

our impact amaze 2016-2017 report

for families with disabled children and young people in Sussex

www.amazebrighton.org.uk



amaze is more than just a charity.

It is a very special community made up of children, young people, parents, carers, dedicated professionals, trustees, volunteers and supporters of all kinds.



welcome

from Rachel & Hugh

Hugh and I are delighted to share this year's Impact Report with you.

It summarises the work we have done in 2016-17 which has been a significant year for Amaze as we launched both the Compass West Sussex and, more recently, the Amazing Futures project: one extending our reach geographically and one to a new audience of young people. New projects like this take a significant amount of time and energy to get off the ground, especially for a small organisation like ours, and we are so proud of the staff who have made them a reality. It's great to hear from families and young people about the impact these are having even after a relatively short space of time.

As it's our birthday year, we are also celebrating the immense impact Amaze services have had with families over the last 20 years and we hope you like the timeline on the centre pages showing our development as an organisation.

Over the years we have had tremendous support from our statutory partners and other funders, and many hundreds of parents and professionals who have contributed their expertise to our work. We want to say thank you and share our birthday celebrations with all of you.

Whilst we are proud of our achievements, and how far we have come, we know there are still many families with disabled children who continue to desperately need better information, advice and support in order to thrive and we will continue to try to reach as many as we can.





Rachel Travers, Amaze CEO

Hugh Clench, Chair of Trustees

"I'm not even joking when I say you have been a lifeline. I have no idea how much stress we'd be going through had it not been for your help and advice and calm, friendly approach. All through this I've felt I've had someone behind me and that is everything to us."



who is Amaze?

Amaze is a Sussex-based charity that gives information, advice and support to parents and carers of children and young people with special educational needs and disabilities (SEND). We also support young people with SEND up to 25.

Most of our services are for families in Brighton and Hove but we offer Independent Support services to both parent carers and young people up to 25 in East and West Sussex. In April 2016 we also extended the Compass scheme into West Sussex.

the problem we address

Children and young people with disabilities or special educational needs and their families often:

- Live in poverty, in overcrowded housing or housing not suitable for their needs
- · Are socially isolated from their peers
- Have poorer educational outcomes or employment/training opportunities
- · Are more likely to live with a single parent
- Have siblings who are overlooked and need support
- Have parents who suffer from poor physical and mental health and many have additional support needs themselves
- · Struggle to find out what's out there to help
- Have more than one child with additional needs or a disability themselves

our vision

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

what makes us special

We believe that children and young people with SEND and their parents are the experts in their own or their child's care and we put their views and experience at the heart of everything we do. We employ a young person intern and over half of Amaze's 42 staff are parent carers themselves. Of the 70 volunteers and trustees who support our work, about half have direct experience of caring for a disabled child. And many of these parent carer volunteers or board members move into paid work with us.

"The thought of my happy, confident, loving but very immature son being bullied and overwhelmed at a mainstream school filled me with dread, and many tears. With Amaze's help, I now believe this has been averted and he has every opportunity to flourish. " generation amaze is at the heart of what we do – supporting the next generation of amazing children with special educational needs and disabilities

celebrating 20 years

Back in 1997 Amaze was launched to provide information, advice and support for families with disabled children. At the time, local parent carers described feeling "lost in a maze" when their child was diagnosed with an additional need and they campaigned to improve the information and support available to them.

20 years on, Amaze has supported a whole generation of children and their families with an ever-expanding range of services, developed according to what parents told us they needed (see page 5).

amazing futures

Our latest Amazing Futures Project is the most powerful and direct embodiment of all this work, as some of the young people whose parents we have supported over the last 20 years are now keen and able to start helping others. Eight of the young people we have recently trained as Peer Supporters have a special educational need or disability themselves, and their parent carers feel their participation in the project is a direct result of Amaze's help over the years; they have been able to build their own and their child's resilience, leading them to now feel able to volunteer their time to help other young people with disabilities.

generation amaze and the next 20 years

We are calling the impact of this 20 years' work 'Generation Amaze', and we are looking to develop new partnerships (with local businesses) to work with us to help fund the next generation of Amazing families.





Amazing Futures is an exciting new project from Amaze, designed to harness the power of peer relationships as part of supporting young people, aged 14 to 25, on their way to more independent futures.

peer support into adulthood confidence and independence better life opportunities



what we do

We give young people with SEND, and their families, the information they need to make the best choices for their lives and give them direct support where and when they need it most. We do this via the following services:

Helpline.

Our SENDIASS (SEND Information Advice and Support Service) helpline is a mine of information, the gateway to our services, and someone to talk to who really "gets it".

One to one support.

Individual SENDIASS help for parents and young people on education, health, social care and transition to adulthood issues.

Publications and online resources.

Handbooks, factsheets, a newsletter, e-bulletin, website and social media channels providing information about SEND issues and services.

Courses and workshops.

On many aspects of caring for a disabled child, essential information and practical strategies for resilience and wellbeing.

DLA and PIP.

Our project provides practical and emotional support in claiming Disability Living Allowance and Personal Independence Payments through a volunteer team.

Compass Database and Card.

The Brighton and Hove and West Sussex registers of disabled children aged 0-25, which inform service planning. Registered children get a Compass Card with discounts and offers at a huge range of leisure facilities.

Independent Support with EHC Plans.

Now offered across Brighton and Hove, West and East Sussex, providing young people and parents with support through the process of getting an Education, Health and Care Plan.

Community outreach coffee mornings.

In Moulsecoomb, Hangleton & Knoll and Whitehawk to reach families that can miss out.

Hosting the Parent Carers' Council (PaCC).

The local forum for parent carers of disabled children in Brighton and Hove, to ensure parent's voices are heard by service managers and commissioners.

Sibling support group.

Giving siblings the opportunity to come together, share experiences, build their confidence and have fun.

New in 2017

SENDIASS for East Sussex: helpline, SEND resources and individual advice now offered for young people and families across East Sussex.

Amazing Futures: our exciting new project supporting young people through peer support and more.

Face2Face Befriending: parent to parent support in the tricky early days, around the time of diagnosis and assessments.



we have a lot to celebrate!

1997

Amaze was founded in 1997 by bringing together two parent carer groups.

Now over 50 per cent of staff and volunteers are parent carers and Amaze also employs two young people with additional needs.

2001

When Amaze took over Brighton and Hove's Disability Register in 2001, it held details of 271 disabled children.

The Compass Register (as it became known) now has over 2,000 children and young people signed up and enjoying the benefits of their Compass leisure card.

2006

In 2006 Amaze's **Helpline** was receiving 2,000 calls per year. This has gone up year on year and we still can't keep up with the demand.

> By 2017 this number has grown to over 3,500 calls per year about a range of topics including finance, education, health, social care and leisure.

2008

Amaze helped set up the **Parent Carers' Council** (PaCC) – the forum for parent carers living in Brighton and Hove. PaCC now has over 320 members and nine Parent Reps sitting on strategic boards across the city.

 Over 250 parents/ carers now attend
PaCC's Community
Outreach Project's coffee mornings in three of the city's most deprived
neighbourhoods.

join us in making the next 20 years just as special!



amazing futures

2013

Amaze has embraced new technology and social media and in 2013 launched a new-look website which now has nearly 30,000 users each year.

> Our Facebook page is well-used with over 1,500 'likes' and we have over 2,000 followers on Twitter.

2014

In 2014 Amaze set up new Independent Support services in both Brighton and Hove and West Sussex.

In 2016 Amaze began delivering Independent Support in East Sussex too, establishing itself as a Sussex-wide charity for the first time.

2016

Amaze launched **Compass West Sussex** in 2016, extending the popular scheme to children and young people aged up to 25.

There are now over 160 offers (discounts or free entry) at a wide range of leisure venues across West Sussex and Brighton and Hove.

2017

In 2017 Amaze set up the **Amazing Futures** project. Peer supporters help young people with additional needs to consider new options as they enter adulthood. Amaze also started offering the **Face to Face Befriending** project.



the stats: April 2016 to March 2017

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

1,975

children and young people aged 0-25 now on the Compass Brighton and Hove Register (3% increase on the year)

1,489

children and young people aged 0-25 added to new Compass West Sussex Register launched April 2016

2,469

visitors per month to Amaze website (18% increase on the year)

informed

79%

of parent carers said they felt more informed about their child's additional needs and the support and services available, after receiving casework support from Amaze

3,543 incoming calls and messages and received by the

Helpline



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



322

members in the Parent Carers' Council (PaCC)

73

people attended PaCC events over the year

7

members in the young people's advocacy group, co-run by Amaze with Speak Out

30+

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

heard

71%

of parent carers said they felt their voice was heard and their views more taken into account, after receiving casework support from Amaze Parent carers felt well supported in relation to their child's additional needs

234

parent carers and young people received info, advice and support (IAS) via ongoing casework in Brighton and Hove

444

parent carers and young people received casework support from the Independent Supporter (IS) Services in Brighton & Hove, East Sussex and West Sussex

308

families received intensive support from the DLA service to make Disability Living Allowance or Personal Independence Payment claims (3% increase on the year) and a further 60+ families were supported to complete the claim application themselves

supported

£68,000

per year funding to Amaze Disability Living Allowance (DLA) Support Service leading to...

estimated annual income for families from the DLA service

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

188

parent carers and young people attended Amaze workshops and courses

166

professionals received SEND training from Amaze staff

81%

of parent carers said that they felt more able to deal with any issues or problems that arise from their child's additional needs, after receiving casework support from Amaze

able

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

17,024 3

copies of our newsletter were distributed coffee mornings held by our Community Outreach Project were attended by 256 parent carers

1,295

likes for the Amaze Facebook page

included

Twitter followers

2,029

the stories: making a world of difference to the lives of local families

michael's story

"My son has a diagnosis of Global Developmental Delay which presents as speech, language and communication difficulties and associated behaviour issues. I would consider myself to be a reasonably able and intelligent man but I felt totally swamped and overwhelmed by the whole process of changing his EHC Plan at transfer to secondary school. What struck me the most was the lack of honest, impartial advice and information. Luckily at this point I found Amaze who I can't praise enough. Our case worker was brilliant, not only did she understand this process, she wasn't phased by it, and she gave me the one thing I craved - information that I could understand."

understanding

future

confidence

support

Michael, parent carer in West Sussex

sammy's story

"Since doing the Amazing Futures programme, I have gained so much confidence and social skills. I have enjoyed the experience of learning new skills and meeting lots of new people both with and without disabilities. The skills Amaze have taught me will help me and will stay with me for life. For this I thank Amaze, and will be continuing with their peer support programme."

Sammy Watson, a young person Peer Supporter

a parent's story

"We had reached a complete brick wall with the school and didn't know how else we could proceed. Having our Amaze caseworker understand our situation and validate and assist us on how to deal with this challenging situation was invaluable. She was incredibly professional but also firm and clear with what was acceptable from the school. She helped to steer the meeting and guide the process to make sure that the agenda was covered and also helped us to express our views clearly about our son's very specific needs. We really don't think that our son would have got the support he needed without her help. We are extremely grateful to her and Amaze."

Feedback from a Brighton family, 2016

"Amaze offers such fabulous support and is a real asset to families in this area. We are all so lucky to have you."

financial summary

For the year ended 31March 2017 (including income and expenditure account)	Unrestricted funds (£)	Restricted funds (£)	Total funds 2017 (£)	Total funds 2016 (£)
Income and endowments from				
Donations and Legacies	62,440	53,394	115,834	117,454
Investment Income	315	-	315	339
Incoming resources from charitable activities				
Grants	140,956	-	140,956	335,158
Services	634,676	-	634,676	344,471
Total incoming resources	838,387	53,394	891,781	797,422
Resources expended				
Raising funds	54,595	-	54,595	53,562
Charitable activities	727,560	63,403	790,963	756,309
Total resources expended	782,155	63,403	845,558	809,871
Net incoming/(outgoing)				
Resources from the period	56,232	(10,009)	46,223	(12,449)
Transfer between funds	(3,516)	3,516		_
Total funds carried forward	434,751	23,791	458,542	412,319

our funders

We'd like to thank all the agencies, organisations and individuals who helped to fund us in 2016/2017.

statutory funders

Brighton and Hove City Council, Brighton and Hove Clinical Commissioning Group, Council for Disabled Children, Department for Education, East Sussex County Council, West Sussex County Council.

grants and other funders

Downlands Educational Trust, Fitton Trust, Hasluck Charitable Trust, Mrs A Lacy-Tate Trust, NatWest Skills and Opportunities Fund , Newman's Own Foundation, Noel Bennett Fund, St James's Place Charitable Foundation, The American Express Fund at Sussex Community Foundation, The Chalk Cliff Trust, The Ernest Kleinwort Charitable Trust, The Gurney Charitable Trust, The Henry Smith Charity, The Ian Askew Charitable Trust, The Insurance Industry Charitable Foundation, The J C Robinson Trust No 4, The Lynn Foundation, Yorkshire Building Society Charitable Foundation

donations & events

Asda, Avatrade, Brighton and Hove City Athletics Club, Cellular Solution, Clinique, Hornall Anderson, HSBC, Komedia, Ladies of The Dyke Golf Club, Paddle Round the Pier, Renaissance Legal, Rotary Club of Brighton, Sainsburys, St Christophers School, St Peter West Blatchington, Starbucks UK, Stiles Harold Williams, Toyota, Waitrose, Wellesley Charitable Foundation

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



huge thanks

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

our patrons

Julia Donaldson Annabel Giles Henry Normal Angela Pell and our good friends Lindsay Hughes and Joe Wilkinson

our trustees

Hugh Clench (Chair) Debby Norris (Treasurer) Karen Smith Sally Howell Debby Norris Sue McMillan Fungi Woolnough-Murau Siobhan Cox Ray Knight



PaCC steering group members/parent representatives

Fiona England Diana Boyde Amanda Mortensen Helen Arnold-Jenkins Lisa Russell Marian Tipler Martin Jones Philippa Hodge Sally Howell Jo Levi Paolo Boldrini

get in touch

01273 772289 (Helpline) info@amazebrighton.org.uk www.amazebrighton.org.uk



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@AmazeBrighton



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Amaze

Community Base, 113 Queens Road Brighton BN1 3XG

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