



ANNUAL REPORT 2008
working with parents of children with special needs





CHAIR AND DIRECTOR'S STATEMENT

Ten years ago Amaze was born. It grew out of a group of parents of disabled children and children with special needs trying to get the best services. With support and funding from Brighton and Hove city council and the local health trusts, Amaze took off. From the start, our mission was to empower parents and encourage service providers to work in partnership with them. And that is exactly what we are celebrating doing a decade later.

A letter we got recently from one mum and dad explains: **'For a number of years we have been struggling with the demands of our wonderful son. He has a range of special needs and until we found your organisation we have had to manage by ourselves. Amaze gave us help to apply and secure Disability Living Allowance (DLA) and the difference it has made to our family is immeasurable.'**

The Amaze DLA project has not just made a difference to that household but to hundreds of families in Brighton and Hove. The project - which provides bespoke help with benefits and tax credits as well as DLA - has increased the income of families by an astonishing £4.4 million over the last three years. Our Big Lottery funding for this work came to an end this year, but thanks to significant funding from the Scottish Power Energy People Trust Amaze has added another string to its bow. Amaze will carry on providing one-to-one DLA and benefit advice, but has linked up with a local organisation Keep the Home Fires Burning to help parents make their homes more energy efficient and keep fuel costs down.

Back to that letter. The couple point out that: **'We have also received advice and support regarding our son's ongoing educational problems and feel so much more confident in raising our concerns with the school, this is directly due to the support we received.'** That support was from Amaze's independent parent supporter (IPS) scheme. Like the DLA project, the IPS scheme relies on a team of trained volunteers.

Training continues to be a large part of our work. As well as running more of our own courses like the Insiders Guides we've also run Triple P parenting courses in partnership with the Children and Young People's Trust. Once again, our courses were co-delivered by staff and parents - putting parent partnership into practice.

Our Helpline is at the core of our service to parents. It is a constant frustration that we need to limit the line to five sessions a week - we know we could at least double that if only we could get the funding. We would like to fund an extra session particularly to support parents whose children are being bullied or excluded - sadly an all too frequent occurrence.

Young people's transition to adulthood involves a new range of support needs and Amaze has not only been working with parents but with school staff as well. The Amaze transition development worker has trained staff at the special schools in Brighton and Hove to deliver person centred transition reviews for pupils in Year 9 onwards.

Amaze runs a unique scheme - the Compass Card - that provides free or discounted access to leisure facilities - like swimming, cinema clubs and soft play. The information we gather from parents applying for a card provides an insight into parent's and children's needs. This year, the information on the Compass database was used to support Brighton and Hove's successful bid to become one of the pathfinder authorities for the government's Aiming High for Disabled Children initiative.



And this year Amaze has developed a new aspect to its work. We have used the experience we've accumulated over the last 10 years to create Amaze Research and Training (ART) to make research and training accessible and useful to parents and allow parents to be active participants in research. And, finally there is our website. It won Best Charity Site and a special Accessibility Award at the 2007 Brighton and Hove Web Awards.

We are immensely proud of what Amaze achieves. It is a shining example of why local charities are essential to communities.

That pair of parents said in their letter - **'you are well named as you have been amazing'** - we couldn't possibly comment!

Jonathan Stearn, Director and **Karen Smith, Chair**



HELPLINE

The helpline is the first point of contact with Amaze for most parents. It offers impartial information and advice coupled with a real understanding of what it means to parent a child with extra needs.

Key achievements in 2007/2008

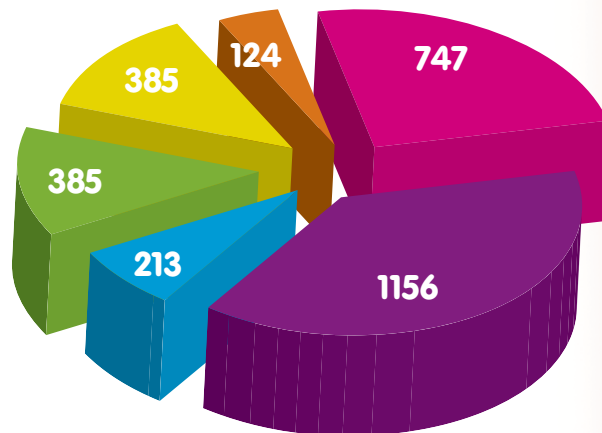
- Numbers calling the helpline went up again this year; we responded to 2344 calls from 837 different parents
- More parents are hearing about our service; 507 parents were first time callers, up from 370 last year
- Parents call from all over the city, but most calls come from the areas with the greatest social deprivation; over a quarter of calls this year came from Moulsecoomb and East Brighton



Parents of disabled children have a lot of demands on their time. They hate being passed on from place to place when they need to find something out or talk something through. Parents often have multiple enquiries and the mix of different enquiries from parents this year illustrates the way the helpline works as a one stop information and advice service. What this chart cannot show is the emotional support that goes alongside this.

Enquiry type summary

Education and Transition	747
Benefits and Finance	1156
Health, Social Care, Housing	213
Compass and Leisure	385
Workshops and Publications	385
General Information	124
Total	3010



“Some places I call I can hear the yawn hidden in the person’s voice. It is so different when I call you. You understand and you listen and you give a real response.” Helpline caller, Spring 2008

DISABILITY LIVING ALLOWANCE (DLA) PROJECT



The DLA project tackles poverty. It costs about three times more to bring up a severely disabled child and yet many parents aren't able to claim the benefits their child is entitled to without help. For parents facing extra challenges, working alongside one of our 17 Amaze volunteers is the only realistic chance they have of making a successful DLA claim.

But it's about more than just the money. DLA Volunteers enable Amaze to offer each family the help that is right for them, in the place where they feel most comfortable to talk.

Key achievements in 2007/2008

- This year Amaze drafted 255 new DLA claims from 238 households. Income for families from Amaze's DLA work totalled over £2,251,900
- We are reaching the most disadvantaged families in Brighton and Hove. Out of the 238 households, almost 50% parents we worked with have chronic health, or mental health needs or are disabled themselves.
- We are reaching the families most at risk of social exclusion. Almost 50% of households were led by single parents. 20% of the parents we helped identified themselves as non-white British. 35% households had at least two disabled children.
- Amaze generated another £1,291,300 by pursuing and supporting parents to claim passported benefits like carers allowance, disabled child tax credits, carer's premium on income support and disabled child premium on income support.

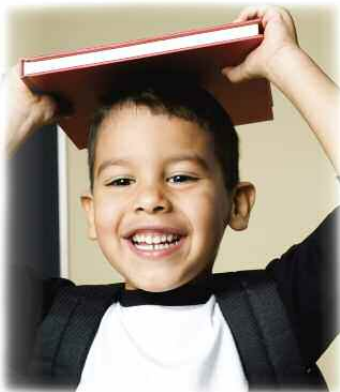


“People say ‘it’s important to tell it how it really is’ but I think it’s the first time I ever have. It was such a relief just to talk and be believed. Nothing I said seemed a surprise.”

Parent speaking about her volunteer

INDEPENDENT PARENTAL SUPPORTER (IPS) SCHEME

School or preschool is a big part of any child's life and if they have extra needs it is often a big worry for their parents. Amaze's independent parental support scheme enables and empowers parents who are trying to get the best education for their child, or sort out knotty problems arising from their special educational needs. Our team of IPS volunteers can help parents think about what they want, express their views and be fully involved. They explain school and local authority procedures, go through reports and support parents at meetings. They have the time to listen and they help parents to work in partnership with their child's school and the local authority.



Key achievements in 2007/2008

- We provided support to 87 new families around education and gave ongoing help to many others.
- We trained eight new Independent Parental Supporters who joined our team of expert volunteers
- We were involved in the planning and rolling out of Pastoral Support Plans in the city

“I felt my concerns were listened to, validated and acted upon.”

Parent who had an IPS volunteer

“She starts at her new school this Friday. And it's thanks to you for helping me with her statement and being a friend when I needed you. She has a smile on her face and feels happy again which is thanks to you all.” Parent who had IPS support from an Amaze staff member



THE COMPASS



Joining the Compass is a win win situation. Families give the Compass database information about their children's needs and the services they use. Their child then gets a Compass card which they can use to swim for free with their family and friends at the city's pools.

Amaze analyses the Compass information and feeds back to service providers and planners. Through the Compass we also send groups of families information updates on events and services relevant to their children. To keep the information fresh we get families to update their details every two years.

Key achievements in 2007/2008

- Compass membership hit 1,000 - that's great because the more children on the Compass the greater its reporting power. It's a huge amount of work to process all the data and administer the scheme - we are proud to have been able to keep up with demand.
- Through funding from BSCKE (Brighton and Sussex Community Knowledge Exchange) academics at Brighton University have been helping us develop better ways of analysing the Compass data - already we have begun sharing the findings with local service providers and with academics and policy-makers in the national and international arena.
- Aiming High found that few local authorities hold good information about families with disabled children - we are delighted that the Compass helps fill that information gap in Brighton and Hove.

“Thank you for the Compass card – it’s proving to be a big hit with Holly. She thinks it’s fab that we can swim for free!”

Parent of a new Compass card holder



TRANSITION DEVELOPMENT

Amaze works with parents and professionals to make the transition from childhood to adulthood a positive experience for young people and their families.

Key achievements in 2007/2008

- Our transition development worker trained staff at the secondary special schools in Brighton and Hove to deliver person centred transition reviews for pupils in Year 9 onwards. All five schools went on to run these transition reviews for their pupils. The reviews focus on involving young people and their parents in planning for their child's future.
- We ran a range of training and information courses that were co-delivered with parents and which were very well attended.

Insiders Guide to bringing up teenagers with special needs - 25 parents attended

Transition information sessions - 20 parents attended

Parents with teens get togethers - 58 parents attended

Changes to benefits at 16 (delivered by our DLA co-ordinator) - 17 parents attended

- We updated and expanded the handbook *Through the Next Maze* for parents with teenagers. 139 copies were sent directly to parents of children with statements going into Year 9.
- Our transition development worker also attended a number of local and regional forums

“It has made a huge difference in that I feel much more confident, empowered as a parent and able to deal with situations more effectively. In addition I have learned to value myself and take care of myself.”

Parent on Insiders Guide to bringing up teenagers course, March 08



COURSES, GROUPS AND WORKSHOPS

Amaze courses and workshops are all about offering parents information, skills or support that enable them to do the best for their children. Most are delivered in partnership with parent trainers. We also contribute to information events and conferences for parents and practitioners.

Key achievements in 2007/2008

- Parents whose children have special needs and behaviour issues welcomed the three Triple P Positive Parenting courses we ran this year.
- Our Insiders Guide courses are designed to offer both information and support for parents bringing up disabled children. We ran three this year - two for parents of teenagers and one for parents of under fives.
- Workshops and training this year for parents and professionals included DLA and other benefits, transition planning, working with parents, education issues, Resilient Therapy and co-facilitation.
- We ran support groups for parents of teenagers and parents who had been on a Triple P course.
- We offered information to parents at events ranging from meeting a handful of parents at a local primary school to dozens at a Children's Trust event in the Brighton Dome.

"It made a big difference knowing everyone else in the group had a child with special needs and the trainers too."

"I feel I respond to a situation now rather than react or overreact!"

Parents at the end of a Triple P course



ART - AMAZE RESEARCH AND TRAINING



Amaze Research and Training is a brand new area of work. It aims to use the experience we've accumulated over the last 10 years to pinpoint best practice, make research and training accessible and useful to parents and workers and break down the theory practice divide.

Key achievements in our first year of operation 2007/08

- Work with Contact a Family as 'parent consultants' to assist with their national support work to improve parent participation - all part of the Government's Aiming High programme.
- Selected by the NHS Institute for Innovation and Improvement to join the Patient and Public Involvement Preferred Suppliers List
- Delivered Parents as Allies training to child minders and play workers
- Two more parents trained to co-deliver our bespoke Insiders' Guide parent support course.

Our collaboration with the Community University Partnership Project (CUPP) at the University of Brighton also goes from strength to strength. This year, we teamed up with geographers at the School of Environment and Technology to learn more about analysing data. We contributed to two chapters of '*Community-University Partnerships in Practice*'. We also developed our Resilient Therapy (RT) work with the School of Nursing and Midwifery to keep parents at its heart. This included more Resilient Therapy parent workshops, producing an RT training film and getting parents to advise on a new book about building resilience. Finally, our ART Director was made a Visiting Research Fellow.

“The positive approach made me feel better.”

“RT is very immediate, very pick-upable. It's very easy to go, okay I will use that tool now ... it's let's try it and see what happens.”

Parents who attended a Resilient Therapy workshop

PUBLICATIONS AND WEBSITE

Time and again parents tell us that they need good quality information to make the best choices for their children. Our publications and website are designed to do just that.

Key achievements in 2007/2008

- Our website won Best Charity Site and a special Accessibility Award at the 2007 Brighton and Hove Web Awards.
- We produced a new, expanded edition of *Through The Next Maze*, with new chapters on health, social care, travel and social lives.
- Our website received over three times as many visitors from Jan to March 2008 as in the same period in 2007.

Amaze publications for parents and carers of children with special needs:

Through the Maze handbook

Through the Next Maze handbook for parents of teenagers

Out of Amaze termly newsletter

Factsheets on specific topics like Choosing a school or Claiming DLA

Amaze's website is at www.amazebrighton.org.uk

"The Amaze handbook is so relevant and essential it hardly leaves my side." Parent writing to thank us for help with DLA

"You deserve your awards – your site is very good."

Graham Thomas, Brighton & Hove Crossroads



STATEMENT OF FINANCIAL ACTIVITIES

For the year ended 31 March 2008 (including income and expenditure account)

	unrestricted funds	restricted funds	total funds 2008	total funds 2007
INCOMING RESOURCES	£	£	£	£
Incoming resources from generated funds				
Grants	-	59,535	59,535	78,607
Donations	4,570	21,700	26,270	4,815
Bank Interest	4,381	-	4,381	2,331
Incoming resources from charitable activities				
Grants	138,166	-	138,166	144,308
Services	60,815	44,000	104,815	24,216
TOTAL INCOMING RESOURCES	207,932	125,235	333,167	254,277
RESOURCES EXPENDED				
Fundraising costs	3,328	-	3,328	2,957
Charitable activities	175,517	142,769	318,286	256,575
Governance costs	3,749	300	4,049	5,211
TOTAL RESOURCES EXPENDED	182,594	143,069	325,663	264,743
Net incoming/(outgoing)				
resources for the period	25,338	(17,834)	7,504	(10,466)
Transfer	(11,841)	(11,841)	-	-
	13,497	(5,993)	7,504	(10,466)
Accumulated funds at 31st March 2007	62,604	28,197	90,801	101,267
Accumulated funds at 31st March 2008	76,101	22,204	98,305	90,801

All amounts relate to continuing activities



NOTES ON THE ACCOUNTS FOR THE YEAR ENDED 31 MARCH 2008

Reporting accountants

Following the partial exemption conferred by the Companies Act 1985, the trustees passed a resolution during the year to forgo having the accounts audited and to have them externally examined instead. As a result Clark Brownscombe stood down as auditors and were appointed as Reporting Accountants. This report has been prepared in accordance with the *Statement of Recommended Practice - Accounting and Reporting by Charities* and in accordance with the Special Provisions of Part VII of the Companies Act 1985 relating to small companies.

Respective responsibilities of trustees and reporting accountants

The trustees are responsible for the preparation of the accounts and they consider that the company is exempt from an audit. It is the reporting accountant's responsibility to carry out procedures designed to enable us to report their opinion.

Reporting accountant's opinion

The accounts are in agreement with the accounting records kept by the company under section 221 of the Companies Act 1985. Having regard only to, and on the basis of, the information contained in those accounting records:

- I. the accounts have been drawn up in a manner consistent with the accounting requirements specified in section 249C(6) of the Act; and
- II. the company satisfied the conditions for exemption from an audit of the accounts for the period specified in section 249(4) of the Act (as modified by section 249A(5)) and did not, at any time within that period, fall within any of the categories of companies not entitled to the exemption specified in section 259B(1).

STATEMENT BY THE BOARD OF TRUSTEES

The trustees believe it is important that they hold as financial reserves the funds necessary to ensure an ordered and proper closing of Amaze. The reserves policy will fund:

- Any redundancy payments due to employees
- Support to employees in finding alternative employment
- Terminating service contracts such as office rent and equipment
- Contingency sum for outstanding liabilities
- Accountancy, audit and other professional costs.

OUR FUNDERS

Statutory Funders

Brighton & Hove City Council, The Children and Young People's Trust, Brighton & Hove City Teaching PCT, South Downs NHS Trust

Grants and Donations

Big Lottery Fund, Brighton and Sussex Community Knowledge Exchange (BSCKE), Chelsea Building Society Charitable Foundation, Children's Workforce Development Council PLR, Community University Partnership Project, Department for Children, Schools and Families (DCSF), Ernest Kleinwort Charitable Trust, The Fitton Trust, Henry Smith Trust, Learning Disability Development Fund, Mercer's Company Charitable Foundation, Noel Bennett Charitable Trust, Partnership Community Safety Team, Royal College of Speech and Language Therapists, Southdowns TR Group, Trusthouse Charitable Foundation, University of Brighton.

CONSULTATION AND COMMUNITY PARTICIPATION

Amaze is committed to keeping parents and disabled children on the agenda and there is no substitute for talking to parent carers when developing policy.

Key achievements:

- Researchers from the Bercow Review into services for children and young people with speech, language and communication needs spoke to parents from Amaze. Key recommendations in the final report reflected what parents said mattered most.
- Amaze used its in depth understanding of the struggles that parents face when claiming Disability Living Allowance to advise a DWP review how the whole process could and should be simplified.
- We made sure that parent carers were fully involved in the development of the Brighton & Hove Parent Support Strategy, taking part in the stakeholder day and through a focus group.
- Information given by parents via the Compass was used to deepen the understanding of the local Director of Public Health about the issues faced by disabled children for his report on children's health.
- We also laid the groundwork for parents to have more influence in years to come. Two Brighton & Hove decision making bodies agreed to pay parents for their ongoing involvement and the new Parent Carers Council started life this year.

Amaze and parents contributed to over 20 other strategic groups, consultations and forums. A full list is available on our website.

“I really wanted to respond to this because I feel really strongly about the service my child got.”

Parent returning a questionnaire for a CAMHS consultation

A BIG THANK YOU

Amaze relies on the support of many different people and organisations. We are particularly indebted to all those parents and professionals who have given their time, expertise and support. Space limits being able to name everyone however there are some individuals and organisations that deserve special mention for their support over the year 2007-2008.

Trustees

Karen Smith (Chair), Alastair Burt (Treasurer), Jane Talbot, Julia Widdows, Hugh Clench, Juliette Teague, Eveline Banfield, Carl McAdam, Jeanne McNair, Kaye Duerdoth, Sandra Chitty, Susmitha Gadiyar, Helen Clarke, Ian Gillett (Treasurer from Nov 07)

Co-opted Non-Voting Committee Members

Jenny Brickell - Brighton & Hove City Council
Yvonne Ely - Brighton & Hove City Council

Staff and freelance workers

Jonathan Stearn - Director from Sept 07
Kim Aumann - Director/ Director of Research & Training
Ros Cook - Assistant Director
Lizzie Batten - DLA Project Co-ordinator
Jenny Broome-Smith - Compass Co-ordinator
Sue Winter - Transition Development Worker
Zoe Brinkworth - PA to Directors
Janet Poole - IPS Scheme Co-ordinator
Charlotte Moroney - Parent Information Worker
Jane Bradford - DLA Administrator
Shirley May - IT Support

Becky Jenner - Fundraiser
Carrie Britton - Parent Trainer and parent involvement work
Samantha Selway - Parent Trainer
Sinead Gillespie - Parent Trainer
Sandra Chitty - Parent Trainer
Francis Swaray - Social Work Student
Jane Harris - Social Work Student

Volunteers

Karin Anjos, Helen Arnold-Jenkins, Vivian Barton, Susan Bradford, Chrysie Brown, Elizabeth Clingan, Debbie Collins, Iseult Hull Flower, Susmitha Gadiyar, Nicola Gibson, Sinead Gillespie, Lisa Hayward, Brenda Hinchliffe, Sam Hull, Nicola Keene, Brenda Mann, Moira Mills, David Natha-Gregory, Claire Peligry, Lorraine Roberts, Sharon Rose, Samantha Selway, Nicole Stamatopoulos, Ian Stephenson, Dr Bob Towler, Tamsin Turnbull, Anna Waters, Holly Watson, Ann Wilkinson, Farah Woosnam

Contributors to Amaze's Research and Training Work

Prof. Angie Hart, Dr Darren Smith, Myra Wiseman, Dr Carl Walker, David Secrett, Dr Paula Mooney, Dr Carrie Britton

Community Partners

Community Base, Odeon Cinema, King Alfred, St Luke's and Prince Regent Swimming Pools

Thanks to all the parents who have acted as parent trainers for the Parenting Pathfinder

Thank you to all the parents who have given generously of their time and opinions to contribute to consultation work this year.



Amaze

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Amaze Brighton and Hove
UK Company Limited by Guarantee No: 3818021
Registered Charity No: 1078094

If you would like to support the work of Amaze you could:

- Join the Amaze membership scheme
- Train to be a volunteer
- Involve your company in sponsorship,
corporate donations, gifts in kind,
or payroll giving, or adopt Amaze as
your charity of the year

If you would like to receive a large print
or text only copy of this annual report
please telephone or email us.

