

out of amaze



For parents of children with special needs in Brighton & Hove

Hail the champions!

PaCC announces the winners of its annual awards for professionals and volunteers who do outstanding work with families of disabled children and young people.

Late last year, PaCC asked you to nominate those Brighton and Hove professionals and volunteers who had made the biggest impact on your lives in 2013. We were looking for individuals or teams who had made life easier for you, who had gone above and beyond the call of duty to support families of disabled children and young people.

We know that there are an awful lot of professionals and volunteers working across the city who are worthy of the title PaCC Champion and you demonstrated that by your response. We received 45 nominations across the four categories - health, education, social care, the voluntary sector - and these came via the web, this newsletter or directly from you at Amaze's Info Fair.

The panel of judges who evaluated your nominations had a very hard job picking the winners but, after much deliberation (and lots of tea and biscuits) we're delighted to announce your PaCC Champions for 2013:

- **Education:** Ollie Kendal, Senco and Teacher, Blatchington Mill School
- **Health:** Vivienne Campbell, Neuropaediatrician, Seaside View,

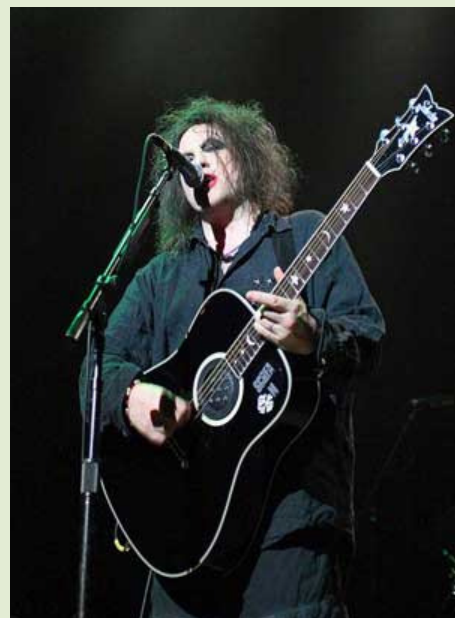
Brighton General Hospital

- **Social Care:** Clare King, Youth Worker, Brighton & Hove City Council Youth Service
- **Voluntary Sector:** Becky Jenner, Director, Extratime

PaCC Participation Worker, Paolo Boldrini, said: "The four winners represent the incredible dedication and energy given to making services and support more responsive to our children and young people. We recognise them for setting good examples."

The judging panel also gave two special awards to recognise 'Outstanding Support' to children with special needs and their families. These went to **Bob Wall, headteacher of Hillside**, and to **mAScot**, the support group for parents of children with autism, for their ongoing passion and dedication.

We'll tell you more about the winners and why they won in the next newsletter. Or you can read the report about PaCC Champion nominees and winners on the PaCC website at: www.paccbrighton.org.uk/what-we-do/pacc-awards/.



Robert Smith raises £22k for Amaze

The Cure's Robert Smith helped Amaze finish 2013 on a huge high when his guitar raised a whopping £22k for Amaze at Bonham's Entertainment Memorabilia Auction on 18 December.

The beautiful black acoustic guitar, inscribed with his signature and the lyrics to an as yet unreleased song, was generously donated to Amaze by Robert, who has a personal connection to a member of staff. He even wrote a letter to accompany the guitar that explained its history and said: "It's a very special instrument for a very special charity!"

The guitar drew interest from all over the world and the final winning bid of £22,000 came all the way from the USA.

We'd like to say a huge thank you to Robert and his family for helping us to continue our work with parent carers of disabled children in 2014.

INSIDE: ABC of SEN Changes • Budget cuts • New autism services • Health round up • Parent stories • Amaze volunteer services • PaCConnects and more...

Summer sports festival warms up

It may seem a long way off, but **TAKEPART Festival of Sport & Physical Activity 2014** will be bigger and better than ever for disabled children and their families.

The Sports Development Team at the council is currently coordinating a fantastic programme for disabled people called 'Amazing Activities', offering free or highly subsidised sessions throughout the two week festival from 21 June to 6 July.

We'll tell you more in the May edition of Out of Amaze – so watch this space!



Out of this world!

Otherworld, one of our newest Compass Card Activities (CCAs), has just finished a run at the Corn Exchange. It's an **immersive theatre** experience for all disabled kids and their families and it has captured everyone's imagination.

"A fantastic experience" said one parent, while another said

"Real sense of wonder and personalisation. Incredible for the money."

Next stop for this unique project is BACA (Brighton Aldridge Community Academy) in Moulsecoomb from 8 to 12 March. We'll give you full info in the Amaze e-bulletin, Compass Team News, and on the Amaze website.



Bullying and ASC services get a closer look

Council **scrutiny panels** are a way of taking a closer look at an issue or area of services. The panels (made up mostly of local councillors) hear

evidence and information from council staff, experts and local people. They use this to make recommendations for the future.

Parents gave evidence at two panels last term with support from Amaze. The topics (bullying and ASC services for children) were important and sensitive so thank you to the parents who stepped up and helped each panel understand how it is for children and families.

We are waiting to hear the report and recommendations from both. We'll put it on the website and our Facebook page when they come out.

New autism services for Brighton and Hove

Autism Sussex has recently launched some great new services for families of children with autism in Brighton and Hove.

They are running **individual advice and support sessions** on Thursday mornings from 10-12 at the Bridge Centre in Moulsecoomb, which offer tailored, one to one advice and support to parents and carers.

The initial meeting is all about gathering as much information as possible, followed by a further session about strategies tailored to your family, with a particular focus on behaviour management and sensory processing. Parents also get a free pack containing practical strategies and resources. This service is completely free of charge and you can book an appointment via the contact details at the bottom of this article.

Autism Sussex is also running a series of **new social groups for children with ASC and their siblings**. Priority will be given to children who are in mainstream schools and who do not usually have access to specialist resources, though the siblings group is open to siblings of children in either special or mainstream schools.

Both children and sibling groups will run once a month on a Saturday,



Tailored advice and support sessions are available at The Bridge in Moulsecoomb.

at Downs View School in Woodingdean. Downs View has a light room, a swimming pool, a soft play space, a gym and a large outdoor play area.

The social group sessions cost £5 per child and the timetable for the day is as follows:

- **10am-12.30pm:** 8-11 year olds and 12-14 year olds
- **1.30pm to 4pm:** (Siblings) 8-11 year olds and 12-14 year olds

The next social group day will take place on **22 February**. To book your child or children onto the groups or to book an appointment for an individual advice session, call 07712 394488 or email emily.christie@autismsussex.org.uk. For more information, visit www.asfamilysupport.org.uk

Online fair pushes all the right buttons

Amaze's Info Fair helped more parent carers to make the most of IT and the internet

About 100 parent carers came along to our **SEN Online Info Fair** at the Bridge Community Centre in Moulsecoomb in November, to meet Amaze staff, visit information stalls or sit in on one of four workshops.

We were delighted to welcome the current Mayor of Brighton & Hove, Councillor Denise Cobb, who 'cut the ribbon' on **Amaze's new website** and the **new Disabled Children's Services pages** on Brighton & Hove's website. The Mayor also got a virtual tour of an iPad from Hove Park pupil, George Gratwick-Sarll, who talked to parents about how technology helps him learn.

Parents who came were asked to give us their feedback about the day and be in with a chance of winning an iPad (read about the lucky winners below). 91% of them said that they felt more confident about finding online information to support their parent carer role after the event. And 85% said they went away feeling more confident about helping their children with SEN to use the internet safely.

We also had some lovely comments from parents about the day:

"It was wonderful and so useful to me as just a normal mum. Thank you"

"A lot of SEN hardware I didn't know existed - will definitely look into



this to improve my son's access to computing and lots of new apps he will love."

One of the themes of the day was keeping our children safe online. If you'd like to see some good resources for parents on this subject, visit www.childnet.com/resources

If you can't get online, call the helpline on 01273 772289 and we can print some information to send to you.

iPad winning parent shows true spirit of Christmas

When Amaze mum and volunteer, Sanda Senanayake, came along to our Info Fair with her friend Farah she never imagined she'd be the winner of an **iPaD**, kindly donated by local digital company **Bright Interactive**. But what's even more amazing is that she gave the iPad to Farah's son Seff!

Sanda and Farah both have sons who are on the autistic spectrum and

met at an **Amaze Insiders' Guide course** a couple of years ago. They were about to leave the Info Fair when Farah encouraged Sanda to fill in the feedback form to be in with a chance of winning the prize.

Sanda explains: "I wasn't going to fill it in because I never win anything. But Farah said 'Nor do I but you never know!' So I laughed and said 'OK. But if I win it I'll give it to you!' We already have a tablet, you see, but I knew that Farah's son really wanted one."

Sanda was delighted to be able to follow up on her promise. "I couldn't believe it when Lizzie from Amaze called to say that I'd actually won! And I couldn't wait to call Farah and give her the good news."

Farah and Sanda came into the Amaze office just before Christmas to collect the iPad and say thanks to us and Bright Interactive.

"I've had a lot of help from Amaze," Farah explained. "Doing courses or

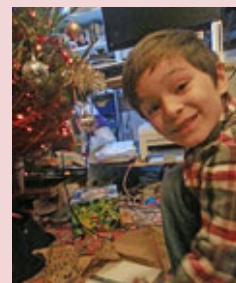
just calling up the helpline in a panic and speaking to someone who says, 'It's OK, it'll pass.' It's helped me to learn to live.

I don't know where I would have been without Amaze'.

Both mums have also had lots of support from **mASCot**, the local group for parents of children with ASC, which had a stall at the Info Fair and runs an online forum.

Sanda summed up what this kind of support means to them as parent carers: "You can't walk this journey by yourself. The more people you have around you, the steadier you can walk."

Once again, thanks to Bright Interactive for helping us to help Sanda make Seff's Christmas!



Seff on Christmas day.



Sanda gave Farah the iPad at Amaze's office before Christmas.

The ABC of SEN Changes in 2014

This year the law on SEND (special educational needs and disabilities) is changing. Some details are still being thrashed out in Parliament and the results of the consultation on the draft SEN Code of Practice is being taken into account. But now the changes are getting close, here is a summary of what is coming.

What happens when?

- **Early Spring 2014:** final details of the Bill and draft Code of Practice being debated and amended
- **Spring 2014:** Children and Families Bill passed by Parliament and becomes law
- **Late Spring:** new SEN Code of Practice published to say how the new system should work
- **September 2014:** the new law and Code of Practice take effect
- **Next three to five years:** existing Statements of SEN converted to Education, Health and Care Plans

What will be different or new?

- Extra emphasis on **parents and children/young people** being **fully involved**.
- A **focus on progress and outcomes** for children and young people, in education **and on transition to adulthood**.
- **Joint working** between education, social care and health about individual children and in commissioning services for children with SEND.
- A **Local Offer** published by the Local Authority (LA) making clear what is available in the area for children and young people with SEND, including what schools are expected to provide.
- **School Action and School Action Plus replaced by SEN Support** and a process of "assess, plan, do and review". The definition of SEN stays the same.
- **Education Health and Care Plans (EHCPs) to replace Statements of SEN.** Statutory Assessment to be a bit quicker and more holistic, but the numbers of children with EHCPs are expected to be much the same as those who get Statements now. EHCPs can run from 0 to 19 and in some cases 25, so Moving On Plans/Learning Difficulties Assessments are also replaced.
- Option of a **personal budget** for support set out in the EHCP.

What's different locally?

September this year is when the changes become compulsory across the country. But Brighton and Hove is a pathfinder for the changes so some bits are already

happening here. For example Brighton's Local Offer will be live and online by the time this newsletter comes out (see page 11 for more details). Everyone who asks for Statutory Assessment for a Statement

is being offered the chance to go straight for an EHCP. Young people with Statements leaving school to go to FE college this autumn are getting a conversion to an EHCP instead of a Moving On plan.



SEN funding has changed too

School funding arrangements changed in April 2013, but overall school and LA responsibilities did not change. So the new funding system should not mean support for your child changes. But it's useful to know how the funding works, as schools sometimes bring it up with parents.

Element 1: all schools get funding based on the number of pupils they have and this is the core funding for every child including those with SEN.

Element 2: every school gets additional money for providing for pupils with SEN. This is shared out based on a formula that is meant to estimate the number of children with SEN the school is likely to have. This is called their "notional SEN budget" and it is expected that schools cover up to £6000 of extra support for a child with SEN from this. This doesn't mean they have this much for everyone as some children will need less.

Element 3: if a school can show that an individual child needs more than £6000 worth of SEN support, they can ask the LA for top up funding from the 'high needs block' that the LA holds. If the LA agrees, the school gets an additional amount to spend on that specific child.

All this applies to mainstream schools, including academies and free schools. The set up for post-16 settings is similar. Special schools get base funding for a certain number of places, but can also get top up funding for individual children. There is no direct link between Statements/EHCPs and top up funding but if a school is asking for top up funding for a child this may well go hand in hand with a request for Statutory Assessment or recommendations from an Annual Review.

Remember you can call Amaze if you want to check out how any of this might affect your family.

Thumbs up for our IPS Service

Our Independent Parental Supporters (IPS) are volunteers who can give parents one to one support with education issues. Last winter we asked for feedback from all the parents who'd used our IPS service in the past year. What did we find out?

Overall parents told us they really appreciate this service and could identify how it changed things for their child and themselves.

"I don't know what I would have done without Amaze. Amaze has been a lifeline for my son and I. My son is now happy at mainstream school and receiving all the support he requires."

The most common topics we helped with were statutory assessment, statement management, admissions/school choice, complaints and appeals, and communication with school.

88% of parents could pick out things they had been able to change for the better for their child as a result of using this service, for example getting better support at their existing school or a change of placement. For some this meant a reduction in things like exclusions, bullying, attendance or behaviour issues.

And parents found the IPS Service helped them too. 70% felt better informed about education services and 64% felt more confident in

sorting out their child's education issues. Over 97% said we gave them space to voice their thoughts, concerns and feelings and that we understood the issues they faced.

IPS Manager, Janet Poole, and her volunteers came in for some very lovely compliments:

"From first contact all Amaze staff were interested, supportive and gave me hope that there could be a positive outcome to my problem."

But the survey also highlighted some issues for us to consider too. One parent felt we should have responded more quickly and we will be looking at our response times as the service is often very overstretched.

Many thanks to everyone who found time to reply to the survey. If you didn't complete the survey but would like to let us know how you've found any of Amaze's services please visit our website at www.amazebrighton.org.uk/about-us/contacting-us and fill in the online feedback form.

What's it like to be an IPS?

"I'm Ruhiya and I've been volunteering as an IPS with Amaze for a year now. It might sound a bit of a cliché but it's been so rewarding and I can see it is a real benefit to other parents.

"The workload varies and I've been able to fit it in with family and other commitments. Although it's a responsible role, I've never felt I was doing it in isolation. It's encouraging and motivating to work with Janet, and being part of the IPS team gives me the chance to share ideas and experiences.

"I have met others who share my passion about SEN within Amaze and beyond, so it's been good for networking and learning. I'd recommend it to anyone who cares about SEN and wants to do something they can really get their teeth into."



Could you be an IPS volunteer for Amaze?

Are you good at:

- Listening?
- Explaining things clearly?
- Working with parents?
- Dealing with bureaucracy, forms and reports?

Do you:

- Have time to commit to 6 mornings of training?
- Have good availability during term time, including coming to regular supervision sessions?

You don't need to know about current SEN education law but will enjoy learning about this and forthcoming changes (see facing page) and how they will work for children and parents in Brighton and Hove.

Call the helpline on 01273 772289 and ask for an IPS information pack

More than a hospital

Many of you will be very familiar with our local hospitals, particularly the Royal Alexandra Children's Hospital (the Alex for short), where your child may see consultants or be sent to after A&E. But you might not know about the extra services or support they can offer to families of children with disabilities or ongoing health needs

CAMHS support for children with medical conditions

There's a new service at the Alex to look after the mental and emotional wellbeing of children with long term medical conditions. Two part time CAMHS workers (psychologist Lana Jackson and nurse specialist Rebecca Groome) can help and advise medical staff to give better psychological support to both inpatients and outpatients at the Alex.

They also do some direct work with children and young people and they're planning groups and a monthly parent drop in. If you think this could help your child, speak to one of the medical staff you see at the hospital and they can make the referral or tell you the date of the next parent drop in.

If your child is not eligible for this service but would benefit from some psychological support, call the Amaze helpline to find out what else is out there for them.

Epilepsy nurse

There's a new specialist epilepsy service based at the Royal Alex. Epilepsy nurse, Jo Whittick, works with children and young people whose epilepsy care is managed by paediatricians at the Alex (up to 18) and the Seaside View Child Development Centre (up to 19). Her job is to make the lives of children and young people with epilepsy as

normal as possible and she can give training, information and advice or act as a link between the family or young person and the various people involved in the child's life. Read more about Jo and how to get referred to her service on the facing page.



Health Passport

Developed by the Specialist Nursing Team at the Seaside View Child Development Centre, the 'Health Passport', is a document that you can take with you to any healthcare appointment that tells the health workers all about your child and their needs.



The 'passport' includes details such as 'How do I show pain and how can you support me?' and 'How am I usually' (vital for our children whose 'usual' may differ from that of other children) as well as information about medication, toileting and feeding. It aims to give health staff an instant snapshot of your child and, hopefully, a more in depth understanding of them and their individual needs.

You can download a copy from the Royal Alex website at www.theroyalalex.co.uk/healthpassport.html. Just fill it in and hand it to health care staff when you arrive for a planned or unplanned visit to hospital or other health care setting.

Further information

For lots of useful information about practical things like parking and visiting, go to the Royal Alex website at www.theroyalalex.co.uk. You can find similar detailed information about Seaside View on the Brighton and Hove website (www.brighton-hove.gov.uk) in the Disabled Children's Services section. Or read more about local health and social care services on the Information Prescriptions website at www.ipbh.org.uk

Amaze produces two really useful health fact sheets called 'Admissions to Hospital' and 'Getting the most out of healthcare appointments'. Download them from our website at www.amazebrighton.org.uk/resources/publications/fact-sheets or call the helpline for copies.



A Day in the Life of an Epilepsy Nurse

Jo Whittick tells us about her work for the new epilepsy service for children and young people at the Alex

I have been a children's nurse for many years, working in a variety of places but my passion for supporting families to care for children and young people with epilepsy began when I was working in a local special school.

I work with children aged up to 18 whose epilepsy care is managed by paediatricians at the **Royal Alexandra Children's Hospital** (the Alex), or up to 19 for those under the **Seaside View Child Development Centre**.

I visit them at home, in nurseries, schools or colleges and in hospital. I can be a link between families and the various people involved in the child's life, giving training, information and advice. Children's needs change as they develop - those for a teenager are very different to a toddler- and it's my job to make their lives as normal as possible.

My first task of the day is to visit a nursery to discuss a new starter, Laura. As the nursery staff are new to epilepsy we talk about what it is, how it presents itself and their fears and concerns. Laura's mum is very much part of the discussion as she is the one who knows exactly what Laura's seizures are like and how Laura is affected by them. We go through what to do in an emergency situation and who to call for help if needed. I leave my contact details and a list of useful websites to get further information.

After this visit I head back to my car

and check my phone. There's a voicemail from a mum of a newly diagnosed 5 year old, who's worried about some issues and wants me to call her. I arrange to see her at her home later that week.

Children's needs change as they develop...It's my job to make their lives as normal as possible.

I try to visit people in their own environment, particularly at the beginning of their child's epilepsy journey. I find we are far more likely to cover everything if our discussions take place in the comfort of the child's home rather than a busy clinic. I get the families to write down their queries, no matter how small, as these can often be the cause of huge anxieties for the child and parents. If I can help to alleviate these anxieties then I feel my job is very worthwhile.

Back in the office I sort through my email messages whilst having a cuppa. A teenager needs advice about a proposed school trip. I let her know I got her message and will reply fully by the end of the week as I need to do a bit of research.

I've just got time for a quick bite before joining the Consultant Paediatricians in the afternoon clinic. This is a good opportunity to get to know all the families who come to the Alex for their epilepsy care and to get an idea of any issues that might

benefit from my input.

A young girl and her mum have an appointment with the consultant and it's clear that the girl's school is having some difficulty in allowing her to access everything on offer. I arrange a meeting later that week to see what I can do to help the school situation. This is a good opportunity to test and receive feedback on a **care plan** I have put together **to encourage inclusion for children and young people with epilepsy**, which will be rolled out once more feedback has been received.

I meet a couple of teenagers during the afternoon clinic. Like every other teenager, life presents many new challenges, doubly so if you also have to cope with epilepsy. Many of these situations, studying for exams, developing relationships, thinking about career choices or wanting to learn to drive, are specific to older children. I am looking at **developing a 'teenage only' group** locally, and already have some young people who are interested.

It's nearly the end of the day so I have a period of reflection and note writing - as a young trainee nurse I learned about the reflective practitioner and it really helps. I check my diary to see where I need to be tomorrow and head off home.

If you'd like to be referred to Jo, please speak to your health visitor, school nurse or paediatrician who can do this for you.

*** Names have been changed to protect identities**



The other four letter word

Pippa Hodge, PaCC member and mum to Leo, tells us why HELP shouldn't be such a dirty word

"Can I help?" How many times have you been asked this question? I know that I've lost count. It's such a lovely question but, I find, so very hard to answer genuinely.

I'm a single parent of three young children, aged 8, 6 and 5. Leo, my youngest, has extensive needs - medical, physical, developmental, behavioural - in short; he's a 'full time job'. I won't use up my word limit telling you all how wonderful he is, let's just take that as read. What I want to talk about is that four letter word - HELP. Not professional help - though I'm a huge believer in the benefits of that - but the offer of help that is fired at you in the supermarket, or the school playground, or in the middle of a crowded kids' party.

Why is "Can I help?" such a hard question to answer? I don't know about you but I find that when I'm asked this question, my standard answer is to gabble "Oh that's really sweet of you, but there's not really anything that you can do. I'm fine, really!" Then I usually change the subject, scurry off, or attend to my

child to defuse the tension. Then the 'head gremlins' start whispering really unhelpful things like "See, it's obvious you're not coping! This person feels sorry for you. You need to get yourself together," etc.

'I've become so used to being the captain of the good ship 'Special Needs' that I'm no good at giving out tasks.'

Only later on do I realise that, yet again, I've allowed a double-headed arrow to hit home: I've refused a genuine offer of support, but I've also allowed negative thoughts to knock me back into a weaker position. And this makes saying yes to the next offer of help even harder.

The truth is I often don't know exactly how someone can help in that moment. I've become so used to being the captain of the good ship 'Special Needs' that I'm no good at giving out tasks. I find it hard to let

go and trust others to do what I do 'properly'. Plus I'm often just too darn tired to think. And, as I'm amongst friends, I'll confess that I worry that if others start helping and doing what I do, there's the small chance they'll be just as good as me, or better, and then what will I do?

Some people remove all the stress of 'The Question' by turning it into an action from the off. A lovely friend of mine noticed that I was exhausted one Friday and just turned up that night with a pot of freshly made bolognese, some pasta and a loaf of garlic bread. No words exchanged, just a hug and slightly watery eyes. But not everyone can be that confident. Maybe they don't want to risk offending us, or doing the wrong thing. But it's vital not to miss the less-formed offers of support too.

So why not try this? **Next time someone says "Can I help?" say "Yes, that would be great!"** without even stopping to think. Because help is the surprise pot of spaghetti bolognese, it's the lovely playdate for your other kids, it's the fresh milk and eggs in the fridge when you come out of the children's hospital a month after you took your child to A&E, it's taking your rubbish to the communal bin to save you having to leave your children even for 30 seconds, it's standing quietly beside you in the playground on the days you feel so wobbly that you fear you'll break down...it's a million and one things that people CAN and WANT to do to make our lives just a little bit easier - and **can we all just agree that we deserve it?**

One final word - I suspect those naughty head gremlins will whisper "But you can't pay them back, you have nothing to give." But actually, we can give back. By sharing our lives with our amazing children, friends learn precious lessons about gratitude, perseverance, patience, imperfection, vulnerability, and maybe gain a fresh look at their own beliefs and gremlins. You see inclusion cuts both ways.



Support as they grow

Did you know that Amaze can offer trained volunteers to help you while your son or daughter is preparing for adulthood?

It should be an exciting time planning for a young person's future – but for young people with special educational needs or disabilities, there can be so many changes to contend with things can get very stressful. Many parents appreciate some help from Amaze during this often difficult time.

‘Having a Preparing for Adulthood parent supporter is like having a knowledgeable friend.’

We have a small team of trained volunteers who support parents with teenagers as they start preparing for adulthood. They can help, for example, to make the case for a young person who isn't able to travel independently to apply for a taxi service from home to college; attend meetings at school or college; help when there's a breakdown in communication between college or school and the parent or young person; provide information about how to access support from adult social care and health services; provide information about all the leisure opportunities a young person might take part in.

Having a Preparing for Adulthood parent supporter is a bit like having a knowledgeable friend. They are not there to take over or boss you about. They will ask you what you need help with, and give you impartial advice and the information you need to make decisions yourself.

So if you've got a teenager and would like one to one support from an Amaze Preparing for Adulthood parent supporter, ring the helpline on 01273 772289. See the back page for details of our great courses for parents of teens.

Finding A Place to Live

Many parents don't feel they have the right information to work out how and where their children might live when they grow up. So our new Through the Next Maze handbook includes a chapter all about the housing options that are available for young disabled people in Brighton and Hove. You can read about the experience of other parents and young people who have made that move and pick up some tips about how they've gone about it.

If your child has a Statement and is in Year 11, you'll be sent a copy of the new handbook in the Spring. But you don't have to wait till then! You can read the chapter called 'A Place to Live' on our website at www.amazebrighton.org.uk/resources/publications/handbooks or call the helpline and we'll print a copy and post it to you.



What's Out There?

**19 March 2014, 11am to 7pm
King Alfred Ballroom, Hove**

Don't miss this information event for young people and adults with learning disabilities or autism and their families. You can find out about the services and support available once your young person becomes an adult.

Lots of providers from health, further education, housing, social care and leisure will have stalls and you can talk to staff and ask them any questions you might have. For further information, email sue@amazebrighton.org.uk or call the helpline.

Update on council budget proposals

Ongoing government austerity measures mean that councils across the country are facing budget cuts. Brighton & Hove City Council has to save £24 million from a total budget of £226m for 2014/5 and is proposing to save £4.7m of this from Children's Services. Here's a summary of how services for disabled children might be affected.

Children's Services delivered by Brighton & Hove City Council cost £55m each year and, as in all departments, managers have a very difficult job to meet their savings targets. Papers detailing the budget proposals can be found at <http://tinyurl.com/o8zjz4h>. The **key proposals** affecting families with **disabled children** are:

- **£78,500** savings across **short breaks services** (about 3% of the total budget)
 - * £17k Tudor House
 - * £32k Drove Rd
 - * £5.5k Outreach
 - * £14k from external short breaks services (including Amaze)
 - * £10k Link Plus
- Estimated **£184,000** savings on **home to school transport** (about 10% of total budget)

The council is hopeful that most of these savings can be achieved through efficiency or 'back-office' savings with minimal impact on frontline services. We hope this is the case, as we know and understand how important a break from caring is for you, and how much children and young people get out of the range of activities the short breaks programme currently offers. We also know how important reliable, good quality, home to school transport is to those families who are eligible.

Co-Chair of the Parent Carers' Council (PaCC), Fiona England, explains: "Short breaks are essential to families with disabled children and mean that many families can go on caring for their disabled child at home, ultimately saving the city money in the longer term."

The PaCC has been working with key partners (**Amaze**, **Extratime** and **Barnardo's**) urging senior council officers



and local councillors to reconsider these proposals and explaining the impact that these cuts would have on vulnerable families.

If you want to ask your local councillor to protect investment in short breaks for disabled children you can complete the Mencap e-petition at this address: www.mencap.org.uk/campaigns/take-action/breaking-point. Or, if short breaks and/or home to school transport is important to your family, you can write to your councillor personally via this website: www.writetothem.com

Unfortunately, the council has to make this level of savings over the next few years too so it would be helpful to suggest what else you think could be cut instead. But you will have to be quick as final budgets will be agreed at the full council meeting on 27 February. We will keep you up to date via the Amaze website (www.amazebrighton.org.uk) and PaCC website (www.paccbrighton.org.uk) and via our Facebook pages - don't forget to 'like' us on Facebook.

Send us your short breaks pics and stories

We'd like to prepare a multi-media presentation for councillors. If you are happy to share photographs of your children enjoying a short break activity, with some words about what it means to your family, please send these to pacc@amazebrighton.org.uk

Tell us what you think of the Local Offer

Brighton & Hove City Council has just published its Local Offer, a detailed online guide to the services it expects to be available for children and young people with special education needs (SEN) aged 0-25 years. All local authorities are now obliged to publish and update this information as part of a directive from central government.

The Local Offer (LO) has been developed in response to the kinds of questions parents have been asking for a long time. For example, "Are there any schools with resource units and, if so, what is their admissions criteria?" Another aim is to help the council identify gaps in provision and act on this.

The Local Offer should include information about all sorts of local services like health, childcare and leisure as well as detailed descriptions of what individual schools can offer in terms of support for pupils with SEN. So it will be particularly important for children without the new Education, Health & Care Plans (EHCPs) which will replace Statements of SEN (see p4).

Parents and their young people with SEN have been involved via Amaze and the PaCC in helping design the LO framework but we now need your help to ensure that it's as useful and up to date as possible.

Please look at the Local Offer at www.brighton-hove.gov.uk/localoffer and email your feedback (both good and bad) to pacc@amazebrighton.org.uk so Nicola and Jade, the PaCC Reps on the LO Working Group, can represent parents' views.

You can also feed comments directly to the council via the comments box on the LO web pages. Your comments can be kept confidential. Thank you!

Get connected

PaCConnects are themed focus group meetings, organised by the Parent Carers' Council, which allow parent carers and professionals to exchange ideas, confront views and work collaboratively.

Apart from giving parent carers the chance to meet regularly, PaCConnects invite guest speakers to answer questions and talk about issues that are important to you. PaCConnects are also a way to gather views on current topics affecting local families with disabled children. We gather suggestions for how to make services more responsive to your needs and pass these on to local services or feed them into strategic groups via PaCC's representatives.

PaCConnects are organised in response to issues highlighted by parent carers. Previous PaCConnects have looked at social care support services, the SEN strategy, children's therapy services and educational psychology. You can read notes from these PaCConnects at www.paccbrighton.org.uk/what-we-do/pacc-connect-events/



PaCConnects are organised in response to issues highlighted by parent carers

The PaCConnect on 8 January looked at the city's **Wheelchair Service**. A group of parent carers were able to put forward their questions to a panel of professionals which included Ann Dyson, Centre Manager, and Lucy Marshall, senior wheelchair therapist, from the Sussex Rehabilitation Centre at Brighton General Hospital; Bridget Morden, Head of Occupational Therapy at the Seaside View Child Development Centre; and Simone Lane, Brighton & Hove City Council Clinical Commissioning Group - children's wheelchair service.

It was a lively forum which looked at the assessment and criteria, the Local Offer (LO) on wheelchairs and equipment, and the choice available to disabled children and parent carers. It was agreed that further work needs to be done to improve the information available to parent carers, and PaCC parents said they were more than happy to contribute to this. We also briefly touched on the role of the Clinical Commissioning Group (CCG) in the city and how we can work with them. You can read the full PaCConnect report on wheelchair services at www.paccbrighton.org.uk/what-we-do/pacc-connect-events/.

We've already planned some future PaCConnects: there's one on mental health services coming soon and later in the year we are planning one on housing adaptations and one on primary health care services with a focus on accessibility of GPs. Check out the Amaze or PaCC website events pages for details. PaCConnects take place approximately every two months at Community Base in Brighton from 9.30am till 12 noon. To hear more, please become a PaCC member. To join, visit www.paccbrighton.org.uk/get-involved/join-the-pacc or call the Amaze helpline for further information.



Pebbles - PaCC Partner in focus

PaCC works with seven partner organisations in Brighton and Hove. One of these is Pebbles, a parent-led community group for children with special needs and disabilities aged four to 14 and their families.

Pebbles was set up by a group of mums who felt isolated and it has evolved into a **weekly drop-in session** that meets every Friday from 3.30 to 6pm at the Manor Road Gym, Whitehawk and a lunch for parents on the first Tuesday of every month at Emmaus in Portslade. They also organise **family days out, respite breaks and holidays** for the whole family. Most activities are subsidised wherever possible.

The Pebbles committee is made up of a small group of mums who work tirelessly to raise funds, organise events and offer support. Committee member and mum, Ally Jones, explains what Pebbles means to her:

"When I first went to Pebbles I had three children under five. My son Travis, who is nine now, hadn't been diagnosed as autistic at that point and I knew virtually nobody with a special needs child. Travis used to scream all the time and hurt his

sisters and we were becoming more and more isolated.

'My two younger daughters found a place where they could relax and not get stared at because of their brother.'

"Meeting the other Pebbles mums was like having a blanket wrapped around me. All of a sudden I had people who knew how I felt. They gave me huge amounts of advice and even helped me with Travis' siblings. My two younger daughters found a place where they could relax and not get stared at because of their brother. They have made lifelong friends with other **siblings** who know how hard it can be to have a disabled sibling who gets a lot of extra attention.

"There is always someone who I can go to for advice and I know that I don't have to worry about not having activities for my children in the school holidays. All my children love Pebbles and Travis, who can have a very unusual dress sense, can be himself and everybody celebrates his effervescent personality!

'All my children love Pebbles and Travis... can be himself.'

"Thanks to Pebbles we have been on trips and holidays that we would never have afforded or been brave enough to do alone. On our many **holidays** at the Knowles Tooth Centre, my children have been part of an extended family where everyone looks out for each other and the parents get to relax more than they ever could otherwise (sadly Knowles Tooth has since closed down).

"I joined the committee so that I could help other parents like me. Pebbles is now part of our life and I can't imagine being without it."

If you would like to join Pebbles or find out more, call 07506 105265, email brightonpebbles@tiscali.co.uk or visit the Pebbles website at www.brightonpebbles.org.uk



PaCC works with new CCG to get your views on health

Have you heard of Clinical Commissioning Groups? Did you know that the local CCG is in charge of managing most health services in the city?



The CCG wants to understand how health services work for users, including disabled children and their families. That's why the PaCC is working closely with them to gather parents' views and experiences.

In April 2013, CCGs replaced Primary Care Trusts (PCTs). Across the country, CCGs manage £60 billion of NHS funds, the remainder of the NHS budget being handled directly by NHS England. Our local CCG covers the same area as Brighton & Hove City Council.

A Clinical Commissioning Group (CCG) commissions (plans and buys) local health services. CCGs all have a governing body made up of GPs, a nurse, a hospital doctor, and two independent lay members. The local CCG funds Amaze to engage parent carers of disabled children in talking about health issues, to gather their views and experiences of local NHS services, and to hear suggestions on what might need to be improved.

Parent carer engagement can take various forms. For example, PaCC keeps parents informed via newsletters, our PaCChat emails, Facebook or PaCConnect meetings.

Parent carer representatives sit on strategic and partnership boards across the city. In all these ways parents' views get to reach the right ears in the CCG. And PaCC and Amaze are not the only organisations involved in this CCG engagement work. Some of the others include The Carers Centre, The Fed, BMECP and Speakout.

From time to time consultations are organised around specific health care issues. For example, in September 2013, Amaze and PaCC promoted a Healthwatch survey on Urgent Care. 41 parent carers expressed their views on pharmacists, GPs, Brighton Station Health Care Centre, Out of Hours GPs, NHS 111, Emergency Dental Services, A&E and Children's A&E. Read what's happening with the results of this survey to the right.

The next CCG topic will be 'wellbeing' in its broadest sense, not just health but also arts, leisure, housing and finances. We'll look at what matters to parent carers and what can be done to improve wellbeing: emotional wellbeing and positive mental health. This will include community factors and services that influence wellbeing, including health and social care, as well as mental health services.

PaCC is organising a PaCConnect on mental health services soon, we will keep you posted. Looking ahead in 2014 there will be more consultation happening around development of GP practices in Brighton and Hove.

Urgent Care findings

Jane Lodge, Engagement Manager of Brighton and Hove CCG tells us about the impact of the Urgent Care Survey.

"The CCG funds a number of local organisations to make sure we hear from those who generally don't get involved in our usual methods of engagement. In late 2013, we asked Amaze to gather the views of parent carers on the city's urgent care services. We wanted to find out whether the range of services were used appropriately, whether people knew about them and what their experiences were. Amaze produced a comprehensive report which gave us useful feedback and suggestions for change, and recounted many personal experiences of where things hadn't gone well.

"Some of the feedback was common to other groups - for example, the need for more publicity around the GP Walk in Centre and out of hours pharmacies - which are being addressed. But much of the feedback was specific to the experiences and needs of parent carers. The CCG is working to look at as many of these issues as possible - some of which have already been highlighted in PaCC's excellent 'Talk Health' report, and are being addressed. Some issues are harder to resolve, and may take some time - for example, increasing awareness of the needs of parent carers amongst the city's GP practices and ensuring continuity of GP.

"We will continue to work with Amaze and PaCC to involve you in making changes, and please let us know if things have improved. We're always happy to hear about your experiences, and we look forward to continuing the positive relationship we have with Amaze and the PaCC."

To tell us about your experiences of local health care services visit www.amazebrighton.org.uk/about-us/contacting-us

Does your child need a buddy?

Dozens of young people with additional needs have already tried our new Compass Card Activities (CCAs), funded by Sport England, but did you know you can get free extra help to settle your 11 to 19 year old into the classes by booking a Leisure Buddy?



We know it can be difficult getting young people to try something new and that's where Leisure Buddies come in. Experienced in working with young people with special needs, Leisure Buddies are specially trained support workers who can help your child get to and from the first few sessions, support them during the sessions and make sure coaches understand exactly what they need to get the best from the classes. Leisure Buddies are a bit like short term **leisure befrienders** and they're absolutely free.

Leisure Buddies are fully trained by local charity Extratime and you can

book a buddy, or find out more, by calling Lisa Nash at Extratime on 01273 420580 or by emailing lisa.nash@extratimebrighton.org.uk CCAs that you can book a Leisure Buddy for are:

- **Archery** inclusive course with Adventure Unlimited for 11-19s (next course dates to be confirmed)
- **Climbing** inclusive session with Adventure Unlimited for 11-19s at Stanley Deason (one session only, but Compass Card holders can join regular sessions afterwards)
- **High Flyers inclusive trampolining** classes for 13-19 year olds on Thursdays 4.30 till 5.30pm in term

time at Moulsecoomb Community Leisure Centre

- **Kayaking** inclusive course with Adventure Unlimited for 11-19s (next course dates to be confirmed, but expected Easter 2014)
- **Fun-fit** weekly multi sport session for 11-19s with special needs. Please note Fun-fit was on hold as we went to press while coaches are recruited, but it should be back soon – call the Amaze helpline on 01273 772289 for the latest.
- **U-Sport** monthly term-time multi sport session for 11-19s with moderate and complex needs from 9.30am till 1.30pm at the Y Club in Hove

Carers' Card



The Carers' Card – the leisure card that aims to promote the **health and wellbeing of carers** in Brighton and Hove – has had a major makeover which will make it much simpler to apply for. The old two tier process of applying for a card is out and so too is the need for a photo ID on the card. There are now around 50 offers on the Carers' Card, so it's well worth having!

How to apply

If your child is under 18 and a Compass Card holder, you automatically qualify for a Carers'

Carers' Card gets a makeover

Card. Call the Integrated Child Development and Disability Team at Brighton & Hove City Council on 01273 295153 and provide your own name, address and date of birth, together with the number on the back of your child's Compass Card. Your Carers' Card will be issued for two years.

If your child is over 18, you'll need to have a current Carers' Assessment to show your eligibility for the Carers' Card. If you've already had one, call the Adult Social Care Access Point on 01273 295555. Staff will refer to the assessment and issue you with a Carers' Card. The card is valid for a year before it needs renewing. If you haven't yet had a Carers' Assessment, call the Adult Social Care Access Point on 01273 295555 for more information.

During a Carers' Assessment, you can also find out about other services to help you such as carers' weekend breaks, a Mindfulness Cognitive Therapy course or the Carers Self-directed Support Grant which can help pay for things that make your caring role easier.

The Young Carers' Card. If you have another child or children aged 8 to 25 who help to care for your Compass Card holder or for an adult who needs care, they can apply for a Young Carers' Card with its range of young carers' offers. The Young Carers' Card is usually issued through the Young Carers Project at the Carers Centre. Email them on info@thecarerscentre.org or call 01273 746222.



The sky's no limit!

Could you push yourself to your limits and undertake a new challenge to raise funds for Amaze?

We are always looking for new and exciting ways to raise funds and this year we are getting excited about a whole range of **active challenges** that might tempt some of you and yours to raise funds for Amaze.

You could try the sponsored London to Paris Cycle Ride or endurance walks like the London to Brighton or Isle of White challenges. Or perhaps you might brave a parachute jump with Skyline Challenge. All of these activities are organised by a qualified third party to full safety standards and guarantee that you will share your challenge with other like-minded participants. And you can take part for Amaze either as a team or an individual. Read more on our website at www.amazebrighton.org.uk/get-involved/fundraise/

If none of these takes your fancy you could design your own challenge or get us to help you design one. We've had supporters who have swum or trekked for us before and we can register our charity to benefit from most overseas challenges.

Whatever your challenge of choice, we will give you advice and offer support with fundraising and publicity. So if you would like to try something different for Amaze this year, contact the fundraising team on 01273 234014 or email nickyb@amazebrighton.org.uk

Keep on running!

Thank you to our 26 amazing Brighton Brooks 10K runners who raised over £5,000 for Amaze back in November and good luck to our 30 Brighton Half Marathon runners on Sunday 16 February. A few places are still available for Brighton Marathon on Sunday 6 April.




Hats off to Jungle Giles

You may have seen our brave patron, Annabel Giles, taking part in 'I'm A Celebrity Get Me Out of Here' in early December. Annabel endured hideous bug showers, 'bushtucker trials' and a camp full of competing celebrities. Her resilience served her very well.

On her return from the ITV smash show, Annabel generously donated her one and only Australian bush hat signed by all 12 celebrity campmates including gold medal-winning swimmer, Rebecca Adlington, reality TV favourite, Joey Essex, and Westlife star and eventual winner, Kian Egan.

We auctioned the hat on our Amaze **ebay page** (see below) and raised a fantastic £360. Huge thanks to Annabel for her generous donation and her ongoing support.

Sell stuff for us!

Amaze's ebay page is  ready and waiting for supporters to auction goods to raise funds. It's a great place for those unwanted or duplicate Christmas gifts!

Log on to www.ebay.co.uk set up a seller account, select **advanced sell** and then **select Amaze** from the **charity directory**. It is free to list an item and you can choose a percentage to donate to us. If you need help with ebay, email nickyb@amazebrighton.org.uk

Parents of teens – two courses just for you!

Amaze has two courses starting **after Easter** for parents of teenagers, each with quite a different twist, so see which might suit you.

The **Insider's Guide for Parents of Teens** is about the next stage in our journey with a disabled child, and the new challenges as they move towards adulthood. It looks at things that may feel a bit tricky like their social lives and relationships, and at how we stay resilient after years of being a parent carer. This course hits the spot for parents of teenagers who will continue to need lots of support as they get older. It runs on **Wednesday evenings** for 6 weeks starting **7 May**.

Triple P Teens is a positive **parenting course** that focuses on behaviour and how we respond to it. It is about keeping a good relationship with our teenagers but finding ways to keep setting safe boundaries. How can we have fewer arguments and more fun? This course will suit parents of teenagers who have additional needs but are moving towards a bit more independence. It's on **Thursday evenings** starting **24 April**.

Planning for the future – Wills and Trusts

Thursday 3 April 10am – 12.30pm at Amaze

Want to think about securing your child's financial future? Find out about writing a will or setting up a trust for your child in this **FREE** workshop run by Philip Warford, Director of Renaissance Legal. This is a serious topic but Phil keeps it lively. Parents say it is really useful.

To book any Amaze course or workshop, call the helpline on **01273 772289** or email info@amazebrighton.org.uk

New group for Dads!

Are you a dad or a male carer of a child with special needs? Would you be interested in joining a new monthly group created especially for you?

The group is a joint venture between Scope and the Seaside View Child Development Centre and will meet monthly in the **Function Room at The Stoneham Pub, Portland Road, Hove from 7 to 9pm**.

Come along and meet other dads or male carers in a relaxed, friendly and social atmosphere. Get to know each other over a pint and a pizza (yes they will be supplying the pizza!).

Each month you can also meet representatives from some of the specialist services in Brighton and Hove that work with families of children with special needs. They'll be



able to signpost you to other services or sources of support should the need arise. The next two confirmed dates are **26 February** and **26 March**.

If you'd like to come along please contact Seaside View on 01273 265780 or email Amanda at amanda.mortensen@scope.org.uk

Amaze helpline:

For information, advice and support, call 01273 772289
Mon to Thurs, 9.30am to 12 noon, *plus* Tues afternoon 12 to 5pm and Thurs eve 5.30 to 8pm *term-time only*.

Save us paper and get this newsletter earlier by email!
Just email your details to info@amazebrighton.org.uk



Amaze

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Some articles in this newsletter represent the personal views of the contributor, rather than Amaze as an organisation. Amaze wishes to advertise all of the events and services listed because we think they may be of interest to parents. However this is not the same as recommending these to you. It is assumed you will make your own decision about whether they suit you and your family.