

# out of amaze



For parents of children with special needs in Brighton & Hove

## Time to TAKEPART

Saturday 23 June, Preston Park, 12 noon to 5pm

Expect a big welcome for kids and young people with disabilities and special needs and their families at TAKEPART Festival Launch Day on Saturday 23 June.



The sports taster and demo event takes over Preston Park from 12 noon till 5pm and the Amazing Zone will provide a fun-filled focal point for the special needs community.

### Amazing Zone

Bigger and better than ever, Amaze will be in the Amazing Zone to provide information on special needs-friendly classes and activities across the city, along with our brand new Compass Card Activities guide and the new Compass Card guide.

### Amazing activities

There'll also be taster activities, tug of war competitions, free

refreshments and a chill-out zone with free massage and aromatherapy for carers provided by Active Lightworks. Tasters will include old favourites like table tennis and boccia, as well as new Compass Card Activity tasters including multi-sports from Moulsecoomb's Saturday Active Club (see page 9).

### Further afield

Amaze staff will be able to signpost you to other stuff in the park on the day too, including a 'Zumbathon'. The Launch Day kicks off two solid weeks of free sports activities across the city, including five local events and the Paddle Round the Pier Beach Festival on 7 and 8 July.

### Read all about it

The TAKEPART brochure provides full details. It's available mid-May in sports centres, libraries and Co-op stores, or from the TAKEPART website – [www.takepartbrightonandhove.com](http://www.takepartbrightonandhove.com)

## Marathon magics up an extra helpline



Sonya and Alex working the crowd.

Our 60 amazing runners at this year's Brighton Marathon managed to raise enough money to fund an extra helpline session this year (see page 14 for details). Quite simply, their fantastic achievement means more parents will get the advice they need, more quickly.

One of our most inspiring runners was Amaze parent, Sonya Pettigrew, who pushed her 8 year old disabled son Alex round the full course in just 7 hours, 15 minutes! Sonya, who also took a fundraising tin on the race, said: 'The crowd went out of their way to help Alex and I round the course and I was overwhelmed by the generosity of complete strangers, they really dug deep! I suppose a cute little smiling Buzz Lightyear was too much for them to resist.'

A huge thank you to Sonya and the rest of our marathon team. See more Marathon pics on page 8.

**INSIDE:** Healthier futures • SEN strategy latest • Marathon pics • Summer fun ideas • New Compass Card Activities • Amaze courses • DLA tips and more

# In Sickness and in Health

Carers Week 2012 puts the spotlight on the health and well-being of carers.



Taking place from 18-24 June, Carers Week is a celebration of the critical role carers play, saving the government a whopping £119 billion per year.

This year's theme is *In sickness and in health*. To coincide with this, the PaCC will be launching their Talk Health report detailing their experiences of various health services

in the City in their role as parent carers (see page 11 for more info).

Amaze is also supporting the Carers Challenge, where carers are matched with senior council or health service managers, MPs or councillors to spend half a day together to enable the professional to learn first-hand some of the pressures of being a carer. This year four parent carers are taking part and we will let you know how they get on in the next issue.

Look out for discussions on the Amaze Facebook group that week too, with questions like, 'How does your caring role impact on your own health and wellbeing?' and 'Are you already feeling the effects of cuts to local services?'

## Tell the FED about your groups

If you run a disability group, club or activity, tell The FED so they can add it to their new Embrace directory of local things to do. Call them on 208934 or fill in the survey on their website at [www.bhfederation.org.uk](http://www.bhfederation.org.uk)

# Your therapy service needs you

Jenny Brickell, manager of the Integrated Child Development and Disability Service, explains that therapy services are actively seeking your views to shape services.

'Our Quality and Standards group meets to ensure that we continue to improve and develop our therapy services and we're delighted to have a member of the Parent Carers' Council attending our meetings. Across all our therapy services we're striving to ensure that the views of parents and children are at the heart of our service.'

'The Speech and Language Therapy Service for school age children is keen

to get feedback from parent carers on your experience of their service. They'll be sending out questionnaires during the summer term either directly to you or through your child's school. Please take the time to reply - we will really appreciate getting your views, and your responses will help to identify where changes need to be made. We'll compile a report and action plan from the feedback which will be shared with parents through Amaze and your child's school.

'This questionnaire will be followed up by ones from the occupational therapy and physiotherapy services, hopefully later on this year. We will keep you posted.'

# Fans, Likes and Tweeters

We want you to find out more about us, our services and other organisations that can help you. To do this we have started using Facebook and Twitter. You can follow us on [@AmazeBrighton](https://twitter.com/AmazeBrighton).

We have a page on Facebook that you can 'like', plus an open group that you can join. We use the page to share information about our fundraising and to spread information from other charities and voluntary organisations.



The group is open to posts from all accepted members. However, be aware that if you join the Amaze group, your profile picture can be seen by group members. Make sure you set your privacy setting to the level you are happy with.

Have you got any other ideas for ways we can use online social media? If so, we would love to hear from you. You can email [zoe@amazebrighton.org.uk](mailto:zoe@amazebrighton.org.uk)

## Website Wishes?

Speaking of online stuff, our website will be undergoing something of a revamp this year. Do you have any ideas that you think might make it better? Or would you like to be part of a user group that helps shape any changes? Email [charlotte@amazebrighton.org.uk](mailto:charlotte@amazebrighton.org.uk) or call 772289 to offer your views.



## Amaze welcomes a new patron



Amaze has a new patron, author and TV presenter, Annabel Giles.

Annabel's son Ted has dyspraxia and some social and communication difficulties and, having used our services herself, she's offered her support in return.

'Before I moved to Brighton seven years ago, I came across Amaze by chance on the internet. We lived in

London at the time and our school options had run out. We wanted to start afresh here and a wonderful lady on the helpline helped me find a school, a doctor, everything, and I've stuck to Amaze like glue ever since.

'I've had lots of help with benefits and lovely Lizzie helped me fill in the DLA forms. Last year, I went on a free Amaze course for parents of teenagers with special needs where I met lots of other parents in the same boat. I even found myself running 10k in aid of Amaze, and I'm someone who won't even run for a bus!

'So I was delighted when I was asked to become a patron, as I truly believe Amaze is a resource that must be kept going, no matter what.'

Annabel joins our other Patrons, Angela Pell and Henry Normal. If you think you might be able to do something to support Amaze, call us or email [info@amazebrighton.org.uk](mailto:info@amazebrighton.org.uk)

## Short Breaks Funding Latest

Brighton & Hove City Council was given £380,000 by central government to spend on equipment and adaptations to enable children and young people with disabilities to enjoy better quality short breaks, more often.

Towards the end of last year, the local team in charge of this money invited bids for the funding from teams within the council and external organisations.

A panel comprising council managers, a parent rep and Amaze then evaluated the bids against a range of measures including the number of children and young people likely to benefit; increased access to mainstream activities; additional short breaks provided; and ongoing sustainability, especially with regard to available day to day funding of the activities proposed.

The Aiming High team have now either funded or committed funding to the following:

Equipment for small organisations offering short breaks	£30,200
Transport to facilitate additional short breaks	£110,800
Therapy equipment	£22,000
Training material and information enhancements	£15,000
Inclusive play equipment and development of parks, inc. new development and changing facility on the Level	£150,000

This leaves £51,400 still to be allocated. The Aiming High team are holding this amount at present, pending the possible development of a new short break facility. Further decisions will be taken on its use during the coming year.

## Help Brighton's SEN vision take shape

We told you recently that the council was working on a new SEN strategy and that Amaze and PaCC parent reps are involved. The SEN Partnership Board has now come up with a draft 'vision' to underpin this strategy and you can comment on it at the council's consultation website at <http://consult.brighton-hove.gov.uk/portal>

If you do respond, pay particular attention to question 4 about the actions you would prioritise to help improve SEN provision. If you don't have access to the internet you can call us for copies instead. Closing date for responses is 15 June.

Amaze and the PaCC are also talking to groups of parents to get their views. Read more about local developments in SEN on page 13.

## Clearer path after ASC diagnosis

Getting a diagnosis that your child is on the autistic spectrum can be a stressful



moment for parents, even if you've been sure for ages that your child has ASC. It can be hard to take in all you hear that day.

Now both Seaside View and CAMHS are giving parents a simple leaflet about what happens next. This is linked to a clearer pathway for post-diagnostic support. This can vary according to a child's needs but includes for every parent the offer of a conversation with the specialist health visitors at Seaside View and a place on a course with other parents.

The hope is to get 'new' parents off to a better start, although there is still scope to improve longer term support for families.



## Have a ball this summer

Our regular round up of holiday play schemes and activities can help your summer go with a boing.

### Special schemes

*Specifically for kids with special needs. They book up quickly, so book a place well in advance if you can.*

**Cherish (13-25s)** 7 to 31 Aug, 10am to 4pm. Mini-bus based days out for young people with learning disabilities. One to one support. 13 to 18 year olds pay £17 (£12 concessions), 19-25 year olds pay £45 (Individual Budget) or £25 (DLA only rate) Call 295192/ 295530.

**Extratime (11-19s)** 30 July to 24 Aug, 8.45 to 5.30pm. Play schemes specifically for young people with disabilities at the YMCA Hove and the Crew Club, Whitehawk. Lots of in-house activities and some days out. Each venue allows up to 18 kids and the scheme costs £20 per day. Call 689687 or visit [www.extratimebrighton.org.uk](http://www.extratimebrighton.org.uk)

**Whoopsadaisy (5-12s).** 23 Jul to 3 Aug, 10am-3pm at Somerhill Junior School, Hove. Olympic Summer Holiday Club for children aged 5-12 with physical disabilities. Playful, friendly sessions with an emphasis on

developing physical, sensory and social skills. Suggested donation £30 per day. Call 07588 555761 or email [sarah@whoopsadaisy.org](mailto:sarah@whoopsadaisy.org)

### Inclusive schemes

*Schemes that provide additional support to include children with special needs. Book well in advance if possible.*

**Brighton & Hove Inclusion Project - BHIP (3-11s)** 24 July to 10 Aug, 8.30am to 6pm, Hangleton Community Centre, Hove. Fully inclusive play scheme for children with and without additional needs. £22/20 per full/short day. Call 07821 541765, 01273 295533, or email [info@bhip.org.uk](mailto:info@bhip.org.uk)

**Extratime (5-16s)** 30 July to 24 August at Ash Cottage, Woodingdean and Hillside school. 8.45am to 3.30pm (£19) or 5.30pm

(£21). Fully inclusive play schemes offering one-to-one support if required. Also run an inclusive playscheme at St Luke's infant school (5-11s). A long day here costs £22. Call 689687 to book.

### Honeycroft (0-11s)

23 July to 31 August, 8.30am to 5.30pm at St. Barnabas Hall, Sackville Road, Hove. Inclusive play scheme, with one to one support, if required. Special promotional offer this summer, 9am to 3pm only £12.50 and 6 weeks for the price of 5. Full day £20. Call 220323 or visit [www.honeycroft.co.uk](http://www.honeycroft.co.uk)

### Parent led social groups

Most parent-led groups for kids with special needs will continue, at least in some form, over the holidays and many of them organise activities over the period. If you attend groups like **Brighton Pebbles**, **Link UP** or **Sweet Peas**, it's worth finding out whether they're doing anything special over the summer. Read more about regular parent led groups on our website at [www.amazebrighton.org.uk/newsandevents/regulargroups](http://www.amazebrighton.org.uk/newsandevents/regulargroups)

### More ideas?

Our 'Fun things to do' factsheet is stuffed with information about local leisure activities or you could visit [www.childfriendlybrighton.co.uk](http://www.childfriendlybrighton.co.uk) and do your own research. The Family Information Service also produce a fantastic booklet called Summer Fun which lists loads of mainstream and more specialised activities in the city. Download it from [www.brighton-hove.gov.uk/summerfun](http://www.brighton-hove.gov.uk/summerfun) or call FIS on 293545 to order a copy.

### And don't forget your Compass Card!

If your child has a Compass Card, they can benefit from loads of leisure offers and discounts in Brighton and beyond. Find out more about the Compass Card on page 9, or via the Compass button on our homepage. Or call us on 772289.

# A day in the life of a mental health practitioner

Abby Maitland, a senior practitioner in the CAMHS Learning Disability Service, describes a typical working day at Seaside View.

## 8.30-9.00am

Start the day at Seaside View catching up on admin. I share an office with nine other people (social workers, OT's and admin staff) which is great for close professional working but can get a bit noisy at times, so this is valuable quiet time.

## 9.15 – 11.00am

Attend the CAMHS LD team meeting at Seaside View. We're an integrated team made up of mental health practitioners from Sussex Partnership NHS Trust and Brighton & Hove Children and Families. This includes me, a senior social worker/therapist for families, specialist nurses, psychologists, a psychiatrist and counsellors for parents. We meet fortnightly to consider new referrals, allocate cases, based on who has the best skills to meet the needs of the child and family, and bring cases to the team for discussion. As most of us are part-time and work across different sites, this is a great chance to get together.

## 11.00-12.30pm

Drive to one of the local special schools where I chair a 'Team around the Child' meeting for a child on my caseload. This involves her parents, teacher and respite carers. Katy has learning difficulties and challenging behaviour and has several care givers involved in her daily life. These meetings, held every 6-8 weeks, help

parents and professionals share ideas and develop and review positive behaviour support plans together. They also foster good communication across the network and ensure a consistency of approach. A positive meeting today, Katy is making great progress in all settings!

**'I like to have the referred child and as many of the family as can be, present at the initial assessment.'**

## 1.00-2.30pm

Back to Seaside View for an individual therapy session with Jim, who has been coming to me every couple of weeks for two years now. Jim is 17, has autism and moderate learning difficulties. He can experience high levels of anxiety and at times has suffered from low mood. Jim loves to tell me about his latest computer games and we chat about his friends and how things are going at home. Jim and I are working together on developing a 'Coping Plan', based on all his strengths and abilities.

## 3-4pm

Home visit to a family, newly referred to the service, to complete an Initial Assessment. David has severe learning difficulties and has been referred because of concerns about his aggression at home and college. As



much as possible, I like to have the referred child and as many of the family as can be, present at the initial assessment. This helps provide different perspectives on the reason for referral and a good understanding of the wider context. We'll agree what things they'd like help with and how we plan to achieve this. Later in the week I'll liaise with the college and the social worker involved, write up the assessment report and share this with the family for their approval.

## 4.30 – 6.00pm

Meet a co-therapist back at Seaside View to plan this evening's family therapy session with the Smiths. We offer evening appointments so that working parents, particularly fathers, can attend, along with the learning disabled child and any other family members it would be useful to include.

Sometimes my work can feel challenging, especially when people are overwhelmed by feelings of despair or hopelessness. But it's always a joy and a great incentive to see how, with the right support, people can maximise their own strengths and resources, and build their resilience.

(All names and identifying information has been changed)





## Healthier futures

All adults (aged 18 and over) with learning disabilities are now entitled to an annual health check and health action plan at their GP Practice. What's more, the individual doesn't need to remember themselves - the GPs will invite them to attend once a year, every year.

Health professionals recognise that many people with learning disabilities live with unidentified health problems. The health check is part of a new proactive approach to ensuring that these often hidden health needs are identified and managed.

The health check takes longer than a normal appointment, as it looks at the person's whole health, and afterwards a health action plan is written for the patient to take away with them. People can complete a health assessment booklet before going to the health check as a way of preparing for the appointment, and it can also be used to record any actions.

Of course, you can choose not to have a health check, but so far the health checks are showing great results in spotting previously unknown health needs, and helping to keep people with learning disabilities as healthy as possible.

You can find leaflets and the health assessment booklet at [www.brightpart.org/healthy.php](http://www.brightpart.org/healthy.php) or contact Natalie Winterton, the Health Facilitator, on 01273 295550 or email [natalie.winterton@brighton-hove.gov.uk](mailto:natalie.winterton@brighton-hove.gov.uk)

## Hospital helpers

Learning Disability Liaison Nurses are there to ensure that people with a learning disability get good and appropriate care when they attend local hospitals. The hospitals they cover are The Royal Sussex and the Eye Hospital in Brighton, Hove Polyclinic and the Princess Royal in Haywards Heath.

### What they do

They support people with planned and emergency admissions, appointments and discharges. They also support hospital staff to understand the needs of people with a learning disability by giving specialist nursing advice and guidance. The liaison nurses help people with a learning disability and hospital staff to make decisions about treatment and care that is person-centred.

### Hospital Passport

The liaison nurses recommend that all people with a learning disability have a hospital passport. This contains all the important information that is needed for looking after that person and should be taken to every appointment or visit to the hospital for staff to look at.

### Communication tools

Each ward and department at the hospitals has access to a Hospital Communication Book. This contains advice, pictures, signs and symbols which can be used to aid communication. There's also a hospital resource pack for staff at the hospital with lots of useful information to help staff to care for people with a learning disability.

The Liaison Nurses are available from Monday to Friday, 8.30am to 4.30pm on 01273 664975.

A leaflet about the liaison nurses, and the Communication Book and Hospital Passport is on the healthy lives page of the learning disability partnership board website at [www.brightpart.org/healthy.php](http://www.brightpart.org/healthy.php)

## Parents of Teens Get Together

Weds 13 June, 10am to 2.30pm, Community Base, Queens Road, Brighton

### Making college work for your teen

Worried about how your teen is going to cope with being at college? Why not come along to this FREE session to meet members of the colleges' special needs teams and hear about the support they offer. Also, hear tips from other parents whose teens are at college now.

To book your place, call Amaze on 01273 772289 or email [sue@amazebrighton.org.uk](mailto:sue@amazebrighton.org.uk)



# Amaze's autumn courses

We have some great courses coming up next term. All are free, delivered jointly by Amaze workers and parent trainers and are a chance to get together with other parents whilst learning something new.

## Insiders Guide for Parents of Teenagers

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.



The next one coming up is the teens course which is for parents of young people aged 13 plus with more significant needs. It covers things like planning ahead, puberty and relationships and building our own resilience.

6 week course starting late October.

## Triple P Teen - Positive Parenting



If you have a child aged 11 or over that is pushing the boundaries a bit then this could be the one for you.

It is all about behaviour and trying to make family life less fraught, whilst helping our teenagers with special needs to develop a bit of independence safely. 8 week course starting mid September.

## Looking after you - taster and course



This one's all about you and is a wonderful mix of Pilates, relaxation and mutual support that addresses the physical and mental stresses of caring.

Come to a taster session on Thursday 18<sup>th</sup> October to try it out before booking onto the five week course on Wednesday mornings starting 8<sup>th</sup> November.



## Robbie the Olympic Torch Bearer

Robbie Heward, a 12 year old pupil at Hillside, has been chosen as one of the torch bearers for the Brighton and Hove leg of the Olympic Flame relay on Monday 16 July. Robbie is autistic and uses a wheelchair over long distances but he will walk his segment and his mum Tania will do it with him.

Tania explained: "Hillside put forward four 12 year olds, including Robbie, to be torch bearers. The school wrote a little blurb saying what was special about each of them and Robbie was chosen."

Tania can't wait to see Robbie enjoying himself on the big day. "He's got supporters coming from school and Chestnut Tree House, where he has respite, as well as friends and family. Our leg may take quite a while cause he's bound to want to stop and talk to his friends!"

The whole process has exploded a few Olympic myths for Tania. For instance, it's not the same torch throughout. Instead, torch bearers often purchase their own, so Tania has bought one for Robbie to practise with and to keep as a memento. Also, it's not a full mile they have to walk but about 300m.

"Thank goodness for that," Tania joked, "If it had been the full mile they would probably have stopped his DLA!"

If you want to see Robbie and the other torch bearers, you can find out more about the specifics of the route at [www.brighton-hove.gov.uk](http://www.brighton-hove.gov.uk)

To book a place on any of these courses, call the Amaze helpline on 772289 or email [info@amazebrighton.org.uk](mailto:info@amazebrighton.org.uk) But hurry as they often book up fast!

## And that's not all folks...

More Insiders Guide and Triple P courses planned for 2012/2013!

Watch this space for details or call our helpline to go on the waiting list.





Clockwise from top left: Jamie in costume for the third year; Janice doing her 'once in a lifetime' marathon; Julius running for us for the third time; James, who is autistic, completing his first race; Amaze staff and supporters at the cheering point; Darren and Gareth in the after glow.

## Thank you very, very much

A huge thank you to Brighton Marathon, our cheering volunteers and most importantly our 60 amazing runners for our year of glory as an official local charity partner.

It was a fantastic day and the hard work and sheer determination of the runners really paid off. So far we have raised over £20,000!

If you've read the front cover you'll already know that some of this money will be used to fund an extra helpline session this year - it'll be on Tuesday afternoons. Parents always tell us how much they need and value the helpline so we're thrilled that we can give them more of it.

**Thank you also to Bex and Bec who raised £927 for Amaze in the Brighton Half Marathon in February.** Bex told us:

'This was my first run and I decided to run for Amaze as they have been such a great support to my best friend Gemma and her family since their baby Thalia was born two years ago with Kabuki Syndrome. Despite Thalia's frequent pain and hospital visits she hasn't stopped smiling and



gives everyone around her such inspiration - not to mention her awesome mummy and daddy - Gemma and Paul.

'I am touched at the amount of donations people made, especially strangers! Thank you to everyone who donated. Myself, Amaze and Thalia's family are extremely grateful.'

**Fancy the Triple Challenge? If you run the 10k, the Brighton Half and the Brighton Marathon for us, we can offer special reduced targets. Email [nicky@amazebrighton.org.uk](mailto:nicky@amazebrighton.org.uk) or call Nicky on 772289.**



## Oh what a night!

We're still smiling about the success of the 2nd BIG CHEER for Amaze that happened in March, in association with Baby Cow Productions Ltd. It was a magnificent night of top class comedy and the audience raised the roof and over £13,000 for Amaze.

Thank you to everyone who bought a ticket and to the incredibly generous comedians who gave their time and talent for free. The line-up was truly glorious: Jason Cook; Jenny Eclair; Ian Moore; Justin Moorhouse, Graham Duff, Julie Jepson and Simon Evans. And thanks to Fozz for his amazing photographs on the night. See [www.photographybyfozz.com](http://www.photographybyfozz.com)

Look out for the BIG CHEER 3 next year!

## Take the wine challenge for Amaze

Elwood Wines (run by Amaze parents) will be doing their 3<sup>rd</sup> Wine challenge at Blakers Park Picnic on 16 June. All proceeds will be donated to Amaze.



## Jungle Fairies

Don't forget to order your copy of colour children's book The Jungle Fairies, written by Amaze parent and trustee Fungi Woolnough-Murau, with a share of proceeds coming to Amaze. Find out more at [www.thejunglefairies.com](http://www.thejunglefairies.com)





# Compass activities for OUR kids

We all know the value of leisure activities for our kids, but feeling confident that your child's needs will be met can be tricky. That's why Amaze has been working with local organisations to develop Compass Card Activities that have teachers or coaches with special needs experience.



The activities we're developing also have discounts for Compass Card holders, when there's a charge, and offer the chance for ongoing improvement through your feedback.

Parents have given our five pilot Compass Card Activities a big thumbs up, but now we're introducing more with funding from the council and the Rooney Foundation. First up are **homework clubs and study support sessions** in local libraries which are now welcoming kids with special needs. "I'm really pleased with the clubs. They're very good" says Pauline Strachen, whose 11, 12 and 14 year olds have additional needs and are attending regularly.

**Two special needs swimming sessions** at Prince Regent are also new. The first, Starfish, is a special needs inclusive class on Mondays from 5.45 to 6.15pm. The second is a family swim for kids with special needs and their families and friends on Wednesdays from 6 to 7pm. Julie Stokes, mum of six year old Jacob who has autism, is delighted with Starfish: "It's brilliant. For the first time ever, Jacob's really enjoying a swimming class".

Another Compass Card Activity, a monthly **multi-sports session for seven to 18s with moderate learning disabilities**, launched at Moulsecoomb Community Leisure Centre on Saturday 5 May. 'Saturday Active Club'

is for kids who want to have fun and includes circuit training, basketball, boccia and table tennis. "This is a fun session that offers lots of different activities and really does have something for everyone" says the council's Active for Life Manager, Emma Greenough, who's been involved in organising Saturday Active Club. The club's on the first Saturday of the month from 10 to 11.30am; look out for the next ones on 2 June and 7 July.

**[Starfish is] 'brilliant. For the first time ever, Jacob's really enjoying a swimming class.'**

BHISP (Brighton and Hove Inclusive Sports Project) is a **brand new after school sports club with free transport from schools** that launched on 16 May and it's Amaze's latest Compass Card

Activity. Geared to 7 to 19 year olds with special needs, this fun, active club at Whitehawk's Crew Club is from 3.30 till 5pm on Wednesdays. There are loads of activities including football, hockey, volleyball, cricket, rugby and badminton. The club's free to Compass Card holders. Call the Crew Club for more info or to book on 608607.

And that's just the beginning! Look out for details about new activities in the Amaze e-bulletin ('Compass Team News'), visit the Amaze website at [www.amazebrighton.org.uk](http://www.amazebrighton.org.uk) (click the Compass Card button on the home page), or come to the Amazing Zone at TAKEPART Festival Launch Day on Saturday 23 June to pick up our new Compass Card Activity guide. **If you want to know more about the Compass Card, call the Amaze helpline on 772289.**

## Got a Carers Card yet?

If you care for a child who has a Compass Card, you automatically qualify for a Carers' Card, so make sure you sign up for one.

Offers on the card are designed to promote the wellbeing of carers and include treats like affordable complementary therapies, mobile hairdressing, adult education classes and discounted leisure centre membership. The latest Carers' Card offer is free bus travel on the Big Lemon Route 44 bus service between the universities and Churchill Square – and there's free travel on the route for Compass Card holders too!

If you want to apply for a Carers' Card, call 295153 if your child is under 18, or 295555 if they're over 18. Have your child's Compass Card to hand – you'll be asked for the number on the back of the card.

# A different kind of normal



Tim Lavender, member of the PaCC, and parent to Tom and Adam, explains what it's like to care for twin boys with additional but differing needs.

**I didn't make it back in time to see Tom and Adam born. Turning up 13 weeks early we weren't ready and neither were they.** My first introduction to my sons was in a claustrophobic Neonatal Intensive Care Unit. No windows, the lights dimmed and hushed voices, punctuated by the constant beep of monitors. In clusters around the room were other solemn looking people huddled around their own incubators, unable to reach their new child behind the perspex.

At no point in the coming weeks did we consider that they wouldn't survive. To fill the time between cot-side vigils I researched all the information I could about premature birth, Necrotising Enterocolitis, brain haemorrhage, hydrocephalus, ventriculo-peritoneal shunting and cerebral palsy. It didn't help. What I was searching for was confirmation that everything would be alright and

we could have our normal lives back with our new family.

We looked for answers from the medical professionals. Predicting the future health and wellbeing of any newborn is impossible but that didn't stop us asking.

**'Things take longer. Things take more planning. Some things are impossible but most things can be made possible.'**

The most intelligent response came from the Professor of Neurosurgery when Tom had his first of many operations. 'There is no way of predicting the outcome' he said 'but when he reaches the age of eight you'll have a pretty good idea of what he'll have to deal with in life.' It didn't

answer the question and yet it did.

Eight years on both Tom and Adam have cerebral palsy as a result of their traumatic births. As with many conditions it can manifest in a variety of ways. Adam shows the mildest of symptoms only evident from rigorous medical tests. Tom has special needs but needs that are not so severe that it's always clear how best to support him. He has a Statement but is in mainstream school. The question has become 'how do we best approach his special needs as he develops?'. If we don't provide enough support he is at a disadvantage. Too much and he may not learn how to grow into an independent adult. Do we treat his situation as special or just a different kind of normal?

Once a week both boys do gymnastics at Brighton and Hove Gymnastics Club who are passionate about including people with disabilities. Tom loves football but his hemiplegia stops him from keeping up with his class mates, so he plays with Seagull Specials where he can keep up. He loves cricket and plays with his school friends at the after school club run by Bat and Ball Cricket Club who make a special effort to include everyone.

Tom also has a weekly piano lesson from Lisa Fitzgerald who, apart from being hugely patient, is passionate about how it has improved his motor skills in his right arm and hand.

We went skiing as a family for the first time this winter. Tom as well. It was made possible with the help of Ski 2 Freedom, a charity that helps people with disabilities to enjoy snow sports.

Things take longer. Things take more planning. Some things are impossible but most things can be made possible.

**Life for us is normal. It's just a different kind of normal. And it is special. Both boys make sure of that.**



# Reaching for the stars

The Parent Carers' Council has begun its process of assessing local services to help them improve their work with parents. The first set of results are in.



The PaCC ambassadors focus their feedback on how the service is measuring up to the Partnership Charter, the new document that sets out rules of engagement between services and parents. The Charter establishes the level of service parents can expect and the contribution parents can make.

So far, we have assessed the following services. The stars demonstrate the level at which services are actively working in partnership with parents. One star demonstrates that they are working at a basic level in parent partnership, two stars show that they are developing their work in partnership with parents and three means they are working at an advanced level of partnership with parents.

## Occupational Therapy Service (Social Care)



### Good points:

- The quality of information has improved a lot despite being out of their hands as a department within Seaside View
- The new prioritisation system provides greater transparency to the service
- The environmental safeguarding project is ground-breaking and provides an opportunity to share good practise with other professionals
- One of the team was nominated for the Big Difference award

### Areas that could be strengthened:

- Parent feedback obtained from the comment box in Seaside View

is not specific to the OT service

- There is no feedback system when parents leave the service

## Drove Road ★ ★

### Good points:

- The young people's assessments and action plans were thorough and the way that they were put into practise was good
- Information for parents and carers was up to date, easily accessible and presented in a clear and client friendly format

### Areas that could be strengthened:

- Better parent participation and representation at the decision making level of the service
- Development of ways to include children in the development of the service

## Link Plus ★ ★ ★

### Good points:

- The inclusion of parents and children in all areas of the service

### Areas that could be strengthened:

- The internet links with the Local Authority could be improved as they were poor in linking to the local Barnardos service

## Physiotherapy ★ ★

### Good points

- The parent carer representation and participation is excellent
- The information is readily available and accurate, reflecting the work that is on going in this area. However, there is a lot of duplication with identical information being available in different places

### Areas that could be strengthened:

- The service is not transparent in letting parents know about its eligibility criteria
- There is no clarity about how decisions were made and who makes them but recognise that this is being looked into

## Talk Health Report News

On 7 March the PaCC Steering Group held their third open event, giving invited parent members the chance to talk health in front of managers from the Royal Alex, Community Health Services, GPs, Seaside View and CAMHS.

As before, we asked parents to share their experiences and make recommendations that might help to make health service experiences more positive for their children.

The Steering Group is compiling a 'Talk Health' report that will be completed by the end of June to share with everyone who came along to the event. It is hoped that the recommendations made in the report will help to drive positive changes in the way healthcare services are delivered in Brighton and Hove.

The report will be available on the Amaze website as soon as it's ready.



# SE7 pilot takes off

Debbie Collins, PaCC's Parent Participation Worker, tells us about the SE7 Pathfinder's progress so far in exploring changes to SEN provision and how PaCC and parents are involved.

'Brighton and Hove is part of a group of neighbouring local authorities, labelled the South East 7, which has been chosen to try out some of the government's proposed changes to the way services are provided for children with special needs.'

'The SE7 pathfinder is now seven months old and has another year in which to complete the work set out in its regional plan. Some of the proposals laid out in the Green Paper are being tried out by all the areas in the SE7 (Brighton and Hove, East Sussex, West Sussex, Kent, Medway, Surrey and Hampshire.) Some are just confined to particular areas.'

## The 'Single Plan'

'The 'single plan' or 'single assessment plan' seeks to amalgamate health, education and social care into one plan of provision for children with SEN.'

'Work on the 'single plan' was kick-started by three parent workshops. Parents were given the opportunity to say what they would like to be included in a single plan and what works and does not work for them in the current statutory system.'

A task group made up of representatives from health, education, social care, SENCOs, LA staff and parents have been meeting every two weeks since then to try and

devise a working single plan. This is nearly complete and once it has been consulted on will be used as the basis for a new plan to pilot on a small group of children. No firm decisions have been made as to who will be included in the pilot but it is likely that the children will have a range of additional needs and vary in age.'

**'We are hoping to... create an assessment tool that could be used in schools to identify areas of good partnership working.'**

## Individual Budgets

'The reforms plan to develop the use of individual budgets to give parent carers more control over organising services for their children.'

'An Individual Budget pilot in social care is due to be run in Brighton and Hove later in the year. The work that has been done to allow this pilot to run has taken a lot of planning and will be used to help influence the work of the Individual Budget proposal in the Green Paper.'

## The 'Local Offer'

'Another of the proposed changes is the development of a 'local offer' -

easily accessible information for parents which sets out the support available in each area for children with SEN and disabilities. It will cover education, health and care services.'

'The work to develop a 'local offer' is being led by a working group of parent reps and workers from Parent Partnership Services, like Amaze, across the region. The group is meeting to draw the regional framework together.'

## Parent Support

'Brighton & Hove and Hampshire are leading on the strand of the proposals that deals with support to parents and carers.'

'Hampshire is looking at current mediation practises across the region, to try and devise a process that is less adversarial for parents and helps improve parental confidence in the system.'

'In Brighton, we are looking at ways to improve partnership working between parents and schools using recommendations set out in the PaCC Education Report 2010 which identified areas of concern to parents. We are hoping to use the principles behind the Partnership Charter to create an assessment tool that could be used in schools to identify areas of good partnership working and areas where practise could be changed to help improve parents' confidence in the schools' delivery of SEN.'

'We'll tell you more about the SE7 pathfinder in future issues.'

If you would like to join the Parent Carers' Council, then email [pacc@amazebrighton.org.uk](mailto:pacc@amazebrighton.org.uk) or call the Amaze helpline on 01273 772289 and give us your details.



# The future of SEN in the city

The PaCC interviews Dr Jo Lyons, the Lead Commissioner, Learning & Partnership for Brighton & Hove City Council, who is chair of the new SEN partnership, about the latest developments in SEN in the City.

In her 25 year career, Jo has worked extensively in the field of SEN as a teacher, psychologist and senior strategic manager. She also has a younger brother with severe disabilities. Jo feels this has given her an added understanding of the challenges that disability brings to a family and the strength and resilience so many families show in dealing with these challenges whilst remaining positive.

**Is it true that the local authority will no longer have responsibility for SEN in Brighton and Hove?**

"No not at all. The new government approach encourages schools to be more autonomous and take greater responsibility for their own school improvement but the local authority still has a clear commissioning role and continues to fulfil its statutory educational duties of which SEN is a key component.

"Locally, we have a very strong learning partnership and we work together with schools and other partners to meet the education needs of children and young people and their families across the city."

**What is happening with the city's SEN strategy?**

"In Brighton and Hove the current SEN strategy is coming to an end and we're developing a new one. We've been very successful at improving SEN provision in the city. The number of special schools judged to be good and outstanding has increased and we have some excellent SEN support services, such as PRESENS and the

Language and Literacy Support Service.

"We've also developed a successful SENCO network. Data shows that the achievement of our children with SEN at age 16 was much improved last year over previous years. Also the gap in achievement between our children with and without SEN is narrowing. This is positive progress compared to the national picture, where the gap at the end of KS4 widened in 2011."

**How have you achieved this?**

"We've improved our approach to commissioning places and achieved greater value for money, which means more money can be reinvested in early intervention. For example, with less children and young people travelling long distances out of the city for their education, we have freed up more money for children with SEN within the city, to ensure their needs are met as quickly and early as possible.

"We've saved over £2million with this approach and reinvested into schools and other areas of special education and support."

**How are you developing the new SEN strategy?**

"We have established a new SEN Partnership Board including school reps, governors, parents, the voluntary sector and other agencies and we're working together to set the vision and priorities for the next three to five years.

"Currently we're consulting on a new vision and strategy, to be published in the autumn, and members of the board will be holding



discussions with parents and partners soon."

**In what other ways are you including parents in decision making?**

"In partnership with schools and Amaze we've reviewed the SEN panel to better involve everyone in decision making and we will be introducing a moderation group including parents.

"This does not mean, of course, that parents will always agree entirely with our decisions but they can be involved in looking at how decisions are made and can monitor and moderate this process. I believe this will make a big difference."

**What's happening with the Complex Needs Project?**

"We're continuing to use the expertise and leadership in our special schools to support and advise on meeting the needs of children with SEN in mainstream school. Funding is included in the special schools budgets to provide this type of outreach support."

**Do we fund SEN well?**

"Yes. When you compare us with similar authorities you can see that funding to special schools and to our mainstream schools for SEN is high. We delegate as much funding as possible to our schools so that they can decide best how to use this to meet the needs of all the children on their roll with SEN."

continued overleaf

There is a lot of confusion about the future of statements. Are they going to be a thing of the past? Do we have high numbers of statements here?

"We will have to wait for the outcomes of the Green Paper and pathfinder projects. But we know from the Queen's Speech on 9th May that the government plans to replace statements with Education, Health and Care Plans by 2014.

"The number of children with statements of SEN in Brighton and Hove is higher than in other similar authorities. We follow the current legislation and the SEN code of practice when managing the statementing process and evidence shows we do this well."

What are the new developments with teacher training in the city?

"The government is making funds available for training SEN support staff and SENCOs. Some of our special schools also offer SEN training as part of their outreach. As we know how important SEN training is for parents, pupils and teachers, we are looking to see if we can offer more training for SENCOs in the autumn."

And finally...

"The most important role of the new SEN partnership is to champion the needs of children with SEN and disability. My vision is that our children will achieve the very best that they can from their education and lead happy, healthy, independent and fulfilling lives. Working in partnership with the children and their parents is vital and we're proud of our relationship with Amaze and the PaCC. Together we have had significant success in managing SEN in the city and meeting the needs of so many children and young people, but we must not be complacent as we do not always get it right. We must work hard to address areas of concern and further build our partnership so we can do even better.

## Don't take it for granted: DLA for ADHD at 16

The DWP is looking to make savings of 20% in DLA spend. So it's no surprise to us that many first adult claims for teenagers with ADHD are being refused.

We believe the thinking is that ADHD is a childhood condition. While it's true that many young people 'grow out of' their worst symptoms, college years are often a real challenge. NEVER take it for granted that because your teen was entitled to DLA before, they will be now. You need to make a strong case and back it up with evidence.

**DWP expects 16 year olds to manage their own medication and treatment. So:**

- If your teen is medically advised not to take stimulant medication, explain why
- If cuts to services mean they cannot access help from CAMHS write this down, explain what has happened
- If they fail to keep appointments or take their medication, say what you do to get them there and make sure they take their medication
- If they are fearless, think they are invincible and the problem is everyone else's, explain this.

On the claim pack, describe what you put in place so your ADHD teenager can continue to learn to be more organised, stay calm, problem solve and stop and think before he/she acts.

Explain how, when this is not in place, your teen is agitated or inattentive and adrift, or at worst explosive. Give real life examples of things that have happened. 'Self-medicates on cannabis' is unlikely to be a persuasive argument...instead think about what you are doing to help your ADHD teen resist unlawful or antisocial behaviour.

Attach the following supporting documents:

- Transition Plan: as this will include specific recommendations about extra support at college
- Statement of SEN, even if your teen left school a few years ago
- Reports, assessments, correspondence from CAMHS
- Copies of requests for help even if that help never materialised

If you have just received a DLA claim pack and your ADHD teen is 15 or over, start collecting this evidence now and start keeping a diary. If you have stopped seeing CAMHS, get back in touch now. Your child gets DLA because of all the extra stuff you put in place. Be sure when you fill in the claim that you can be clear about what it is you are doing that's extra and different.

**NEW HELPLINE SESSION NOW OPEN!**  
The helpline is now open all day on Tuesdays from 9.30am to 5pm during term-time. Call us on 01273 772289.





# More than just words

The new format DLA claim pack has a page about communication but the prompts only ask about writing, BSL, lip-reading and signing. What can you say about a child who says too much, too little or just regularly chips in and says the last thing you expect to hear? Here's some questions to help you think about what you might include on the form.

**Do they get in a muddle and cannot organise their thoughts?** Maybe they don't put what they are saying into context, miss out key pieces of information or tell you things in the wrong order. So you find yourself saying 'I'm lost. Let's start again. Who was there? What happened first?'

**Do they struggle to judge just how much detail you want** and say far too much, so you both lose track of the point they were making? Or alternatively miss out very relevant information so you are misled.

**Do they interrupt and talk over other people** even when they are clearly having an important or private conversation?

**'He interrupts but he hasn't got anything to tell us. We can see him struggling to think of anything and saying something completely random.'**

**Do they say things without thinking** and make personal remarks? Does your child say out loud things the rest of us might think but know to keep to ourselves? Some children just 'tell it as they see it', and freely offer unsolicited advice. They don't understand that what they say can hurt other people's feelings.

**Do they have trouble listening to what other people** are saying? Many children are easily distracted and 'zone out'. Unless you say their name before you speak, they may not even think you're speaking to them. Or they may struggle to 'keep up' and make sense of what other people say. Does your child make mistakes because they've misunderstood? Do you make a point of keeping it simple and just giving instructions a bit at a time?

**Do they not stop for breath so other people can't get a word in edgeways?** Does your child talk at you? Some children have lots to say but aren't interested to hear what anyone else thinks. They don't invite your comments or ask 'interested' questions. If anyone offers a different opinion, your child is likely to ignore this.

**Do they relentlessly answer back?** Can your child argue black is white? Are they always right! Do they struggle to see things from anyone else's perspective? Do they have such a keen sense of justice that they wade into battles that aren't theirs to fight?

**Do they struggle to read between the lines when someone else is talking?** Their understanding tends to be literal and they miss 'hidden' messages and implied meaning. You have to say what you mean and mean what you say. Can they misread other people's feelings or intentions?



**Do they find it hard to keep a conversation going?** They don't have any social chit chat and knowing when to join or what to say feels like torture. Even greetings don't come easily. Other people might say your child is impolite.

**Do they find it hard to tell if someone listening to them is bored?** Does your child keep talking even when the other person has started speaking to someone else, returned to what they were doing or even walked away?

**'The man has said goodbye. That means we stop talking and leave him alone.'**

**Do they go on and on about the same things?** Some children ask the same questions repeatedly even though they know the answer. Others take every opportunity to switch the conversation back to one of their special interests.

**Do they seem to be the last one to get the point of a joke?** Does your child enjoy slapstick humour but not understand why people are laughing when the joke depends on word play?

**All these are perfectly relevant to include on a DLA claim pack, but you might not guess it! If you need some more advice about claiming DLA, call our helpline on 01273 772289.**



## Pirates invade the Duke's on 3rd June!

The next autism-friendly screening at The Duke's cinema is the new Aardman animation, *Pirates! In an Adventure with Scientists!* on Sunday 3 June.

Screenings are for all children with special needs and their families. Doors open at 10.30am for free drinks and biscuits and the film starts at 11am.

Children pay £2.50 and adults go free. You can buy tickets on the door, or book in advance on the cinema's booking line on 08719 025 728 (mention the Compass Card).



## Amaze AGM and Information Fair

**Friday 23rd November**

This year's Amaze annual general meeting will be on Friday 23rd November.

Once again we plan to run a really useful information fair for parents on the day. More information in the October newsletter.

## Could you volunteer for us?

Amaze is urgently looking for volunteers to support parents as their child makes the transition to adulthood.

We'll match you with parents of 15 to 16 year olds with learning difficulties. You'll give the parents emotional and practical support as they plan for their child's future.

You'll need to be good at listening, researching information and explaining it clearly.

Essential training will run once a week on Thursdays, from 10am-2pm starting Thursday 14 June for 5 weeks. Travel expenses paid.



Email [info@amazebrighton.org.uk](mailto:info@amazebrighton.org.uk) for an information pack.

## Amaze helpline:

For information, advice and support, call 01273 772289, Mon to Thurs, 9.30am to 12 midday, Tues afternoon 12 to 5pm, Thurs eve 5.30 to 8pm

*This summer the helpline will close from Monday 6th to Thursday 16th August. Reopens Monday 20th August*



### Amaze

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### Want this newsletter by email?

Then email your details to [info@amazebrighton.org.uk](mailto: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.

