

# out of amaze

For families with children and young people with SEN and disabilities



## More Amaze support in East Sussex

After supporting Brighton & Hove families for 20 years, Amaze has secured funding to extend some of our best-loved services to families in East Sussex too.

### Information, advice and support

Since September of last year, East Sussex families have been able to get advice and support from Amaze via our **SENDIASS helpline** (read more on page 4).

Alongside this telephone support we've been busily building up our East Sussex written information including this **newsletter** (welcome to the first joint edition!), **fact sheets** and an **updated website** that's packed with information for parent carers and young people across Sussex.

We hope to be offering regular **workshops** to families in East Sussex and Brighton & Hove on issues like EHC Plans, preparing for adulthood and SEN Support. See page 15 for details of what's coming up soon.

### Help with DLA and PIP

East Sussex families can already attend any of our **DLA or PIP workshops** (including those in Brighton) or call the helpline for advice on claiming disability benefits. And over the next few months, Amaze is working in

partnership with **Citizen's Advice Hastings** to develop a pilot project that will provide more **targeted advice** for families who need extra support with claiming DLA or PIP. This will complement the brilliant work Citizen's Advice volunteers are already doing.

### Amazing Futures

Launched in Brighton & Hove in 2017, Amazing Futures offers peer support and group activities to young people aged 14-25 with special educational needs and disabilities (SEND). We're really excited to be expanding Amazing Futures into East Sussex and are now **looking for Peer Supporters aged 18-25** who can help support **young people with SEND** (see below). The project is open to anyone across the county but will run out of Eastbourne initially.

The East Sussex fun really starts on **29 November** with regular Thursday evening **support and activity groups for young people with SEND** including an art session and a games and pizza night, all at the DC3 Project Space, Eastbourne. Contact Claire Piper for details (see below).

### Be an Amazing Futures Peer Supporter

Amaze is looking for young people aged 18-25 (with or without additional needs) who could be **Peer Supporters for 14-25 year olds with SEND**. You'll get training and support to help young people with SEND to identify future goals and then help them to achieve them.

- **East Sussex Peer Supporter training - Thurs 15 and 22 Nov and Jan 2019** 5-7.30pm, at The DC3 Project Space, Eastbourne BN22 7NA. Contact Claire Piper, Amazing Futures Coordinator for East Sussex, on **07484 915038** or email [claire@amazesussex.org.uk](mailto:claire@amazesussex.org.uk)
- **Brighton & Hove Peer Supporter training - starts Jan 2019** Contact Sue Winter, Amazing Futures Coordinator for Brighton & Hove on 07483 111648 or [sue@amazesussex.org.uk](mailto:sue@amazesussex.org.uk)



## 'Hidden children' in headlines

School exclusions have become a big story everywhere



Nationally the government has woken up to the fact that exclusions are rising and some groups of children are at a higher risk of exclusion. In fact, children with SEND are six times more likely to be excluded than children without.

The Department for Education is carrying out a **review** about what can be done to change this. Former children's minister, Edward Timpson, is leading the review and visited Brighton in July to talk to local parent carers. Amaze and Brighton & Hove PaCC were delighted to host this as we know the impact that exclusions can have on families. The parents made sure Ed Timpson heard how formal exclusion is part of a bigger picture that includes **unofficial exclusion**, part time timetables, children out of

school and children home educated by default and not by choice.

**Brighton & Hove** parents will be glad to know that the city council shares their concerns and has a new "Hidden Children" Strategy that aims to not let any children miss out on a full-time education whatever the issues may be for them (medical needs, risk of exclusion, awaiting a special school place, etc). The strategy was discussed at the Children, Young People & Skills Committee in September with a commitment to track individual children so things are addressed and aren't allowed to run on for months or years.

**In East Sussex** 'Hidden Children' are also a priority. ISEND services work closely with schools to support them to understand and meet expectations around lawful exclusion and off-rolling; to keep pupils safe and learning. 'Hidden Children' are identified, tracked and supported in a variety of ways including a multi-agency panel that meets regularly to ensure that any children missing education (including those awaiting a

special school place) are tracked back into education. The local authority promotes guidance on the appropriate use of part-time timetables, the criteria under which schools can off-roll and what they should do if a child is believed to be missing education. 'Hidden Children' are also a focus of the new East Sussex SEND Strategy, which is being co-produced with parent carers, schools, education services and health and social care partners.

And to end with a real positive, there was a **landmark legal ruling** in August that makes clear for the first time that all schools must make sure they have made appropriate adjustments for autistic children, or those with other disabilities, before they can resort to exclusion. This closes a loophole in the Equality Act that meant schools didn't have to make reasonable adjustments for disabled children when they have a 'tendency to physical abuse' - even when that behaviour is down to a lack of appropriate support for their additional needs.

**If your child is missing education, make sure your local authority knows and Amaze SENDIASS can help with this too. Read more about SENDIASS on page 4.**

## Brighton & Hove Buses becomes an Amaze partner



Brighton & Hove Buses have become the latest Sussex-based business to support Amaze in our 20<sup>th</sup> year.

Brighton & Hove Buses' Managing Director Martin Harris told us:

"We are absolutely thrilled to be an official partner of Amaze during their 20<sup>th</sup> anniversary year celebrations."

"As well as helping to support and advise families of children and young people with special educational needs and disabilities, Amaze also helps us to administrate the discounted travel scheme for Compass and Carers Card holders. All details including how to

apply can be found here at [buses.co.uk/carers](http://buses.co.uk/carers)."

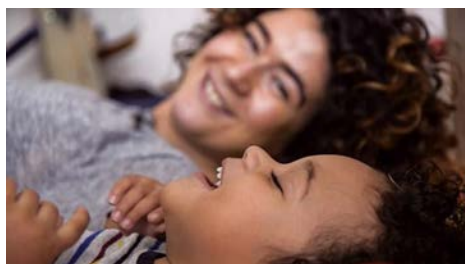
### About Brighton & Hove Buses:

Under their two brands - B&H Buses and Metrobus - they operate 416 buses, across 75 routes, and serve 3,000 bus stops across B&H, Sussex, Surrey and Kent. That's 65.3 million passenger journeys each year!

**If you are a local company who is interested in supporting Amaze in our 20<sup>th</sup> year, or know of one who might be, find out more at [amazesussex.org.uk/support-us/corporate](http://amazesussex.org.uk/support-us/corporate)**



## DCP and Amaze press for more funds for health and social care



Many of you may have seen 'Fighting for my Child', the BBC's powerful Panorama documentary following the lives of three families caring for **children with complex disabilities** in the summer (you can still catch it on iPlayer at [bbc.co.uk/programmes/b0bc2ch6](http://bbc.co.uk/programmes/b0bc2ch6)).

The programme came about partly as a result of hard work by the Disabled Children's Partnership (DCP) and their 'Secret Life of Us' campaign to raise awareness of the struggle families face to get the help and support they need for their disabled children. Amaze is proud to be a member of the DCP – one of more than 60 charities all campaigning together for better health and social care for disabled children.

Recent DCP research (carried out by Development Economics) found that

there is a £1.1 billion shortfall in funding for health services for disabled children and £433 million extra needed for social care.

Amaze will be raising this evidence with our local MPs, asking them to press the government to commit more spending to disabled children as part of the Comprehensive Spending Review (the process by which the government sets its forward spending plans).

The DCP is also calling for an Early Intervention and Family Resilience Fund to help prevent family breakdown. The fund would:

- increase access to services like short breaks
- increase the availability of services like short breaks
- support parents and young people to work or study

Keep an eye out on our website and our Facebook group to hear more about how you can get involved and contact your MP. Or visit [disabledchildrenspartnership.org.uk](http://disabledchildrenspartnership.org.uk) for more information.

## Our new website

If you haven't had a chance to check out our new website yet, please visit [amazesussex.org.uk](http://amazesussex.org.uk). It has even more information about services and support for families of children with SEND, now covering both **Brighton & Hove AND East Sussex**.

It's also much easier to use, especially on mobiles, with separate sections for parents and young people, a pop-up menu and search button and text broken down into shorter, expandable chunks. Do visit soon and tell us what you think via the feedback form on our 'contact us' page.



## Open for parents

If you live in **East Sussex** and you're worried about managing your child's behaviour, supporting their development and wellbeing, or you want support and advice to help build a positive relationship with your child, **Open for Parents** can help.

They run **workshops** across the county about parenting issues ranging from 'sleepless nights' to 'coping with teenage emotions'. They also run **Triple P Stepping Stones courses** specifically for families of children with additional needs and have a helpline open every Thursday from 11am to 1pm where you can discuss issues particular to your family. Call 01424 725800 or visit their website to book a workshop and find top parenting tips and resources at [openforparents.org.uk](http://openforparents.org.uk)

## Want to continue getting this newsletter?

We've printed extra copies of this edition of Out of Amaze to reach families in East Sussex, as well as posting directly to Brighton & Hove family homes as usual. However, going forward, we can't afford to keep sending out individual postal copies, particularly as the numbers keep growing and growing.

From the next issue, we'll be **moving all our individual readers over to an e-mailed version** of the newsletter instead. If we already have your email address, this will happen automatically so you just need to

check your inbox (or spam folder) in late February 2019 and you'll find a copy there. If we don't have your email address and you'd like **to keep receiving the newsletter**, please send it to [charlotte@amazesussex.org.uk](mailto:charlotte@amazesussex.org.uk).

If you can't access email and still really need a printed copy, just let us know. We'll make sure you still get one via snail mail. Finally, all schools and libraries will still receive printed reference copies, so you can have a browse through their copies when you visit.



## Spotlight on SENDIASS

SENDIASS is Amaze's information and advice service for parents and young people in East Sussex and Brighton & Hove. It's our busiest service, at the heart of everything we do.

SENDIASS stands for 'special educational needs and disability information advice and support service'. Every local authority has to make sure children and young people with SEND up to 25 and their parents have access to a local service that provides impartial information and advice on all things to do with SEND. Amaze provides this in East Sussex and Brighton & Hove. This means the two local authorities fund it but Amaze runs it and, as a parent-led charity, we are able to make sure it really is impartial and independent. Because we also do other work with parents and young people, Amaze SENDIASS can offer wider information on things like health, leisure and disability benefits, as well as SEND education issues.

### Who can use SENDIASS?

Most people who use SENDIASS at the moment are parents who have a child or young person with SEND. But you don't need to have a diagnosis or be having any kind of assessment; we can give advice to anyone who is

worried their child might have SEND. SENDIASS is also there for older children and young people to use by themselves or alongside their parents. We are working on making SENDIASS more suitable for young people and to have information designed especially for them.

### How does it work?

**Information** that parents and young people can find easily and use for themselves is key. Our website - **amazesussex.org.uk** - is the first place to start. It has sections for parents and young people, with information on most topics that come up when living with an additional need and direct links to further information and services. Our resources include over 40 fact sheets about SEND issues and specific conditions.

Sometimes you need a person to point you to what you need to know or

talk through what to do next. That's the purpose of the SENDIASS **helpline** which is open every weekday from 9.30am to 2.30pm with a couple of advisers on the line. They try to answer calls as they come in but, in practice, they are usually calling back the many people who leave messages or email us. All messages are returned but it can take a couple of days or more if things are very busy. They can call you outside helpline hours if necessary.

SENDIASS helpline workers aim to have a thorough conversation with you that leaves you ready to take whatever next steps you need to, but sometimes things are complicated or a person can't follow things through by themselves. On these occasions, we will offer some **individual follow up** from a SENDIASS worker by phone and email or occasionally face to face.

SENDIASS also tries to reach more parents and young people by running **workshops** and attending **events**. If you run a parent group or service for families you can invite us to visit.



### Our SENDIASS team

Gillian, Gaynor, Lyra, Ruhiya and Sav all work three days a week, and Lesley, Michelle and Siobhan do five hours a week each. Our coordinator, Emma, does four days. We also have some great volunteers. It's a knowledgeable and skilled team, but not huge to cover the area, so we are looking hard at smart ways to reach more families, such as writing step by step guides and using social media. Ideas about what would work are welcome.

Our SENDIASS helpline is open Monday to Friday, 9.30am to 2.30pm. Email [sendiass@amazesussex.org.uk](mailto:sendiass@amazesussex.org.uk) or leave a message on 01273 772289 so an adviser can contact you.



# Making a strong DLA claim for night time needs

If your child regularly needs help at night, or needs you to be awake to watch over them, you may be entitled to extra money. This is called the highest rate of the care component of Disability Living Allowance (DLA).



Getting DLA for wakefulness at night is not easy; it helps to be clear about the rules and forensic in your approach. Your child's needs have to be significantly in excess of other children the same age who do not have their illness or disability; you will need to persuade the DWP that your child's needs are exceptional.

**Night is after the household has closed down.** So, if your child goes to bed at 8pm and you turn in at midnight, any help needed before midnight would count as help during the day. DWP suggests 11pm is when night time might start but if your child is awake at night, it's likely your best opportunity for sleep is as soon as they settle the first time. Be clear that if your household closes down at 9.30 pm that's when night needs start in your family.

**Use the night time page:** sounds obvious but this is towards the end of the claim pack. It's easy to be misled into writing about nights on the 'settling in bed' page.

**Keep a sleep/wake diary:** this will be your most

compelling evidence. Keeping a written log of what happens at night might feel like the very last thing you want to do but it's really worth investing time in this. When are you up? What alerted you? What did you do? When did you get back to bed?

**Explain what happens** if you ignore the fact that your child is awake: any risk of injury to themselves, deterioration in their health, complaints from neighbours or damage to property.

**Make comparisons** between this child and other younger siblings, a twin or peers.

**Describe the impact on the rest of the family.** Do you have unusual sleeping arrangements to lessen the impact of your child's wakefulness on the rest of the household?

**Include copies of supporting evidence from other sources** that are consistent with what you say. This might include: reports from practitioners that state your child is awake at night; concerns from school or school transport about day time naps, lethargy and the impact on their learning and behaviour the next day; and referrals to specialists and waiting lists for help. You could also include strategies that are already in place but have no effect.

**Draw on research and include this:** use the internet to look up things like how much sleep other children of the same age ordinarily need. Give medical or therapeutic reasons why your child needs help at night or say whether your child's wakefulness at night is consistent with their diagnosis.

Some parents have told us they also invited the DWP to stay a week, stay awake and see for themselves! Such a bold offer sends the DWP a clear message but as far as we are aware, this offer has never been taken up.

## Need help with claiming DLA or PIP?

Amaze has **fact sheets and other written information** about claiming DLA and PIP on our website ([amazesussex.org.uk/resources/fact-sheets](http://amazesussex.org.uk/resources/fact-sheets)). We can also give you 'close-fit' prompt materials that can help you think about the kinds of things you might need to put on a claim. Our **SENDIASS helpline advisers** can help you to think through whether it's worth making a claim and give you practical information about the process.

For more expert advice, look out for our **workshops on DLA and PIP** in Brighton & Hove and East Sussex (see [amazesussex.org.uk/events](http://amazesussex.org.uk/events)). Our workshops are run by our DLA Project Manager, Lizzie, who has two decades' experience in helping parents make successful claims.

Finally, if you are really stuck and you live in **Brighton & Hove**, you may be able to get some more **individual support** with your specific claim. Call our helpline on 01273 772289 or visit [amazesussex.org.uk](http://amazesussex.org.uk) for more information.



# Our secret life with Liv

Amanda Mortensen, mum to Livvy and manager of our Face 2 Face befriending project, tells us what it's like caring for a child with complex needs and why she's supporting the DCP's 'Secret Life of Us' campaign

"Olivia was the most perfect baby. I know all new parents say that but she really was. Tiny and exquisitely beautiful, she was relaxed and undemanding and, bar a few feeding issues and some reflux, our first born was a dream. Looking back at photos of my young self then, I see I had absolutely no idea what lay ahead and was almost completely unaware of a whole secret generation of disabled children that our little girl would soon be joining.

"Livvy was diagnosed with autism at 18 months. Silent but humming she would zoom around our house, obsessed with music and food. It was clear she had severe learning difficulties, but we still had so much hope in those early days. I just wanted to stop the world so she could catch up.



Amanda and family in the real 'Secret Life' days

"I remember feeling hugely isolated at that time - we used to drive around in our car and not get out, looking longingly out the window at 'normal' families doing things that were just too stressful for us to contemplate. I now realise it wasn't just us living a 'secret life' with Livvy, her siblings were too. Liv has had to come first and for many years I could not take

her out without a carer (and for many years I didn't have enough hours of support).

"How did I get by? I found solace in other parents. Setting up Sweet Peas parent support group was the most resilient move I made, and meeting Lorraine Roberts, founder of Pebbles, another Brighton & Hove group, was a lifeline. Her house was a 'safe house' where I could go without judgement and slowly, we started to access regular childhood activities: the park, her brilliant special school, even the supermarket.

"Then, without warning, Liv started having seizures and we were back into that devastating darkness again. At 10 we were told our little girl was "locked in a world of seizures" with epileptic encephalopathy (believe me this is not an uplifting Google search).

"Fast forward to today and Livvy, 17, is now a profoundly disabled young woman. She has a gastro-jejunostomy for fluids and nutrition and is only able to eat a small amount. Her seizure activity is almost continuous. We have night carers, day carers, morning and weekend carers, respite. She has severe scoliosis and has a big operation next year.

"Her ability to access normal life is totally dictated by her health and what's in place to help us and families like us. For example, Sussex has



become a lot more inclusive since those early days, but changing places are still few and far between and if Livvy has a big seizure, often accompanied by a bowel movement, we have to go home.

"Getting support still feels like a lottery and I have had plenty of fights over the years to get what we need as a family. But for the first time now, transitioning to adult services, health, education and social care are actually working together and it hasn't been the fight I was expecting to get her adult respite funded at Chailey Heritage.

"Others may not be so fortunate. There are hundreds of families across Sussex who are not able to have the day to day life that lots of people take for granted. Funding has never been so squeezed and some families are breaking apart behind closed doors. This is why I'm working with Amaze and the Disabled Children's Partnership to lobby government for more funding to support families with disabled children. Until changes are made at national government level, secret lives like ours will continue."

## Join the DCP's 'Secret Life of Us' campaign

Amaze is a member of the **Disabled Children's Partnership**, a growing coalition of more than 60 organisations campaigning for better health and social care services for disabled children and their families. Read more on page 3 and get behind the campaign at [disabledchildrenspartnership.org.uk](http://disabledchildrenspartnership.org.uk)





## Less support, more demands

During the past few months, Brighton & Hove PaCC has carried out two consultations around the health care needs of parent carers facing additional challenges.

One consultation was done in collaboration with Friends, Families and Travellers (FFT), a charity that works to address problems facing **Gypsy and Traveller communities** (see [gypsy-traveller.org](http://gypsy-traveller.org)). We looked at the specific needs of Travellers who are also carers of children or young people with additional needs or disabilities. We also organised a table tennis session where two coaches with Down's syndrome trained young Travellers in their weekly class.

Our findings show that awareness of disabilities among Travellers is widespread: "There is a lot of community support going on here, we help each other out. Everyone knows what's going on in a family and people are ready to help. Children are aware of a child who has additional

needs or a disability and they respect that. I have never felt any barrier within our community". The report did, however, find that their status as Travellers could have a detrimental effect on what support they receive. Amaze will carry on working with FFT and support Travellers.

The second consultation looked at parent carers who are also **carers of family members with dementia**. This was part of a wider consultation in Brighton & Hove looking at how to improve the diagnosis and support of people with dementia and their carers.

The biggest problem these parent carers reported was the difficulty they have in juggling competing demands, which makes it hard to organise appointments. One parent said, "the biggest issue is simply time... I constantly feel as though I am failing my daughter and my mum – they both have many appointments and neither can really go anywhere unless I take them – I know I should do more to help them stay well but I am always juggling competing demands." One of the recommendations from our report is to offer parent carers respite to enable them to care for two generations.

Recommendations from both reports have been passed on to our local Clinical Commissioning Group. To see the reports in full, please visit [paccbrighton.org.uk/resources/reports/health-social-care](http://paccbrighton.org.uk/resources/reports/health-social-care)



Young Traveller at Brighton Table Tennis club.



## PebbsFest!

This year, our PaCC partner Pebbles celebrated their 10<sup>th</sup> anniversary. Pebbles is a brilliant Brighton & Hove support group for families of children and young people with additional needs. To mark this milestone, one of the Pebbles dads, Kit Hinton, had the idea of putting on a festival accessible for everyone.

Sally Howell, a Pebbles' parent, says: "He wanted our families to be able to experience going to a festival, something that many would find too daunting a prospect."

So after a year of planning, PebbsFest was born on 7 July 2018 with a rainbow-themed day bathed in glorious sunshine. Bands gave up their time to perform; there were side stalls, including face painting, retro games and an extremely popular 'crock smash'; a lunch time barbecue, children's tea party and a wonderful curry feast in the evening.

"The atmosphere was really amazing," says Sally.



## Putting PDA on the map

Inspired by our parent rep Paul Goodwin, PaCC is working to raise awareness and recognition of Pathological Demand Avoidance (PDA), a type of autism spectrum condition.

### Pathological Demand Avoidance

(PDA) is increasingly recognised as a profile within the autism spectrum. PDA is not included in the diagnostic manuals for autism, so many professionals are reluctant to diagnose the condition. However, the existence of demand avoidant behaviours among some people with autism is becoming broadly accepted.

Parent carers tell us that many children with the PDA profile are undiagnosed and struggling at school without the right support. Schools can lack training in the techniques needed to support children with a PDA profile which can lead to them being at risk of exclusion, reduced timetables or unable to attend school due to the trauma they have suffered.

The behaviour strategies recommended for PDA are quite different – and sometimes the opposite – from strategies advised for autism without PDA. Parents feel that greater recognition of PDA will enable schools and families to access the correct advice and use the right strategies. PaCC will continue to raise

these issues with Brighton & Hove Inclusion Support Service (BHISS).

In 2017, PaCC Rep, Paul Goodwin created a Facebook page, Connor PDA, to raise awareness of Pathological Demand Avoidance. Since then, over 800 people have joined the page and its followers include Anna Kennedy OBE (autism ambassador), Kevin Healey (former director of the National Autism Society), and Tania Tirraro (founder of Special Needs Jungle).

Paul has also set up a **live chat** group through mASCot (a Brighton-based parental support network for families with autistic children). There have been two coffee mornings arranged at mASCot's base where

members could meet and talk face to face. And earlier this year, Paul and other parents met with Edward Timpson OBE (the former children's minister) to provide evidence for a review of school exclusions (see page 2). Paul has also raised PDA awareness amongst Amaze families and PaCC members.

The good news is that although the local authority has been reluctant to 'diagnose' PDA, **support and recognition is increasing in Brighton & Hove**. For example, Education, Health and Care Plans are starting to include 'demand avoidant' when describing a person's special educational needs. Also, Seaside View ran a demand avoidant workshop this term, and in October there was a PDA workshop for parents arranged by the PDA Society. BHISS has said they can signpost families to sources of help.

PaCC would like to see an **increase in training** being given to professionals, services and schools about PDA. This would benefit not only the people with this profile, but also their families. PaCC would also like a greater emphasis to be placed on **identification of the causes of the anxiety behind PDA** (e.g. sensory needs, routine changes) to ensure a coherent approach that includes interventions for these 'causes', as well as for the PDA itself.

Search for '**Connor PDA**' on **Facebook** and find out more about PDA on the National Autistic Society website at [www.autism.org.uk](http://www.autism.org.uk)

### What is PDA?

**Pathological Demand Avoidance (PDA)** is recognised by the National Autistic Society as a profile within the autism spectrum. People with this profile have an extreme need to avoid everyday demands and expectations.

It is driven by anxiety and a need to be in control, and can make life incredibly stressful and difficult for the individual and their family. Children with PDA can end up out of education, with families reaching 'breaking point' due to the challenging behaviour often associated with PDA.





## Pizzas and Spiderman dancing

This summer, PaCC's Community Outreach Project (COP) organised two summer events where parent carers from our regular coffee mornings and their families could get together and have a bit of fun.



*"Even I felt at ease as...we were in a safe, secure environment where we could relax and have fun."*

The event at St. Richards had a sensory space, a DJ and a real Spiderman crawling on the floor. A parent commented; *'Honestly...we thought we would pop by, and didn't expect to stay for long, as we weren't sure how well our boys would cope at this party. But we ended up staying*

*the whole two hours, because they felt so comfortable there. Even I felt at ease, as I felt we were in a safe, secure environment where we could relax and have fun. Thank you to everyone who made today possible."*

Children and young people had fun with lots of games and a delicious buffet. A young person said *"I am actually scared of Spiderman ... but I am not scared of cakes. Bring me one more!"*

Our regular COP parent carer coffee mornings take place in Moulsecoomb, Whitehawk and Hangleton during term time. They are a space for parent carers to meet other parents and find out what's going on in the city around services for their families. To find out more email [paolo@paccbrighton.org.uk](mailto:paolo@paccbrighton.org.uk), call 07484 051753 or visit [paccbrighton.org.uk/what-we-do/coffee-mornings](http://paccbrighton.org.uk/what-we-do/coffee-mornings)

The Wild Park event was a perfect, relaxing day with games and pizza-making thanks to Community Oven, a community organisation that 'nourishes the community'. See [communityoven.co.uk](http://communityoven.co.uk).

One parent said it was a great day out: *"Kids were able to run around and also make their own pizza which was cooked in a proper wood-burning oven right in front of them. And I had time to catch up with other parents and meet new friends!"*



### COP Coffee mornings for parents and carers of children with additional needs

Brighton & Hove PaCC runs regular coffee mornings for parent carers of children with SEND around the city.

- **Moulsecoomb and Bevendean** (The Sunflower Support Group): 2nd Tuesday of every month at Moulsecoomb Primary School
- **Hangleton & Knoll**: 3rd Tuesday of every month at St Richards Church and Community Centre, Hangleton
- **Whitehawk**: The last Thursday of every month at the Whitehawk Inn

For more information visit: [paccbrighton.org.uk/what-we-do/coffee-mornings](http://paccbrighton.org.uk/what-we-do/coffee-mornings)





## PaCC Awards

We're asking parent carers to think about the professionals or volunteers you've worked with that have gone the extra mile for you.

It could be a social worker who's got you through a crisis, a TA who's given your child fantastic support at school or anyone in the health, education, social care or voluntary sectors who has helped you and your child, who you think deserves a special thank you.

Not only is this a great chance to show your appreciation but also a way of celebrating the best work in health, education, social care and the voluntary sector. To vote, please visit [paccbrighton.org.uk/get-involved/nominate-pacc-champions](http://paccbrighton.org.uk/get-involved/nominate-pacc-champions)



## PaCCConnect - 'Services and support for my child'

**Tuesday 13 November**  
**9.30am to 12.30pm**

Hanover Room, The Brighthelm,  
North Road, Brighton, BN1 1YD.

Have your say on shaping special educational needs and disabilities provision in Brighton & Hove from 2019 onwards. Please email [admin@paccbrighton.org.uk](mailto:admin@paccbrighton.org.uk) if you would like to attend.



Photo by Alexis Maryon

## Disability Pride rides again

This July saw the second ever Disability Pride in Brighton. PaCC steering group member and Vice Chair of Disability Pride, Martin Jones, tells us what's so special about the event.

"Disability Pride is a day for all our community to celebrate how they live their lives and the pride they have in their achievements, family and friends. It's the brainchild of Jenny Skelton, Chair of Disability Pride, who first had the idea for the event after her daughter, a young person with a hidden disability, experienced discrimination in a local pub.

"Thanks to Jenny, Brighton was the first British city to hold such an event last year and when I helped with the PaCC picnic, I saw the uplift it gave to all the people there.

"This year I was busy helping run the main event, so it was fantastic that PaCC and parents from our partners, Pebbles, mASCot and Extratime, stepped up to run the picnic and sensory tent."

"Puppet shows, bands, celebrities, comedians, art, exhibitions and dance were all on the menu, and all performed by people with a disability. Next year we expect the event to grow further and will make sure we use feedback to give the community the day it wants and values. It's success is best measured by the number of people who enjoyed it.

"The point of Disability Pride was highlighted by the smiles, laughter and friendship shown on the day, but this is all thanks to people with disabilities and their families and friends getting involved and coming together as a community." Visit [disabilitypridebrighton.com](http://disabilitypridebrighton.com) to find out more about the event.

### 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 [paccbrighton.org.uk/get-involved/give-us-your-views](http://paccbrighton.org.uk/get-involved/give-us-your-views). You can also join our closed Facebook group at [facebook.com/groups/parentcarerscouncil](https://facebook.com/groups/parentcarerscouncil)

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





## Our children, their voice, their future

Meet the East Sussex Parent and Carers' Council (ESPaCC) which represents the voice of parents and carers of children and young people with SEND aged up to 25 in East Sussex

ESPaCC is one of 152 parent carer forums (PCFs) across the country – one in every county or unitary authority (see Brighton & Hove's forum on previous pages). All forums get a grant from the Department for Education to represent the voice of parents and carers of children and young people with special educational needs and disabilities (SEND), and to develop ways for them to participate in shaping decisions about policies and services that affect their child.

ESPaCC is also part of the National Network of Parent Carer Forums (NNPCF), working closely with our neighbouring PCFs in the South East to develop a strong regional and national voice.

ESPaCC's members are all volunteer parents and carers of children and young people with additional needs, and their management committee and parent carer representatives sit on strategic decision-making boards and workstreams.

### What does ESPaCC do?

ESPaCC aims to work in co-production with SEND professionals to help

ensure local services and provision better meet the needs of families, children and young people in East Sussex.

ESPaCC gets involved both locally and nationally in a number of activities such as writing reports, hosting and facilitating events such as EHCP workshops, primary health information days, and our very popular Wills and Trusts and Mental Capacity Act sessions.

### Parent carer participation

ESPaCC says, "Co-production happens where parents and carers are equally valued members of the team and,

### East Sussex Parent and Carers' Council (ESPaCC)



when we work alongside professional colleagues, services and provision can be shaped to better meet the needs of our families."

Parent carers can become parent representatives and undertake specific pieces of work. Training is given to help the parent representative become more confident, especially in attending meetings with professionals, and to help them join us in working in partnership.

### How to get involved

- Visit the ESPaCC website at [eastsussexpacc.org](http://eastsussexpacc.org)
- Help ESPaCC to provide better information about parents by completing the membership form at: [eastsussexpacc.org/membership-form.html](http://eastsussexpacc.org/membership-form.html)
- Join EsPaCC's Facebook page [facebook.com/EastSussexParentandCarersCouncil](https://facebook.com/EastSussexParentandCarersCouncil)
- Follow ESPaCC on twitter at [twitter.com/ESPaCC](https://twitter.com/ESPaCC)

To find out more, email the Membership and Participation Lead at [membership@eastsussexpacc.org](mailto:membership@eastsussexpacc.org)

### ESPaCC Wills and Trusts Workshop

5th December 2018, 10am to 1pm  
Kings Centre, Eastbourne, BN23 6PT

For families of a disabled or vulnerable child it's important to consider how to provide for that child if you're no longer there to care for them. Philip Warford from Renaissance Legal will explain how Wills and Trusts can be used to protect the vulnerable and ensure benefits are not lost. This is a free event – to book a place visit [willsandtrustsdec2018.eventbrite.co.uk](http://willsandtrustsdec2018.eventbrite.co.uk)





## Say hello to Claire

Claire Piper is the new Amazing Futures East Sussex project coordinator. Claire has been working in community-based arts projects in East Sussex for many years and is a parent carer of a teenage son with additional needs. She says: "It's been great to see how the groups in Brighton & Hove run and just how much young people are responsible for planning what happens. I can't wait to get to work with young people with SEND in East Sussex to develop their Amazing Futures."

See our cover for more on the Amazing Futures East Sussex launch.

## Amazing Talent Show

Following on from last year's great show, Brighton & Hove's Amazing Futures project will be hosting another young people's **talent show** on Friday 14 December from 7 to 10pm in the Conference Room at Community Base, Brighton.

Anyone up to 25 who is connected to Amaze can come and perform. And whatever your talent is, you'll be welcome to take part. Everyone will get about five minutes.

It's definitely not a competition, but a celebration of young people's talents. Contact Sue on 07483 111648 or [sue@amazesussex.org.uk](mailto:sue@amazesussex.org.uk)



# Amazing Futures

## Helping young people with SEND into employment

Since launching in Brighton & Hove in 2017, over 80 young people have participated in our Amazing Futures peer support project and it's already clear how their confidence and skills have grown as a result. They've developed new social networks and connections in their community, found out about options for their future, and several have gone on to get **paid employment**.

Amaze is now working with a team of people called the special educational needs and disabilities (SEND) Young People Employability Steering Group in Brighton & Hove. They want to support young people with SEND into employment. They would like to find out how best to do this so they have given Amaze some money to fund a young person for five hours a week to help them with this.

Eliph Hadert, who has been the **Young People's Intern** with Amazing Futures for the past seven months will be doing this work. Eliph has recently started a Foundation Course in Art & Design at the MET, so she has stepped down from her Internship role but she is very excited about working on this new project and it fits in better with the time she has free from her course. We are in the process of appointing two new Young People's Interns for

both Brighton & Hove and East Sussex Amazing Futures projects - read more in the next issue.

Eliph will be asking [young people] how they went about finding a job, what support they had to get it and what support they have in their job.

Eliph will be talking to young people who have jobs, asking them how they went about finding a job, what support they had to get it and what support they have in their job. She will also be speaking to young people who want a job and asking what they might be finding difficult about getting one.

Eliph will give feedback to the Employability Group about the young people's views and experiences of looking for and finding work.

**If you are a young person and would like to share your experiences about looking for a job or being in work, please contact Eliph:**  
[eliph@amazesussex.org.uk](mailto:eliph@amazesussex.org.uk)





Jo (right) collecting a cheque for £515 from Andy Keen, landlord of the Albion Inn, Fishersgate, who had a Karaoke night in aid of Amaze.

## Fundraising goes Sussex-wide with Jo

Meet Jo Van Rooyen, Amaze's new Sussex-area fundraiser.

Jo says, "I recently joined the Amaze team to help extend our fundraising into Sussex. We really need funds to grow our services and reach more families geographically. I would love to hear from East or West Sussex-based businesses, clubs, community groups or individuals who would like to get involved in raising money for, and awareness of, Amaze. Please contact me at [jov@amazesussex.org.uk](mailto:jov@amazesussex.org.uk)"

Jo is seen here collecting a cheque from Andy Keen, landlord of the Albion Inn, Fishersgate. The Albion

**"I'd love to hear from Sussex-based businesses, clubs, groups or individuals who would like to get involved in raising money for Amaze."**

Inn raised £515 for Amaze on August bank holiday by hosting a karaoke night. Huge thanks to all the staff, owners and locals involved.

## Firm family favourites

Our Compass Card is currently available to children and young people with significant additional needs who live or go to school in Brighton & Hove or West Sussex. Since we launched the card in West Sussex in April 2016, we've added over 200 venues with Compass Card deals – almost all of which can be enjoyed by Brighton & Hove cardholders too.

Our offers stretch right across Sussex and into parts of Surrey and Hampshire. Brighton-based Compass Card parent, Louise Howe, loves the variety and says Earnley's Butterflies, Birds and Beasts near Chichester is a firm favourite: "It's a fascinating little gem of a place where you can get close to nature." Email [compass@amazesussex.org.uk](mailto:compass@amazesussex.org.uk) to tell us about your favourite Compass Card leisure offer.



## The best things in life are free

The Compass Team at Amaze gives away hundreds of free tickets to Compass Card families every year. The freebies are usually offered via our e-newsletter, 'Compass News B&H', so if you're a Brighton & Hove cardholder, keep an eye out for it in your inbox every Thursday tea time.

Towards the end of the year, we'll be giving away 300 Circus Starr tickets for circus variety shows in Brighton and Crawley in early January. Here's what one parent who attended last year said: "Just wanted to say a big thanks for the tickets... [my daughter], who has autism, thought it was amazing and as parents it was joyous to watch her laughing and relaxed."

**"It was joyous to watch her laughing and relaxed."**

Circus Starr is just one example of dozens of Compass Card giveaways. Others in the past year include free fairground rides at Horsham Sunday and free tickets to Brighton Festival event, 'I Wish I was a Mountain'.

If you gave the Compass Team your email address when you registered for a Compass Card in Brighton & Hove or West Sussex, you should automatically get Compass News, but make sure you tell us if you change your address so you can be sure to keep receiving it.

# Making the most of annual reviews

Does your child have an EHCP? How can you make sure the annual review of their plan captures where they are at and where they should be heading?

## What is an annual review?

The Annual Review is your opportunity to formally discuss the progress that has been made towards the outcomes on a child or young person's Education, Health and Care (EHC) plan, and to adjust those outcomes and the help they are getting, if necessary. It is also a chance for you to improve any part of the EHC plans that you are not happy with.

The Annual Review (AR) must happen at least every 12 months but if you have serious concerns about an EHC plan, you can request an early review at any point.

## Preparing for the meeting

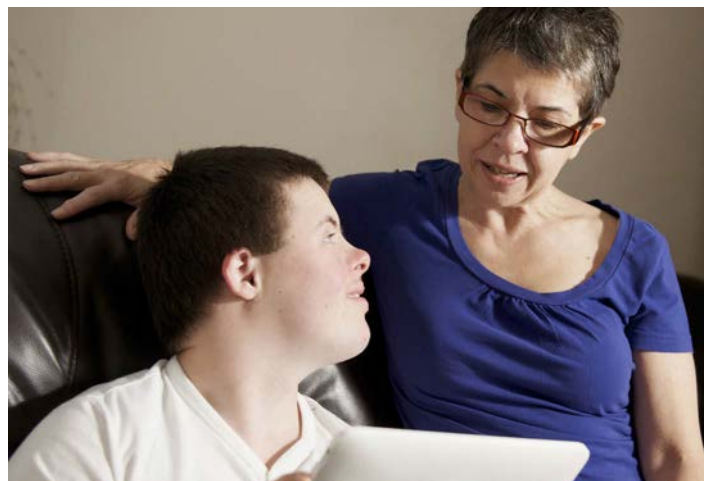
You are the expert on your child, so the written contribution of your parental views is as important as all the professional reports. Make sure you send your views in a few weeks before the Annual Review meeting so that it can be forwarded to all the professionals working with your child. If you are not confident about writing your views, you can ask your SEN caseworker or Assessment and Planning Officer at the local authority to record them for you. You can also contact Amaze SENDIASS if you would like our written guidance on the parental contribution.

## You are the expert on your child, so the written contribution of your parental views is as important as all the professional reports

All the professionals working with your child or young person should produce reports which are copied to you two weeks before the meeting. If you don't get them in time, you can ask to postpone the meeting. Read the reports carefully and write a list of questions and points you would like to make in the meeting. Have there been any changes over the last 12 months? Have any outcomes been achieved? Has all the provision been effective?

It is important to involve your child or young person in the meeting too. How will they record and express their wishes and views? They may wish to attend all or part of the meeting.

From Year 9 onwards, each annual review should also focus on preparing for adulthood, so make some notes with your young person about aspirations for employment, independent living, being part of their community and health.



## At the meeting

The meeting must focus on what progress has been made towards each of the EHC plan outcomes and whether the outcomes need to be changed or updated. Make sure you take a copy of the current EHC plan with you, as well as the questions you wrote down beforehand. You could take someone with you to prompt you on the questions you have prepared and to take notes for you.

If any part of the plan is not clear, you should discuss it at the meeting. The EHC plan belongs to your family so it must be written clearly in a way that you can understand.

At the end of the meeting check the list of questions and points you wanted to make to ensure they have all been addressed. If the meeting runs out of time you should ask for another appointment to finish going through the plan.

## What happens next?

Within two weeks, the school/college must send a record of the meeting to the local authority and a copy to you. Check to see that it matches what was said and agreed at the meeting. Contact the local authority if you feel the notes do not reflect what was discussed.

Within four weeks, the local authority will make a decision based on what was discussed at the meeting. They may decide to make no changes to the EHCP, but if there are changes, you should be given 15 days to read the draft and request amendments, if necessary. They can also decide to cease a plan if the outcomes have been achieved. You can appeal the local authority's decision if necessary.

**Amaze SENDIASS workers can advise on EHC plans and annual reviews, so call our helpline or email [sendiass@amazesussex.org.uk](mailto:sendiass@amazesussex.org.uk) if you need more advice.**



# What's happening this Winter ?

## In Brighton & Hove

### How to claim PIP workshop

Tues 13 November, 9.45am to 12.30 pm, Conference Room, Community Base, Brighton BN1 3XG.

Learn 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.

### How to claim DLA workshop

Weds 21 November, 9.45am to 12.30 pm, Conference Room, Community Base.

Lizzie Batten, Amaze's disability benefits expert, will help you identify whether your child is likely to get DLA and how to make a strong claim.

### Wills and Trusts workshop

Weds 28 November, 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.

### Amaze AGM and PaCC Awards

Friday 30 November, 10.45am to 12.45pm, Brighthelm Centre, North Road, Brighton BN1 1YD.

Formal summary of Amaze's year and chance to hear more about the 'Secret Life' of carers in Sussex plus PaCC Awards. Open to families across Sussex - see back page.

### Amazing Futures Talent Show

Friday 14 December, 7 to 10pm, Conference Room at Community Base.

A celebration of young people's talents, anyone up to 25 who is connected to Amaze can perform.

### Insiders' Guide to Teens with SEND

Fri 1 Feb to Fri 15 March, 9.45am to 12.45pm, Hill Park School, Brighton BN41 2FU.

Six-week course covering both the practical issues and your feelings around parenting a teenager with SEND, as well as tips for building teenagers' resilience.

All these Amaze courses, workshops and events are free and most are available to families in Brighton & Hove and East Sussex. To find out more or to book, email [info@amazesussex.org.uk](mailto:info@amazesussex.org.uk) or call 01273 772289

## In East Sussex

### How to claim DLA workshop

Weds 7 November, 9.45am to 12.30pm, Hollington Youth Centre, St Leonards, TN38 9LL.

See details in Brighton & Hove column

### How to claim PIP workshop

Mon 19 November, 9.45am to 12.30pm, Hollington Youth Centre, St Leonards, TN38 9LL.

See details in Brighton & Hove column

Amaze workshops are free. To book, email [info@amazesussex.org.uk](mailto:info@amazesussex.org.uk) or call 01273 772289

### Steps to encourage inclusion

For parents of children with ASC, with Andy Cutting from the National Autistic Society.

Thurs 1 November, 10.30am to 12.30pm, The Pellham, Holliers Hill, Bexhill on Sea TN40 2DD

Email [eastsusseximpact@gmail.com](mailto:eastsusseximpact@gmail.com). Tickets £3 on door

AND...Thurs 8 November, 7 to 9pm, The Phoenix Centre, Lewes, BN7 2RD.

Tickets cost £3 via [tickettailor.com/events/icontact](http://tickettailor.com/events/icontact)

### Understanding autism

Free four-week course for parents of children with autism

Weds 14 Nov to Weds 5 Dec, 6.30 to 8.30pm, Bexhill Community Centre, 10 Station Road, TN40 1RE. To book, email [info@autismtrain.co.uk](mailto:info@autismtrain.co.uk) or call 01424 845562.

### Wills and Trusts workshops

Weds 5 December, 10am to 1pm, Kings Centre, Eastbourne

Free ESPaCC workshop with Philip Warford from Renaissance Legal. To book your place visit

[willsandtrustsdec2018.eventbrite.co.uk](http://willsandtrustsdec2018.eventbrite.co.uk)

### Emotional development and autism

Thurs 13 December, 7 to 9pm, The Phoenix Centre, Lewes, BN7 2RD. iContact workshop with Amanda Fletcher from Thinking Families. To book a place, tickets cost £3 via

[tickettailor.com/events/icontact](http://tickettailor.com/events/icontact)

### Class+ for East Sussex

Regular Coffee and Chat sessions and workshops on specific issues for parents of children with ASC/

communication difficulties across the county. For dates and times visit [facebook.com/CLASSPlusEastSussex](https://facebook.com/CLASSPlusEastSussex)

More Amaze workshops on EHCPs, SEN Support and Starting Secondary will be coming in the new year. So keep your eye on our Facebook page and visit [amazesussex.org.uk/events](http://amazesussex.org.uk/events)



## Can you help keep Amaze running?

We are recruiting runners now for the following races.

- Brighton 10K – 18 Nov 2018
- Brighton Half Marathon – 24 Feb 2019
- Eastbourne Half Marathon – 3 Mar 2019
- Hastings Half Marathon – 24 Mar 19
- Brighton Marathon – 14 Apr 19

Please get in touch to find out more on [fundraising@amazesussex.org.uk](mailto:fundraising@amazesussex.org.uk) or 01273 234014



## Another BIG Cheer for Amaze

Thanks to everyone who came to the 7<sup>th</sup> BIG CHEER for Amaze on 11 October at Komedia Brighton. As always, the show was a rip-roaring success and our brilliant comedians Maisie Adam, Jenny Collier, James Farmer, Justin Moorhouse, Matt Richardson, Joe Wilkinson and compere Ross Smith raised the roof and over **£5,500** for Amaze to continue supporting you and yours.

# Come to our Amazing Carers event and AGM

Friday 30 November, 11am to 12.45pm  
Brighthelm Centre, North Road, Brighton



On Carers Rights Day, Amaze's AGM will provide an opportunity for carers, Sussex-wide MPs, councillors, commissioners and other partners to hear directly from parent carers from across Sussex about their personal experiences of caring for children with additional needs. And there will be an opportunity to ask the parent carer 'experts' questions or chat to them informally over lunch which is at 12.45pm.

We will touch on Amaze being part of the Disabled Children's Partnership (DCP) national campaign and what this is asking ministers to consider as part of the government's spending review.



The agenda will then briefly cover our AGM's 'formal business' before presenting awards to our Brighton & Hove Face to Face volunteer befrienders and the PaCC Award-winners.

You can just turn up on the day, but if you want to stay for lunch please email: [info@amazesussex.org.uk](mailto:info@amazesussex.org.uk)

Could you help sponsor this newsletter and get great publicity? Email [nickyb@amazesussex.org.uk](mailto:nickyb@amazesussex.org.uk) now.

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 [wellesleycharitablefoundation.co.uk](http://wellesleycharitablefoundation.co.uk)



## Amaze helpline:

For information, advice and support, call 01273 772289.  
Monday to Friday, 9.30am to 2.30pm



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113 Queens Road  
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W: [amazesussex.org.uk](http://amazesussex.org.uk)

