

out of amaze



For families of children with special educational needs and disabilities in Brighton & Hove



Get sporty on The Level at TAKEPART Launch Day

Saturday 18th June, 12 noon to 5pm at The Level

Amaze has a stall at the wonderful TAKEPART Launch Day, the sports taster event that really does include everyone. The event is moving to The Level this year and there's a brand new **Disability Active Marquee** where children and young people with additional needs and their friends and family can chill out when they need a break from the general hubbub.

Amaze will be in the Disability Active Marquee handing out the latest offer guides for the Compass Card in Brighton and Hove and West Sussex – and talking about all the new offers that have been added for families in the city as a result of the recent expansion (see right).

The new marquee is part of the Disability Active Zone, which will showcase a range of activities that help disabled people in Brighton and

Hove find new ways of staying active. You can try out inclusive activities like sound tennis, table tennis, football, boccia, capoeira, cricket, golf and all-ability bikes – and Amaze will be able to point you in the right direction if you're wondering what to do next. Come and see us and discover a new sporting interest!

TAKEPART Launch Day is the first day of the two week TAKEPART Festival taking place across Brighton and Hove. It culminates in the Paddle Round the Pier event on Sat 2nd and Sun 3rd July. The **Access Beach at Paddle Round the Pier** is an ideal way of getting your disabled child or young person into the water with all the support they need and it's completely free. For more info, call 07717 303259 or email access@paddleroundthepier.com

West Sussex Compass means more fun for all

On 8th April Amaze launched a West Sussex version of the Compass Card. This is great news for West Sussex families of course, but it also means lots more fun for Compass Card holders in Brighton and Hove too.

Why? Because virtually all the offers negotiated for Compass Card West Sussex will be shared with Brighton and Hove – and in the same way, most of the offers in Brighton and Hove will be shared with West Sussex. That means more offers all round and deals that extend across West Sussex and into parts of East Sussex, Hampshire and Surrey. There were **37 new offers and counting** for families in Brighton and Hove as we went to press.

Turn to **page 4** for details on some of the brilliant new offers and how to download the Compass Card app and see the full range.



Amaze CEO, Rachel Travers; Isobel, Thomas and Debbie May and Peter Evans, former West Sussex CC Member for Children and Families at the launch of the Compass Card West Sussex.



More changes in education

With all the proposed changes to education in the news lately, you may be feeling anxious about what this means for your child's future schooling. Here we look at some of the key proposals around education, both locally and nationally, and what we are doing to make sure your views are heard.

Catchment areas

Brighton & Hove City Council is looking at ideas for new catchment areas for their secondary schools and giving more priority to children who get free school meals. There was a consultation about this in April to get a sense of local opinion. This will be followed by firm proposals and a more formal consultation in the autumn.

Amaze responded to the consultation to say that any changes should be used to look at how the admissions system can offer good opportunities throughout the city for children with SEND. We think parents would generally like to see more even numbers of SEND pupils in each school and for all secondary schools to offer a good welcome and take a healthy share of children with SEND.

At the same time parents of children with SEND should have some choice, so they can pick a school which is as local as possible but suits their child's individual needs. We will try to make sure parent carers are kept informed about the next stage on these proposals so you can give your views.

Academies or not?

Though the government has dropped its controversial plan to force all schools (except special schools) to become academies by 2022 it still wants to "see all schools become academies" and the revised white paper will introduce sweeping powers for the DfE to force schools in "underperforming" local authorities to convert to academy status. We know this throws up lots of worries for parents of children with SEND.

Legally, academies have the same duty as local authority-run schools to follow the SEND code of practice, the Equality Act, guidance on supporting pupils with medical conditions and exclusion. But parents' experience around the country suggests that academies are not always as inclusive and welcoming as they should be.

PaCC and Amaze have shared this concern with Brighton & Hove City Council and we will keep representing the views of parent carers and the needs of children with SEND as the detail of the white paper emerges.

Changes to special education provision

In March, the council's Children, Young People and Skills Committee approved revised proposals for the restructure of **Educational Psychology and Learning Support Services**. Read all about this on page 10. March and April also saw consultations on proposed changes to the way the city provides special schools and pupil referral units. Lots of parents took part, by completing an online survey or by attending meetings like the PaCConnect event in March. Now there are three project groups working to turn the ideas for change into firmer proposals.

One group is looking at creating two **integrated hubs** (east and west) for children with learning difficulties, merging schools and bringing other services into the hubs. Another is looking at a **hub for children with social, emotional and mental health needs (SEMH)**. The third group is looking at **preschool special provision** and ways of creating an integrated nursery. PaCC parent reps and Amaze are taking part in all three. The local authority is happy to hear views and ideas from parents throughout this process.

On June 6th a report based on the consultation and the project groups' work will go to the Children, Young People and Skills Committee. If this is approved, things will become more definite, but there'll be a formal consultation and a plan to bring in the changes over three or more years so there will be no loss of special school places and as little impact on individual children as possible.

To give your views on the proposals, you can email the local authority on sendreview@brighton-hove.gov.uk. Or you can email PaCC on admin@paccbrighton.org.uk. If you have individual concerns about your child, contact Amaze via the helpline on 01273 772289.

New system for assessing and awarding social care

Brighton & Hove City Council is trialling a new and hopefully fairer way of assessing and allocating social care. The Resource Allocation System (RAS) from FACE was 'soft' launched on 25th April, which means it will run alongside the current assessment processes for the time being to make sure that the RAS is working properly.

Carl Campbell, team manager for disabled children's social care, told us, "I want all families to be reassured that the purpose of the RAS is not to reduce support packages. It is simply a tool for allocating resources more fairly. In the short term, there will be no changes to support packages, but, over time, the RAS will help us come up with more appropriate and fairer support packages."

The local authority hopes that the new RAS will mean that families with similar needs receive similar resources.



Time to celebrate the carers

6th to 12th June is national **Carers' Week**, the annual campaign to raise awareness of caring, highlight the challenges that carers face and recognise the contribution they make to families and communities throughout the UK. This year, Carers Week is focusing on building **Carer Friendly Communities**, asking people to recommend organisations that are already carer-friendly and inviting

other organisations to use a checklist to commit to becoming carer-friendly. Find out more at www.carersweek.org

Locally, you can come and see Amaze and other carers' organisations at a Carers' Week information and advice event at Jubilee Library on Monday 6th June, from 11am to 7pm.

And we're getting involved in the local campaign by using social media to get people talking about the need to support parent carers. If you're on Twitter, use **@carersweek** and **@amazebrighton** to tweet what's important to you as a parent carer, or as a professional supporting carers. Or do the same on our Amaze or PaCC Facebook groups. You could even tell us more about your life as a parent carer via our website at www.amazebrighton.org.uk/get-involved/tell-us-your-story

Three cheers for the volunteers

In our last issue we told you how much we love all our volunteers at Amaze, and we're saying it again because it's officially Volunteers Week 2016! As a charity we are dependent upon the goodwill and commitment of our volunteers who provide direct support to families applying for DLA, assist our helpline

staff, support education casework and help in our busy office. A huge thanks again to all our existing volunteers.

If you want to get involved, we are **looking for volunteers** to be part of our **DLA project** and for people who can help with our **fundraising** and **communications**. Please email info@amazebrighton.org.uk



Nothing about me, without me

'Nothing about me, without me' is a brilliant new teaching pack that is designed to support teaching and learning about disability equality in local schools. The pack, developed by Carousel and Brighton and Hove City Council, includes lesson and assembly plans, films featuring local children and young people and a positive images photo pack. It has been created to support Personal, Social, Health and Economics Education (PSHE) teaching at primary and secondary.

You can find all the resources at www.carousel.org.uk/nothing-about-me-without-me. If you think your child's school could benefit from some disability equality training, remind their teacher or SENCO about this great new resource.



Amaze IS expands into East Sussex

Amaze is delighted to announce that we will be extending our **Independent Support** service into East Sussex. The contracts to offer support with EHC planning to parent carers and young people were awarded in early May and we'll be offering the service from the beginning of July. Watch this space for more details and spread the word to any parent carers you know who live in East Sussex.

More fun with the West Sussex Compass



Continued from cover

Here's just a few of the new offers Brighton and Hove Compass Card holders can enjoy thanks to the recent extension of the Compass into West Sussex:

- Free gym use and free swimming for Compass Card holders at K2 Crawley.
- Special deals at five performance venues in West Sussex including Chichester Festival Theatre and The Hawth
- Discounts at three West Sussex bowling alleys, including Horsham Superbowl
- Discounts in the big outdoors, including Lodge Hill activity centre and Earnley Butterflies, Birds and Beasts near Chichester
- Taxi discounts from Hove & Adur Carcabs, ABCA Taxis Lancing and Star Cars in Crawley
- Health and fitness discounts at South Downs Leisure, Impulse Leisure, Arundel Lido, Mid-Sussex Golf Club and more
- Football club discounts in Crawley, Lewes and Worthing.

You can check out all the offers on the **Compass Card B&H app** – by far the most effective way of keeping fully up to date. We've added all the new shared offers to the app and you can take advantage of them straight away. Just go to Google Play or the App Store, search 'compass card' and download it today. And if you've got it already, make sure you've got the most recent version – we've made quite a few improvements in recent months. You can also see all the offers on the Amaze website at:

www.amazebrighton.org.uk/services-and-support/the-compass-card/compass-card-offers

Enter the Cloud Forest with Otherworld

Otherworld is coming to The Old Market (TOM) in Hove for its last Cloud Forest show run before returning in the autumn with a new theme, so make sure you don't miss it. This sensory jungle-themed environment brings together storytelling, immersive theatre, music, explorers, video and light technology and a range of jungle creatures to create an experience the whole family can enjoy - and there's a discount for Compass Card families.

Cloud Forest after school sessions are from 4 to 5pm on Weds 29th June to Fri 1st July and there are shows on Sat 2nd and Sun 3rd July all day, with a Cloud Forest Immersive Cinema Event from 6 to 7pm on the Saturday. The Old Market is at 11a, Upper Market Street, Hove BN3 1AS. Book via The Old Market Box Office on 01273 201801, or online via www.theoldmarket.com



Buddies to help you get out

Two very different local projects, Farm Buddies and Gig Buddies, share a similar aim - to help people with additional needs to get out and about doing something they enjoy.

Farm Buddies puts people with additional needs together with local farms where they can work one day a week on regular farm jobs like animal care, under farmer supervision. The atmosphere is relaxed and inclusive and suitable for anyone with mild or moderate additional needs aged 9-90. Participants get fresh air and exercise whilst gaining confidence, self-esteem and skills. For more details, visit www.farmbuddies.org.uk.



Gig Buddies is a Sussex-based project that pairs up local people with and without learning disabilities (and/or autism) to be friends and to go to events together, especially live music. Volunteers go to gigs they'd probably be going to anyway, but with someone with a learning disability. And they get to share their passions and make strong friendships. To find out about getting a Gig Buddy or becoming one, contact Stay Up Late on 01273 468168 or visit www.gigbuddies.org.uk.

Mums' lunches, sibling camps and a social space for the whole family

Sally Howell from Brighton Pebbles tells us about all the things the parent support group is organising for local families with kids with additional needs.



Siblings enjoying the outdoor life at last year's Pebbles camping trip just for them.

Brighton Pebbles is a group that supports the whole family, not just our children with special needs. Our main activities are things that the whole family can do together in a safe, non-judgemental environment – this includes a weekly drop in session, days out and holidays. But we also plan activities just for siblings so that they can spend some quality time with their parents and other children with similar life experiences. We even plan activities for parents, such as regular 'Mums' lunches' (open to Dads too!) and an upcoming Mums' weekend away at the lovely Micklepage farmhouse near Horsham."

Mums' lunches on tour

Our Mums' lunches are a regular event on the first Tuesday of every month (except during school holidays) and they're usually held at the café at Emmaus in Portslade. We've decided to trial taking our Mums' lunches "on tour" to see if we can attract parents from other parts of the city. Our next two are on

- **Tues 7th June** at Brighton Garden Centre at the **Race Hill** in Brighton
- **Tues 5th July** at the **Pebbles Beach Hut** (near Carats Café)

Come and join us from 12 noon onwards. We really look forward to meeting you.

Siblings' camp

Following the success of last year's Pebbles siblings' camping trip, we are planning another trip this year during the summer holidays. We're also planning a camp for the whole family so that our children with additional needs also get a chance to experience camping. To make this work we are planning that camp over a weekend during term time, so parents can go along on the Friday to set up the camp first, and then bring the children after school so it's all ready for them. On the Sunday everyone will just leave in the evening and then once the children are safely at school on Monday, parents can go back and clear up.

New outside play space

Our regular weekly drop-in sessions are at the Manor Gym in Whitehawk on Friday afternoons from 3 to 6pm. Whilst there is a big sports hall at the gym for children to run around in, one thing that has always been missing is a safe, enclosed outside space. Some time ago, we were granted some capital funding from Brighton & Hove City Council to create this space and we're now pleased to report that the project is actually happening very soon, ready for the summer sunshine! There will be a totally enclosed fenced area of soft playground surface which will be accessed from the sports hall. It will give the children the freedom to move from inside to out and back independently and safely.

"There will be a totally enclosed fenced area of soft playground surface which will...give the children the freedom to move from inside to out...independently and safely."

Lastly, we are pleased to say we are now official! Brighton Pebbles was set up in 2008 as a parent led community group and whilst we've gone from strength to strength during this time, we have only just actually registered as a charity. To join our mailing list and find out what we have going on, email brightonpebbles@tiscali.co.uk, ring Lisa on 07506 105265 or visit www.brightonpebbles.org.uk for more information.

To claim or not to claim: how to handle DLA reviews

Claiming DLA first time round can be tough. Then, just as you've got used to the extra money, your award comes up for renewal. Have things changed? Should you claim again? What will the DWP expect this time?

Remember why you need the money

Some of us buy in extra speech, physio or occupational therapy or counselling. We may use it to pay for equipment, special toys, our child's hobbies, extra after-school or holiday activities. Our child's DLA might keep the house warmer for longer, buy special foods, replace clothes or pay for train fares to appointments. We've been able to spend the money in whatever ways we think will best promote our child's health, family life and wellbeing.

Just as important, the extra income means we may be able to do less paid work and have more time for our children. We doggedly get up at night to return a child to their own bed; we rise earlier so there's plenty of time to practise buttons; we eat together to show our child once more how to hold their cutlery. We become adept at building 'therapies' into everyday activities, adapting our communication and problem solving. Most of all we are actively teaching skills other children pick up effortlessly; this practice and reinforcement happens many a times a day, often over years.

Don't be afraid of change

Because children are extraordinary and because our patience, work and extra effort pays off, the difficulties many have as a younger child may begin to resolve. The DWP too, will be expecting things to have changed. So, when a DLA claim pack hits your door mat, for the second or third time it might be harder to identify what is

extra or different about the help your child needs now.

Newly emerging needs might be more subtle and harder to write about. As one parent put it, *"It was easier to write at five years old that Sam can't carb count or manage his insulin than explain that his sense of invincibility at 13 is not enough to keep him safe from a hypo"*.

But don't be put off. The only reason not to claim again is if concerns about your child have all but disappeared.

Put the effort in

Put as much, if not more, effort into claiming this time as you did first time round. Use your child's previous claim to work from and amend it. Use this time to gather up to date reports and assessments. Treat a DLA review as if it is a new claim and 'tell it how it is'.

Say as much as you can about the extra help your child needs. This may be hands on practical help, but just as important, is all the prompting, encouraging and extra explaining you do. The other aspect of 'looking after' is watching out for, anticipating problems and being ready to intervene in situations where other children the same age would be cautious and able to keep themselves



safe. If you aren't sure what it's reasonable for your child to do for themselves or take responsibility for, make comparisons with what you expect of their siblings, or ask other parents.

Plan ahead

Think about how you will manage without the extra money too either now or further into the future. Many young people who get DLA as a child will not have needs significant enough to be awarded Personal Independence Payment at 16. And if they are, when your son or daughter leaves home, they will take their disability benefits with them.

Once your child reaches 14, it may be worth beginning to think about returning to work. Use school hours to access courses, training, voluntary or some paid work. Give yourself plenty of time to plan for a household budget that does not include your child's DLA and other 'passport' benefits.

For further advice and information about DLA Reviews, call our helpline on 01273 772289 or email helpline@amazebrighton.org.uk

Amaze workshops on DLA Renewals and claiming PIP

Get ready for your DLA review: Tues 28th June, 10am to 2pm

PIP and post-16 benefits: - Thurs 6th Oct, 10am to 2pm

Both workshops take place in the Conference Room at Community Base, 113 Queens Road, BN1 3XG. The sessions will be run by our DLA Project Manager, Lizzie Batten. Light lunch will be provided. Book your place early by calling 01273 772289 or emailing info@amazebrighton.org.uk



A good year for the PaCC

This year has been PaCC-ed with more vital work gathering and sharing your views and celebrating our lives as parent carers. We thought we'd take a moment to celebrate our best bits.

More members

We were delighted to see our **membership rise** to 285 in 2015/16 and we hope it grows yet again this year. If you'd like to join the PaCC, just email admin@paccbrighton.org.uk

New team structure

2015 saw the 10- strong PaCC steering group vote to restructure our core team. Fiona England (Chair), Diana Boyd (Vice Chair), Paolo Boldrini (Participation Officer and Outreach Worker) and Jo Levi (PaCC Administration and Communications Assistant) form PaCC's new structure, working alongside our very active steering group.

At the heart of shaping change

As many of you will know, two big education transformations are underway in Brighton and Hove: the **redesign of special school provision and the redesign of specialist outreach** to mainstream schools. From board level meetings to PaCCConnect parent events, our reps have been very busy making sure your voice is heard where it counts.

PaCC has been broadly supportive of the intention of these two redesigns. We supported the plan to merge buildings and management teams into 'integrated hubs' (see overleaf), but we also expressed serious concerns about the potential loss in specialisms from the EP/LSS restructure and we stated clearly that we did not support any reduction in the numbers of frontline staff. We

wrote full '**position statements**' on the SEND proposals which we hope reflect your views and can help shape the future of SEND services in the city.

January and February 2016 also saw the PaCC team write a position statement on Brighton and Hove's **proposed budget** for the next financial year. PaCC worked closely with councillors and local authority managers and, as a result, we were very pleased to see a reversal of a cut to the social care budget. PaCC will continue to work with the council to look at social care provision in the city. Read all our position statements at www.paccbrighton.org.uk/what-we-do/pacc-connect-events

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Focus on mental health

This year PaCC worked closely with the local Clinical Commissioning Group (CCG). As part of Brighton and Hove's five-year Mental Health and Well Being Strategy, we ran a mental health focus group with steering group members, commissioners and senior managers in the city and then held a **PaCC Connect forum on mental health** for parent carers - more about this overleaf. Our key partners (Extratime, Scope Face 2 Face, Barnardos Link Plus, Kaleidoscope, Pebbles, Mascot, T21 and Sweet Peas) were also very active in helping us to give feedback to the CCG.



PaCC's 2016 calendar featured photos and stories about our children and their best friends.

Celebrating our families

Alongside our strategic work we also made time to celebrate the lives of parent carers and their families and supporters in Brighton and Hove.

Our **PaCC 2016 calendar** featured wonderful photos and stories about our children and their best friends. Huge thanks to our PaCC rep, Pippa Hodge, for pulling all the photos and stories together for the calendar. And at the Amaze Info Fair in November, we recognised and celebrated some of the outstanding local professionals who work with our children at the **PaCC Award ceremony**, presented by Tom Bewick, Lead Councillor for Children's Services.

Finally, we were delighted to see the extension of PaCC community outreach work in the city. A **third coffee morning** for parent carers is now up and running in Whitehawk, alongside the established Hangleton and Knoll and Moulescoomb groups.

We couldn't have done any of these amazing things without your support and feedback. Thank you all very much and we look forward to hearing more from you in the coming year. Visit www.paccbrighton.org.uk



Involving all our communities

We want to improve the way we represent parent carers and we are aware that there are some people in Brighton and Hove whose needs and views have not been as well heard or as visible as others. Thanks to some small funding from Healthwatch Brighton and Hove, we recently spoke to Black, Asian & Minority Ethnic (BAME) parent carers, to hear their stories and experiences and to find out how to better engage and include them in what Amaze and PaCC do. Recommendations were collated into a report which you can download at www.paccbrighton.org.uk/resources/reports

Some of the recommendations in the report include:

- **a more culturally sensitive approach to what PaCC and Amaze do** – better awareness of how disability is seen in different

communities and practical changes such as more use of interpreters or translation. One parent commented, "I haven't experienced barriers in accessing health and social care services but it is difficult for those who can't access English."

- **a more visible PaCC and Amaze presence at Brighton and Hove's BAME events** such as Black History Month or Refugee Week. As one parent suggested "Reaching out to the community? ...They won't go to you. Things like DLA, they won't know about Amaze. You need word of mouth and to publicise Amaze's benefits"
- **involvement of BAME parent carers in creation of Amaze and PaCC information** to reflect their needs and engage them in an appropriate way



- **greater engagement of BAME parent carers in PaCC**, for example having a BAME parent sitting on Steering Group or providing interpreters at events
- **more partnership working with local BAME organisations**

"You need word of mouth and to publicise Amaze's benefits"

During the next few months we will look at the recommendations in the report and start working more with parent carers and organisations that provide support to BAME communities.



PaCConnect on Mental Health

At the end of April, we held a PaCConnect forum to update parent carers on the latest developments in mental health locally. Gill Brooks, Commissioning Manager for Children's Mental Health and Wellbeing, gave an overview of recent improvements which include the welcome addition of new mental health support workers employed directly at the Royal Alex Hospital,

three secondary and eight primary schools across Brighton and Hove. After receiving much needed funding, CAMHS is also working to improve waiting times, which we know is a major concern for parent carers.

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At the meeting parent carers were also given the opportunity to discuss their concerns with key professionals.

Issues raised included the need for a clear pathway of support for children with SEND, the gap in mental health provision for children who are not eligible for support from the Learning Disability Team and the need for a key point of contact when awaiting assessment.

Although some progress has been made, PaCC is aware that there are still many shortfalls in the service. We will continue to represent parent carers on the CAMHS Partnership Board and keep discussions open between mental health professionals and parent carers.

To read the 'Children and Young People's Mental Health Transformation Plan 2015-2020', visit www.brightonandhoveccg.nhs.uk/plans



Update on restructure of Educational Psychology and Learning Support Services

The proposed restructuring of the city's Educational Psychology and Learning Support Services (EP/LSS) announced last year has been very controversial. More than 10,000 people signed a petition against the proposed changes and opponents featured on local radio and TV. Because of the strength of feeling about the proposals, the council decided to broaden what was originally just a staff consultation to include everyone who might be affected by the changes.

PaCC held a forum to discuss the proposals in March and, together with Amaze and other parent representatives, we helped analyse the responses to the consultation, which led to a revised proposed structure for the EP/LSS. We also joined the Stakeholder Group which advised and reviewed the new proposals. These are the most important changes to the restructure as a result of the wider consultation:

- More teachers will remain in the Learning and Communication team, which means a smaller increase in support staff in the Social, Emotional and Mental Health team
- There's an agreement to maintain a number of staff with specialist expertise in key areas, e.g. autism, sensory impairment and speech and language
- Teaching staff will remain on teachers' pay and conditions, but specialist teachers will be expected to do some work out of term time.

There's an agreement to maintain a number of staff with specialist expertise in key areas, e.g. autism, sensory impairment and speech and language.

PaCC also met with Mary Daly, an independent consultant appointed to review the proposals, assessing (among other things) whether they would improve outcomes for children and young people. Mary's report acknowledged some risks with the restructure but concluded that "the amended proposals will enable a more effective service to the families and children and young people with SEND in Brighton & Hove."

The final structure of the unified EP/LSS was agreed at the Children and Young People's Committee on 7 March, and is on track to be in place by September 2016. You can find this final structure and Mary Daly's report on the council's website in the Council and Democracy section. Or you can access the report here: <http://tinyurl.com/jxudo43>

Make your views count. Join the PaCC by emailing admin@paccbrighton.org.uk or tell us what is concerning you at www.paccbrighton.org.uk/get-involved/give-us-your-views
You can also join our closed Facebook group at www.facebook.com/groups/parentcarerscouncil



Making cancer care work for you

As part of our ongoing work with the local Clinical Commissioning Group (CCG), we recently asked you how cancer services could be more responsive to your needs.

You told us that not having time to attend appointments, due to caring for your child, was the biggest barrier you faced to timely screening. To address this, parents who completed our consultation said they'd like to be offered **appointments at more suitable times**.

On cancer prevention, you told us that **"positive and engaging messages – not scaremongering headlines"** – should be displayed in GPs, newspapers and magazines, social media and on TV.

You suggested that post-screening support could include **bespoke counselling** that takes into account the fact parent carers will have to carry on looking after their child with additional needs. And you'd like to see an **improved cancer care system** which is easier to navigate.

Your ideas, comments and suggestions have been fed back to Brighton & Hove City Council and CCG. These will be taken into consideration while drafting the CCG's new five year plan which aims to improve cancer diagnosis and offer the best provision of cancer medical care. Read the full report at www.paccbrighton.org.uk/resources/reports



Latest on integration of special schools from PaCConnect forum

The council are proposing to integrate Brighton and Hove's six special schools and two pupil referral units into three school 'hubs'. The idea is to create one hub that focuses on social, emotional and mental health and the other two on learning difficulties. These developments have created many questions among parent carers.

To help address your concerns and discuss these proposals, we held a PaCC Connect on 16th March where we invited professionals from the council, the head teachers of three special schools, along with parent carers.

Parents said they were worried about the upheaval these changes may create for their children, and worried about whether their child would be placed in an inappropriate school. They also raised concerns about the loss or dilution of specialisms (see the piece on EP/LSS restructure on page 9) and specialist classes and about mixing children with conflicting needs. There was reassurance from the council that the schools themselves would be making the decisions about class placements and that each case would be dealt with based on an individual child's needs. Discussion with parents was considered paramount at every stage.

The changes will be phased in over four years and the idea is to share specialisms rather than dilute them. Staff numbers will remain the same as will the number of places available - there may even be more. The council held an online consultation that ended on 22nd April, however consultation is still ongoing and PaCC will keep parent carers up to date on any further changes or developments.

If you are a parent carer who is worried about the changes or has a question for the council then please email the SEND team at sendreview@brighton-hove.gov.uk

How fair is Brighton and Hove for you?

Launched in September 2015 – The **Fairness Commission** was formed to look at ways to make Brighton and Hove a fairer and more equal place to live. Although it was set up by the council it is an independent body. To read more about the Commission visit www.brighton-hove.gov.uk/content/council-and-democracy/fairness-commission.

PaCC held a PaCConnect on 24th February for parents to feedback their ideas and contribute a report to the Fairness Commission. This included problems and possible

solutions for the unfair situations that exist for parent carers and their children. These issues included a lack of affordable and appropriate childcare available to working carers, lack of support and respite and general concerns about the cuts to already dwindling services.

To read PaCC's report visit www.paccbrighton.org.uk/resources/reports. The Fairness Commission will publish its final report and recommendations soon, so watch this space.



Green fingered fun for parent carers

The Magic Garden is a **community allotment for parents and carers** of children with disabilities and special educational needs situated in the Lower Roedale Allotments site, Hollingdean. It is funded by Brighton & Hove Food Partnership, the Sussex Community Foundation and the Mental Health & Wellbeing Innovation Fund.

You don't need to have experience or knowledge about gardening and growing vegetables to take part, as the friendly and knowledgeable Anna is there to guide and support you. Anna says 'The garden is a space for you to enjoy, you can come every week or just drop in when you can'.

The garden is open **every Friday during term time**, from 10am to 12noon. You can call Anna in advance on 07964 722979 or email magicgardenbrighton@gmail.com and arrange to meet at the main gate for Lower Roedale at 10am.

So if you've ever wanted to try a bit of digging or planting, get down to the Magic Garden at Plot 13, Lower Roedale Allotments (just off Lynchet Close) Hollingdean BN1 7FP (the number 50 bus goes there). Gardening is great exercise and brilliant for your mental health and wellbeing. It helps you relax, get some fresh air while meeting other people, and don't forget all that free salad!

For more information, visit www.facebook.com/groups/magicgardenallotment



BSMQ boys are box office gold

A huge shout out to the guys at the **Big Screen Movie Quiz** for raising **£523** at their annual movie trivia extravaganza at Komedia. Finding Deano, Independence Dave, Texas Jamesaw Massacre and Eddie Kruger kept 35 teams royally entertained with a hilarious mixture of filmed rounds and comic business and they threw in some amazing prizes, including a raffle to win two flights to New York. Sadly the Amaze team didn't win - we must bone up on our movie knowledge for next year - but our £523 is prize enough. Thanks BSMQ! For more information on the quiz visit www.facebook.com/BIGSCREENMOVIEQUIZ

Our running heroes



Jagger Peggs at the Mini Mile finish line.

Thank you to our team of heroes who ran this year's Brighton Marathon and 10k back in April. In glorious sunshine, they pounded the streets of Brighton cheered on by record crowds of enthusiastic locals.

Greg Hewitt, Stephanie Faint, Reuben Young, Chris Sethi, Julius Brinkworth, Paul Clare and Aisling Crean

completed the Marathon; Clodagh Warde, Shell Teague, Zara Arnold, and Ian Peggs ran the 10k and, last but not least, 7 year old Jagger Peggs smashed the mini mile for us.

We must also say a special thanks to Team Peggs, including Greg, Ian and Jagger, who have collectively raised over £14,000 for Amaze this year from a number of races. Ian and Laura Peggs have used Amaze services over the years for their autistic son and wanted to go the extra mile for us.

Could you run for us?



Aisling Crean and Paul Clare near the finish.

Don't miss...

Paddle Round the Pier – July 2nd–3rd

We're delighted to have been chosen as one of Paddle Round the Pier's local charities for 2016. The renowned beach front festival, run entirely by volunteers, has raised over £300,000 for charities so far.

Can you help over the weekend?

Amaze is looking for volunteers to shake fundraising buckets, help at the disabled access beach or even get involved in building your own raft. For more information, see www.paddleroundthepier.com or email nickyb@amazebrighton.org.uk



Clinique Pamper Night – 9th June

Enjoy a night of pampering at Clinique, in Boots, North Street on Thursday 9th June all in aid of Amaze. You'll get advice from the experts, gifts and discounts and a chance to try the latest products. Why not bring a small group, enjoy some bubbly and relax for the evening? Tickets cost £15 which includes £5 off purchases. This event is always very popular so please reserve your space soon.

Wanted! Fundraising volunteers

We are looking for volunteers to get involved in all types of fundraising from cheering at running races to staffing events, forming a committee or learning some new skills in our office. If you have some time on your hands or are interested in pursuing a fundraising career please get in touch with Nicky (see left).

For all your fundraising enquiries, call Nicky B on 01273 234014 or email nickyb@amazebrighton.org.uk

Getting support with finding employment

Jan Hickley tells us about Supported Internships and how a course at Plumpton has helped her son Brandon, 24, to get into the workplace.

"Last year my son Brandon was thinking about finding work when we heard about a course that might help. The course is called 'Supported Internship' and will be starting again in September at Plumpton College. Depending on experience, it's a one or two year course for young people aged 17 to 24 with a learning disability who would enjoy the benefits of employment. No specific qualifications are required as long as they have an EHC (Education, Health and Care) Plan or Statement of SEN, and students study English and Maths alongside their other sessions.

"The first few months of the course are in college. You spend three days a week getting to know the group, going out and about, learning basic job skills such as writing CVs, interviews, etc. and having lots of visits from employers. Then in the latter part of the course the intern, as they are called, is prepared for an individual placement in an unpaid role that suits their interests. From the beginning of the second year, the intern spends up to six months based with that employer and a college staff member is with them for support as long as they need it. The whole idea is that they may be offered paid employment at the end. Even if they don't stay there, they get a great reference and have proper work experience to show another employer.

"Brandon is working two days a week for Brighton & Hove City Council in the Town Hall Register office,

supported by Clare from college and the other two days he's doing his course at Plumpton.

"At first he was rather nervous about the whole idea. We even had to go out and buy him some office wear as his 'rock' and 'skull' T shirts, jeans and biker boots might not have given the right impression! On his first day I took him along to the Town Hall and met up with Clare from the college and Paul from the Register office who made Brandon (and myself) feel very welcome.

"At first I didn't think I was capable of performing the tasks but I've been told I'm doing a great job and the staff like my handwriting"

"Brandon is based in the Search Room. His work involves sorting and processing replacement Birth, Death and Marriage certificates. Occasionally he hand writes certified copies of marriage certificates too. This requires a great deal of concentration as it is a legal document. "



Brandon at work in Brighton Register Office.

Brandon says: "At first I didn't think I was capable of performing the tasks but I've been told I'm doing a great job and the staff like my handwriting".

Hannah and Emily at the Register office are really pleased with how it's going too: "Brandon has improved his skills since he started work here and the quality of his work is brilliant. It's a pleasure to work with him as he is polite to all members of staff and his attendance and punctuality has been fantastic". And Clare, his support worker from college, says: 'I am full of admiration for his determination and developing resilience. The commitment and effort Brandon has shown have been really rewarding to observe. Despite finding aspects of the work challenging at times he has kept going, which is a valuable learning experience in itself.'

To find out more about the Supported Internship course, call Mel Simmonds on 01273 892108 or email her on jobcoach@plumpton.ac.uk. For any other information about this article, you can email janhickley99@hotmail.com

Say yes to NCS!

Tedd Giles tells us about taking part in the National Citizen Service and why he'd urge other young people to do it too.



"My time at NCS was incredible fun. We had two introductory sessions at Brighton Youth Centre as an ice-breaker. I was between leaving school and starting college and was scared about not knowing anyone. Honestly, it was a bit awkward at first, but it got easier to talk to people after 10 minutes.

"On our first week as a team we went to Wales for the team building session. This was a lot of fun as it really pushed our boundaries, and brought the group together. We did rock climbing, gorge walking and tug-of-war - it was really cool.

"Week two was at Sussex University. We edited footage we'd filmed from the first week. Our video was

awesome, thanks to a genius on our team!

"For week three we helped plan and organise leaflets and flyers for Trans Pride. Some of us helped organise the event and others made leaflets and spread info all over Brighton. I was on the sub-team for the leaflet and poster creation. The first time we messed up some names and had to redo everything! We worked really hard at this.

"NCS has been one of the best experiences of my life and anyone who doesn't go is really missing out!"

"On our final week we helped set up the stall, made bunting and a balloon arch in the colours of the Trans community, and also ran a clothes swap and a cake stand.

NCS has been one of the best experiences of my life and anyone who doesn't go is really missing out!"

What is the National Citizen Service?

The National Citizen Service is a once-in-a-lifetime opportunity for 16 and 17 year olds (and up to 25 for young people with SEND) to spend four weeks learning new skills, making friends and having fun. Running in the spring, summer and autumn, young people have a short time away from home and take part in a team project that will help their community.

NCS brings together young people from different backgrounds and helps them develop greater confidence, self-awareness and responsibility, as well as working on skills like leadership, teamwork and communication.

It costs just £50 and there is a bursary if you can't afford it. Brighton NCS is based at Albion in the Community at the Amex Stadium. To find out more, call the NCS on **01273 878220** to have a chat about the support they can offer and to book for the summer programme.



Healthy cookery course for 18-25s with SEND

This free one-day cookery course, run by the Big Fig, is all about teaching young people how to eat healthily. They'll plan a healthy meal and help to prepare it. And at the end, they'll get photos of their meal and a copy of the meal plan to use again. The six-hour course is tailored to meet the needs of young people with SEND and takes place on **Thurs 4th August 2016** in the Conference Room, Community Base, 113 Queens Road, Brighton BN1 3XG. To book a free place contact the Amaze helpline on 01273 772289 or email info@amazebrighton.org.uk

Year 9 booklets for you

Amaze has booklets for both young people and their parent carers full of helpful advice about what to expect at Year 9 annual reviews. They cover transfers from Statements to Education, Health and Care (EHC) Plans and how reviews from Year 9 onwards should start to focus on planning for your child's future once they leave school. If your child already has a Statement or EHC Plan, both booklets will be sent to your home via the local authority.

Amaze is also running **Preparing for Adulthood Info Sessions** which will look at these Year 9 reviews on **6th and 12th July** and on **14th and 21st September**. See the back page for more details.

Call the Amaze helpline to book your free place: 01273 772289 or email info@amazebrighton.org.uk





Summer fun sorted

School summer holidays can seem like an awfully long time for mums and dads, and finding things to fill the days with can be harder if your child has additional needs. This run down of inclusive play schemes and activities should give you plenty of ideas and help get your summer sorted sooner.

Inclusive schemes

Extratime (5 years+)

Mon 1st to Fri 26th August at Ash Cottage, Woodingdean and Hillside School, Portslade. 8.45am to either 3.30pm (£19) or 5.30pm (£21). Fully inclusive play scheme offering one-to-one support if required. Also at St Luke's Primary School (5-11s). A long day here costs £22. You can visit www.extratimebrighton.org.uk or call 01273 420580 to book.

Special schemes

Cherish (16-25s) Tues to Fri, 2nd to 26th Aug, 10am to 4pm. Mini-bus based days out for young people with learning disabilities. One to one support. 16 to 18 year olds pay £17 (£12 concessions) per day, 19-25 year olds pay £45 (Individual Budget) or £25 (DLA only rate) Call 01273 295171/ 295530. Booking forms are available from 30th June.

Extratime (11-19s)

Mon 1st to Fri 26th August at Crew Club, Whitehawk and The Village Centre, Portslade. 8.45am to 5.30pm (£23). Youth schemes for young people with disabilities, offering one-to-one support if required. Call 01273 420580 or visit Extratime's website at www.extratimebrighton.org.uk to book.

All special and inclusive play schemes book up quickly, so contact them early to make sure you get a place.

Parent led social groups

Most parent-led groups for kids with additional needs continue over the summer and many of them organise holiday outings or activities. If you attend groups like **Brighton Pebbles**, **Mascot**, **Kaleidoscope** or **T21** it's worth finding out what they are doing over the summer. You can find out what

the Pebbles gang are doing on page 5. You can call the Amaze helpline to get details of local parent support groups or visit www.amazebrighton.org.uk/services-and-support/parent-support-groups

Further info

Amaze's has two fact sheets about leisure: **'Fun things to do'** lists oodles of local leisure activities and **'Leisure'** gives advice and tips on how to choose and settle your child into an activity. You can download them at www.amazebrighton.org.uk/resources/publications/fact-sheets. And don't forget to check out the latest leisure offers attached to the **Compass Card** (see page 4).

Every summer, the council also publishes **'Summer Fun'**, a colourful booklet stuffed with ideas for things to do in the summer for kids with and without additional needs. Look out for it in your children's book bag or you can find a copy in your local library or leisure centre. Also, the **Local Offer**, Brighton & Hove's online listing of services for children and young people with SEND, has information about leisure activities and schemes. Visit www.brighton-hove.gov.uk/localoffer

Finally, you can do your own research for regular and one-off activities and events at local listing websites www.kidsinbrighton.co.uk or www.childfriendlybrighton.co.uk

If you have any questions about leisure or childcare, call our helpline on 01273 772289.



Ask an expert

This issue's experts are Philip Warford of Renaissance Legal and Ros Cook, Services Director for Amaze.

"My husband and I have a 10 year old daughter with SEN and we know that we need to make Wills. We can't decide who should be her guardian as we feel it's a lot to ask someone to take on. What should we do?"

Philip says:

"A guardian is someone who will take on the caring role for your daughter should you and your husband die whilst your daughter is under 18. The guardian doesn't really need to be financially astute, it's the care of your daughter which is important.

"It's very common that parents of a young child who can't decide on who should be their child's guardian end up ignoring the issue and do not put the appropriate plans in place. The risks of not tackling this issue is that if the worst did happen, there could



be family arguments and uncertainty for the child at a difficult time. It is also likely that the Court would need to be involved to appoint an appropriate person to care for the child.

"The only way to avoid potential problems is to choose the guardian you think is suitable and would carry out your wishes for your daughter's future. Here's a few points that might help you make this decision.

"The guardian will make all the decisions relating to the child, such as where they live, education and medical decisions. Any person who has Parental Responsibility (PR) for the child can appoint a guardian. It's worth noting that the mother automatically has PR but a father who is not married to the child's mother may not automatically have PR.

"Any individual can be appointed as a guardian, and you can appoint more

than one to act as joint guardians. It is usually best for parents to agree on who to appoint as a guardian. If there are different guardians appointed, be aware that only the guardian of the second person to die will take up the position. You must appoint a guardian in writing, signed and dated so a Will is often the best way to do this.

"You can also include conditions in a Will. For example, that a guardian can act until your daughter reaches a certain age or that a substitute guardian can be named if the original person can't act. You can also ensure that the financial aspects of your Will are aligned with the appointment of a guardian to allow money to be available to assist them with bringing up the child.

"If you want any more advice around this issue, why not come along to the **Wills and Trusts workshop** I'm running with Amaze on **Tues 29th November.**"

For individual legal advice call Renaissance Legal on 0845 505 60 50 or visit www.renaissancelegal.co.uk NB: If you show your Compass Card, you can get a 10% discount on fees at Renaissance Legal.

"My son will change school in September and I am a bit anxious. What can I do to make it go well?"

Ros says:

"Of course you are worrying. We all do when our child has to start somewhere new. But most children adjust and settle in just fine. I am sure you are making sure he doesn't pick up on your nerves. Sound positive and confident that he will enjoy his new school, but leave room for him to say if he has any worries of his own.

"Before the start of the holidays ask his current teacher and Senco what information they have shared with the new school and what



transition activities they are doing. This should be reassuring but if you think your son needs an extra visit it's not too late to ask. The Senco at the new school won't have a lot of time to talk to you before he starts but make sure you have their name and contact details. Email can be a good way to contact secondary school staff as you don't have the face to face contact you have at primary school. Check which other children are going to the same school even if they are not close friends. During the summer you could try to meet up with another child moving to the same school.

"What else would be helpful to do over the summer? It depends on your son's individual needs but here's some ideas. Practise the journey to school.

Get his new uniform early so he can try it on and get comfortable. Do you need to remove scratchy labels or practise buttons or a tie? Make sure he understands what a timetable looks like and how it works. Look at the school website together. Often they have photos of staff and buildings. Look for a list of clubs and activities; pick out one for him to join early on. Make sure he knows the lunch arrangements and where the loos are.

"In the last week of the holidays get into a good routine so he is ready for early mornings and won't be too tired. Then send him in with a big smile and cross your fingers!"

Coming soon

Understanding EHC Plans

Weds 15th June, 10am to 1pm at Amaze. A session run by Liam and Debbie for anyone about to request assessment for a plan or who is coming up for a transfer from a Statement to an EHCP.

Get ready for your DLA review -

Tues 28th June, 10am to 2pm at Amaze. Lizzie will explain how to prepare for and complete your child's DLA renewal. How can you get ahead and make sure you have a strong claim?

Preparing for adulthood in Year 9 Reviews

Weds 6th July, 10am to 12 noon and Tues 12th July 6.30 to 8.30pm at Amaze. Session run by Debbie and Sally for parents of children moving into Year 9 with a Statement or EHCP. **AND....**

14th Sept, 10am to 12 noon and Weds 21st Sept, 6.30 to 8.30pm at Amaze.

PIP and post-16 benefits

Thurs 6th Oct, 10am to 2pm at Amaze Lizzie will guide you through the process of claiming PIP. What's different from DLA and what else should you know about benefits after your child turns 16?

Planning for the future, Wills and Trusts

Tues 29th Nov, 10 to 12 noon at Amaze. Phil Warford from Renaissance Legal makes this complex subject easy to follow.

PLUS Triple P Stepping Stones and Insiders' Guide courses in the autumn, details to be confirmed.

All these workshops and courses are free and take place at Community Base, 113 Queens Road, Brighton BN1 3XG. To book a place or find out more call 01273 772289 or email info@amazebrighton.org.uk

Does your small group or charity need support?

If so, Wellesley Charitable Foundation may be able to help.

Wellesley Charitable Foundation is the charitable arm of Wellesley Wealth Advisory, a financial services company based in Burgess Hill. Wellesley Charitable Foundation aims to provide support to children in the Sussex area, with a particular interest in health issues and creating opportunities for improvement through sport.

Wellesley is already supporting local charities like Amaze, Extratime and Whoopsadaisy.



Wellesley would be pleased to hear from **smaller charities or individuals** who feel they could benefit from their support. Call 01444 244551 or email lynnf@wellesleywa.co.uk to find out more. Or visit www.wellesleycharitablefoundation.co.uk for further information.

Our thanks

A big **thank you to Brandwatch** for supporting our recent parent carer information survey by donating an iPad Mini as a prize. Their huge generosity meant that we got lots of really useful responses to the survey. **Could your company donate a prize?** If so contact nickyb@amazebrighton.org.uk

We'd like to thank **Wellesley Charitable Foundation**, the charitable arm of Wellesley Wealth Advisory, Sussex-based financial advisers, for its contribution towards the costs of producing this newsletter.

Wellesley Charitable Foundation helps ill or disadvantaged children and their families in Sussex and the surrounding counties. For more information, visit www.wellesleycharitablefoundation.co.uk



We'd also like to thank Brighton & Hove City Council for its vital funding of our information products.



Amaze helpline:

For information, advice and support, call 01273 772289. Monday to Friday, 9.30am to 2pm, Wednesday to 4pm



Amaze

Community Base
113 Queens Road
Brighton BN1 3XG
T: 01273 772289
E: info@amazebrighton.org.uk
W: www.amazebrighton.org.uk

