



## The secret life of parent carers

This year, Amaze joins national charities in throwing a spotlight on the additional challenges faced by parent carers and asking for more of the help you need.



Amaze and PaCC are always working hard to help people understand just how tough life can be for parents and carers of disabled children. This year, that same message is being echoed loud and clear by a coalition of 50 national charities behind the **'Secret Life of Us' campaign** - a new crusade to raise public awareness of the daily struggles disabled children, young people and their families can face and, in the longer term, to improve health and social care services.

The 'Secret Life of Us' identifies a distinct gap in the public's understanding of disability; 43 per cent of people say they don't know anyone with a disability, despite one in five people being disabled and 97

per cent of parents with a disabled child say the public do not understand the kind of challenges they face every day. So the campaign's website is addressing this lack of understanding by featuring lots of real-life stories of disabled kids and their families at [disabledchildrenpartnership.org.uk/secret-life-of-us](http://disabledchildrenpartnership.org.uk/secret-life-of-us).

Locally, Amaze and the Parent Carers' Council (PaCC), have also been showcasing your stories and gathering evidence to illustrate what works and what further support is needed. As part of our 20<sup>th</sup> birthday celebrations, we produced a new film, **'Generation Amaze'**, that focuses on the positive impact of our work with a generation of families in Brighton and Hove. You can see it [amazebrighton.org.uk/resources/our-videos](http://amazebrighton.org.uk/resources/our-videos)

Parents in the film speak very movingly of how we've helped them over the years, but also of some of the challenges they and other parent carers face on a daily basis; challenges that mean they rely on local services like short breaks to survive as carers.

We also gather hard data about

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### Talent on show

Two recent Amaze events have shown just how talented our local young people are and given them a brilliant opportunity to express themselves.

15 young people performed at the **Amazing Talent Show** in December. The fabulous acts included a rapper, dancers, singers, guitarists and a violinist. 50 people came to the event which was hosted by the young people involved in the Amazing Futures Project. Having had such positive feedback, we're hoping to make it an annual event, so all your talented children and young people should get rehearsing for the next show.

November was lit up by the second **Face 2 Face Fashion Show**, in aid of our befriending project. Children and young people with additional needs sported the latest Gap fashions and strutted their stuff on a catwalk at Downs View Link College, accompanied by some brilliant tunes. Thanks to Gap Brighton, Guy Lloyd of Juice FM for being our compere, and to Dickie and Cheesecake productions for playing DJ.



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## 1.6 million PIP claims to be reviewed after government changes declared unlawful

Everyone who gets Personal Independence Payment will have their claim reviewed after a High Court ruling in December found that the government's latest regulations were "blatantly discriminatory" to people with mental health conditions.

New rules introduced in March 2017 had changed the way that points were

awarded for the mobility component of PIP, excluding people who couldn't get out and about due to "psychological distress". This meant that many young people with autism and/or serious mental health issues were unlikely to score enough points to get even the standard PIP rate for mobility (worth £22 a week), let alone

the enhanced rate (£58 a week).

On 21<sup>st</sup> December, High Court judge Mr Justice Mostyn found that the government's exclusion of "psychological distress" in awarding the enhanced mobility rate of PIP was "blatantly discriminatory" and could not be justified. Linda Burnip, co-founder of Disabled People Against Cuts, the campaigning group pictured here celebrating outside the Royal Courts of Justice, said of the judgement, "It will make a huge difference for thousands of disabled people with mental health support needs."

The new ruling means that people with mental health conditions can now get enough points to qualify for the enhanced mobility rate of PIP. The DWP will now look again at all decisions made since 17<sup>th</sup> March 2017, and some 220,000 people are expected to receive additional money and backdated payments.

To find out more about PIP, download our fact sheets about PIP claims and face to face assessments, at [amazesussex.org.uk/resources/publications/fact-sheets](http://amazesussex.org.uk/resources/publications/fact-sheets).

## Progress on changes to special schools and more

**Things are moving ahead gradually with the changes to special school provision in Brighton and Hove.**

The big news late last term was that Rachel Burstow will lead the West Hub (which includes Hillside and Downs Park) and Adrian Carver the East Hub (which incorporates Downs View, the Cedar Centre and Downs View Link College). Rachel and Adrian have both said they are committed to co-production, which means actively involving parents in shaping the plans for their hubs and this is underway with meetings in January and February.

Adrian and Rachel are also going to work together to ensure that

there is equity of provision, so that although the hubs have their own character, the offer to families will be just as good at each. The West Hub will not involve much change to the Hillside and Downs Park buildings but at Downs View there will be major building work likely to start this September.

Recruitment is still in progress for an Executive Headteacher for the third hub, which is for pupils with

social, emotional and mental health (SEMH) difficulties, combining Homewood College and the two pupil referral units. We are also waiting for news about which mainstream secondary school will host a new special facility and where a new specialist nursery (to replace Jeanne Saunders) will be.

We'll publicise updates from the council and the new hub heads as we get them

**You can keep up to date with the latest information on Brighton and Hove's special school reorganisation via our website at [amazesussex.org.uk/news-and-events](http://amazesussex.org.uk/news-and-events)**



## Peer Supporters do us proud

Our 20<sup>th</sup> birthday bash in December was not just a celebration of the amazing work we've done with families in Brighton and Hove over the last 20 years - it also gave us the chance to put our new **Amazing Futures Peer Supporters** centre-stage and trumpet their achievements and the success of the project so far.

Sue Winter, the project coordinator, gave the invited audience an engaging overview of what they've been doing and what they've learned, and one of the volunteers, Danielle Garratt, spoke first-hand about the confidence

she has gained from first being an intern with Amaze and now a peer supporter.

The peer supporters were then invited onstage, one-by-one, to accept certificates for completing their four-week training course from Amaze patron and world-renowned children's author, Julia Donaldson. Their poise and self-confidence walking up on to the stage and talking to Julia in front of so many people made us all very proud of them and the project. Read more about peer supporters on page 14.

## AAA for Stanford Infants

Apologies to **Stanford Infants** for mistakenly attributing their hard won **Autism Awareness Award** to Stanford Juniors in the last issue. To rectify our mistake, we asked Emma Remnant from the Infant school to tell us more about the AAA award process.

"We were keen to apply for the AAA," says Emma, "as - having not had a child with a formal ASC diagnosis at the school for many years - we wanted to ensure our practice was as supportive and inclusive as possible. The six seminars were informative and practical and it was great to have the chance and purpose to read around

the subject fully.

"The hard work started with pulling together evidence and initially we were rather daunted; would we be able to find enough evidence of Autism Aware work within our school? But our supportive tutor, Rachel MacDonald-Taylor, visited the school and encouraged us to take her on a Learning Walk. By the end of the Walk we were amazed at just how much evidence we did have to demonstrate our inclusive practice and autism awareness. It was hard work but very rewarding and we'd encourage other schools to take part."



## Independent Support stays for now

We're very pleased to announce that our Independent Support (IS) service will be continuing to help parents and young people with their Education, Health and Care Plans (EHCPs) for the next few months and possibly longer.

After much uncertainty, the Department for Education confirmed in January that they will continue to fund Independent Support while they look at how best to support children with SEND and their parent carers in the long term.

Since our IS service was launched in Brighton and Hove in September 2014, we have worked with 1300 families and we've had some fantastic feedback about the impact this support has had on their lives.

*"I can't put into words the relief I feel and how much you have helped in these two EHCPs"*

*"I feel with you by my side I was able to really get my point across as well as having the confidence to do so"*

We've also been delighted by the positive working relationships that have grown out of Independent Support, with our staff working together with SEN professionals and the SEN team at the local authority to get the best for children and young people.

Updates on the IS service will follow as we know more.

## A Normal Family

Look out for 'A Normal Family', a new book by Amaze patron Henry Normal about the 'everyday adventure' of living with his autistic son, Johnny. Launching on March 22<sup>nd</sup>, it's a warm and humorous tale that we're sure will resonate with many of our families.





## Grants to help you have more fun

Did you know that Mencap Brighton & Hove offers £200 grants for people with learning disabilities and their families and friends to do more of the things they love?

This might be a day out, help with paying for train tickets to visit family and friends or even help towards the cost of a holiday.

The grants are available to children and adults with learning disabilities and you can apply online at [www.brighton-mencap.org](http://www.brighton-mencap.org). If you need a paper form or any advice on filling it in, call 01273 479620.

## New online PDA forum

There's a new online forum for Brighton and Hove parents of children with ASC (or suspected ASC) who don't fit the typical autism profile and who find the usual strategies recommended for children with ASC don't seem to work.

Parents who run the group identify pathological demand avoidance (PDA) as a helpful way of understanding their child and you can read more about PDA at [www.pdasociety.org.uk/what-is-PDA](http://www.pdasociety.org.uk/what-is-PDA) or the National Autistic Society's website: [www.autism.org.uk/about/what-is/pda.aspx](http://www.autism.org.uk/about/what-is/pda.aspx)

If you want to speak to local parents going through similar issues around diagnosis and behaviour, visit: [www.pdahelp.wixsite.com/brightonhovepdaforum](http://www.pdahelp.wixsite.com/brightonhovepdaforum)

## The secret life of parent carers cont...

your lives in the course of delivering our services. For example, we ask lots of questions about the needs of parent carers when you apply for or renew a Compass Card in Brighton and Hove.

Our analysis of your responses to our Compass form questions in 2017 paints a pretty stark picture:

- 54 per cent of parent carers are providing over 35 hours of additional care each week (22 per cent over 100 hours/wk)
- 53 per cent have not had a break from their caring role in more than 6 months (32% reporting they have never had a break)
- Only 37 per cent of parent carers say they get a good night's sleep
- 30 per cent of parent carers say they have their own disability/long term health condition, with 50 per cent saying their physical health (and 60 per cent their mental health) has been affected by their caring role
- 68 per cent have said they can't work, or have reduced how much they work, as a result of their caring role
- 17 per cent report they're skipping meals as there isn't enough money to feed the whole family

PaCC has also just published a **report on 'Carers Needs Assessments'** which flags up the need for more respite, counselling and preventative services like peer support and advice, rather than crisis-driven responses. Read more about this on page 8.

PaCC and Amaze's local findings very much reflect what's going on all over the country. As part of the Secret Life of Us campaign, national charity Contact has compiled a wide-ranging report, **'Caring more than most'**, about the daily lives of parent carers. It is striking how closely their findings match what you have told us locally. 'Caring more than most' finds

a quarter of parent carers provide over 100 hours of care a week and 56% provide 35 or more - almost twice the amount provided by other types of carers.

The report also underlines the fact that "disabled children and their families are at a significant disadvantage in...their economic situation, health, employment and housing", and that parent carers' lives are likely to be much more significantly affected by their caring

## 22 per cent of parent carers in Brighton and Hove are providing over 100 hours of caring a week.

role than carers of other people.

In response to these findings, Contact is demanding more health and social care services such as short breaks, therapies, personal care, etc. And they say this can only be achieved by reversing the national and local trend of funding cuts and reduction of already insufficient services. Read the 'Caring more than most' report at [www.contact.org.uk](http://www.contact.org.uk)

In Brighton and Hove, Amaze and PaCC are working with councillors and senior officers to highlight the pressing needs of families with disabled children and asking them to protect these much needed services and support. We're also working hard to secure continued funding for our services that offer crucial support to parent carers - including our Face 2 Face befriending service.

If you're struggling with your caring role right now, visit the Survival Strategies section of our website for information and advice about what help is out there, including counselling and parent groups, or call our helpline on 01273 77289.

# Day in the life of a Family Practitioner

Karin Anjos tells us about her work supporting children and young people with social, emotional and mental health issues and/or additional needs

“There is no such thing as a typical day or week for me,” says Karin. “On any given day I could be visiting a family at home, meeting with a parent in school or going to a Team Around the Family (TAF) meeting, or perhaps running a workshop. I really love the variety of it – I don’t think I’m cut out for 9-5 in an office every day!

“It’s very busy – there are four of us working part-time so that’s equivalent to two full-time staff, covering the whole city. We’re part of the Brighton and Hove Inclusion Service (BHISS) and work closely with the other BHISS teams including the Primary Mental Health Workers who are based in secondary schools.”

Karin told us how the Family Practitioners work in schools:

“We operate a system of ‘book-ins’ where schools get a two-hour slot in which they can book half-hour appointments for four parents to discuss anything that’s worrying them about their child’s behaviour or wellbeing. This might be anxiety or bullying, or maybe a child has suffered a bereavement or the parent might want to talk about their child’s behaviour and what might help.

“What happens next really depends on that initial conversation. Perhaps we’ll work with the school to give them some extra support, or we might offer them some ongoing support ourselves – perhaps through some home visits, for example. If the child is at a secondary school, we might ask the Primary Mental Health Worker attached to the school to get involved (every secondary school in Brighton

and Hove now has a Primary Mental Health Worker based there up to 2 days a week) or we might refer them to CAMHS (Child and Adolescent Mental Health Services) for more specialist assessment or intervention.

Family Practitioners also run workshops in schools for parents and carers (and staff, where possible). “We cover lots of different topics. We’ve done sessions on behaviour, anxiety, managing emotions, sensory issues, executive functioning and attachment, and we’re just piloting a new play workshop.”

**“We operate a system of school ‘book-ins’, where parents can discuss anything that’s worrying them.”**

“These school-based workshops are open to parents and staff from surrounding schools too and you’ll usually hear about them from your school, on displays, in book bags or in the weekly newsletter most schools send out.”

“The one-to-one work we do with families is usually in their own home, though it could be in the school environment if that works better for them. It’s usually up to six sessions around a particular issue and that can be quite specialist. For example, we’ve got an ‘enhanced adoptive parenting’ programme for adopters and kinship carers which covers behaviour and attachment and play. We’ve also got quite tailored programmes on anxiety,



additional needs, ASC/ADHD (and managing the behaviours associated with them), and selective mutism.

“We also run groups for parents and carers based on particular issues or techniques like building resilience, protective behaviours, anxiety and autism. If we’re working with a parent who would benefit from one of these groups we’ll let them know about it but you don’t have to be getting direct support from us to come along. Ask your school or check Amaze’s events listing or the Local Offer to see if there’s one you’d like to attend.

For Karin, the best thing about the job is seeing things get better for families: “I was working with a parent recently who hadn’t really connected with her child after post-natal depression. In one of our sessions, I played with the child and mum said, ‘Oh I’ve not done that before’. So we practised some short five minute sessions on play techniques and then mum spent 10 mins a day playing with them regardless of how they’d behaved and it really made a difference to their relationship and the child’s behaviour.

**If you think you might benefit from talking to a Family Practitioner, speak to your child’s teacher or the school SENCO. And look out for school-based workshops and groups sessions on school displays or newsletters and flyers.**

# Friends for life

In Brighton and Hove we're lucky to have lots of groups where families with disabled children can meet up with other mums and dads like them. Amanda Mortensen, our Face 2 Face coordinator, tells us about the groups overseen by her project.



"Face 2 Face is all about emotional support," says Amanda. "Our volunteer befrienders, all parents of disabled children themselves, provide one-to-one support, but we've also developed a number of groups from parents telling us where the 'gaps' are."

There are currently four groups: a monthly group **for families who have a child with autism under 7**; a monthly **dads group**; a weekly **preschool group** and a **'breakfast' drop in group**, recently set up by a dedicated volunteer.

"Being a parent carer can be incredibly isolating, not to mention frightening at times," says Amanda, "particularly at the very early stages when we know something is going on with our child but may not know what, or have just received a diagnosis. Making new connections during these difficult times can be incredibly helpful."

"And there's something about the camaraderie of a group," she adds, "that gives you the space you need to offload and share ideas, and it's great to be able to do that in a supportive, non-judgemental environment."

Emily, mum to Orla, who has recently received a diagnosis of autism and who attends the autism

group at Turner Children's Centre says: "The group is such a lifeline to us to have a space where the kids can be themselves and we don't feel like we're different or have to explain ourselves. We can meet other parents in the same situation and feel less isolated and share tips and strategies."

Becky, mum to Jessie aged four, who has autism and high anxiety, adds: "Jessie has grown in confidence which has been wonderful to see."

The Dads Group is held in The Stoneham pub once a month. Set up by our dad befriender Reza, the group has grown and grown and is now run by Darren, dad to Amy. Chris, one of the regulars at the group says: "Many dads [of disabled children] don't have an outlet where they can talk or meet other men who know what they are going through. The men's group offers that outlet, whether it's for

sharing experiences or knowing people just 'get it'."

Another Dad's Group regular says, "The group is fun and there is a real strength in its unforced atmosphere - there should be one in every city in the country."

All our Face 2 Face groups are led by our volunteer team and started by parents. We make sure we complement what's already out there and we work closely with Brighton & Hove City Council. The council supports the groups with venues (Turner centre for the autism group) and skilled staff - Natalie our skilled play worker at the autism group and Jacquie, our very experienced nursery worker at PRESENS.

To find out more about any Amaze Face 2 Face groups email Amaze at [info@amazesussex.org.uk](mailto:info@amazesussex.org.uk) or call 01273 772289. You can also find details of lots of other parent support groups in Brighton and Hove at: [www.amazesussex.org.uk/services-and-support/parent-support-groups](http://www.amazesussex.org.uk/services-and-support/parent-support-groups)

Our Face 2 Face project recently secured £10,000 from the **Insurance Industry Charitable Foundation** towards its befriending work (they previously supported our Amazing Futures Project) and we are looking forward to working with them. Thanks to Sussex Community Foundation, Chalk Cliff Trust and Brighton & Hove City Council for also supporting the Face 2 Face Project.

## Dads group

Last Thursday of the month, The Stoneham Pub, Portland Road, Hove.

Contact: Darren at [dazmonkey72@googlemail.com](mailto:dazmonkey72@googlemail.com)



## Breakfast Club

Monthly meet up for parents at any stage of the journey. This group moves around the city.

Contact: Amanda on 07917887526 [amandam@amazesussex.org.uk](mailto:amandam@amazesussex.org.uk)

## Autism group

for under 7s with a diagnosis of autism or being assessed. Toys, soft play, outside space, refreshments. Second Saturday of the month at Turner Children's Centre.

Contact: Amanda on 07917887526 [amandam@amazesussex.org.uk](mailto:amandam@amazesussex.org.uk)

## PRESENS group for under 4s

on the PRESENS register at Jeanne Saunders or in nursery. Mondays, term time, 12.30-2.30pm. Contact: [jacquiebrett@brighton-hove.gov.uk](mailto:jacquiebrett@brighton-hove.gov.uk)



Our 2017 PaCC Champions proudly displaying their awards at the Amaze AGM.

## PaCC Champions shine at the Amaze AGM

Every year the PaCC Awards are an opportunity to thank those people who work alongside our families in Brighton and Hove and go the extra mile to help us. The awards highlight the services that are so vital to our families as well as thank those special individuals who've really made a difference. This year we included a new 'Community Business' category for local organisations that independently provide a service for parent carers and their families.

Pinaki Gosh, Executive Director for Families, Children & Learning, presented the awards at the Amaze AGM and the winners were divided into six categories.

### Education

**Antigone Nikiteas – Teaching Assistant and Personal Assistant**

"Antigone has got an amazing ability to help and build confidence in children. She is the only person who is able to deal with challenging behaviour and avoidance. She has made an enormous difference to us."

### Lyndsey Judge – SENCO

"Society needs more people like Lyndsey and as she is so amazing, I feel like she deserves an award for all the hard work she does to make such a difference to people's lives."

### Health

**Lisa Craig – Occupational Therapist**

"Brave, strong, sure and very loving and kind - all these words describe Lisa and it takes courage to witness a family in pain over days, months, years and to keep being hopeful and kind and open to helping in whatever way works."

### Social Care

**Amanda Graham – Personal Assistant**

"Despite her heavy workload, she was there for us when times were incredibly hard for us as a family. It

would be lovely for her to realise how much she is appreciated and what a wonderful person she is."

### Voluntary Sector

**Pippa Hodge - Co-ordinator of T21**

"Pippa has grown and developed the fledgling T21 group into a thriving community and gives immeasurable support to many, many families who are forging lifelong links for themselves as parents and a crucial friendship network for the children. She is quite simply brilliant!"

### Community Business

**Catherine Newell – Support Group Facilitator**

"Catherine provides a safe and confidential place for parent/carers to offload and dig deep with the many anxieties and fears they have surrounding their situation...She helps us to help ourselves and our situations to see the light in front of us. The group is so enlightening - it's unique and needs recognition."

### Outstanding Contribution

**Lizzie Batten - Amaze DLA Project Manager**

"Incredible Lizzie is a force of nature in the voluntary sector. She helped me to fill out my DLA form twice - once when my son was first diagnosed and again five years later when we needed to renew. It was so reassuring to have someone there who's an absolute expert in the field. She is a shining star at Amaze and her reputation is untouchable - she is very worthy of an award"

### Nominate your PaCC Champion for 2018

If you have a PaCC Champion you'd like to nominate for 2018, please visit [www.surveygizmo.com/s3/4099298/PaCC-Champions-Nomination-Form-2018](http://www.surveygizmo.com/s3/4099298/PaCC-Champions-Nomination-Form-2018)



# Your needs as carers

Our new report on 'Carer's Needs Assessments' shows that, despite the latest legislation, many parent carers have never had their needs assessed or are not aware when they have

PaCC and Amaze recently asked you to tell us about your experience of having your needs as carers assessed. We developed a simple online survey, in association with the Carers Centre, which we sent to all parents in Brighton and Hove on the Compass disability register.

The consultation was done as part of our work with the local Clinical Commissioning Group (CCG), though the report identifies concerns that cross both health and social care services, some of which are provided by Brighton & Hove City Council.

## What the law says

The law around carer's assessments is complex but in essence the Care Act 2014 and the Children and Families Act 2014 strengthened the right for carers of adults, carers of under 18s and young carers to have an assessment of their own needs too. The right to a parent carer assessment is separate to the duty to assess the needs of a child but can be carried out alongside this as part of a holistic family assessment. This is what usually happens in Brighton and Hove.

Local parent carers of under 18s usually have their needs assessed as part of the Strengthening Families Assessment (SFA). This may be via a local social work team or the Children's Disability Team at Seaside View. Parent carers can also ask for a separate, more formal carer's assessment of their needs (as carers of adults often get) but you're unlikely to be offered one unless you ask for it.

## What you told us

Of the 113 parent carers who took part, 81 per cent said they'd never had a formal carer's assessment and 71 per cent had never been offered a social care assessment. Of those who had received a carer's assessment, only 30 per cent said this was recorded and written down.

**81 per cent [of parents] said they'd never had a formal carer's assessment and 71 per cent had never been offered a social care assessment**

Whilst we can't be sure that everyone who responded to the survey would be eligible for a carer's assessment, the results suggest that many eligible carers are either not getting any assessment or, where the child/family is assessed, it's not clear to the family that this includes a carer's assessment. As one parent commented, "I didn't even know that I was entitled to an assessment and no professional has ever suggested that we need a social care plan for my son."

## What you need

Parents said that they currently get most of their support from charities, voluntary organisations and community groups and from their family and friends. Public sector support comes via GPs, SENCos, Seaside View, CAMHS and therapists, amongst others.

Parents who responded told us they want **more counselling** for themselves and their children/young people. They'd also like **more information** and advice on what's available for them and their families.

Parent carers would like to be able to access **more courses** to support them as carers, and see more training offered to professionals around SEN and disabilities.

Parent carers say they need **more respite**, including activities and support groups, as well as **more befriending and peer support**. And parent carers want to see **more preventative services** instead of crisis-driven responses.

Our recommendations as a result of the report include:

- More clarity on which parent carers are likely to have their needs assessed, how often and by whom, and for these details to be shared
- Professionals using the SFA to identify if there is a carer in the family and include their needs in any assessment
- Better recording and communication about assessments of carer's needs as part of the SFA
- Continued, secure funding for social care services and services that provide information, advice and support to parent carers
- Increased investment in counselling for carers and their families
- An end to proposed budget cuts for critical preventative services (see page 10 for more on this)

The report and its recommendations have been passed on to the Brighton and Hove CCG and Brighton & Hove City Council and we'll follow up on any outcomes in later editions. Read the full report on PaCC's website at:

**[www.paccbrighton.org.uk/resources/reports](http://www.paccbrighton.org.uk/resources/reports)**



## Ping pong in Malmo with Leo

Mum and PaCC steering group member, Pippa, tells us all about her son's amazing table tennis experience in Sweden

My son Leo (9, Trisomy 21, autism and a very wonky heart) has been going to monthly table tennis sessions at Brighton Table Tennis Club (BTTC) since early 2017. The sensory aspects and the physical internal feedback really motivate him and he seems to have a natural talent.

One day, Tim from the club dropped me a line, inviting me to bring Leo along to a workshop for young players with disabilities. My mind was already whirling with the logistics of this

when I realised that he meant Leo had been invited to join the BTTC team at a three- day **Malmo Parasport Youth Edition Games**. Yes, Malmo. In SWEDEN! Well, it seemed rude not to.

With flight and hotel funding from ESSE (an inclusive sports funding stream within ERASMUS) and a donation from MENCAP for expenses, some hilarious passport photos attempts ensued, then we were off.

What an experience! To be surrounded by athletes with various

disabilities, all earmarked as 'Young Talents' in their respective disciplines of table tennis, wheelchair basketball or swimming, was heart-burstingly empowering. Players were encouraged to try each other's sports, as well as being introduced to Boccia and Showdown (a table hockey game for players with visual impairment) prior to the serious competition day.

Leo blossomed before my eyes, interacting with confidence and getting right into the middle of all the action. Leo was able to play table tennis in a huge stadium, under the lights, in between the competition matches. Perhaps a taste of what's to come if he can follow in the footsteps of his T21 BTTC heroes Harry, Chris and Andrew, who not only compete internationally and win medals, but are also now qualified coaches – the first in the world!

Why not come and get your ping on with us? **T21 Table Tennis sessions** take place monthly, on the first Sunday of the month, 11am-1pm at The Fitzherbert Centre, 36 Upper Bedford Street, Brighton BN2 1JP. The first session is free, it's £4 after and siblings are welcome. Find us on Facebook @BrightonTTC.

## Meet our new PaCC Partner

PaCC works closely with various charities and voluntary organisations across Brighton and Hove that are also involved with supporting parent carers and their families. Our newest PaCC Partner is Zitha Anaiss, founder of **ASAP - Autism Support and Awareness Promotion - for black and minority ethnic communities**.

Zitha worked with autistic children in the black and ethnic minority community for five years. In this time she met with people from the community who were

struggling to raise their autistic children. This prompted her to start a group called ASAP to help raise autism awareness within these communities in Brighton and Hove.

It can be hard for families with autistic children in the BAME community to socialise because of the stigma associated with autism, language barriers and other difficulties. Often parents end up suffering from isolation and depression due to a lack of support and understanding.

ASAP helps parent carers and their families to meet regularly, exchange



their experiences and take part in social activities together. **To find out more about ASAP, please email [zitha.anaiss@yahoo.com](mailto:zitha.anaiss@yahoo.com)**



### Paolo makes the Happy List

Our very own Paolo Boldrini was added to the Brighton and Hove Happy List for 2017. Launched last December, the Happy List honours those people in our community who help to create more happiness.

As well as running our fabulous coffee mornings and being part of PaCC, Paolo helped found the Migrant English Project which provides English lessons for refugees and is also a trustee for Refuge Radio which runs community projects that help people with social isolation and mental health issues. Anyone who has met Paolo will know what a warm, caring person he is – and how much he deserves to be on the list. Well done Paolo!



### Travel training back in focus

Brighton & Hove City Council wants to work in partnership with parents and carers to explore ideas around independent travel training.

There will be an initial focus group held on Thursday 15<sup>th</sup> March in Committee Room 2 at Brighton Town Hall, to talk to a small group of parents about ideas, barriers and the support required. A wider engagement exercise, most likely a survey, will follow, which we will publicise here or via our website.

If you have any questions or comments, please contact Richard Barker at [richard.barker@brighton-hove.gov.uk](mailto:richard.barker@brighton-hove.gov.uk)

## PaCC influences council rethink on budget cuts to disability services

Proposed cuts have been shelved in favour of additional funds for short breaks and employment services

In December, Brighton & Hove City Council released budget proposals that included a £100k reduction in short break/respite services and a £50k reduction to the Children's Disability Service, which offers a social work and early help service. PaCC has been working tirelessly since then to persuade senior officers and councillors just how essential social care services are for many families with disabled children and how much unmet need still exists in the city (see cover and see page 8 on our carers' needs consultation). So we're delighted that the latest budget reverses these cuts and instead includes additional funds for certain short breaks and employment services.

£90k has been allocated to the city's new special school hubs to deliver out of school respite care in the early evenings, holidays and, as appropriate, at weekends. Details are to be confirmed, but we've been reassured by Regan Delf and the new hub heads that this wraparound care will also include children and young people with EHCPs in mainstream schools, who are eligible for social care.

A further £90k has been earmarked for the council's Youth Employability Service (YES) to help more young

people with special educational needs and disabilities to access sustainable employment, education or training.

We believe we played a significant part in these proposed investments. We took key councillors to the city's two residential respite homes – Drove Road and Tudor House – and introduced them to children and young people and staff. PaCC Chair, Fiona England, says, "Our local councillors could see first hand the impact of having a child with highly challenging behaviour and/or 24/7 physical and medical needs. It's a sobering experience for those who do not live with SEND day to day".

We also worked hard to convey that more needed to be done for young people with additional needs as they transition to adulthood - that it's unacceptable that 42 per cent of 20 year olds with SEND are not in education, employment or training, compared to 7 per cent of their non-disabled peers.

Read our full position statement on the budget proposals here:

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

Note: The final budget will be agreed just after we go to print so may be subject to change.

### Make your views count

Join the PaCC by emailing [admin@paccbrighton.org.uk](mailto:admin@paccbrighton.org.uk) or tell us what is concerning you at [www.paccbrighton.org.uk/get-involved/give-us-your-views](http://www.paccbrighton.org.uk/get-involved/give-us-your-views) You can also join our closed Facebook group at [www.facebook.com/groups/parentcarerscouncil](http://www.facebook.com/groups/parentcarerscouncil)

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



## Universal Credit: cuts for families with disabled children

The Government says Universal Credit (UC) is designed to make work pay. But for parents whose caring responsibilities prevent them from working, this isn't an option. Under UC, out of work households with a disabled child are at particular risk of being worse off, but we think many working parents with disabled children may lose out too. So what's changed?

### Cuts to the child disability addition

Under UC the principle that low income families with disabled children get extra money remains. A child getting the highest rate of the care component of DLA or the enhanced rate of the daily living component of PIP will continue to get an additional payment equivalent to the sum paid under tax credits. Under UC this higher amount is also extended to children who are registered severely sight impaired.

### The lower disability addition, paid to children getting any other rate of DLA or PIP, is being cut by more than 50 per cent

As a result, many families are likely to be worse off. Families without work will be worse off by £1,656 a year for each disabled child. If you have several children who qualify for the lower disability addition, your family will lose out two or three times over.

### Limiting payments of the child element to the first two children in a family

This will make it harder for lone parents to set up home with a new partner and their kids as a blended family. It is also likely to make it harder for social services to place children with kinship carers, such as aunts and uncles.

### No Universal Credit for disabled children with 'Looked After' status in care or away at school

This could mean a loss of up to £600 a month for a child at residential school or accommodated on a voluntary basis, even if they come home at weekends or for school holidays. If a child keeps their 'looked after' status, even for times spent with their family, under UC no payments will be made. If you aren't sure about your child's status check with their social worker.

Under UC, once a child has had 'looked after' status for six months, they will no longer be counted as part

of the household when calculating the number of bedrooms a family needs. So some families will see a cut in the amount of help they get towards housing costs. They may also lose protection from the 'benefit cap' if they are no longer counted as having responsibility for a disabled child and do not claim a disability benefit themselves.

### UC stops if a child is temporarily away from home for more than six months

This includes children in hospital. And again, families will be at risk of losing help towards rent and protection from the benefits cap.

### Harsh rules for carers waiting for a decision on a disability benefit

A full-time carer needing to claim UC and waiting for a DLA or PIP decision will still be required to look for work.

### Cuts to payments for disabled parent carers

Under UC, a severely disabled parent caring for a disabled child can either qualify for a carer element payment or an extra payment as a result of their own limited capacity for work, but not both. A disabled lone parent will lose out by around £30 a week.

In a two parent household, the non-disabled parent may qualify for the carer element, so the household can claim both a carer's and an incapacity payment.

### What about transitional protection?

If you find yourself entitled to less money under UC than you were paid before, you get an extra top up payment. However, if you have to claim UC for the first time because your circumstances change, or you choose to claim UC and you are already getting welfare benefits, there is no transitional protection. And if you are claiming UC, you lose transitional protection, as soon as you report a change of circumstances.

For advice on UC, contact Money Advice Plus ([moneyadviceplus.org.uk](http://moneyadviceplus.org.uk)) or your local Citizen's Advice Bureau.

# Our Amazing new sponsors

We're delighted to introduce and thank two of our new corporate partners who have each pledged £1000 to support Amaze's work in our 20<sup>th</sup> birthday year and beyond.



**Madison Web Solutions** is a friendly, multi-disciplinary online agency that specialises in design, branding, illustration, web development and marketing.

Matt Chambers, Madison CEO, explains what they do: "Publicly we've spent the last eight years working across many sectors such as charities, local authorities and SMEs in and around the south east producing robust websites, CRMs and digital marketing campaigns. But that's only half our story. Behind closed doors we've quietly built a reputation among some of the UK's most creative agencies, producing white-labelled websites for international law firms, high-street banks, airlines, recruitment agencies, and some of the world's largest retailers.

Matt explains why Madison got involved with Amaze: "We believe people are colourful and seeing disability as a 'different ability' is our motto. We always strive to harness peoples' true potential, which has had great results! We hope that being publicly involved with Amaze will encourage people who really want to make a change to choose us when they commission a new web agency, allowing us to continue to develop this approach and give more opportunities to everyone.

Find out more at [www.madisonsolutions.co.uk](http://www.madisonsolutions.co.uk)



## Pyramid Educational Consultants UK Ltd offers a

wide range of consulting services and products for educators and parents of children and adults with autism and related disabilities. PECS supports families and professionals to improve the skills and lives of people with communication difficulties.

The **Picture Exchange Communication System (PECS)** is a tried and tested approach that uses pictures to develop communication skills. More than just using pictures for visual support PECS is a system that develops important communication and social skills. PECS is appropriate for a wide range of children and adults with communication difficulties, including autism.



Louise Hotchkiss, Client Services Manager at PECS, told us why they decided to be a sponsor:

"As a local company we were thrilled to be given the opportunity to support Amaze and the incredibly important work they do. Both PECS and Amaze are trying to achieve the same end goal, that of helping children with additional needs to be the best they can and to have the most fulfilling lives possible.

To find out more, visit [www.pecs-uk.com](http://www.pecs-uk.com)

## Join Madison and PECS and be an Amazing corporate sponsor

We'd like to find more corporate sponsors for our 20<sup>th</sup> birthday year. If you are a local company or know a company who might like to get involved and enjoy many mutual benefits, contact Nicky B on 01273 234014 or email [nickyb@amazesussex.org.uk](mailto:nickyb@amazesussex.org.uk). And if you'd like to find out more about our work, watch our 'Generation Amaze' video at: [amazebrighton.org.uk/resources/our-videos/](http://amazebrighton.org.uk/resources/our-videos/)



## Don't miss out on Compass Card freebies

The 189 regular offers on the Compass Card are just part of the story; behind the scenes, the Compass Team also gives away hundreds of free tickets to Compass families every year.

We regularly give away tickets to Komedia's Sundae Club, local charity the ABC Fund provides us with tickets for trips (including the Father Christmas canal trip on Chichester Canal) and we gave away 300 free tickets for Circus Starr shows in January. There are plenty of one-offs too, including free theatre shows, Amex stadium tours and much more.

Free tickets can make a real difference to the families we work with. Apart from making an outing with the family affordable, multiple ticket giveaways also mean you can be confident you'll be among families with similar experiences.

"Just wanted to say a big thanks for the tickets we received for the Circus Starr show. We enjoyed it so very much and it was brilliant to be surrounded by families like ours. [Our daughter], who has autism, thought it



was amazing and as parents it was joyous to watch her laughing and relaxed. The show was funny, silly and engaging... a real hit!" said one family after Circus Starr in January.

Here, another parent gives the Father Christmas canal trip in December the thumbs-up. "I just wanted to say a big thank you for the canal trip. My daughter had such a lovely time and she smiled the whole way through. The volunteers on board were great and it was so well organised. Picking up Father Christmas along the way was just lovely and the looks on the children's faces was magical. I had one very happy little girl when we left."

To keep up to date with Compass Card giveaways, make sure you open our e-newsletter, Compass News B&H, on a Thursday evening – and if we don't have your email address, just drop us a line at [compass@amazesussex.org.uk](mailto:compass@amazesussex.org.uk) or call the Amaze helpline on 01273 772289.

## Rate and review Compass Card offers with our app

We've just added a Trip Advisor-style feature to our Compass Card app that lets you 'star rate' and comment on Compass Card offers. It's very simple; you just go to the individual listing on the app, then touch the star rating at the top, touch the number of stars you want to give and add your comment.

You'll need to install the latest version of the app to get the new feature. If you haven't got the Compass Card app already, search 'compass card' in the App Store or Google Play and download the West Sussex or Brighton and Hove version.

## Over 180 Compass Card offers

The Compass Card is still expanding. At the end of January, there were 189 regular Compass Card offers at 303 venues across Sussex and beyond. Recent additions are the Attenborough Centre for the Creative Arts (the old Gardner Centre); a discount on a range of activities at Chailey Heritage; free carer tickets at five Sussex Past venues; and a generous 20 per cent discount at Hove café, Viva Vinyl.

While the weather's still unpredictable, it's well worth checking out the quirky museums run by Sussex Past. These cover both East and West Sussex and include a new audio described trail, listening bench and sound installation in the Gun Garden at Lewes Castle; England's longest medieval water filled moat at Michelham Priory House and Gardens near Hailsham; and Marlipins Museum in Shoreham, where you may be surprised to discover the seaside town's unique role in the UK's silent film industry.

# Spotlight on our peer supporters

Meet some more of our fab Amazing Futures volunteers, and find out why they decided to be peer supporters.

Our peer support volunteers continue to do great work supporting young people with additional needs, both one-to-one and at our Amazing Futures activity groups.

Continuing from our last issue, we'd like to introduce you to some more of these fab volunteers—meet **Danielle**, and **Sammy**!



## Danielle, 24

As our Amazing Futures intern last year, Danielle helped get the peer support project off the ground. She's currently volunteering with Carousel, the Oska Bright film festival and the

Mymarc art club. She's interested in working with young people.

Danielle became a peer supporter to gain new experiences and skills, and meet new people. She recommends peer support as a way to make new friends and help sort problems.

In her spare time, Danielle enjoys creating art, playing computer games and spending time with her friends.

If Danielle ruled the world everyone would have to abide by two rules:

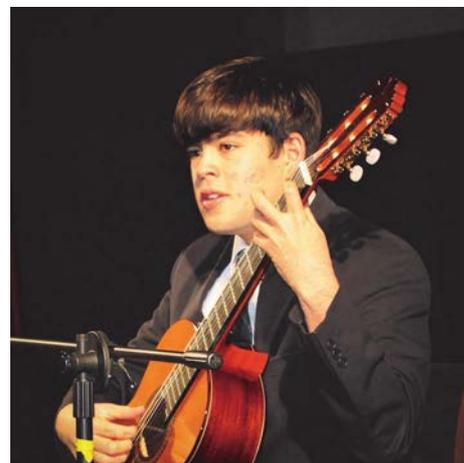
- Have peace and tranquillity
- Trust people

## Sammy, 19

Sammy is currently studying Music, Performing Arts, and History at 6<sup>th</sup> form college. He'd like to work in the music industry when he's older, preferably as a session musician or song writer.

Sammy became a peer supporter because he likes helping others, and felt that as Amaze had helped him over the year he wanted to repay the favour.

He says becoming a peer supporter



is a good learning experience, and you meet some very nice people, and it looks good on your CV too!

Sammy has a wide range of interests; as well as playing guitar and piano, he's a keen sports player, enjoying both football and cricket, and he also likes to play a wide variety of board games.

If Sammy ruled the world, there's just one rule everyone would have to follow:

- Everyone is equal, and any discrimination of any sort is forbidden.

## Brandon lands his first job

Our warmest congratulations to our Amazing Futures peer supporter Brandon—who we featured last issue—on successfully getting a part-time job with Screwfix in Hove!

Brandon has worked hard to prepare for work, growing his skills and confidence through volunteering as a peer supporter with our Amazing Futures young people's project.

He also undertook Independent Travel Training with Grace Eyre, after

hearing about it through Amaze, enabling him to travel to and from his job by himself. You can see him in his new Screwfix uniform on the right.

We wish you all the best, Brandon!



## Interested in Amazing Futures peer support?

If you're 18+ with or without additional needs and would like to join our team of Peer Supporter volunteers, or if you're 14-25 with special educational needs or a disability and would like to have a Peer Supporter, please call Sue Winter on 07482 111648 or email [sue@amazesussex.org.uk](mailto:sue@amazesussex.org.uk)

## Rocket Artists present Art by Johnny

A group of artists with and without learning disabilities is launching a free, inclusive exhibition on **World Autism Awareness Day**, featuring art by Johnny Carroll-Pell, a young autistic artist.



Johnny painting 'Two Circus Figures' at his first session in The Rocket Artists Studio.

Johnny comes from a creative background - he's the son of our patrons, screenwriter Angela Pell and writer and producer Henry Normal - but it wasn't until he began going to the MyMarc sessions at Amaze, run by Sue Winter, that he got the taste for art. It became a passion and through the MyMarc sessions he heard about The Rocket Artists.

Johnny's mum, Angela, told us both programmes have a real respect for the young people who attend: "They don't see them as 'kids with challenges doing a bit of art'. They treat them as artists, no different to any other and they are never made to feel any less because of their disabilities."

Johnny's love of painting big pictures first began at MyMarc, and he's been painting giant figures ever since. "We now have a wall at home covered in B&Q tarpaulin with plastic sheeting on the floor (akin to Dexter's 'kill room'!) where he loves to express himself."

The exhibition aims to provide an opportunity for people to connect through a celebration of art, inclusion and diversity. It will also be in support of Amaze—see our website for more information.

Alongside the vibrant exhibition, there'll be a programme of events, including Johnny's parents launching their book about living with autism - '**A Normal Family**'- and autistic adult, Ros Blackburn, giving a talk.

**When:** April 2<sup>nd</sup>-29<sup>th</sup>, Wednesdays - Sundays 11am-5pm

**Where:** Phoenix Brighton, 10-14 Waterloo Place, BN2 9NB

Email [gallery@phoenixbrighton.org](mailto:gallery@phoenixbrighton.org) for more information.

## Life skills at Downs View

**Downs View Life Skills College (DVLSC)** in Patcham, Brighton, is for adult learners (19+) with a range of needs, but particularly young people with severe learning difficulties (SLD), profound and multiple learning difficulties (PMLD) and SLD with autism. The college aims to support adult learners in a functional, practical way, closely based on their needs, interests and choices.

**Adrian Carver, headteacher**, explains: "The life skills part of our curriculum reflects the 'Preparation for Adulthood' themes of employment, independent living, friends, relationships and community, and good health. Within these themes, we develop some core aims for individual young people based on their Education, Health and Care Plan, and their aspirations for their future. We want to make each young person as independent as possible in relation to their needs. This might mean they focus on learning to care for themselves or develop their skills in relation to work or volunteering."

Life skills classes at DVLSC run alongside more traditional classes that help students develop core skills in communication, functional literacy and numeracy, PSHE, employability, citizenship, creative arts and more.

The college has access to great facilities too, as Adrian explains: "We're located on part of the site at Patcham House School. We have dedicated classrooms, quiet rooms and a physio room, as well as access to specialist rooms in the school for food technology, ICT, etc. And there are also outdoor areas for leisure and to develop work skills such as grounds maintenance. All our classrooms have computers, interactive whiteboards and iPads, and we use assistive technology such as Eye-Gaze to support learner engagement.

"We also have a flat in Hove that helps to develop independence; it has a kitchen, classroom, bedsitting room and bathroom, and a garden that the students maintain."

**If you would like further information, contact Adrian Carver at Downs View on 01273 601680.**



## Amaze workshops

We're running lots of really useful workshops in Brighton over the coming spring and summer terms...

**Decision making - Thurs 15<sup>th</sup> March**  
9.30am-12.30pm, Conference Room, Community Base

Can parents still make decisions for their child once they are an adult? Phil Warford from Renaissance Legal guide you through who can make decisions on behalf of another person according to the law.

**Personal Independence Payments (PIP) - Thurs 7<sup>th</sup> June**, 9.45am to 1pm, Conference Room, Community Base.

Lizzie from Amaze explains 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 14<sup>th</sup> June**, 9.45am to 1pm, Conference Room, Community Base. Get ready for your next DLA review with Lizzie, our benefits guru will help you be prepared to put in a really strong claim.

**EHCP Annual Reviews (up to Year 8) May/June 2018, day TBC**

9.30am-12.30pm, Amaze Meeting Room, Community Base. Find out how your child's annual review should work and prepare to get the most out of the next one.

**EHCP Annual Reviews (Year 9 and above)- July 2018 day TBC**, 9.30am-12.30pm, Amaze Meeting Room, Community Base.

How should your child's annual review change from Year 9 onwards to start looking at their future and preparing for adulthood?

**All our workshops are free. To book, call the helpline on 01273 772289 or email [info@amazesussex.org.uk](mailto:info@amazesussex.org.uk)**



## Amazing Futures team make some noise for Ed Sheeran

Four of our Amazing Futures Peer Supporters - Hayley Jones, Danielle Garratt, Hannah Fox and Eliph Hadert - enjoyed some free tickets given to Amaze by **Global's Make Some Noise**, for the Jingle Berry Ball concert at the O2 in London where the highlight was seeing Ed Sheeran performing.

Global is supporting Amaze and our six partner organisations - Extratime, Pebbles, T21, mASCot, Barnardos LinkPlus and Sweetpeas to provide drop in sessions, outings and activities for hundreds of disabled children and families in Brighton and Hove during the coming year.

## 'What's out there?' Information Fair for people with learning disabilities



**Tuesday 10<sup>th</sup> July 2018 at King Alfred's Leisure Centre**

Come along to find out what is on offer for adults with learning disabilities and young people in transition to adulthood. There'll be lots of stalls and activities. Get this date in your diary if you are a young person approaching adulthood or their parent.

## Amaze helpline:

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



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