

out of amaze



For parents of children with additional needs in Brighton & Hove

Amaze wins national health impact award



Amaze CEO, Rachel Travers, and Chair, Hugh Clench, accepted a GSK Health Impact award on behalf of the whole Amaze team at a glittering ceremony on 15th May at London's Science Museum. The award is in recognition of our work to help improve the lives of parent carers of disabled children and children with additional needs in Brighton and Hove. Read more on page 15.

SEND Changes – what do you need to know?

Come along to this event organised by Amaze and the council's SEN team on **17th July** from 9.45am to 2.30pm at the **Brighthelm Centre** and find out all about coming changes to SEN and disability.

September 1st is the deadline for the planned changes to the special educational needs system. At this joint event for parents and SENCOs, Amaze and the SEN team will try to answer all your questions and help you to understand what the coming changes mean for you and your child. Read all about the changes on page 4 and get full details of the event on the back page.



TAKEPART wants you!

The 2014 TAKEPART Sport and Physical Activity Festival has more on offer for disabled children, young people and adults than ever before.

Back in 2010 a dedicated special needs area called the Amazing Zone first appeared at the Launch Day of the TAKEPART Sport & Physical Activity Festival in Preston Park. We've come a very long way since then and TAKEPART 2014 promises to be the best one yet.

The Amazing Zone will be back for the **Family Launch Day** in Preston Park from 12 noon till 5pm on **Saturday 21st June** and Amaze will be there with our new Compass Card guides and our most comprehensive 'Fun Things to do for all Ages' fact sheet ever.

We'll be telling families all about our latest **Compass Card Activities** and providing lots of inspiration and ideas, so make sure the date's in your diary.

There'll be lots of **taster sessions** in and around the Amazing Zone including All Ability Bikes, multi sport and athletics, football, cricket, table tennis, boccia, climbing wall, zumba, sound tennis for the visually impaired and wheelchair rugby.

Turn to page 6 for further details about the Launch Day and the two week festival.

INSIDE: SEND Changes • DLA appeals • Carers Week special • New Compass Card Activities • Mental health survey • Making college work and much more...

Let's have an amazing National Carers Week!

Caroline Lucas, MP for Brighton Pavilion, talks about her work to strengthen the rights of carers in new legislation and urges us to celebrate the contribution that carers make to our community as a whole.



Caroline Lucas outside the Houses of Parliament.

This week marks National Carers Week which highlights the vital role that carers play in every community across the UK. I would like to take this opportunity to add my thanks to every carer for the invaluable work you do and also thank the staff and supporters of charities, like Amaze, who support them.

As MP for Brighton Pavilion, I meet many people doing amazing things for the good of our local community. Some of the most inspiring people I meet are carers. They care, often daily, for loved ones – usually with little or no respite or recognition.

It's my privilege as an MP to be able to speak on their behalf direct to government. It's essential that carers' voices are heard and that they get the help they need and deserve. I lobby Ministers on the rights of all carers – and will continue to do so.

Most recently, I've been pressing the government about important omissions in both the Children and Families Bill and the Carers Bill, around the protection of the legal rights for carers of children and young adults (see the news story on page 3). This is not the only gap; the Bill penalises

young carers by only offering support to those undertaking substantial amounts of care on a regular basis – a requirement that it removes for adult carers.

Providing carers with the support they need is their right and our responsibility. Yet Amaze found that around 70 per cent of carers they surveyed felt completely or mainly alone in their caring role. Such a lack of support can have a devastating impact on the families involved.

It's crucial that carers get access to the support they need, and that we recognise and reward their work in our community. The work of charities like Amaze is crucial to ensure carers can access the support they deserve, and its own efforts were recognised at the GSK Impact Awards in May.

“Providing carers with the support they need is their right and our responsibility.”

I am delighted that Amaze won at this year's awards. It was one of only 10 winners from over 400 charities across the country who applied for GSK's UK community investment programme. Amaze won because of the real impact they are having on the lives of families in Brighton and Hove. The judging panel found Amaze makes a real difference to people's lives and they have helped give families with disabled and special needs children a voice and added that Amaze is a fantastic example of how a small community based organisation can provide valuable healthcare support for local families.

So this week, let's pause to remember, and to celebrate, the tireless work of the carers in our community and the groups that support them. Then let's press on to secure carers the rights they deserve.

Caroline Lucas, MP for Brighton Pavilion

National Carers Week shines a light on the UK's 6.5 million carers

National Carers Week (9-14th June) is the annual awareness campaign that celebrates and recognises the contribution made by people who look after someone who is ill, frail or disabled. The campaign aims to improve the lives of carers and the people they care for, and hundreds of organisations and individuals join in each year to raise awareness at a local and national level.

Would you like to get involved? You could do something simple like pledging your support online or something a little more daring like creating a PR stunt. You can get lots of ideas at www.carersweek.org/get-involved.

New Children and Families Act marks a victory for parent carers

On 13 March, the Children and Families Bill received royal assent, becoming the Children and Families Act 2014. The Act is the result of over two years' work trying to put the views of parents and carers at its heart.

The Bill had a last minute amendment to ensure that parents caring for a disabled child will be given the same right to support as those looking after a disabled adult.

Before this change was announced, parent carers seemed to have been left out of the legislation, falling through the gap between the Care Bill, which gives adult carers caring for disabled adults and older people enhanced rights, and the Children and Families Bill, which gives similar enhanced rights to young carers. Concerted campaigning from local and national parent carer charities like Amaze and Contact a Family was successful in getting the Bill



reworded to make sure that the rights of parent carers equal those of carers of disabled adults.

From September 2014, the new law will introduce a number of changes to how children and young people with special educational needs (SEN) are supported in schools and colleges.

Read more about the coming SEN changes on page 4 and come to our **SEND event on 17th July** (see page 16).

Scope gets creative about supporting parent carers



National disability charity, Scope, has come up with some creative new ways of improving the health and wellbeing of local parent carers.

Their new **'Sing For Joy' choir** is specifically for parents of disabled children and children with additional needs and all abilities are welcome.

So, if you love to sing, why not go along to a free session with vocal coach Juliet Russell of Vocal Explosion on 11th June at 7.30pm (venue to be confirmed). They are also launching a new therapeutic **creative writing course**, starting this June and running over six months.

Finally, Face 2 Face is looking for **new befrienders** to help support parent carers around the time of diagnosis or any new difficulty. Training starts in September and they have a few places left.

For information about the choir, the creative writing therapy course or becoming a befriender, email amanda.mortensen@scope.org.uk or call Amanda on 07436 810608.

Carers' Card re-launched for Carers Week

There have been changes to the application process for the Carers' Card in the last few months and the whole process is simpler. That's great news for hard-working carers across the city who can take advantage of the 50+ offers on the card – including a 40% discount on membership at Freedom Leisure sports centres in Brighton and Hove.

The card gets its official re-launch during Carers' Week (don't worry, this doesn't mean existing card holder have to re-apply) when the council will also be launching the Brighton & Hove Carers' Register. A bit like a carers' version of The Compass database, joining the register and providing details on their role will entitle carers to a Carers' Card and will keep them up to date about local carers' services, events and activities.



"The Register will enable us to have regular communication with carers, to get feedback on their experience of services and support and to get suggestions and ideas for new services – in particular, places carers would like to be able to use their Carers' Card," says Brighton & Hove City Council's Katy Razavi who coordinates the Carers' Card project.

The Carers' Register is already in place for carers of people over 18 and will be introduced for parent carers in the coming months. If you want to know more about applying for a Carers' Card, call our helpline or visit www.amazebrighton.org.uk/services-and-support/the-carers-card.



Ready for SEND Changes?

This September brings the biggest changes to the special educational needs system in 30 years. Read our summary of what's coming and you'll be prepared.

New law and Code of Practice

The changes on SEN and disability (SEND) are set out in Section 3 of the Children and Families Act 2014 that was passed this spring. The guidance about how this should be put into practice will be set out in a new SEND Code of Practice. The second draft of this came out in April so we have a good idea now of what to expect.

Good news or bad?

The aim of the changes is to cut out some of the frustrations of the current system; to link up education, health and care better; to involve parents, children and young people more; to make information easier to find; to make transitions go more smoothly; to focus on outcomes for the child including preparing them for adulthood. Plus all schools (including academies and free schools) and Further Education providers are included. So good news overall but nothing can take all the worry and glitches out of the SEND world.

Goodbye Statements, hello EHCPs

The new **Education, Health and Care Plans** will be for more or less the same set of children as currently get Statements. They should be child centred and include more about health and social care, but education will still be the core. It's good to know most young people will keep their EHCP to 19 and in some cases to 25. And there will be the option to request a **Personal Budget** for some elements of the plan.

SEN Support

The two levels School (or Early Years) Action and Action Plus are going. Instead the idea is to teach all children well and this should mean fewer children need "SEN" help. But when they really need something different and extra, this will be called **SEN Support**.

This has a **four stage cycle: "assess, plan, do, review"** which is described as a graduated approach. The early years setting, school or FE college

must inform parents and involve them in the planning and review. And planning must say what support is being put in place, the impact this is expected to have and dates for review.

Moving through these four stages should become more detailed and frequent and draw in more specialist expertise if the child is not making progress. There are no specifics about how to record this (unlike IEPs in the old system) but the Code says the school should meet parents at least three times a year and provide some sort of record about support, outcomes and progress.

Including everyone?

Every school (and college) must use **"best endeavours"** to make sure children with SEN get the support they need. They should be able to engage in the activities of the school alongside pupils without SEND. There is a clear duty on maintained schools and academies to make arrangements to support children with **medical conditions** and there's separate guidance on this. Ask us how to get a copy if this applies to you.

Better information

The **Local Offer** is new and puts all the information about local services for children and young people with SEND in one place online at www.brighton-hove.gov.uk/localoffer. And there has to be a local Information Advice and Support Service for parents and young people to turn to if they need advice on education, health and social care.

It's a lot to take in so to hear more, come along to **our SEND Changes Information Event on 17th July** at the **Brighthelm Centre**. By then the final Code of Practice should be available and the local authority should be able to say how things will work locally.

To book a place call the Helpline on 01273 772289 or email info@amazebrighton.org.uk

Planning for more 'Independent Support'

Earlier this year the government announced an additional £30m investment over the next two years to provide a new form of support for families with children with SEND.

New 'Independent Supporters' will help to build resilience in families by offering a range of support during the new 20 week time frame for developing a single Education, Health and Care Plan (which are to replace Statements of SEN from September). For example, an Independent Supporter might liaise across different agencies or help advise on personal budgets. The level and nature of the support will be tailored to the particular family.

Independent Supporters will be **independent from the local authority** and recruited by the private, voluntary and community sectors. The current draft of the Code of Practice (see opposite) includes Independent Supporters as something that all local authorities should make available.

Amaze, in a partnership with parent carer forums and other partners across Brighton and Hove, East and West Sussex and Hampshire, has been selected to gather evidence about what parent carers and young people say works well when it comes to accessing services and support. Our findings will be used when looking for organisations to deliver the new IS role.

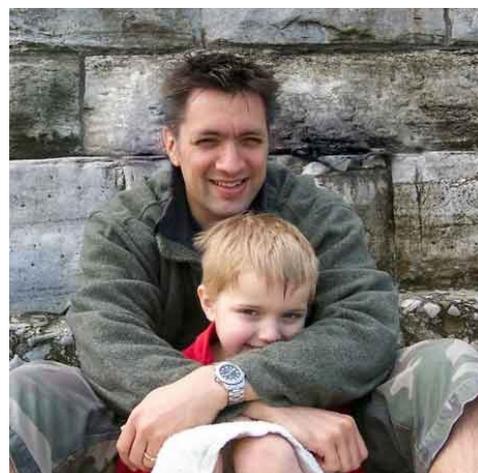
The new Independent Supporters should be **available to families in the autumn** and we will update you with details on how you can access this in our next edition.

Read more about the Independent Supporter programme at:

www.councilfordisabledchildren.org.uk/what-we-do/independent-support

Amaze courses and workshops for parents

Parents say Amaze courses are good because they cover topics they want to know about, in a friendly atmosphere and alongside other parents that understand how it is to have a child with extra needs. Most are delivered with parent trainers. Amaze is planning its courses and events for parents for the year ahead. Have a look to see what might suit you.



Triple P courses are all about behaviour and parenting positively. Doing Triple P with Amaze means you know the course is geared to special needs and disability. We will run Triple P Stepping Stones for parents of under 12s in the autumn and Triple P Teen for parents of over 11s starting after Christmas.

Looking After You is our super stress-busting course that mixes a space to talk, with practical relaxation techniques and a bit of Pilates to take care of our bodies too. We expect to offer a Looking After You course in the autumn. Parents who do LAY can't praise it enough.

Insiders Guide courses are special because they offer a mix of useful knowledge with a chance to check out where we are in our journey as parent carers and get together with parents at a similar stage. If you and your child are going through the process of getting a Education Health and Care Plan (EHCP) you should get a personal invitation to come to an IG course with other parents in the same position. But we hope to offer one or two other IG courses so call and express an interest to help us choose which to run.

If you are interested in a course, call the Helpline to find out more. You can go on the waiting list and, when we next run that course, we contact everyone on the list to give them first chance to book.

We also run one day workshops and events. Call the helpline to book any of these coming soon:

- **Making College Work** on 24th June (more info on page 9)
- **SEND Changes – what you need to know** on 17th July (more on back page)
- **Planning for the Future – Wills and Trusts** in December, date to be agreed

And finally don't forget the monthly **coffee mornings in Moulsecoomb and Hangleton**, run jointly by Amaze and local community workers. These often have a topic or speaker so call us to find out more, or find them on Facebook by searching for [Amaze Families Network Coffee Morning](#).

TAKEPART continued ...

The two week TAKEPART festival has lots more activities for you to try – and it's all free or low cost.

Local clubs across the city will be offering inclusive taster sessions and there will be a range of sessions specifically for disabled kids and/or adults too. All disability-friendly activities will be highlighted with a **yellow star** in the TAKEPART Festival programme available now in libraries, sports centres, bars and cafes, council buildings and schools. You can also visit www.brighton-hove.gov.uk/takepart to check out the festival online.



Tailored disability sessions include **wheelchair rugby, football, and basketball, sound tennis, hockey for the hearing impaired** and a **learning disability Health Walk**. Sussex County Cricket Club and Portslade Cricket Club will be hosting free **disability cricket tasters** from 11am till 3pm on Saturday 5 July. And don't forget the fantastic **Access Beach at Paddle Round the Pier** on 5 and 6 July – a brilliant opportunity for kids with additional needs to take to the water (you can book by emailing disability@paddleroundthepier.com).

"We want everybody in Brighton and Hove to have access to sport and we're really excited about TAKEPART 2014. There's more on offer for children and adults with additional needs than ever before," says the council's Sports Development Worker Shanni Collins who's coordinating the TAKEPART disability programme.

Compass gets creative

We've been working hard on our programme of Compass Card Activities (CCAs) and hope you'll be inspired by our latest additions.

There's a **pilot street dance CCA** for 11-19s delivered by JP Omari and the Streetfunk team at Marina Studios. Two mini-courses are on the cards in the half term holidays – October 2014 and May 2015.

Monthly **Make Your Mark art workshops** for over 16s will run from 10am to 1pm on the first Saturday of the month at Prestamex House. They cost £15 for Compass Card holders. For more information, call Sue Winter on 07400 963 087 or email sue.winter@icloud.com

There's also a free five-session **cookery course** for teenagers from Brighton & Hove Food Partnership (BHFP), starting in January 2015. These are very popular so book early – you can do so from 1st December.

Finally, Fun-fit, our weekly multi-sport class for 11-19s is on hold. We weren't able to confirm full details as



we went to press, but we're planning to re-launch a high quality session which will meet families' expectations later this year.

Look out for updates in the Compass e-bulletin or on our website at www.amazebrighton.org.uk

CCAs are special needs-friendly activities with experienced coaches that are supported and monitored by Amaze and they usually give a discount for Compass Card holders too. You can get all the CCA details you need from the new CCA guide (read all about it below).

New guides to Compass fun!



It's the time of the year when we add new offers to your Compass Card and produce our new guides – so come along to the Amazing Zone on Saturday 21 June and pick 'em up from the Amaze Info stall!

We've got an improved Compass Card offer from **Brighton Bowlplex** and new offers from **Forest View Holiday Home** in the New Forest and **High Sports climbing wall** at Withdean

Sports Complex. We are also unveiling an exciting programme of Compass Card Activities (CCAs) that includes new **monthly art workshops** and **pilot street dance classes** from Marina Studios (read more above).

If you can't get down to the Amazing Zone, you can download our latest guides from our website at www.amazebrighton.org.uk.

Just click on the Compass Card link to download your copies from mid-June, or call the Amaze helpline on 01273 772289 and we can send you copies through the post.



Summer fun starts here

It's never too early to get planning for your kids' summer break. Read our round up of summer schemes and activities for kids with special needs and get some of those long (hopefully sunny) weeks filled up now.

Special schemes

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

Cherish (16-25s) Tues to Fri, 5 to 29 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 295192/ 295530.

Extratime (11-19s) Mon 28 July to Fri 22 August, 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 young people and costs £23 per day. To book, call 01273 420580 or visit www.extratimebrighton.org.uk

Whoopsadaisy Holiday Club for children with physical disabilities

These are fun active sessions that focus on improving existing physical skills and developing new ones.

(0-5s) 11 to 15 Aug, 10am to 12pm and 1 to 3pm, Whoopsadaisy Pavilion, Preston Park. The theme is 'Charming Stories' and suggested donation is £15 per 2 hour session.

(5-12s) 28 July to 8 August, 10am to 3pm. This year's theme is 'Animal Planet.' Suggested donation £30 per day. Call 07775 774651 or email info@whoopsadaisy.org

Inclusive schemes

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

BHIP Holiday Play Scheme (3-11s)

28 July to 8 Aug, 8.30 or 10 am to 4 or 6pm, West Blatchington Primary School, Hove. Inclusive play scheme

for children with and without additional needs. £23/21 per full/short day. Call 07821 541765, 01273 295533 or email victoria@bhip.org.uk to book.

Extratime (5 years+)

Mon 28 July to Fri 22 August 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. You can visit www.extratimebrighton.org.uk or call 01273 420580 to book.

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, Kaleidoscope or T21** 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 other groups or visit www.amazebrighton.org.uk/services-and-support/parent-support-groups/

Other ideas

Our 'Fun things to do' factsheet has just been updated and is crammed with information about local leisure activities—download the latest version from our website or call the helpline for a copy.

'Summer Fun', the brilliant booklet from The Family Information Service lists loads of mainstream and more specialised activities across the city throughout the summer. You should get one via your child's school or nursery or you can download it from www.brighton-hove.gov.uk/summerfun or call FIS on 293545 to order a copy. Finally, you could do your own research on websites like www.childfriendlybrighton.co.uk

Appealing DLA decisions: if it feels important, do it!

If your child's claim for DLA is turned down, or you don't get the result you expected, don't give up. Over 50% of decisions are overturned when you ask another decision maker to look at the claim again and over 70% of appeals are successful.

The Department for Work and Pensions (DWP) can look at any part of the award again, even a part you are happy with. So it's important to seek advice before asking for a decision to be looked at again, just to make the best of this opportunity.

You can challenge a non-award, or argue that you feel your child should be entitled to a higher rate of either the care or mobility component, or the length of the award.

First, contact the DWP: say what it is that you do not agree with and why. If you did not keep a copy of the claim, ask for a copy of everything you've submitted so far, as well as any extra reports requested by DWP. Ask for a Statement of Reasons as well.

Go through all this paperwork carefully. Has any evidence been overlooked? Do you need extra reports to support what you say? Stick to timescales. Write giving detailed reasons why you disagree with the decision.

Whether or not the decision is changed, you will get a mandatory reconsideration notice. To appeal, you need to submit this notice along with a completed form SSCS1. Get this from



www.gov.uk website or by ringing the DWP on 08457 123456.

You can submit an appeal in writing, or even send someone to act on your child's behalf but we think **it's best to attend yourself and speak from the heart.**

Before the hearing, send in extra evidence as soon as you can. If you only get a report at short notice, don't worry, the panel will accept evidence on the day.

Appeals can take a year to be heard, so make time to read through your 'bundle' of papers several times. What's important is how things were at the time you made the claim: so it's worth refreshing your memory.

What parents say about appeals

"There's no reason to be scared about going to Tribunal because, you know it, it's your life. Amaze is right: you just have to tell it how it is."

"I had visions of standing in a dock being interrogated. But on the day everyone was really nice, put me at my ease and explained everything very clearly. The Panel was kind and respectful and had read the papers. They had grasped the issues: their questions were relevant. There was nothing that I felt was attacking or interrogating. But it is an emotional roller coaster and they were fine when I became upset."

"I was impressed by the process: it felt fair, so even if the Tribunal had not been able to award DLA, I think I could have accepted that. But they acknowledged the extent of it all and overturned the DWP decision."

"The DWP statement of reasons felt really patronising. It didn't take on board the amount of emotional support as well as the practical stuff."

"You know, in the end, the DWP didn't even send a representative to the hearing."

"It's not a massive victory: I still have my little man and he really struggles every day, but money opens doors and now I can pay for the counselling he needs."

"Somehow having Harry's problems acknowledged has meant more than the money. I have been heard and believed rather than knocked and that has been really important to me."

If you would like to get advice on making a DLA claim or asking for an unsuccessful claim to be looked at again, call our helpline on 01273 772289.

Planning for your young person's future - your views coming soon!

Thanks to all those of you who took the time to fill in the survey Amaze sent out to parents of teenagers and young people recently. We received over 100 completed surveys.

We are in the middle of inputting all of your responses so that we can analyse what the general themes are – what you've found helpful and what's not been helpful when planning for your young person's future.

We will use the information to try to improve services and support to parents and young people throughout



the city. In our October newsletter we'll tell you more about what we found out from all of your experiences and what the plans are to make improvements.

Assert support for young people with AS

If your child has Asperger Syndrome (AS) or high functioning autism (HFA) you may already have heard of local charity, Assert. They offer lots of services to people with AS or HFA including one to one support, benefits advice and support with accessing volunteering opportunities. They also run monthly drop ins and other social events. And parent carers can get one to one support too or attend a monthly mutual support group.

But you may not have heard of some of their most recent projects...



Health walks

If your young person with AS or HFA is over 16 and would like to get out, and become a bit more active whilst meeting up with others, then Assert's

walking group might be for them. This relaxed and supportive group meets once a month in a variety of locations in and around Brighton and offers a chance to meet likeminded people whilst enjoying an exercise that is great for both mind and body.

The event is free although they usually end in a café so people bring money for refreshments.

Life skills course

Assert's life skills course is for people with AS or HFA aged 16 or over. Assert work with the young person on communication, organisational skills, anxiety and relationships and give them the practical support they need.

The six-month course covers things like managing stress and finances, staying safe and using public transport and is run in small, friendly groups, every two weeks. There's also two hours of dedicated support per month too.

If your young person would like to join Assert's walking group or find out more about their life skills course email lifeskills@assertbh.org.uk or call 01273 234850.

Making college work

Find out about how local colleges support young people with additional needs.

Tuesday 24th June
10.00am – 12.30pm
Amaze, Community Base, BN1 3XG

If you're worried about what things will be like when your young person goes to college, here's an event that's not to be missed.

Amaze is running an information session for parents and carers where you can meet staff from local colleges. They will tell us how they support young people with additional needs and there'll be plenty of time to ask your own questions too.

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



Through the Next Maze out now

Our 2014 handbook for parents of young people with disabilities or additional needs aged 14 and over is now available.

The latest edition contains all the latest information on benefits, social care, education and employment, and you can also read our new chapter all about housing options for your child when they grow up.

You can download the handbook chapter by chapter from our website at www.amazebrighton.org.uk/resources/publications/handbooks or call the helpline for your full copy.

Brighton sets budget for 2014/15

After much debate amongst local councillors, Brighton & Hove City Council's budget for 2014/15 has finally been set, with an agreed increase of 1.99% to local council tax.



Continued reductions in funding from central government made the process very challenging as the council had to make savings of over £16.7 million for the year ahead.

Despite the best efforts of some of the local voluntary organisations that support families with disabled children (such as Amaze, Extratime and Barnardos) to influence policy, the **original budget papers included proposals to cut short breaks** for disabled children by £108,000 and home to school transport by £184,000.

Officers maintained that these reductions could be made through efficiency savings, but there was understandable concern that this might not be the case. The Parent Carers' Council (PaCC) decided to express their concerns about these proposed cuts and several **PaCC members wrote directly to their local councillors**, in particular about the importance of short breaks services.

Following much debate, there was a **joint budget amendment** from the Green, Conservative and the Labour and Co-operative groups which included using an unallocated £23,000 from a contingency fund:

- To reverse the £9,000 (2% reduction) cut to Community & Voluntary Sector contracts for short breaks for disabled children

- To reverse the £7,000 (2% reduction) cut to the Link Plus short breaks service
- To use £7,000 towards reversing part of the proposed £68,000 cut to residential short breaks

Whilst the proposed cuts to residential short breaks were only in part reversed – 21% of the total short breaks budget saving – we should take some comfort from the fact that the voices of parent carers were listened to, as this amendment was one of only three where a budget cut was overturned.

“The voices of parent carers were listened to, as this amendment was one of only three where a budget cut was overturned.”

Worryingly, it is predicted that the council will need to continue to make £20 to £25 million worth of savings every year for the next five years and officers are about to start a review of how better outcomes and value for money can be achieved across SEN and Disability services going forward.

Amaze and the PaCC will be involved in this review and we'll keep you updated about how the voice of parent carers and children and young people themselves can be best included in these ongoing debates.

If you have any comments or views on the council's budget or how PaCC should best influence this, email fiona@paccbrighton.org.uk



PaCC website now live

You can now find out everything you need to know about PaCC at www.paccbrighton.org.uk

You can get details of upcoming events, read PaCC reports and Partnership Charter feedback and sign up to the PaCC chat e-bulletin.

You can also read the life stories of some of our members and how they came to join PaCC. And you can join PaCC yourself via a simple online form.

If you are into social media, you can also find [PaCC's Facebook group](#) via the Facebook icon on the bottom of the home page. Just click on the icon and make a request to join.

Compass gets appy!

The Compass Card is going to get its own **smartphone app** later this year, thanks to the generosity of local company, DabApps!

So if you have a tablet or smartphone, you'll be able to download the app and search for Compass Card offers and Activities while you're out and about.

The collaboration between Amaze and DabApps came about via Community Works and the Brighton & Hove Skills Exchange programme – where commercial companies give their expertise to community groups and voluntary organisations for free. We're hoping to launch the Compass Card app in November 2014, so watch this space.





T21 and other things that I like

T21, one of PaCC's seven partner organisations, is a local support and social group for children and young people with Down's syndrome and their families. Rather than just tell you what T21 does, we thought we'd let group member, **Bethan Brown Evans**, tell you all about the group and how it fits into her busy life. So Bethan and her mum, Chrysi, had the following chat.

"What do you want to say about Down's syndrome?"

"I have Down's syndrome - it's OK to have Down's syndrome. Down's syndrome is cool and you don't worry about it; it's just an extra chromosome, that's all.

"I like being me, I love me. I'm proud of having Down's syndrome. I'm proud I'm deaf too. I can sign very well and chat with my deaf friends and my hearing friends.

"Sometimes, some things are hard for me to do. I try hard and my mum helps me to be independent. I like being more independent."

"What do you enjoy doing?"

"I love my family and my friends. I go to choir and sing with my mates. I like to go to gigs and see bands and I like dancing. I love Blue Camel Club (see

the back page for details). I go to college and I love it, I do life skills. I like bowling and going to the cinema. I love camping in the summer, I've got my own tent. Now I just want my own PA so I can be more independent."

"I'm proud of having Down's syndrome."

"What do you want to say about T21 group?"

"I like the T21 group, I like to be part of it and it's fun. I like the picnics and the party and it's nice to see my friends and meet new friends. I love the babies and the toddlers and the children and we all have Down's syndrome. I can help and I can play with them and they are really cute.

"T21 is on Facebook, and I am a member now because I am a young adult and I can tell everyone what I am doing in my life."

"T21 is good for mums and dads because you can have a rest and a chat...and you can make new friends."

"What would you say to the mums and dads of younger children with Down's Syndrome?"

"I would say...don't worry; Down's syndrome is cool and it's ok. To the kids I'd say, 'You will grow up and have fun and be happy. You can go to college and pass your exam' - I just did a maths exam and I passed. You can have a job and work hard and have your own money. And you can be more independent just like me.

"T21 is good for mums and dads because you can have a rest and a chat and a cup of coffee or some wine, and you can make new friends."

To find out more about T21, email emmaparker148@btinternet.com or join their [Facebook group](#). Just type T21 Brighton & Hove into the search box at the top of any Facebook page and send them a request to join the group.



Mental Health Matters!

In February, PaCC organised an online survey and focus group to gather parents' views of local mental health services for both themselves and their children.

This consultation, funded by the local Clinical Commissioning Group (CCG), will be used to inform a new **Mental Health and Wellbeing (MHWB) Strategy** being developed by the CCG together with Brighton & Hove City Council. It's part of a wider national interest and investigation into people's mental health and how this affects their physical health too.

From our previous Talk Health consultation and regular parent carer surveys, we know that caring for a child with a disability can put a serious strain on the wellbeing of their parent carers. So PaCC are pleased to be involved in making sure the mental health of parent carers is reflected in the new MHWB strategy.

Thank you to the 88 parent carers who gave us their views; 73 via the online survey and 15 at the PaCCConnect Mental Health forum. This feedback was combined with comments about mental health from our Parent Carer Surveys in 2011 and 2013.

Key findings

The majority of parents considered themselves fairly happy (the average was 6/10). The things making parents feel less good included: uncertainties about their child's future and their health; increased likelihood of relationship breakdown and their financial situation.

The things which parents reported helped them to build their emotional strength included: connecting with friends and family; getting support and respite; keeping active and volunteering.

Key recommendations

Service providers should work with parents, have positive attitudes to parents and **see them as allies**. The report stresses the vital **importance of good communication** and also the importance of shared **training and support**, such as rolling out 'parent journey' training for GPs and CAMHS workers. The report suggests services should regularly **seek and act on parents' feedback**.

Parent carers would like to access **services that are flexible and responsive**, tailored to individual children and young people and their families and not vice versa. This means offering clinics and appointments at times and venues that are convenient to them.

Some **specific areas were identified as needing improvement**. These included crisis response, the transition from child to adult services and the care pathways for specific conditions like ASC or eating disorders.

Parents told us they would like to receive **more counselling, for longer periods**, and see more investment in services to improve the wellbeing of disabled children, for example **more respite and short breaks** or **more social groups** for specific conditions.

We are also pleased to be able to report that parents said Amaze's DLA project, training and Compass Card Activities all helped to improve their or their child's mental health and wellbeing.

Read the full PaCC report on mental health on the PaCC website at www.paccbrighton.org.uk/resources/reports or call the helpline for a copy.



Complain for change

The Parliamentary and Health Service Ombudsman has launched an awareness campaign, '**Complain for Change**', targeted at people with a learning disability and their families. It encourages us to complain to the NHS if we or our children have received poor care.

As part of the campaign, a short animated video and a range of posters and leaflets have been produced with tips on complaining. Visit www.ombudsman.org.uk/complainforchange to find out more.



GPs learn about parent journey

More training for GPs about the life experience of parent carers was a key recommendation in both PaCC's Talk Health and Mental Health and Wellbeing reports. So we're delighted that this has already been happening this spring. Parent trainers from Amaze delivered three sessions and virtually all the GP surgeries in the city sent someone along. Even better – the feedback was great: "A very useful session." "Very helpful hearing from actual parent carers."

Nursing staff from the Alex and GP reception staff are next in line for training. Let us know if you see a change at your local surgery.

Take that step and get a ramp!

PaCC Mum, Ruby Kearns, says it's about time local businesses got serious about their duty to include people with disabilities and their families.

As residents of one of the UK's most diverse and culturally rich cities, one of life's greatest pleasures is to just get out there and explore. We're saturated with places to eat and drink in, shops to shop in, shows to be shown and we have fabulous architecture, wonderful parks, a famous pebbly beach, a pier and our bustling, eclectic town centre... all surrounded by beautiful countryside. But, perhaps more importantly than even all this, people in Brighton and Hove feel proud to be part of its positive, progressive ethos: the community's tolerance, inclusion and unashamed celebration of diversity and its many subcultures.

However, unfortunately, in many practical ways, this supposedly progressive ethos falls far short of embracing my eight year old son, Arlo. He is barred from entering most of our shops, restaurants and cafés, and denied access to many of its leisure facilities. Not because he's ever caused any trouble – on the contrary, he is a kind, gentle soul. He is barred from most business premises because, thanks to an accident that could happen to anyone at any time, he uses a wheelchair.

“Hundreds of Brighton and Hove's business owners seem ignorant about, or to feel no obligation towards, providing access to everyone.”

All over our city, shops, cafés and restaurants are ignoring the



Reasonable Adjustments Duty, part of the Equality Act 2010, that makes it a legal requirement for businesses to take steps to make sure disabled people are not discriminated against when accessing their services. The nature of these 'adjustments' very much depends on the type of premises, but it could mean simple things like altering a 'no dogs' policy to allow for guide dogs or making sure there's a temporary ramp available for the entry. Read more on the [EHRC website](#).

Despite this law, hundreds of Brighton and Hove's business owners seem ignorant about, or to feel no obligation towards, providing access to everyone. Whether it's fear, dislike or ignorance of disability, or because they may have to cough up a bit of money for a ramp, they seem to have decided the duty doesn't apply to them.

Fortunately, it does apply. And those that are able to make 'reasonable adjustments' but choose not to, are in contravention of the law and could be prosecuted. If you feel

that a shop or restaurant has failed to provide reasonable access or facilities to disabled customers, you can write to them and complain. If you're not satisfied with their response you could try complaining to someone who upholds standards for their type of business such as a membership body. Failing that, you can even bring a claim for disability discrimination in the county court. For advice on this, visit www.advicenow.org.uk

Inclusion is something that is continually evolving in our society - after all, it's not so long ago some ignorant business owners were reluctant to let black or Irish people onto their premises. But while we wait for attitudes to inclusion to evolve, my child is left crying on the pavement because, like thousands of other wheelchair users, he can't get up one or two steps that could easily be ramped to get into an ice cream shop, or park café, or a pub for a Sunday roast.

“My child is left crying on the pavement because, like thousands of other wheelchair users, he can't get up one or two steps that could easily be ramped.”

He certainly doesn't deserve to have to listen to a manager or owner spluttering nonsensical health and safety excuses, or citing Heritage issues, as to why he or she has deemed my son not worthy of entering their premises.

Business owners, the Duty applies to all of you. If your premises can be ramped, then please buy a ramp! You might be surprised how quickly the extra money from this new population of customers, their friends and family will pay for it 10 times over!

A Day in the Life of a Helpline Adviser

Amaze helpline adviser, Emma Parker, explains what it's like to work on the front door to Amaze's services.

My son Jack has additional needs and I remember making my first call to the Amaze helpline when he was about three to see if we could get some help with filling in his DLA form. I never guessed that eight years later I'd be on the other end of the phone!

“You may have visions of a row of advisers, all busily talking into their headsets; in reality it's just me, the phone and a computer.”

I usually do the helpline on Thursday morning. There are five helpliners altogether and we each cover one or two of the six sessions a week. If you've ever called the helpline you may have visions of a row of advisers, all busily talking into their headsets; in reality it's just me, the phone and a computer, in a very small room in the Amaze office. But I love the helpline and I've been part of the team for about three years.

After I've dropped my son at school and grabbed a coffee on the brisk walk to the office, my first job is to see how many calls are already in the book – today it's four. These are messages from previous sessions where we have not been able to get hold of the caller yet. Next I take the new messages off the answerphone and record them in the book too – we write the name of the caller, the date, time received and the subject of the call. Sometimes it's really difficult to hear a name or number clearly, so it's

really helpful when callers say their number twice. Today there are seven new messages – sometimes there are two, sometimes 19, but seven is about average. I also check the emails and once I've done all this, I start responding to the calls and emails in the date and time order that they came in. Though, of course, if there's an emergency that takes priority.

Today I have a long chat with a Mum who has received her child's proposed Statement and wants advice about choosing the right school. We talk about her child's needs and which schools might be the best fit. We agree that she'll make appointments to visit the suitable schools and I email her Amaze's factsheet 'Choosing a School' which gives some useful prompts for questions to ask schools when visiting.

We also talk about all the extra help and supervision that her child needs at home and agree that making a DLA claim would be worthwhile. Mum will call the DWP for a claim pack which we can then help her to complete. It was a satisfying call where I felt that I'd left Mum feeling like she had a plan for taking things forward. Afterwards I type up the details of the call onto our database. We do this for each call so parents don't have to explain their full story from scratch if they call again.

Next there's a quick call to book a place on our Triple P Teens course and one to sort out a lost Compass Card. Then I speak to someone who wants help with their son's DLA renewal. There are always calls about DLA and education. And lots of parents call for help with thinking through getting a



diagnosis, or finding fun activities for children where they will be welcome. I think "Fun Things to Do" must be the Amaze factsheet I send out most often.

I take another call from a parent who's just arrived in Brighton with a young child from another country where they were diagnosed with ASC. We talk about the support Amaze can offer with benefits, education and the Compass Card but agree that the priority is to find a pre-school place, get support from PRESENS and Seaside View and connect with some parents whose children also have autism via local groups. It's great when you can help a parent link up with other parents. I know from my own experience how much this matters.

“Sometimes there are no easy solutions and that is difficult, but talking things through can help.”

I really enjoy working on the helpline; every day is different. But it's always very busy and, when I'm on a long call with a parent, I do worry that there are others not able to get through because it's just me with one phone. Sometimes there are no easy solutions and that is difficult, but talking things through can help. So, if you can't get through, do always leave a message and we will phone you back as soon as possible, but it just might not be as soon as we'd like.



Sait Kasap pushed daughter Summer for the whole course.

Keeping Amaze running

Sunday April 6th 2014 was the fifth Brighton Marathon. We'd like to say a huge thanks to all our marathon runners for helping Amaze to keep on running: **Alexander Kent, Chris McGrath, Chloe Mason-Brown, Mark Weiner, Natalie Silverman, Reuben Young, Sally Polanski, Sait Kasap, Soulla Wright and Joshua Bateup and Sarah Grevatt** who ran the Mini Mile.

Ros and Steve's anniversary walkathon



It's been 25 years since our Operations Director, Ros Cook, and her husband, Steve, walked down the aisle and to celebrate this quarter century of marriage, they walked a lot further - 100km from London to Brighton to raise funds for Amaze and our friends at Extratime.

We asked Steve why they'd decided to do the walk. "Ros and I have done a lot of walking over the years, some of it together, and we quite like the idea of a challenge, so this seemed a suitably ridiculous thing to do. I know someone who did it last year and the tears of joy on their face when they

described the quantity of blister plasters they got through was a pleasure to behold. When they calmed down, they said they hoped to be walking unaided again very soon."

And Steve had one more reason for taking up this anniversary challenge - one that husbands everywhere will appreciate: "It saves having to buy some flowers!"

"It saves having to buy some flowers!"

Ros and Steve completed their walk on 25 May. Amaze would like to say a huge congratulations to them both for this amazing feat. If you would like to celebrate their achievement, you can add to their final sponsorship total on their fundraising page at

www.justgiving.com/Steve-Cook19

If you'd be interested in doing a similar challenge call the fundraising team on 01273 234014 or email nickyb@amazebrighton.org.uk

GSK Award has a big impact on Amaze

As you read on the cover, Amaze is celebrating winning a national health impact award for our work to improve the lives of parent carers in Brighton and Hove. The GSK Impact Awards, now in their 17th year, are designed to recognise and reward charities doing excellent work to improve people's health. They are funded by GlaxoSmithKline and managed in partnership with the King's Fund.

As one of only ten winners from over 400 charities across the country who applied, the award represents a great endorsement of Amaze's work and secures us a whopping £30,000 in unrestricted funding to continue to support local families. The award also give us access to training organised by The King's Fund.



GSK filming DLA project manager, Lizzie Batten, and volunteer, Sanda Senanayake, to promote the award.

Katie Pinnock, Head of UK Community Investment at GSK said: 'Amaze is a fantastic example of how a small community based organisation can provide valuable healthcare support for local families. Their work makes a real difference to people's lives and they have helped give families with disabled and special needs children a voice. We hope the funding and training they have access to through the GSK IMPACT Awards will help them continue to provide much needed services and support for families that need them.'

Dates for the diary



Clinique Pamper night

Due to popular demand Amaze will host another Clinique Pamper Evening at Boots Brighton, North St, on **Thursday 19th June** from 7.30 to 10pm. To reserve your place, email nickyb@amazebrighton.org.uk



The Blue Camel Club

Monday 23rd June, 7 to 10pm at the **Brighton Dome's Corn Exchange**.

This club night is for over 18s with learning disabilities to get together and enjoy DJs, VJs and live music. Tickets are £5 or £1 for carers. You can buy your tickets in advance from the Dome Box office on 01273 709709 or www.brightondome.org

BIG CHEER for Amaze 4 coming soon!

The BIG CHEER 4 is coming. We are delighted to announce our stand-up comedy event is back. This year it will be part of the Brighton Comedy Festival and will take place at Brighton's Komedia on **Thursday 16th October** from 8 to 10.30pm. Save the date and look out for further information.

SEND Changes Event Thursday 17th July

9.45am to 2.30pm, Brighthelm Centre

Have you heard about the changes coming to SEN and disabilities this year? Want to know how this might affect you and your child?

This crucial workshop is all about the changes to the SEND system that will be introduced on 1st September. We will look at **EHC Plans** (and how they are replacing Statements of SEN), the **Local Offer** and **Personal Budgets**. And we will explain how **SEN Support** will be replacing School Action and School Action Plus.

Senior staff from the SEN Team and workers from Amaze will be there to tell you more and answer questions.



SENCOs and heads from local schools have also been invited. Plus, Andrew Baxter from the Department for Education will explain what is different about the new SEN Code of Practice and we'll see how Brighton & Hove plan to put it all into practice.

So come and join other parents and find out what's happening. Lunch and refreshments will be provided. To book, call 01273 772289 or email info@amazebrighton.org.uk

Amaze helpline:

For information, advice and support, call 01273 772289 Mon to Thurs, 9.30am to 12 noon, *plus* Tues afternoon 12 to 5pm and Thurs eve 5.30 to 8pm *term-time only*. This summer the helpline will close from Mon 4th to Fri 15th August. It will re-open on Monday 18th August.

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



Amaze

Community Base
113 Queens Road
Brighton BN1 3XG
T: 01273 772289

E: info@amazebrighton.org.uk
W: www.amazebrighton.org.uk

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

