



for children and young people with special educational needs and disabilities in Sussex

impact report 2019-20



"The extra work you've all been doing and continue to do to support SEND families because of Covid-19 difficulties is exceptional and I wanted to say a huge thank you, and thank you for always being there. To know that there is support out there if my family need it is invaluable."

### Welcome

The Covid-19 crisis hit in the last month of the 19-20 financial year, bringing with it lots of additional and significant challenges for children and young people with SEND and their families – with many feeling highly anxious, more isolated and 'left in lockdown' with little support. We are immensely proud of the hard work, resilience, innovation and responsiveness of our staff and volunteers in meeting families' needs in such a continuously changing environment. Read more about what we've done during the pandemic on page 10.

In pulling this report together, however, it's also been lovely to think back on all the brilliant work Amaze was doing pre-Covid, without any restrictions.

One of our key goals is to support young people with SEND into meaningful education, employment and training – something that's become even more critical as we live through the uncertainty of the pandemic. It's been fantastic, therefore, to set up our **Looking Forward** project with pilot funding from the Careers and Enterprise Company. In its first year, Looking Forward has delivered 240 personcentred information, advice and guidance sessions for young people with additional needs on their next steps in education, employment or training .

At the same time, our **Amazing Futures** peer support project for young people with SEND goes from strength to strength. Since it began, we've trained 69 **Peer Supporters** (young volunteers aged 18-25) to support over 200 young people with additional needs aged 14-25, either one-to-one, or in our Amazing Futures groups. Most of our volunteer peer supporters have additional needs themselves, and the project helps them gain valuable new skills and confidence. We're immensely proud that 54 of our peer supporters have gone on to gain paid or voluntary work experience or attend further or higher education following their time with us. For a great example, read Eliph's story on page 5.

Another notable achievement this year has been getting more than 4500 children and young people with SEND signed

onto the Compass disability register and leisure card schemes in Brighton & Hove and West Sussex. A recent independent evaluation of the **Compass** by the University of Brighton found that 71 per cent of those surveyed said the card "helped to give their family a better sense of belonging, or feeling part of the community" as well as the significant financial benefits of cheaper leisure.

#### "The Compass Card gives my child the opportunity to enjoy outings and activities I'd never think of trying and significantly improves their quality of life."

Throughout the year, we have continued to provide our range of critical advice and support services to parent carers and young people. Our SEND Information, Advice and Support Service (**SENDIASS**) alone helped over 3,000 individuals in Brighton & Hove and East Sussex, with many of the cases becoming more complex and taking more time to talk through, due to Covid-19. This means we are under increasing pressure to reach and prioritise support to the most vulnerable families, including those from BAME communities, travellers and refugees. See page 5 for a powerful case study from a Syrian family.

Like other charities, as we move through this pandemic, we face an uncertain funding future. But we will keep trying to support as many families with disabled children as possible; providing a range of trusted and tailored information resources and safe and supported spaces for parents and young people to come back together again, which we all know we need.

Rachel Travers (CEO) & Hugh Clench (Chair of Trustees)





### **Our values**

Listening is at the heart of all we do - on our helpline, in our benefits advice and peer support work, and also in the way we plan and develop our services according to what families tell us they need. The word itself captures our values perfectly.

LOCAL We are local people who know our area and understand how to support families in Sussex.

The needs we address

Children and young people with special educational needs and disabilities (SEND), and their parents and carers, face multiple challenges: navigating a world of assessments, diagnoses, reviews and applications, let alone therapies, treatment or medication.

Statistically they stand a much higher chance of being bullied, being excluded from school, having mental health problems, parents who split up and not moving into paid employment. They might be working with a web of different professionals from across health, education and social care and their needs might change depending on their age, disability or transition stage.

This complex world can feel incredibly lonely and many families tell us they feel 'lost in a maze'. They are desperate for high quality, impartial information, advice and support to help them navigate their way through it.

Amaze is here to address this and work with young people and parent carers to guide them through what can be, for some, a difficult journey. **INDEPENDENT & IMPARTIAL** We're an independent charity, so any info or advice we provide is impartial.

**SUPPORTIVE** Despite the high demand for our service, we support everyone by prioritising; giving more intensive support to the most vulnerable, and helping others to be more self-servicing.

**TOGETHER** The needs of disabled children and young people and their families are at the heart of all that we do. We work together with families, and SEND professionals, to plan, develop and improve services.

**EMPOWERING** We empower disabled children and young people and their parent carers by building their confidence, knowledge, skills and resilience.

**NON-JUDGEMENTAL** We listen and offer advice without criticism, prejudice or judgement.

### **Our impact**

We know that Amaze services help people feel more 'empowered', 'listened to' and 'accepted'. The consolidated outcomes star for our services to parent carers presents an average change against each of our core indicators.

Parent carer feels that their voice is heard and their views are taken into account about their child's needs

Parent carer feels included, understood or connected to others in a similar situation

#### OUTCOMES FOR ALL CASEWORK SERVICES 2019/20

Average Start
Average End



Parent carer feels well-informed about their child's additional needs and the support and services available to them

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

Parent carer feels emotionally strong, resilient and good in themselves



### **Special Educational Needs Information, Advice & Support Service**

"Thank you so much for listening and for your advice. This is incredibly helpful and I've a much clearer picture of what I should be doing next to support my daughter."

Special Educational Needs Information, Advice and Support Service (SENDIASS) provides information and advice to children and young people with SEND, and their parent carers, in East Sussex, and Brighton & Hove.

Access to clear and impartial information on topics like education, health, social care, leisure, preparing for adulthood and disability benefits is essential for families to make the best of life with SEND. Our website has **information** and **downloadable resources** so parents and young people can help themselves. Our **newsletter** moved



For independent advice on their particular situation, parents and young people can contact the **SENDIASS helpline** to get a call back from an adviser who is trained and has real life understanding of the issues. Our **workshops** cover key topics in a friendly group format.

Parents and young people whose situation is very complex or who are less able to advocate for themselves, can get **one-to-one casework** support.

This year we have been using more booked advice calls so helpline callers know when they will hear from an adviser. Our Children and Young People's worker has also been working directly with young people.



Education 61% Health 15% Money & Benefits 12% Social Care Housing 5% Compass & Carers Card 3% Amaze Workshops & Training 2% Employment 1% Housing 1% Leisure 1%



#### Haya's story

"I'm a mother of three children. My eldest child has a disability. We came to the UK from Syria last February.

"We applied for DLA and our application was rejected because the DWP says that we have to be living in the UK for at least two years to apply. However, Lizzie from Amaze said the DWP had made a mistake, and she applied again and sent a request to consider our child's circumstances. When she met us, she discovered that our other two children have disabilities as well.

"As refugees, we've felt extremely homesick, as we are unable to speak the language and the system is very different from back home. Yet, we're very grateful for the continuous help and support we've received from Lizzie, as newcomers to the country. We hope that our voices will be heard through her."



"Where I am now is so different from where I was when I first got involved with Amaze. A lot of my friends don't have SEND, so it was hard for me growing up because it felt like everyone was getting regular jobs apart from me. Getting the Amaze internship was a really big deal because it was my first time being trusted to have a job.

"When I started with Amazing Futures I was very low. I didn't really have much hope for the future and I didn't really have much of a plan. I think working has given me a lot more stability and now I'm a lot more motivated to move forward with my life. I'm living independently in supported accommodation, I'm going to university, and before I didn't even have decent A Levels. And I'm actually confident that I'm going to study something I want to do.

"I've also got paid work facilitating art groups at the museum – something I would never have been confident enough to do without facilitating groups in Amazing Futures. So I'm being paid to do things that I enjoy, and I feel like there's a lot more hope for the future.

"I know it's going to be difficult, the future, and there's going to be challenges but I feel a lot more prepared. Because when I look back to how I was, it just seems impossible that I'm where I am now. So I kind of know that the future's going to be okay, if that makes sense."







# **Amazing Futures**

"Being a volunteer peer supporter has really helped me make friendships and keep them. I'm getting better at talking to different people. The links Amaze has to organisations also helped me to move out to live independently."

Amazing Futures is a peer-to-peer support project for young people aged 14 to 25 with special educational needs and disabilities in Brighton & Hove and East Sussex. Trained teams of young people, with and without additional needs, act as volunteer peer supporters. They provide one-to-one peer support and help run a range of activity sessions. The project also offers them leadership courses, training and volunteering opportunities and paid internships, helping them to develop their self-confidence and prepare for the future.

Amazing Futures belongs to young people – they co-produce the project and, at regular engagement sessions, they tell us what they want. Collectively they also shape other organisations' services, feeding into consultations and sharing their views.

# **Looking Forward**

Young people with additional needs tell us that finding work is often an area of great concern so our Looking Forward programme has been working with young people in Brighton & Hove and East Sussex to raise aspirations and to identify their next steps in education, employment and training.

Involving parent carers can be vital to identifying and maintaining any placement after the age of 16, so we have welcomed parent carers to many of our sessions with young people and created useful online resources. Post-16, there are lots of options for young people, so we want them (and their families) to have access to the information they need to make informed decisions about the future.

"Looking Forward helped me discover things about myself that I didn't even know...and that helped me boost my confidence."





### Support with claiming Disability Benefits

"I'm still in shock as I really didn't think she would get anything and I know how hard it is. It means we can get a kitten as our 21 year old cat died two years ago and a new one will fill a hole in our family and provide us with much needed animal therapy."

A successful claim for **DLA** or **PIP** can generate between £7k and £13k in benefits for families on low incomes. The money helps pay for the extra costs of caring and strengthens families' resilience. It enables young people to make choices that can change their lives.

Our disability benefits work offers young people and parent carers the expert advice and support they need to make a successful claim for DLA or PIP. The support includes phone and email advice, written resources, regular workshops and practical one-to-one support for families or young people who are really struggling. Our DLA/PIP project is available in **Brighton & Hove** with some support available in **East Sussex**.

Social distancing measures mean we are developing new ways of working remotely with families who face the biggest challenges.

# **The Compass**

Discounts at a full range of leisure venues across Sussex is just the beginning for families and young people in **Brighton & Hove** and **West Sussex** with a Compass Card. The unique scheme makes cardholders and their friends and family feel more welcome at venues and has far-reaching social and emotional benefits too. The information from Compass application forms also provides powerful data to help decision makers shape and improve services for children and young people in Brighton & Hove and West Sussex.

The Compass Card is available for 0 to 25s with significant additional needs who live or go to school in **Brighton & Hove** or **West Sussex**, or who are looked after by social services in these areas.

"The Compass Card gives my child the opportunity to enjoy outings and activities I'd never think of trying and really significantly improves their quality of life."



In the coming year, we will continue to increase Compass Card membership, re-establish leisure discounts which were affected by Covid-19 restrictions and provide more data to inform the development of SEND services in Brighton & Hove and West Sussex.



AMAZE 7

# Face2Face

"Farah has been an incredible support. She phoned me, she texted me, and we met regularly. I felt like I had somebody who really understood the challenges that my family faced and that helped not just me but my entire family navigate a very difficult time. She did this as a volunteer and the commitment she showed to me was amazing."

Many parents of children with additional needs and disabilities can feel lonely and overwhelmed. Our Face2Face project offers **emotional support** to help reduce their isolation and face the future more positively.

The Face2Face project provides one-to-one **befriending** and **social groups**, delivered by a team of trained parent carer volunteers. The one-to-one support is flexible and is dependent on the needs of the individual families. Our groups in Brighton & Hove include a dads' group, a breakfast drop-in and an autism group for under 7s.

Face2Face one-to-one support is available in **Brighton & Hove** and **East Sussex**. We also work in partnership with Reaching Families who deliver the project in West Sussex.

In 2020/21, the project will focus on developing our work in East Sussex where we hope to start some new groups to connect families together, both virtually and in person.







### **Community Outreach Project**

Our **Community Outreach Project** (COP) creates **safe and supportive spaces** for parent carers in Brighton & Hove to meet up and talk about themselves and their family. They can find out how Amaze and other organisations in the city can help, and meet the professionals who plan and deliver SEND services. Parents who attend tell us they feel less alone, their confidence grows and they have the information they need to be empowered to expect and ask for more for their children. Topics covered this year included: 'Supporting Siblings', 'Claiming DLA & PIP', 'Yoga and relaxation', 'Sensory Processing Disorder', 'Annual Reviews of EHC Plans' and 'Caring for an autistic child'.

Our coffee mornings run monthly during term time in Moulsecoomb and Bevendean, in partnership with the **Sunflower Support Group**; in Hangleton & Knoll in partnership with the **Hangleton & Knoll Project** and in Whitehawk. In Moulsecoomb and Bevendean and Hangleton & Knoll, the groups are planned and run by a steering group of parent carers who have come together to form community groups.

"These groups are invaluable and are helping to save my sanity! We're so often let down/ignored by other services and this provides a vital support and information role."





## Strategic work: Amaze, PaCC and ESPCF

In addition to delivering services, Amaze continues to prioritise our influencing work, attending a wide range of strategic and partnership meetings across Sussex, representing the community and voluntary sector and highlighting the needs of vulnerable families. We are active members of the **Disabled Children's Partnership** and during 2019 we were asked by **Contact** to lead on a project reviewing parent carer participation in the London Borough of Haringey.

We continue to host the **Brighton & Hove Parent Carers' Forum** (PaCC) and, during 2019, we were delighted to support parent carers from **ImPACT** and **iContact** in developing the new parent carer forum for East Sussex – the **East Sussex Parent Carer Forum** (ESPCF). Both forums work pro-actively to foster collaborative working relationships, whilst constructively challenging partners to co-produce services.

LondonIssuing joint communications from Amaze, PaCC and<br/>ESPCF to key strategic leads, MPs and Ministers during<br/>the Covid-19 crisis has been a great example of where<br/>we have jointly influenced policy and practice<br/>successfully, at both local and national level, improving

We encourage parent carers to join their local parent carer forum to ensure their voices are heard by decision makers.

Amaze staff capture the views of young people and

intelligence and trends with the parent carer forums.

work which is held and represented by the forums.

services and outcomes for disabled children.

This has added value for the broader parent carer voice

parent carers who use our services and join the

children's disability registers, and we share this

We also work closely with the  $\ensuremath{\textbf{West}}$   $\ensuremath{\textbf{Sussex}}$   $\ensuremath{\textbf{Parent}}$   $\ensuremath{\textbf{Forum}}$  .











#### **Our Coronavirus response**

Amaze acted very swiftly to develop an **online FAQ resource** for families at the start of the Covid-19 lockdown – translating the complex and ever-changing government guidance into locally relevant, accessible, SEND-specific content. We are pleased that local families turned to us for this advice – the new Coronavirus pages on our website had over 4,000 visits in the first couple of months of lockdown – and we have actively shared these resources with regional and national partners. We know they have been used far and wide, for example, paediatricians in York were giving out our Covid-19 FAQs to their families!

We quickly set up our staff to work effectively from home, and switched all our **face-to-face** individual and group work to **phone**, **email**, or **Zoom groups**. This has worked well for most parents and young people but we also redeployed some staff to make proactive **check-in phone calls** to the people we were most worried about being isolated during lockdown.

Our Face2Face and Amazing Futures teams, led by their users, have been really creative at thinking up **activities online**, and more recently in **small groups at the park**.

These include virtual arts and crafts, coffee mornings, cookery and 'meet my pet' sessions.

We have also been working hard to influence and improve the way our local, regional and national partners have developed their services, policies and strategies as a result of the pandemic – involving often daily, then weekly, **meetings with partners and parent reps** to determine the latest issues. We put out a **Covid-19 survey** to identify what the biggest challenges were for families. Finding that 'access to education during lockdown' was top of the list, Amaze worked with our local parent carer forums to suggest best practice with schools.

When we identified other big issues facing local families of children with additional needs, we worked quickly with our partners in Brighton & Hove to come up with innovative solutions, for example, producing a letter to grant access to priority shopping slots for parent carers and dedicating space in local parks for SEND families. We also co-ordinated partnership letters to all Sussex MPs and Amaze's CEO was invited to attend a meeting with the Children and Families Minister, as a member of the Disabled Children's Partnership.

### Our funders

We'd like to thank all the agencies, organisations and individuals who helped to fund us in 2019/20.

#### **Statutory funders**

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

#### **Grants and other funders**

Careers and Enterprise Fund, Chalk Cliff Trust, David Solomons Charitable Trust, Global's Make Some Noise, Hasluck Charitable Trust, The Henry Smith Charity, J C Robinson Trust No 4, Lynn Foundation, Masonic Charitable Foundation, Mrs A Lacy-Tate Trust, National Lottery Community Fund, Noel Bennett Fund, Pannett Charitable Trust, R S Brownless Charitable Trust, Sir Jules Thorn Charitable Trust, St James's Place Foundation, Sussex Community Foundation.

#### **Supporters**

Bewilder Box, Brighton & Hove Buses, BUPA, Energy for Life Fitness, Guyatri News, Komedia Brighton, Ocado, Remarkable TV's Pointless, Renaissance Legal, Sainsbury's, Semolina, Waitrose.

Brighton & Hove Ladies Golf Team, Councillor Alex Phillips, Amaze Dads Group, Sue McMillan.

And thank you to all our wonderful Amaze runners, cyclists, fundraisers and community champions.



#### STATEMENT OF FINANCIAL ACTIVITIES FOR THE YEAR ENDED 31ST MARCH 2020

U	Inrestricted funds (£)	Restricted funds (£)	2020 Total funds (£)	2019 Total funds (£)	
Donations and grants	73,764	131,366	205,130	221,866	
Grants Services	573,110 345,447	-	573,110 345,447	350,754 426,302	
Investment income	767	-	767	594	
Total	993,088	131,366	1,124,454	999,516	
EXPENDITURE ON Raising funds Charitable activities Staff costs Property costs Administrative costs Other costs	80,177 724,046 50,314 93,698 26,200	- 126,446 10,924 15,938 23,594	80,177 850,492 61,238 109,636 49,794	71,319 770,404 51,212 97,182 35,206	
Total	974,435	176,902	1,151,337	1,025,323	
NET INCOME/(EXPENDITURE) RECONCILIATION OF FUNDS Total funds brought forward	18,653 490,328	(45,536) 51,772	(26,883) 542,100	(25,807) 567,907	
TOTAL FUNDS CARRIED FORWAR		6,236	515,217	542,100	





# Thank you

#### Our staff and volunteers

We want to give a special mention this year to our amazing staff team who are always outstanding but have really stepped up to meet the incredible demands of working through the pandemic, when many of them were also caring for their disabled child at home.

Amaze is also very lucky to be supported by a large family of volunteers who give us their experience, expertise and commitment for free. This year 5,000 volunteer hours were given to Amaze at a value of almost £61,000. Though we cannot thank all our volunteers individually, we are truly grateful.

#### **Our patrons**

Angela Barnes, Julia Donaldson, Annabel Giles, Henry Normal, Angela Pell, Joe Wilkinson.

#### **Our trustees**

Hugh Clench (Chair), Debby Norris (Treasurer), Dan Barfoot, Shelley Bennett, Siobhan Cox, Moe Hamdhaidari, Sally Howell, Fungi Murau, Debbie Tuesley, Alison Plant.



#### **Our contacts**

C 01273 772289 (helpline) Open Monday to Friday, 9.30am to 2.30pm

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