



Impact Report 2015

"You've been such a help, I'm so grateful.
If I ever win the lottery I'm giving it all to
Amaze (well most of it anyway)!"

Amanda Jowers Harding, parent carer



**How Amaze improves the lives of families
of children and young people
with special educational needs and disabilities**

Who is Amaze?

Amaze is a charity that provides information, advice and support to families of children and young people with special educational needs and disabilities (SEND) in Brighton and Hove. We also provide Independent Support services to both parent carers and young people up to 25 in West Sussex.

Our vision

We want to see a world where families with children and young people with special educational needs and disabilities feel valued, included in their community and supported to thrive.

The problem we address

Families with children with disabilities or special educational needs :

- Often live in poverty, in overcrowded housing or housing not suitable for their needs
- Are socially isolated from their peers
- Are more likely to live with a single parent
- Suffer from poor physical and mental health
- Struggle to find out what's out there to help
- Often have more than one child with additional needs or a disability themselves

What we do

We give families the information they need to make the best choices for their child or young person and give them direct support where and when they need it most. We do this via the following services:

- Helpline
- Publications and online resources
- Courses and workshops
- Help with claims for Disability Living Allowance
- One to one support with education, health and social care issues
- One to one support with preparing for adulthood
- Compass Leisure Card and inclusive leisure activities
- Independent Support with Education, Health and Care (EHC) Planning
- Community outreach programmes

“Over the years I have turned to Amaze for your invaluable service and your help and kindness has made and continues to make a big difference to our lives - thank you.”

What is distinctive about us

We believe that parents are the experts in their child's care and we put the views and experience of parent carers at the heart of everything we do. Over half of Amaze's 32 staff are parent carers themselves. Of the 50 volunteers who support our work, about half have direct experience of caring for a disabled child and our Board of Trustees is made up of at least one third parent carers together with SEND professionals. And many of these parent carer volunteers or board members become staff members. Since 2008, Amaze has supported the Parent Carers' Council (PaCC), the local forum for parent carers of disabled children who work together to help improve services and support in Brighton and Hove.



Executive summary

Families with disabled children tell us that life is complex. They often say that it can feel like they're in a 'maze' as they try to cut through all the jargon to find out about their child's disability and the support available for them, especially when their child has just been diagnosed.

"When my son was born he was in special care for three weeks and we knew when we left that he had cerebral palsy and it was going to be quite severe. We were sent home on our own and we didn't know anything. Didn't know who to phone. Didn't know anyone."

It can make a huge difference to a parent carers' ability to cope if they have access to good quality and **impartial information, advice and support (IAS)**. Amaze has successfully provided this service (previously called the Parent Partnership Service) in Brighton and Hove for the last 18 years. We do this via our Helpline, publications, website, events and workshops and more recently, through active use of social media.

We also champion the views and experiences of parent carers and put them at the heart of all the services we develop or the services we help others to develop. Whilst this will always be a key priority, a central theme of the **new Children and Families Act 2014** is the need to also give children and young people with SEND a louder voice in how services are developed and delivered for them. Amaze has responded: leading a **regional research project** (together with partners in East and West Sussex and Hampshire) to find out what both parent carers and young people with SEND would need to support them with new SEND Reforms, then setting up new services to meet these needs.

The new Children and Families Act came into effect in September 2014 and introduced new ways for children with SEND to be assessed and supported, including the replacement of the old Statements of SEN with new Education, Health and Care (EHC) Plans and the extension of SEND support services from 19 to 25.

Amaze won new contracts to provide the 'Independent Support' service – offering support to

parents and young people with SEND during the new EHC process – which we are now delivering across Brighton and Hove and West Sussex. Despite the complexities



Amaze CEO, Rachel Travers

involved in **expanding our services both geographically into West Sussex and to a new client group** (young people), we are delighted that recent evaluations from this new service show that **96% of users are completely satisfied** with the support from their Amaze Independent Supporter.

During the past year we have also been developing new information products and extending our helpline support and Compass Card offers to young people up to age 25. An external review of the Compass Card by JB Juventus in November illustrated just how essential accessing more affordable, inclusive, leisure opportunities is for Amaze families: **83% said the Compass Card had improved their quality of life.**

The continuing pressure on household income and benefits, coupled with all the changes in the SEND world, has meant that our **Helpline continues to face unprecedented demand** (up 18% on the year) and during 2014/15 we dealt with **4868 calls**. Unfortunately we could not respond 'live' to most calls; instead we operate a call back system where we return messages left, the majority within 48 hours. We know this isn't good enough so we have introduced a **new case management system** and have trained up **new Helpline volunteers**, both of which should help us to answer more calls as people phone in.

Whilst our new contracts have **significantly increased our income this year (by 59%)** and will do for next year too, these are time limited. Plus, our core funding contracts will be retendered during 2015 and we anticipate having to continue to respond and innovate in an increasingly unstable funding environment.

We are immensely grateful to all our funders and our committed team of staff, volunteers, trustees and patrons who work with such dedication and flexibility so that Amaze can continue to support so many families stuck in that 'maze'.

Rachel Travers, CEO and Hugh Clench, Chair



2014/15 in numbers

1

Parent carers were **more informed** about their child's additional needs and the support and services available to them

16,549

Amaze newsletters were distributed - up 38% in 5 years

4868

calls handled by our helpline. An 18% increase on last year

107

parent carers attended information events about SEN changes



"I'm now clear about the rights of my child and our rights as parents."

2

Parent carers felt **well supported** in relation to their child's additional needs

96%

of parents and young people who had Independent Support said they would recommend the service

699

families received practical and emotional support from our IAS and DLA services

£3m

added to families' incomes as a direct result of the help we gave them with claiming DLA and associated benefits

"Amaze has made me feel incredibly supported - thank you!"

3

Parent carers felt **more able to deal with any issues** that arose from their child's additional needs

72%

parent carers of Compass Card holders said the Card had helped reduce their

53

parents who came to a Preparing for Adulthood info session said they felt more confident about taking action to help their child.

81%

participants on our Insiders' Guide courses reported improved mental wellbeing after the course



"Ben now has the Compass Card in his wallet and uses it himself. He is no longer self harming. He is growing in confidence and has a great deal of independence."

4

We helped more families to have **a sense of being included, understood or connected** to others in a similar situation and to their wider community

1812

children and young people aged 0-25 were registered on The Compass (up 11% on last year) and getting regular, up to date information about their community.

21

families who had never used Amaze before were engaged via our POPP coffee mornings in more deprived areas of the city.

262

new children and young people got a Compass Card for leisure discounts and inclusive leisure

“When you have a disabled child it is easy to feel like you are in your own bubble and that the ‘outside’ world doesn’t really understand the challenges you face on a daily basis. The Compass Card really breaks that feeling down as there are always activities that **we feel really welcome** to take our son to and the ‘outside’ world really starts to feel much **more welcoming and caring.**”



5

We made sure that the **voice of parent carers and young people was heard** and their views were taken into account on issues relating to their family's needs

25

external consultations were carried out to gather parent carers views on issues from SEND changes to sharing patient records.

44

strategic boards, groups or forums were attended by Amaze staff or PaCC representatives

132

parent carers and 11 young people worked with Independent Supporters to produce Education, Health and Care Plans.

“It was very helpful and enabled our son to have his voice and views heard independently (and not through us his parents)”

“She was able to **put forward our wishes**, when at times in the review it became overwhelmingly emotive as it isn't a normal occurrence to speak about our son's limitations or can't dos ... so really made a **difference** there!”

Our work and its impact

Helpline

Our helpline is the gateway to all our other services. Parents who call us can speak to a **trained adviser** about any issue that is worrying them and, if they need more intensive support, they'll be referred on to one of our face to face services.

Our helpline this year was busier than ever. We handled 4868 calls (up 18% on last year) but we were not always able to respond to parents' queries as quickly as we would like. To improve our response times going forward, we're **extending the Helpline opening hours** and **training up new volunteers** to work alongside the primary adviser.

"Just wanted to say thank you SO much for the chat the other day. Your kind voice at the end of the phone was just what I needed to hear...your help and kindness has made and continues to make a big difference to our lives - thank you."

Publications and online resources

We publish a **huge range of information** for parents and carers about SEND issues, services and developments and we do this in lots of different formats such as handbooks, newsletters, factsheets and online content.

Our **online audience and activity increased** significantly this year with our redesigned website attracting 2300 visitors each month (up 77% on the last financial year) and community of Facebook friends increasing to 634. We are using expert training from American Express Brighton to **develop our use of social media** over the next year as well as gathering more data about the impact of some of our print publications.

"We received the handbook in the post this week and found it very useful. It's led to us applying for a carer's card for my wife and to us uncovering benefits in our Duke of York's cinema membership that we had not been aware of."

Courses and workshops

We run regular courses for parent carers called Insiders' Guide, Triple P and Looking After You as well as one-off workshops on more specific subjects. Parents who attend our courses tell us they feel **more confident** about making **informed choices** for their children and that they really benefit from **meeting other parents** in the same boat. And this is not just anecdotal: a 2012 evaluation of our Insiders' Guide course* found that each £1 invested in developing and delivering the course produced a social return on investment (SROI) of £24.99.

"The IG course has helped me feel a lot less isolated and helped me feel like a better person and I'm not actually a bad mum."

*Forecast of Social Return on Investment of Insiders' Guide 'Journeys for Living and Learning' by Carrie Britton PhD., MSc., Dip.C.O.T.

Independent Advice and Support Service

Our Independent Advice and Support Service (IASS) gives dedicated, one to one support to those parent carers and young people who need extra help to sort out difficulties they're having with education, health or social care. Our IASS workers might go to school meetings, speak to services on their behalf or just be there in a crisis.

The IASS was launched in September 2014, in response to changes in legislation brought in by the new Children and Families Act. It replaces our old Parent Partnership Service (which had a stronger focus on educational support) and can support parents with children and young people **up to 25** as well as the children and **young people** themselves.

"Many thanks for Janet's invaluable support with our meeting yesterday...It definitely meant the meeting went better than we had hoped."



Disability Living Allowance Project

Our DLA service sends expert staff or volunteers to parent carers' homes to help them complete 40-page claim forms for Disability Living Allowance. This **highly innovative service model** generated **£3m pounds** for local families in DLA and associated benefits in the last year alone. Costing just £74k per year to run, this means that **every £1** we spend on the service **generates £44 for local families**.

But the money is just part of the story. An independent evaluation by the University of Brighton in 2012 recommended to commissioners that the DLA project be considered a **"highly effective mental health intervention** for carers of disabled children as it helps validate their experience and begins to boost and support their resilience and self esteem, in addition to providing obvious financial benefits."

"Getting the highest level of DLA for her was a massive validation that she was really ill. And so actually getting that money, it was like somebody's recognising this."

"The impartial, professional advice and support cannot be praised enough. I/we as a family could not imagine going through such a stressful/unclear process without the input of an Independent Supporter from Amaze."

Independent Support

Launched to help families cope with the changes introduced by the new Children and Families Act, our Independent Support Service helps parent carers and young people to manage the process of getting an Education, Health and Care Plan. We run the Independent Support Service for both Brighton and Hove and West Sussex and we're delighted to report that in the six months since the service was launched, 96% of the people using an Independent Supporter gave us a **satisfaction rating of 5/5** and would said they would recommend the service to their friends.

Compass database

The Compass is the **children's disability register** for Brighton & Hove, run by Amaze. Families fill in a four page form about their child's needs and the services they use or want and in return they get a Compass leisure card (see below) and regular and targeted e-mails about stuff that matters to them. 98% of parents told JB Eventus that the Compass made them feel **well informed about leisure activities** that can meet their needs.

And it's not just families that we can keep informed. By storing and sharing the aggregated data that families supply with the local council we help them to plan services more effectively. For example, registered families were invited to contribute their views to **25 different consultations** in 2014/15.

"I just wanna write to thank you so much for the email updates from Amaze. Keep the updates coming!"

Compass card and activities

Children and young people who are registered on the Compass database get a Compass leisure card which gives them discounts, offers and freebies at a huge range of local **leisure** outlets as varied as cinemas, libraries, farms, bowling alleys, libraries and gyms. We also run inclusive leisure activities or CCAs, in partnership with local leisure providers (and part funded by Sport England), where children and young people benefit from **coaches with SEND experience**, and programmes that take account of their additional needs. There are currently 14 CCAs to choose from including multi-sports, cookery, trampolining, archery and street dance.

An in-depth and independent evaluation of The Compass conducted by JB Eventus* in November 2014 found that having a Compass Card had a **significant effect on the whole family's wellbeing**. For example, 72% of parent carers felt having a Compass Card had helped **reduce stress** and 83% felt it **improved their quality of life**.

Compass registrations continue to grow. There were 1,812 children and young people registered in 2014/5 up 11% on last year. This year, Amaze also secured funding to increase the Compass age range from 0-20 to 0-25 (in line with SEN changes) and we started to offer **registration to 20-25 year olds** in December.

"On the whole I think the Compass Card has given the whole family much more confidence and a strong sense of community"



"As a family we are so thankful for the Compass Card. It has been a real game changer. Apart from the range of activities our son can now enjoy there are many knock on benefits for the rest of the family, such as generally feeling more positive and integrated."

JB Eventus estimated the Compass has an economic impact in the city of over £1m per year and represents **£11.88 in economic and social value for every £1 spent** on the scheme by B&H City Council.

Parent Carers' Council

Amaze supports and hosts the Parent Carers' Council, the **local forum for parent carers of disabled children** in Brighton and Hove. This year, PaCC membership reached 248 and includes 12 trained 'Parent Reps' who sit on strategic groups and boards within the city to make sure that **parents' voices are heard** by the people who plan or develop services.

Not surprisingly, given the scale of the changes introduced by the new Children and Families Act, the PaCC has had a very busy year: they organised **six major consultations** with parent carers on issues such as the review of SEND services, integrated care and mental health and wellbeing and held **two PaCConnect Forums** on home adaptations and the SEND Review. They also developed a striking new four-page pull out within Amaze's termly newsletter to **increase awareness of their work**



"Working as a PaCC 'Parent Rep' can be challenging, but it's almost always interesting. Sometimes it feels like one step forward, two steps back - particularly in the current climate of council cuts - but at other times I really feel I'm making a difference."

Community Outreach

To make sure we are **reaching families** who would most benefit from our services, we hold regular **monthly coffee mornings** (in partnership with local community organisations) in Moulsecoomb and Hangleton & Knoll, two areas of the city where parents might be particularly isolated or vulnerable.

The sessions now have a regular theme or guest - often related to health or wellbeing - and they are successfully **raising awareness of Amaze's services and other services for disabled children** that might otherwise feel quite elusive to the parents who attend.

Families tell us they feel **less isolated** because they're meeting other parents like them and we have noticed a significant increase in **skills and confidence** among members of the groups: they are now running Facebook pages, choosing their own group names and applying for pots of funding.



"The huge benefit of the group is the opportunity to speak to other people who have children with similar problems and issues"



What help from Amaze means

We gave 699 families face to face support last year. Most of these first make contact via our helpline. They speak to an adviser and if they need more ongoing specialist support then they might be referred on to one

of our case workers for help with things like school, EHC Plans, benefits, getting a break or preparing for adulthood. The personal story below shows just how much of a difference this can make to a family.

Case study - Anita and Kyle

"My son Kyle struggled every day with issues and things going on in his life. Kyle is 13 years old and he suffers with anxiety very badly which brings on panic attacks, mood swings, fear of crowds - the list is endless. On top of this he also suffers with psoriasis which has a major impact on his life and school where he's been picked on and name-called over it. He's a very sensitive boy so takes it very personally. It's so hard on any child with a disability when taunted. And for us parents, it's very hard and hurtful to go through - our children suffer enough.

"Kyle also has learning difficulties, poor reading, lack of understanding and being dyslexic doesn't help. I felt his school never gave him the time or understanding he needed. I was just at my wits end not knowing what to do with it all and then someone told me about Amaze.

"I said **"Amaze, what's that?"** I looked up their website and read a few things on there and gave them a call. Best thing I did. I can't tell them enough how thankful I am to them. The poor ladies who rang me had me going on and on but they listened to me and never rushed me and understood where I was coming from. I have to thank them from the bottom of my heart for the help, understanding and support they have given me.

"My thanks firstly goes to the whole Amaze team for the wonderful work they do, for their time and support. Then my thanks go to Lizzie (DLA lady) who helped me fill out forms, who spoke to my son, who listened to me. With her help I now receive DLA for my son which will make such a big difference for him and his life.

"And my biggest thank you is to Ruhiya. Without her, Kyle would not now be getting the support and understanding in school. She is truly an amazing lady who was always on the phone if I needed her, came to school meetings and made them sit up and listen. Now Kyle is slowly but surely making progress and being helped and understood. I can't thank Ruhiya enough for all she's done for my son Kyle and myself. I feel now I can stop going in circles and see things better and know it's all going in the right direction at last.

"If it was not for Amaze I know me, and more so my son, Kyle, would be fighting a never ending battle. So Amaze. Thank you so much for everything you do for me, Kyle and others. You deserve a medal."

** All names have been changed to protect anonymity*



Financial Summary

For the year ended 31 March 2015 (including income and expenditure account)

	Unrestricted Funds £	Restricted Funds £	Total Funds 2015 £	Total Funds 2014 £
INCOMING RESOURCES				
Incoming Resources from Generated Funds				
Grants	-	77,354	77,354	60,734
Bank Interest	354	-	354	769
Fundraising and donations	58,165	-	58,165	91,966
Incoming Resources from Charitable Activities				
Grants	400,541	-	400,541	313,987
Services	<u>240,804</u>	<u>-</u>	<u>240,804</u>	<u>22,343</u>
TOTAL INCOMING RESOURCES	<u>699,864</u>	<u>77,354</u>	<u>777,218</u>	<u>489,799</u>
RESOURCES EXPENDED				
Fundraising costs	47,084	-	47,084	41,927
Charitable Activities	547,433	61,068	608,501	385,531
Governance Costs	<u>2,805</u>	<u>-</u>	<u>2,805</u>	<u>2,458</u>
TOTAL RESOURCES EXPENDED	<u>597,322</u>	<u>61,068</u>	<u>658,390</u>	<u>429,916</u>
NET INCOMING/(OUTGOING) RESOURCES FOR THE PERIOD	102,542	16,286	118,828	59,883
TRANSFERS	-	-	-	-
NET RESOURCES FOR THE PERIOD AFTER TRANSFERS	102,542	16,826	118,828	59,883
ACCUMULATED FUNDS AT 31 MARCH 2014	<u>300,165</u>	<u>5,775</u>	<u>305,940</u>	<u>246,057</u>
ACCUMULATED FUNDS AT 31 MARCH 2015	<u>402,707</u>	<u>22,061</u>	<u>424,768</u>	<u>305,940</u>

Income and resources generated by fundraising are £135,519. Fundraising costs are £47,084. We estimate on average our fundraising income is three times that of the costs of fundraising.

Our Trustees believe it is important to hold enough financial reserves to ensure an ordered and proper closing of Amaze if this was ever necessary. The reserves cover three months operating costs, any redundancy payments due to employees, support to employees in finding alternative employment and the termination of service contracts.

Our funders

We'd like to thank all the agencies, organisations and individuals who helped to fund us in 2014/15.

Statutory funders

Brighton & Hove City Council, NHS Brighton and Hove Clinical Commissioning Group, Learning Disability Development Fund, Department for Education, National Children's Bureau, Council for Disabled Children

Grants and other funders

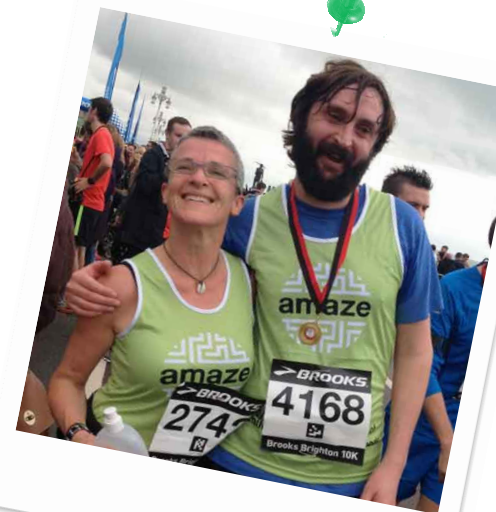
Brighton & Hove Community Works, Doris Pacey Charitable Foundation, East Brighton Trust CIC, Ernest Kleinwort Charitable Trust, Glaxo SmithKline Kings Fund Award, Sport England Inclusive Sport Fund, Sussex Community Foundation, The Henry Smith Charity, Lynn Foundation, Otherworld/Same Sky, Spielman Charitable Trust

Donations & Events

Baby Cow Productions, Brighton and Hove City Athletics Club, Brighton College Prep School, Charity Chuckle, Dorothy Stringer High School, ITV's The Chase Game Show, Stiles Harold Williams, Susanna Cassam Music Tuition, Wellesley Wealth Advisory

Individuals

Thank you to all our wonderful Amaze runners, fundraisers and sponsored event participants.



A huge thanks

Amaze could not do the work we do without our brilliant staff and we thank them for their time, expertise and ongoing commitment. We'd also like to say a huge thank you to all our many and varied volunteers who give their time and expertise for free to help us help more families with disabled children.

Our patrons

Julia Donaldson, Annabel Giles, Henry Normal and Angela Pell

Our trustees

Hugh Clench (Chair), Ian Gillett (Treasurer), Karen Smith, Sally Howell, Debby Norris, Fungi Woolnough-Murau, Ian Elwick, Siobhan Cox and Ray Knight

Our volunteers

Jackie Ames, Zena Barton, Nicola Bateman, Lea Berland, Rosie Chapple, Alfred Cook, Matilda Cook, Oswalde Corke, Jade Duffill, Susmitha Gadiyar, Brenda Hinchcliff, Christina Holter, Mark Kelly, Christine Lee, Brenda Mann, Paula McGeown, Phil McMahon, Mai Osman, Maree Parava, Clare Parr, Bruce Piper, David Poole, Susie Roper, Sue Rosenfield, Carole Sanderson, Sandamalee Senanayake, Sue Timpson, Cherie Trott, Jill Weeks and Ann Wilkinson.

PaCC steering group members and parent representatives

Helen Arnold-Jenkins, Reza Ataie, Diana Boyd, Debbie Collins, Jade Duffill, Fiona England, Hazel Herovitsch, Pippa Hodge, Martin Jones, Ruby Kearns, Tim Lavender, Amanda Mortensen, Emma Parker, Claire Peligry, Lisa Russell, Marian Tipler, Jill Weeks.

Get in touch:

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