



# IMPACT REPORT 2014

How Amaze is changing the lives of parent carers  
in Brighton & Hove



## What is Amaze?

Amaze is a Brighton and Hove based charity that provides information, advice and support to parents of children and young people with special educational needs (SEN) and disabilities.

## Why do families need us?

Families with children with special educational needs or disabilities face multiple challenges. And these challenges are not just related to the extra care and support they have to give to their child.

### Poverty

Families with disabled children are more likely to live in poverty than their non-disabled peers<sup>1</sup> and yet it costs on average three times as much to bring up a disabled child<sup>2</sup>.

### Social and emotional isolation

Having a disabled child or a child with significant needs can put huge strain on a relationship.<sup>3</sup> As a result, disabled children are more likely to be brought up in lone parent households.<sup>4</sup> And even couples that stay together can find they feel very isolated, as their experience of being a parent is very different to that of their friends and family.<sup>5</sup>

### More than one disabled family member

Many parents with disabled children also have a disability or health condition themselves or are caring for more than one child with additional needs<sup>6</sup>. Or parent carers may have learning difficulties that can make it much harder for them understand and manage all the extra paperwork and meetings that having a child with additional needs inevitably brings.

### Battle fatigue

Despite some excellent provision in the city, families tell us they sometimes feel they have to fight to get the help they need. Information can be out of date or hard to come by; not everyone wants to hear their opinion; they have to repeat their story to what can seem like an endless stream of professionals; and they are often turned down for services the first time they apply.

### Poor health

All these challenges mean that many parent carers have mental health issues like depression or anxiety and have little or no time to think of their own wellbeing.<sup>7</sup>

1. Four in every 10: Disabled Children Live in Poverty (The Children's Society 2011)
2. Counting the costs 2012: The financial reality for families with disabled children across the UK (Contact a Family 2012)
3. No time for us: Relationships between Parents who have a Disabled Child (2003 Contact a Family)
4. Families with children in Britain: Findings from the 2008 Families and Children Study (FACS) (Department for Work and Pensions 2008)
5. Forgotten Families: The impact of isolation on families with disabled children across the UK (Contact a Family 2011)
6. Amaze Annual DLA Survey (2011 – 13)
7. PaCC Mental Health and Wellbeing Report 2014

## What we believe

Our vision is that all children with special educational needs and disabilities and their parents are able to flourish and thrive and that they are respected, included and supported in the wider community in which they live.

Our aim is to inform, support and empower parents of children with disabilities and special educational needs. We want parents' voices to be heard and we want to build their confidence and resilience so that they can support their children to lead happy and integrated lives, fulfilling their potential.

## What we do

Amaze is a holistic information, advice and support service for parent carers. We work primarily in Brighton and Hove. We offer a range of services that are designed to make parent carers' lives easier and build their resilience.

Our **helpline** is usually the first port of call for information, expert advice, or just a listening ear when things are tough. From here we connect families with other local services or offer them hands-on support with specific issues from our 'one-to-one' services: we help complete **claims for Disability Living Allowance**; sort out **problems at school or college**; and work with families to help make their child's **transition to adulthood** easier. We are also trying to reach particularly isolated families through outreach work in some of the most deprived parts of the city.

We keep families informed about local services, offers and events via our **newsletter, website, e-bulletin and social media** and produce lots of **different literature** designed to answer their most common questions. And we run **workshops and courses** to give them more practical, ongoing skills and help them connect with other parents.

We run the local council's register of disabled children - **The Compass database** - and use the data we gather to help the local council plan services more effectively. When parents register their child on The Compass, they get a **Compass Card** which gives them a fantastic range of leisure discounts and benefits, and access to our **Compass Card Activities** programme - disability-friendly classes with experienced coaches. We also develop the offers on the **Carers' Card**, which provides discounts to improve the wellbeing of carers.

We host the **Parent Carers' Council (PaCC)**, Brighton and Hove's forum for parent carers, which works to make sure the views of parent carers are heard when planning or changing services and raise awareness about national and local issues that affect our families.

We work in partnership with statutory agencies and other organisations that support families with disabled children, to help shape the future of services and legislation.

## Colleen's story \*

" Things were really bad. I didn't go out and felt really depressed. I had no help with my little boy, Finley, who was three at the time. He was delayed but we didn't know what was wrong. I had financial problems and problems with the council as my kitchen was falling apart but they were refusing to fix it.

" Lizzie helped me with the DLA forms and I wouldn't have been able to do them without her. They're massive and I'm not good at spelling and writing. I've never been good with forms. He's coming up to 5 now and I know Amaze will help me again and we may get more help as he's up at night.

" Toni also gave me a lot of emotional support as well as helping me phone up the council and get Layla into Young Carers. She really helped with my housing situation. Amaze also put me in touch with Seaside View and I have a keyworker now.

" The (Moulsecoomb) coffee mornings have been amazing. If they were anywhere else there's no way I would go. Because they are in walking distance and in Finley's school I can get there. It's been brilliant meeting other people. I didn't know anybody before they started and I was really isolated. Also people visit and it's great to get advice.

" I'm much more on top of things now. Amaze has been brilliant and they've also put me in touch with other organisations I wouldn't have known about. We've got more support and I'm less isolated."

\* Parent and child names have been changed to protect anonymity

# 2013-14 in numbers

" Thank you so much for the very supportive phone call on Thursday. I felt as if a load had been lifted from my shoulders! It really helped to be so well listened to and to know there is fantastic support and advice available.

Cathy Whitestone, parent

" I just want to say thank you to Amaze representative, Lizzie, who helped me complete my DLA form today. She spent the better part of a day helping me, and she even accompanied me to my hair appointment so that she could finish the job! I am so grateful for Amaze's help, from helping me complete DLA forms to helping me fight for my son's transport. Many, many times over, thank you for your continued help and support. "

Meredith McGill, parent

" 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 and everyone on the course. "

Darryl Cole, parent

**4111** calls were handled by our helpline



**15,835** copies of Out of Amaze, our **termly newsletter**, were distributed to parents and professionals across Brighton and Hove

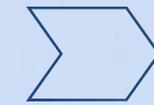
Our new **website** averaged **1300** visits per month and Facebook likes grew to **456**



Our DLA staff and volunteers helped **305** families to make **DLA applications**, bringing in an estimated **£2.8m** in benefits



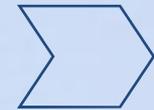
Our **education casework** staff and volunteers helped **159** parent carers to resolve education issues



**51** parents of young people got one to one support with **planning for their child's transition** to adult services.



Our volunteers gave **3011** hours of their time to Amaze this year, which is worth over **£52,000** to the organisation.



**240** parent carers attended Amaze **courses and events**



**1634** children and young people were registered or re-registered on the **Compass database**, an increase of **7%** on the previous year



**70** leisure discounts and offers on the **Compass Card** including **8** new **Compass Card Activities** and around **50 Carers' Card** offers



The **Parent Carers' Council** has **227** members, an increase of **8%** on the previous year.



The **Partnership Outreach Project** held **20** coffee mornings in Moulsecomb and Hangleton, two of the most deprived wards in the city



## ...and how it helped

**Having someone to turn to** makes parents feel **less isolated**. Parents who call our helpline say they feel **better informed** and able to understand the issue they are facing and take appropriate action. And they feel **relieved** to have a space that they can share any problem without judgement.

**Doing the research for parents** means they're more likely to **take up services** that are right for their child and family. And being **better informed** means they are **more confident**, more able and **more resilient**. Because they hear about events and services relevant to them, they're **more engaged and included**. Parents also tell us that our friendly writing style and parent quotes make them feel **less alone**.

**Extra income** generated from DLA (and other associated benefits) per family is around £8-13k per year. This easing of financial pressure not only **reduces deprivation** but has knock on effects like **improved mental health** and **family cohesion**.

**Fewer school placements break down** and parents have **increased confidence in special education provision** after working with an Amaze volunteer.

**Getting one to one support** during a young person's transition to adult services, **reduces pressure** and **improves parents' resilience**. We **increase parents' knowledge** of what's out there for young people and adults and provide them with someone who can **share their anxieties** and concerns.

**Working together** with volunteers enriches Amaze's expertise and that of the volunteers themselves and means we can help more parents, more often.

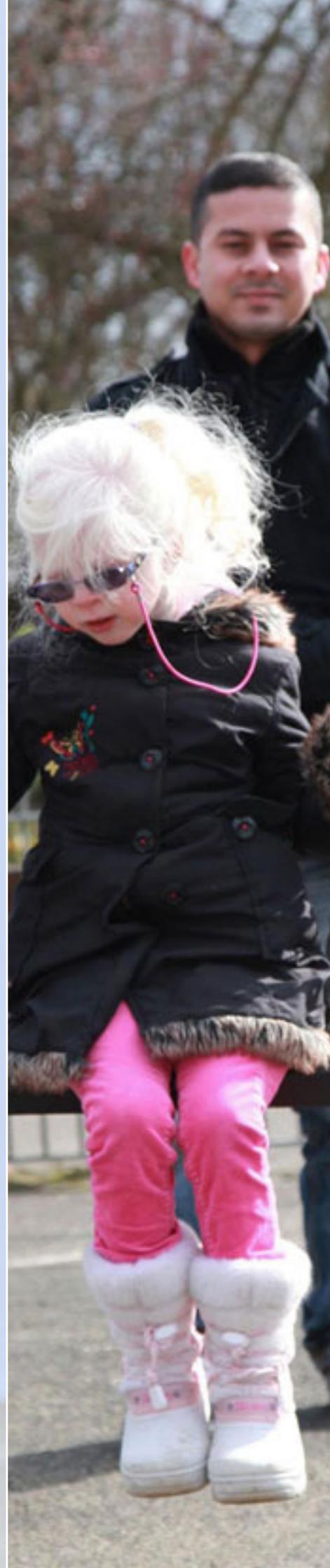
**Acquiring extra skills** and strategies **increases parents' confidence and resilience**. Learning alongside other parents can create friendships and **reduce feelings of isolation, anxiety and stress**. The fact that most of our courses are co-delivered by parents **stresses the value of the parent carer's own experience**.

**Regular targeted communication** with Compass Card families means parents are **more aware** of what's available to them locally and they have more opportunities to meet other parent carers and feel **socially included**.

**Greater access to leisure opportunities** means families can have more fun and **improve their wellbeing**. We estimate the Compass Card saves the average family **£685 a year** at local leisure outlets. Compass Card Activities give families a **short break** and **improve the confidence and fitness** of children and young people.

**Involving parent carers** in local decision making leads to **improved and more responsive local services**.

**Finding families who haven't been in touch with us before** means we can connect them with our services and others that can help. We can help **reduce poverty and social isolation** and **improve the wellbeing** of the family as a whole.





## Alison's story \*

"We left London to escape domestic violence. Billy had a diagnosis of global developmental delay to begin with but then they said he had Asperger's. No one had ever spoken about how the violence might have affected him. Billy had been at a speech and language unit at mainstream school in London but in Brighton they said he was high functioning, so he'd be fine in mainstream. So I picked a school nearby. Billy was there for three years: it was horrible. He was bullied. One of the other mums said, 'Phone up Amaze'. So I did just to find out what they did. **I found out loads of stuff, things I'd never have found out otherwise because no one tells you.**

"Amaze helped with school meetings. **As soon as you tell the school Amaze is coming, they take notice. It's like I've got someone who is standing alongside me and speaking up for me.** Billy was really unhappy, being excluded for days at a time and sat away from the other children. The school used to put him on the computer to keep him quiet: stop him from kicking off. Amaze got school to agree that Billy's problems weren't because of me and got everyone to agree to Downs Park Special School. This made all the difference.'

"**The first time I rang, Amaze suggested claiming DLA. I had tried before but kept getting turned down.** They said I could have someone to help. I think I said 'Really?' Being a parent it's hard to know what to put [on the form] and I have real problems in reading and writing. It felt OK to say the difficult stuff. They weren't surprised at anything I said. They wrote it all down, just as I said it. If I didn't have the support I wouldn't have gone for it again. **The minute Amaze got involved I got it.**

"I don't know how I'd manage without it. Billy's quite bouncy and if I couldn't afford good food, you know, if we had to eat cheap food, the E's set him off. He's very hard on everything and the **DLA helps to replace what gets broken and I can afford the internet and his special interests.** We go out places and that's really important to burn up all this extra energy. It pays for school trips. Some days Billy just can't do buses, the extra money means we can take a taxi. **I'm on benefits so I could never afford all this otherwise.**

"I've done two Triple P courses (Positive Parenting Programmes) with Amaze. Stepping Stones when Billy was younger and, more recently, the teenager one. That's been really helpful: how to talk to him...not shouting up the stairs. Yes, he has special needs but he's also a teenager. PPP helped me sort out which [behaviour] is which - teenage hormones or autism. **I have more strategies in my tool box, so I know if one thing doesn't work, I can try something else.**

"Billy has grown into an amazing person who is learning to embrace his autism. He fits in at Downs Park. He still has his moments but he gets up happy and wanting to go to school and he's learning. **At last I'm confident** about leaving him at school: they never exclude him.

"Amaze keeps families together. If you're having a crisis you can just pick up the phone and have a chat. Amaze never say, 'Look we're really not here for that.' **You always feel encouraged.** The message is "You're doing OK, stay with it."

\* All names have been changed to protect anonymity

# Financial summary

For the year ended 31 March 2014 (including income and expenditure account)

	Unrestricted Funds £	Restricted Funds £	Total Funds 2014 £	Total Funds 2013 £
<b>INCOMING RESOURCES</b>				
Incoming Resources from Generated Funds				
Grants	-	60,734	60,734	37,699
Bank Interest	769	-	769	630
Fundraising and donations	91,966	-	91,966	61,072
Incoming Resources from Charitable Activities				
Grants	313,987	-	313,987	368,136
Services	22,343	-	22,343	15,323
<b>TOTAL INCOMING RESOURCES</b>	<b>429,065</b>	<b>60,734</b>	<b>489,799</b>	<b>482,860</b>
<b>RESOURCES EXPENDED</b>				
Fundraising costs	41,927	-	41,927	32,260
Charitable Activities	328,901	56,630	385,531	375,089
Governance Costs	2,458	-	2,458	2,348
<b>TOTAL RESOURCES EXPENDED</b>	<b>373,286</b>	<b>56,630</b>	<b>429,916</b>	<b>409,697</b>
<b>NET INCOMING/(OUTGOING)</b>				
<b>RESOURCES FOR THE PERIOD</b>	<b>55,779</b>	<b>4,104</b>	<b>59,883</b>	<b>73,163</b>
TRANSFERS	-	-	-	-
<b>NET RESOURCES FOR THE PERIOD AFTER TRANSFERS</b>	<b>55,779</b>	<b>4,104</b>	<b>59,883</b>	<b>73,163</b>
<b>ACCUMULATED FUNDS AT</b>				
<b>31 MARCH 2013</b>	<b>244,386</b>	<b>1,671</b>	<b>246,057</b>	<b>172,894</b>
<b>ACCUMULATED FUNDS AT 31 MARCH 2014</b>	<b>300,165</b>	<b>5,775</b>	<b>305,940</b>	<b>246,057</b>

## Notes

- Income and resources generated by fundraising are £117,132. Fundraising costs are £41,927. We estimate on average our fundraising income is three times that of the costs of fundraising.
- 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

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.

## Our funders

Amaze is partly funded by statutory bodies and we generate our other income from fundraising and donations. We'd like to thank all the agencies, organisations and individuals who helped to fund us in 2013/14.

### Statutory funders

Brighton & Hove City Council,  
Brighton and Hove Clinical  
Commissioning Group, Learning  
Disability Development Fund,  
Department for Education

### Grants and other funders

Ernest Kleinwort Charitable Trust  
Noel Bennett Grants Fund  
Sport England Inclusive Sport Fund  
Sussex Community Foundation  
The Henry Smith Charity  
Blagrove Trust  
American Express  
Cullum Family Fund

### Donations & Events

Robert Smith of The Cure  
Mr Gordon Stewart, Legacy  
Brighton Brooks 10k  
Brighton Rotary Club  
Brighton College Prep School  
Sainsbury's Western Road  
Dean Wilson LLP  
G-Whizz Cycles  
Charity Chuckle

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

If you are interested in funding or fundraising for Amaze, read more about it on our website at

[www.amazebrighton.org.uk/get-involved/fundraise](http://www.amazebrighton.org.uk/get-involved/fundraise) or email [nickyb@amazebrighton.org.uk](mailto:nickyb@amazebrighton.org.uk)

# Thank you

Amaze could not do the work we do without the time, expertise and commitment of the following people and organisations. We'd like to say a huge thank you to them all.

## Our trustees

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

## Our patrons

Henry Normal, Angela Pell and Annabel Giles

## Our volunteers

Helen Arnold-Jenkins, Zena Barton, Nicola Bateman, Natalia Borg, Carol Burns, Madelaine Cable, Rosie Chapple, Alfie Cook, Matilda Cook, Oswalde Corke, Sally Cristin, Allison Dickson, Alison Field, Susmitha Gadiyar, Sandra Gallon, Nicola Gibson, Becky Hartfield, Edward Hartfield, Brenda Hinchliffe, Hannah Jeffries, Ray Knight, Gillian Kitchener, Kerry Korkunc, Christine Lee, Beth Lister, Brenda Mann, Wendy McCarthy, Hannah Osborne-Dowle, Mai Osman, Clare Parr, Bruce Piper, David Poole, Lorraine Roberts, Sharon Rose, Susan Rosenfield, Carole Sanderson, Sandamalee Senanayake, Sonya Smith, Catriona Strong, The Swaisland family, Sue Timpson, Lucy Urquhart, Jill Weeks, Ann Wilkinson, Helen Wyatt, Ruhiya Yousuf

## Our staff

Rachel Travers - Chief Executive Officer, 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, Paolo Boldini - Parent Participation Worker, Nicola Keene - Database Administrator, Charlotte Moroney - Publications & Website Manager, Emma Parker - Helpline Advisor, Janet Poole - IPS Project Manager, Sue Winter - Transition Development Worker, Fiona England - PaCC Co-chair, Tim Lavender/Jill Weeks - PaCC Co-chair, Hazel Herovitsch - Helpline Adviser/Transition Caseworker, Amanda Mortenson - Outreach worker

## Freelance Workers and parent trainers

Carrie Britton - Consultant & Senior Trainer, Kim Aumann - Consultant & Senior Trainer, Helen Arnold-Jenkins - Parent trainer, Sandra Chitty - Parent trainer, Claire Peligry - Parent trainer, Kim Smith - Parent trainer

## PaCC steering group members and parent representatives

Reza Ataie, Diana Boyd, Gilli Davidson, Medeni Elwick, Fiona England, Angus Goldfinch, Sophie Gove, Martin Jones, Ruby Kearns, Tim Lavender, Amanda Mortenson, Marian Tipler, Claire Turner and Jill Weeks

## Social Work Student

Jeri Lee Donovan



## Amaze

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

E: [info@amazebrighton.org.uk](mailto:info@amazebrighton.org.uk)  
W: [www.amazebrighton.org.uk](http://www.amazebrighton.org.uk)