



for disabled children and young people in Sussex

www.amazesussex.org.uk

welcome from Rachel & Hugh

We are delighted to share our 2017-18 Impact Report with you. We are proud of the powerful impact that our work has on the lives of families and children and young people with special educational needs and disabilities (SEND) across Sussex, despite the challenging financial and political climate.

During this year, Amaze has succeeded at bringing in additional and more income streams including new partnerships with Henry Smith and the Big Lottery Fund, as well as new statutory grants and contracts with East Sussex County Council. This means we have been able to offer some of our tried and tested services to more people who need them and we are seeing some great results.

Whilst we are very proud of our new infographic on page 6-7, we are not a numbers factory. Children and young people with SEND and their families have significant challenges and we hope the case studies in this report give you a sense of how we put the needs of each child and their parent carers at the centre of our services, which enables us to give them tailored and holistic support specific to their situation. We are able to prove that this, in turn, increases their confidenceand resilience, and strengthens their voice to shape the decisions that affect them.

In addition to providing services, we also work hard to influence and improve local, regional and national policy and strategy. We host and support the Brighton and Hove PaCC and we work alongside the parent carer forums in East and West Sussex. We also co-facilitate a young people self-advocacy group and host a young people's advisory group in Brighton. Both these groups support young people with SEND to identify and communicate their needs to decision makers.

Whilst we are doing our best to support more families, demand continues to rise and we have waiting lists for most of our services. We are trying to raise additional funds so we can reach more families across Sussex. As public spending continues to reduce we are often asked to do more for less. We are making the case that statutory services need to take the brave decision to invest more (not less) in early, preventative services like ours to avoid higher costs arising later on. So far, we're relieved and proud that Amaze's excellent reputation for high quality, impactful services, innovation and responsiveness has meant we've fared better than most in retaining our funding, and for this we're thankful to all our current partners and funders. Long may it continue.





Rachel Travers, Amaze CEO

Hugh Clench, Chair of Trustees

our vision

A world where families with children and young people with special educational needs and disabilities are valued, included in their community and supported to thrive.

who is Amaze?

Amaze is a charity that gives information, advice and support to families of children and young people with special educational needs and disabilities (SEND) in Brighton & Hove and Sussex. We also support young people with SEND up to 25.

the problems 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

what makes us special

We recently asked families who use our services what makes Amaze unique. Many said that our staff "walk the talk" and have their own lived experience of having a disability or a child with a disability. They said we offer both professionalism and compassion and are respected by families and professionals alike.

The following organisational values underpin all our work:

- We listen and are responsive to the needs of families
- We provide families and young people with a voice, influencing decision makers by sharing our learning about what families need
- We are independent from statutory agencies and provide impartial information, advice and support
- Parent carers and young people with SEND themselves are the experts and our services are 'person-centred' and 'co-produced' by them
- We empower parent carers and young people by building their confidence, knowledge, skills and resilience
- Our services are of a high quality, provided by experienced and knowledgeable staff who are approachable and trustworthy
- As demand for our services remains incredibly high, we prioritise our services to support the most vulnerable, and support others to be more 'self-servicing'

what we do

We provide a range of different information, advice and support services to parent carers and to children and young people with SEND. These vary across Brighton & Hove and Sussex according to the funding we receive.

Core Amaze services which we aim to provide in each area as a minimum, include:

information

in a variety of formats including online, face-to-face and paper-based. In Brighton & Hove and West Sussex this is supported by managing each local authority's disability register (The Compass).

voice and influence

at a local, regional and national level, using intelligence gathered from providing services and Compass data, supporting the local parent carer forums and young person's advisory groups to affect change and co-produce service developments.

We also provide other essential, 'added value' services including:

Helpline advice and support

and signposting on subjects that cover education, health, care and other important aspects of a family's life

More in-depth **casework** for families facing particular challenges

DLA and PIP benefits casework

Increasing opportunities for leisure, sport, activities via the **Compass Card**

Training workshops and courses

Peer support and more informal opportunities for parent carers and young people to network and support each other e.g. befriending, coffee mornings, parent support groups, young people's peer support groups

Brighton & Hove Parent Carers' Council



The Parent Carers' Council is a forum for parent carers of children with additional needs who work to help improve services and support in Brighton & Hove.

The PaCC core team includes parent representatives who sit alongside professionals from the local authority on strategic boards. They help to ensure that the parent voice is heard when decisions are made that directly affect their children.

PaCC is a project hosted by Amaze.



our plans for 2018-21

Over the last three years Amaze has expanded our services both geographically (across Sussex) and from solely supporting parent carers¹, to also providing services and engagement activities to young people with additional needs directly.

We decided to increase our focus here as we have learnt from families how 'transition to adulthood' is one of their most stressful times. We also wanted to increase the impact we have on young people living independent lives.

Our new business plan for 2018-21 builds on our 21 years' experience and, for this next period, we want to make sure that all families contacting us understand what we do in each area and that they are receiving an excellent service.

We will continue to shape our services in response to needs and want to raise more funds to increase the number of core and 'added value' Amaze services that are available to families across Sussex.

Our strategic priorities are to:

Increase knowledge to empower families and young people by providing a range of high quality, information, advice and support services.

3 In ar Su

Improve policy, practice and services across Sussex by providing intelligence from Compass Registers, service delivery and engagement work.

1 Parent carers – we acknowledge that it is not only 'parents' that are carers, and that there are often siblings, unrelated carers, foster parents etc who support children with additional needs. We use 'parent carers' throughout but use this term to encompass a range of family situations.



our work across sussex

Compass registers



children and young people aged 0-25 on the Compass

West Sussex Register

leisure venues across B&H and West Sussex offer discounts and free entry

Workshops and training (mainly B&H, some E & WSx)

parent carers attended Amaze workshops and training courses

Brighton SENDIASS - Helpline

3,616

incoming calls, messages and emails responded to

individual parent carers and young people supported

Brighton SENDIASS

- Casework

parent carers and young people supported



Websites, social media and publications (B&H, E & WSx)

25,561

individual visitors to the

Amaze website

18,590 copies of our newsletters

distributed (B&H)

1,836 likes on Amaze Facebook Page

593

Facebook group members

2,30

followers on Amaze's Twitter feed

Amazing **Futures Project** (B&H)

young people received support

young people peer supporters

Young people's activity group sessions

meetings of The Young People's Advocacy Group

PaCC and **Community Outreach** Project (B&H)

354

PaCC members

COP coffee mornings in the three most deprived neighbourhoods, attended by

parent carers

DLA Service (B&H)

302

families received intensive support from the DLA Service to make claims for Disability Living Allowance or Personal Independence Payment and a further 50+ families were supported to complete the application themselves

estimated annual income for families



Independent Supporter Service (B&H, E & WSx)

41

parent carers and young people received casework support

East Sussex SENDIASS

(from 1 September 2017)

1,131

incoming calls, messages and emails received between 1 September 2017 and 31 March 2018

individual parent carers and young people supported

Face to Face Befriending Service (B&H)

86

parent carers supported face-to-face: 48 supported one to one by Face 2 Face. single home visits, 42 parents matched with a befriender

154

families attended Face to Face Groups

children with SEND have attended one of our groups and 24 siblings have attended

our impact powerful people stories

Amaze has helped me with lots of things. Billy was really unhappy at school and was excluded for days at a time and sat away from the other children. Amaze got school to agree that Billy's problems weren't because of me and got everyone to agree to the right school placement. This made all the difference.

Amaze also suggested claiming DLA. I had tried before but kept getting turned down. They said I could have someone to help as I have real problems in reading and writing. It felt OK to say the difficult stuff. They weren't surprised at anything I said. The minute Amaze got involved I got it. I don't know how I'd manage without it. He's very hard on everything and the DLA helps to replace what gets broken and I can afford the internet and his special interests.

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

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

Alison

Mother of Billy, who has autism

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

Men aren't very good at talking about what's really going on in their heads. For men who are dads of disabled kids, the importance of having a safe place [to talk] is heightened even more.

We not only have the stress of parenting but the added stress of parenting a child with disabilities. This can mean the difficulty of managing a child with a physical disability often for 24 hours a day - both the actual hands on coping plus managing the battle to ensure their child is properly cared for by society. Or it can mean the difficulty of parenting a child with emotional and behavioural problems, the day to day battle of wills or physical aggression, the constant feeling of failure, the eternal sense of being judged by parents of 'normal' children.

There's also the fight for recognition by the authorities - to prove your child is indeed disabled and not just badly behaved. And holding together a relationship and finding a job that works around everything. All these things take their toll.

The men's group offers an outlet, for sharing experiences or just knowing that people 'get it'. The consequences of not coping are well known and shown in divorce rates and mental health problems. Society needs to offer support and for this group of men the Amaze Dads' Group does exactly that.

My name's Brandon, I'm 20 and I'm at college. I like going to the cinema, watching football, and going out with my friends. I became a peer supporter with Amaze because I wanted to become more independent and to help other young people.

Being an Amazing Futures Peer Supporter has definitely helped me get more confident and get more skills. Amaze told me about some Independent Travel Training, which I did with another charity, and I can now get the bus on my own.

I'm really happy as I've recently got a job in a [DIY] shop. At some point in the future, I want to move out and get my own flat and Amaze has told me about Shared Lives [in an Amazing Futures information session].

Brandon

A 20 year old volunteer with our Amazing Futures project

" **Being an Amazing Futures Peer Supporter** has helped me get more confident and get more skills. "

My daughter, Elena, hadn't had any support put in place despite several meetings with college lecturers to discuss her needs. There was a high risk of Elena becoming permanently disengaged with education and she experienced severe anxiety. Elena had been experiencing great difficulty with social relationships which her lecturers felt was due to her attitude and that she should simply moderate this to improve the situation. Elena had received several warnings about her behaviour and was told that a further warning would result in her being excluded.

We spoke to Amaze who explained the graduated response to SEN and the duty of colleges to make reasonable adjustments for young people. We understood these options needed to be worked through before we could apply for a needs assessment that could lead to an EHC plan. Amaze helped improve our communication with the college, including identifying key things to be discussed and the creation of an Additional Needs Plan, which was informed by an educational psychologist's recommendations. Elena is now settled and enjoying college.



Chris

Father of Joe and Finley who both have learning difficulties

" The men's group offers an outlet, for sharing experiences or just knowing that people 'get it'. "

Athena

Mother of Elena, who has a diagnosis of Autism Spectrum Condition

" Amaze helped improve communication and Elena is now settled and enjoying college. "

impact outcomes

Children and young people with SEND and their families feel more lonely, isolated and excluded from their local community, and from things like employment and leisure. We know that Amaze services can help people feel more 'empowered', 'listened to' and 'accepted'.

This diagram shows (on average) how much more positively parents and young people feel after they have used Amaze's services.

Outcomes for all Casework Services 2017/18:



"I have realised that we are not alone and that there is always a person to lend an ear, so that we can air our thoughts and concerns among like-minded people. I don't think any of us realise just how much this group helps us all, but a problem shared and all that ..."



heard informed supported



parent carer feels

supported in relation

to their child's

additional needs

parent carer feels able

to deal with issues or

problems that arise

from their child's

additional needs



financial summary

1	For the year ended 31March 2018 (including income and expenditure account)	Unrestricted funds (£)	Restricted funds (£)	Total funds 2018 (£)	Total funds 2017 (£)
-1	Income and endowments from				
	Donations and Legacies	93,405	151,135	244,540	110,478
	Investment Income	32	_	32	315
32	Incoming resources from charitable activities				
	Grants	283,804	16,500	300,304	146,312
1	Services	560,058	_	560,058	634,676
	Total incoming resources	937,299	167,635	1,104,934	891,781
	Resources expended				
	Raising funds	64,402	-	64,402	54,595
16	Charitable activities	798,478	132,689	931,167	790,963
	Total resources expended	862,880	132,689	995,569	845,558
Y	Net incoming/(outgoing)				
102	Resources from the period	74,419	34,946	109,365	46,223
	Funds brought forward	434,751	23,791	458,542	412,319
5	Total funds carried forward	509,170	58,737	567,907	458,542

our funders

We'd like to thank all the agencies, organisations and individuals who helped to fund us in 2017/18.

statutory funders

Brighton & 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

Assheton-Smith Charitable Trust, Big Lottery Fund, C M Keyser Charitable Trust, Chalk Cliff Trust, Ernest Kleinwort Charitable Trust, Fitton Trust, Friarsgate Trust, Garfield Weston Foundation, The Henry Smith Charity, Insurance Industry Charitable Foundation, Mrs A Lacy-Tate Trust, Noel Bennett Fund, Sir Jules Thorn Charitable Trust, Sussex Community Foundation, Woodroffe Benton Foundation.

donations & events

Adur Council, Airstream, Brighton Firework Events, Butlers Wine Cellar, Clamp Boxhall, Co-op, Franco Mancos, Gayatri News, Legal & General, Lloyds, Manjus, Rotary Club of Brighton, Semolina, St Christopher's School, The Bull Pub Ditchling, Wellesley Charitable Foundation, Wild Stag Studio.

corporate partners

Barwells Solicitors, Brighton & Hove Buses, Currys PC World Hove, Madison Solutions, Picture Exchange Communication System PECS

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



thank you

Amaze could not do the work we do without our brilliant staff, trustees and PaCC reps, 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) Shelley Bennett Siobhan Cox Sally Howell Ray Knight Sue McMillan Fungi Woolnough-Murau

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Amaze

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