

out of amaze



For parents of children with special needs in Brighton & Hove



Takepart in an Amazing day!

Come and see Amaze at the best sports taster event ever on Saturday 22 June in Preston Park – the Takepart Festival Family Day!

Amazing Zone

Amaze will be in the Amazing Zone, handing out the very latest Compass Card and Compass Card Activity guides, as well as information about other leisure opportunities in the city.

The Amazing Zone, a vibrant **special needs friendly area** that provides a welcome to all, will be offering a full range of **sports taster sessions**, an opportunity for you to register your interest in our brand new Compass Card Activities (see page 15 for more info), leisure information and a **chill-out zone with free massage for parents**, courtesy of the lovely therapists from the Anahata Health Clinic.

New to the zone this year are Alternative Activities, a whole range of fun physical activities; and **yoga**

from Tatti Bumpkins. There'll be old favourites too, including **table tennis** (hosted by coach Shaun from the English Table Tennis Club), **boccia**, **Polybat** and **multi-sports**.

Outside the Zone

We'll also be able to point you to other taster activities outside the Amazing

Zone that might interest you. There will be **all ability bikes** in the park, close to the Amazing Zone, with an array of bikes that can be used by everyone. Adventure Unlimited is providing a **climbing wall** and Seagull Specials are organising **wheelchair football** and **wheelchair basketball**.

Takepart Festival

The Takepart Family Day is the launch pad for two weeks of sports taster activities, including community events and the fabulous Paddle Round the Pier Beach Festival on 6 and 7 July at Hove Lawns.

Apart from Paddle Round the Pier, stalls and entertainment, there's the **Accessibility Beach** and free **bodyboard**, **paddleboard**, **boat and kayak taster sessions** for children and young people with disabilities and special needs. To book a session, email disability@paddleroundthepier.com or call 07963 051742. Family and carers are encouraged to join in and wetsuits and all-terrain beach wheelchairs are provided.

For more info about Takepart, pick up a programme from your local library or sports centre, or visit www.brighton-hove.gov.uk/takepart

Tell us what you want and win!

If your child has a Compass Card, we want to know how you use it and what offers you'd like to see on the card in future. Complete the Compass Card survey in the centre of this newsletter and return it to us by Friday 12 July (or hand it to one of the Amaze Team in the Amazing Zone at Takepart) and you could win one of three glorious prizes – a pod of your own on the Brighton Wheel; lunch for two at L'Eglise, the highly rated French restaurant in Hove; or a family ticket for Sea Life Brighton. You can also complete it online via the link on the homepage of our website at www.amazebrighton.org.uk

Helping hand for our handbook

Amaze secures £10,000 funding for 'Through the Maze'.

We'd like to say a huge thank you to Sussex-based **Wellesley Wealth Advisory**, a Principal Partner Practice of St. James's Place Partnership, for introducing Amaze to the **St. James's Place Foundation**.

Following a visit to our offices to carry out due diligence, St James's Place Foundation gave us a much appreciated donation of £10,000 for our handbook, **Through the Maze**. Tony Hannigan, Wellesley MD, presented the cheque to Amaze at a PaCC Steering Group on 24 April.

This donation, along with core funding from the local council, means Amaze will have more funds to research, write and publish the next two editions of *Through the Maze*, which will bring you all the latest information on changes in education, benefits and social care. If you haven't already got a copy of the handbook, call the helpline to request one.

"It does what it says on the tin and is a fantastic guide through the special needs maze." A parent

Working with local organisations like Wellesley Wealth Advisory enables us to continue to provide our services to you. Tony Hannigan is passionate about supporting local families with disabled children. He fully endorses the work Amaze does signposting families to available support, particularly in the current legislative and economic climate.

When presenting the cheque, Tony also took the opportunity to introduce the Wellesley Charitable Foundation



Tony Hannigan, Managing Director, Wellesley Wealth Advisory meets the PaCC Steering Group and Amaze CEO, Rachel Travers

to the Steering Group. The Foundation will be officially launched later this year and is fully committed to providing support to children, and charities supporting children, in Sussex, including Amaze.

For info on Wellesley Wealth Advisory, call 01273 455636 or email: info@wellesleywa.co.uk



New helpline to fight LD hate crime

Stop Hate UK have launched a new 24 hour **helpline service**, Stop Learning Disability Hate Crime, in England and Wales. People who have experienced, witnessed or know someone who is experiencing Learning Disability Hate Crime can contact the helpline on 0808 802 1155 for support and information. It's open 24 hours a day, every day of the year and it's free!

Twitter Dad

What's it like being the father of a child with a disability? A local dad has started to tweet about life with his daughter. Follow him on twitter **@disabledkidsdad**

PaCC connects you with SEN insiders

Would you like to know more about what's happening with SEN locally? Then come along to the PaCC Connect Education focus group on 19 June and get answers to your most pressing education questions from the people who really know what's going on.



Regan Delf, Brighton & Hove's Head of SEN and Jo Lyons, Lead Commissioner, Learning and Partnership, will tell you what's happening in SEN locally and you will have the opportunity to ask how planned changes might affect your child at school.

The focus group will take place from 11am to 1pm on Wednesday 19 June in the Conference Room at Community Base, Queens Road, Brighton. If you wish to attend, call us on 01273 772289 or email debbie@amazebrighton.org.uk. In the meantime, you can get a heads up on some of the potential changes and developments in SEN locally by reading the interview with Regan Delf on page 13.

Free childcare for two year olds

Did you know that from September 2013, some two year olds will be entitled to **15 hours of free childcare per week** during term time? That's 570 hours spread over the year, and the free childcare starts from the term after their second birthday.

Unlike the universal free childcare for three year olds, your two year old is only eligible if you are in receipt of key benefits like Income Support; Income-based Jobseeker's Allowance; Employment and Support Allowance; Child Tax Credit (with an annual income below £16,190 and NOT in

receipt of Working Tax Credit); guarantee element of State Pension Credit; or support under Part VI of the Immigration and Asylum Act 1999.

Children are also eligible if they are looked after by the local authority, or have a child protection plan.

The **Family Information Service** is the main enquiry point for parents and they will check eligibility using the same system as the free school meals checker. To find out more, visit www.brighton-hove.gov.uk/fis



Amaze website gets a makeover

Thanks to funding from Brighton & Hove City Council and Blatchington Court Trust, we're about to complete a **major redesign of our website**. All the essential info about Amaze and other local services will still be there, but there are lots more pictures, new ways of finding related pages and documents and stronger links between our site and those of other local organisations. We've also used the money to try and make the site **more accessible** for all users.

Visit the site soon at our usual address (www.amazebrighton.org.uk) and give us your feedback via the online feedback form or by emailing charlotte@amazebrighton.org.uk. A brilliant new PaCC website will also follow shortly so watch this space!

Corporate support grows

A big thank you to **Santander Consumer** and **Warren Evans Bed Company** for their recent support for Amaze. Members of staff from Santander Consumer raised £1,350 for Amaze which they hope to double up under the Santander UK matching scheme. Their Charity, Sports and Social Committee organised a large annual event including cake sales, car washing, quiz nights and raffles and Amaze was one of four lucky charities to receive their support.

Warren Evans Bed Company donated £250 to Amaze and their



Vic Hill from Santander presents a cheque for £1350 to Debbie Collins of the PaCC and Amaze

staff joined an Amaze cheering point to support runners in the Brighton Marathon.

Please get in touch if your place of work could support Amaze like this.



Our 'Gifted' TV patron

For those of you who enjoyed *Snow Cake* - the movie about an Autistic woman starring Sigourney Weaver - the writer (Amaze Patron, Angela Pell) and director, Marc Evans, have teamed up once again to bring you a Sky Arts Playhouse (June 13th, 9.30 pm on Sky Arts 1).



'Gifted' stars Rhys Ifans as a man with a special ability - in a tender little tale of the unexpected. *Snow Cake* hit the screens seven years ago and Angela has been writing non-stop ever since. 'Gifted' is the first thing she has had produced since then. She says, 'Writing for me has been a bit like bringing up our special needs children... I have learnt never to give up - and to always remember there is magic in persistence'.

New Facebook Group for Epilepsy

Epilepsy can be a devastating condition, and parent carers who have a child or young person with epilepsy often describe feeling fearful and isolated. Connect with other local parents who have a child with the condition and gain support and empathy on a brand new Facebook group called Epilepsy Kids Brighton. Simply ask to join via Facebook or email Amanda Mortensen at: amanda@amazebrighton.org.uk

Representing You

Amaze CEO, Rachel Travers, explains more about the work we do to shape services and promote the voice of parents locally.



You will all know about the many useful services that Amaze staff and volunteers provide to families with disabled children in Brighton and Hove. What we don't publicise as much is all the work we do behind the scenes attending meetings across the city.

Last year, between us, we regularly attended 59 different strategic and decision making groups and sub groups. As the (part time) Amaze CEO, I attended half of these - no wonder I often feel like I'm always in meetings!

Our role at these meetings is to ensure that the needs of disabled children and their families are at the centre of decision makers' thinking when health, education, social care, leisure and other services are being designed, delivered, evaluated or reshaped.

We take what we hear from parents who use our services, attend our focus groups and complete our surveys and use it to feed in key messages to the city's decision makers (*see box*). So thank you to all of you who completed the recent Amaze Parent Carer survey - telling us what you need and think ensures that we are giving informed opinions. We will report the findings from the survey in the next issue.

"Services for disabled children will not be reduced during 2013/14. We will keep up the pressure to maintain budgets for 2014/15."

The Parent Carers' Council (PaCC) has provided trained parent representatives to sit on 22 of these strategic groups, supported by Amaze. These 'reps' are able to speak from personal experience, so their anecdotes and 'real-life' examples really enrich our key messages.

Locally, I believe that Amaze and the PaCC have been



working incredibly effectively together over the last four years, building positive relationships with the relevant service providers and local councillors and politicians, to bring about improvements. City councillors know that cutting services for disabled children and their carers would not only be morally wrong and short sighted, but vocally challenged by us all, and we have managed to ensure that services for disabled children will not be reduced during 2013/4. We will keep up the pressure to maintain budgets for 2014/5.

We are also trying to influence regional and national developments. I currently have a seat on the SE7's Regional Steering Group and we have recently had a reply from the Minister for SEN, Edward Timpson MP, about our concerns with the draft Children and Families Bill.

For more regular and immediate feedback about this representation work we do on your behalf, connect with the Amaze Facebook page – just click on the Facebook icon on our home page and 'Like' us. If you are not already a member, please consider joining the PaCC. You can also join in debates on the Amaze and PaCC Facebook groups.

HAVE YOUR SAY ON PARENTING ISSUES! The Big Debate on parenting in Brighton & Hove launches on 4th June. Watch out for discussions, surveys and more on the streets and in the parks, on Facebook, Twitter and in the local media. Join a focus group if you want to have your say. We'll let you know more on our website and Facebook page as we hear it.

Stepping up to secondary

How to make the transition to big school run smoothly.



Every September thousands of children in our city make the leap from primary to a large and bustling secondary school. All children can feel anxious about the move and for children with additional needs these worries can feel overwhelming.

Amaze has loads of experience in supporting parents and carers to make the transition as smooth and positive as possible. Lots of parents have shared their top tips with us so we can share them with you.

Think positive and be prepared

Be as positive as you can about the move - if you're anxious it will rub off on them. Our fears can turn out to be myths and misunderstandings. People say things to us like "I can't see him coping in a big school", but nearly all children cope and most flourish.

Things may actually be better at secondary than primary for some children. Big schools bring new opportunities, more possible friends, more activities and clubs. All local schools have experience of supporting children with special needs. They may not always get it right but most things are fixable.

Here are some things you can do to smooth the transition:

Make a list with your child of the things they are looking forward to about the new school.

Make sure some things in your child's life stay the same, like an activity or group they already enjoy.

Buy the uniform early and get your child to try it on.

Practice the journey to school as often as you need to, including getting them to do it alone with you shadowing at a distance if they will be travelling independently.

Deal with their worries

Find subtle ways of checking what your child is worried about and try to deal with it beforehand. For example:

There'll be lots of new people and will I make friends? Let your child know that everyone will feel like this.

Will I get lost? Remind them that they will usually be going with a group and can follow others till they learn the way. Pick out key landmarks. You could even take photos together.

Will I be able to keep up with the work? Talk about how they have managed before. Point out that they will have new subjects but the work won't necessarily be harder.

Just before term starts

Make sure they have all the gear they will need and involve your child in this so they feel things are really ready.

Get into the right routine in plenty of time so they won't be overtired during their first week.

Pack a comforting object - something that reminds them of home can be really helpful. Make sure it's something discreet that they can tuck in a pocket or bag. Choose it together beforehand and talk about how they can use it.

We have many more suggestions in our fact sheet 'Stepping up to Secondary'. Call the helpline for a copy or download it from our website.

Continence Q&A

All children vary as to how much help they need and at what age they achieve toilet training. A child's disability or learning difficulties may delay toilet training or they may have associated urinary and/or bowel problems. Some children will always need help with personal care. Whilst toileting may be forgotten as the child's other needs take priority, it is nonetheless very important for your child's wellbeing.



Q. Who can help ?

A. Your Health Visitor or Early Years Worker and Nursery staff, School Nurse and classroom staff can give you information and support. They can signpost you if they feel more specialist help is needed.

Q. At what age can my child get free nappies/pads?

A. From 4 years if a Continence Assessment identifies a need for your child to use nappies/pads.

Q. How do I get a Continence Assessment for my child ?

A. Ask your Health Visitor or School Nurse. If they don't know tell them to contact the Specialist Nursing Team at Seaside View for advice.

Q. Who supplies nappies/pads ?

A. Paul Hartmann currently supply products via Sussex Community Trust. Tel. 01706 363323
www.hartmann.co.uk

Amnesty! Nappies, pads and their delivery costs Sussex Community Trust £66,000 per year! If you have unwanted nappies taking up space in your home, Seaside View will be very glad to receive them as other children can use them. Just drop them off at reception.



A day in the life of...

Alain Glen, a Specialist Health Visitor at Seaside View.

I have been nursing for the last 16 years. I am an adult and a children's nurse and I have been a qualified Health Visitor for six years. I worked as a Health Visitor in Glasgow prior to coming to Brighton, and I have been at Seaside View for the last 18 months.

I am an early bird and I like to get into the office before anyone else. The peace and quiet gives me the opportunity to catch up on emails, write up notes and plan my day ahead. My job has a large remit and covers children from 0-19 years. I also work closely with my colleagues at the Royal Alexandra Children's Hospital and have many projects in the pipeline to try and improve services for our families across Brighton and Hove. I am certainly kept very busy!

My first appointment today is a meeting with the Ward Managers and Lead Nurse at The Royal Alex. We are meeting to discuss the final draft of the 'Health Passport' that I have been developing over the last 4-5 months (*see the facing page*). I'm really proud of it and hope that it proves useful to families who have children with special needs. It's great to be able to discuss the rolling out of the Passport and my colleagues are all really enthusiastic about it. The meeting is very positive and I leave on a high note to go to my next appointment.

"It's always helpful to share what's going on for the family and I am keen to do whatever I can to help lighten the load."

My next visit is to the family of an autistic child who has sleep problems. It is my first visit so it involves a lot of information gathering to try and get a

sense of what is going on for both the child and family. Getting this kind of detailed picture is vital to ensure that any intervention I plan can have a chance of success. It is so important to support parents, as sleep deprivation can have a very negative impact on family life. We agree to use a sleep diary and arrange another appointment for the following week.

Onwards to my next visit to one of the children for whom I am a Keyworker. This child has a rare genetic syndrome and I meet with the family at agreed intervals to see how things are going and offer ongoing support. We have a chat (usually over a cuppa) and identify if there is anything that needs to be done. It's always helpful to share what's going on for the family and I am keen to do whatever I can to help lighten the load. We agree a plan of action for me to work on and arrange my next visit.

Heading back to the office, I reflect on the day I've had, the families I have met and chatted to, and the things I still have to do. I manage to catch up with my manager and feed back about the great meeting at the Royal Alex.

My day doesn't end there as I am co-facilitating the 'Time Out for ASC' course this evening. So it's a quick dash home to get changed and eat then off again!

I am very lucky to be in a job that I love. It has its challenges and can be quite emotionally draining at times but I feel it is such a privilege to be part of a family's life. Hopefully, in whatever way, my families feel they are supported and know that I always have their best interests at heart.

Need some Face2Face support?

Has your child recently had a diagnosis of a disability or SEN? Or are you going through new difficulties with your child? If you are a parent carer and you would like to speak to another parent who understands what you are going through, you can ask for a befriender, as **Face 2 Face befriending launches** in Brighton and Hove on **Wednesday 26 June** at the Friends Meeting House.

A befriender offers emotional support and somebody to talk to at a very difficult time. Face2Face is a network of trained, volunteer parent bidders who support you to navigate the worrying and confusing experience of having a child diagnosed with support needs. Find out more at www.scope.org.uk/services/brighton-and-hove-face-2-face

You can self refer or be referred by any care or support professional. Call the scheme's co-ordinator, Amanda Mortensen on 07436810608 or email amanda.mortensen@scope.org.uk for more information.

Passport to Health

Do you find visits to hospital and healthcare settings stressful? Are you fed up of having to go over and over your child's individual likes, dislikes, what they eat, don't eat, what makes them anxious, how they communicate, whether they're likely to fall out of bed?

A brand new 'Health Passport', developed by Alain Glen and other members of the Specialist Nursing team at Seaside View, promises to greatly improve the experience of children with special needs and disabilities in health care settings.

Developed with parent carers from the outset, the Passport includes details such as 'How do I show pain and how can you support me?', 'What makes me anxious' and 'How am I usually' (vital for our young people whose 'usual' may differ from that of other children) as well as information about medication, toileting, feeding and communication. It reflects the unique nature of our children and will give health staff an instant snapshot of your child and their needs.

Nurse Consultant Tracey Young says: "The specialist nursing team are keen to improve the experiences of disabled children in hospital. We hope that this Passport, alongside other initiatives like training and the introduction of communication aids, will really make a difference."

Download the Passport at www.amazebrighton.org.uk/advice-for-parents/health/hospitals or call Seaside View on 01273 265780 for a copy. Simply fill it in and hand it to health care staff when you arrive for a planned or unplanned visit to any healthcare setting.

Whoopsadaisy on the move

Whoopsadaisy is a local charity that works with children with physical disabilities like cerebral palsy. It is the only charity in East Sussex that offers Conductive Education, a system of learning which builds upon children's existing abilities and skills, and helps prepare them for tackling the challenges of everyday life more independently.

The charity was founded in spring 2008 by Nina Holland (Trustee), with just two children. Today, there are regular sessions for the under-fives (helping up to 12 children each week) and over 30 families are on their register for school-aged children.

Conductive Education

Children with cerebral palsy (CP) have motor impairment. Their posture, co-ordination, balance and mobility are all affected, and CP is also often complicated by additional issues such as speech, communication and learning difficulties. Whoopsadaisy says: 'Conductive Education motivates children to achieve important goals such as learning to crawl, sit up or walk. A typical CE session consists of a series of physical tasks, tailored to the child and aimed at improving co-ordination, raising body awareness and practising movements essential for independent living. We work in small groups and provide much-needed support to families.'

Under fives

Whoopsadaisy currently runs three under fives parent and child groups each week, which focus on developing physical skills as well as sensory, social and communication skills. There's lots of fun, with singing, games and art, in a friendly, family atmosphere. Parents learn tasks, activities and songs for their children to practice at home.



School-aged children

To ensure that progress is not lost once the children start school, Whoopsadaisy also runs regular Saturday Schools and Holiday Clubs (*see page 14 for more information*).

Costs?

Whoopsadaisy parent and child groups are free and parents attend with their children. Holiday clubs and Saturday schools have a suggested donation and give parents an opportunity for a much needed break.

A new home

Whoopsadaisy plans to take on an additional 'conductor' and have just secured a new, accessible, home of their own at the former Ladies Bowls Pavilion in Preston Park. The move will mean they can offer an even wider range of services and more sessions, to both existing and new families, on site. If all goes well, they will move into the Pavilion in the summer.

For more information call 07588 555761 or visit their website at www.whoopsadaisy.org

How PIP adds up

In the last newsletter we explained the timescale for rolling out Personal Independence Payment (PIP), the new benefit that replaces DLA for working age people. Here we look at what's different about PIP, the new criteria to decide who qualifies for the benefit and, if they do, the rate they'll be paid. We also look at how to make a strong claim.

How does the new PIP differ from DLA?

Each component of PIP will be paid at one of two rates known as standard and enhanced rate: the DLA care component currently has three. Realistically, this means that if you are currently getting the lower rate of the care component, you're more likely to be at risk of being turned down for PIP.

DLA rules allow for people with certain conditions to automatically qualify for certain DLA components at specific rates. Under PIP no-one (other than the terminally ill) will have any automatic entitlement.

Nearly all awards will be time limited, with very few indefinite awards. We also think most awards are likely to be shorter and reviewed more frequently.

There will be a new assessment process involving a face-to-face meeting with a health professional for most claimants.

Who will get PIP?

PIP will use a points-based system to work out whether someone qualifies for the benefit, and if so, at what rate. This new type of 'objective assessment' will focus on your ability to carry out everyday activities, and the challenges you face. Each activity will be assessed and scored. Points will reflect the level of difficulty you experience in the following areas:

- preparing food and drink
- taking nutrition
- managing therapy or monitoring a health condition
- bathing and grooming
- managing toilet needs or incontinence
- dressing and undressing
- communicating
- engaging socially
- making financial decisions
- planning and following a journey
- moving around



The number of points you score in the last two categories will determine if you get the mobility component, and at what rate. Scores in the other categories will determine whether you get the daily living component. If you score 8 points, you qualify for the standard rate of component, if you score 12 points or more you will qualify for the enhanced rate. More detail about the scoring system for PIP is available at www.disabilityrightsuk.org

The weekly payment rates for PIP are the same as the rates payable for DLA.

Rate	Daily living component	Mobility component
Enhanced	£79.15	£55.25
Standard	£53.00	£21.00

What we like

The new assessment prompts you to explain the challenges you face doing a task safely, to an acceptable standard, as often as you need to, and in a reasonable time. This includes asking about the help you need, as well as the individual way you tackle that task, if you don't have someone to help and have to 'get by'.

PIP includes a broader range of practical skills than were included under DLA. For example, handling money, understanding how much things cost, how much change to expect at the shops, etc., are new key tasks.

PIP shines a torch on social skills: asking about your ability to mix and get on with other people. It's easier to know where to include how a young person struggles to 'read' other people's intentions or understand how what they say or do impacts on how others feel towards them.

There is no page asking about night time needs and we really welcome this. Under the old DLA rules, no matter how dependent you were on others to do things for you, if you slept through the night, you were only ever entitled to the middle rate of the care component.

Under PIP it will be easier for young people with severe learning difficulties to be awarded the enhanced rate of the mobility component. The DLA rule that linked being awake at night to getting the higher rate of the mobility component (on the grounds of severe learning difficulties) is swept away too.

Making a strong case

Make it a top priority. Don't assume that because your child has always been awarded DLA, they will get PIP. You have a lot to lose if the claim is refused. Put as much effort into this as you did with their first DLA claim.

Don't try to tackle it alone, so call in a favour and ask a friend to help.

Use the information booklet that comes with the claim pack to help you think a bit more 'out of the box'. Or ask Amaze for examples of things to include.

Send supplementary evidence that supports what you say: up to date assessments, care plans, medical reports or psychiatric reviews, and, if they have or have had one, a copy of their Statement of SEN. If you have mislaid copies ask advice givers for another. If a young person is overdue a re-assessment, chase this up.

Explain if evidence seems out of date: for example, if a Statement of SEN hasn't been amended for years, say this is because everything on it is still relevant. Add annual review notes to support this.

'Tell it how it is', go into detail and be forensic: the more help you need, the more points you will score. But even if you just need a bit of help, it's worth writing this down. Even if a young person can 'sort of' get themselves dressed, if you explain why it takes them so long or how much time you spend explaining and negotiating what's appropriate to wear, this should still get some points.

Include the help your child needs and doesn't get. Give examples to show how they miss out, what happens or goes wrong when they don't have that help or supervision.

Tell them about waiting lists or cuts or reorganisations to services your child needs and cannot access. For example, say if you are paying for therapeutic interventions because these aren't available locally.

Where there is plenty to say, fill up the text boxes. If you run out of space add extra pages. The clearer picture you are able to give on paper about your child's needs as a young adult, the more likely it is that the assessor will be able to make a decision without a face to face interview.

If you need more help with the form, Amaze has a small team of volunteers who can meet and go through the claim pack with you and your son or daughter. Call the helpline on 772289. Worried about timescales? Then read the PIP article in the last newsletter, downloadable from the 'publications' page in the Resources section of our website.

Affordable, accessible holidays for you and yours



It may not be too late or too expensive for you and your family to have a great summer holiday. Forest View is an accessible holiday home for families with disabled children on the edge of

the New Forest. The caravan sleeps six and includes a mechanical bed, mobile hoist, mobile shower chair, security and safety features. It is provided via the Short Breaks team at the council and is situated on the Shorefield Country Park in New Milton, a fantastic holiday site with an indoor heated swimming pool, sauna, gym and beauty spa, as well as a bar and restaurant with entertainment in season. All prices are significantly reduced from the actual prices offered from Shorefield. If you are interested then please call 01273 295530 or email forestview@brighton-hove.gov.uk.

There is also a holiday home available on the Isle of Wight, for families with children that meet Brighton's short breaks eligibility criteria. This caravan is situated at Park Resorts, Shanklin, and is close to the beach, town centre, transport links and local entertainment. See the Lower Hyde park on the Park Resorts website at www.park-resorts.com for details or contact The Isle of Wight Short Breaks Unit for more information on 01983 823168 or by emailing kelly.quinn@iow.gov.uk

Summer holiday launch for i-go leisure card



The i-go card for disabled children and young people in East Sussex is due to be launched in time for the school summer holidays. A Rocking Horse and East Sussex County Council initiative, i-go is a discount leisure card, similar to the Compass Card in Brighton and Hove, which will be available to 0 to 25 year olds with significant additional needs living or going to school in East Sussex, outside Brighton and Hove. Most families will find their child is eligible for one or the other, but some will be eligible for both – for example if you live in Brighton and Hove, but your child goes to a school in East Sussex, or vice versa.

To get info about the new i-go card, call East Sussex Information for Families on 0345 60 80 192. To find out more about the Compass Card, call the Amaze helpline on 01273 772289.

Talk Health makes a difference

Find out how PaCC's health report is already having an impact on the way health services work with families.

On 20 March the Parent Carers' Council invited representatives from the Royal Alexandra Children's Hospital, Seaside View, CAMHS and GPs to come back and tell parents what changes they had made since our 'Talk Health' report was written last summer. You can read the full report and the notes from the day at www.amazebrighton.org.uk/pacc/survey_reports

Here's a summary of some of the key developments that each of the services told us they have made as a result of the report.

The Royal Alex

- **New car parking arrangements** are now in place to prioritise families who have blue badges (*see the box below*)
- Staff from Seaside View are giving staff from the Royal Alex **disability awareness and parent journey training** so they have a better sense of your family's needs
- **A new Health Passport** is now available which gives everyday details about children with complex needs (*read more on page 7*)
- **A new specialist epilepsy nurse** is going to be funded to work with local children who have complex epilepsy

Seaside View

- **A physiotherapy technical instructor** is now in post to help support the work of physiotherapists in schools

- **Clearer information on the therapy appointment waiting list** will be given to parents when they receive a letter from the therapist
- **New early years groups** have been relaunched following feedback from families, and these are better attended
- **New parent-friendly leaflets** about each service and its eligibility criteria have been written, with the help of the PaCC
- Children with complex needs in mainstream schools will soon be getting a **new health care plan** which outlines their individual requirements

CAMHS

- **New leaflets** are being developed that will explain more about the different tiers within the service and eligibility criteria
- **A simpler referral process** will hopefully ensure young people are referred to the correct service

more quickly

- **Greater transparency about waiting times** is being provided by better information at the point of referral
- **Clearer pathways for children and young people with autism** have been developed in each tier
- **A new psychologist based at the Alex** will help support children and young people with long term health conditions

GPs

- **A new website** for GPs is being developed and the designers will work with the PaCC to ensure that the section on young people with disabilities is appropriate
- GPs will be receiving **training in the parent journey** in their protected learning schemes during the year
- GPs will be urged to give children with additional needs **priority when booking appointments and if possible a quieter area to wait in**

Amaze and the PaCC will continue to work closely with health service managers and commissioners to deliver improvements. Please tell us if you notice any improvements in these services (or not) by emailing pacc@amazebrighton.org.uk

Parking progress at the Royal Alex

Blue Badge holders can now drive to the front of the (often long) queue at the Alex, show their blue badge and be given priority over other drivers to access the disabled bays inside. This was introduced after PaCC and Amaze worked with the hospital management team to discuss ways of improving access.

The Royal Alex has also recently increased the number of disabled bays inside the hospital car park and there



are now 16 available.

However, do note that there are now no disabled bays directly opposite the Royal Alex entrance. These are now designated bays for Oncology patients who don't get blue badges, but need accessible parking.



My blessing in disguise

Nicky Gibson, PaCC member, shares the joys and challenges of being mum to her son, Isaac.

Isaac recently turned nine and managed to utter one of his longest sentences ever, 'I'm nine but still (the) same guy' he said. Even a year ago, we could not have imagined an almost complete sentence like this, but throughout his life we have been very much aware of Isaac's depths, wit and joy.

True to form, Isaac arrived on his due date and at home. Obsessed with dates, it was fitting that his recorded time of delivery was 11.11pm, apparently an auspicious number. We'd just finished watching 'The Lost Prince', a dramatization of the story of little Prince John, the youngest child of George V and Queen Mary, who died tragically at the age of 13. John suffered from epilepsy and a developmental disorder and was kept hidden away, raised entirely by a governess who loved him and helped him flourish despite the lack of affection from his blood family.

The film and Isaac's appearance that night made me think a lot about the concept of 'blessings in disguise' and how proud we should be of our special young people and the

opportunity that they give us, their carers, to evolve too.

'If there is one word that sums up Isaac, it is radiance.'

We initially put Isaac's lack of speech and other difficulties down to the fact that he is the third of our three boys. We just assumed he would take longer to develop. Eventually though, we were referred to see the wonderful Dr Chapman at Seaside View. She listened carefully to our concerns and suspected Fragile X. It turned out to be Ring Chromosome 18, which affects around 1 in 200,000 people. I don't remember feeling sad or depressed about this. Instead I thought, 'Here's a challenge - let's get on with it'.

Isaac was assessed at the Jeanne Saunders Centre and now attends our local mainstream primary. This was a leap in the dark, as we'd assumed that his needs would best be met by a dual placement. His school, however, is one of the more enlightened and

inclusive ones and, having fought hard for a watertight Statement, we feel that, for now, he has a good package of support and social inclusion. He has made some great progress and absolutely loves learning. Anyone who works with Isaac remarks on what a delight he is.

The next challenge will be ensuring that Isaac moves to a secondary school where he can achieve his potential but also feel safe and supported. He has severe and complex language difficulties, which will of course affect his ability to access an increasingly difficult curriculum, but also his ability to socialise and function in the world beyond home. This is already beginning to have an impact on his behaviour sometimes, as he gets very frustrated when he cannot express himself. Travelling on public transport can be particularly fraught.

He also has some autistic features. For example, he recently became distressed at an unexpected change to his routine and attempted to run back to school to resume his normal activity for that day. With little road safety awareness, this was a very frightening experience for all of us.

In the wider context, there is also, of course, the challenge of living with increasingly damaging government policy which devalues our more vulnerable people. One day, Isaac will make the most loyal, kind and diligent employee, but he is going to need lots of support and a good education to achieve that.

Isaac has taught us all a lot over the years and inspired me to help others. As well as being an active member of The Parent Carers' Council, I also support parents on a national helpline for SEN and am a parent representative on the SEN Panel, as well as chair of Link Up.

If there is one word that sums up Isaac, it is radiance. He really loves life and just by being his good honest self, helps others to find joy in it too.

PaCC Champions revealed

Last November the PaCC asked you to nominate the professionals and volunteers from Brighton and Hove who had made the biggest impact on your lives in 2012.



Jenny Brickell accepts her special award for building partnerships with parent carers

We were looking for the people who had made that extra effort above and beyond the call of duty to support families of disabled children and young people.

We know that there are an awful lot of professionals and volunteers working in health, education, social care and the voluntary sector who are worthy of the title PaCC Champion and you demonstrated that by your response. We received over 40 nominations across the four categories via the internet, this newsletter and directly from you at the Amaze Information Fair.

We assembled as diverse a panel of judges as we could muster and locked them in a room until they had reached agreement. In truth, we could have justified selecting any of the nominees put forward, but we could only afford one trophy in each category.

The winners were announced at the Talk Health Event held in March at the Brighthelm Centre.

The award for **outstanding contribution in the Education Sector** was presented to **Julie Lawrence**, a **teaching assistant at Patcham High School**.

"Julie goes beyond the call of duty to ensure everything runs smoothly and

regularly communicates with me on all aspects of the school day. This gives me peace of mind which is priceless."

The **Health Sector Award** went to **Julie Yeats** for **Special Needs Dentistry at Conway Court**.

"Julie Yeats has worked patiently with my previously phobic son. She provided dental equipment to take home for role play and my son is now transformed and enjoys going to the dentist and happily has treatment now."

The **Voluntary Sector Prize** was awarded to **Gillian Kitchener** from **Kaleidoscope**.

"We are very lucky to know Gillian. She has and is making a very positive difference for many children and young people in her work running Kaleidoscope. She has challenged peoples' thinking and attitudes with endless strength, determination and a wicked sense of humour."

Occupational Therapist Jane Cleaver won the **Social Care Award**.

"Jane is kind, caring and always listens. She responds straight away to any problems I have and is very thorough. The work that she has requested for us has improved our standard of living and made a huge difference to my son's life and mine."

We also wanted to recognise the outstanding commitment to building partnerships with parent carers made by Jenny Brickell, Service Manager for the Integrated Child Development & Disability Service. We didn't have an award for this so we created a special one and presented it to Jenny to say thank you for all her effort.

School Transport latest

On 27 March a small group of parents and headteachers met with Gil Sweetenham, the council's Strategic Commissioner for Contracts, to talk about transport to school. This was a follow up to the PaCConnect workshop on Transport held in November 2012.

Many parents had raised concerns about the school transport retendering process that was carried out by the council last summer. They were concerned about the lack of communication about the changes, the lack of understanding of children's needs, health and safety issues and some taxis not providing escorts.



Gil assured the group that no cuts would be made to the transport budget in 2013/14 and it was also unlikely that any cuts would be made the following year. He agreed that in the future head teachers and parents needed to be involved in the tendering process.

Some improvements have been made in the communication between families and the taxi companies - some drivers are now ringing the family just before they arrive in the morning. However, parents reported that there are still situations where the routes or taxi staff change frequently, which is very difficult for many children with special needs.

Changes have been proposed to help improve the service in the future. One suggestion is to move the transport team to within the SEN team, who better understand our children's needs. Parents also wanted the council to review whether the transport providers were meeting required standards and care. Gil retired recently. We will continue to meet with his replacement, Michael Nix, and keep you posted.

Heads-up on the future of SEN

Brighton & Hove's new head of SEN, Regan Delf, met Amanda Mortenson from the PaCC, to outline her vision and plans for special educational needs in the city.

Ask Regan Delf about her approach to SEN in Brighton and Hove and she is passionate but pragmatic. "The provision in the city is good, in some schools very good, but it's never a done deal," she says. "We want to give parents the best possible deal - not necessarily a utopian deal, but never less than a good deal."

Regan's background stands her in good stead. As a former secondary school teacher, principal educational psychologist and school improvement and SEN adviser working at the Department for Education, she has 'seen how it is' in around 50 different local authorities. Her mantra is to be creative, push the boundaries of educational thinking and think local. Why, says Regan, would we want our young people miles away in an out-of-county placement that we have no easy way of monitoring well if we can offer the same quality of provision in Brighton and Hove?

There are gaps in provision that Regan is keen to fill, and fill well. "As a commissioner of SEN places, I need to look at existing provision," she says. "For instance, we've realised we need **more specialist SALT and autism places at secondary level and less places for dyslexia** - we know this from the data, with pressure on places in the former and year on year vacancies in the latter, so we need to ensure provision meets need." In line with Regan's thinking, from September, **there will be more secondary places for children with a significant speech and language difficulty and/or autism spectrum condition.**

Regan is also keen to think creatively about how a child's needs are met. "Commissioning for children

shouldn't be limited. We are looking at **more creative packages, working with social care to get the best outcome for children with very challenging lives.**" She says: "Early help is crucial, as is really effective joint working between education, health and social care, to make sure children and young people get the right support to do as well as they can."

"We need a more holistic approach to autism"

As head of SEN, Regan's team is responsible for all the children in Brighton and Hove who have a Statement. "As part of this, we look closely at school improvement and ask schools, 'are your interventions right?'" And although the local authority's relationship with schools has changed ("We are not the 'boss' of the school - schools are more autonomous than they used to be."), that doesn't mean they leave them totally to it. "We will take a closer look if parent carers bring something to our attention, or if data or Ofsted reveal an issue." She says that Ofsted's new 'Parent View' is also taken seriously.

So what are Regan's main challenges going forward? The city's provision for autism in the city is a key one. "We need **a more holistic approach to autism.** We are looking to introduce a **tiered training package in schools** and have extra funding allocated to this. If we can't find the necessary expertise locally, we will look externally."

The SEN team is also looking very carefully at **closing the gap between children with and without SEN** at all



stages but **particularly at the end of Key Stage 4** (aged 16). "The gap is too wide. Good progress isn't enough for some children who need to catch up - they need to make accelerated progress," she says. "We need to be more ambitious. What really makes the difference is access to the best teaching. We almost need to take a **new approach to target setting** - not just to set targets for a year or two ahead but look at that child's whole life - what's the ultimate aim? Is it independent living for example, and how do we achieve this?"

Of course, it is a time of flux for SEN with, for example, the introduction of new legislation next year. "We will be **supporting young people up to 25** under the Education, Health and Care Plan system from September 2014. This poses challenges but also opportunities. We are **actively pursuing expanding choice and provision** for this age group under this new remit."

At such times, Regan feels, the role of parent carers becomes even more crucial. "Good relationships with parents are key. And I know how hard it can be to take on your child's school. I'm a parent too."

To meet Regan Delf and ask more questions about SEN, come to the PaCC Connect meeting on education on 19 June. To attend email debbie@amazebrighton.org.uk or call the Amaze on 01273 772289.

Sort your summer soon

Summer (or what passes for it in this country!) will be upon us any day now and before you know it, so will the school holidays. Don't get caught out with a house full of bored kids and seemingly endless days to fill. Read our round up of summer schemes and activities for kids with special needs and sort out your summer now.

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) Tues to Fri, 6 to 30 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 01273 295192/295530.

Extratime (11-19s) Mon 5 to Fri 30 August (excl. bank holiday), 8.45am to 5.30pm. Youth schemes specifically for young people with disabilities at the YMCA Hove and the Crew Club, Whitehawk. Lots of in-house activities and days out. Each venue allows up to 18 kids and costs £20 per day. Visit www.extratimebrighton.org.uk or call 01273 420580 to book.

Whoopsadaisy (5-12s) 29 July to 9 Aug, 10am-3pm at Ladies Bowls Pavilion, Preston Park (tbc). Summer holiday club for children aged 5-12 with physical disabilities. This year's theme is 'Interesting Occupations.' Playful, friendly sessions with an emphasis on developing physical,

sensory and social skills. Suggested donation £30 per day. Call 07588 555761 or email caroline@whoopsadaisy.org (read more about *Whoopsadaisy* on page 7).

Inclusive schemes

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

BHIP Holiday Play Scheme (4-11s)

29 July to 9 Aug, 8.30 or 10.30am to 4 or 6pm, West Blatchington Primary School, Hove. Inclusive play scheme for children with and without additional needs. £22/20 per full/short day. Call 07821 541765, 01273 295533, or email info@bhpi.org.uk

Extratime (5 years+)

Mon 5 to Fri 30 August (excl. bank holiday) at Ash Cottage, Woodingdean and Hillside School, Portslade. 8.45am to either 3.30pm (£19) or 5.30pm (£21). Fully inclusive play schemes offering one-to-one support if required. Also at St Luke's Infant School (5-11s). A long day here costs £22. Call 01273 420580 to book or visit www.extratimebrighton.org.uk

Honeycroft Play Scheme (2-11s)

29 July to 30 Aug, 8.30am to 5pm or



9am to 3pm at St. Barnabas Hall, Sackville Road, Hove. Inclusive play scheme. £3 per hr. Call 01273 220323 or email honeycroft.cafe@gmail.com

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. If you attend groups like **Brighton Pebbles**, **Link UP** or **Sweet Peas**, it's worth finding out what they are doing over the summer. You can call the Amaze helpline to get the contact details of these and lots of other local parent led groups or search for 'support groups' on our website.

Other ideas

Our 'Fun things to do' factsheet is stuffed with information about local leisure activities—download it from our website or call the helpline for a copy. Alternatively, you could visit 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 or call FIS on 293545 to order a copy.

Don't forget your Compass Card!

If your child has a Compass Card, they can benefit from loads of leisure offers, discounts and activities in Brighton and beyond this summer. Read about Compass activities overleaf. For info on all offers, call the helpline, visit our website or speak to us in the Amazing Zone at TakePart on 22 June (see cover).

Have you tried a Compass Card Activity (CCA) yet?

Developed by Amaze in partnership with local activity providers, CCAs are special needs-friendly activities you can trust. Each provides teachers or coaches with special needs experience, opportunities to feedback, information on other activities and usually a discount for Compass Card holders.

We've come a long way since we launched our first two CCAs back in February 2010. There are now around 20 to choose from and although most of the latest CCAs are specially designed for teens, others are suitable for much younger children. For full information, look at our new CCA guide – you can pick up a copy in the Amazing Zone at the Takepart Festival Family Day (*see front page*), or online at www.amazebrighton.org.uk

In the meantime, here's information about our latest CCAs.

U-Sport for teens

Friendly, active **multi-sport club** for 13-19s with moderate and complex needs, 9.30am till 1.30pm on Saturdays. Club where young people can **socialise, learn new skills and improve fitness** – and a break for parents too. Monthly four-hour session launches 15 June at the Crew Club Whitehawk and will usually alternate between the Crew Club and the Y Club on Marmion Road Hove. Cost per session £14. Book now by calling Lisa Nash at Extratime on 01273 420580, or email lisa.nash@extratimebrighton.org.uk

Fun-fit for teens

Weekly opportunity for 13-19s to have fun and get fit at this new weekly **multi-sport session**, 5.30 to 6.30pm on Mondays at King Alfred Leisure Centre in Hove. Expect **circuit training, boccia, table tennis** and

much more. Exclusive session for teens with special needs and for young people with more complex needs if they attend with a carer, Leisure Broker or befriender. Call 01273 292729 to book, or just turn up. Bring Compass Card for 50 pence off entry price of £4.



Adventure activities for teens

Adventure Unlimited is running **kayaking and archery courses** and individual **climbing sessions** at specially discounted prices for Compass Card holders. The next three day kayaking course is in the summer holidays. The archery course runs November/December this year and early next year. Individual climbing sessions are Thurs evenings at Stanley Deason Leisure Centre. Booking is

essential – contact Adventure Unlimited on 01273 681058 or info@aultd.org

Cookery for teens

Cookery courses from Brighton & Hove Food Partnership. The first, for pupils at Patcham House, Downs Park and Cedar House, is already underway. The next is 4.30 till 6.30pm for five weeks from Thurs 27 September to Thurs 25 October and carers are welcome. Call BHFP on 01273 431700 to book, or email cookery@bhfood.org.uk

Coming soon...

Six week inclusive **trampolining** courses for teens planned from September at Moulsecomb Community Leisure Centre. And **Otherworld**, a delicious **sensory drama therapy experience in a spacescape** with astronauts, is also launching later this year. Otherworld is for all ages and siblings and parents are welcome. Watch this space!

Compass offers too!

There are more Compass Card offers than ever before in the new Compass Card guide. New additions include a **10% discount on taxi fares** with Brighton & Hove Radio Cabs; **Paradise Park offering half price entry** for the Compass Card holder and up to five others; and a **10% discount on holiday playschemes at The Academies**.

Carers' Card - have your say

If you've ever had thoughts about the offers you'd like to see on the Carers' Card, you can fill in a very short Carers' Card survey online at <http://bit.ly/15ADocb>. Closing date is 25 July 2013.

Applying for a Carers' Card is getting simpler. There's a new application process from 1 June and the photo ID has gone. The card is for anyone with an ongoing caring responsibilities, including parent carers and young carers from age 8. Amaze develops the offers on the Carers Card and there are now well over 50 of them, so it's well worth applying!

If you want to apply, call 01273 295153 if your disabled child is under 18, 01273 295555 if they're over 18. Parent carers of Compass Card holders automatically qualify for a Carers' Card. Have the Compass Card to hand when you call; you'll be asked for the number on the back of the card.



Coming soon....

Sun 16 June - 'All Stars' screening at Duke of York's

The next autism-friendly screening is the **recently released comedy, All Stars (U)**.



Doors open 10.30am for free coffee, tea, squash and biscuits. Amaze volunteers will be on hand.

Weds 19 June—PaCC Connect focus group about SEN with Regan Delf and Jo Lyons

Meet SEN and Commissioning Heads to discuss how changes to SEN might affect your child's education. 11am to 1pm at Community Base. Call Amaze if you want to attend.

Thurs 20 June - Clinique Make Up Fundraiser

Amaze will be holding a **Clinique Makeup Party Fundraiser** at Boots, North St, on Thurs 20 June from 7.30 to 10pm. Call Nicky B on 01273 234020 for limited places.

And next term...

Looking After You – our super **stress-busting** course that mixes talk, **relaxation techniques** and a bit of Pilates.

Triple P Teen – **positive parenting** and **managing behaviour** for parents of over 11s.

We don't have dates for these yet, but if you are interested (in these or any other Amaze courses) just call the helpline to find out more. You can go on the waiting list for any course that would suit you and when we next run that course, we contact everyone on the list to give them first chance to book a place. So give us a call!

Our heroes

The 4th Brighton Marathon on Sunday 14 April was an adrenalin-filled high for Amaze and raised over £5,000!

Thank you to our heroes Steve Allen, Malcolm Bateup, Darren Beaney, Julius Brinkworth, Joe Franchi, Charlotte Graham, Jonathan King, Sam Langdon and Mini Mile runners Sarah Grevatt, and Joshua Bateup.



Julius Brinkworth celebrates completing his fourth Brighton Marathon, all of them for Amaze.



Joe Franchi completing his third race in a row for Amaze and raising over £2000!

Could you be a hero like Joe and Julius? If so, places are available now to join Amaze running teams in the Brighton Brooks 10k on 17 November, The Brighton Half Marathon on 16 February 2014 and the next Brighton Marathon on 6 April 2014. Call Nicky B on 01273 234020 or email nickyb@amazebrighton.org.uk

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*.

This summer the helpline will close from Mon 5 to Thurs 15 August. It reopens on Mon 19 August.



Amaze

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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.

