



## Support for young people with SEND to get work-ready

Looking Forward, Amaze's new career support programme for young people with additional needs launches in March.

We were thrilled to hear late last year that we were successful in a funding application to the Careers and Enterprise Company to set up a new rolling career support programme for young people with special educational needs and disabilities (SEND) aged **14-25 in Brighton & Hove and East Sussex**.

Launching in March 2019, Looking Forward will offer young people one to one **information, advice and guidance**, and **work skills training** in groups. The project will also offer workshops and information fairs for both young people and parent carers.

The programme aims to boost young people's confidence and awareness of their options in terms of employment, education, training and

volunteering. It will support around **100 young people** over an 18-month period to identify their own aspirations and take steps to achieve them.

Families have been telling us for many years how hard it is for young people with additional needs to prepare for the world of work as they move into adulthood. Research shows

that young people with SEND are more likely to experience poor educational and employment outcomes than their peers. Nationally **30% of disabled young people aged 16-24 are not in education, employment or training (NEET)** compared to 9% of non-disabled young people, according to the House of Commons Library Briefing Paper 2018.

We know that it's vital young people with SEND get support to talk through and fully understand their options, and to develop an action plan that's truly theirs. It's clear that career support services locally are overloaded, and with demand so high, they can struggle to meet the varied needs of young people with SEND.

Looking Forward will work closely with **partner agencies** including schools and colleges, supported employment and internship providers, and organisations that provide volunteering opportunities for young people.

Our advisors will support young people to identify and address any barriers to achieving their aims, and help them with the choices before them. They will also organise and deliver training and other events, depending on the needs of the young people in the project.

### Does this support sound like something you or someone in your family would benefit from?

Get in touch to find out more and let us know your thoughts on how we can make this service as effective as possible.

**Please note:** this service is open to all **14-18 year olds** with additional needs, and to **19-25 year olds** who have an EHC plan. (This is because of requirements in our funding for the project.)

#### For more information:

Contact Liam: [liam@amazesussex.org.uk](mailto:liam@amazesussex.org.uk) or 07483 111659.

# More investment needed for disabled children from central government

The continuing increase in demand alongside budget decreases year-on-year is putting local authorities and schools under heavy financial pressure, affecting some of the services families with disabled children rely on.

Councils across the country have seen significant, real term reductions to their budgets since 2010, with most central government grants ceasing by 2020. This has coincided with an **increase in demand** for social care and health services, so many local authorities are facing significant financial challenges.

## Local Sussex families are telling us:

- There is not always enough capacity in current services to support their child's additional needs
- They cannot always access them easily
- If their child does not have a diagnosis or Education, Health and Care plan (EHCP), they can be left with insufficient support
- Services still do not always communicate well with each other
- Some families feel pushed into crisis

Amaze is working alongside **ESPaCC** and **Brighton & Hove PaCC** (parent carer councils) plus other parent support groups to ensure the views and concerns of parent carers are heard by senior officers, and to suggest ways services, policies and communication can be improved.

## Pushing for change

Amaze is also actively working to influence central government policy and spending plans, for example with our work as part of the **Disabled Children's Partnership**, as we know more investment is needed for many local services.

**In December, Amaze wrote to all 16 MPs across Sussex** to ask that they write to the Treasury to increase

funding for disabled children in this year's Comprehensive Spending Review. We have heard back from **Caroline Lucas** (MP for Brighton Pavilion), **Peter Kyle** (MP for Hove) and **Lloyd Russell Moyle** (MP for Kempton and Peacehaven), who all used our letter to seek an additional (national) investment of **£1.5 billion** to ensure disabled children and their families have the support in place when they need it.

## East Sussex 'Core Offer'

East Sussex County Council (ESCC) published a 'Core Offer' in December setting out **what services they can realistically provide** in the current financial climate. It has been used to lobby central government, which to date has brought in an extra **£5 million funding** for East Sussex, but budgets remain extremely tight.

Amaze has written to the Leader and CEO of the ESCC to **express our concerns** about the potential impacts of introducing the Core Offer and associated cuts in services for families with children with SEND, and we will continue to work with the Disabled Children's Partnership to influence central government policy.

## Provision in schools

We know that there have been many discussions lately about whether all local schools are doing enough, and have sufficient funding, to welcome,



include, support and achieve good outcomes for pupils with a wide variety of additional needs.

Amaze hears many excellent examples where children with SEND are included in their local school, building links with their local community. But we also hear from families where they don't feel their child is sufficiently supported, or able to cope in a mainstream (or sometimes specialist) setting.

## How we can help you

We'd like to remind parent carers and young people with SEND that Amaze runs the local **information, advice and support service (SENDIASS)** in Brighton & Hove and East Sussex, where we support families to ensure the needs of their children are met.

This includes those who want their child to be educated in their local mainstream school as well as those who want to look at what other placements may be available to them.

All of our SENDIASS advisors have completed the rigorous **IPSEA legal training** and give impartial information and advice based on SEND law.

## Get in touch

Call the Amaze SENDIASS helpline on 01273 772289 or email [sendiass@amazesussex.org.uk](mailto:sendiass@amazesussex.org.uk)

**If you would like to write to your local MP to ask them to influence government spending you can find their details at [theyworkforyou.com/mp/](http://theyworkforyou.com/mp/)**



## Face 2 Face peer support launching in West Sussex

Our popular befriending project is expanding.

Amaze Sussex is working in partnership with **Reaching Families**, a charity that supports families with children with additional needs, to pilot Face 2 Face befriending in West Sussex.

Face 2 Face provides emotional support to parents of children with disabilities and additional needs, through a network of trained volunteers who are all parent carers themselves.

Training starts in March (**March 5th to April 30th**) and runs in school hours in **Worthing**. If you're a parent carer living in West Sussex and you would like to find out more about

being a Face 2 Face befriender please contact Rachel at Reaching Families on 07535 386687 or [rachel@reachingfamilies.org.uk](mailto:rachel@reachingfamilies.org.uk).

Meanwhile in Brighton & Hove we now have 30 trained befrienders and our newest cohort has just finished training.

The plan is to in time be able to offer Face 2 Face across Sussex, covering Brighton & Hove, West and East Sussex.

Email Amanda Mortensen at [amandam@amazesussex.org.uk](mailto:amandam@amazesussex.org.uk) if you would like to train as a Face 2 Face befriender in the future or if you would like support from the project.

## 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 early June 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.

## Speech and language disorder name change

**Developmental Language Disorder (DLD)** is the name used now to describe a child with speech, language and communication needs that are long term and interfere with everyday life and learning, but are not linked to having other conditions, such as cerebral palsy, Down Syndrome or autism.

In the past DLD was known as **specific language impairment (SLI)** but the name has changed so that it better reflects the types of difficulties children have. There is no obvious diagnosable reason for these difficulties, but it seems that the part of the brain responsible for speech and language might be wired a little differently in these children.

A child with DLD may struggle to understand the language used in the classroom, or they may have lots of ideas but find it hard to make sentences to say what they are thinking. Studies have shown that in five year olds, **DLD affects about 7.6% of children**.

Find out more about DLD: [bit.ly/2sWcXjg](http://bit.ly/2sWcXjg)

## Special Compass deals March 16th

It's **Disabled Access Day on Saturday 16 March** and the Compass Team at Amaze is joining forces with a number of Compass Card Partners to celebrate! Look out for some very special Compass Card offers to mark this national day of inclusion. Keep an eye out for news in our e-newsletter, Compass News, on the Compass Card website at [compasscard.org.uk/news-and-events](http://compasscard.org.uk/news-and-events) or via the Compass Card Facebook page ('Amaze Compass Card').

## Day in the life of East Sussex's ISEND Teaching and Learning Provision (TLP)

East Sussex TLP works with children who are too ill to go to school because of their mental or physical health. We asked Jess Holliday, Deputy Service Manager of ISEND TLP to tell us about her work.

"ISEND TLP is made up of teachers, support workers and administrative staff across four locations (Lewes, Hastings & Rother, Eastbourne & Hailsham and my area, Wealden). We work closely with schools and health services such as CAMHS to get children back into school and learning with their peers.

"We work with children who have injuries, health conditions, life-limiting illnesses and mental health related issues. To access our service, a child must be on roll at an East Sussex school, have been absent due to ill health for at least 15 consecutive days or have a chronic health condition. They also need to have medical evidence, usually from a consultant paediatrician.

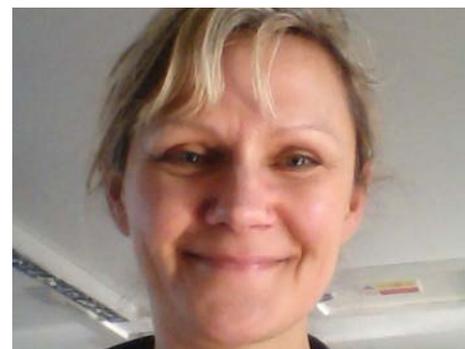
"When a child is referred to us, we gather information from them, their family, the school and other professionals and develop a personal education plan. This usually includes set teaching hours in one of our **dedicated learning centres** in Battle, Lewes or Eastbourne and eLearning via our virtual learning platform. Children who are too ill to travel may also be able to access one-to-one teaching time in their home until they're well enough to either return to school or attend one of the learning centres.

"It's a bespoke plan tailored to the individual child's needs," says Jess, "and the child's voice is at the heart of what we do. We also work with schools to make sure reasonable adjustments to meet the child's needs are in place for their return to school."

"At our learning centres, children have timetabled lessons from **specialist teachers** in English, Maths and Science in small groups of their peers (around 10 students). They are expected to wear school uniform or smart clothing and attend for the length of a normal school day. This can help to rebuild their resilience around being in a school setting. It's about balance: giving the young person the support they need but also encouraging them to take the next step, perhaps joining a small study group in their school or doing their **e-learning** in the school library."

**"It's about balance: giving the young person the support they need but also encouraging them to take the next step."**

Jess is keen to stress the part that support workers play in the service: "Often our support workers are the first and last person children will work with in the service. At the outset, they gather the needs and views of the young person and their family, signpost them to helpful services, and support them to get to grips with the virtual learning platform. Later, they can provide very practical support with getting them back to school. A support worker might rehearse the journey to school, for example, in the week before they return. Or they'll be waiting at the gates for them each morning to walk them to the classroom for the first week back.



They also have weekly one-to-one meetings to check in with children who are back in school."

Finally, Jess and her colleagues provide support to families who have chosen to home educate. This involves seeing and celebrating evidence of what they're doing, making suggestions for further learning and sign posting them to useful resources. They also make sure families are informed about their roles and responsibilities, and those of the local authority.

"Together with the School Nursing Service, we also run **monthly drop-ins** across the county for families who are home educating or those who may just be thinking about it. You can go along anonymously, or as an alternative to a home visit, and ask any questions you may have and we'll give advice and a listening ear."

When Jess mentions she's also the designated safeguarding officer and an 'identified professional' behind ISEND's front door three or four times a year, it starts to seem like a very big job indeed. We asked her how she copes with the workload.

"Being fluid and flexible is crucial. I focus on solutions, not problems.

"Enjoying the job really helps too! I work in a really close team of amazing professionals who are always looking for new ways to support children. And there's no greater privilege than seeing a young person who's coming from a really hard place start to participate in life and education again, with their whole life ahead of them."

More about TLP: [bit.ly/2DEaX4f](https://bit.ly/2DEaX4f)

# Our top tips for claiming DLA

Disability Living Allowance (DLA) is a financial lifeline for many of the families we work with. If you're applying for DLA for your child, read our tips so you can make the strongest case possible. The DWP, which processes claims, is more likely now than ever to look for compelling evidence that your child needs more help than other children their age.

## 1. Get it date stamped

When you first claim, get the form directly from the **DWP helpline** on **0800 121 4600** because it will be date stamped. As long as you return it within six weeks, any award will start from the day you rang.

**Avoid downloading a claim form:** the text boxes only allow you space to write a couple of sentences and often this is not enough. It's much easier to add extra pages to a paper claim form.

## 2. Make it a top priority!

DLA awards can be worth a lot of money. It's a **passport benefit** to other allowances and sources of financial help. So it's worth investing time to get it right. You'll have a lot to lose if your child's claim is refused.

Expect to work just as hard on a DLA review as you did on the original claim. DWP sends out review claim packs five months before an award runs out—time to gather evidence that supports what you say about your child. Download our factsheets **What is DLA?** and **Tips for claiming DLA** from [amazesussex.org.uk/resources/factsheets](http://amazesussex.org.uk/resources/factsheets).

## 3. Make use of the facts

It's worth waiting for **supporting evidence** before you make a first claim. Use medical reports, advices, assessments, your child's Education Health and Care plan, and SEN Support plans (sometimes called

Additional Needs plans) to back up what you say. But be wary of school reports: they are written to be shared with your child and so are usually very positive. If you've mislaid a report, ask for another copy. If your child is overdue any sort of re-assessment, now is the time to chase it up!

## 4. Ask Amaze

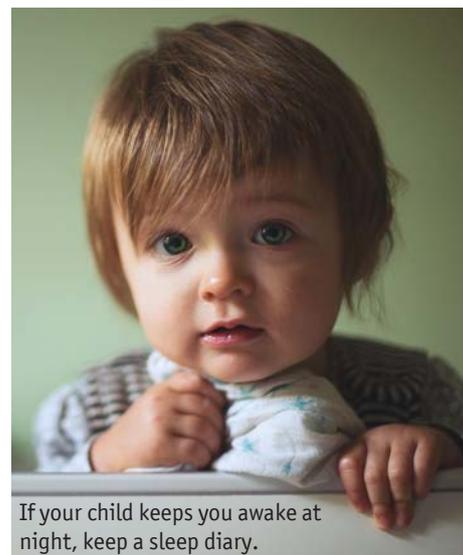
Ring our helpline on **01273 772289** with an up to date 'pen picture' of your child. We may be able to send you **more detailed resources** to help you think about what's useful to include. We may also be able to **check your draft**.

Look out for **DLA workshops**: we run these regularly in Brighton & Hove and across East Sussex and they are a chance to find out how to make a strong claim for DLA, share tips and pick up useful hand-outs.

If you are still stuck, Amaze may be able to offer a **home visit**. But this service is limited, and due to funding restrictions it's only available to families in Brighton and Hove.

## 5. Tell it how it is

It's easy to forget what other children the same age can do for themselves. **Make comparisons** between younger siblings or friends and your disabled child. **Don't gloss over the difficult times**. Even if it feels ridiculous, try to get it down. Include anecdotes that



If your child keeps you awake at night, keep a sleep diary.

illustrate when your child has misread a situation, the muddle or frustration when your child hasn't had help, and unsupervised disasters. Nights are hard to get supporting evidence for, so we strongly suggest keeping a **sleep diary** for a week or so.

## 6. Take a belt and braces approach

The claim pack has very little space to include much detail and you may well have to use the **extra pages** at the back. Better still, attach what you want to say as handwritten notes or a typed word document. **Keep a photocopy** of your claim and advices: **never post original documents**.

## 7. Posting the claim

The DWP needs at least **eight weeks** to make a decision so get your review pack back in good time, or you'll find you're without money while your child's claim is assessed. To be sure it arrives securely we suggest posting by **Special Delivery**.

## 8. Disagree? Act quickly

The DWP doesn't always get it right, but timescales are short, so **act quickly** if you want a recent decision to be looked at again.

Thanks to **Henry Smith Charity**, **Masonic Charitable Foundation**, **Garfield Weston Foundation** and **Brighton & Hove City Council** for funding this work.

# What to do when your child is finding it hard to go to school

School refusal can be a confusing and frustrating issue. We've got some tips on how to navigate this challenge.

Most children say at some point that they don't want to go to school, but for some children this can become a frequent problem, and even stop them from going to school at all. It's worrying, both because we want our children to learn and be happy at school, and because we know we have a **legal responsibility** to ensure our child attends. It can also be very confusing to try to untangle what's going on, and figure out what to do about it. Here are a few ideas:

## If this is a new problem:

**Stay calm** and ask gentle open questions. Your child will be anxious already, so lectures won't help. It's worth bearing in mind they may not actually be able to tell you what's wrong. Be sympathetic but sound positive about school. **Don't make being at home too attractive**, but it's usually better to offer incentives for going to school than penalties for not.

## It's important to talk to the school early on and aim for a team approach.

It's important to talk to the school early on and aim for a team approach. **There may have been a trigger**, whether something at school like bullying or struggling with work, or at home like a bereavement or moving house. You want to explore this with the school without blaming each other. **It may be a combination of things**, and your child might have been "just about managing" until something quite minor caused a

tipping point.

Think about what may be difficult for them and what might help. Do they have an **underlying need** that hasn't been picked up? If you already know they have additional needs, are these being met? Have the academic demands on them changed? Are there new sensory issues? Are they becoming isolated socially? These are all things you may be able to address, in partnership with the school, before school refusal becomes entrenched.

## If it has been going on for some time:

The longer a child is off school the harder it becomes to turn this around, but it can usually be done, so long as the school is flexible and you can work with them. Progress can be slow and you may need to try a variety of things—a mentor, school counselling, a safe space, a reduced timetable? Ask the school about getting advice from an **educational psychologist** or a local authority advisory service like **BHISS** in Brighton and **CLASS** or **ESBAS** in East Sussex. If you and the school agree to try a gradual return, bear in mind any part-time arrangement should be **temporary**. If they can't get back to full time you might need to look at an **Education, Health and Care plan (EHCP)** or a change of placement.

## What's the legal position?

Parents are responsible for making sure their child attends school. Schools are **under pressure** about attendance, so even if they're understanding, they may still send out scary letters and even move towards a fine. Make sure you've been asking the school for help and working with them. If your child is simply too anxious and distressed to go, they may need to be off sick. In this case you need to show you are trying to get medical help for them. Ask the school if they can refer your child to other services, e.g. **CAMHS**.

## What about home education?

Parents can choose to home educate their child. If this is what is right for you and your child it can be a **positive choice**, but you should not feel pressured to do this to avoid prosecution for non-attendance or because the school seems unable to meet their needs. **Always make sure you get advice first**; it's important to understand all the options, and some support is only available to your child if they're enrolled at a school. **If your child can't go to school for health reasons** (including mental health) they should be offered home tuition until they can, or alternative provision if it is clear that there is no suitable school for them in the longer term. Ultimately, though, most of us would prefer our child to be able to go to their local school, and with the right help and advice that should be achievable.

## For more information

- call our **SENDIASS helpline** on 01273 772289 or email us at: [sendiass@amazesussex.org.uk](mailto:sendiass@amazesussex.org.uk)
- [contact.org.uk/advice-and-support/education-learning/handling-absence-from-school](http://contact.org.uk/advice-and-support/education-learning/handling-absence-from-school)
- [notfineinschool.org.uk/families](http://notfineinschool.org.uk/families)
- [heysigmund.com/how-to-deal-with-school-anxiety-no-more-distressing-goodbyes](http://heysigmund.com/how-to-deal-with-school-anxiety-no-more-distressing-goodbyes)



Left to right: Mimi Banks, Rob Low, Laura Ielpo, Elana Woodham, and Nickie Poulton, proudly showing off their awards at the Amaze AGM.

## PaCC awards presented to local superstars

The end of 2018 saw another group of inspiring and deserving PaCC Champions take home their PaCC Award trophies. It's a pleasure for PaCC to be able to give thanks every year to some of the exceptional people in Brighton & Hove who have helped parent carers and their children through what can be a very difficult journey.

This year Pinaki Ghoshal, Executive Director for Families, Children and Learning presented the awards at the Amaze AGM and the winners were divided into four categories:

### Education

#### Nickie Poulton – Teaching Assistant at Downs View

"Nickie is an amazing human being! She works tirelessly for the Friends of Downs View committee, taking on the main bulk of organising fundraising events for the school. Without her they would be lost! She has selflessly helped us so much to look after our

son during the holidays. She's just amazing and gives all her energy and life to the school and our children!"

### Health

#### Rob Low – Head of BSUH Audiology

"Rob diagnosed my son's profound hearing loss when he was just 3 and a half weeks old. His kindness on that day, his understanding and genuine care for our son and our whole family meant that I walked out a little shaken, yes, but feeling safe and supported... He has been a tireless and passionate champion of the city's deaf children. He was at the forefront of the national newborn screening programme and leads an outstanding team of paediatric audiologists."

### Social Care

#### Laura Ielpo – Personal Assistant

"Laura is an amazing woman! Laura works full time but always makes time to look after our son, and be there for us as a family. Laura has helped our son overcome fears: he recently had

his first ever haircut in 11 years! He loves her and tells her so all the time. She is selfless, caring, compassionate and so kind... Laura has brought our son so many smiles, fun, and laughter; things no money can buy. We can never thank her enough for all she does for us as a family - we love her and would be lost without her, and we feel so lucky to have her in our lives."

### Voluntary sector (joint winners)

#### Mimi Banks – mASCot Programme & Development Co-ordinator

"My son has many additional needs including severe anxiety and selective mutism. He has never accessed a club in his life until we found mASCot. The 11+ youth club is a wonderful place; he can truly be himself without judgement. Thanks to Mimi making him feel warmly welcomed he actually talks, interacts, and eats whilst he is there - so very special."

#### Elana Woodham – Volunteer at Sweetpeas

"Elana is an amazing woman with a big heart and she is great with my twins—they think the world of her! She has provided me with so much support, advice, and kindness since the first time I went to Sweetpeas, which has been invaluable to me. Elana needs to be recognised for her outstanding work."

### Nominate your PaCC Champion for 2019

If you have a PaCC Champion you'd like to nominate for 2019, please visit:

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



## Provision gaps and changes to GP services: what you had to say

We've been busy asking our parent carers for their views on two important topics: changes to the way we get support from our GPs, and gaps in provision of services for our families.

### Changes in how we get support from our GPs

The NHS is looking at expanding the ways in which people can get support from their GP surgery. One of the additions being considered is the possibility for people to contact a GP and be **diagnosed through an online system**. This would be an additional service and **would not replace face-to-face appointments**.

Some parents told us that they like the face-to-face interaction with their GP, but many parents told us that the proposed online system could overcome many of the difficulties they experience when they need to get advice from their GP, for example:

- Trying to book a face-to-face appointment at eight in the morning while at the same time facing the sometimes very challenging task of getting your child to school
- The long waiting times at the GP surgery, while your child gets understandably more and more

anxious

- Trying to find a parking space at the surgery

...many parents told us that the proposed online system could overcome many of the difficulties they experience when they need to get advice from their GP...

We heard from parents that they want reassurances that online consultations would be carried out only by **qualified people**, would not generate **misdiagnoses**, and the system would be **safe**. If the online consultation flags a health need which

needs following up, then parent carers want to be seen by the GP in a **timely manner**.

We've passed these recommendations on to the local Clinical Commissioning Group (CCG) and they've contributed to the ongoing debate around changes to ways you can access your GP.

### Gaps in provision

The second consultation looked at where the gaps in provision of services for our families are, so that the city's **new SEND strategy** for 2019-2022 could reflect our families' needs.

The majority of parent carers who responded **didn't feel that current services satisfied their child or young person's needs**. Many of you told us you feel the lack of service provision risks impacting on your child or young person's social opportunities, quality of life, ability to live independently, chances to find employment and access to health care.

Some of the services which were felt to be inadequate or lacking include social, emotional and mental health support, support for children and young people with an autism spectrum condition, sensory services including music therapy, and wellbeing support services within schools. Another area of concern was transition and what the future holds for our young people.

We've passed these recommendations on to the local authority. PaCC is working very closely with Brighton & Hove City Council and the local CCG to make sure that the needs of our families are reflected and addressed in the SEND strategy. Amaze and PaCC will also ensure **referral pathways** to Carers Centre services for young people age 25+ and their families are clear and functional.

To see the reports in full, please visit [paccbrighton.org.uk/resources/reports/health-social-care](https://paccbrighton.org.uk/resources/reports/health-social-care)



# Planning the future: a new strategy for SEND in Brighton and Hove

PaCC is taking a key role in reviewing and developing the SEND strategy for the city.

The **SEN Partnership Strategy 2013-2018** has been extended by an additional year to allow for preparation of a new strategy. We've asked the local authority for a detailed review of what has—and hasn't—been delivered over the last 5 years, which we'll share with you and ask for your comments and views.

The local authority and other partners are developing a **new strategy** from 2019, reflecting the big shifts in SEND law and practice since 2014. This will provide an overview of priorities around SEND across the city for the coming three to five years. It's in its early stages, but some core principles have already been laid out.

In November, we hosted a **PaCCconnect** event, so we could ask you for your experiences and views, to

help shape the new strategy. **Georgina Clarke-Green** (Assistant Director for Families, Children and Learning) and **Carolyn Bristow** (Head of SEN Statutory Services) attended so they could hear directly from parents about their experiences and priorities.

Based on this meeting and other conversations, the local authority has suggested **four broad priorities**: inclusion, SEND journey, SEND sufficiency of services and provision, and transitions. We're also drawing up a list of **parent carer priorities**, including support for parent carers (for example, respite or training), inclusion in mainstream schools, mental health, and post-16 pathways. The strategy will cover all ages, to reinforce the focus on **transition to adulthood**, and creating life-long

opportunities for our children.

The local authority has been clear that while they'll lead the process, they want this strategy to be created in full **partnership** with other stakeholders, especially those that will be involved in delivering it. We agree – in particular, it's essential for mainstream schools to contribute and fully sign up, in order to tackle key issues like bullying, exclusions, children out of education, and to create better academic outcomes for children with SEND.

The council doesn't want this to be a strategy which sits on a shelf gathering dust once it is written—and neither do we. It will feed into action plans, and a **PaCC rep** will be linked to each of the priorities to scrutinise delivery of the strategy. A strategic board will oversee its delivery.

Through ongoing conversations with our community, as well as formal events, we're looking forward to representing parent carers in the development of a strong strategy, focussed on achieving real change and improvements for children and young people with SEND and their families.

## PaCC speaks out against short breaks budget reductions

We've written to local politicians raising concerns around **short breaks savings** in the **proposed Brighton & Hove budget for 2019/20**. We're raising the same concerns as in previous years, asking how savings can be achieved when specific budgets like direct payments and inclusion funding for one to one support at mainstream after-school and holiday clubs are under significant pressure due to high demand.

Other budgets under pressure include residential respite overnight stays, and short breaks in the

voluntary sector, for example Barnardo's and Extratime. Both managers and parent carers have reported that these extremely valued services are in such demand that they are having to put families on waiting lists.

We've been working with the local community and head teachers and officers from the new SEND hubs to create **extended day provision** in the city as a way to stretch limited resources for short breaks provision. However, as we've stressed in our position statement, this potentially exciting project is still in very early



stages, and won't help budget overspends in the next financial year.

Considering the significant ongoing issues around short breaks, **we have recommended budgets this year remain the same** and are not reduced.

View our full position statement here: [paccbrighton.org.uk/what-we-do/pacc-position-statements/](http://paccbrighton.org.uk/what-we-do/pacc-position-statements/)

## Meet Vicky, our fab new PaCC rep

Vicky tells us a little bit about PaCC Partner Barnardo's Link Plus's short breaks and fostering service, and puts a call out for foster carers.

A warm welcome to our **new PaCC rep, Vicky Lloyd**, who is a parent carer and works for **PaCC Partner Barnardo's Link Plus**.

"I have been working in the disability world for 20 years in my role at Barnardo's Link Plus, a short breaks and fostering service for disabled children. My interest lies in the voice of the child and inclusive education, and I hope that I can support PaCC to promote the views and wishes of families around these issues."

Link Plus is a trusted specialist service providing high quality, child-centred **fostering and short break care** for disabled children and their families since 1998. They are funded mostly by Brighton and Hove Council and managed by Barnardo's in a positive, long-standing partnership and are **judged "outstanding"** by OFSTED.

**"...we urgently need more carers. If you know someone who has a love for children, a sense of humour, time, energy and patience, as well as a spare bedroom we would love to hear from you!"**

Looking after a disabled child requires a tremendous amount of energy. All parents need a break from their children once in a while, but for our families it can be even more important and more difficult to arrange informally with friends and family. The aim of the service is to



New PaCC rep, Vicky Lloyd (right) with some of her Barnardo's Link Plus colleagues

"link" families who are in need of a regular break with other local families who can be part of the team around the child.

Vicky says "We have a team of amazingly dedicated, resourceful and compassionate carers who constantly astound me with their energy, skills, humour and tireless commitment to disabled children and their families. However **we urgently need more**

**carers.** If you know someone who has a love for children, a sense of humour, time, energy and patience, as well as a spare bedroom we would love to hear from you!"

**Find out more about Barnardo's Linkplus:**

[www.barnardos.org.uk/fosteringandadoption/fostering/brightonandhovelink.htm](http://www.barnardos.org.uk/fosteringandadoption/fostering/brightonandhovelink.htm)

### 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



## Boosting the East Sussex parent carer voice

The East Sussex Parent and Carers' Council (ESPaCC) updates us on their recent event to recruit new parent carer representatives.

On January 24th **ESPaCC** held a highly successful event to recruit new **parent carer representatives** to help boost the parent voice in East Sussex. We invited anyone interested in joining the team to attend, and the response was overwhelming; **21 parent carers** were offered a place at our training event, and 17 were able to attend. The new reps will attend meetings with the local authority and health services, bringing an invaluable perspective, plus transferable skills that could benefit ESPaCC behind the scenes too.

The lead speaker was **Lara Roberts**, a Steering Group Member for the South East region of the **National Network of Parent Carer Forums (NNPCF)**. She gave parents an insight into the purpose of the NNPCF, and where ESPaCC fitted into the bigger picture, with 150 other parent carer forums across the UK, and an amazing 90,000 members. Lara also ran some fun team building activities that parent carers enthusiastically engaged with—probably because the reward was chocolate!

**Michelle Nice**, Partnership Development Lead for ESPaCC, gave a presentation on how EsPaCC works. She went over ESPaCC's recent projects and how we've worked with

health services and the local authority to develop services together, and the benefits this co-production brings.

**Julie Forsyth and Pollie Rafferty** both gave talks about what it was like to be a parent carer representative.

**Pollie told us how she was nervous attending meetings at first, but as her experience grew, so did her confidence.**

They've both been reps for some time now, and Julie has recently become **ESPaCC's Vice Chair**. Julie shared her passion for the parent voice in East Sussex and how parent carers are a necessary force in changing services for children with additional needs.

Pollie told us how she was nervous attending meetings at first, but as her experience grew, so did her confidence. We know it can be

intimidating at first, so that's why parent carers are always paired up with a mentor rep at the beginning until they feel confident to go alone.

Michelle explained how parent carers could become involved with ESPaCC and the next steps to take, which included filling in a form sharing **personal interests and relevant experience**. We find this really helpful so we can identify the right roles and projects for each parent carer. She also explained that representatives can give as much or as little of their time to volunteering for ESPaCC as they choose. We know parent carers have difficult and challenging lives and there may be times our reps might need to step back for a short time.

The day was enjoyable and interesting, and everyone went home full of enthusiasm about signing up as a parent carer representative.

We received some **great comments** from the parent carers that came along, including:

"So lovely to find a solution focused group locally."

"Friendly, relaxed, informative and inclusive."

"Thank you for making us very welcome, and making us feel we have something to give."

"Friendly and inviting, coming together to help us become a parent voice."

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



**Our Children, Their Voice, Their Future**

If you are interested in knowing more about ESPaCC, becoming a member, or joining us as a parent carer representative, please visit our website at [eastsussexpacc.org](http://eastsussexpacc.org)

# Amazing Futures takes off in East Sussex

Bryony, our new East Sussex Young People's Intern, tells us all about the launch of our **Amazing Futures East Sussex** peer support project.

Hello, it's Bryony from the **Amazing Futures East Sussex** team in **Eastbourne**. We've had such a great time over the last few months; it's been very busy here, especially with our three launch events.

Thankfully some of the Brighton team came over to help us. We did all sorts of activities including print-making, board games and Christmas card making!

The first session went really well. We rolled paint onto gelatine printing plates, then we used card, stamps, feathers and lots of other things to create designs.

**“The group was very excited when we told them that the next launch event would be board games, Scalextric and pizza.”**

We played games like Dobble—a fast-paced matching game—and **Sally Polanski**, Amaze's deputy CEO, even joined in on the fun. We had lots of food, drinks and laughter as we got to know one another, and the group was very excited when we told them that the next launch event would be board games, Scalextric and pizza.

The second session was loads of fun too. As everyone arrived we split into different groups; some raced to help set up the Scalextric track and others joined me on the board games table. Marie from the Compass team came down to join us and helped run the Scalextric races.

It was a close battle but in the end a winner was crowned and they won a box of Milk Tray as a prize. The rest of



Young people having fun at the Amazing Futures East Sussex group in Eastbourne

the group got to share a box of Roses so everyone who wanted a chocolate got one. By this session everyone had become more familiar with each other and spirits were high. Just in time for Christmas...

When everyone arrived for the third session they found we had transformed the DC3 workshop for Christmas. We had pinecone and bauble decorating with paint and glitter, Christmas card making, Christmas jokes (yes they were terrible!) and even played The Price Is Right. Everyone had a great time and one of the young people brought in cake. The loveliest part was everyone got to take home their creations and a card from the team.

It was great getting to know everyone and I'm sure that 2019 will

bring plenty more adventures for the Eastbourne Amazing Futures Project!

Bryony

The Amazing Futures East Sussex peer support activity group meets every other Thursday at the DC3 Project Space, 1-5 Seaside, Eastbourne BN22 7NA

If you think you might like to come along, get in touch:

Call Claire on 07484 915038 or email [claire@amazesussex.org.uk](mailto:claire@amazesussex.org.uk)

Find out more about our groups in Brighton & Hove and East Sussex from our website:

[amazesussex.org.uk/young-people/groups](http://amazesussex.org.uk/young-people/groups)

## East Sussex peer support volunteers wanted!

The next step for the project is to train up some volunteers who can provide **one to one peer support** to young people with SEND.

You need to be **aged 18-25**, live in **East Sussex**, and either have **special educational needs or disabilities (SEND)**, or have had experiences that help you understand what it's like to have SEND.

Find out more here: [amazesussex.org.uk/young-people/groups/volunteer-with-amazing-futures](http://amazesussex.org.uk/young-people/groups/volunteer-with-amazing-futures) or contact Claire (see above.)

# Amazing Talent Show a great success



One of our youngest performers, Angelina, playing some Haydn.

Our **Amazing Talent Show** returned to Brighton in December, and 12 children and young people with additional needs treated us to a brilliant show.

The performances covered everything from dancing to DJing, with music ranging from Haydn to Abba, and even a little festive Wham. Our **Young People's Intern** for Amazing Futures Brighton, Shamann, did a brilliant job introducing all the acts, as well as sharing his own rap compositions with us.

In the second half, peer supporter Kiana DJed for our disco. The young people took advantage of the snack

table while the oldies busted some fresh moves on the dancefloor from the 90s, 80s, and beyond!

The young people in our **Amazing Futures Brighton** group came up with the idea for the show last year, and it was such a success we had to run it again. We plan to make it an annual celebration.

If you missed the show, check out the **video montage** at [youtube.com/amazebrighton](https://youtube.com/amazebrighton), with clips of all the performances—but not our dancing!

## Performers needed for Disability Pride 2019!

We're looking for children and young people aged 0-25 with additional needs who might like to share their talents at **Disability Pride in Brighton** this year. Can you sing, dance, juggle, do magic? Whatever your talent, we'd love to see it!

Get in touch with Sue on 07483 111648 or email [sue@amazesussex.org.uk](mailto:sue@amazesussex.org.uk) if you'd like to take part, or find out more.

## Upcoming music workshop run by our Young People's Intern for Amazing Futures Brighton, Shamann

Shamann tells us a bit about himself, and his upcoming music production and lyric writing workshop for young people with SEND at Amaze.

I started work at Amaze as the new **Young People's Intern** for the Amazing Futures Brighton project late last year. They provided me with peer support training, and I've since helped train a new team of peer supporters as well.

I'm in my third year studying at the Northbrook Met (formerly Northbrook College) in Worthing, and this year I began studying **Level 3 music production**. It's a two year course, and by the time I graduate I will have gained a lot of useful skills and experience, which I intend to use to make it into the music industry. I'm also interested in leading **music workshops**.

As part of my professional development, Amaze has partnered up with **Audioactive**, who are going to be providing me with a mentor to help me become a music workshop leader, running music production workshops for mASCot.

I'm also leading an upcoming **taster music workshop** at Amaze for young people with SEND, using the skills I've learned at college and in my music journey so far.



Shamann performing his rap compositions at the Amazing Talent Show

My taster **music production and lyric writing workshop** at Amaze for young people 14-25 with SEND will run on **Tuesday 16th April from 2-4pm**.

The workshop is free, but places are limited. If you're interested in coming along, contact Sue: [sue@amazesussex.org.uk](mailto:sue@amazesussex.org.uk) or 07483 111648

## Awesome funders great and small

Cake sale, tapas night, nativity or pub crawl...there are umpteen ways your **school, company or community group** could raise funds for Amaze, and our fundraising team are there to make it easy for you.

Over the last few months, all kinds of people and organisations across Sussex have raised funds to support Amaze's work. They include **Arthur Ward's Crazy Rhythm Band, Bewilderbox, Clubbersize Brighton, our patrons Julia Donaldson and Henry Normal, Downsview School, Eastbourne Beacon, Hangleton Primary School, Hanover Pub Crawlers, Personnel Selection, Preloved of Brighton and the Five Ways Shops, Semolina Bistro, St Bartholomew's School, The Geese Pub and Uckfield Rotary Club.**

Every one of these fundraising superstars did it differently so we thought we'd take a moment to explain what some of them did to give you some ideas about how you, your company, your child's school, or your community group could think creatively to raise funds for our work with families with disabled children across Sussex.

**Uckfield Rotary Club** held a tapas night fundraiser for Amaze with a raffle and a quiz and delicious Spanish style food—all cooked by the Rotary President, Martin Doyle. Thank you to all the members of Uckfield Rotary for your continued support of Amaze in 2019.

**Hangleton Primary School staff and parents** collected a fantastic £480 from



Uckfield Rotary Club



Hangleton Primary School

their children's Christmas performance.

**Eastbourne Beacon** (previously the Arndale Centre) sold raffle tickets for the popular Win a Car prize draw—which was won by Marilyn Kearley from Newhaven. We were one of 48 charities represented at this event and raised £196.10 throughout the day.

**Personnel Selection** simply gave us the money they'd usually spend on Christmas cards.



Personnel Selection

Could your **community group, school, or company** support

Amaze? It doesn't have to be complicated and it doesn't have to raise a fortune—every little helps and every penny counts. Visit [amazesussex.org.uk/support-us/donate/why-donate](http://amazesussex.org.uk/support-us/donate/why-donate) to see what just a modest contribution can do for the families we work with.



## Keeping Amaze Running

**Eastbourne 10K** - We are one of the official charity beneficiaries of this race and would like to get a team together for **30 June 2019**. Register now at [eastbourne10km.wordpress.com](http://eastbourne10km.wordpress.com) or contact [jov@amazesussex.org.uk](mailto:jov@amazesussex.org.uk) for more information.

**Brighton Half Marathon** - we'll say a proper thank you to our Brighton Half runners on 24 February in the next issue but for now - thank you, you were Amazing!

If you are interested in running any Sussex race for Amaze, please call Amaze Fundraising on **01273 234014** or email [fundraising@amazesussex.org.uk](mailto:fundraising@amazesussex.org.uk)



## Packed house for Nature V Human Nature

Amaze Patron, **Henry Normal** held another poetry night in aid of Amaze on 6 February at Komedia Brighton. 'Nature V Human Nature' explored our relationship with human and non-human life and it was a very funny and uplifting evening that raised over £1,000 for our work.

Contact [fundraising@amazesussex.co.uk](mailto:fundraising@amazesussex.co.uk) or call **01273 234014** to find out more about how your school, company, or community group can support Amaze

# What's happening this spring?

## In Brighton & Hove

### Education Health and Care plans

Thurs 14th March, 9.30am to 12.30pm, Amaze Room, Community Base, Brighton BN1 3XG.

A SENDIASS session all about EHCPs. Does your child need one? Hear how to request the EHC needs assessment, get the most out of the process and end up with a good plan.

### How to claim DLA workshop

Weds 20th March, 9.45am to 12.30pm, Amaze Room, Community Base, Brighton BN1 3XG.

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.

### How to claim PIP workshop

Tues 26th March, 9.45am to 12.30pm, Amaze 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.

### Decision making workshop

Weds 3rd April, 10am to 12.30pm, Conference Room, Community Base, Brighton BN1 3XG.

Find out about how decision making changes once your child is an adult. Phil from Renaissance Legal explains the Mental Capacity Act, Powers of Attorney and how the Court of Protection might help.

### Wills and trusts workshop

Weds 15th May, 10am to 12.30pm, Conference Room, Community Base, Brighton BN1 3XG.

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.

### iPad workshop

Friday 15th March, 10.30am to 12.30pm, Amaze Room, Community Base, Brighton BN1 3XG

We've partnered with Family Fund to host a workshop to help you better understand how your iPad works, and make the most of it as a parent carer of a disabled child.

## In East Sussex

### How to claim PIP workshop

Tues 5th March, 9.45am to 12.30pm, Lindfield School, Eastbourne BN22 0BQ.

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.

### SEN Support workshop

Date and venue to be confirmed soon

This SENDIASS workshop explains what to expect from SEN Support and how to make sure it is working well to help your child in school.

### Annual reviews workshop

Date and venue to be confirmed soon

If you want to prepare for an annual review of an EHC plan, then this SENDIASS workshop is for you. Understand the annual review process and get tips on how to use it to get the best from your child's plan.

### Education, Health and Care plans

Date and venue to be confirmed soon

A SENDIASS session all about EHCPs. Does your child need one? Hear how to request the EHC needs assessment, get the most out of the process and end up with a good plan for your child.

### Class+ for East Sussex

Regular Coffee and Chat sessions and workshops on **specific issues** for parents of children with ASC or communication difficulties across the county. CLASS+ is part of the ISEND service in East Sussex. For dates and times, plus regular SEND-related information, follow their facebook page: [facebook.com/CLASSPlusEastSussex](https://www.facebook.com/CLASSPlusEastSussex)

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.

Contact us if you're interested in a workshop with no date and we'll get in touch when we have more info.

There'll be more Amaze workshops on EHCPs, SEN Support, benefits and annual reviews in the future, so keep your eye on our Facebook page and visit [amazesussex.org.uk/events](https://www.amazesussex.org.uk/events)



## Ten year anniversary

We surprised the CEO of Amaze, **Rachel Travers**, last week with this big bunch of flowers, to celebrate her **10 year anniversary** at the helm.

She said "I love working at Amaze, with a fantastic, supportive team of staff and volunteers who often make the impossible possible!"

Amaze is also looking forward with the **new Amaze strategy 2018-21** published at the end of last year. See [bit.ly/2DBSVQ4](http://bit.ly/2DBSVQ4) for what we hope to achieve for families and young people with SEND over the next few years.

## Recommend a friend

**Know someone in Brighton & Hove or West Sussex who'd benefit from a Compass Card? Recommend a friend and both of you could win a prize!**

We're launching a new 'Recommend a Friend' scheme with a prize draw on Monday 8th April.

Just fill in our Recommend a Friend flyer and give it to a friend; when we receive your friend's Compass Registration Form, we'll enter you both in a prize draw for a meal for two at **Polpo Brighton worth up to £100** and a **£50 Love2Shop voucher**. You can find the flyer at [compasscard.org.uk](http://compasscard.org.uk) or email [compass@amazesussex.org.uk](mailto:compass@amazesussex.org.uk) with your name and address. Of course, the more friends you recommend, the more chance you have of winning the prize draw!

## New SEND Strategies in Brighton & Hove and East Sussex

For five years, local authorities and clinical commissioning groups (CCGs) have been implementing the SEND reforms. But now it's time to review how well this has gone and where future focus and improvements are needed. These priorities will be set out in **new, local, SEND strategies**.

**In Brighton and Hove** a range of professionals and PaCC reps have been reviewing progress and are identifying priority areas for the future—flip back to page 9, in the PaCC pull-out section, for more on that.

**In East Sussex** the new **SEND Strategy (2018-21)** is about to be launched, setting out four areas of focus:

- Building capacity for inclusion in schools and services
- High quality provision, outcomes and aspirations

- Transition throughout the journey of the child

- Communication and engagement with families and children and young people

These include areas that were highlighted by the **Ofsted Local Area Inspection of SEND (2016)**, and also incorporate actions from the **'Building Parent Carer Participation'** report (Amaze 2017) and the **'East Sussex Strategic Review of High Needs Funding'** (iSEND 2018).

Each has a working group (made up of a range of practitioners and parent carers) to drive forward the required change in each of these areas.

Amaze staff, and ESPaCC reps, will be involved in each of these groups. Check back in future editions for progress updates.

**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



### Amaze

Community Base  
113 Queens Road  
Brighton BN1 3XG  
T: 01273 772289

E: [info@amazesussex.org.uk](mailto:info@amazesussex.org.uk)

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

