of fully-trained volunteers getting to know the young people at our peer support groups.

Volunteers will be matched up with young people looking for one-to-one support with developing skills and independence, exploring interests, or thinking about future goals.

We'll be introducing you to a few of these brilliant volunteers each newsletter. This term, meet **Brandon**, **Eliph** and **Thea**!



## Brandon, 19

Currently studying at college, and volunteering with Shelter, Brandon became a peer supporter because he wanted to help young people become more independent and learn to support each other. He told us it makes him happy to be able to help.

He likes to go to the cinema, watch football, and go out with his friends,

and he hopes to work in a shop or with computers when he's older, as well as travel the world.

If Brandon ruled the world, everyone would have to:

1. Be nice to everybody
2. Have more chocolate
3. Have more fruit



## Eliph, 21

Eliph currently studies art at the Friends Centre, where she also teaches beginner's sewing. She would like to work supporting children with additional needs, or in a museum. She enjoys dressmaking and art, and recently started learning to quilt – she always has projects on the go!

Eliph became a peer supporter because she received peer support in college and found it very helpful. She likes the idea of giving back and gaining skills at the same time.

If Eliph ruled the world, the three rules everyone would have to follow are:

1. Everyone is treated equally regardless of age, nationality, gender or disability
2. Everyone is financially supported to achieve their dreams and reach their potential
3. Everyone gets a puppy



## Thea, 24

Thea studies Floristry at Plumpton College, and would like to have her own florist's shop one day. She is also a carer for her mum, who's blind and needs help 24 hours a day. Thea became a peer supporter because she really likes helping people out, and wanted to help young people learn and gain confidence. She enjoys theatre and the creative arts, but she also likes to kick back and watch a film or hang out with her friends.

If she ruled the world, the three rules everyone would have to follow are:

1. Stop fighting and be kind
2. Be yourself and have fun
3. Don't be shy and have confidence in yourself

## Interested in Amazing Futures peer support?

If you're 18+ with or without SEND and would like to join our team of Peer Supporter volunteers, or if you're 14-25 with SEND and would like to have a Peer Supporter, please contact Sue Winter on 07482 111648 (Tuesdays, Wednesday or Thursdays) or email [sue@amazebrighton.org.uk](mailto:sue@amazebrighton.org.uk)



## Home to school transport issues

Home to school transport remains a sticky issue for some local families, with stress peaking at the start of the school year in September. PaCC is working hard with the local authority to make the process work better next year.

PaCC knows that some families started the school year not feeling well-informed or confident about how their child would get to school. And from the School Transport Review recently announced by the Secretary of State for Education, after a concerted campaign by Contact, it's clear that difficulties with school transport for disabled children are happening all over the country.

Some local parent carers tell us that they are still being told about transport decisions, including driver and escort information, far too late. We have discussed this with Anna Czepil, Head of SEN Statutory Services at Brighton & Hove City Council and Richard Barker, Head of School Organisation. Anna says, "The SEN and Transport team are working with PaCC to review and improve the current transport application process. Our aim is for parents to be aware of transport arrangements before the summer holidays wherever possible. We want to work with schools and families to receive annual application forms earlier in the year - we want to make the process more simple and timely overall."

PaCC is pleased that we will now be **meeting termly with the local authority** to try and improve the school transport process for September 2018.



We were also pleased to see the council communicating swiftly via Amaze and our partner groups' social media channels that transport would remain in place at the start of this current term, if families hadn't heard anything.

### Statutory duties round transport for 5-16 year olds

PaCC is keen to make sure that parent carers understand the government's eligibility criteria for home to school transport. Eligibility is quite straightforward to understand and we urge you to read these clear new guidelines from Contact (previously

Contact a Family)

[www.contact.org.uk/advice-and-support/education-health-social-care/education/transport-to-school-and-college/#England](http://www.contact.org.uk/advice-and-support/education-health-social-care/education/transport-to-school-and-college/#England). PaCC has requested that the local authority also share these guidelines with parent carers.

### Post 16 Transport

The national guidelines for post-16 transport are different - eligibility is not so straightforward as when your child is under 16. This year Brighton and Hove will review the post-16 transport policy and PaCC is working with Richard Barker to ensure that parent carers are kept fully informed during this process. PaCC feels strongly that parent carers of post-16s should not have to give up work in order to take their young people to school or college. They should also be able to take their younger siblings to school. We will be looking to see that the new policy ensures that parent carers can maintain these essential aspects of family life.

The final bit of work PaCC is doing in this area is ensuring that home to school transport remains a top priority in the next stage of **planning the new special school hubs**.

Looking to the future, the local authority is keen to improve processes around home to school transport, so please do let us know if you have any suggestions by emailing [admin@paccbrighton.org.uk](mailto:admin@paccbrighton.org.uk).

**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](https://www.facebook.com/groups/parentcarerscouncil)**





## A great day for disability

The first ever Disability Pride in the country was right here in Brighton and Hove and PaCC was part of the action.

On a beautifully sunny day back in July, thousands of people from the Brighton and Hove community got together to celebrate Disability Pride.

Organiser Jenny Skelton was moved to create the event, the first of its kind in England, after her disabled daughter Charlie experienced discrimination in a pub during last year's Pride festivities in Brighton.



PaCC Administrator, Jo, and her son Freddy enjoying the bubbles on the day

Her aim is to make Brighton a more inclusive and welcoming place for everyone – and she hopes that Disability Pride will encourage this.

Amaze joined in the fun with a stand on New Road, and PaCC held a picnic in the Pavilion Gardens which was a great success. Lots of our members and their families came along to enjoy face painting and a fabulous bubble show.

As a first time event there were inevitably a couple of teething troubles – for example, the electric cable covers made it hard for wheelchair users in some areas – but these minor issues didn't detract from the overall joy of the day. As Lisa Russell, a PaCC mum who attended said: "What an amazing, uplifting event for all ages. It was lovely to be a part of and it can only get bigger and better from here. Let's hope all of Brighton and Hove celebrates Disability Pride next year". Find out more at [www.disabilitypride.org.uk](http://www.disabilitypride.org.uk).

## PaCC Awards

Thank you for all your nominations for the PaCC Awards 2017. It's always a pleasure to hear about those individuals or teams who've really gone the extra mile in their work to support our children and young people and ourselves.

The awards will be presented on Friday 24<sup>th</sup> November at the Amaze AGM and 20<sup>th</sup> Anniversary celebrations – see the front cover for details. For information about previous winners go to:

[www.paccbrighton.org.uk/what-we-do/pacc-awards/](http://www.paccbrighton.org.uk/what-we-do/pacc-awards/)



## Safety Net for parents

Julie Stokes, the Children and Families worker from Safety Net, has recently come along to some PaCC coffee mornings, talking to parents about the parenting challenges they face. Our coffee mornings are held regularly in Whitehawk, Moulsecoomb and Hangleton.

Julie's been looking at 'Giving Clear Instructions' and parents have talked together about their experiences and considered some new strategies they might try.

There are other free Safety Net events that parents can attend. Julie is currently running workshops on 'Self Harm' and 'Anxiety' across the city. If you are interested, email [julie.stokes@safety-net.org.uk](mailto:julie.stokes@safety-net.org.uk).

Safety Net works with children, schools and families to promote wellbeing and help keep children safe. Visit [www.safety-net.org.uk](http://www.safety-net.org.uk) for more information.





## Inclusion in mainstream schools

Working together to help our children succeed.

PaCC repeatedly hears feedback about the struggles of children and young people in mainstream schools, as well as how difficult it is for parents to get their voices heard. PaCC has been particularly struck by the variability across the city.

### PaCC has identified work with mainstream schools as one of our priorities.

PaCC has therefore identified work with mainstream schools as one of our priorities. In the context of funding pressures on schools, where cuts can disproportionately hit children with

SEND, it is increasingly important to ensure the voice of parents and carers is heard in all schools.

Since PaCC does not have the capacity to work with every school, we have taken steps to work across schools. Our reps now attend both the primary and secondary SENCO forums and, earlier this year, we hosted a PaCCConnect all about inclusion in mainstream schools. A large number of parent carers came along, as well as representatives from the local authority, Councillor Vanessa Brown, and SENCOs. The aim of the session was to gather parent views on what works around inclusion in mainstream schools, and what doesn't. These

valuable views have been compiled into a report, which is being shared with the SENCO forum, heads forum, and the SEND Partnership Board. Read the full report on our website at [www.paccbrighton.org.uk/resources/reports](http://www.paccbrighton.org.uk/resources/reports).

We're currently identifying areas for future strategic work with schools and the local authority, such as ensuring children with EHCPs are more able to attend their local school, and embedding co-production between schools and parent carers. PaCC is also asking for a city-wide commitment that cuts to provision do not disproportionately affect children with SEND.

We see this work as the start of a process to improve consistency of inclusive practice across Brighton and Hove, to do all we can to ensure our children reach their full potential.

## Your views on pharmacies and medicines

Just before the school holidays we asked parent carers about their experience of using pharmacies. Specifically the role of pharmacies around prescription and management of medicines and how parent carers and their children could be more included in this.

We found out that the majority of parents were happy with the explanations of what medicines are for, what they do and possible side effects. However, considering that many parents and their children take multiple medicines they would like to know **more about interactions between different medications**.

Parent carers are confident enough to ask their pharmacist for more information about the medicines, and 79 per cent of parent carers can easily find and use an open pharmacy when they need

one. However some parent carers suggested the quality of information and advice could be improved. They also felt having a **private space where they could speak confidentially** with the pharmacist would be useful.

Whilst the majority of parent carers are aware of many of the different services that a pharmacy can provide, only 42 per cent knew that the pharmacist can review and help manage their medications and/or provide health checks. We also found that just over 10% of parents who took part in the survey preferred to take alternative remedies or not to take medicines at all when they are ill.

Overall parent carers are satisfied with pharmacy services. However, parent carers find the management of repeated prescriptions very challenging. **Better communication between GP and pharmacy**, and coordination of the different agencies



involved could resolve some of these issues.

This report was sent to the local Clinical Commissioning Group and Brighton & Hove City Council who, through their Brighton & Hove Communities and Third Sector Investment Prospectus (TSIP), fund Amaze and PaCC to gather information and recommendations on health care and social care services.

**Read the full pharmacies report at [www.paccbrighton.org.uk/resources/reports](http://www.paccbrighton.org.uk/resources/reports)**



### Benji

This is Benji (age 5) in an adventure playground. He loves all things in playgrounds, especially swings, but has recently got into climbing frames and the like, which is great for his physical skills but quite challenging for his parents! As someone who is not walking on his own yet the play area as a destination is a real motivation to walk. He finally got rid of his tracheostomy in September so we can now go to these places



with a lot less equipment which makes getting there and playing there much more straightforward. He also started school in September and is loving it. The school have been great at learning how to deal with his gastrostomy, his hearing aids and the challenges that having Downs syndrome can bring. On, and he loves the climbing frame there as well. Benji also really likes water play!



## PaCC Calendar

We're hoping to have secured funding for our much-loved calendar by the time you're reading this newsletter. In the meantime, we're working to put it together to be sent out in time for Christmas. Our theme for this year is 'My Brighton'.

Is there a place in Brighton that your child just loves to be? Would you like your child to star in the PaCC Calendar 2018? Your child could even take one of the pictures themselves.

We can't wait to see your lovely entries. Email your submission to [admin@paccbrighton.org.uk](mailto:admin@paccbrighton.org.uk) with two good quality photos and a short paragraph explaining why your child loves that particular place. Entries will be taken on a first come, first served basis.

## Stay connected

PaCC members will now receive an e-bulletin every quarter to keep you updated with our latest news.

If you'd like to receive the bulletin and you're not already a member of PaCC, you can join us by visiting our website: [www.paccbrighton.org.uk/get-involved/join-the-pacc](http://www.paccbrighton.org.uk/get-involved/join-the-pacc)

You can also join our Facebook group. Visit [www.facebook.com/groups/parentcarerscouncil](https://www.facebook.com/groups/parentcarerscouncil) and send us a request to join.



# Drusillas day out

It seems a long time ago now, but in August a group of families from the **Moulsecoomb Sunflower Support Group** and **Whitehawk Coffee Morning** treated themselves to a day out at Drusillas Zoo Park, near Alfriston, East Sussex.

The outing idea came from the parent carers who attend the coffee mornings, and it was made possible thanks to funding from East Brighton Trust and contributions from Amaze and Trust for Developing Communities (TDC), which paid for travel on a Big Lemon coach and entry to the Park.

Everyone had loads of fun, with lots of activities, animals to see and large play areas for the children. The outing gave the families a bit of relief, fun and time to relax.

One parent commented: "My kids absolutely loved it! It was great for them to be in a big group with other kids and to make new friends."

The coffee mornings, currently running in Moulsecoomb, Whitehawk and Hangleton & Knoll, are a space for parent carers to come together, feel less isolated and find out about

services available for them and their families. Each coffee morning focuses on a topic which is suggested by the parent carers. During the next few months we will look into changes around CAMHS services, how to give clear instructions to your child and the council's Local Offer website.

Email [paolo@paccbrighton.org.uk](mailto:paolo@paccbrighton.org.uk) to find out more or call 01273 234862.

You can also find details of upcoming coffee mornings in the events section of the Amaze website at [www.amazebrighton.org.uk](http://www.amazebrighton.org.uk).



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

contact For families with disabled children

Department for Education



# Amaze seeks 20 extra special corporate partners

Can your company help fund the next 20 years of Amazing support for families with disabled children?

2017 is our 20<sup>th</sup> birthday year. To mark the occasion we are launching the **'Generation Amaze'** campaign to celebrate the impact we have had over the last 20 years and raise money to support the next generation of families who need our help.

For our 20<sup>th</sup> birthday we would like to develop **relationships with 20 Amaze Partners, each willing to donate £1,000.** For this, they'll receive the following benefits:

- Company logo, information and contact details on our website at [www.amazebrighton.org.uk](http://www.amazebrighton.org.uk), which has nearly 40,000 visitors per year
- A quarter-page feature article specific to your company in an edition of the Amaze Newsletter, circulation 17,000 (three editions per year)
- Invitation for your staff to attend a champagne reception to hear more about our work and meet some young people with additional needs, as well as Amaze staff and supporters. You'll also be able to network with other partners
- Acknowledgement in a short film which will be shown as part of our 20<sup>th</sup> birthday celebrations and used on social media channels
- The chance to sponsor some of our prestigious public-facing events such as BIG Cheer for Amaze
- Promotion across other key Amaze communications, such as social media, our e-bulletin and website
- Acknowledgement in press releases sent to local media
- Our logo, strapline and links for your use in your own promotions
- Opportunities for employees to get



celebrating twenty years  
and our first generation of  
amazing young lives

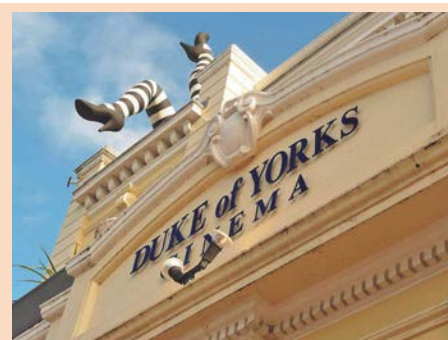
involved in team-building and fundraising events

- A chance to meet your corporate social responsibilities by supporting a really worthwhile, local cause

Just as importantly, we are also seeking **opportunities for disabled young people to gain work experience**, employment skills and confidence in the work place.

In Brighton and Hove, 42 per cent of 20 year olds with special educational needs are not in education, employment or training compared to 7 per cent of their non-disabled peers (BHCC SEND Review 2015).

Please contact Nicky B if you could offer a work placement, skill session or tour of your organisation, or if you are a company (or are connected to a company) that might like to be one of our partners. Just call Nicky B on 01273 234014 or email [nickyb@amazebrighton.org.uk](mailto:nickyb@amazebrighton.org.uk).



## On the big screen

Local film makers, Nuepix, have been visiting a number of families and Amaze events in recent months to try to capture the essence of Amaze's work over the last 20 years in a short film.

**'Generation Amaze'** will be shown in a **private viewing at the Duke of York's Cinema** in Preston Circus, on 4<sup>th</sup> December from 6 to 7.45pm.

We are inviting corporate partners to celebrate with us, so if you know of any local businesses that might like to attend, contact Nicky B on [nickyb@amazebrighton.org.uk](mailto:nickyb@amazebrighton.org.uk). You will be able to view the film on our website and Youtube channel too.

On the night we'll also be celebrating our new Amazing Futures team of young people peer supporters – read about some of them on page 6.



## Star bakers

A huge thank you to Andrew and Harry from Cottesmore St Mary Catholic Primary School, Hove. They raised just over £100 for Amaze from a school cake sale.



## Universal Credit hits hard

Universal Credit is a radical, new means-tested benefit for people in or out of work and it's rolling into Brighton and Hove now.

The government says UC will make claiming benefits simpler and make it easier to move from welfare into work. Campaigners say UC is tipping more families into poverty.

The changes affect single people, couples and households with one or two children. There will be no new claims for Income Support, Income-based Job Seekers Allowance, Working Tax Credit, Child Tax Credit, Income-related Employment and Support Allowance or Housing Benefit. If you are already claiming any of these benefits and you report a change of circumstances or have a break in your claim, you will be moved to Universal Credit. For the time being, families with three or more children will remain on existing benefits, because the new IT system cannot process more complex claims.

### Key features of UC

**Claims can only be made online and you will need an email address and a bank account.** You may be able to get support with making a claim but you'll need to ask for this right at the start.

**You'll have a work coach and an online journal** and you'll be expected

to meet with a work coach regularly. The journal is a way of communicating with your work coach, recording details of work searches, interviews, training and so on.

**The right to benefits comes with new responsibilities: most claimants are required to be available and searching for work 35 hours a week!**

You have to sign a 'claimant commitment.' And even if you're in work, you may have to skill-up or look for more hours and better pay.

**Certain conditions apply to claimants with additional needs.** People getting DLA or PIP will have to 'pass' a Limited Capability for Work assessment and claimants who were previously in the work-related activity group of ESA will be expected to make preparations towards being ready for work. Claimants with children as young as two will need to attend work-focused interviews. And there will be sanctions if you fail to comply.

**There are no conditions for carers.** To be sure you count as a carer, your child needs to be getting at least the middle rate of the care component of DLA and you need to be their primary carer. Pregnant women and claimants

of Pension Credit age are also exempt.

**The Benefits Cap was also tightened last year to £384.62 a week for households with children:** this amounts to £20,000 a year and includes housing costs. The Benefits Cap does not apply to households claiming DLA, PIP or ESA support so if you're not already claiming DLA or PIP for someone in your household who is sick or disabled, make this a priority.

**Households will make a single claim and couples will usually have to decide who will claim.** This doesn't mean leaving the responsibility to someone else. Make sure you're involved in your household finances - check statements and bills together.

Universal Credit will only be split if you have good reason to believe payments made solely to one partner will leave the household in hardship, and you must make this clear when you claim. We suspect you will need to be frank about a past history of debt as a result of gambling or addiction, or domestic abuse.

**Universal Credit includes housing costs.** If you are already in rent arrears and your tenancy is at risk, or there are other compelling reasons why you need the housing element of your UC paid directly to your landlord, be clear about this the first time you meet your work coach.

**Payments will be made monthly by credit transfer, like salaries,** so it may be harder to make the money last. You might want to arrange to pay regular outgoings by direct debit so that these leave your bank account a few days after your Universal Credit is paid. But before you can do this you'll need to get over the next hurdle...

**The first seven days of a claim aren't counted and payments are made four weeks in arrears,** so your first payment is unlikely to be made for about six weeks. Most families are unlikely to have funds to bridge this gap so it's worth planning early by cutting out non-essential spending,



cutting back on essentials and rescheduling debt if you can. Consider saving with the East Sussex Credit Union to access an affordable loan if you need it.

**The DWP can make 'advance payments' on account to cover delays and one off expenses** but you will need to demonstrate that you cannot meet basic unavoidable costs by other means. Make a list of all your outgoings for food, travel, mortgage, rent, utilities, minimum debt payments, etc. and any penalties you might get for late payments. You will need evidence to back this up such as bank statements, receipts, etc. Show how you have trimmed your expenditure over the last few months so your work coach can confirm you've made every effort to make ends meet. If your bank can't offer or extend an overdraft, include evidence of this too.

## Better or worse off?

The government says UC directs support towards the most vulnerable families but this doesn't bear scrutiny. Though they guarantee that no one will be worse off at the point of moving over to UC, this 'transitional protection' ends when you notify the DWP of most changes of circumstances or if there's a break in your claim. New claimants will be worse off than if they'd been able to claim equivalent 'legacy' benefits.

A reduction in the basic disability addition for children under UC means that unless your child gets the highest rate of the care component of DLA, once any transitional protection is broken, you will be worse off. We think this means that **at least half of families with disabled children are likely to be worse off under Universal Credit**. For more advice on UC, contact Hove-based Money Advice Plus ([www.moneyadviceplus.org.uk](http://www.moneyadviceplus.org.uk)) or the local Citizens Advice Bureau ([www.brightonhovecab.org.uk](http://www.brightonhovecab.org.uk)). And read more on UC in the next issue.

# Amaze courses and workshops

We are taking bookings now for four really useful workshops taking place either side of Christmas:

## Bullied at school?

**Fri 17<sup>th</sup> November, 9.45am to 1pm, Amaze Meeting Room, Community Base.**

This session, run by Amaze IAS advisors, will look at what to do if you think your child is being bullied.

## Preparing for the future – wills and trusts

**Weds 13<sup>th</sup> December, 10am to 12.30pm, Conference Room, Community Base.**

Let Phil from Renaissance Legal guide you through the best way to plan ahead for your child by writing a will and look at whether setting up a trust is the right plan for you.

## Personal Independence Payments (PIP)

**Thurs 8<sup>th</sup> February, 9.45am to 1pm, Conference Room, Community Base.**

PIP has replaced DLA for everyone over 16. Lizzie will explain how claiming PIP is different from DLA and how to involve your son or daughter in their claim so they are ready for the face to face interview.

## Disability Living Allowance (DLA)

**Thurs 15<sup>th</sup> February, 9.45am to 1pm, Conference Room, Community Base.**

Get ready for your next DLA review. Lizzie – our disability benefits guru – will help you be prepared to put in a really strong claim.

We have two **Insiders' Guide courses early in 2018**. They aim to build your resilience with a mix of practical ideas and time to look at how it feels to have a child with additional needs. All Insiders' Guide courses are co-delivered by a professional and a parent carer who has been there too.

## Insiders' Guide for parents of teens

**Friday mornings 10am – 1pm: 26<sup>th</sup> Jan, 2<sup>nd</sup>, 9<sup>th</sup>, 23<sup>rd</sup> February, 2<sup>nd</sup> and 9<sup>th</sup> March, Hillside School training room**

Join other parents of disabled teenagers to look at the new issues we face as our kids grow up. With Sue from Amaze and Louise, a parent of a teenager.

## Insiders' Guide for parents of children with ADHD

**Six mornings starting in February, date and venue to be confirmed**

Understand your child with ADHD better, and build up your skills and survival strategies alongside other parents in the same position.



Parents completing one of our Triple P courses earlier this year.

**All our workshops and courses are free. To book or register your interest, email [info@amazebrighton.org.uk](mailto:info@amazebrighton.org.uk) or call our helpline on 01273 772289**



## Are you making the most of your Compass Card?

More than 2,000 children and young people in Brighton and Hove now have Compass Cards\*. But are you making the most of the card and all the offers, freebies and special deals it brings? The six steps below will ensure you are.

### 1. Know your Compass Card offers

There are now around 160 Compass Card offers at about 260 places across Sussex and beyond, so even we find it hard to keep up! Make sure you have our free Compass Card app on your iPhone or Android phone and you've got the most up to date version. Just search 'compass card' in the App Store or Google Play and download the Brighton and Hove version. Now you can easily search for offers, or filter offers according to your interests. You can also map them too and look for offers in a particular location.

### 2. Don't forget the Compass Card website

If you don't have an iPhone or an Android phone, or you want to search through offers on a tablet, laptop or desktop computer, head to the

Compass Card website offers page at [www.compasscard.org.uk](http://www.compasscard.org.uk). All our offers are there too because the app talks to the website; such is the joy of modern technology!

**There are now around 160 Compass Card offers at about 260 places across Sussex and beyond.**

### 3. Free things

Compass Card offers are just the beginning of the story. We also give away hundreds of **free tickets** to Compass Card families every year via our weekly e-bulletin, Compass Team News B&H. So make sure you check your inbox on a Thursday evening. The e-bulletin is also packed with info on new offers, special theatre deals, one-

off Compass Card events, leisure news and much more.

### 4. Instant information via Facebook

Our **Compass Card Facebook page** is full of topical leisure information, including the latest autism-friendly screenings; leisure prize draws; news on what the Compass Team is up to; and leisure stories from further afield. Just search 'Amaze Compass Card' and 'like' us on Facebook to keep up to date.

### 5. The Carers' Card

If your child or young person has a Compass Card Brighton and Hove, you can also apply for a Carers' Card for yourself and anyone else who has an ongoing caring responsibility for your Compass Card holder – including siblings over eight, who can get a Young Carers' Card. The Carers' Card gives you discounts on a whole range of things designed to help you look after your own health and wellbeing – including Keycard discounts on Brighton & Hove Buses, and deals on yoga, meditation, cinemas, theatre tickets, complementary therapies and sports centre membership. You can apply online for a Carers' Card and it's quick and simple. For details of where to apply, see below.

### 6. Gully's Days Out

You can also apply for a Gully's Days Out card if your child has a Compass Card. The card costs £15 per year and entitles you to free tickets at a range of venues across Sussex.

To find out more about the **Carers' Card and Gully's Days Out Card** and to apply, visit [www.compasscard.org.uk/compass-card-offers/carers-card-gullys-days-out](http://www.compasscard.org.uk/compass-card-offers/carers-card-gullys-days-out)

\*The Compass Card is for children and young people aged 0-25 in Brighton and Hove and West Sussex who have significant special educational needs and/or disabilities.



# Ask an expert

Phil Warford from Renaissance Legal and Gillian Kitchener, SENDIASS adviser, answer your questions.

**I'm about to write Letters of Wishes to support my Will and Trust Deed, what should I include?**

**Phil says:**

"A Letter of Wishes gives you the opportunity to express your personal wishes using language that is not as formal as that used in a Will or Trust Deed. These Letters do not form part of the Will or Trust and can be amended easily in the future.

Typically, Letters of Wishes cover:

- **Funeral wishes** - Most wills include a clause stating a preference for burial or cremation, but you might like to tell your family and friends additional information about the send-off you would like, e.g. hymns and where the service will take place.
- **Letters to Guardians** - The guardians appointed in a will are responsible for making decisions about the welfare of a child whose parents have died before the child reaches 18. A Letter of Wishes can tell the guardians about areas of your child's life that you want them to



know about. For example, the education your child should have, the friends and relatives they should keep in contact with, the activities your child enjoys or lifestyle choices that the family have made that you would like your child to continue with.

- **Personal belongings** - Many wills make no reference to personal items. In a Letter of Wishes you can give your Executors information about how you would like your personal belongings to be distributed.
- **Letter to Trustees** - Arguably the most important, this covers a personal overview of what the Trustees should consider when using the Trust fund to benefit your family, for example the football clubs they follow or what they enjoy doing. If you have a child who is disabled or has SEN, then this might include things like medical treatment that your child needs. You may also like to give some guidance about your wishes for your child's living arrangements, with the Trust fund helping out where benefits are not sufficient.

Remember to keep the Letters of Wishes under review and update them when things change. And come along to Phil's free **Wills and Trusts workshop** at Amaze on **Wednesday 13<sup>th</sup> December** for more advice - details on page 13.

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

**"I've got to find a primary school for my little girl who's just been diagnosed with autism and I don't know where to begin. Can you help?"**



**Gillian says:**

"Finding the right school for a child with additional needs can take longer and will probably involve meeting and talking to more people. Read the council's **School Admissions booklet**

to check the deadline and practicalities of applications and start doing your research as early as possible.

"Most children with additional needs, including those with an Education, Health and Care Plan (EHCP), attend mainstream schools, so look at your local schools first. If your child has an EHCP, you can include special schools in your search too.

"A good place to begin is Brighton and Hove's **Local Offer** at [www.brighton-hove.gov.uk/localoffer](http://www.brighton-hove.gov.uk/localoffer). All the city's mainstream and special schools have a page on there that explains how they support children with special educational needs and disabilities with links back to the school's website to find out more.

"Attend as many school **open evenings** as you can. You should also make an appointment with the **special educational needs or inclusion coordinator (SENCO)** at your favourites, to have a more detailed discussion about your child's needs. Find out if the staff have experience of teaching children with similar needs; if not, are they willing to learn and do they have the support to learn these new skills?

"If possible, make any **appointments during school hours** so you can have a sense of how the school works, what space is available and whether you can imagine your child there. And don't forget to ask other parents of older children with similar needs. They will give you the best sense of how a school supported their child.

"Download Amaze's **"Choosing a School" fact sheet** at [www.amazebrighton.org.uk/resources/publications/fact-sheets](http://www.amazebrighton.org.uk/resources/publications/fact-sheets). It includes a list of helpful questions to ask. Ask the same questions at each school to help you compare and contrast the schools.

"And remember **Amaze can help**. Whilst we cannot recommend a particular school to you, we are able to help you think through the process. **Call our helpline on 01273 772289 to talk through your options.**"



## Autism Aware Award winners

Three more local schools recently completed their Autism Aware Award (AAA), which demonstrates their commitment to and knowledge about supporting pupils with autism. Congratulations to **West Blatchington Primary** (pictured here), **Goldstone Primary**, and **Stanford Juniors**, who join a group of other schools who've already completed the award such as St Luke's and Hove Park.

Specialist staff from the three award-winning schools were given their AAA certificates by Mo Bham, Head of Brighton & Hove Inclusion Service, at the forum for primary SENCOs in October. More local schools will be working towards their AAA in the coming months.



## Carers Rights Day

Amaze and PaCC will be marking **Carers Rights Day** on **24<sup>th</sup> November** by asking parents and carers to share their stories about what it's like to care for a child or young person with additional needs and what help they need in their caring role. You can share your stories on our Facebook group, Twitter (using [#CarersRightsDay](#)) or in person at our AGM event also on 24<sup>th</sup> November - see the front page for full details.

# Amazing Futures Talent Show

Calling all budding performers for an amazing celebration of talent on Friday 15<sup>th</sup> December.

As part of our 20<sup>th</sup> birthday year celebrations we're holding an **Amazing Futures Talent Show** for children and young people under 25 with special educational needs and disabilities.

We are really excited to see what kinds of talents our young people want to share. It might be singing, dancing, juggling, magic, playing an instrument or maybe a bit of poetry or acting. Anything goes, and if you tell us in plenty of time we may be able to provide musical accompaniment for your act.

The talent show is on **Friday 15<sup>th</sup> December, 7.30 to 10.30pm** in the Conference Room at Community Base,



113 Queens Road, Brighton BN1 3XG.

Tickets cost £2.50 and we'll be providing some refreshments. If you'd like to perform in the show, contact Sue on 07483 111648 or email [sue@amazebrighton.org.uk](mailto:sue@amazebrighton.org.uk). Or just come along to cheer on the talented performers.

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 2.30pm



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