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ANNUAL REPORT 2012

working with parents of children with special needs

Joint statement from the CEO and Chair

This April saw us complete the final year of delivering our first Amaze Business Plan (2009-12) and we're delighted to report the organisation has continued to grow in resilience and reputation over this time. Our turnover increased 48% in this three year period, bucking the trend among other voluntary and community sector organisations and representing a significant achievement in light of the current economic environment.

This is partly due to the impressive work of Amaze Research and Training (ART), who delivered training and consultancy across the UK, but also to our ability to justify the need for additional investment into our core and new services from a variety of funders including the statutory sector, trusts and individual donors. During 2011/12 we were fortunate to receive a grant from the Transitions Fund to further develop our fundraising expertise and this too has been a factor in building our financial resilience.

However, despite securing this improved financial position with staff and volunteers working tirelessly, the needs of the families we work with continue to increase. Demand keeps going up and we have waiting lists for most of our services.

Calls to our helpline rose again, by 7% on the year (an 86% increase over the last

5 years with no uplift in funding for the helpline to reflect this). Our DLA, education and transitions casework (new this year) continues to be in great demand and invaluable to parents.

In addition to service delivery, Amaze staff have been heavily involved in supporting the Brighton and Hove City Council in the SEN SE7 Pathfinder, engaging parents with new proposals to introduce a single education, health and care plan, personal budgets, a local offer and initiatives to increase parental confidence and support. These changes are now being put into the new Children and Families Bill and will begin to impact families in March 2013.

'I met a local parent today who has had support from you – she said you had been brilliant. It sounded like you helped her negotiate DLA and carers allowance which has allowed her to balance family life. She is now doing a key skills course and a cookery course – it seems much of her confidence comes from the support she has had from you.'

A local professional

Over the year, Amaze staff and parent representatives from the Parent Carers Council (PaCC) sat on 37 meetings of strategic partnerships, boards and subgroups across the City adding a richness and reality to discussions about service developments, delivery and strategy. PaCC has continued to grow in influence during 2011/12 and now has over 190 members. During the year PaCC chose to consult parent carers on what they felt about some of the city's health services. The resulting 'Talk Health' report (published in July 2012) will hopefully increase awareness about the key concerns these families face and bring about improvements.

Looking forward, significant reforms are underway which are already having an impact on families with disabled children in education, health and welfare/benefits. Amaze needs ongoing capacity to stay abreast of these changes so we can best support and advise parent carers through the ever more complex maze. Unfortunately much of the additional income for this year was one-off funding which, together with a much reduced projection for training income, means we expect to see reductions in income over the next few years unless we can identify other sources.

In November, we carried out our first ever parent carer survey which told us 43% of parent carers have not had a day off from caring in over 6 months and 46% say that additional caring responsibilities have had a negative impact on a spousal/romantic relationship (in 27% cases contributing to the relationship breaking down), and 63% parent carers feel isolated. Also, 76 per cent of parents had experienced mental ill-health and 65 per cent had experienced physical ill-health as a result of their additional caring role.

We are hopeful that with evidence like this to support our lobbying we can make the case to commissioners to continue to invest in services and support for disabled children and their carers, two of the city's most disadvantaged, isolated and socially excluded groups.

Rachel Travers, CEO and Hugh Clench, Chair



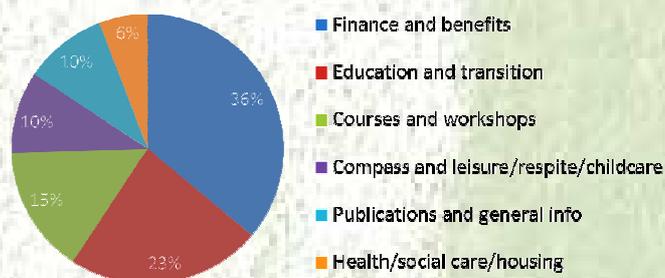
Helpline

Our helpline is the first stop for most parents using Amaze. The helpline advisers listen and give advice, but also link parents to Amaze's other activities such as the IPS scheme or our courses. More than a quarter of callers are ringing us for the first time. They might be starting to think their child has additional needs or have just got a diagnosis they want to talk over. Other first time callers have been struggling on for years feeling isolated and blamed for their child's difficulties and getting little support. A conversation with someone who understands and who can help them plan a way forward can be a lifesaver.

"It was such a relief to talk to someone who understands, thank you so much."

Key figures for 2011/12

- We had 3934 calls, 582 of which were from new callers. Calls have risen by 86% in the past five years
- Parents across the city use the helpline. This year most calls came from Moulsecomb, Portslade, Hollingdean, Hanover/Elm Grove, Hangleton and East Brighton
- Money or benefits and education issues continue to be the most popular topics (see chart below)



Publications and website

Finding out your child has a disability or special need can be a bewildering and frightening experience. There's a whole world of services and terminology you need to get your head around whilst at the same time dealing with the feelings you have about the different turn your life has taken. Not surprisingly many parents feel overwhelmed and desperately in need of advice from someone who's been there before.

Amaze's handbooks, fact sheets, newsletter and website are designed to offer that friendly, experienced advice, just when parents need it most, in a way that's easy to understand.

'There is nothing that I don't like about Through the Maze and it is used frequently as a reference for information

Parent responding to a survey about Through the Maze

Key achievements :

- Distribution of our termly newsletter, Out of Amaze, grew to just over 13,600
- We produced a new, updated edition of Through the Next Maze for parents of teenagers and over 300 copies were distributed
- Our website got over 36,000 visits - very impressive for a 'local' site

Education support via the IPS Scheme

Parents of children who are disabled or have additional needs often need extra support and information to help their child get the best out of school. The IPS Coordinator and a team of trained volunteers understand how education works and offer parents this vital one-to-one support. Sometimes just talking things through or having someone come with them to a meeting can give a parent the confidence to get their views across. At other times a parent may need detailed advice about what they can reasonably expect from a school or education service. The IPS scheme is a key part of Amaze's role as the Parent Partnership Service for Brighton and Hove. We aim to help parents advocate positively for their children, whilst building partnerships with schools and services.

Key achievements in 2011/2012

- We provided one-to-one support on education issues to 137 new families and gave ongoing help to many others
- We trained new Independent Parental Supporters who joined our team of dedicated volunteers.
- We improved our understanding of SEN law to offer parents accurate advice.

'Thank u for all your support today. I felt in control for once.'

Parent thanking the IPS co-ordinator

Disability Living Allowance project

The DLA project tackles poverty. It's harder to hold down a job and much harder to live on benefits if you have a disabled child. Yet working alongside one of our volunteers to complete the DLA form is the only realistic chance many parents have of claiming the extra benefits their child is entitled to. This is what we do.

Key achievements in 2011/2012

- Amaze drafted 282 DLA claims. We calculate the annual income generated from our DLA work totals over £2 million, with a further £1 million generated by supporting parents to claim passported benefits like carers allowance and disabled child tax credits.
- We are reaching the most disadvantaged families in Brighton and Hove with over 44% living on benefits. 45% of households were lone parent families.
- We are reaching the families most at risk of social exclusion: 24% had two or more children with special needs; 19% had at least one parent with mental health problems; 21% had at least one parent managing physical disability, learning disability or chronic illness of their own and 4% needed support from an interpreter

'It was such a relief just to talk and when I read it back my own words jumped off the page: it was all there, unscrambled, coherent and just what I had wanted to say. So, thank you.'

A parent commenting on the completed DLA form

Courses and workshops

Amaze courses bring parents together to learn new skills and ideas in a friendly and supportive environment. Most courses are co-delivered with parent trainers so parents can be confident that we'll be speaking their language and making sure the course is relevant to them. As well as our regular courses, we ran workshops in partnership with local professionals, including workshops on communication and coordination run by Speech & Language and Occupational Therapists from Seaside View and a Wills and Trusts seminar with a local solicitor. We also spoke or ran information stalls at a variety of events for local parents and professionals.

"I came away after each session feeling so much lighter than I did when I first arrived."

Key achievements in 2011/12

- Four 'Triple P' positive parenting courses helped parents support their child with their behaviour
- Three 'Insiders Guide' courses built parents' resilience in bringing up disabled children, mixing practical knowledge with a look at the emotional side of being a parent carer
- Two 'Looking After You' courses addressed the physical and emotional stress of caring, with Pilates and relaxation techniques
- Around two hundred parents enjoyed over 45 stalls and a pamper area at this year's health-themed Information Fair



Transition Development

Many parents of young disabled people say the transition from childhood to adulthood is the most stressful time for them and their child. Amaze works with parents and professionals to try to change this and make the transition to adulthood a more positive experience for families.

Key achievements in 2011/2012

- Our training and support groups provided parents of teenagers with much-needed information and an informal space to meet other parents in a similar situation. They included: Transition Information Sessions; Insiders Guide to Bringing up Teens with Special Needs; Planning for the Future (Wills and Trusts); and our regular Parents of Teens Get Together.
- We updated our handbook, Through the Next Maze, and sent copies to parents of teenagers with Statements of SEN.
- Amaze Transition Support Volunteers provided information, advice and emotional support to individual families as their children were moving on from special school to college
- Parent representatives and Amaze's Transition Worker contributed to a number of strategic boards regarding transition related issues

'The whole series of workshops have been really informative - how on earth would we find out this info without them?'

The Compass and Compass Card

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

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

Key achievements in 2011/12

- The number of children on The Compass rose by 2.5% to 1500
- Four new Compass Card offers were added - Big Lemon buses, Brighton Wheel, Rainbow SongTime and Yellowwave Beach Sports Venue
- 12 statistical reports or analysis provided to local partners for commissioning reports or service development initiatives e.g. BHCC strategy on child poverty
- We ran the 'Amazing Zone' at the launch day of the TAKEPART Festival of Sport, increasing the attendance of families with additional needs from a handful to hundreds

'[My son] looked so happy - wonderful'.

Parent commenting on Compass Card Activity, circus skills from BandBazi

Parent Carers' Council (PaCC)



The PaCC continued to grow with support from Amaze. Our aim is to raise the profile of the parent carer experience - make others aware of the challenges we face and help influence and improve the services our children receive. The steering group, made up of 15 parent carers, represents parents on strategic decision-making groups across the city and parent carer groups that serve our children and their families.

Our profile has grown with greater recognition from not only services within Brighton & Hove but also both regionally and nationally.

Key achievements in 2011/12

- Membership grew from 165 to 190 parent carers and we represented 650 families through our partner organisations (there's some overlap between these families)
- PaCC published a comprehensive report on health care for children with special needs in the city, setting out parent carer concerns and recommendations for improvements
- Following the PaCC report on Therapy Services for disabled children, we monitored implementation of several

recommendations. A PaCC steering group member now sits on the Therapy Quality and Standards group to influence changes to services

- PaCC and Amaze wrote a full response to the Government's Green Paper on the SEN system in schools and colleges and have since been heavily involved in the work of the SE7 pathfinder. Brighton & Hove is leading on support to parent carers and is working closely with the PaCC to inform this work.
- Our Partnership Charter, written by parents in collaboration with service providers, was successfully developed and will now be used as a tool to improve services for families.
- We produced our third awareness-raising PaCC calendar and distributed them to almost 400 parents and professionals
- The fourth annual PaCC Awards recognised those local professionals who demonstrated care and service beyond the call of duty, as voted on by parents. This year we voted for professionals to become champions in the voluntary, health care, education and social care sectors and gave awards to each of these individuals.

ART - Amaze Research and Training

ART has been offering a training, research and consultancy service since 2007.

Key achievements in 2011/12

- Five parent forums commission ART to support their participation work
- Six education and benefits workshops delivered to West Sussex parents
- New Adult and Community Learning Fund project develops Insiders' Guide examining outcomes using 'Social Return on Investment' methodology - results show that every £1 invested in the course creates a social value of between £25-£38
- Parent carers attending Insiders' Guide report significant changes for themselves and their families as they became equipped, informed, confident and connected
- Three further sites across the country trained in delivering Insiders' Guide

- Senior ART Associate took the parent participation agenda forward in her role as co-chair of the National Network of Parent Carer Forums and SE7 Parent Carer Participation Adviser
- Jointly written chapter included in Benneworth, P. (ed) (2012) University engagement with socially excluded communities: towards the idea of the engaged university, Springer: Dordrecht, NL.

ART's work to integrate and share research and practice that promotes resilience continued to grow.

- Amaze's resilient-building approach cited in the Director of Public Health Annual Report, NHS Brighton & Hove
- The Resilient Therapy (RT) toolkit for parents of young people with mental health difficulties available on website

and included in the ESRC's short film for 2011 Festival of Social Sciences

- The third Resilient Therapy Community of Practice commissioned by East Sussex Public Health got underway and includes 16 youth workers and four parent carers
- Ongoing collaboration with Etienne Wenger, international expert and co-founder of the Communities of Practice approach continues
- Nine 'Understanding Resilience and Resilient Therapy' sessions delivered to diverse audiences.

ART's Director, Kim Aumann, retired in July 2012 and we would like to thank her for her outstanding contribution to both ART and Amaze. Amaze will continue to link theory, research findings and the experience of parent carers and practitioners, to promote best practice.

Statement of financial activities

For the year ended 31 March 2012 (including income and expenditure account)

	Unrestricted Funds £	Restricted Funds £	Total Funds 2012 £	Total Funds 2011 £
INCOMING RESOURCES				
Incoming Resources from Generated Funds				
Grants	5,250	32,000	37,250	58,503
Donations	13,971	-	13,971	2,325
Bank Interest	222	-	222	141
Fundraising	21,156	-	21,156	32,039
Incoming Resources from Charitable Activities				
Grants	347,998	36,100	384,098	270,305
Services	18,675	-	18,675	37,860
TOTAL INCOMING RESOURCES	<u>407,272</u>	<u>68,100</u>	<u>475,372</u>	<u>401,173</u>
RESOURCES EXPENDED				
Fundraising costs	4,156	20,505	24,661	23,557
Charitable Activities	343,632	57,755	401,387	363,051
Governance Costs	2,548	-	2,548	2,059
TOTAL RESOURCES EXPENDED	<u>350,336</u>	<u>78,260</u>	<u>428,596</u>	<u>388,667</u>
NET INCOMING/(OUTGOING) RESOURCES FOR THE PERIOD				
	56,936	(10,160)	46,776	12,506
TRANSFERS	(5,103)	5,103		
NET RESOURCES FOR THE PERIOD AFTER TRANSFERS	51,833	(5,057)	46,776	12,506
ACCUMULATED FUNDS AT 31 MARCH 2011	<u>116,957</u>	<u>9,161</u>	<u>126,118</u>	<u>113,612</u>
ACCUMULATED FUNDS AT 31 MARCH 2012	<u>168,790</u>	<u>4,104</u>	<u>172,894</u>	<u>126,118</u>

*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.

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:

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

A very big thank you to...

Our funders

Statutory funders

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

Grants and other funders

Brighton & Hove Learning Disability Partnership Board, Department for Education, Transition Fund Grant, Ernest Kleinwort Charitable Trust, Noel Bennett Grants Fund, Scottish Power Energy People Trust, Sussex Community Foundation, The Fitton Trust, The Henry Smith Charity, University of Brighton, Adult & Community Learning Fund, Blatchington Court Trust, East Sussex County Council,

Donations & Events:

Baby Cow Productions, Brighton Dome, Brighton and Hove City Athletics Club, Brighton College, Brighton Marathon Grounded Events, Butler's Wine Cellar, Cogapp, Dean Wilson LLP, Duke of York's Picture House, Elwood Wines, F10 Architecture, Ferrero UK, Job Centre Plus, Just Good friends, Latest Homes, Lewes Barbican Rotary, Nutshell Construction Ltd, Pardon My French, Photography by Foz, Ramskill Designs, Revolution Films, Sainsbury's West Hove, St Andrews Parish Church, Stanford Infants School, Studio 57 Clinic, TP Training

Comedians: Rob Brydon, Steve Coogan, Jason Cook, Graham Duff, Jenny Éclair, Simon Evans, Julie Jepson, Justin Moorhouse, Ian Moore

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

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

Community partners

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

Our supporters

Amaze relies on the support of many different people and organisations. We're particularly indebted to those who have given their time, expertise and support. Limited space means we can't thank everyone individually, but the following deserve a special mention for their support in 2011/12.

Patrons

Henry Normal, Angela Pell and Annabel Giles

Trustees

Karin Smith, Chair person to Nov 11
Hugh Clench, Chair person from Nov 11
Ian Gillett, Treasurer
Diana Boyd
Kaye Duerdoth, resigned Nov 11
Susmitha Gadiyar
Sally Howell
Carl McAdam, resigned Nov 11
Debby Norris
Fungi Woolnough-Murau
Ian Elwich
Tony Gove
Siobhan Cox

Volunteers

Linda Hill, Lisa Mitchell, Helen Arnold Jenkins, Julie Stokes, Becky Hartfield, Edward Hartfield, Lynne Swaisland, Sue Timpson, Jill Weeks, Ann Wilkinson, Helen Wyatt, Alison Field, Matilda Cook, Alfie Cook, Nicky Beanland, Jess White, Tom Blackburn, Hannah Jeffries, Wendy McCarthy, Jane Barnett, Janet Finn, Dani Arrowsmith, Shiromi Cabraal, Allison Dickson, Steve Harmer-Strange, Hazel Herovitsch, Ant Miles, Liz Ross, Simon Scardanelli, Jonathan Scott, Julie Stokes, Donna Walker, Julieanne McVincent, Kerry Korkunc, Keilly Blann, Natalia Borg, Carol Burns, Rosie Chapple, Oswalde Corke, Clare Galler, Nicola Gibson, Brenda Hinchliffe, Gillian Kitchener, Ray Knight, Paula Little, Brenda Mann, Hannah Osborne-Dowle, Mai Osman, Bruce Piper, Lorraine Roberts, Sharon Rose, Susan Rosenfield, Samantha Selway, Sandamalee Senanayake, Joanne Shannon, Catriona Strong, Bob Towler

Our staff

Rachel Travers – Chief Executive Officer
Kim Aumann – Director ART
Ros Cook – Operations Director
Nicky Bagilhole – Fundraiser
Lizzie Batten – DLA Project Co-ordinator
Ann Blackburn – Compass Card/Carers' Card Development Worker
Zoe Brinkworth – Finance Manager
Tina Brownbill – Database Manager
Debbie Collins – Parent Participation Worker
Nicola Keene – Database Administrator
Charlotte Moroney – Publications & Website Manager
David Natha-Gregory – Helpline Advisor
Janet Poole – IPS Project Co-ordinator
Sue Winter – Transition Development Worker

Freelance workers and parent trainers

Karin Anjos – Parent trainer
Helen Arnold Jenkins – Parent trainer
Carrie Britton – Consultant and Senior ART Associate
Sandra Chitty – Parent trainer
Professor Angie Hart
Shirley May – IT Support worker
Josie Melia – ART Associate
Emma Parker – Parent trainer
Claire Peligry – Parent trainer
Samantha Selway – Parent trainer
Kim Smith – Parent trainer

PaCC steering group members and parent representatives:

Amanda Mortensen (Chair), Tim Lavender(Chair), Juliette Teague, Jill Weeks, Marian Tipler, Sarah Pickett, Nicola Gibson, Doreen Wallace, Sharon Garcia, Martin Jones, Ruby Kearns, Gilli Davidson, Susmitha Gadiyar, Emma Parker, Kerry Korkunc, Angus Goldfinch, Medeni Elwick, Claire Turner, Chrysi Brown, Hannah Osborne-Dowle, We have 190 members which would be too many to name individually. Many thanks for the contribution they have made to consultations over the year.

Social Work Student

Phillipa Fleming



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