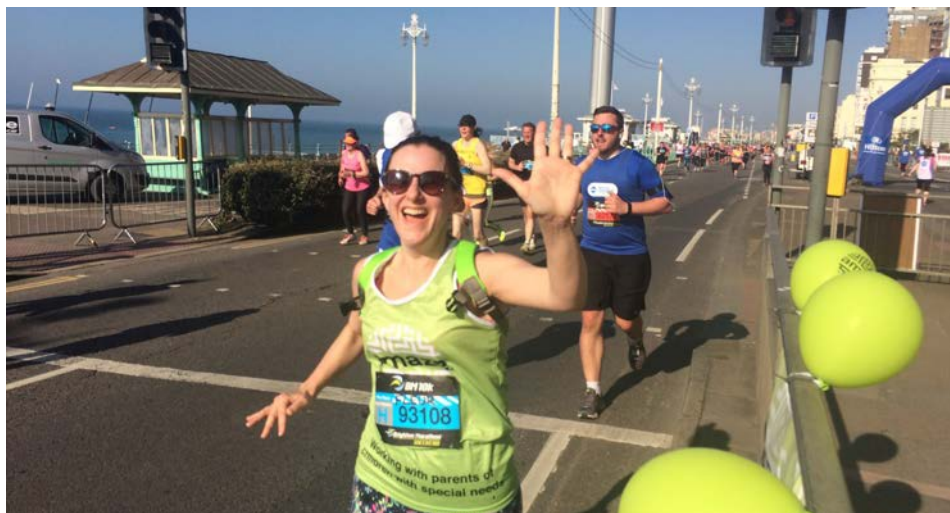


# out of amaze

For families with children and young people with SEN and disabilities



Getting through the summer doesn't have to feel like a marathon... See p15 for more on the amazing folk who've been raising money running for Amaze. **Pictured:** Fleur Tindal doing a fab job running for Amaze in the Brighton Marathon 10k.

## Here comes summer

Summer is just around the corner and the school holidays will be upon us before we know it. How can we keep our children busy and ourselves smiling?

### Looking after ourselves

This is first on the list because we so often put ourselves last, but thinking through **what helps us cope and be resilient** is essential for summer survival. We've shared some ideas throughout this newsletter to help, including: planning ahead for changes, how to get a Carer's Card and thinking about befriending.

**Connecting with other parents** is a top tip; if you're not already part of a group now could be a good time to join, especially as some run social and family events in the summer. See this info on our website: [bit.ly/2vyeHkf](http://bit.ly/2vyeHkf) or call the **SENDIASS helpline** (01273 772289) to get contact details for groups near you.

### Filling the day

Write a list of **fine day activities** and **rainy day alternatives** that work for your child so you don't have to think on your feet every day. Remember, you're not the only one in this boat; **swap ideas** with other parents on a parent forum or Facebook group.

If you don't already have a **Compass Card** ([www.compasscard.org.uk](http://www.compasscard.org.uk)) or **I-Go card** ([bit.ly/2H4I5E7](http://bit.ly/2H4I5E7)) check to see if you are eligible and apply now,

so you have a the card in time for the holidays. Both cards give access to loads of **great leisure offers**.

**swap ideas with other parents on a parent forum or Facebook group**

In Brighton be sure to pick up a copy of the council's great **"Summer Fun"** booklet from a library if you don't get one via school. A good website for **accessible days out around the UK** is [dayoutwiththekids.co.uk](http://dayoutwiththekids.co.uk) and you can get a free copy of the **Rough Guide to Accessible Britain** here: [bit.ly/2IQdqcB](http://bit.ly/2IQdqcB)

### Summer schemes

These can offer fun for children and a break for you, but if you're looking for specialist and inclusive schemes **don't waste any time** as they get booked up early. The **Local Offer** in each area ([eastsussex.gov.uk/localoffer](http://eastsussex.gov.uk/localoffer) or [brighton-hove.gov.uk/localoffer](http://brighton-hove.gov.uk/localoffer)) is the best place to start your search. The **Brighton Family Information Service** ([www.familyinfobrighton.org.uk](http://www.familyinfobrighton.org.uk) or call 01273 293545) and **ESCIS** in East Sussex ([escis.org.uk/category/family-information/](http://escis.org.uk/category/family-information/)) are also mines of information.

### In this issue:

**Befriending launches in East Sussex p2 • Carers Centres & Carers Cards p4-5 • Transition tips p6 • Brighton PaCC pull-out (feat. marchformASCot, Mental health consultation, Short breaks reductions) p7-10 • Changes at 16 p11 • Disability Pride p10, 12, 14 • Courses and workshops p16**

# Peer power

Amaze's befriending service for parent carers, Face2Face, is expanding across Sussex.

The befriending service, which has been running in Brighton & Hove for six years, is working in partnership with support charity **Reaching Families** in **West Sussex** and is now able to offer befriending with a team of seven West Sussex befrienders.

In **East Sussex**, training starts next month in **Eastbourne** and we hope to be able to offer befriending from September. The training is intensive and runs over seven to eight weeks covering the core elements of befriending and peer support, active listening, safeguarding, boundaries and the parent journey.



Local parent carer and new Face2Face project worker, Louise Howe

Meanwhile, in Brighton & Hove, we are delighted to announce that **local parent carer Louise Howe** has joined us as our project worker. Louise originally had a befriender when she faced her own challenges with her son and then went on to become a befriender herself.

## West Sussex

West Sussex Face2Face is now able to offer befriending to parent carers who live in West Sussex and have a child up to the age of 25.

Please contact Rachel Fielding at [rachel@reachingfamilies.org.uk](mailto:rachel@reachingfamilies.org.uk)

"My journey began several years ago when I found myself in the darkest of times and having a befriender made me feel stronger," says Louise. "I got a lot of help from Amaze along the way and I felt I then could give something back as a befriender myself. The training was excellent and helped me discover so much more about myself and my life. After years of volunteering and setting up the breakfast club I am now the project worker and I have never felt as much passion and commitment in a role before."

**Feeling stronger is a key outcome of peer support.** As part of the Face2Face training, we run a session on resilience and looking after ourselves, one of the core concepts behind peer befriending.

The magical ability to 'bounce back' when facing intense challenges around parenting a disabled child can seem elusive. Peer befriending helps by offering **key emotional support** to families, particularly around the time of diagnosis or new challenges (such as an additional diagnosis or difficulties at school).

## East Sussex

We are very pleased to announce we are piloting Face2Face East Sussex, in Eastbourne initially. We are looking for befrienders to join our training course which starts next month. The training will be in Eastbourne but is open to parents across East Sussex as long as they are able to travel.

Please contact Amanda Mortensen at [amandam@amazesussex.org.uk](mailto:amandam@amazesussex.org.uk) for more information.



We know that Face2Face helps parents feel more emotionally strong, resilient and good in themselves. We also know that training as a befriender can have a really transformational effect on our ability to cope and see the future more positively. "It's made me really look at what I've been through and how I have come out smiling," says Kelly, one of our recently trained befrienders. "It's definitely made me focus on the positive."

**"Before your visit I had no hope," said one parent we recently visited. "Now I feel full of hope so thank you."**

Parents report that Face2Face peer support gives them **a sense of hope for the future**, often at their most challenging and lowest time. "Before your visit I had no hope," said one parent we recently visited. "Now I feel full of hope so thank you."

## Brighton & Hove

Befriending continues in Brighton & Hove and we are also running our successful groups (monthly breakfast club, autism group for under 8s, a group in partnership with PRESENS for under 5s and a monthly dads group).

Please contact Louise Howe for more information at [louise@amazesussex.org.uk](mailto:louise@amazesussex.org.uk)

## New SEND strategy for East Sussex

East Sussex has now launched its new **Special Educational Needs and Disabilities Strategy 2019-2021** which can be found here:

[czone.eastsussex.gov.uk/inclusion-and-send/send-strategy/](https://czone.eastsussex.gov.uk/inclusion-and-send/send-strategy/)

The strategy sets out the number of children with SEND, the types of education provision and other services they are currently receiving, and some projections for future demand.

It highlights what the challenges are and what will be prioritised over the next three years, including

sections on how pupils and families can be involved.

The strategy will be subject to a **continuous review cycle**, informed by focus groups for each of the four priority areas:

- 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, children and young people

## What Amaze does and where

Check out our quick guide:

Service	Brighton & Hove	East Sussex	West Sussex
<b>SENDIASS</b> information, advice and support service for parents, children and young people	✓	✓	(Provided by West Sussex SENDIAS)
<b>Compass</b> disability register and Compass Card	✓	(Provided by i-GO)	✓
<b>DLA and PIP</b> help with claims	✓	✓ but less intensive support	(Provided by West Sussex County Council)
<b>Face to Face</b> parent befriending	✓	✓ Eastbourne area	✓ with Reaching Families
<b>Amazing Futures</b> young people's peer support activities	✓	✓ Eastbourne area	(See West Sussex Local Offer for alternatives)
<b>Looking Forward</b> young people's career support programme	✓	✓	(See West Sussex Local Offer for alternatives)

Note: as well as our direct services, we also work **behind the scenes** to try to influence how other services, policies and practices are developed locally and nationally. **We use the experiences we hear from parents and young people** in our advice and support work, as well as the **data we collect** via the Compass, surveys and other feedback to influence decision-

makers and service providers.

This is a good reason to make sure you've signed up to your **local disability register: The Compass** in Brighton & Hove and West Sussex or the iGO in East Sussex.

We also work with the three **Sussex parent carer forums** – PaCC, ESPaCC and WSPCF and we host PaCC in Brighton and Hove.

## Children's Disability Team change

Brighton and Hove's social care teams for **children's disability** and **adult learning disability** are coming together to be a **life-long service**. The new service will have 0-13, 14-25 and 25 plus teams as a key aim is to make **transition to adulthood** work better. Parents and young people will notice the changes from the autumn.

## ESPaCC Focus Groups

The **parent carer forum** in East Sussex (ESPaCC) ran **three focus groups** in March. The themes were: children's mental health; children's disability services (social care); and supported employment pathways. A summary of each discussion and next steps can be found here: [bit.ly/2GRwDwo](https://bit.ly/2GRwDwo)



Visual menu at Jigsaws Café, Eastbourne

## A cafe with a difference to try this summer

**Jigsaws Café** in Eastbourne was designed to provide a safe and welcoming place for **children and adults with autism & learning difficulties**. With a **sensory room**, and two separate seating areas, Jigsaws is the perfect place to venture out. Find them at: **74 Seaside, Eastbourne BN22 7QP**



## Caring for you as carers

Have you heard of your local Carers Centre? You can find one in both East Sussex and Brighton & Hove, offering a range of support, mostly to parent carers of over 18s.

If you care for someone aged 18 or over you could be using your local Carers Centre's services now as well as Amaze, and it's reassuring to know they'll be there when you "outgrow" Amaze as your child reaches 25. Both centres offer a range of information, support and activities, including a couple even if your child is not yet 18.

### Brighton & Hove



The Carers Centre has been providing family carers in Brighton & Hove with support and advice since 1988 and is now a key partner in the **Carers Hub** ([carershub.co.uk](http://carershub.co.uk)) for the city.

All parent carers, whatever the age of their child can sign up to receive Carers News, their **quarterly newsletter** with local and national information for carers: [carershub.co.uk/members/](http://carershub.co.uk/members/).

Their **Young Carers** service is available to siblings of disabled children under 18 as well as young carers of adult family members.

If the young person you care for is 18 or over, the full range of Carers Centre services are on offer. To find out more look at their website:

[thecarerscentre.org](http://thecarerscentre.org).

Via the Carers Hub, they provide general information, advice, support and signposting for carers, plus help with Carers Assessments. Call 01273 977000 or email [info@carershub.co.uk](mailto:info@carershub.co.uk).

**Carers' Activities** are peer-support groups and workshops, social coffee mornings, and information sessions on topics such as manual handling, first aid and coping with stress.

The **Carers Reablement Service** matches volunteers to carers who want to achieve personal goals for change, for example to go to a gym, use a computer, attend a book group or learn to cook.

### East Sussex



Care for the Carers has been supporting unpaid carers across East Sussex since 1989. All parent carers whatever the age of their son or daughter can sign up for their **CareLine Magazine** for local and national information for carers and their **monthly e-newsletter** for regular updates: [bit.ly/2DDFqQ0](http://bit.ly/2DDFqQ0)

**Carers' Activities** are also open to carers of under 18s. These social

activities, days out, courses and treats are an opportunity to have fun, relax, or socialise with other carers. Check what's on via the Facebook page **@careforthecarers** and website [cftc.org.uk](http://cftc.org.uk) or by calling 01323 738390.

If the young person you care for is 18 or over, Care for the Carers' other services are also for you, including:

- **Gateway** – telephone (01323 738390) and drop-in (Highlight House, 8 St Leonards Road, Eastbourne, BN21 3UH) service delivered by carer support workers, providing advice, information and support to carers. Open Monday to Friday, 9am to 5pm. Use the Gateway to find out more or book all other services.
- **Carers Information and Advice Groups**
- **Carers Wellbeing Groups**
- **Mental Health Carers Support Groups.**
- **Young Adult Carers (YACs) Groups** – for carers aged 17-25yrs
- **Carers' Clinics** – one-to-one appointments with a Carer Support Worker
- **Supported Self-Assessment** – face-to-face or telephone support to complete the Carers Self-Assessment
- **Time to Talk Counselling** – 12 sessions of free counselling to support you to cope with the emotional impact of your caring role.
- **Healthcare Appointment Respite Grant** – Funding to meet the costs of respite so that you can attend your own healthcare appointments or courses that help in your caring role.





## Don't forget your Carers' Card

Did you know that both East Sussex and Brighton & Hove have Carer's Cards? Getting one is a resilient move to look after yourself as a parent carer without breaking the bank.

The **East Sussex Carers Card** offers savings and discounts at shops, cafes and leisure venues around East Sussex, including some lovely complementary therapies and treats, and all day parking at the **Conquest Hospital** and **Eastbourne District General Hospital** for just £1.70. The card is run by Care for the Carers. You can sign up online and view a directory of where discounts are available at [www.cftc.org.uk/get-a-carers-card](http://www.cftc.org.uk/get-a-carers-card) or by calling 01323 738390.

Parent carers of Compass Card holders in **Brighton and Hove**, are automatically eligible for a Carers' Card. It brings dozens of discounts that focus on your health and wellbeing including membership discounts at **Freedom Leisure centres**, student rates on **Brighton & Hove Buses Key Card**, concessionary rates at **The Duke's cinemas**, 20% discount at Venetian restaurant **Polpo** in

Brighton and special rates on complementary therapies, meditation, yoga and more.

Young carers aged 8 to 25 can also apply for a **Young Carers' Card** with all the benefits of the Carers' Card, plus special deals including free gym) and free swimming at **Freedom Leisure centres** in the city. The card is run by Brighton & Hove City Council and the Compass Team at Amaze negotiates the offers. There's a guide to Carers' Card offers here: [bit.ly/2XNvtIe](http://bit.ly/2XNvtIe) and more information about the card on the Compass website here: [compasscard.org.uk/compass-card-offers/carers-card-gullys-days-out/](http://compasscard.org.uk/compass-card-offers/carers-card-gullys-days-out/)

Look out for special Brighton & Hove Carers' Card offers to celebrate Carers Week 10 to 16 June! We'll be telling you all about them in our e-newsletter, Compass News Brighton & Hove.

## iContact celebrates autistic women and girls on World Autism Day at the Depot Cinema in Lewes

This Autism Acceptance Day (also known as Autism Awareness Day), **iContact** – a Lewes-based autism support group – hosted an event at the Depot cinema in Lewes. As autism is **under-diagnosed** in women and girls, they chose to make autistic women and girls their theme for the event.

Representatives from iContact spoke in a Q&A before the showing of the film **Snow Cake**, and were thrilled to be joined by the film's screenwriter, **Brighton local and Amaze patron Angela Pell**. The film is a drama focused on the friendship between an autistic woman and a man who is traumatised after a fatal car accident.

Over the past two years iContact has been working with the Depot on a number of projects, including **weekly autism-friendly screenings**, as some people on the autism spectrum find ordinary cinema visits difficult or stressful.

The screenings offer a **more relaxed experience**, with an easy-going attitude to comings and goings, so people can move around or take a break if they need to. They also make sure the sound is not too loud, the house lights are not so dark, and there are no trailers or adverts.

The Depot's autism-friendly screenings run **every Sunday** - see website for details: [lewesdepot.org/access/autism-friendly](http://lewesdepot.org/access/autism-friendly) For info on other autism-friendly screenings: [bit.ly/2EWfvXa](http://bit.ly/2EWfvXa)

For more information about iContact visit: [icontactautism.org](http://icontactautism.org)

# All change

A summer challenge for many of us is helping our child be ready for upcoming transitions in September: starting school, moving up to secondary or to college. New starts can be positive and exciting, but change is often hard for children with additional needs, so as parents how can we help?

First, let's **check in with our own feelings**. If we are worried about the next step for our child, they may pick up on it, so it matters to take care of ourselves and do things that support our own resilience.

Make sure you have someone you can talk to about any concerns outside your child's earshot. **Parent Facebook groups** are a good option to connect with people who share your experience – local ones include **Amaze, ImPACT** and **mAScot**. Bear in mind if you ask "Does anyone have experience of this school?" you'll get some parents saying it's great and others saying the opposite; every child is different.



It will help your peace of mind to be clear about **practical info**. For example, get the **contact arrangements** with the new school or college clear. At each stage there tends to be less direct contact than before; at nursery you may talk daily, at primary school you may need to book a time to speak to the class teacher or SENCO. Email is a good way to communicate with secondary school staff, whilst colleges start by assuming they will talk to the young person not you, so you'll need to find

out where to go if you need to step in.

Your child's new setting should have **extra transition arrangements** for children with SEND and may well invite you in. If not, try to meet someone from their **SEN team** before the end of this term. Write down what they should know about your child (strengths, interests, medical information, what works for them) and check the arrangements for your child's support. Make sure you and your child know the systems for things like lunches and using the loo.

## Make sure you and your child know the systems for things like lunches and using the loo.

Use the summer holidays to ease your child into the change. **It's helpful if your primary-aged child can recognise their own name** or a picture of themselves at school, so stick up name and picture labels at home. **If there's a uniform, buy it early**. Get your child to try it on and see what needs practising like buttons or a tie, or adapting for their particular needs.



Your child may be more comfortable if you wash it and sort out scratchy labels. **Practice the journey to school** so it's familiar.

**Give your child opportunities to talk or ask questions but don't force it.** For some children it will help to look at pictures; maybe look at the school website together. Use visual timetables or social stories. You could write or draw together some things they are looking forward to at the new school. This can be fun, but may also help you spot and deal with things they are worried about or just don't understand yet.

Before the end of the holidays **get into a routine for bedtimes and getting up** so they won't be overtired during their first week. Would choosing a **"transitional object"** suit your child? That's something they can carry around at school that is a link with home, that they keep in a pocket and touch or look at or smell when they need to.

And finally, plan an activity with them for the first weekend after they start that is nice but also familiar.

## For more ideas:

- **"Starting Secondary" factsheet:** [amazesussex.org.uk/resources/fact-sheets/](https://amazesussex.org.uk/resources/fact-sheets/)
- **contact.org.uk/news-and-blogs/is-your-child-starting-a-new-school-our-parent-adviser-offers-her-top-tips/**
- **www.autism.org.uk/about/transition/starting-or-switching.aspx**
- The **SENDIASS helpline** offers information and advice: 01273 772289, [sendiass@amazesussex.org.uk](mailto:sendiass@amazesussex.org.uk)



Connor, 11, waving his flag for autism acceptance

## First ever mASCot autism march is a great success!

March 2019 saw the first ever **March4mASCot**. This month long celebration was created to fundraise for the projects which PaCC partner mASCot runs for their members, raise awareness of mASCot and autism, and promote **autism acceptance**. Most importantly, it was to show how proud we are of our children and young people – particularly those who are neurodiverse.

During March, mASCot members arranged events to help achieve the aims of March4mASCot. One of these events was a children's party and the

children who attended had loads of fun. March4mASCot ended with a relaxed march, starting at Hove Lagoon and finishing at Black Rock. This was enjoyed by all the people who took part, including Connor, 11, who is autistic and has a diagnosis of ADHD (see picture).

**mASCot is a parent-led peer to peer support network** for families who have a child or young person with an autism spectrum condition or neurodevelopmental differences. For further details please visit [www.asc-mascot.com](http://www.asc-mascot.com).

## Short breaks budget reductions halved following PaCC input

As in previous yearly budget discussions, **PaCC continues to challenge short breaks savings proposals** in Brighton and Hove's 2019-20 budget.

PaCC has reported year on year that the Compass statistics clearly show that **a significant number of families in the city are in need of more support**; parent carers need essential respite and children and young people need opportunities to access the community with the correct level of support.

The council's short breaks saving target in the 2019/20 budget was £140k. PaCC talked at length with councillors highlighting significant concerns. **In February's full council meeting, a decision was made to reverse half of the £140k saving to £70k.**

In making this decision councillors listened to officers and made the judgement that the extended day (a plan to offer a mix of **after school, weekend and holiday social care opportunities**) at the SEND hubs in the city will be more cost effective and increase social care opportunities for more families.

**PaCC remains concerned about unmet need** and will continue to raise this priority issue.

PaCC will continue talks with officers, maintaining a dialogue around the need to achieve an inclusive broad range of short breaks activities and provision for families that need it.

## T21 families get their party on for World Down Syndrome Day

PaCC Partner T21 tells us about celebrating their loved ones on World Down Syndrome Day, March 21st.

Every year, **World Down Syndrome Day** is marked on the third month on the 21st day (**March 21st**). This day was chosen to represent the condition, because a person with Down Syndrome (**also called Trisomy 21**) has three copies of chromosome 21 rather than the usual two.

For the fifth year running, families and friends from across Brighton & Hove and surrounding villages gathered together to mark World Down Syndrome Day. We celebrated our loved ones with a disco featuring **DJ Ross**, a singalong music session with Dave from **Little Pickles** music, ping pong with **Brighton Table Tennis Club** coaches and more.

As well as a table groaning with food, we had a spectacular cake from **Eclipse Foods**, and an epic raffle, with prizes donated by friends and local businesses. **Thank you so much to all our lovely donors.** It was wonderful to bring everyone together, allowing old friends to catch up, and new friendships to begin.

**T21 Brighton & Hove was set up in 2014 to offer friendship and support to children and young people aged 0-25 and their families.** As time has gone on, our membership has increased and we are now so pleased that we have members with Down Syndrome/Trisomy 21 who are in their 30s and 40s.

We run a Bumps, Babies & Preschool monthly meet up, park play dates, twice monthly table tennis sessions, summer picnic, World Down Syndrome Day annual party and other social meet ups.

**Anyone who has Trisomy 21/Down Syndrome or their parent carer** who would like to join our group and closed Facebook page (**T21 Brighton & Hove**) will be very warmly welcomed. Please email [T21Brighton@gmail.com](mailto:T21Brighton@gmail.com).

Belated **happy World Down Syndrome Day** to any other folk who are also powered by that extra 21st chromosome!

We hope we can meet you soon.

## NICE news for deaf children

Updated guidance from NICE for NHS provision of cochlear implants leads to more flexible approach.

Welcome news from 'NICE', the body that sets guidelines for NHS provision. On March 7<sup>th</sup>, they **updated their guidance for the provision of cochlear implants** for deaf children and adults with a sensory neural hearing loss.

The **hearing cut-off level** at which cochlear implants could be offered has been brought down significantly, and the guidance recommends a **more flexible approach** to analysing hearing patterns. This means that many more children and adults will fall within the criteria and be able to request an implant if they wish.

The change will take some months to be fully implemented into clinical practice, but as implant centres steadily increase their capacity **over the next five years**, the numbers of patients per year receiving cochlear implants is expected to double.



T21 families celebrating their loved ones on World Down Syndrome Day, March 21st.



# Mental health and wellbeing services – prevention is the way forward

Responses to our recent consultation on mental health and wellbeing services in Brighton & Hove highlight that parent carers continue to feel their children's complex mental health needs are not being met.

We know from the media that there is a national crisis in meeting the mental health and wellbeing needs of children and young people across the country. So it was timely that our latest Brighton & Hove consultation asked parent carers for their experiences of accessing these services over the last three years. This report builds on previous PaCC consultations and provides a good opportunity to reflect on progress made.

Amaze and PaCC representatives have been working with colleagues on the **Brighton & Hove Children and Young People Mental Health Partnership Group** around implementation of the '**Mental Health Transformation Plan 2015 – 2020**'. There have been various service improvement initiatives introduced in recent years, including a recommissioned **Community Wellbeing Service**, the **Schools Wellbeing Service** and a redesign of the **Specialist CAMHS service**.

However, despite these changes our report highlights a desperate need for more services, in part because of the **rising levels of poor mental health in children and young people with SEND**.

Very few parents who responded to our consultation reported an improved experience of mental health and wellbeing services:

"Time taken between referral and receiving treatment [and] access to therapy was lengthy."

"Getting through the barrier and

getting in touch with anyone at CAMHS is very difficult."

Waiting lists and scarce provision of services are seen as key challenges to accessing support. **Parents reported dissatisfaction with communication**, particularly in how families are kept informed about referrals and waiting times. Parent carers feel that the system fails children and young people by not providing support quickly enough when needs have been agreed. Families commented that the system continues to focus not on prevention but on crisis.

Parent carers would like to see more **joined-up services**:

"I think the system is fragmented. Whilst they [individuals working in health, education, social care] all greatly individually contribute, I think the funding structure goes for a fragmented approach, which as a



parent you have to bridge'.

**Our recommendations underline the importance of prioritising support for children and young people with SEND**, as the issues they experience are often so complex.

These findings align with the development priorities identified in the 2018 'Transformation Plan' update. **We hope the insights and suggestions parents have generously shared will be useful to commissioners in planning next steps**. The report will be submitted as evidence to the Sussex-wide **independent review** of children and young people's mental health services. We also hope that the Clinical Commissioning Group (CCG) will prioritise investment in the neuro-developmental pathway, which has been identified as a key area for development.

## The CCG have responded:

Thank you to all parent carers who contributed, the CCG welcomes your feedback. We recognise that the next phase of improvements must take into account the specific mental health and emotional needs of children and young people with SEND, including:

- The re-commission of the **Children and Young People's Community Wellbeing Service** (new contract to begin by June 2020); this offers an opportunity to address known gaps like access to services for children and young people with SEND.
- A bid to be part of the second wave of **"trailblazer"** areas offering **expert mental health support in schools**; this will include a specific focus on special schools and the needs of vulnerable groups, such as students with SEND
- Continuing to improve the **neuro-developmental pathway**

**You can read the full report and its recommendations here:**  
[paccbrighton.org.uk/reports](http://paccbrighton.org.uk/reports)



## Coffee morning groups become community groups

During the past few months both the **Hangleton & Knoll parent carer group** and the **Sunflower support group in Moulsecoomb** have become community groups, with their own constitution, committee and bank account. The groups can now apply for funding to support extra activities, planned and organised by parent carers involved with the groups, whilst Amaze and PaCC continue to support the monthly sessions.

This fantastic achievement was possible because parent carers connected with each other at the

sessions and decided to get involved and grow it into something more – talk about parent carers' empowerment!

A big thank you to **Claire Johnson**, **Community Development Coordinator** at **The Hangleton & Knoll Project** that supported and facilitated the group in West Hove and to **Helen Jones**, a **Community Development Worker** who helped the parent carers attending the Sunflower Group in East Brighton to navigate the complexity of becoming a community group.

The **Sunflower Group** takes place every second Tuesday of the month at **Moulsecoomb Primary School**.

The **Hangleton & Knoll Parent Carer Group** takes place every third Tuesday of the month at **St Richards Church and Community Centre**.

There is also a **monthly coffee morning in Whitehawk** which takes place every last Thursday of the month at the **Whitehawk Inn**.

If you want to find out more about the coffee mornings please email Paolo at [paolo@paccbrighton.org.uk](mailto:paolo@paccbrighton.org.uk) or call 07484 051753.



Sunflower Support Group in Moulsecoomb



Blowing bubbles at the PaCC Picnic last year

## Disability Pride returns!

After two scorching summer successes we're looking forward to more fun events at Disability Pride 2019.

The event will run at **Hove Lawns** on the **14<sup>th</sup> July from 11.30am to 7pm**.

Last year PaCC held our picnic and we'll be there again, so come along and find us.

Keep an eye on our Facebook page for more details nearer the time:

[bit.ly/2UHjeLn](https://bit.ly/2UHjeLn)

You can also follow Disability Pride on Facebook: [bit.ly/2ISiccS](https://bit.ly/2ISiccS)

## PaCC plans for the year ahead

Every year the **PaCC Steering Group** meets to review what we've achieved over the past financial year, and what we want to focus on going forward.

This year, towards the end of March, we gathered in the **Friends Meeting House** and talked about our accomplishments over the previous year (2018-19). We looked at how suggestions from our November **PaCCConnect** are shaping the **Brighton & Hove SEND strategy**.

We discussed **PaCC involvement** with the **merging of special schools into hubs**, as well as successful focus groups on Pathological Demand Avoidance (PDA), and Education Health and Care Plans post-16. We also celebrated helping to **prevent respite budget cuts** by reducing the proposed savings from £140,000 to £70,000.

We know our influencing work around SEND services can sometimes feel slow, and there is a long way to go. This is why for the coming year we'll continue our involvement with the **Brighton and Hove SEND strategy** to ensure parent carers voices are heard when making plans for the city.

Other priorities for PaCC include: working to improve **post-16 provision** so that young people can have a better future and access training and employment, plus a focus on **kids who 'fall between the gaps'**, particularly around mental health and education.

**Thank you for supporting us during the past 12 months**, we believe that together we have a stronger voice. See below if you would like to join PaCC.

### 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/your-views](https://paccbrighton.org.uk/get-involved/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

# No surprises—be ready for changes at 16

One way to stay resilient as parents caring for children and young people with SEND is to make sure things don't take us by surprise. Here's the heads up on some key changes around decision-making and benefits that come when our children reach 16.

## Start young

When our children are little it's hard to imagine them being expected to make decisions for themselves when they turn 16 but that's what the **Mental Capacity Act** says must happen, unless it's clear that they don't have the capacity to do so.

And if they don't, **as parents we won't automatically be able to carry on making decisions for them**, so it makes sense to teach them how to make choices and express an opinion. This is especially important for children who don't find communication easy; **we want their voice to be heard when we can't speak for them**.

It's hard for young people to make big decisions if they haven't had plenty of practice as a child making smaller ones. Summer can be a good time to practice as we're usually in less of a hurry.

## Education Health and Care plans

SEND law says that your child becomes a "young person" at the end of the academic year after they turn 16, and can make decisions in their own right, including taking control of their EHC plan if they are able to, so **the local authority should start addressing things direct to them**.

But your youngster can choose to say they want you to do this on their behalf, and if they don't have capacity to do it themselves the local authority should continue to ask you.

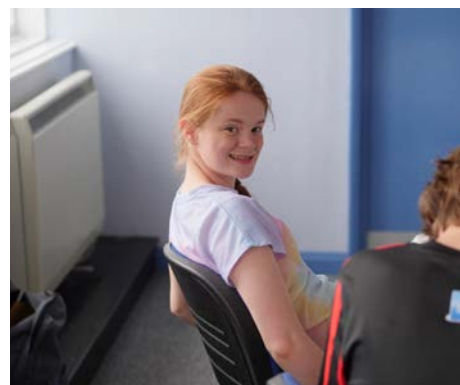
## Benefits

**At 16, young people have the right to manage their own money.** Most don't feel ready to take on this responsibility, but **to continue to manage your child's benefits means taking on the role of 'appointee'**. An appointee acts on a young person's behalf in all benefits matters, not just PIP.

**to continue to manage your child's benefits means taking on the role of 'appointee'.**

If you haven't had a letter from the DWP to ask whether you will be your child's appointee, **call a few months before your child turns 16**. The DWP must visit to arrange this and unless your child has an EHC plan, they will need to meet you both.

If a young person tells the DWP representative they want to take responsibility for managing their own money, the DWP will pay their benefits direct to them. So it's worth having a conversation about this ahead of time!



**Personal Independence Payments (PIP) replaces DLA at 16 but it's harder to claim.** Most young people are expected to start their own claim over the phone and will be required to attend a face-to-face assessment. Don't expect to make a successful claim without **recent supporting evidence**. Timescales are short so it's worth getting prepared ahead of time. If your teen doesn't have an EHC plan or recent reports from a health professional, you will need to think how to get up-to-date evidence, maybe even use some of their DLA to pay for an assessment.

Getting DLA for your child is no guarantee of PIP at 16, so be forewarned, this benefit is hard won. That said, if it feels right to claim then do it, don't be put off. **Call the Amaze helpline for advice.**

But if your child no longer needs the extra support that held them together in earlier years: if they have flourished into a healthy, resilient, capable young person, **enjoy the moment!** Have fun helping your child plan for the future you hardly dared hope for in the past and be glad you don't need to claim PIP for them.

## Find out more:

- **Mental Capacity Act:**  
[scie.org.uk/mca/introduction/mental-capacity-act-2005-at-a-glance](https://scie.org.uk/mca/introduction/mental-capacity-act-2005-at-a-glance)
- **Amaze factsheets on "Involving Young People", "What is PIP", "Tips for Claiming PIP" and "PIP Face to Face Assessments":**  
[amazesussex.org.uk/resources/fact-sheets/](https://amazesussex.org.uk/resources/fact-sheets/)
- **Gov.uk—Become an appointee for someone claiming benefits:**  
[www.gov.uk/become-appointee-for-someone-claiming-benefits](https://www.gov.uk/become-appointee-for-someone-claiming-benefits)

# Celebrating young people at Disability Pride

Young people who come to the **Amazing Futures Brighton** peer support activity sessions are looking forward to celebrating Disability Pride on **Sunday 14<sup>th</sup> July**. We've been talking together about the things they're each proud of – which is what **Disability Pride** is all about.

We love hearing about the many achievements of the young people with additional needs at Amazing Futures Brighton.

A number of the young people who have trained as volunteer peer supporters have gone on to get paid work at **Legal & General**, **Screw Fix**, **the Dharma School**, and **early years nurseries**. Some young people are at university, others are still at college.

We've checked in with our current and past interns:

**Danielle**, Amaze's first intern, runs training sessions with a number of organisations she volunteers with. She's helped adapt and run workshops with **YMCA's Right Here mental health & wellbeing project** for pupils at **Downsview Hollingdean School** and for young people at **Amazing Futures Brighton**, helping to build their resilience.



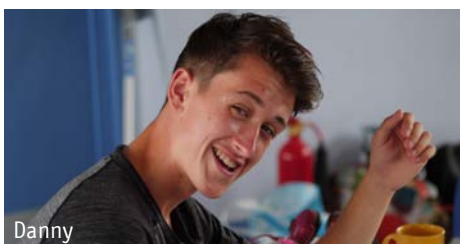
Danielle

She helps **Carousel** run training sessions with cinema staff on how to make their cinemas more accessible to people with learning disabilities. She also helps **Speak Out** provide training for the **Thumbs Up Scheme**, raising awareness of how businesses can provide a better service to people with learning disabilities.

She volunteers at **Mymarc's** art workshops for young people with SEND, helps select films for the **Oska Bright film festival**, has gone to

Blackpool for a national advocacy conference, and more.

Danielle says doing the internship at Amaze has given her the **confidence** to do so many things she's never done before. She's a fantastic role model for young people coming to the **Amazing Futures Activity Sessions**, and we're so pleased she still volunteers despite all her other commitments. Danielle is a shining example of a young person with disabilities working hard to achieve the things she wants in life.



Danny

**Danny**, the second **Amazing Futures intern**, has had a few jobs since leaving Amaze and is hoping to work as a Leader for **Camp Canada** this summer.



Eliph

**Eliph**, our third intern, is working very hard doing her **Art & Design Foundation Course** at **the Met**, as well as working for Amaze helping develop the **Looking Forward** project. Eliph also runs art workshops for **Brighton Museum & Art Gallery**.

**Shamann**, our fourth intern, is also a student at the Met, at their Northbrook campus, where he is doing



Shamann

a **Music Production** course. As part of his internship, Amaze and **AudioActive** have been supporting Shamann with his professional development. He has been mentored by a worker from **AudioActive** to help run music production workshops for young people at **mASCot**, and recently ran a music and lyric writing workshop for **Amazing Futures**.

**Danielle is a shining example of a young person with disabilities working hard to achieve the things she wants in life.**

**Amazing Futures** is supporting some of our peer supporter volunteers to become **workshop leaders**, learning how to plan and run sessions for young people. **Jesse** plans and leads the drama group, and young people will be running art & crafts and sports sessions over the summer.

We'll be celebrating all young people's achievements – whatever they might be – at **Disability Pride** on **14<sup>th</sup> July**. Please come and meet some of these very remarkable and resilient young people and see their **Celebratory Self Portraits**.

## Looking Forward support available in Brighton & Hove and Eastbourne

Support now available for young people with SEND as they look to their future

As part of their preparation for adulthood young people need to think about their next steps in education, employment and training. **49% of people with disabilities are not in employment**, so it's vital that young people with SEND get the support they need to figure out the best path for them.

The choices ahead can seem overwhelming, so we've set up the Looking Forward project to work with young people and help them to identify their next steps.

Looking Forward offers a variety of options for young people to choose from:

- **one to one action planning** to encourage aspirations and look at ways to move towards their goals
- **training sessions** on skills needed to find a job, college, or training placement e.g. CV writing and interview techniques
- **Workshops** to look at choices and next steps (which parent carers can also attend)

Young people can choose to attend the sessions that interest them and we will support them to identify what they want to do, and how they'll get there.

The project supports young people to **develop their resilience** so they feel more confident in moving toward their goals and the challenges that go with this.

Looking Forward is available in Brighton and Eastbourne. **Any young person aged 14-18 with SEND is eligible.** Young people **aged 19+** can also attend if they have an EHC plan. It's a rolling programme so young people can access activities to suit their needs.

For further information, please contact Liam on 07483 111659 or [liam@amazesussex.org.uk](mailto:liam@amazesussex.org.uk)

## Young people tell us what they want

Young people with special educational needs and disabilities (SEND) across Brighton & Hove and East Sussex have been helping Amaze to shape the **information, advice and support service** we offer to young people directly.

In February, students at **East Sussex College** in Hastings and the **Met College** in Brighton took part in consultations with Sally, our Young People's Worker, about how they find out information, and how they would like support from Amaze.

Amaze also participated in the **Speak Up Speak Out** event in Eastbourne on 21<sup>st</sup> March. This youth voice event was co-produced by the East Sussex disabled young people's voice group **The Able Group** and **East Sussex County Council**.

58 pupils with SEND aged 12-18 from a range of 13 mainstream and special schools attended to give their views on a number of topics and take part in Amaze's eight consultation

activities. We designed these to be fun, inclusive, and accessible. We got some great feedback—one young person taking part told us, "I'm really enjoying this, it's really fun."

Claire from our Amazing Futures East Sussex project, and Bryony (our East Sussex Young People's Intern) helped out and provided an area where young people could just relax and create art.

### What has Amaze found out?

Young people want support from an Amaze advisor by **meeting them in person**, and to be able to **text them beforehand**. One student explained: "So you can tell them how you're feeling, get advice and support and they can give advice about the best



Sally, Bryony and Claire (left to right)

way. **Listening two ways**". They often want us to involve their parents too.

The **top three ways** in which young people seek information about their additional needs, or about support available to them is to **ask their parents and carers, staff at schools or colleges**, and turn to **YouTube**. We are now planning to create some **YouTube information clips** which will be available for young people.

**Watch this space!**

# Let's hear from our Compass Card team in Brighton & Hove...

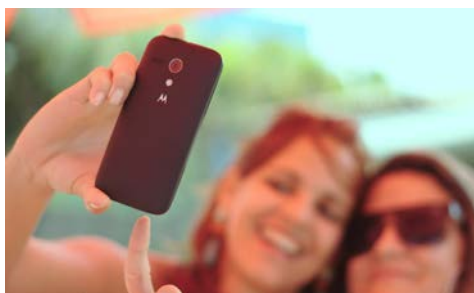
## Want to be in a film?

The Compass Team at Amaze is asking young people to **video themselves using their Compass Cards**, visiting Compass Card venues and having fun so they can star in a cool film that will be launched later this year. The team is asking young people and their friends and families to send short video clips to **Katie** at the Compass Team by **Monday 10 June 2019**.

There's a **prize draw for everyone who sends a clip**, so you could win:

- Two pairs of tickets to the **Connaught Cinema** in Worthing
- Five family tickets for a **City Sightseeing** open top bus tour in Brighton & Hove
- A go karting session for two people at **Brooklands Go-Karts**

Live in East Sussex? Apply for an i-Go card for great leisure discounts: [bit.ly/2H4I5E7](http://bit.ly/2H4I5E7)



- in Worthing
- A bouncing session for two people at **Air Arena trampoline park** in Chichester
- A go karting session for two people at **Selsey Go Karts**

Full details here: [bit.ly/2LfJQ6x](http://bit.ly/2LfJQ6x) or email [katie@amazesussex.org.uk](mailto:katie@amazesussex.org.uk)

For information about the Compass Card, visit [compasscard.org.uk](http://compasscard.org.uk)

## Celebrate Disability Pride with the Compass team!

We're pushing the boat out for Brighton Disability Pride this year with a range of special Disability Pride Compass Card offers and 'Disability Proud' prize draw.

### Disability Pride Compass Card offers

There are a range of **unmissable, time-limited Compass Card offers** from our lovely Compass Card Partners to help you get into the party spirit for Disability Pride. The team was still confirming deals as we went to press, but here's a quick snapshot of those that are confirmed already:

- **Wheelchair climbing session** for £10 and a £5 **climbing taster session** for Compass Card holders with **High Sports** at **Withdean Sports Centre** in Brighton
- **Free cinema tickets** for Compass Card holders with autism or special

educational needs to two '**Blue Oasis**' screenings at **The Capitol** in Horsham during July

- Compass Card holders already get a **free carer ticket** at **Sussex Prairie Garden** near Henfield, but they'll also be able to **take a friend for free too** over the weekend of 13 and 14 July

### Disability Proud prize draw

You'll find information about our glorious Disability Proud prize draw on Compass Card and Amaze social media and through our weekly e-newsletter, '**Compass News B&H**'.

We'll be asking you to tell us what

## Compass Card discounts are the tip of the iceberg...

If you thought the Compass Card in Brighton & Hove was all about **leisure discounts**, think again. True, there are discounts at around 300 venues across Sussex and beyond, but underpinning the card is a sophisticated database, '**Compass B&H**', the **disability register** for the city.

So when a young person or parent carer applies for a Compass Card by filling in a Compass Registration Form, the information is transferred to the disability register by the team at Amaze. No one's personal details are shared outside Amaze, but the **collated data** is a powerful tool that can **directly benefit disabled children and young people** by helping local services plan better.

The **i-Go scheme** run by East Sussex County Council works the same way, supporting an East Sussex disability register.

Not only is the Compass Card expanding leisure opportunities, Compass data is working hard below the surface to bring real change and improvement. Win-win!

makes you burst with pride as a Compass Card holder or as the parent of a Compass Card holder and we'll be running a prize draw for everyone who contributes.

Again, we're indebted to our **Compass Card Partners** for their donations. Prizes confirmed so far include a year's membership to **Freedom Leisure centres** in Brighton & Hove, two family season tickets to **Sussex Prairie Gardens** and two family day tickets to **Bocketts Farm**.

Check out our e-newsletter **Compass News B&H** for full info on offers and prizes closer to the time.



Brighton Marathon bike riders: #teamAmaze

## Marathon efforts for Amaze

Brighton Marathon day on Sunday the 14<sup>th</sup> of April saw a great deal of action for Amaze.

Six dads from Amaze's Face2Face project, **Adrian Elkin, Darren Walker, Neil Man, Paul Nelson, Peter Mapledoram** and **Rob Boulton**, whizzed around the very chilly marathon route in the first 'BM Ride' – a 50 kilometre bike ride at the crack of dawn – **raising over £2000** as a team!

Not far behind were heroic 10K runners **Caraline Glass, Magdalene Haywood** and **Paul Mickleburgh**. Hot on their heels came our inspiring marathon runners: **Aaron Smithson, Holly Cleasby, Ian Peggs, Malcolm Stringer, Michael Tink, Paul Evans** and **Toby Merrett**.



Harvey with dad Malcolm Stringer



Lisa Smith-Wallace, London Marathon runner

Thanks to **Lisa Smith-Wallace**, Amaze also had a super speedy London Marathon runner. Lisa's time was an amazing 4 hours 33, and she's individually raised **well over £1,400**.

**Thank you so much to all our runners and riders** for your hard work raising money for families with disabled children. A fantastic team, keeping Amaze running in many ways.



Last year's Eastbourne 10k quick out the gate

## Eastbourne 10K

Amaze is excited to be one of the **beneficiary charities** of the popular Eastbourne 10K. If you're an Eastbourne local, come out and cheer with us! The race starts and finishes at the Middle Prom between the RNLI museum and the bandstand on Eastbourne seafront on **Sunday 30th June from 9am**.

Huge thanks to **Sue Fry** from **Small Fry Fitness Events**, and **Liz Lumber** for organising this seafront race and raising awareness of Amaze and of our **Amazing Futures** project in Eastbourne.

This race is full now, but **we're always looking for people willing to get their running shoes on for Amaze**, so get in touch if you think this could be you. Or if running isn't for you, how about cycling? A bake-off more your style? **Contact Jo on 01273 234014 or email [jov@amazesussex.org.uk](mailto:jov@amazesussex.org.uk)**

## Beach Life Festival Bungee Jump

**Calling all thrill seekers:** bungee is back at this year's Beach Life Festival in Eastbourne on **Saturday 13th July**. Do you dare take on the **175ft challenge** to raise money for Amaze? If bungee's on your bucket list, like it was for **16 year old Jack Collington**, now's your chance.

Jack's little sister Katy, 3, was diagnosed last year with autism and global development delay. Their mum **Rebecca Reilly** applied for DLA but was rejected, so she called the **Amaze helpline**. "Amaze helped me to claim DLA for Katy. Lizzie was really great at following up and helped me double check all the forms. I wouldn't have been able to do that without you," she said.

Katy attends the **Hopscotch Children's Nursery** in Peacehaven, where with specialist one to one support she is learning to communicate using Makaton and PECS.



Katy and Rebecca Reilly with Jack Collington

"Because of the DLA money, Katy can now go to nursery four days a week." Rebecca explained.

Jack has never done a bungee jump before but as soon as he heard about the Beach Life bungee said, "I'll do that!" He's proud to be doing the jump for his little sister and Amaze.

**Fancy taking the plunge?** Register today via **[VisitEastbourne.co.uk](http://VisitEastbourne.co.uk)** and select Amaze from the dropdown menu. Registration is £20.

Alternatively **contact Jo for more information** and a Bungee Jump Fundraising pack (contact details in the green box.)

# Amaze workshops this summer

## SENDIASS workshops

Free sessions for parents from our SENDIASS advice team:

**SEN Support** - what to expect from SEN Support and how to make sure it is working well to help your child in school.

⇒ Brighton Thurs 13th June

⇒ Bexhill Thurs 23rd May (next in September)

**Education Health and Care plans (EHCPs)** - how to request the Education Health and Care needs assessment, get the most out of the process and end up with a good plan for your child.

⇒ Brighton Thurs 20th June

⇒ Eastbourne Thursday 27th June

**Annual Reviews** - understand the Annual Review process and get tips on how to use it to get the best from your child's plan.

⇒ Brighton Thurs 4th July

⇒ Crowborough Tues 9th July

**Preparing for Adulthood and Annual Reviews from Year 9 onwards** - will run in Brighton and East Sussex in September. Reserve a place now.

## DLA and PIP workshops

Free for parents and professionals from Amaze's disability benefits expert Lizzie:

**How to claim DLA** - identify whether your child is likely to get DLA and learn how to make a strong claim.

⇒ Brighton Weds 26 June

⇒ Crowborough Mon 8th July

**How to claim PIP** - learn how claiming PIP is different from DLA and how to involve your son or daughter so they are ready for the face to face interview.

⇒ Brighton Tues 4 June and Weds 3 July

⇒ Crowborough Tues 25th June

**All these Amaze workshops are free and available to families in Brighton & Hove and East Sussex.**

**To find out more and book, email [info@amazesussex.org.uk](mailto:info@amazesussex.org.uk) or call 01273 772289.**

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

## Seeking East Sussex Trustees

We're seeking three people living or working in East Sussex to join our **Board of Trustees** to help ensure we make the best possible use of our funding to help families there.

We particularly welcome applications from **parent carers, business owners or SEND professionals**.

If selected you would be provided with a **comprehensive induction** and join our fabulous trustee team (currently all parent carers, but also skilled professionals in accountancy, law, PR, marketing, strategy and SEND).

This is a **voluntary role**, requiring you to attend five meetings a year (normally during the school day). We can pay travel expenses.

To find out more, or express an interest, please email [rachel@amazesussex.org.uk](mailto:rachel@amazesussex.org.uk).

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

We'd like to thank **Wellesley Charitable Foundation**, the charitable arm of Wellesley Wealth Advisory, Sussex-based financial advisers, for its contribution towards the costs of producing this newsletter. Wellesley Charitable Foundation helps ill or disadvantaged children and their families in Sussex and the surrounding counties. For more information, visit [wellesleycharitablefoundation.co.uk](http://wellesleycharitablefoundation.co.uk)



## Amaze helpline:

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



### Brighton

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)

### East Sussex

Suite 11, Highlight House,  
8 St Leonard's Road,  
Eastbourne, BN21 3UH

