



working with parents of children with special needs

ANNUAL REPORT 2009



CHAIR AND DIRECTOR'S STATEMENT

This has been a hard year for many as the country slid into recession and some of our families found themselves facing even greater financial uncertainty than usual. At Amaze, we know that disabled children are more at risk of living in poverty than their non-disabled peers. We have reported that the proportion of children on the **Compass** (the city's register of disabled children) is several times higher in the more deprived areas of Brighton and Hove than in the least deprived.

Lack of income is a major factor in deprivation. 41% of calls coming into our Helpline this year were from parents needing help or advice on financial matters. Our **DLA project**, which helps families claim Disability Living Allowance and related benefits, has been running at capacity all year, with 246 families provided with one-to-one support to complete the detailed application form. The project continues to provide an invaluable service, putting a whopping £2 million into parents' pockets during the course of the year from only £50,000 of project investment.

The **Aiming High for Disabled Children** programme got underway in Brighton and Hove with the Children and Young People's Trust (CYPT) agreeing how to allocate this new money with local partner organisations (including Amaze) and parents. The vision of the programme is for all families with disabled children to have the support they need to live ordinary family lives. This presents a real opportunity for families to be provided with more local services and also offers an exciting platform for parents to have more of an input into how services are set up and delivered locally.

Families have been telling us for years that one of their most urgent needs is to get regular and reliable short breaks from their day to day caring responsibilities. At this year's AGM, Amaze facilitated a session with parents to identify what kinds of short breaks they would like for their children. This information was fed into the commissioning strategy for the Aiming High programme. We are hopeful that now the money has been allocated, services will start to increase and families will begin to see the benefit from all this additional investment. We are less hopeful about the amount the Primary Care Trusts have allocated to the Aiming High programme. Unfortunately this money has not been ring fenced and we are waiting to hear how the local allocation of money will benefit families in the city.



At Amaze we know that parents are key to improving the life chances of disabled children and children with special educational needs. Throughout what we do as an organisation we try to ensure we are parent-led. We continue to be guided by a team of dedicated trustees, the majority of whom are parent carers themselves and we are lucky to have a dedicated team of staff and volunteers, again many of whom are parents.



But this year we wanted to do more, so we helped set up the **Parent Carers' Council (PaCC)**, a brand new forum for parent carers in the city, supported by Amaze. The aims of the PaCC are to formalise much of Amaze's work engaging the views of a wide cross-section of parent carers; to raise awareness of our children's needs and gain recognition of our role as parent carers; and to improve local services so they become more family-focused.

We know the next three years will be difficult for Amaze as our funding base is squeezed while financial pressures continue on individuals, companies and the public purse. But we aim to diversify our funding base and think of creative new ways we can best support and empower Brighton and Hove's parent carers and their families. A challenge then, but as Amaze's Chair and new Director, it's one that we look forward to meeting.

Rachel Travers, Director and Karen Smith, Chair

HELPLINE

A friendly voice and reliable information is what parents tell us they want when they call the **Amaze Helpline**. For most parents it's their first direct contact with Amaze. It offers them impartial information and advice and the chance to speak to someone who understands their situation. We would like to extend the Helpline so more parents can get through first time, but the Helpline team work hard to make sure we respond to every message.

Key achievements in 2008/2009

- Numbers calling the Helpline went up 23% this year; we responded to 2889 calls, 301 of which were from first time callers.
- Callers have children across the range of ages and special needs; a fifth of our calls came from parents of under fives this year.
- Parents call from all over the city but we get more calls from areas that have more families and are less well off. This year most calls came from Moulsecoomb, East Brighton, Hangleton, Portslade, Queens Park, Hanover and Hollingbury.
- The Helpline opened on Friday mornings in term time this year and we were able to offer more advice on bullying and exclusions, thanks to funding from the Sussex Community and Ironmongers Foundations.



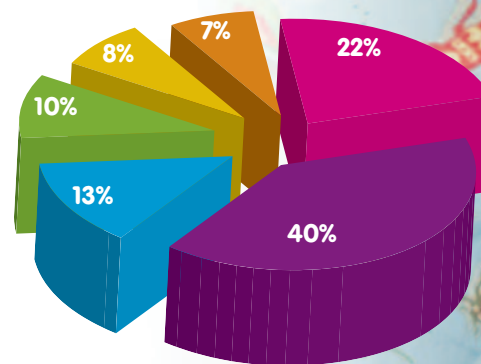
A strength of our Helpline service is the range of information and advice on offer. A parent might ring for advice about problems at school but by the end of the call have also booked onto a parenting course and found out that they could claim DLA. This is reflected in the mix of different topics covered in calls this year.

'Amaze is an absolute godsend and at my lowest points you have always offered me a kind ear.'

Part of a thank you email from a parent

Helpline enquiries 08/09 by subject

Publications & General Information	7%
Health, Social Care, Housing	8%
Courses & Workshops	10%
Compass & Leisure	13%
Education & Transition	22%
Finance & Benefits	40%





INDEPENDENT PARENTAL SUPPORTER (IPS) SCHEME

Education is fundamental to the wellbeing of all children but if your child has special needs there can be extra worries and complications in making it work for them. The IPS scheme is a vital part of Amaze's role as the Parent Partnership Service for Brighton and Hove. The IPS Coordinator and volunteers offer parents one-to-one support to make sense of the education system and work through any difficulties. They can support parents at meetings, help them understand reports or get their views down in writing. Parents appreciate the help of an IPS when things are tricky, perhaps when a placement seems to be breaking down or their child is at risk of exclusion. It is a role that has to strike a balance between helping parents advocate for their child but also work in partnership with schools and services.

Key achievements in 2008/2009

- We provided one-to-one support on education issues to 88 new families and gave ongoing help to many others.
- We trained five new Independent Parental Supporters who joined our team of dedicated volunteers.
- We trained staff and volunteers to offer parents more advice and support on bullying and exclusions.

'I feel that Amaze always works in my best interest and my son's interests too.'

'It lifts the heaviness off your shoulders.' Parents commenting on the IPS service

THE DISABILITY LIVING ALLOWANCE (DLA) PROJECT

The DLA project tackles poverty. It costs about three times more to bring up a severely disabled child yet many parents aren't able to claim the benefits their child is entitled to without help. Working alongside one of our 20 volunteers is the only realistic chance many parents have of making a successful claim.



This year rising energy prices led us to look at how to help families identify what they can do to make their homes more affordable to run. A grant from Scottish Power

Energy Trust allowed us to extend our DLA work to include an energy audit and advice about energy efficiency measures. We are also able to signpost families to grants and debt advice.

Key achievements in 2008/2009

- This year Amaze drafted 246 new DLA claims.
- This year we calculate that income from Amaze's DLA project generated over £2 million of extra income for local families.
- We are reaching the most disadvantaged families in Brighton and Hove. 40% of the families we work with are living on benefits.
- We are reaching the families most at risk of social

exclusion. 43% of households were led by single parents. 34% had two or more disabled children. 6% needed support from an interpreter. 21% had at least one parent with mental health problems.

- Amaze calculate that we generated another £1 million 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.
- We are pulling families out of fuel poverty. Extra money from disability related benefits means that families are spending less than 10% of their income on fuel costs.

'At the time it doesn't feel like the money's important because you're desperate for your child to be well. But it just goes on and on. He rarely gets to school, so we're both at home. If he's cold, I just put the heating on. So I was glad of the help with the DLA. I still have to budget but if I had to worry about the bills, I might fall apart.'

Parent of a child with leukaemia





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 2008/2009

- We ran a range of training and information courses that were co-delivered with parents:
 - Insiders Guide to bringing up teenagers with special needs* - 15 parents attended
 - Transition information sessions* - 10 parents attended
 - Parents with teens get together* - 52 parents attended
- We distributed 118 copies of our latest Through the Next Maze handbook to parents of children with statements going into Year 9. We also updated the transition information on our website.
- We continued our support to special schools to ensure young people and their parents are fully involved in planning for their future life after school.
- Our transition development worker participated in a number of local and regional forums.

‘This has been a really enriching and valuable experience. Lots of practical advice. It has changed me – I feel less isolated and have made new friends who understand how I feel – invaluable!’

Insiders Guide participant, January 09

THE COMPASS

The Compass is great news for the families we work with. Parents provide Amaze with information on their child's needs by filling in a Compass Registration Form. The details are collated by Amaze and used anonymously to develop services in the city for children with special needs.

But that's just the beginning. Being on The Compass means we can keep parents in the loop on the news, information and services that matter most to them. Kids on The Compass also get a **Compass Card** - and with it, access to free and discounted leisure across the city.

Key achievements in 2008/09

- This year we developed partnerships with a number of local leisure providers to give families on the Compass more chances to have fun. Card holders now enjoy discounts at the Sealife Centre, Westows World of Play and Funplex; free gym sessions at King Alfred and Prince Regent leisure centres if they are 16-19; and regular autism-friendly cinema screenings at the Duke of Yorks Picturehouse. Watch this space for more offers!
- Compass membership is now over 1,200 and growing - 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.
- The Compass database is seen as an excellent resource locally for shaping services and communicating with families. We're delighted that the Compass secured significant funding from Aiming High this year to allow us to further develop our offer for parents.

'We are using the Compass Card for me and my child when we go swimming and it is really beneficial.'

Parent of a Compass Card holder



PUBLICATIONS AND WEBSITE

Amaze believes that parents need the right information to ensure their disabled children get the same chances as other children. But finding out what services are out there can often be difficult and time-consuming. We make the calls and do the research so parents don't have to. And we convey that information via a range of publications that are written in a language that everyone - not just professionals - can understand.

Key achievements in 2008/2009

- Our website had over 22,000 unique visitors - not bad for a local site!
- Solihull's local authority was so impressed with our website content that they used Aiming High funding to purchase parts of it for their own web presence.
- **Through the Maze** handbook: updated and 700 copies distributed.
- **Through the Next Maze**: completely updated and 600 copies distributed.
- **Out of Amaze** termly newsletter: over 10,000 distributed to parents and professionals locally.

Amaze publications:

Through the Maze handbook; **Through the Next Maze** handbook for parents of teenagers; **Out of Amaze** termly newsletter; Fact sheets on specific topics like **Admissions to Hospital** and **Choosing a School**.

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

'The Through the Maze books arrived today. Everyone who sees them comments on how useful they are and would like a copy.'



'Many thanks for a very informative website. We have always felt fairly 'clued up' in relation to our children's benefits but with 16+ looming your information in this area was very helpful, clear and concise.'

Emails received from a health service worker and a parent

COURSES AND WORKSHOPS

Amaze courses and workshops bring parents together with others in a similar situation and offer them information, skills or support relevant to their lives bringing up children with extra needs. A thread running through all our courses is the aim of building resilience for parents and children to meet the challenges they face, big and small. Most of our trainers are parents themselves. We also contribute to information events and conferences for parents and practitioners.

Key achievements in 2008/2009

- We ran four **Triple P Positive Parenting** courses which have proved popular with parents whose children have special needs and behaviour issues. And we got training so we can offer **Triple P Stepping Stones** next year for parents of children with a wider range of needs.
- Our **Insiders' Guide** courses were written by and with parents so as to offer both information and support about bringing up disabled children. We ran two this year for parents of teenagers and found funding to do more next year.
- Workshops and training this year for parents and professionals included **DLA** and other benefits, dealing with **bullying**, **Carers Voice** training, **transition** planning, **Resilient Therapy** and making the most of technology.
- We shared information with parents at events of all shapes and sizes from a coffee morning for parents of pre-schoolers to a huge community sports event in the park.

'I got useful ideas – how to be happy and supportive to my child.'

'It was welcoming, warm and relaxed. I got time to speak and I learned a lot.' Parents at a workshop on bullying





ART - AMAZE RESEARCH AND TRAINING

ART draws on Amaze's experience of working with parents to promote best practice and to make research and training accessible and useful to both parents and practitioners working in this field. In our second year of operation, we've had local, national and international requests for training and consultancy.

Key achievements for 2008/09

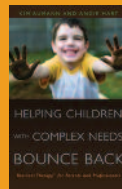
Training:

- Four local authorities commissioned ART to train parents in participation work.
- Carer's UK engaged ART to deliver seven **Carers Voice** courses across the country.
- **Building resilience and Resilient Therapy (RT)** training was co-delivered with parents to the local children's workforce.
- We delivered five sessions about issues for disabled children and their families to undergraduate and post graduate nurses and health workers at the University of Brighton and provided presentations at three conferences.

Community University Partnership Program (CUPP)

- We worked with the University of Brighton's School of Environment and Technology to expand our knowledge of childhood disability geographies, and with the School of Art and Architecture, to use inclusive arts as a tool for building resilience with learning disabled teenagers.
- University of Brighton Business students recommended ways of marketing ART.
- Our resilient therapy Community of Practise brought together parents, practitioners and academics, once a month, to develop RT-based work with children and families.

This year, with help from parents, we also wrote and published a Resilient Therapy book, **Helping children with complex needs bounce back: Resilient Therapy for parents and professionals.** (Aumann, K. and Hart, A) and our resilient therapy work was profiled at a number of local, national and international conferences.



'I hadn't approached my child this way before – RT made me rethink some things I am doing. The positive approach made me feel better and I feel motivated to try again.' Parent who attended a Resilient Therapy workshop

STATEMENT OF FINANCIAL ACTIVITIES

for the year ended 31 March 2009 (including income and expenditure account)

	unrestricted funds	restricted funds	total funds 2009	total funds 2008
	£	£	£	£
INCOMING RESOURCES				
Incoming Resources from Generated Funds				
Grants	76,669	57,695	134,364	61,135
Donations	3,040	-	3,040	26,270
Bank Interest	3,497	-	3,497	4,381
Incoming Resources from Charitable Activities				
Grants	120,866	20,000	140,866	136,566
Services	59,241	-	59,241	104,815
TOTAL INCOMING RESOURCES	263,313	77,695	341,008	333,167
RESOURCES EXPENDED				
Fundraising costs	2,496	-	2,496	3,328
Charitable Activities	253,632	77,588	331,220	318,286
Governance Costs	2,799	-	2,799	4,049
TOTAL RESOURCES EXPENDED	258,927	77,588	336,515	325,663
NET INCOMING/(OUTGOING)				
RESOURCES FOR THE PERIOD	4,386	107	4,493	7,504
ACCUMULATED FUNDS AT 31st MARCH 2008	76,101	22,204	98,305	90,801
ACCUMULATED FUNDS AT 31st MARCH 2009	80,487	22,311	102,798	98,305

All amounts relate to continuing activities



NOTES ON THE ACCOUNTS FOR THE YEAR ENDED 31 MARCH 2009

Reporting accountants

During the year the trustees passed a resolution to retain Clarke Brownscombe as our 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

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, Brighton & Hove Primary Care Group.

Grants

Community University Partnership Project, Department for Children, Schools and Families (DCSF), Henry Smith Trust, Ironmongers Foundation, B&H Learning Disability Development Fund, Scottish Power Energy People Trust, University of Brighton, Sussex Community Foundation.

Donations

Ernest Kleinwort Charitable Trust, Legal & General staff. We would like to thank all those individuals who made a donation to Amaze. Although we cannot mention them all by name we are very grateful to them and they are vital to our continued success.

THE PARENT CARERS' COUNCIL (PaCC)

A brand new parents' forum, specifically for parents with children with additional needs in the city, was set up in July 2008. By the end of this year it had 60 members and continues to grow.

Key achievements:

- A steering group has been established.
- A questionnaire and focus group led to a PaCC report on 'More Therapies in the Community'. This report included contributions from 67 families. It was presented to managers at the CYPT and councillors, and parents' recommendations resulted in a review over the summer to address the parents' concerns.
- Recognition of the role of parent carers in planning and developing services – with PaCC elected representatives on several groups and boards.
- Raising the profile of parent carers in the city with the council's Overview and Scrutiny Committee looking into services for disabled children for the first time.
- Partnership with the TreeHouse Trust to network with three other regions developing parent participation.

OTHER CONSULTATION & COMMUNITY PARTICIPATION

Amaze is committed to keeping the interests of parents and disabled children to the forefront with policy makers and service providers.

Key achievements:

- We brought together parents for a focus group for a DCSF national survey on parental experience of services for disabled children.
- We used the Compass database to keep parents informed about local consultations relevant to their child's particular needs, for example targeting parents who had used CAMHS recently to let them know about a parent feedback event.
- Amaze and parents contributed to over 20 other strategic groups, consultations and forums. A full list is available on our website.



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 and expertise this year. Space limits being able to name everyone, however there are some individuals and organisations that deserve special mention for their contribution during 2008-2009.

Trustees

Karen Smith (Chair), **Ian Gillett** (Treasurer), **Alastair Burtt** (to Dec 08) **Hugh Clench**, **Eveline Banfield** (to Sept 08), **Carl McAdam**, **Jeanne McNair** (retired), **Kaye Duerdoth**, **Sandra Chitty** (to Nov 08), **Susmitha Gadiyar**, **Helen Clarke**, **Sally Howell**

Co-opted Non-Voting Committee Members

Jenny Brickell - Brighton & Hove City Council

Staff and freelance workers

Rachel Travers (Director from Jan 09), **Jonathan Stearn** (Director to Dec 08), **Kim Aumann** (Director of Research & Training), **Ros Cook** (Assistant Director), **Lizzie Batten** (DLA Project Co-ordinator), **Jenny Broome-Smith** (Compass Co-ordinator to Jan 09), **Sue Winter** (Transition Development Worker), **Zoe Brinkworth** (Office Manager), **Janet Poole** (IPS Scheme Co-ordinator), **Charlotte Moroney** (Parent Information Worker), **Jane Bradford** (DLA Administrator to December 08), **Holly Watson** (Compass & DLA Administrator from Jan 09), **Nicola Keene** (Compass & DLA Administrator from Jan 09), **Tina Brownbill** (Compass Database Manager from March 09), **Shirley May** (IT Support), **Becky Jenner** (Fundraiser), **Samantha Selway** (Parent Trainer), **Sandra Chitty**

(Parent Trainer), **Kim Smith** (Parent Trainer), **Claire Peligry** (Parent Trainer), **Helen Arnold-Jenkins** (Parent Trainer), **Jac Matthews** (Community of Practice Facilitator), **Carrie Britton** (Parent Trainer and PaCC Parent Participation Coordinator), **Debbie Collins & Nicola Gibson** (Co-chairs of the PaCC), all the PaCC steering group members.

Volunteers

Karin Anjos, **Vivian Barton**, **Chrysie Brown**, **Brenda Hinchliffe**, **Brenda Mann**, **David Natha-Gregory**, **Lorraine Roberts**, **Sharon Rose**, **Nicole Stamatopoulos**, **Dr Bob Towler**, **Tamsin Turnbull**, **Ann Wilkinson**, **Farah Woosnam**, **Sue Rosenfield**, **Emma Parker**, **David Felsenstein**, **Os Corke**, **Phil McMahon**, **Sue McManoman**, **Marina Pietrasko**, **Alison Sheen**, **Kim Tugwell**, **Hazel Sharpe**.

Moira Mills and **Zara Arnold** who were with us on sabbatical thanks to American Express

Contributors to Amaze's Research and Training Work

Prof. Angie Hart, **Dr Darren Smith**, **Myra Wiseman**, **Dr Carl Walker**.

Community Partners

Community Base, **Duke of York's Cinema**, **Funplex**, **Kidz Stuff Festival**, **King Alfred Leisure Centre**, **Odeon Brighton**, **Prince Regent Swimming Complex**, **Saint Luke's Swimming Pool**, **Sea Life Brighton** and **Westow's World of Play**

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



Amaze

Community Base
113 Queens Road
Brighton BN1 3XG

Tel: 01273 772289

Email: info@amazebrighton.org.uk

Website: www.amazebrighton.org.uk

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.

Amaze Brighton & Hove *

UK Company Limited by Guarantee No: 3818021

* Registered Charity No: 1078094

