

out of amaze



For parents of children with special needs in Brighton & Hove

SEN - The Future

Amaze Info Fair and AGM, Friday 23 November at Hove Town Hall, 9.30am to 1.30pm

There's so much going on in education at the moment and we want parents to get the full picture so this year's info fair is all about the future of SEN. There should be something for you whether your child is at pre-school or heading to college, and whatever their additional need. You can also catch up with other parents and enjoy free refreshments.

Speakers

You can hear about the new SEN Strategy for the city and the changes the government is making to SEN over the next couple of years from the people responsible for making it happen. There'll be a chance for questions too so you can work out what it means for your child.

Stalls

There'll be a wide and varied range of stall holders including SEN and learning support services, parent groups and after school activities – see a full list on our website.

Workshops

Choose from an inspirational hour with an Educational Psychologist or get some ideas to try at home from a

learning support teacher. Book these free education workshops now by calling our helpline on 01273 772289. Our parent carers' forum, PaCC, will lead a focus group with an education theme. Call the Amaze helpline if you want to be part of that discussion.

Event timetable

9.30am-1.30pm: Drop into the Amaze Information Fair anytime to browse the stalls

10am: Talk on SEN – The Future inc. Q&A with key council officers

11am: Education workshops - book now by calling Amaze

12.15pm: PaCC discussion

1.30pm: Amaze AGM to report on the year's work and to appoint new trustees. Lunch provided but you need to book to attend this.

You can just turn up to the event but if you want to take part in a workshop or stay for the AGM, you need to call us on 01273 772289 to book. We're so keen for you to join us that we will refund your travel costs. Just ask when you sign in on the day.



Give a Big Cheer for Phill Jupitus!

We are delighted to announce that the third BIG CHEER for Amaze will have the fantastic Phill Jupitus as its headline act. Best known for TV's *Never Mind the Buzzcocks* and *QI*, he's also a brilliant stand-up comic, a great DJ and even a musical theatre star.

Phill will be joined by other leading comedy names - Angela Barnes, John Moloney, Ray Peacock and Raymond and Mr Timpkins - on what promises to be one of Brighton's hottest comedy nights out. So book early to avoid disappointment!

Amaze and its patrons will be hosting the BIG CHEER, in association with Baby Cow Productions Ltd, on **Thursday 7th February 2013 at Brighton's Theatre Royal**. Tickets are on sale now and there's a discount for Compass Card families. To book, call 0844 871 7650 or visit www.atgtickets.com/brighton NB: may not be suitable for under 16s

INSIDE: SEN latest • Compass activities • Universal Credit • Transition support project • Amaze courses • PaCC Awards • Parent carer stories and more...

Local SEN strategy takes shape

Last term's consultation on the vision to underpin Brighton & Hove's new SEN strategy was completed and now the council has to work with schools and parents to take that vision and turn it into a five year strategy everyone wants to sign up to. Five priority areas have been agreed and these are:

- To combat disadvantage for pupils with SEN and disabilities
- To improve the assessment and identification of SEN and disabilities
- To create and ensure high quality provision for all children and young people with SEN and disabilities
- To work proactively and collaboratively with parents, children and families
- To improve transition arrangements post 16 and services for young people up to the age of 25

The council will be asking parents what is most important to achieve under these headings and we will let you know how you can get involved. At our Info Fair (see cover) the council will talk about the strategy and you will have the chance to ask them questions.

Try Individual Budgets?

IBs are all about giving you more control over how your child is supported. If your family is already getting a social care package or using direct payments to arrange care, you might want to consider joining the IB Pilot. There's a booklet about it which you can view on our website or you can call the helpline for a copy. To join the pilot, call Sharon Sartin on 01273 295806.



SEN changes a step closer

In September the government published draft legislation on SEN and disability as part of the Children and Families Bill.

This means the ideas in the SEN Green Paper are on the way to becoming law in 2013. These include Education Health and Care (EHC) plans that can run from 0 to 25 to replace Statements of SEN. Read more about how some of these ideas are being trialled in Brighton and Hove in the SEN Pathfinder update on page 11.

Some key changes

FE and sixth form colleges, academies and free schools will all have the same duties around SEN as maintained schools do now. The right to request a mainstream school has not been weakened. The definition of SEN stays the same so emotional and behavioural difficulties still count as SEN. The SEND Tribunal will only be able to consider issues relating to the educational provision in an EHC plan,

although there will be an obligation on local authorities and health services to work together (joint commissioning). Mediation will be compulsory before appealing a decision or plan and there's going to be a pilot allowing children to appeal to the tribunal.

Duty to provide auxiliary aids and services

Schools have been covered by disability discrimination rules since 2001 but were exempt from the requirement to provide auxiliary aids and services. This changed on 1st September so schools are now obliged to take 'reasonable steps' to provide equipment and personal assistance for disabled pupils. We think it may take a few test cases before it's clear what this will mean in practice.

HELPLINE HOURS LATEST

The helpline is now open all day Monday from 9.30am to 5pm during term time. We are also open Tues to Thurs 9.30 to 12 midday and Thurs evening 5.30 to 8pm. Call us on 01273 772289



New key SEN staff for Brighton & Hove

The council has been hard at work recruiting some new key members of staff in the last few months. Regan Delf is the new Head of SEN replacing Gill Henry. Regan's extensive SEN experience includes work as a teacher, an educational psychologist and school improvement officer and she has worked on SEN improvements in Brighton and Hove.

Regan says: "I am delighted to take up the post of Head of SEN in the City. This is a time of major change with our Pathfinder status and new legislation in SEN planned for 2014. I am committed both now and in the future to working in partnership with parents of children and young people with SEN to deliver high quality educational provision and good outcomes for all and hope to work closely with Amaze and PACC to do this."

David Higgins replaces Caroline Elton as the manager supporting Tudor House, Drove Road, Keyworkers, Cherish and Outreach and Lore Riedel is the new manager of the Disabled Children's Social Work team replacing Miranda Wharam. David was previously the manager of the Young Carers Project at the Carers Centre and Lore was the practice manager of the social work team.

Compass expands for PIP

From 8th April 2013 the Government is introducing a new benefit called Personal Independence Payment (PIP) which will replace Disability Living Allowance (DLA) for anyone aged 16 or over. We'll give you more info about this in a later newsletter.

At the moment, to be registered on The Compass database, children are usually either eligible for DLA, or have a statement of SEN.

We'll be expanding this to include 16-19 year olds who move from DLA to a PIP, so they won't miss out on Compass membership and Compass Cards.



...and offers keep getting better

The things you can get with your Compass Card and Carers' Card just keep getting better! The Compass Card now has over 65 special deals across Brighton and Hove and the Carers' Card is not far behind with around 45.

For those of you who don't know about either, the Compass Card is for 0-19s with significant special needs and/or disabilities and the Carers' Card is for parent carers and others in the city with ongoing caring responsibilities.

The latest addition to both cards is The Old Market (TOM) in Hove, a recently renovated, dynamic

performance venue. Look out for some great offers on TOM shows in the coming months. The Royal Pavilion and Museums service, already a Compass Card partner, has extended its deal to provide free entrance to Brighton Museum and Art Gallery's paid-for exhibitions and introduced a Carers' Card offer too.

To apply for a Compass Card for your child, call our helpline on 01273 772289. Once your child has a Compass Card, you automatically qualify for a Carers' Card: call 295153 if your child is under 18, or 295555 if they're over 18.



Transport trouble

As we write this newsletter some parents are telling Amaze how unhappy they are about how changes to their children's transport to school were handled at the start of term. They say last minute planning left them anxious and uncertain. Sue Shanks, the lead councillor for children has apologised on behalf of the council and promised that council officers will look into why things went wrong. If you want to talk directly about this, come along to our transport focus group on Tues 23 October, 10-12, at Community Base.

SEN panel change

The panel that makes decisions about Statutory Assessment and Statements is trying new ways of working. Ros Cook from Amaze went to observe the new style panel in action. Ros says: "It was good to see the care the panel takes with these crucial decisions despite having a lot to get through. There's good expertise around the table and adding headteachers and SENCOs to the panel makes sense. It reminded me how important it is that the panel gets the right information to consider as they rely on paper evidence."

The panel would like to trial having a parent carer representative on the panel as well as inviting individual parents to speak to them about their child's needs when they are deciding about a request for Statutory Assessment.

Universal Credits explained...



Featured in the Guardian this year, Emma and Chris Ford have three children with autism. They stand to lose around £2,700 under Universal Credits. This is because of reductions to the disability additions to tax credits for their two children who are not getting DLA at the higher rate for care.

Most people agree the benefits system is too complex. Some also think that it doesn't reward moving into work and traps families in poverty. Next year, the government plans to introduce a radical new approach to welfare benefits called Universal Credits (UC). What will this mean for the most vulnerable families?

The government says UC will make claiming benefits more straightforward and make it easier to move from welfare into work. However, in a recession and a political climate where welfare is regularly described as 'spiralling' and 'unsustainable', will UC lift more families with disabled children out of poverty or is it a tool to reduce the costs of welfare? We think there are likely to be winners and losers.

The timescale

From October 2013 there will be no new claims for Income Support, Income based Job Seekers Allowance, income related Employment and Support Allowance, housing benefit and budgeting loans. If you are already claiming any of these and you report a change of circumstances or have a break in your claim for any of

these benefits you will be moved to Universal Credit. There will be no more claims for tax credits from existing claimants after April 2014. So families claiming this will be migrated to UC within the next two years.

The government expects that all other existing benefit claimants will be migrated to UC by 2017. This means the current and the new system will be running side by side for at least 4 years and even this feels somewhat unrealistic.

At the same time community care grants, crisis loans and council tax benefit will be abolished and replaced by local authority schemes. Councils will have to think about how best to support families in crisis and how to prioritise who gets the bigger share of a smaller budget for housing benefit. Alongside these changes, Disability

Living Allowance (DLA) for adults is replaced by Personal Independence Payments (PIP).

Many other benefits still sit outside UC and these include Child Benefit, Carers Allowance, DLA for children, Statutory Maternity Pay, Statutory Sick Pay, State Pension, Pension Credit, winter fuel payments and 'passport benefits'. So though a lot will change, much will stay the same.

Twelve key features of Universal Credit (UC)

It is an integrated means tested benefit for people in or out of work, replacing current benefits and tax credits. It includes allowances for adults, additions for children, child care costs, limited capability for work, caring and housing costs.

Claimants have to be 18 or over and not in education to make a claim.

Under UC there will be no equivalent to ESA that some severely disabled students currently claim. We wonder what provision will be made for 16 and 17 year olds who cannot live at home? So far we don't know.

You keep more of any money you earn. A much more generous earnings disregard will 'reward' moving into work. Working families will be better off but for many families with disabled children, for lots of reasons paid employment is not a practical or realistic option.

The right to welfare comes with new responsibilities for most claimants. You are required to sign a 'claimant commitment'. Although there will be more conditions and greater sanctions for most claimants, *there is no conditionality for carers. To be sure you count as a carer, your child*

needs to be getting at least the middle rate of the care component and you need to be their primary carer. Also exempt is anyone claiming DLA or PIP, pregnant women and claimants of Pension Credit age.

Some conditionality for a few: work focussed interviews for those with children aged 2, 3, or 4, and work preparation for those with limited capability to work.

Everyone else is required to be available and searching for work. In-work conditionality requires workers to prepare (skill up), look for more or better paid work (if you are working at the minimum wage). Compliance will mean looking for more hours and better pay. There will be sanctions if you fail to comply for no good reason.

A Benefits Cap is likely to be set at £350 a week for single claimants, £500 for couples/lone parents and will adversely affect larger families, including kinship carers and families living in areas where rents are high. *The Benefits Cap does not apply to households claiming DLA, PIP or ESA support. If you are not already claiming DLA for someone in your household who is sick or disabled, now is the time to do this!*

A guarantee of no cash losers at the point of migration to UC but 'transitional protection' to cover any shortfall will wither away over time, as other elements of UC rise. It will also end on specified changes of circumstances or if there is a break in your claim.

Administration by a single agency: the DWP using a new IT system, making 'real time adjustments'. It is hoped this will reduce fraud, error and overpayments. But the timetable is tight and the devil is in the delivery. What happens if the system fails or makes mistakes?

Claims will be made online. We worry that this is unrealistic. What if you do not have a computer or cannot afford to be online? Or you need face to face support? Where can you get help? Will your data will be secure?

Households will make a single claim and couples will have to decide who will claim. This doesn't mean leaving the responsibility to someone else. Never be in the dark when it comes to money, always share the task of managing your household finances: check statements and bills together because UC offers up new challenges.

'Real time adjustment' places a duty on claimants to notify the DWP, usually online, of any change of circumstances, apart from employee earnings. All over payments are recoverable so it makes sense to keep DWP updated. There will be a £50 penalty if you don't.

Universal Credit will include housing costs. These are usually paid directly to the landlord or mortgage lender. In future this will be paid directly to households. When you've not had to take responsibility for your housing costs before, you could feel like you have more money. *It could be easy to fall into arrears, so don't be tempted to dip into this money.*

Payments will be made monthly in arrears by credit transfer, like salaries. Most of us are used to getting chunks of money paid at intervals through the month. It will be harder to make the same money last longer. *You might want to arrange to pay regular outgoings like rent, mortgage repayments and utility bills by direct debit so that these leave your bank account a few days after your Universal Credit is paid.* We are told the DWP will have a system for making 'payments on account' for delays and one off expenses, but all these will be recoverable. Local council schemes to



Carers of young children who do not get at least the middle rate of care for DLA will be required to attend work-focused interviews as part of their claim.

replace community care grants and crisis loans are likely to be harder to access. *So think about opening an account with the East Sussex Credit Union, so you can save a bit each month and access an affordable loan in an emergency.*

Will we be better or worse off?

The government says UC targets support at the most vulnerable families but this doesn't bear scrutiny. UC will be introduced on the back of £18 billion of cuts to benefits and tax credits announced in 2010, cuts in the sorts of services most used by families with disabled children, a new format DLA claim form which is no easier to fill in and a switch from uprating benefits by the consumer price index rather than the retail price index (which better mirrors the rate of inflation). This effectively means year on year your UC will buy you less.

A reduction in the basic disability addition for children under UC means unless your child gets the highest rate of the care component of DLA, you will be worse off. We think this means that at least half of families with disabled children are likely to be worse off under Universal Credit.

If you are worried about benefits changes or just want some more advice, you can call our helpline on 01273 772289.

Uniquely mine

Our new patron, Annabel Giles, shares her experience of having a son with 47, XYY Syndrome, a chromosome disorder.

I first knew there was a problem with the baby when I was 18 weeks pregnant. I had a scan, and they found a hole in his heart and a lump on his brain; two 'soft signs' means there's something up. I had a test done which took blood out of the baby's liver; it turned out he had 47,XYY Syndrome.

Quick biology lesson for you: every human being is made up of 23 pairs of chromosomes. Women have 46 Xs and men have 23 X and 23Y. Ted has an extra Y, which means he's just a little bit different.

I didn't know if this was bad news or not. It was only 14 years ago, but we didn't really have computers at our disposal then, and so I rang everyone I could and found out as much as possible. I already have a sister with a chromosome abnormality (Velo Cardio Facial Syndrome) and so I wasn't perhaps as concerned as someone else might be. In all my research, I didn't hear one reason for terminating the pregnancy (even though that was on offer) and anyway, I was already in love with my bump.

One in a thousand men is born with 47,XYY Syndrome. If a man is over 6ft tall, the odds go down to one in a hundred. Many are unaware they have it, and many have no other problems. Ted, however, is also on the autistic spectrum, albeit high functioning. And that lump on the brain turned into a cavernoma, a cluster of blood vessels which could turn troublesome at any time.

He was a very naughty little boy, but also a charming one! He was very slow to speak; on the morning of his third



birthday, he could only say "cake? Party?" He had speech therapy though, and soon caught up. I can't STOP him talking now...

He also has very little common sense, but a great sense of humour. He is an emotional person, and a very kind one. He's hopeless with money but very good with numbers.

He has attended mainstream schools up until last year, when he was lucky enough to go to a school especially for Aspergers and similar conditions. He loves it, especially as it's a boarding school, and he can avoid my nagging! But the most obvious sign of his extra Y is his height. At 14 years old, he's 6'3", and takes a size 13 shoe. You'll probably spot him in the town, he's the tallest teenager around!

Need more advice or information on rare conditions?

If your child has a rare condition, it can sometimes be more difficult to get the information you need. Contact a Family, a national organisation that offers support and information to parents of children with disabilities - produces a comprehensive directory of specific conditions and syndromes with details of their family support networks. We have a copy of this directory that you can view at Amaze or you can see one at the Seaside View Child Development Centre. You can also contact Unique, a charity that offers advice and support about rare chromosome disorders and which links families whose children have similar conditions.

Contact a Family - 0808 808 3555 or www.cafamily.org.uk

Unique - 01883 330766 or www.rarechromo.org

A Day in the Life of an ASCSS Specialist Teacher

Mary MacPhail tells us how she came to work for the Autistic Spectrum Condition Support Service (ASCSS) and what she does in a typical day.

I've been a teacher for 21 years. My interest in autism started whilst working as a SENCO at a London primary with an autism unit attached. I became a teacher in the centre and then I was seconded to the LA's ASC outreach service. I've been doing outreach work for Brighton's ASCSS for the last three years.

First thing every day, I check my emails and diary at home. I have about 54 children on my caseload, based at 21 primary schools and one large secondary across the city, so it takes quite a lot of thought and planning to maximise my time.

My first appointment is an annual review meeting for a boy in Yr 3. It's the first review since he got a Statement last year. Before the meeting, I've observed him in his class and the playground and written up a report to inform the review. At the meeting, together with his parents and class teacher, we check that the wording of the Statement is still appropriate, and discuss his progress on last year's targets. For example, he is now great at using greetings but still has problems with talking to unfamiliar adults. So we set a broad target around this for the coming year which we will look at in more detail in our termly Individual Education Plan (IEP) meetings.

After this I walk to another primary school close by for a meeting with their SENCO about some things that have come up recently. Jade is refusing to go outside at break time and getting very upset. Between us we look around the problem and consider practical solutions - perhaps it would be good to take the pressure

off by saying she doesn't have to go outside every day? Perhaps we could introduce a buddy system or organise some games to entice her out? We settle on a plan and arrange a follow-up meeting for a few weeks time.



"I like getting to know the pupils... seeing how they make progress and surprise everyone"

I stay in the same school and do an autism awareness session next. It's with a Yr 6 class that includes Jacob, a boy with ASC. We talk about what autism is, how the condition affects Jacob, and how they might help. We will probably put together a 'Circle of Friends' from his peer group that could go forward with him into secondary school. Jacob is not at this session but sometimes the child with ASC will participate and some talk about their condition to their peers themselves.

Lunch! I eat it on the way to my next school where I work alongside a teaching assistant who would like support with getting Jessica to follow

classroom routines. We discuss good ways of communicating and using 'Social Stories™' as a tool to help Jessica understand why she should join her peers on the carpet for story time. My job is to help school staff to be more skilled at including children with ASC but they are the people who work closely with her and know her really well, so it's about valuing that and having realistic expectations.

My last session is spent at the same school doing a classroom observation of a boy who has just been diagnosed at Seaside View. I am looking out for signs he has understood the learning and that socially he isn't isolated. It's a great way of finding out what he is struggling with and what he can do well. Observations last about half an hour, or often longer the first time, and the number I do for a pupil depends on how things are going for them. I then observe him in the playground because it's really important to see how he's coping in that unstructured part of the day too. Before I leave, I feed back my observations to the SENCO and make a follow-up appointment.

At least once a week, I try to get back to the office to catch up with emails, reports, filing, etc. and we have a staff meeting every fortnight. I'm lucky to work in a great team who all have a passionate interest in autism and we really support each other in what we do. I'm also lucky to work with so many brilliant teachers.

There are challenges of course. The hardest thing is not being able to please everyone all the time, and the time-pressure is huge, but I really love my job. I like getting to know the pupils, even if it is a little distant, walking alongside them and seeing how they make progress and surprise everyone. It's about remembering how much harder children with ASC have to work than other children and I love it when other adults get that.

*All names and identifying information have been changed



Jack Parker, aged 10, tries the climbing wall at Saturday Active Club.

CCAs - As easy as ABC

Have you tried a Compass Card Activity (CCA) yet? These special needs-friendly activities for kids with a Compass Card are changing lives, so take a deep breath and try one out this autumn. We spoke to three families who are glad they did.

Debby Norris is mum to 5 year old Jazmine who has autism. She's a big fan of CCAs, starting off a couple of years ago with the autism-friendly screening at the Duke of York's cinema. "I'd never been out with Jazmine and been able to sit down, but with Amaze volunteers on the doors, I sat down and had a cup of coffee; it was bliss!" she says.

Now she and Jazmine have two more CCAs under their belt: Starfish swimming class at Prince Regent and trampolining with Sussex Central YMCA at the Y Club. "At Starfish, they're very experienced. They said 'Ok, we need to work with you' and I relaxed instantly. At trampolining, the staff are fantastic. They're really engaged with the children and Jazmine has learned to wait her turn, react to directions and understand the procedures. It's a very big deal".



Jazmine loves trampolining at the Y Club

"Jazmine has learned to wait her turn, react to directions and understand the procedures"

10 year old Jack Parker, who has Down Syndrome, has tried four CCAs: the Duke's autism-friendly screening, Starfish swimming, trampolining and Saturday Active Club. "Mixing with other kids, letting off steam and physical activities are really good for Jack" says mum Emma. "Starfish has increased his confidence in the water and the calibre of the coaches is great. I'm really impressed with the coaches at Saturday Active Club too – they're very enthusiastic and the activities are brilliant for the kids. CCAs are improving his confidence and that's wonderful".

There are plenty of CCAs for older kids too, including homework clubs across the city, Saturday Active Club, BHISP and two inclusive youth clubs at the Y Club on Fridays and the Crew Club on Mondays and Thursdays.

12 year old Kali who's registered blind, has been going to the Y Club's trampolining classes since 2010. She's now at Level 10 and attending another class at Portslade Leisure Centre to add to her skills. "We feel really welcomed at the Y Club and it's great for Kali's self esteem" says mum, Amanda Zaninetti. Kali's also just tried the new inclusive youth club at the Y Club. "They made her feel very welcome and she took a school friend; it's great to have something so integrated. She definitely wants to go back" says Amanda.

All three families encourage others to give CCAs a go. "Don't be afraid to take a risk. We've got to be out there to make a difference" says Debby. "It's a really positive experience for parents and children" says Amanda. "Give it a go and have a chat with the organisation before you go if feel worried".

Want to find out more about CCAs?

Click the Compass Card link at www.amazebrighton.org.uk, sign up for our e-bulletin, Compass Team News, or call the Amaze helpline on 01273 772289

R U up 4 the London 2 Brighton Challenge?

It's 100km from London to Brighton. You can walk it, run it, or do a bit of both and help vital funds for Amaze.



Team Taxi! at the start of last year's London 2 Brighton Challenge which raised £1665 for Amaze.

The London 2 Brighton Challenge is like no other. The 100km route from city to coast takes place through day and night, over the bank holiday weekend of 25 - 26 May 2013, and participants can complete it as a walk, a jog or even an ultra long marathon.

Team Taxi! members Dave, Lou, Chris, Charlie and Sam took the challenge last year and managed to raise a whopping £1665 for Amaze. They walked the 100 km through day and night and lots of mud for 30 hours.

And their incredible feat inspired Amaze to sign up for the challenge next year - so could you take on the longest walk of your life for us?

To find out more about the London 2 Brighton Challenge visit www.london2brightonchallenge.com

For more information about doing this challenge for Amaze, please contact Nicky B on 01273 234020 or email nickyb@amazebrighton.org.uk

Fancy a declutter in aid of Amaze?

We now have our own charity page on Ebay, the online auction and shopping website. You can sell pretty much anything to raise money for Amaze through this page so maybe you fancy having a clear out and selling some stuff for us at the same time? Just click on the link from our home page and follow the simple instructions to support us in this way. Or if you prefer to shop then you can browse our items and buy something instead. Look out for some very exciting memorabilia, which we will be auctioning soon!



DATES FOR YOUR DIARY

Sunday 18 November 2012 -

Brighton Brooks 10k run

Friday 23 November 2012 -

Amaze Info Fair and AGM (see cover)

Wednesday 5 December 2012 -

Christmas Carol Celebration (see below)

Thursday 7 February 2013 -

BIG CHEER for Amaze 3 (see cover)

Sunday 17 February 2013 -

Brighton Half Marathon

Sunday 14 April 2013 -

Brighton Marathon

Saturday and Sunday 25/26 May 2013

London 2 Brighton Challenge

Christmas Carols ...

Get your festive season off to a great start by joining Amaze, our friends, families and supporters for a Xmas celebration with a real gospel choir! Enjoy carols, mulled wine and mince pies and plenty of good tidings. It's on Wednesday 5th December from 6.30 to 9pm at City Costal Church, North Street, Portslade. Tickets available on the door (£6 or £4 for Compass card holders). Christmas is a time for coming together so we really hope to see you all there.



..and Christmas cards

Amaze is planning to save money and trees this Xmas by only sending electronic cards. Why not do the same and donate what you save on stamps and cards to us? If you or your employer want to take part, email: nickyb@amazebrighton.org.uk Nicky will send you our electronic greetings card to forward.



My journey as a parent

by Debbie Collins, PaCC's Parent Participation Worker

My first daughter, Gemma, was the textbook baby. So you can imagine our joy when, shortly after her first birthday, we discovered that I was pregnant again. We'd always wanted more than one child and were keen to have a small age gap between the two.

My pregnancy was a breeze and apart from the extreme tiredness and the craving for strawberry jam I was well and nine months later I gave birth to Zoe, a little sister for Gemma, who was a miniature version of her sister with red hair. The only strange thing I noticed about Zoe was the bright pink colour of her skin.

I suppose it was easy for me to notice that Zoe was not developing as she should because she wasn't my first child and I had many friends with children of a similar age. When their kids started to sit, crawl and walk, Zoe's progress was much slower. She never babbled or chatted like other babies and often she would appear as if she existed in her own little world, giving vacant stares, unresponsive to our prompting.

Round about this time she was absolutely devoted to me. If I was not around for any period of time or her routine was changed in any way she

became inconsolable. She didn't appear to notice her dad and treated him as if she had taken a particular dislike to him. This made our family dynamics very difficult to manage.

As Zoe passed her first birthday we realised that she was different to other children her age and that she had significant difficulties with communication. I found this really hard to accept and started to deny that there was anything wrong.

“We had to learn to cope with other people's reactions to our daughter and accept that what was normal for us as a family was not normal for others”

When I finally admitted to myself that we needed help I didn't know where to turn. My health visitor was brilliant and instead of leaping in and giving me lots of advice she listened to me for over an hour. When I had finished she took control and referred me to the places where we could get the help we needed.

Following rigorous tests and examinations Zoe was eventually diagnosed with global developmental delay and severe learning disabilities and started to attend the Jeanne Saunders Centre. The sense of loss of a 'normal' family life was intense and slowly I realised that our lives were going to be very different from the dreams I had held. Goals that I had subconsciously set for us had to be re-established and boundaries re-drawn. Our family life was going to be very different from what other families take so much for granted.

We have had several hiccups over the years as Zoe has got older. Two years of very disturbed nights, for instance, when she became nocturnal and came into our room every 15 minutes! This led to my husband and I functioning on auto pilot for quite a long time though, even then, life went on and Zoe seemed to be completely unaffected by her strange new timetable.

For the last twelve years Zoe has been at Hillside. She is a star at the school and although she is not able to read or write or talk this has not stopped her entering into school life fully. She has been in the dance festival for the last seven years, has been on several school holidays and played Ariel in the Tempest in a schools' Shakespeare production.

Having a child with special needs is life changing not just for the child but for the immediate and extended family as well. Different aspects of family life change and we had to learn to cope with other people's reactions to our daughter and accept that what was normal for us as a family was not normal for others.

Zoe is hard work, constantly on the go and always wanting my attention but at the same time she has taught me a lot about myself. She has changed me in to a better person, less judgemental and more sympathetic to the needs of others.

SE7 Pathfinder update

Brighton & Hove continues to be part of the SE7 pathfinder which is testing out new ways of meeting the needs of children with special educational needs.

The draft provision for SEN changes in the Children and Families Bill was published in September and shows that the government is going ahead with most of what was in the Green Paper. The findings from the pilot areas like Brighton will help influence the debates in parliament next year, the detail in the final bill that gets passed and the guidance that will follow when it is made law in 2014. This means that **we as parents still have a real opportunity to shape the future of SEN for our children as new ways of working are tried out here** and the results are fed back to government.

In Brighton & Hove the pathfinder team have been signing up families and schools to join four pilots across the city. Here's an update on what's been happening with each of the areas of work so far.

The Single Plan

The single plan or Education, Health and Care Plan (EHCP) is the government's idea to amalgamate all the services into one plan for individual children with SEN. **Twelve schools are taking part in the pilot, to look at how they might implement a single plan for some pupils. 30 families are in the process of being signed up by those schools and will start, this term,** to trial a single plan for their children. The pilot aims to include children of all ages with a range of disabilities who currently get support for their special educational needs via SA, SA+ or who have Statements of SEN. Parents and children who take part don't lose their rights under the existing system

but have agreed to see if something new and different may be better.

Individual Budgets

The government wants to give parents more control through Individual Budgets and has asked pathfinders to try this out in different ways. Here there are pilots for social care and transport. The social care IB pilot will



be offering families control of their own budgets to buy short breaks or respite. The transport IB pilot offers parents whose children currently have home to school transport an option to try a personal budget to arrange their own transport. The idea is that this could give families more flexibility over travel and also help to give some young people more independence through travel training tailored to their needs. Transport can be a sensitive subject so some parents may be concerned by this but there is no obligation to take part in the pilot. **The council still has a duty to provide to families who don't want to organise it themselves.** For more details on transport call the council on 296032.

The Local Offer

The local offer is the government's idea for making sure parents can find out what is available in their area. It should include both the things that are widely available for children with special needs as well as more specialised services for children with greater education, health and care needs. It's a challenge to make it thorough but not too complicated.

Each school will have its own information in the local offer and a couple of local schools will be trialling writing this kind of info soon. The SE7 is working on a framework for the local offer which will be broadly the same across all seven local authorities though the detail will vary. Parents and reps from the seven parent partnership services like Amaze have been working on this, but now each local authority has to put it into practice. Brighton has a working group including parents that will meet for the first time soon.

Parent Support

There's a team working on improving parental confidence made up of representatives from education, the local authority and parents. We have devised a questionnaire for parents and schools that looks specifically at the areas of communication, information and involvement. The team will use the responses to the questionnaire to look at how each school and its parents can work together to tackle some of the issues raised. Schools and parents working together is key to improving how schools meet the needs of children with SEN. **Four schools have volunteered to take part in the pilot and this term we will be setting up meetings between these schools and parents of children who attend the school.**

More on the Pathfinder in the next issue.

Amaze reaches out in Moulsecoomb and the Knoll

Amaze is piloting a new approach to reaching families with children with special needs who may be particularly isolated.

Whilst Amaze is in touch with 60 per cent of the local population of disabled children, we know that the remaining 40 per cent may be missing out on vital benefits and support.

Brighton and Hove Link and Brighton and Hove's NHS have funded us to see if we can find and support some of these families, whose voices are under-represented in decisions involving their children's health.

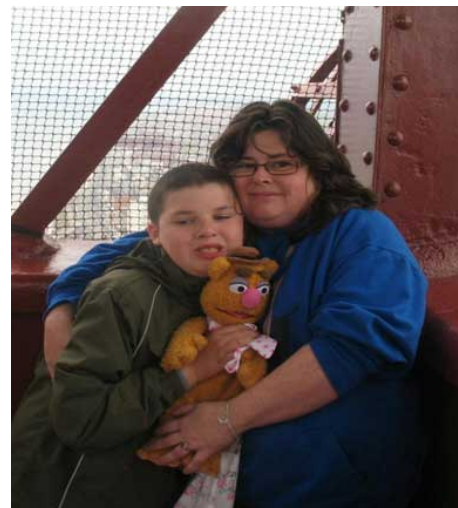
Amaze has identified two areas in the city that have a particularly high number of families who get DLA but are not currently on Amaze's Compass Database - Moulsecoomb and Hangleton & Knoll. Working in conjunction with local community organisations, Trust for Developing Communities and The Hangleton & Knoll Project, **Amaze aims to get to the heart of these communities**

through door knocking and visiting local community groups.

We held our first coffee morning in July at Moulsecoomb Primary School. Families there told us they didn't know what support was available or struggled to access it and were keen for more services to be delivered in their area. They had various concerns such as getting their child enough support in school, struggling to get a diagnosis or coping with more than one child with special needs.

Amaze and the TDC are supporting local families to set up a local parent carer support group. This will involve **regular coffee mornings in Moulsecoomb Primary School's Community Room**. Please join us!

At the same time, we are starting our pilot in Hangleton & Knoll with door knocking scheduled in the Knoll



Hangleton and Knoll mum Rhianydd and her son Owen.

area in October and **an initial coffee morning scheduled for 6 November at St Richard's Church in Egmont Road, Knoll**. Please come along.

We hope to really make a difference to families who may be facing lots of difficulties. Families may not only be parenting a child with special needs, but they may also have a disability themselves, have financial difficulties, or speak English as a second language.

For more information about the project contact Amanda at amanda@paccbrighton.org.uk

Talk Health with the PaCC

This summer PaCC published their third big report, 'Talk Health', representing the views of local parent carers. The report, which analyses local health services, has already been getting a lot of attention and has been well received by local decision makers. Talk Health looks at local health services including The Royal Alexandra Children's Hospital, Seaside View, Child and Adolescent Mental Health Services (CAMHS) and GPs. We have so far presented our findings to members of the emerging Clinical Commissioning Group (replacing the PCT), the Disabled Children's Strategic Partnership Board, to senior managers at Seaside View and to the city's Health Overview and Scrutiny Committee - who have agreed to champion the report and ensure we get some answers to the recommendations we made.

Key recommendations suggested by parent carers include:

- prioritising children with special needs at the hospital (for parking, consultations and operations)
- an increase in parent participation and understanding of their expertise and knowledge in their child's care
- more paediatric training for professionals
- more community support (an epilepsy nurse, for example) and
- improved experience with GPs (including home visits for disabled children and improving GPs understanding of disability as they are often children's key health professional, particularly after the age of 16).

Find the full report at www.amazebrighton.org.uk

Who are your PaCC Champions?

It's awards season again. The PaCC wants to recognise the great work that goes on with our children in Brighton and Hove and we need you to tell us about the outstanding people of the year.

You know who we mean. That professional or team who just made life a little bit easier for you, who put in the extra effort or battled on your behalf to improve the standard of care. A great example of a PaCC Champion is Sue Crane, the recently retired speech and language therapist from Seaside View, who twice in recent years has won an award for her excellent delivery of care and her knowledge and expertise.

PaCC's parent participation worker, Debbie Collins, explains what made Sue so special: "Sue is much loved by all the parents whose children she has

seen over the years because, although she is a professional in every way, she has such a gentle nature and really seems to understand what the parents are going through."

Can you think of another professional like Sue who you would like to see recognised for their great work?

Or maybe it's the person who has been quietly supporting you for years and to whom you never really knew how to say thank you properly. Well now you can by making them a PaCC Champion.

Nominate online at:

www.surveygizmo.com/s3/1028407/PaCC-Champions-Nomination-Form-2012 or via the Amaze home page and help us to find the PaCC Champions for social care, health, the voluntary sector and education. Once we have received your responses, a panel of judges made up of parent carers will review the nominations and decide the winners.

Alternatively, send the completed form below to Tim Lavender, Parent Carers' Council, c/o Amaze, FREEPOST SEA 14216, Brighton BN1 3ZZ or you can email your nominations to tim@paccbrighton.org.uk.

Please take a few minutes to say thank you for the great work done by people in Brighton and Hove.

Nomination form for PaCC Champion award

Nominate someone working in any service or capacity, who you feel deserves recognition for their excellent work with a child or children with special needs.

Your PaCC Champion:

Name

Job/Team

Category: Social care ☐ Health ☐ Education ☐ Voluntary sector ☐ ? (tick appropriate box)

Use this space to tell us why you would like to nominate your PaCC Champion. You could tell us about a specific act on your behalf, the difference they have made to your family or what your life might be like without them.

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Your contact details:

Name Tel

Please return the completed form to Tim Lavender using either the freepost address (Parent Carers' Council, c/o Amaze, FREEPOST SEA 14216, Brighton, BN1 3ZZ) or email tim@paccbrighton.org.uk by the 20 November 2012.



The Transition Support Project

Planning the future for any young person is tricky, but things can be even more complicated when you have a teenager with disabilities or special needs. That's why Amaze is trying out a project that gives parents of teens in Years 10 and 11 the hands-on help they need.

What's it all about?

The Transition Support Project uses specially trained volunteers to provide parents with one-to-one advice and support to help get the best for their teenager. All the volunteers have a particular knowledge or interest in the transition from childhood to adulthood, or are parents themselves

who have experience of what it's like. Having a Transition Support Project volunteer is a bit like having a knowledgeable friend. They are not there to take over or boss parents about. They'll ask what help parents want and give impartial advice and the information and support that parents need to make decisions themselves. Volunteers add to the support young

people and parents should be getting from school and their LDD adviser.

What sort of things might a volunteer help with?

- Help to think which college might be best for a young person to attend and the sort of support they need when they get there
- Thinking about what will happen once a young person leaves college
- Finding out what financial support is available
- Finding things to do during school and college holidays
- Making the most of local services
- Going to meetings and visits with parents

All volunteers have had enhanced CRB (Criminal Records Bureau) checks. Parents might want their young person to be involved in meetings with a volunteer, but the parent will need to be there as well. Volunteers can't work with teenagers on their own.

If you would like a Transition Support volunteer to help you, call the Amaze helpline on 01273 772289.

Could you represent the views of parent carers of teenagers?

Amaze and PaCC are looking for two parents of teenagers to become parent representatives on Brighton's Learning Disability Partnership Board (LDPB) and the Transition (to adulthood) Forum. It's a great way of finding out how adult services work and what's on offer, as well as getting to know the people who run and organise services.

The LDPB meets on a Monday morning, every two months. The meeting is attended by people with learning disabilities, carers and professionals working in adult services and the voluntary sector. You would be representing the views of parent carers at these meetings, so you would also be expected to attend Amaze's Parents of Teens sessions (also every two months) to gather parents' views and then feedback what's been discussed at the Board. The Transition Forum is a smaller meeting which focuses on improving how young people and their families are supported as they become adults.

If you are interested, call the helpline on 772289 or email sue@amazebrighton.org.uk for more information.

Amaze courses latest

Amaze courses are free, delivered jointly by Amaze workers and parent trainers. They are a chance to get together with other parents whilst learning something new. Most of this term's courses will be underway by the time you read this but we have more coming up next term. **To book a place or get on a waiting list for these courses, leave a message on the helpline on 01273 772289 or email helpline@amazebrighton.org.uk**



THE INSIDERS GUIDE

Insiders Guide courses are special because they offer a mix of useful knowledge with a chance to check out where we are in our journey as parent carers. They last for six mornings. We've got two coming up.

...for parents of children with complex needs

This is aimed at parents whose children have severe or profound learning difficulties (age 3 to 12). We know it can sometimes feel like you are living on a different planet from most families if your child has these needs, so come and spend time with parents like you and that includes the trainers. This starts next term but sign up now.

...Pathfinder Insiders Guide

Starting Monday 5 November, this course is for parents taking part in the Pathfinder to try out single plans. If you are one of these parents you should have had a personal invitation but if you missed this please call us now.

LOOKING AFTER YOU

These are all about you - a wonderful mix of Pilates, relaxation and mutual support that addresses the physical and mental stresses of caring. A five week course starts on Thursday mornings starting 8 November. If this is full when you call we can put you on the list for the next one in the new year.



TRIPLE P - POSITIVE PARENTING

If you feel you spend too much time dealing with behaviour hassles and not enough enjoying life with your child, Triple P could be the course for you. It is all about behaviour and trying to make family life less fraught. We run one version for parents of 2 to 12 year olds called Stepping Stones and a Teens version. Both last 8 weeks. Stepping Stones starts in January 2013 and the next Teen course will be later in the spring.

Get ON2 Flexible Learning for teens

If your teenager isn't on a college course yet and you are worrying about what they can do, you might like to know about new ON2 courses that run throughout the year. Based at colleges in Brighton and Hove and beyond, ON2 flexible Foundation Learning programmes are designed to help young people develop the skills and confidence needed for work, training or further education.



Courses are developed around what the learner wants to do and where they want to progress to and include subjects like childcare, music production, construction and art & design. They take into account students' learning needs and support and advice are offered along the way or whenever needed.

The courses are either roll-on, roll-off or have regular starts throughout the year. The courses are for learners aged 16-18 working predominantly at entry and level 1, and up to age 25 for learners with learning difficulties and disabilities.

Contact local colleges to find out more about ON2 courses or take a look at the young person-friendly ON2 prospectus on Facebook at [ON2BrightonandHove](https://www.facebook.com/ON2BrightonandHove).



Desperately seeking volunteers!

Amaze needs skilled volunteers who can spare a few hours a month to support our work. Do you have:

- Excellent knowledge of IT networks and hardware to help support our IT needs?
- Great PR and writing skills to help with promoting our events?

If so then call the Amaze office on 01273 234020

Are we speaking your language?



Do you know someone or work with someone whose first language is not English? Do you wish you could tell them about Amaze and what we do in a way they understand? If so, you may be pleased to know that our leaflet is available in six different languages: Arabic, Bengali, Cantonese, Farsi, Polish and Portuguese. You can download the leaflets from our website at www.amazebrighton.org.uk/resources/publications/leaflets or call the helpline to request the version you require.

Rocky Horror ticket giveaway

We've got a pair of tickets to give away for the first night of the Rocky Horror Show at Theatre Royal Brighton on Friday 21 December at 5.30pm. Expect a thrilling production with timeless classics like Sweet Transvestite, Damn It Janet and Time Warp. Be warned though, there are some naughty bits and the show is recommended for over 14s.

If you've never seen it, The Rocky Horror Show follows the fortunes of squeaky clean sweethearts Brad and Janet on an adventure they'll never forget with Rocky and Magenta.

Compass Card families just need to send us their name, the Compass Card

holder's name, plus your address, telephone number and email address (if you have one) by Friday 9 November. If we have your email address, Amaze can tell you about last minute theatre offers and send you our weekly e-bulletin, Compass Team News.



You can enter by email at compass@amazebrighton.org.uk or by post to Amaze, Community Base, Brighton BN1 3XG. We'll inform the winners by mid-November.

Amaze helpline:

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

Our last helpline before the Xmas holidays will be Thurs am on 20 December. We will re-open on Weds 2 January 2013.



Amaze

Community Base
113 Queens Road
Brighton BN1 3XG

T: 01273 772289

E: info@amazebrighton.org.uk

W: www.amazebrighton.org.uk

Want this newsletter by email?

Then email your details to info@amazebrighton.org.uk

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.

