

# out of amaze



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



## ‘Local Offer’ goes live!

Amaze Info Fair - Friday 21st November, Hove Town Hall

Getting the right information about what is out there for you and your child should now be much easier with the launch of **Brighton & Hove’s Local Offer**. This new online resource at [www.brighton-hove.gov.uk/localoffer](http://www.brighton-hove.gov.uk/localoffer) lists everything that Brighton & Hove expects to be available for local children and young people who have special educational needs and/or disabilities from birth to age 25.

But sometimes it also helps to ask about things **face to face** rather than look them up on a website. So this year’s Amaze Information Fair gives you the **Local Offer - live!** It’s your chance to meet, in person, a range of the services detailed in the Local Offer, which will be formally launched by MP Caroline Lucas and Director of Children’s Services, Pinaki Ghoshal, on the day. Join us at Hove Town Hall on **Friday 21st November** for stalls,

workshops and the chance to meet up with other parent carers.

### Stalls and goodies

There will be **40 plus stalls** from a whole range of services and organisations including Seaside View, the SEN team, the ASCSS, PRESENS, the Youth Employability Service, short breaks and leisure providers, health information and much more. You’ll also find parent support groups, PaCC and Amaze.

There should be something for you whatever your child’s age. Plus we will be providing **free refreshments, pampers treatments and goody bags** too. So

come along - you may run into old friends or even make new ones!

### Event timetable

**9.30am-1.30pm:** Drop into the Amaze Information Fair anytime to browse the stalls  
**10am:** Workshop 1  
**11am:** Workshop 2  
**12 midday:** Workshop 3  
**1.30pm:** Amaze AGM to report on the year’s work and to appoint new trustees. Lunch provided but you need to book for this.

### Workshops

Choose between:

1. Supporting your child who worries
2. Statement to EHC Plan - how and when?
3. Getting the most from the Local Offer

Read more about these workshops on page 5.

### Getting there

This year’s Info Fair is at Hove Town Hall, Norton Road, BN3 4AH. We can send you directions. There is parking in Norton Road and lots of buses stop nearby (1, 2, 5, 6, 25, 46, 49 and more) or Hove Station is ten minutes walk. We can reimburse your bus or train fare too – just bring your ticket.

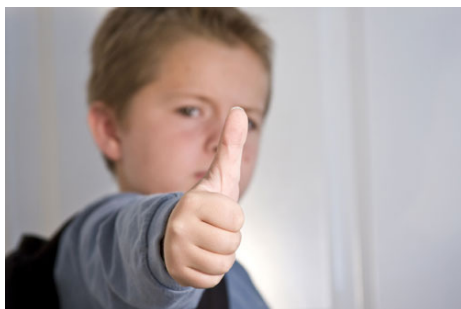
You can just turn up on the day but if you want to attend a workshop or stay for the AGM you need to book. So call the helpline on 01273 772289.

**INSIDE:** SEND Changes and Independent Support • Working memory • Siblings special • Compass Card extends to 24 • Anti-bullying week • and much more...

## Amaze wins Independent Support contract for Brighton and Hove and West Sussex

This summer, Amaze was delighted to hear that we had won the contracts to run the new **'Independent Supporter' services** in both Brighton and Hove and West Sussex.

'Independent Supporters' will be offering support and advice to parent carers and young people going through the process of assessment for the new Education, Health and Care (EHC) Plans or as they transfer from a Statement to an EHC Plan. Read all about how this will work on page 6.



## Action on ASC

Parents of children on the autistic spectrum will be pleased to hear that the Scrutiny Panel on ASC children's services completed its report into local services for children with ASC and this went to the city's Health and

Wellbeing Board in July. Scrutiny Panels are a way for a council to shine a spotlight on a particular service or issue.

Recommendations from the report are being followed up by an ASC Working Group through an ASC action plan which also links into the council's broader SEN Strategy. There have already been some new developments: a **specialist educational psychologist and speech and language therapist** have been appointed; there is more and **better training on ASC** for schools, other professionals and parents; and an **ASC conference** is

## Let's Stop Bullying 4 All

This year's **Anti-Bullying Week**, taking place from 17th to 21st November, is all about putting an end to bullying for kids with SEN and disabilities. **Turn to page 9** to read all about this national campaign and find out how you and your child's school can get involved.

planned for March 2015 for both parents and professionals.

One of the strongest recommendations from the Scrutiny Report was about support for families at home. There is some way to go on this, but one positive is that the role taken by Alicen Haire in **supporting parents as part of the ASCSS** (Autistic Spectrum Condition Support Service) is **set to continue**. Amaze, PaCC and mASCot are all part of the ASC Working Group so you can ask any of us for more information about how this progresses.

## Personal budgets pilot makes recommendations

Disabled children's social work managers in Brighton and Hove and some of the families who use their services have been involved in a pilot project to examine the use of **Personal Budgets** to plan and pay for social care services like short breaks.

An evaluation of this Personal Budgets pilot has just been completed and a series of initial recommendations have been made which it is hoped will lead to greater equity and more personalised packages of support.

The pilot tested something called the Resource Allocation System (RAS) – a tool that the social care team will use to help determine the amount of money allocated in a Personal Budget. They will also take

into account a family's wider personal circumstances and create an accompanying Support Plan. Supporters of Personal Budgets are confident that this way of working means **greater transparency and participation in the planning and allocation of resources**.

There is still a great deal of work to be done but, thanks to the involvement of the pilot families and practitioners at Seaside View, the pilot means social care now have a much clearer idea about how to make Self Directed Support achievable for families that request this.

Jenny Brickell, Head of Integrated Child Development and Disability Services, says: "We are committed to developing transparency and a



personalised approach to providing support to families, and developing Personal Budgets in social care. We still have some way to go but we are making active progress."

Seaside View Managers and one of the authors of the evaluation report will be arranging a session for parent carers to think about next steps. We'll let you know about this session as soon as we have further details.





## Compass benefits to be extended to 24 year olds

Amaze has secured funding from Brighton & Hove City Council and the Learning Disability Development Fund (LDDF) to extend the Compass Card upper age limit from 19 to 24 years old. It's great news for older Compass Card holders and a real boost to leisure opportunities for young people with additional needs.

Existing Compass Card partners have agreed to extend the age range for card offers where appropriate, and we plan to introduce some new offers targeted to older Compass Card holders. It's going to take us a few months to introduce the changes - we're planning a full launch in time for the next edition of Out of Amaze in February 2015.

If you have a young person who is about to hit 20, or who is 20 to 24 and no longer has a Compass Card, you don't need to do anything. The Compass Team at Amaze will make direct contact with families with a young person who is eligible for the card. But please do tell us if your contact details have changed by calling the helpline or by emailing [compass@amazebrighton.org.uk](mailto:compass@amazebrighton.org.uk)

## New Compass app to launch in November

Imagine being able to search for Compass Card offers and activities on your phone while you're out and about... The good news is you'll soon be able to do just that with our brilliant new free app, 'leisurecard', which has been developed by local company DabApps. Leisurecard will work on Android and Apple platforms and is designed for smart phones and tablets. Amaze is planning to launch the app at our Information Fair on Friday 21st November, so make sure you come along to the Compass stall to see it in action.

The collaboration between DabApps and Amaze came about thanks to Community Works and Brighton & Hove Skills Exchange where commercial companies offer their expertise free to community groups and voluntary organisations.

## Dyslexia guidance out now

This summer, the council published an updated 'Guidance for schools on dyslexia and literacy difficulties'. Though written to provide guidance to teachers and professionals to support the inclusion and progress of kids with dyslexia in school, it's also something the council are keen for parent carers to read too.

The document sets out the local authority's **definition of dyslexia** and the graduated response to intervention or '**waves**' of support that will be provided for children who have been identified as having dyslexia or literacy difficulties. For example: Wave 1 recommends using some very specific teaching strategies and creating a 'dyslexia-friendly' classroom for the children in question; Wave 2 introduces what the council calls 'evidence-based interventions' like the Accelerated and Lexia technology based reading programmes; Wave 3 might include specialised teaching, more training

for school staff and advice from other B&H support services as well as Language Support Service (LSS) programmes, Reading Recovery and/or specialist ICT.



The guidance also gives advice on the criteria used to judge whether a child needs Wave 2 or 3 intervention.

Download the dyslexia guidance document from the council's website at [www.brighton-hove.gov.uk](http://www.brighton-hove.gov.uk). The easiest way to find it is to type 'dyslexia guidance' into the search engine at the top right of the page. Alternatively, call Amaze and we can print out and send you a copy.



## Our Ann's a Champion

Our Compass Development Worker, Ann Blackburn, has been highly commended in the Sport & Physical Activity Champion of the Year category, part of the City Sport & Physical Activity Awards 2014. Ann was recognised for her work in including disabled children and young people in the sports life of the city. The awards ceremony was held at the Royal Pavilion on 22 October. We've always thought Ann was a champion, but we're delighted that others recognise it too!



## Working memory: what's the problem?

If your child has problems with remembering things even for a short time they may have poor working memory. Here we tell you how to recognise the problem and recommend some things that can help.

### What is it?

Working memory is the mental workspace we use to store information while we are working other things out in our heads. We use it all the time to do things like remember an address whilst looking for a pen and paper to write it down or follow spoken directions to an unfamiliar destination.

Working memory is a sort of mental jotter when we don't have written instructions to fall back on or a calculator to work out the solution.

If we are interrupted or distracted, information held in our working memory is gone for good. It's only available over very short periods and only for as long as we continue to pay attention to it.

We all have different limits to our working memory and though the amount of information a child can

hold in theirs increases as they get older, children with poor working memory may always struggle.

**Children with poor working memory...can easily get overloaded so that they forget what they're supposed to be doing, or where they've got to in a task.**

Their working memory can easily get overloaded so that they forget what they're supposed to be doing, or where they've got to in a task. The information is lost and they have to go back to the beginning and start again.

### How to read the signs

A child with poor working memory is likely to:

- appear to have a short attention span
- seem as if they weren't listening when the task was explained
- forget part or all of messages and instructions
- struggle with spelling, reading, writing and maths
- lose track of where they've got to when they have to think and do
- have exercise books full of incomplete and abandoned work

It's much harder for children to keep up with their classmates and build on new knowledge and skills if they never get to finish their work at school or see tasks through to the end.

### What impact does it have?

Liam, 13, explains how his memory affects his every day life at school:

"The teachers talk really quickly.

They say 'write down a title' and while I'm trying to write down a word I can't remember how to spell, I'm trying to listen while the teacher is saying what to do next. Then I've forgotten the title. I don't know what's happened. It's just gone! So I have to copy off my friend and see what they've written. I look at more than one person's book in case they got it wrong. It would definitely be handy if they could say it in fractions.

"If it's a new word, like in science, they have to say it about 20 times before I get it. The only way I can remember is if it's written on the board and they say it in bits and give you time to write each part so you don't have to write and listen at the same time.

"We have to do three pages but I can only get half a page down. They say 'That's a pathetic effort'. But I can't remember three pages of writing."

## What can help?

What helps children with working memory problems to stay on track, keep up and learn?

- Spoken instructions that are simple and straightforward
- Step by step, task specific instructions that are regularly repeated or written and given out
- An atmosphere that encourages children to ask for help
- Having useful spellings on cards on the whiteboard and, for older pupils, a glossary of new

vocabulary and key words for each topic at the back of exercise books

- Recording work in bullet points rather than whole sentences
- Printed handouts that cover all the key messages from that lesson
- Folders or files to keep these resources organised and safe
- Dictaphones, laptops and voice recognition software to record work, mobile phones to set reminders and calculators for mental maths

Children need lots of practice before

using these strategies and resources becomes second nature or they feel confident that it's OK to ask for help. Often, encouraging these good habits is where we can help at home.

**"It would definitely be handy if they could say it in fractions."**

If you think your child may have significant problems with working memory, ask your child's school for an educational psychology assessment.

## Amaze workshops and courses for parent carers

This term we've got one course and several great workshops for you.

**Looking After You** starts Tuesday 4th November so contact us right now to see if we have spaces left. This super stress-busting course runs for six Tuesday mornings in the Conference Room at Community Base.

Over the six sessions you'll get space to talk, along with practical relaxation techniques and some bite-size Pilates.

**Starting to plan for your child's future as an adult** is a session for parents of young people in Year 9 at school, who have a Statement (or EHC plan).

The Year 9 annual review is when the focus should start to shift to what your son or daughter needs to get ready for life after school.

Prepare for this with Sue from Amaze and other parents in a two hour workshop at Amaze on either 4th Nov, 10am to 1pm or 6th Nov, 7 to 9pm.

**Wills and Trusts – Planning for the Future** is a chance to get a grip on another side of planning ahead. Want to think about securing your child's financial future? Come to this friendly workshop with Phil Warford from Renaissance Legal to find out about how best to write a will or set up a trust for your child. It's in the Conference Room at Community Base, 10am– 12.30pm, Weds 3rd December.

### Info Fair Workshops

And don't forget the three workshops during our **Info fair on 21 November...**

**Helping your child who worries:** 10 to 11am. Last time Paul Myszor (educational psychologist) ran this session on helping your child at home with worries and anxieties, it was packed out, so we've asked him back!



**Statements to EHC Plans:** 11am to 12 noon. If your child has a Statement this should transfer to an EHC plan sometime in the next three years. Don't panic...Graham Read (Head of SEN) can fill you in about how and when this will happen.

**Getting the most from the Local Offer:** 12 noon to 1pm. The Local Offer is meant to be the best place to find out what's available for your child, especially if they don't have a Statement/EHC Plan. Let Howard Nottingham, educational psychologist, show you how it works and then he'll ask you how to make it even better.

And **Triple P** courses are coming next term so call now to go on the list.

**Email [info@amazebrighton.org.uk](mailto:info@amazebrighton.org.uk) or call 01273 772289 to book or to find out more about any of these workshops**



# SEND Changes update

And more help for parents and young people

**September 1st was a red letter day for special educational needs and disabilities (SEND), when the changes we have told you about for the past year finally took effect.** If your child is on school action/action plus your school should talk to you sometime between now and Easter about switching them to SEN Support. Education, Health and Care (EHC) Plans have replaced Statements of SEN for all new requests for assessment. Children and young people with existing Statements and Moving on Plans will be transferred to EHC Plans between now and 2018 (see box below for an idea of when). The Local Offer is up and running (see our cover story) and there are some changes to the advice and support you can get.

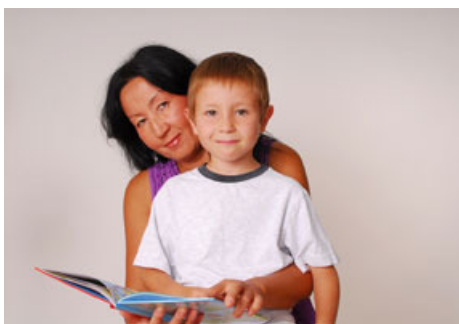
## Amaze goes up to 25

Amaze has always offered impartial information and advice to parents of children aged 0 to 19 with SEND on education, health, social care, disability benefits and more. Since September we can now offer this to parent carers of young people up until their 25th birthday. We're busily building up our expertise on the issues that affect this older age group.

We are also updating all our information in the light of the SEND changes. A **new edition of Through the Maze** is out and we're changing our website and factsheets as fast as we can. In the meantime our helpline is ready to offer advice on everything that is new including EHC Plans, Personal Budgets, SEN Support and the Local Offer.

The new law on SEND says that young people should also be able to get information, advice and support

for themselves. The local authority is deciding how to provide this locally and details should be available soon.



## Independent Support

This is a new service just for parents and young people going through the EHC Plan process. The government recognised that some families would need extra help to make the most of the new style EHC plans, so they invested some money to provide Independent Supporters and we're happy to say Amaze won the bid to offer these in Brighton and Hove. We're also providing Independent Support in West Sussex. By the time you read this, our staff teams should have been recruited, completed nationally accredited training and be ready to provide support.

The role of the Independent Supporter is to work with parents and/or young people during the period of assessment and writing of an EHC Plan, making sure they have the

information they need, understand what is happening, can contribute their views and make choices or give preferences at key points in the process. This support will be offered to some families whose children are getting a plan for the first time and some who are transferring from an existing Statement. Young people (16 to 25) can have support alongside their parents or have their own Independent Supporter.

## Getting an Independent Supporter

Though lots of families will be going through the EHC Plan process, we can't provide everyone with a dedicated Independent Supporter. In depth support is for parents and young people who might find it hard to be properly involved in their EHC Plan without it, though we should be able to give everyone some level of help.

Parents and young people can ask us for Independent Support. Call the helpline on 01273 772289 or email [info@amazebrighton.org.uk](mailto:info@amazebrighton.org.uk). We'll offer advice and support over the phone whilst working out with you whether you need a dedicated Independent Supporter.

You can also be referred by someone working with you such as a SENCO or Casework Officer in the SEN team. The professional should first get your permission then fill in the referral form available via our helpline or by emailing [independent.supportbh@amazebrighton.org.uk](mailto:independent.supportbh@amazebrighton.org.uk).

## EHC Plan Transfer timetable

There is a rolling programme to transfer Statements of SEN to EHC Plans. This year Brighton & Hove expect to transfer children and young people in school Years 2 and 11 and possibly Years 5, 9, 12 and over. All pilot EHC Plans from the SEN Pathfinder will transfer. Everyone should have switched by April 2018. All Moving On Plans (aka Learning Difficulties Assessments) should either have transferred to an EHC Plan (or ceased because the young person has left education) by September 2016. Your school or college should contact you about a transfer review meeting if you are switching this year.

# A Day in the Life of the BILT

Manager, Mark Holdaway, explains the work of the Behaviour and Inclusive Learning Team, the Behaviour Support Service for primary schools in the city.

“Behaviour can be a very emotive subject”, says Mark Holdaway, manager of the BILT. “By the time we have become involved with a child, communication between a child’s parents and the school can be very strained. During our involvement, we try to listen and to help all parties make sense of a child’s behaviour. We can offer the schools extra training and meet with the family in school, to provide support, planning and to share successes.”

If a school is having difficulty managing a child’s behaviour, they will make a referral to the Behaviour and Inclusive Learning Team. The team of six, managed by Mark, is based at Middle Street Primary School but they do outreach work at schools all over the city. “At the moment,” Mark says, “we’re working with about 30 schools in the city a week”.

Once BILT have received a referral they work closely with the school, the child’s family and the child themselves. “Last week, for example,” says Mark, “we met with 8 year old Jordan’s\* family and school. Jordan has been sitting under the table a lot during lessons and leaving the classroom.

“We sat down with Jordan’s mum and teachers and asked them all why they think he’s sitting under the table so much. This really sums up our approach: we are interested in the why, not the what. If we can understand why a child is exhibiting a particular behaviour, we can begin to look at what strategies might help. And as soon as parents see that we are not there to wag the finger but to listen, tensions ease.

“We found out that Jordan’s home

life is more chaotic than usual at the moment with a house move and his father’s return to the house after a period in custody. Having two new teachers in job share and a new classroom is taking time to adjust to, and his mum is finding it really hard to cope. We suggest some simple strategies: for example, Mum will create a visual timetable for what happens at home (homework, TV, dinner, etc.) that mimics timetables used at school. And mum and the teachers agree to use similar ‘scripts’ when they talk to him about his behaviour, highlighting ‘choices’, and how they are ‘worried about him.’ We also suggest getting his aunty to help give mum a break. We’ll meet again in about a month to discuss his progress.

## “We are interested in the why, not the what.”

“For more urgent cases, where a child’s school placement is in danger of breaking down, we’ll review an action plan, ideally, every two weeks. This is the case with Darren\*, aged 10, who our team is working with.

“Darren’s behaviour in class and the playground has not improved and his fixed term exclusions are becoming more regular. He’s been referred to the Educational Psychology team for assessment, but in the meantime we meet to see if the school is able to give him more intensive one to one support. As this is not possible, and given that his behaviour is likely to lead to a permanent exclusion, we need to consider other options. This might be a ‘managed move’ to a new



school or perhaps a placement in the Pupil Referral Unit (PRU) in Lynchet Close.

“In partnership with the school and family we decide that we’ll refer him to the Behaviour and Attendance Partnership to see if a place at the PRU is applicable or available. Spaces at PRU are limited and placing a child in the unit, away from their school and community, has to be carefully considered. We do everything we can to maintain links with their old school, which continues to hold them on roll during their time at the PRU.

“Darren does get a place at the PRU for 12 weeks, during which time we’ll gain a greater insight into him and his behaviours. After the 12 weeks he’ll either go back to his old school, to a new school or stay at the PRU for another cycle or two while an EHC Plan is possibly formulated. The PRU operates a revolving door policy and aims to return children to mainstream education whenever possible.”

“The biggest test for us,” says Mark, “is helping our teaching colleagues to develop resilience and learn to manage the challenges they face in mainstream school creatively and flexibly. We help them to see that theirs is not an isolated experience and that their skilled contributions can make a huge difference to a young person, if not now, then in the future.”

\*All names have been changed to protect anonymity.

# Mind your language!

Pippa Hodge examines the complex issue of the language surrounding disability and how we can educate people to choose their words more wisely.

Imagine there was a Language Sensitivity Spectrum drawn as a line from cool blue to red hot. At the blue end sit those of us who think it doesn't really matter how a disability or a condition is described; and at the reactive red end sit those of us who are often very uncomfortable with the words and terms used by professionals, friends, family or passers-by.

My son has Down's syndrome - he was born with an extra chromosome. The medical term for this is Trisomy 21. He is not a Down's Boy or a Special Needs KID. And he is definitely NOT a Retard (grrrrr). And first and foremost, he is Leo. I think you can already sense which end of the Language Spectrum you'll find me.

Also, language shifts like fashion: whatever terms we decide to own for ourselves and for our young people get hijacked and before you know it you're hearing them being bandied disrespectfully around the playground, or office, in pursuit of a cheap laugh or to cause humiliation.

I made a private promise to myself at the beginning of 2014, that I would step up to inappropriate language, if I felt it marginalised my son, or threatened to make his 'rightful space' smaller. It's been an interesting year! I quietly explained to a close friend why making a loud public joke about 'being in the special needs corner' was an unhelpful throwback to darker times. Let's just say it was an 'Ouch!' moment, and it's left a small but definite crack in the friendship. But I knew that it mattered and I don't regret it.

I have also had several conversations this year with friendly people from

older generations where the common terms were different, and where 'truisms' around certain conditions were the norm; "Downs children are such happy souls" or "Poor boy, wheelchair-bound", etc.

**He is not a Down's Boy  
or a Special Needs KID.  
And he is definitely  
NOT a Retard (grrr).**

On these occasions, I've chatted, and gently explained that the language is a bit different these days, and that since 'community' is really important, I'd hate their friendliness to be rebuffed because of a language misfit!

I think this is a key point - it's all about the intent behind the words. If the intent is genuine, and the words have just 'missed', then you can take a calm breath, step in, and offer your perspective. It's helpful to repeat the phrase that works best for you. I might say, for example, "We went to a great picnic with local families who all



have a child with T21." Hearing a phrase to imitate can be a great relief to people who might worry they are being offensive, but don't know how to ask for guidance without being more offensive still! Some parent carers print up simple cards that explain their child's condition and give an internet source for further info, and quietly hand that out. Whatever works for you.

I'd like to stress that I'm not trying to start a revolution here - none of us have had enough sleep for that! - and of course there are times when I let comments go by, because I'm too tired or too wobbly to engage, or the moment isn't right. But I see no reason why we can't help tweak the language and terms of reference used toward and around our children. By using 'person-centred' language we can help create a positive sense of identity for our child and their siblings, family and friends.

## Amaze is changing their language too

Here at Amaze, we've been debating the use of the term 'special needs' for a while now. As Pippa points out, though it might have been considered the most cherishing, empowering term a decade ago, meanings have a tricky habit of changing and these days you are just as likely to hear 'special' used in an ironic or downright derogatory way in relation to disability.

We want to make sure that the language we use reflects both the prevailing terminology used by government and services and the terms our parents are happiest with. For this reason we have changed our 'byline' to 'Working with parents of children and young people with special educational needs and disability (SEND)'. We will also gradually replace the use of 'special needs' with 'additional needs' throughout our literature to reflect a growing desire for recognition that our kids are kids like any other - they just need extra support.





## Let's stop bullying for all

We all know that bullying is a serious issue and that children with SEN and disabilities are more likely to be bullied and bullied for longer. This November's Anti-Bullying Week is trying to tackle this ongoing problem.

Anti-Bullying Week 2014, from 17th to 21st November, shines a fierce light on the incidence and impact of bullying on children with SEN and disabilities and aims to get schools, colleges and young people themselves to work together to eradicate bullying for all. The Anti-Bullying Alliance (ABA), organisers of the campaign, have come up with a three pronged plan of attack:

- **To stop the bullying of children with special educational needs and disabilities** by equipping schools, colleges and youth services with resources to develop youth-led anti-bullying initiatives and encourage inclusive attitudes amongst children and young people
- **To educate those who support and work with children** to recognise children and young people who may be particularly vulnerable to bullying - encouraging an inclusive approach within all anti-bullying education
- **To challenge 'disablist' language** by ensuring the school and wider community understand that the use of any discriminatory language is wrong and will not be tolerated (See our article on the facing page).

Schools, colleges, youth clubs and any other organisations that work with young people can find lots of useful resources on the Anti-Bullying Week website (see below) including ideas for getting young people talking about bullying, as well as lesson plans and activities.

So why not do your own bit of awareness raising and ask your child's school what they're planning to do for Anti-Bullying Week this year? If they are unsure of the issues, ABA offers a programme of free training and resources to help them play their part in reducing bullying for children with SEN and disabilities.

Visit [www.anti-bullyingalliance.org.uk/anti-bullying-week](http://www.anti-bullyingalliance.org.uk/anti-bullying-week)

### Bully proof Brighton

For many years, Amaze has raised concerns about the increased likelihood of bullying for children with special educational needs and disabilities; we have worked with the local authority on their Bullying Scrutiny Committee and held workshops in schools and for parents to help them recognise bullying and find ways to tackle it.

Our fact sheet, '**Bullied at School**', gives you ideas for how to support your child when bullying is happening. It also lists places to contact for more information and advice. The council recently produced a useful leaflet for parents about bullying called '**Safe from Bullying**'. You can download both of these documents from our website at:

[www.amazebrighton.org.uk/advice-for-parents/education/bullying-discrimination-exclusions](http://www.amazebrighton.org.uk/advice-for-parents/education/bullying-discrimination-exclusions)

Another local organisation that can help is **Safety Net**. They run **assertiveness courses** and groups for 8-13 year olds who have been affected by bullying and have lots of resources for parents to share with their children. Call 01273 411613 or visit [www.safety-net.org.uk](http://www.safety-net.org.uk).

And if your child has been the victim of a hate incident or bullying because of their disability, either in or out of school, you can contact the **Community Safety Team** on 01273 292735 or [www.safeinthecity.info](http://www.safeinthecity.info)

Finally, if you think your child is being bullied, or is involved in bullying others, and you want some more personal advice, call our helpline on 01273 772289.



## Getting it right for the siblings

Sometimes the sheer level of care and attention our disabled children need means that the needs of their brothers and sisters can get overlooked. Here Lynne\* tells us how the SIBs group at Downs Junior School helped her daughter to cope with the challenges and joys of having a disabled sister.

"I had been a children's disability social worker for some time when Freya\* our second child was born with Down's syndrome. In some ways my job gave us a bit of a head start but in many ways was no preparation at all. One of the pacts we made as parents early on was to try our best to make sure that Maya\*, our eldest daughter, then aged two and a half, did not become a sibling carer. We tried to do all the things you are supposed to – ensuring she had time and attention from us; supporting her resilience through friends and activities outside the family and enabling her to express her feelings about her sister.

"Nearly ten years on I wonder whether we've achieved our original aim. It's inevitable that Maya has occasionally been asked to keep an eye on her sister – this is often the lot of the older sibling. Whilst she hasn't become a 'young carer' in the sense that she takes responsibility for her sister's care, we haven't necessarily been able to protect her from the mix of emotions that can be generated from being the sibling of a disabled child – ranging from pride in their achievements through to frustration, anger and embarrassment. What I also hadn't anticipated was the potentially isolating experience of being the sibling of a disabled child.

"We're fortunate that in our community, Freya is well known and liked – sometimes to the extent that Maya has felt overshadowed by her indomitable younger sister!

"We were acutely aware of these

complexities and how best to support each child. So we were pleased and relieved when the wonderful SEN team at Downs Junior School had the foresight to establish a SIBs group. What was surprising was the numbers of children who came forward to participate. The fact that the group operated in school served to normalise things and meant that the children were not stigmatised."

Maya says, "I have a sister with Down's syndrome. She is like any other kid but needs more support and help from adults. This means I sometimes feel a bit left out and lonely. My sister can act unexpectedly, suddenly sitting down on the floor or not wanting to do things. We have to wait around and stay patient, which is not easy. I have experienced this a lot and felt I was the only person that was feeling my feelings. I was wrong.

"At my old school, back in the autumn, the SIBs group started. Open to anyone with a brother or sister with a disability, we had an hour each week



to discuss our feelings, circumstances and scenarios. Some weeks we had an activity planned, others we played a game and sometimes we had a conversation. In my new secondary school, there isn't a SIBs group and I miss that. All children experiencing what I do should be able to have this type of help. The SIBs group helped me make new friends, discover more about different disabilities and realise that I'm not the only one."

Lynne says: "Wouldn't it be wonderful if all schools could take on this initiative or for there to be a city-wide SIBs support strategy?" Visit [www.sibs.org.uk](http://www.sibs.org.uk) for information or contact Amaze if you want to talk about services for siblings in the city.

\*All names have been changed to protect anonymity

**Emma Hearn, Inclusion Leader and Assistant Head at Downs Juniors** says,

"We are very proud of our SIBs group. It has given our children a sense of community and pride. They have the chance to express their feelings in a safe and supportive environment whilst at the same time having some fun and letting off steam.

"During a recent disability awareness week, two of our youngest members talked to their classes about their brothers. They spoke with confidence and honesty and gave the other children a real insight into the reality of living with a disabled sibling. Without our SIBs group this would not have happened.

"Janice Stephens, who set up and runs the group, is tireless in her efforts to ensure that all children in our school are included, valued and supported. We thank her deeply for all that she does for the children, parents and staff."

# Space for them too

PaCC member, Lorraine Roberts, tells us how Brighton Pebbles gives brothers and sisters a place to have fun and share their experience of having a sibling with a disability or special educational need.

Like most people, I remember precisely the moment I was told that my son had a disability. The well-meaning health visitor gave me a weird poem called "Holland" with reassurances that "it would all be okay... just different... it's the same child", and I couldn't help but think "Why me?" Little did I know then the huge impact that that news was going to have on my life; the constant battles, the emotion, the endless meetings and the realisation that life would never be the same again.



Then, a while later, as I was taking tentative steps towards acceptance another blow happened – this time harder – siblings! No one mentioned the huge impact that disability would have on every aspect of their lives. As parents, we might feel we haven't signed up for a life of disability, but our other children certainly didn't!

My son Fionn is 12 now, attends Hillside School and is thriving. He has autism, severe learning difficulties, speech and language disorder, challenging behaviour and complex medical issues, meaning that until recently life was very difficult for us as a family. Accessing mainstream

activities was challenging for Fionn and many day to day things that most families take for granted such as a trip to the supermarket, cinema or family holidays became a distant memory.

**"It's not unusual at Pebbles to see a six year old encouraging a boisterous autistic 13 year old to replace a 'cuddle and squeeze' with a high five."**

Fionn would become very distraught being away from his normal routine and would spend hours screaming, head banging and hitting himself and others. We chose to stay at home or go on long drives to nowhere. This meant that my other two children were forced to stay at home too and we became very isolated. My daughter stopped bringing her friends home for tea, and as he got older she'd avoid returning home until after bedtime because his constant outbursts were too distressing for her.

Being part of Brighton Pebbles has been a lifesaver for me and my family. It was set up nearly seven years ago for families with disabled children who found it difficult to access mainstream activities. Pebbles gives them a chance to play and be supported by others in a safe, non-



judgemental environment. The group meets weekly after school and arranges days out and holidays.

Central to the Pebbles ethos is the role of siblings and the recognition of their daily challenges and over the years, they have developed events just for siblings, the most successful one being a yearly camping trip. This year it was at Knockhatch Adventure Park, where the children played into the early hours, building fires, toasting marshmallows and generally having a great time. There were no rules or expectations, just fun. Our next trip is a Christmas weekend away to a country farmhouse.

Our siblings often demonstrate amazing understanding and empathy towards each other and their disabled brothers and sisters. It's not unusual at Pebbles to see a six year old encouraging a boisterous autistic 13 year old to replace a 'cuddle and squeeze' with a high five, or fetch them a drink, or repeat some crazy sentence just to make them happy.

The role of the sibling is all too often ignored, and siblings need to be recognised and valued more throughout the city, not only for their amazing caring roles, but for their resilience and courage. I feel amazing pride for all of our Pebbles siblings (a feeling shared by all of our parents). They are a fantastic bunch of kids, who embrace disability, both its challenges and its positives.

**To find out more about Pebbles, call 07506 105265 or visit [www.brightonpebbles.org.uk](http://www.brightonpebbles.org.uk). Or call Amaze to find out about other sibling groups in Brighton and Hove.**



# How the council is shaping the future of SEND services in Brighton and Hove

This summer, Brighton & Hove City Council began a review of all the services it provides for children and young people with special educational needs and disabilities (SEND), including social, emotional and mental health difficulties, and behavioural needs. The review will consider services provided by the **council** (e.g. SEN assessments and planning, support services in schools, short breaks, Direct Payments, transition support), **health partners** (e.g. occupational therapy, CAMHS, The Royal Alex, counselling) and those commissioned from the **community and voluntary sector** (e.g. Amaze, Extratime, Barnardos).

The law is changing so the council wants to ensure its services are set up in the best possible way to meet its responsibilities under the new Children and Families Act 2014, so that children, young people and their families get the support they need. They want to ensure the council spends its money wisely to:

- deliver high quality, integrated SEN, health, care and disability services from 0-25 years
- ensure excellent practice in identifying and assessing SEN and disability
- provide a new framework for the way certain services are commissioned 'jointly' by the council and health
- improve transition arrangements to adulthood and ensure extended assessment and services from 19 to 25
- provide more choice for families and increase the use of Personal Budgets and Direct Payments
- engage parents and young people more effectively in decision making

In September, PaCC and Amaze circulated details of an online survey and two consultation events held by the council that asked families to consider what works well and not so well in SEND services. They also asked for ideas on



how services might be improved. Professionals such as SENCOs, head teachers, social workers and community and voluntary sector staff will also be giving their views.

More specific focus groups are being planned for later in the year – which PaCC and Amaze will publicise. These might focus on more specific topics like mental health services, short breaks and services for children and young people with challenging behaviour. The council wants to better understand where services are (or could be) making the most difference to the lives of local families.

Amaze and the Parent Carers' Council are keen to ensure the views of parent carers and children and young people with SEND are heard so they'll be supporting families to participate in these consultations. In addition, Amaze staff and PaCC parent representatives are feeding in the views of families we work with and will continue to do so throughout the review period.

The SEND review will end in December 2014 with a final report and recommendations to be discussed by councillors in March 2015. We'll provide an update on where the review has got to in the February newsletter.

## PaCConnect on the SEND Review - 5 November - BMECP Centre, Brighton

Do you want to find out more about the SEND review? Have you got any creative ideas about how the local authority can improve its services? Do you want to find out how PaCC has been involved in the review so far? Then come along to our PaCConnect forum all about the SEND review on 5 November at BMECP Centre, 10a Fleet Street, Brighton BN1 4ZE from 9.30am to 12 midday (coffee from 9.15am).

In the second part of the forum you will be able to meet Regan Delf, Acting Assistant Director, Children's Services, Brighton and Hove, Jenny Brickell, Head of Integrated Child Development & Disability Services and Jacqueline Coe, Project Manager, SEND Review.

If you would like to attend or have a question you would like us to ask on your behalf, then e-mail [paolo@amazebrighton.org.uk](mailto:paolo@amazebrighton.org.uk) or call Paolo on 01273 234862 or the Amaze helpline on 01273 772289.

# Who are your PaCC Champions for 2014?

Help us kick start the awards season by telling us about a professional or an organisation that has been very special to you during the past 12 months.

For the past five years PaCC has promoted and celebrated the exceptional work that goes on with our children in Brighton and Hove and this year is no different. We need you to help us identify a professional, a team or an organisation that has made life that little bit easier, put in the extra effort or battled on your behalf to improve the standard of care you and your family receive.

Last year, we received a staggering 47 nominations, each one highlighting the incredible work and passion that some local professionals put into supporting you and your children. You can see the full list of 2013 winners in health, education, social

care and the voluntary sector at [www.paccbrighton.org.uk/get-involved/nominate-pacc-champions](http://www.paccbrighton.org.uk/get-involved/nominate-pacc-champions)

And you gave us some very affecting reasons for your 2013 nominations. For example, our winner in the Health category, Vivienne Campbell, a neuro paediatrician at Seaside View, was nominated with the following endorsement: "I trust that Vivienne Campbell will always give me an honest and sometimes frank view of my son's healthcare. She will happily take the time to discuss in great detail any aspect of my son's condition and yet I always leave meetings with a positive outlook on the situation."

We know that this year there are likely to be just as many people who go the extra mile for you and your child, and we need you to nominate them. You can do that online at:

[www.surveymzmo.com/s3/1819315/PaCC-Champions-Nomination-Form-2014](http://www.surveymzmo.com/s3/1819315/PaCC-Champions-Nomination-Form-2014)

Once we've received your responses, a panel of parent carer judges will review the nominations and decide the winners.

Alternatively, complete the form below and return to Paolo Boldrini by 21st November 2014 at the address below. Or email your nomination to [paolo@amazebrighton.org.uk](mailto:paolo@amazebrighton.org.uk).

Please take a few minutes to say thank you for the great work done by people in Brighton and Hove, and help us to find the PaCC Champions for 2014 in social care, health, the voluntary sector and education.

## Nomination form for PaCC Champion 2014 award

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

### Your PaCC Champion(s):

Name ..... Job/Team .....

Address (if known) ..... Tel no. ....

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

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

.....

.....

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### Your contact details:

Name ..... Tel .....

Please return the completed form to Paolo Boldrini, PaCC Participation Worker, c/o Amaze, FREEPOST SEA 14216, Brighton, BN1 3ZZ or email your nominations to [paolo@paccbrighton.org.uk](mailto:paolo@paccbrighton.org.uk) by 21st November 2014.

# More fun for everyone

An update on our latest Compass Card Activities (CCAs)

## Fun-fit Spiral

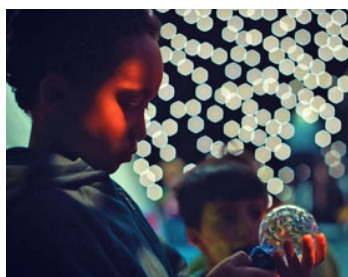
Fun-fit Spiral, our weekly multi sports session for 11 to 19s, launched on Sunday 14 September. Delivered by local charity, Spiral Sussex, the two hour Sunday session is run by award-winning coaches Lisa Nobbs and Paul McCullum. Fun-fit Spiral runs in term time every Sunday from 2 till 4pm at Carden Primary School (free parking in the car park on Carden Avenue) and Compass Card holders pay just £3.50 per session. Call Spiral Sussex on 030 30 40 2860 to find out more, or just turn up. You'll need to stay for your child's initial sessions. There are no Fun-fit Spiral sessions on 26th October, 21st and 28th December and 4th January (to allow for school holidays).



Award winning Fun-Fit Spiral coaches, Lisa Nobbs and Paul McCullum.

## Streetdance

The charismatic JP and his award-winning Streetfunk team are piloting a new street dance class for 11 to 19s with additional needs at Marina Studios this half term holiday and we hope there will be another in May half term next year. The class runs from 1.30 to 2.30pm, Mon 27th to Fri 31st October. Call 01273 253679 to book or for more information.



## Otherworld

Otherworld, our sensory, interactive Compass Card Activity that includes everybody and is different every time, is back in the New Year with a splash and a distinctly fishy theme. Local children are helping to create the project's spectacular new underwater environment and organisers are promising more amazing journeys. Catch the wave in January 2015.

## Leisure Buddies

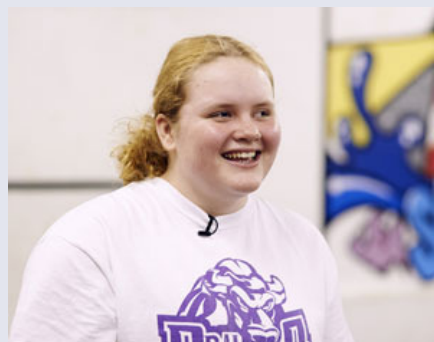
Don't forget you can book a free Leisure Buddy for six of our Sport England-funded CCAs for young people – archery, climbing, kayaking, High Flyers trampolining, Marina Studios street dance and Fun-fit Spiral. Leisure Buddies are fully trained, short term leisure befrienders who can travel to and from activities and support your child during the course or class. Call Extratime on 01273 420580 to book, or email [lisa.nash@extratimebrighton.org.uk](mailto:lisa.nash@extratimebrighton.org.uk)

To find out the full range of Compass Card Activities on offer, download the CCA guide from the Compass Card Activities page of our website or call the Amaze helpline on 01273 772289 and ask them to post you a copy.

## Kali's Paralympic hopes

Kali Holder, a 14 year old Compass Card holder who is visually impaired, is following in the footsteps of judo Paralympian, Ben Quilter, by setting her hopes on the **2016 Paralympics** in Rio. Kali started intensive judo training with Brighton Judo Club earlier this year and trainer Laurence Buckingham, who trained Ben, says: "She's got a natural flair for the sport that you can see a mile away – I've got high hopes for her".

Kali's interest in sport was fired by one of Amaze's first Compass Card Activities, Take a Leap trampolining, which she started in 2010. Kali says: "[Take a Leap] helped my confidence and led to me finding out about other things and making connections".



Kali moved to a school outside Brighton in September, but she will continue to train with Brighton Judo Club in the holidays. We wish Kali lots of luck at her new school and in her Paralympic hopes.

Take a Leap **trampolining** classes are a great way of introducing 7-15 year olds with additional needs to the joys of trampolining. Classes are at the Y Club in Hove on Mondays and Thursdays. Call 01273 731724 for timings. Teenagers with additional needs can also try our inclusive trampolining Compass Card Activity, High Flyers, from 4.30 to 5.30pm on Thursdays in term time at Moulsecoomb Leisure Centre. Call 01273 622266.





## Get active for Amaze

Do you fancy an active challenge to help raise funds for us? Or perhaps you know a local hero like Simon (above) who is willing to go the extra mile?

**Simon Cooke**, part of the Brighton Sea Swimmers Club, is training for a world record attempt for the earliest (and coldest ever) cross channel swim in May 2015. Simon will be raising funds for Amaze and we'll be tracking his progress and giving him lots of encouragement.

You might prefer a more land-based challenge like **Melanie Dunnaway** and **Richard Cole** who completed the Isle of Wight Challenge this August, walking 66 miles right round the island over 28 hours straight. They raised over £1,380 for Amaze.

If you fancy doing a sponsored trek, cycle ride or skydive in the UK or

overseas, visit [www.doitforcharity.com](http://www.doitforcharity.com) and choose from a range of pre-organised challenges that you can do for us.

Of course, you don't have to attempt something quite so intrepid as Simon's world record attempt or Melanie and Richard's epic walk. You could take a more conventional fundraising route and do a sponsored run for us such as the forthcoming Brighton 10K, Half Marathon or Marathon.

For more advice on any of these fundraising activities (or any ideas of your own) contact Nicky on 01273 234014.



### Annabel wins £25k for Amaze

Our patron, TV star and presenter, Annabel Giles, won £25,000 for Amaze on ITV game show, 'The Chase' in September. Annabel was part of a celebrity team including comedian Julian Clary who managed to beat The Chaser, one of Britain's finest quiz brains, and raise thousands for their chosen charities, including Amaze.

Rachel Travers CEO of Amaze said "Amaze is sincerely grateful to our patron Annabel for this valuable and unexpected contribution, which will make a massive difference to our small charity and will mean we can support more local families with disabled children."



### BIG CHEER 4 all

Huge thanks to our brilliant comedians and audience at the 4th BIG CHEER for Amaze on 16th October at Komedia Brighton.

The side splittingly funny final line-up was Nick Helm, Joe Wilkinson, Holly Walsh, Zoe Lyons, Angela Barnes and Justin Moorhouse and a wonderful night was had by all - full report in the next issue!

### Bottoms up!

Thank you **Brighton College Prep School**, **Quaff Fine Wines** and **Get Started - Cooking for Life** for a fabulous evening of Spanish wine and tapas tasting on 26th September. Guests enjoyed a delicious evening and bid for prizes that raised an impressive £2,700 for Amaze. Look out for this event next September as we plan to run it annually.



Winning bidders enjoy a boating prize from last year's event.



## Win tickets to 'One Man, Two Guv'nors'

We've got a pair of tickets to give away for the Theatre Royal Brighton show the Daily Mail called "The funniest Show on the Planet". Tickets are for the 7.45pm opening night show on **Tues 16th December**.

Open to Compass Card families, you just need to send your name, the Compass Card holder's name, plus your address, telephone number and email address (if you have one) by Mon 17th November.

We'll inform the winner by the end of November so send your entries to Amaze at the address below, or email [compass@amazebrighton.org.uk](mailto:compass@amazebrighton.org.uk)



## Try This!

**10am to 12 noon, Sat 1 November**  
at King Alfred Leisure Centre, Hove.

This action-packed **sports taster event** gives 5-19 year olds with additional needs the chance try basketball from the team at Fun-fit Spiral, cricket from Sussex County Cricket and multi-sport, boccia and new age kurling from Active for Life's Saturday Active Club. Everything is free and there's even a sport goody bag for the first 60 participants. No need to book, just turn up!

## Fancy a cuppa?

If you live in Hangleton & Knoll or Moulsecoomb and you fancy getting together with other parents of kids with additional needs, why not come along to one of our monthly coffee mornings, run jointly by Amaze and local community workers. These regular, informal meetings are a great chance for a get together but also often have a topic or speaker.

The next Moulsecoomb coffee mornings are on **4th November** and **9th December** in the Community Room at Moulsecoomb Primary School. The themes for these are yet to be confirmed but we hope to have CAMHS at one or both.

The next Hangleton & Knoll get together is on the **18th November** in

their usual venue, St Richard's Community Centre, Egmont Road. The meeting will include an Autism Sussex workshop on sensory problems.

If you'd like to find out more about the coffee mornings, email [amanda@amazebrighton.org.uk](mailto:amanda@amazebrighton.org.uk) or call the Amaze helpline.



Amaze's Ros Cook enjoying visiting the Moulsecoomb group earlier this year.

# 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 Christmas the helpline will close from Weds 24th December for the festive period. It will re-open on Mon 5th January.

Save us paper and get this newsletter earlier by email!  
Just email your details to [info@amazebrighton.org.uk](mailto:info@amazebrighton.org.uk)



## Amaze

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T: 01273 772289

E: [info@amazebrighton.org.uk](mailto:info@amazebrighton.org.uk)

W: [www.amazebrighton.org.uk](http://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.

