



ANNUAL REPORT 2013

working with parents of children with special needs

Joint statement from the CEO and Chair

This year we were delighted to win the much coveted 'Biggest Impact' award at the inaugural Community and Voluntary Sector Forum Sector Stars Awards 2012. This award recognised the tireless work of all our staff, volunteers and supporters involved with Amaze to help local families with disabled children.

Receiving the award in November, from then Mayor Bill Randall, gave the team a great boost during what has been another very busy year, with demand for our 'award winning' services not letting up.



Our helpline, for example, responded to 4,278 calls (a massive 9 per cent increase on the year and a 102 per cent increase over the last six years). We were able to add an extra weekly helpline session this year, using money raised by the fantastic team of runners we managed to attract as one of Brighton Marathon's local charity partners for 2012.

This year, we managed to retain our income levels at £482k, whilst cutting our costs to £410k, allowing a surplus to be added to our reserves at the end of the period. Fundraising continues to be very successful, bringing in £56k of much needed unrestricted funds as well as helping to raise Amaze's profile locally.

Our supporters don't just help us raise money. A team of 32 committed volunteers now support our case work providing parents with individual support on disability benefits (DLA), education and preparing for adulthood (transition). We also have four regular volunteers who ensure the smooth running of our office. We would like to say a huge thank you to all of them.

In November, the University of Brighton published an independent evaluation of the Amaze DLA project which found that our DLA volunteers worked in 'a sensitive and professional way', letting parents just talk then extracting the necessary

information to complete the 41-page DLA form. The researcher found the service had a very 'profound effect on people's lives' and 'led to significant improvements in the family's financial and mental health and wellbeing.' You can read the full report in the Resources section of our website.

One of the most striking findings from the DLA Evaluation was that all parents interviewed were receiving (or had recently received) pharmacological treatment for mental health problems, most commonly depression. This led us to make mental health a key theme for our 2013 parent carers survey which found that 18% of 341 respondents said they were depressed/ anxious/ stressed all or most of the time. 20% said they felt socially isolated, 25% never got a good night's sleep and 30% felt like they were neglecting themselves.

"When you're dealing with a child with additional needs, I think it's the energy levels, resilience, to keep going at a sustained level of caring... because other people don't understand what it's like to be consistently up at night..."

Parent interviewed for DLA Evaluation

Amaze and the Parent Carers' Council (PaCC) representatives continue to convey the needs of children with disabilities and their carers in as many meetings, evaluations and reviews as possible. Most of our partners are listening and services are getting better.

For instance, we have continued to be actively involved in supporting Brighton & Hove City Council in the SEN SE7 Pathfinder, ensuring that parent carers are involved in the development of the new single Education, Health and Care Plan, Personal Budgets, the Local Offer and initiatives to increase parental confidence and support. Also, 2012 saw the launch of the PaCC's Talk Health Report, setting out what progress parents wanted to see in local health services for their disabled children.

Sadly, some parent carers still report having to wait unacceptably long to see the relevant professionals and this is likely to get worse as public sector cuts continue well into 2014. Our recent survey found that only 15% of parent carers who responded were currently provided with any short breaks or respite via social care services. Of these parent carers getting respite, 30% said their package had already changed significantly in the last 12 months, and 82% said that if this package was further reduced it would have a devastating impact and they would be unlikely to be able to cope.

Families with disabled children face multiple challenges. But at least locally they know they have the support of Amaze and the PaCC to help press for improvements and retain investment in supporting the needs of their children.

Rachel Travers, CEO and Hugh Clench, Chair



Disability Living Allowance Project

The DLA project tackles poverty. It's harder to hold down a job and much harder to live on benefits if you have a disabled child. Each additional challenge makes claiming DLA harder. But what hits every parent, even the most resilient, is the misery of focusing on what your child can't do, rather than what they can.

'It's like someone's tipped a bag of scorpions into your lap and you have to pick each up, one at a time'

Parent explaining how it feels to complete a DLA claim

Working alongside one of our volunteers is the only realistic chance many parents have of claiming the extra benefits their child is entitled to. This is what we do.

Key achievements in 2012/2013

- We drafted 309 new DLA claims: 10% on last year. We calculate the annual income generated from Amaze's DLA work totals over £2.3 million.
- We are reaching the most disadvantaged families in Brighton and Hove: 41% are living on benefits; 45% are lone parent families. A third live in the four most deprived wards
- We are reaching the families most at risk of social exclusion: 26% had two or more disabled children; 18% had at least one parent with mental health problems; 23% had at least one parent managing an illness or disability of their own; 11% had experienced domestic abuse; 4% needed support from an interpreter.
- Amaze calculate that we are likely to have generated another £1 million by supporting parents to claim passported benefits like carers allowance and disabled child tax credits

Education support via the IPS Scheme

Parents of children who are disabled or have additional needs often need extra support and information to help their child get the best out of school. The Independent Parental Support Team Manager and her trained volunteers understand how education works and offer parents this vital one to one support. The IPS scheme is a key part of Amaze's role as the Parent Partnership Service for Brighton and Hove. We aim to help parents advocate positively for their children, whilst building partnerships with schools and services.

Key achievements for 2012/13

- We provided one-to-one support on education issues to 147 new families (an increase of 7% on the previous year) and gave on going help to many others
- We maintained our team of 12 Independent Parental Support volunteers
- We further improved our understanding of SEN law to offer parents accurate advice

"We can't thank you enough. The positive difference has not only affected our child but us too and I am feeling cautiously optimistic about the future for the first time in years (which is not an exaggeration!)"

Parent thanking the IPS Team Manager

Helpline

Parents call our helpline because they know they will get reliable information from an adviser who really understands what it means to care for a child with additional needs. Despite rising numbers of calls, we make sure every parent is listened to properly and gets an individual response whether that is a straightforward bit of information or the chance to unpick a complex issue about their child. The helpline also links parents to our other services such as help with DLA, the Compass and our courses for parents.

"Thank you for the advice and the handbook...it's helped me so much already. I'm thinking about DLA and will contact Amaze for more advice if I need to"

Parent emailing the helpline after a call

Key figures for 2012/13

- We had 4278 calls, 529 of which were from new callers. Calls have risen by 103% in the past six years
- We added a new afternoon session so we offer six sessions a week in term-time and four in the school holidays
- Parents across the city use the helpline but we get more calls from areas that have more families and are less well off. This year most calls came from Moulsecoomb & Bevendean, East Brighton, Hanover & Elm Grove and Hangleton & Knoll
- Money/benefits and education issues continue to be the most popular topics for calls



Publications and website

Our publications continue to provide a much needed and much admired resource for parents and carers of children with special needs and disabilities and the professionals who support them.

"I love the newsletter - very informative and attractively presented."

Parent responding to a survey about our publications

Key achievements this year:

- Distribution of our newsletter, Out of Amaze, grew by 1500 with total yearly distribution now at 15,152 copies
- We updated our handbook Through the Maze for parents of children up to 14, and over 250 copies were distributed
- Our website audience grew by 10 per cent on last year, to just under 40,000 visits (just under 30,000 unique visitors)
- Thanks to funding from Brighton & Hove City Council and Blatchington Court Trust, we began a major piece of work to improve the design and usability of our website. The new site will launch officially in November 2013.
- We sold the content of Through the Maze to Somerset County Council to repurpose for use in their area

Amaze courses, workshops and events

Amaze courses and events are always in demand because they offer relevant information and ideas, together with the chance to meet other parents in similar situations. Parents know they will be delivered in a parent-friendly style, usually with parent trainers taking the lead. Evaluation of our longer courses shows clear improvements in parent's sense of mental wellbeing at the end of the course. As well as our regular courses, we ran workshops in partnership with local professionals on topics including helping your child with anxiety, writing skills and visual processing. We also gave presentations or ran an information stall at a variety of events for local parents and professionals.

"Thank you so very much for such an incredible course and for being so supportive and a wealth of knowledge. I know you have made such a huge impact in my life."

Parent attending a Triple P course

Key achievements in 2012/13

- Four 'Triple P' positive parenting courses helped parents support their child with their behaviour, tailoring this to their child's special needs
- Three 'Insiders Guide' courses built parents' resilience in bringing up disabled children, mixing practical knowledge with a look at the emotional side of being a parent carer
- Two 'Looking After You' courses addressed the physical and emotional stress of caring, with Pilates and relaxation techniques, and follow on groups helped maintain this
- 'SEN – The Future' was the theme for this year's parent information fair. Over 150 parents attended

Preparing for adulthood

Research shows that the transition from childhood to adulthood for disabled young people and their families is often the most stressful period of their lives. Amaze works with parents and professionals to try to change this to ensure good outcomes and make the transition to adulthood a more positive experience for everyone.

Key achievements in 2012/2013

- We piloted a small Transition Support Project, training volunteers to provide one to one information, advice and support for families in their own homes
- We ran the following courses for parents of young people: Insiders Guide to Bringing up Teens with Special Needs; Planning for the Future (Wills and Trusts); the change from Disability Living Allowance to Personal Independence Payments; Housing and Support Options and Transition Information Sessions
- We distributed our Through the Next Maze handbook to parents of teens with a Statement of SEN
- We gave individual advice and information to parents about transition-related issues
- Parent representatives and Amaze's Transition Worker contributed to a number of strategic boards regarding transition related issues

"I understand more about Personal Independence Payments – I didn't know anything about it before today."

Parent attending our DLA/PIP workshop

The Parent Carers' Council (PaCC)

The PaCC has continued to grow with support from Amaze. We work to raise the profile of the parent carer experience - making others aware of the challenges we face and help influence and improve the services our children receive. The steering group has welcomed three new parents this year and continues to represent parents on strategic decision making groups across the city. As well as increasing local recognition, our profile has also grown regionally, with our involvement in the work of the SE7 pathfinder pilot, and nationally, with the connection to the National Network of Parent Carer Forums (NNPCF) and Contact a Family (CAF).

Key PaCC achievements in 2012/13

- Membership grew to 210 parent carers and we represented 650 families through our partner organisations (there's some overlap between these families)
- Our Talk Health report was championed by the Health and Wellbeing Overview and Scrutiny committee (HWOSC) who charged each of the health services to produce a report evidencing the changes they had implemented since our original recommendations were published. Parents were invited to the Talk Health follow up event to hear more detail from the key service managers about these changes
- The PaCC has continued to be heavily involved with changes in SEND as part of the SE7 pathfinder work and continues to lead on improving support to parents and carers in schools. Two parents are now active members of the SEN Partnership Board
- PaCCConnect workshops gave parents the opportunity to meet professionals from the SEN, social care and therapy teams to ask questions and learn more about the service
- The fifth annual PaCC awards saw champions from health, education, social care and the voluntary sector receive awards for making a real difference to our families. A special achievement award was presented to Jenny Brickell for her work in promoting partnership working
- The Partnership Charter assessed 10 services this year helping those services improve the way they work with parent carers



The Compass and Compass Card

The Compass is Brighton and Hove's 'disability register' of children with significant special educational needs, disabilities or complex health needs. Registration is voluntary and the database is held independently by Amaze on behalf of Brighton & Hove City Council. The Council and other local service providers use anonymised data from The Compass to plan and deliver services.

Every child on The Compass gets a free Compass Card, a leisure incentive card that provides discounts and special offers across the city. The Compass is invaluable for keeping in touch with families and allows Amaze to keep parent carers up to date on the things that really matter to them.

Key achievements in 2012/13

- The number of children on The Compass rose by 2% to 1526
- Compass e-bulletin sent almost every week to Compass families with email addresses (currently 80% of registered families), as well as targeted mailings
- Statistical data provided to local partners for commissioning reports and service development initiatives
- Six new Compass Card offers added – The Academies, Brighton & Hove Radio Cabs, Natasha Nice home hairdressing, Paradise Park, Portslade Sports Centre and T.O.M (The Old Market). Ad hoc offers and freebies for are also on the increase – free tickets to Sparks in the Park in Horsham and the Children's Festival were just two examples
- Six new Compass Card Activities developed for kids with special needs – BHISP after school club, Saturday Active Club, Family Swim and Starfish swimming class at Prince Regent Swimming Complex and inclusive youth club sessions at the Crew Club and the Y Club
- We provided a wide range of leisure information in the 'Amazing Zone' at Takepart Festival Launch Day in June 2012. The zone, initiated by Amaze in 2010, attracted over 500 visitors

The Carers' Card

Brighton & Hove City Council launched the Carers' Card in June 2011 to promote the health and wellbeing of carers across the city, including parent carers. Amaze developed the initial 25 offers on the card and continues to develop offers for the Carers' Card and to promote the card to parents looking after a child registered on The Compass database, who automatically qualify for a Carers' Card.

Key achievements in 2012/13

- 18 new Carers' Card offers were added including Brighton & Hove Radio Cabs, Brighton Natural Health Centre, Brighton Science Festival, Painting Pottery Café, Portslade Sports Centre, Royal Pavilion and Museums, The Outdoors Project, T.O.M (The Old Market), Whitehawk Inn and Yoga Haven
- The Compass e-bulletin, which is usually sent out weekly to parents with a child on The Compass, provided regular updates on new Carers' Card offers. The Carers' Card was also promoted via the Amaze website and at key events like Takepart Festival Launch Day in June and the Amaze Info Fair in November.
- Amaze facilitated two Alexander Technique College Carers' Workshops at Community Base to help carers deal with the stresses and muscular pain of everyday life; and a Pamper Event at City College that provided 10 carers with a full morning of reflexology and aromatherapy

"The Carers' Card gives me access to things I couldn't possibly afford otherwise. It's about being able to have those treats."

Parent commenting on the Carers' Card



"The way the session is run makes going to the cinema a pleasant experience"

Parent commenting on the autism-friendly screenings at the Duke of York's cinema.

The Partnership Outreach Pilot (POPP)

POPP is a community engagement project aimed at strengthening our relationship with parent carers in the less well-resourced areas of the city. Working with The Trust For Developing Communities in Moulsecoomb and The Hangleton & Knoll Project, POPP has knocked on doors to engage with families directly and has held monthly coffee mornings in both areas. Feedback so far has been positive and over 40 parent carers have attended coffee mornings.

The project aims to increase the sense of belonging to a community of other local families with disabled children, to reduce isolation, to give these parents a stronger voice and to provide a support network for families. This in turn should increase confidence and resilience and improve outcomes through Amaze and the local partners' support. We hope that these groups of parent carers will eventually become self-sustaining.

This innovative project has the potential to reach out to groups of parent carers who would really benefit from Amaze's support, as well as being signposted to other services. However, the challenge going forward is to secure further funding to continue the current project and reach more communities that are seldom heard.

"I am really glad I came today. It has been real respite for me and it's been great talking to other local parent carers. I have also picked up tips from other parents which is fantastic."

Parent visiting coffee morning in Hangleton & Knoll

Statement of financial activities

For the year ended 31 March 2013 (including income and expenditure account)

	Unrestricted Funds £	Restricted Funds £	Total Funds 2013 £	Total Funds 2012 £
INCOMING RESOURCES				
Incoming Resources from Generated Funds				
Grants	2,699	35,000	37,699	37,250
Bank Interest	630	-	630	222
Fundraising and donations	61,072	-	61,072	35,127
Incoming Resources from Charitable Activities				
Grants	368,136	-	368,136	384,098
Services	<u>15,323</u>	<u>-</u>	<u>15,323</u>	<u>18,675</u>
TOTAL INCOMING RESOURCES	<u>447,860</u>	<u>35,000</u>	<u>482,860</u>	<u>475,372</u>
RESOURCES EXPENDED				
Fundraising costs	32,260	-	32,260 ¹	24,661
Charitable Activities	337,368	37,721	375,089	401,387
Governance Costs	<u>2,348</u>	<u>-</u>	<u>2,348</u>	<u>2,548</u>
TOTAL RESOURCES EXPENDED	<u>371,976</u>	<u>37,721</u>	<u>409,697</u>	<u>428,596</u>
NET INCOMING/(OUTGOING) RESOURCES FOR THE PERIOD				
	75,884	(2,721)	73,163	46,776
TRANSFERS	<u>(288)</u>	<u>288</u>	<u>-</u>	<u>-</u>
NET RESOURCES FOR THE PERIOD AFTER TRANSFERS	75,596	(2,433)	73,163	46,776
ACCUMULATED FUNDS AT 31 MARCH 2012				
	<u>168,790</u>	<u>4,104</u>	<u>172,894</u>	<u>126,118</u>
ACCUMULATED FUNDS AT 31 MARCH 2013				
	<u>244,386</u>	<u>1,671</u>	<u>246,057</u> ²	<u>172,894</u>

¹ Income and resources generated by fundraising are £98,771. Fundraising costs are £32,260. We estimate on average our fundraising income is three times that of the costs of fundraising.

² It is good practice to hold three months' worth of operating expenses in case any of these core funders have to terminate these agreements without notice, and the Trustees believe it is important they hold enough financial reserves to ensure an ordered and proper closing of Amaze in these circumstances. The Trustees only wish to have these financial reserves at a minimum level. The reserves policy will fund:

- Three months operating costs
- Any redundancy payments due to employees
- Support to employees in finding alternative employment
- Terminating service contracts such as office rent and equipment
- Accountancy, audit and other professional costs

All amounts relate to continuing activities. There have been no recognised gains or losses other than the results for the year and all surpluses or deficits have been accounted for on an historical cost basis.

A very big thank you to...

Our supporters

Amaze relies on the support of many different people and organisations. We're particularly indebted to those who have given their time, expertise and support. Limited space means we can't thank everyone individually, but the following deserve a special mention for their support in 2012/13.

Patrons

Henry Normal, Angela Pell and Annabel Giles

Trustees

Hugh Clench (Chair)
Ian Gillett (Treasurer)
Diana Boyd
Karen Smith
Susmitha Gadiyar
Sally Howell
Debby Norris
Fungi Woolnough-Murau
Ian Elwick
Tony Gove
Siobhan Cox
Ray Knight

Volunteers

Jane Barnett, Nicky Beanland, Tom Blackburn, Natalia Borg, Carol Burns, Shiromi Cabraal, Rosie Chapple, Alfie Cook, Matilda Cook, Oswalde Corke, Allison Dickson, Alison Field, Janet Finn, Susmitha Gadiyar, Clare Galler, Sandra Gallon, Nicola Gibson, Becky Hartfield, Edward Hartfield, Linda Hill, Brenda Hinchliffe, Hannah Jeffries, Gillian Kitchener, Kerry Korkunc, Christine Lee, Brenda Mann, Wendy McCarthy, Lisa Mitchell, Mai Osman, Bruce Piper, Lisa Radley-Martin, Lorraine Roberts, Sharon Rose, Susan Rosenfield, Sandamalee Senanayake, Joanne Shannon, Sonya Smith, Julie Stokes, Catriona Strong, Lynne Swaisland, Sue Timpson, Jill Weeks, Jess White, Ann Wilkinson, Helen Wyatt

Community partners

We would like to thank all the leisure providers in Brighton and beyond who offer such wonderful benefits and discounts to our Compass Card holders. Although we cannot mention you all here, we are extremely grateful for your generosity and support.

Our funders

Statutory funders

Brighton & Hove City Council, CCG Brighton & Hove, South Downs Health NHS Trust

Grants and other funders

Brighton & Hove Learning Disability Partnership Board, CVSF, Department for Education, Ecorys UK Ltd, Ernest Kleinwort Charitable Trust, Noel Bennett Grants Fund, Sport England Inclusive Sport Fund, Sussex Community Foundation, The Fitton Trust, The Henry Smith Charity, University of Brighton, Adult & Community Learning Fund, East Sussex County Council, Ian Askew Charitable Trust, St James's Place Foundation, Wellesley Wealth Advisory



All our wonderful marathon runners, fundraisers, donors and sponsored event participants

Amaze would like to thank all the fundraisers and donors who raised vital funds and increased awareness of our work. Although we cannot mention you all by name, we are so grateful for your continued support.

Donations & Events:

ABN AMRO Finance, Baby Cow Productions Ltd, Brighton Brooks 10K, Brighton Half Marathon, Brighton Marathon Grounded Events, Butler's Wine Cellar, Charity Chuckle, Dean Wilson LLP, Ferrero UK, The Grand Hotel, G-Whizz Cycles, Jak Designs, Latest Homes, Pardon My French, Photography by Foz, Portslade Brownies, Roedean School, Rotary Club of Brighton, Russell New, Santander Consumer Ltd, Southwick Flower Club, Studio 57 Clinic, Theatre Royal Brighton, TP Training, Virgin Media, Warren Evans. *Comedians for BIG Cheer*: Phill Jupitus, Angela Barnes, John Moloney, Ray Peacock, Raymond and Mr Timpkins, Roland Rivron

Our staff

Rachel Travers - Chief Executive Officer
Kim Aumann - Director ART
Ros Cook - Operations Director
Nicky Bagilhole - Fundraiser
Lizzie Batten - DLA Project Manager
Ann Blackburn - Compass Card/Carers Card Development Worker
Zoe Brinkworth - Finance Manager
Tina Brownbill - Database Manager
Debbie Collins - Parent Participation Worker
Nicola Keene - Database Administrator
Charlotte Moroney - Publications and Website Manager
David Natha Gregory - Helpline Advisor
Janet Poole - IPS Project Manager
Sue Winter - Transition Development Worker
Amanda Mortensen - PaCC Co chair
Tim Lavender - PaCC Co chair
Emma Parker - Helpline Advisor
Hannah Osborne-Dowle - Helpline Advisor
Hazel Herovitsch - Transition Caseworker

Social Work Student

Toni Rigby

Freelance workers and parent trainers

Helen Arnold Jenkins - Parent trainer
Carrie Britton - Consultant & Senior ART Associate
Sandra Chitty - Parent trainer
Claire Peligry - Parent trainer
Samantha Selway - Parent trainer

PaCC steering group members and parent representatives

Reza Ataie, Chrysi Brown, Gilli Davidson, Medeni Elwick, Fiona England, Sharon Garcia, Nicola Gibson, Angus Goldfinch, Sophie Gove, Martin Jones, Ruby Kearns, Marian Tipler, Claire Turner, Jill Weeks

We have 210 members which would be too many to name individually. Many thanks for the contribution they have made to consultations over the year.



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