



For disabled children
and young people in Sussex

Impact Report 2020-21



“Amaze is a sanctuary. I feel blessed I stumbled across them on my Google search. They have no agenda other than to offer genuine, generous and helpful support. Thank you from my heart.”

Welcome

Like everyone's, our work in 2020-21 was defined by the global Covid-19 pandemic, which brought many additional and significant challenges for children and young people with SEND and their families.

Research by the Disabled Children's Partnership, as part of their **'Left in Lockdown'** campaign, revealed that families with disabled children felt abandoned during the pandemic, with vital support reducing or stopping altogether. As assessments and services were paused or delayed, some children's conditions worsened; others' needs were not identified, and the mental health and wellbeing of the whole family deteriorated.

Because of this, our top priority was to let families know we were still here for them. During the first lockdown, for example, we quickly identified the most vulnerable families on our case lists and made **check-in phone calls** to see if they were OK. This proactive support was much appreciated and many families told us we were the only agency who had been in touch.

“The sentiment in the card made us all a bit teary, and really made us feel like we hadn't been forgotten in these weird times.”

Realising that families with disabled children were struggling to keep up with the complex and ever-changing Covid-19 government guidance, we worked swiftly to create locally relevant, accessible, **SEND-specific coronavirus information online**. These Covid-19 pages had over 20,000

page views during the year, and helped to attract 52,000 new users to our website, a 42% increase on the previous year.

Our **SENDIASS advice line** continued to support nearly 2000 people with over 4500 calls and emails. Callers had more complex SEND queries, needing longer advice sessions. This, coupled with a reduction in national funding, led to people having to wait longer than usual for help, but when parent carers got help they found it as valuable as ever.

“I was given great advice and I feel supported and heard. I'm in a lonely place right now and suddenly feel like I have someone by my side to help me advocate for my son.”

As the pandemic continued, and the financial, physical and mental health of parent carers came under increasing strain, we had to adapt the way we worked in response to increasing demands for help. In our **disability benefits (DLA and PIP) work**, for example, we offered more online training and resources, whilst prioritising more targeted support to the most vulnerable parents. Our **Face 2 Face befriending** groups for parent carers continued to meet on Zoom or kept in touch via WhatsApp, and we delivered one to one befriending support by phone or email. These new ways of working were so successful that we will keep many of the digital options going forward.

Our **Amazing Futures peer support groups** are a social lifeline for local young people with SEND, even more so



during the pandemic, when many of them told us they had not left the house due to anxiety. Because of this, we returned to small, in-person groups outdoors as soon as the weather and restrictions allowed, helping to build back confidence and skills.

We continued to support young people to plan for their future via our **Amazing Futures Careers Service** but, unfortunately, we were limited in how many we could help as funding for this service reduced during the year. This was despite a growing need for advice as some college courses or placements were cancelled.

As an organisation, we dug deep to become nimbler and more flexible than ever before, adapting our service offer each time the guidance changed, setting up all staff to work remotely from home, and supporting our many parent carer staff, who had to balance their jobs with providing care to their disabled children.

We saved money by reducing our office and travel costs and furloughing staff and, whilst we could not raise money from our normal **fundraising** events, we thankfully secured more funding than expected by drawing in additional Covid-19 grants. We are grateful to our existing funders and partners who continue to invest in Amaze, but frustratingly we once again face **funding shortfalls** in the coming year. With parent carers and young people with SEND at the heart of Amaze, however, we are confident that we can demonstrate our impact to funders in order to retain and develop our outstanding services.

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



Our values

Listening is at the heart of all we do - on our advice line, 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.

L LOCAL AND LIVING IT We are local people who know our area and understand how to support families in our area. Many of our staff, volunteers and trustees are carers or are disabled.

I INDEPENDENT & IMPARTIAL We are an independent charity and any information or advice we provide about services is impartial.

S SUPPORTIVE We support everybody we can; making the best of our resources, developing peer support and being more hands-on for those that need it most.

T 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.

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

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



Special Educational Needs Information, Advice & Support Service

The **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.

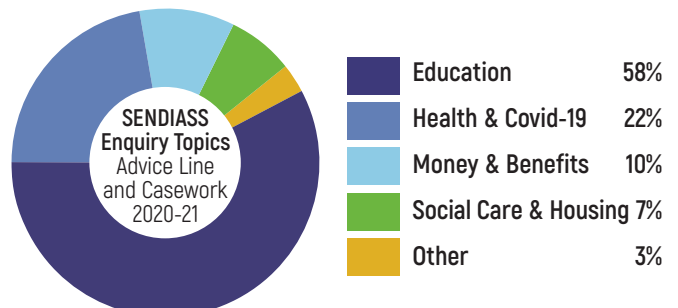
We continued to offer impartial, expert SEND advice throughout the pandemic, dealing with 3,025 enquiries from 1,948 people.

Staff shortages (as many parent carer staff had to work reduced hours) alongside high call volumes meant that some callers had to wait longer for a response. Despite this, we received incredible feedback from parent carers about how valuable they found this service.

“There was a lot I didn't know so this was such a great help. She was lovely, knowledgeable and followed up our call with an email with relevant links to further information. I couldn't have asked for better help. Thank you.”

SENDIASS also made the most of digital media during the year, offering advice via brand new online Covid-19 content, a regular e-newsletter and Zoom workshops on key topics like EHC Plans or getting SEN support. Our well established social media channels meant we were able to communicate vital information on things like vaccines for carers, very quickly.

In 2020-21, Amaze also provided in-depth case work support to 227 parent carers and young people whose situation was very complex and were less able to advocate for themselves. Many more families than we can support need this service but, unfortunately, this capacity has had to be reduced, due to decreases in funding from central government.



Gillian's story

"Firstly, I have to take the time to say how amazing Lyra has been in helping me get an EHCP plan for my son, Will. I had no clue what I needed to do and couldn't find anything really clear on what my next steps would be. But, after contacting yourselves, Lyra explained the system to me and explained what each step would be and what I needed to do.

Without her, I would have given up and that's not fair. I would just like to add that her professionalism and her persistence is amazing and her phone manner and emails were always professional and written in plain English so that I could understand.

I honestly don't know what I would've done without Amaze and you've actually saved me a few times because each of my children all have an illness or a disability."



Our impact

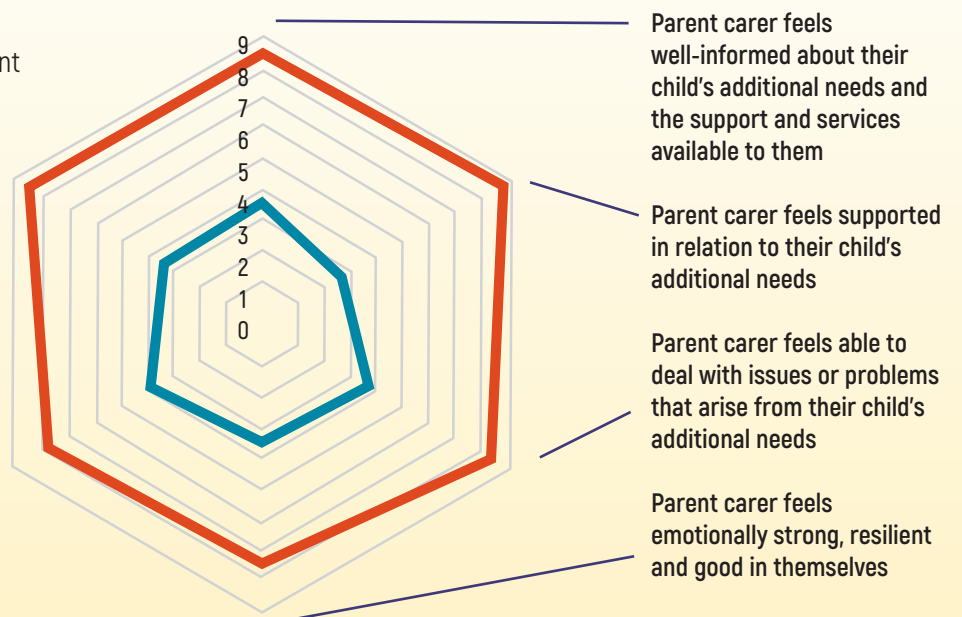
We know that Amaze services help people feel more 'empowered', 'listened to' and 'accepted'. The consolidated outcomes star for our services to parent carers presents an average change against each of our core indicators.

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 2020/21

— Average Start — Average End





Amazing Futures

“It feels really good to be back together again.”

Amazing Futures supports young people with SEND aged 14-25 on the journey to adulthood in Brighton & Hove and East Sussex. Young people joining the project identify goals they want to work towards, such as making friends, developing self-confidence or finding a job, and work with each other, our trained peer supporters, paid interns and staff, to achieve these.

Throughout the Covid pandemic, our service provided invaluable support to vulnerable young people experiencing anxiety and isolation. Activity sessions and peer support took place online or outdoors, until the regulations and Covid-safe operating procedures allowed us to come back inside. This helped young people stay connected and focused on their wellbeing. We provided one-to-one careers advice on the phone or via Zoom – supporting young people and their families to access

information and navigating post-16 options, which had become even more unclear and limited than before.

In spite of unprecedented challenges and uncertainty, we celebrated new young people-led groups, such as an LGBTQ+ peer support group, and the launch of **Amazine**, an online newsletter produced by and for young people every month. We ran training in youth group leadership and sports coaching, young people developed new life skills in things like cooking and yoga, and we supported them to take up traineeships, apprenticeships, volunteering opportunities and paid work.

“It put a lot of confidence in me. It helped me to improve my interview skills and to better analyse and showcase my unique selling points”



Pagane's story

"I was diagnosed with autism when I was 18 years old and navigating the world of special educational needs proved to be difficult because I was not completely aware of the support I could receive. Amaze helped me to apply for Personal Independence Payment (PIP) and was there every step of the way. During this process, I learnt about Amazing Futures and decided to become involved in the project as a volunteer. The training taught me a lot of valuable skills that I regularly use in my personal and professional life such as active listening and proactively looking after my wellbeing.

The volunteer work started in December 2019 and was an invaluable experience because it provided a safe and inclusive place to offer peer support and to try new activities such as yoga, capoeira and animation. My long-term volunteering helped me to enhance my research skills and one of the ways in which I utilised this was by becoming one of the main writers for Amaze's online magazine, Amazine.

Through Amaze I found out about an improvisational comedy course. I signed up and quickly became interested in improv and how the skills gained from it (self-confidence, adaptability and public speaking) can translate to real-life scenarios. I set up an Amaze drama group as a way to offer other young people the chance to learn skills that they can use at and beyond Amaze.

I have received support from Amaze's careers advice team to help me put my best self forward during my job applications. I developed my CV and honed my interview skills in a way that celebrated my differences.



Volunteering at Amaze developed my interest in improving the way young people with SEND are represented in society. This motivated me to apply successfully for a paid internship at Amaze. Through my work, I raise awareness of SEND and, more importantly, take action on ensuring that employers and educational providers take the initiative to make their spaces more inclusive. I take in the views of the Amazing Futures participants and incorporate them in the way the project is run.

Overall, Amaze has helped me to become an enthusiastic and conscientious individual. I attend a large number of sessions, and I have gained the confidence to be a leader who stands up for myself and others."



Face 2 Face

“It’s nice to have a beer, a chat about any old rubbish (in a good way), some friendly ribbing, but also a supportive nod from those that ‘get it’ that being a parent can be bloody hard sometimes.”

Many parents of children with additional needs and disabilities can feel lonely and overwhelmed, and this was exacerbated by the pandemic restrictions.

Face 2 Face provides **one-to-one befriending** in Brighton & Hove and East Sussex, 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. This year, our befrienders adapted to supporting families on the telephone, when we weren’t allowed to meet in person.

We also run **regular social groups** for parent carers – we have a Dads group, a Breakfast Club, a Brunch Club and various autism groups – and they all continued to meet and support each other online or via WhatsApp during the lockdown.



Community Outreach Project

The **Community Outreach Project (COP)** creates safe spaces for parent carers to come together, support each other and hear more about what’s available in Brighton & Hove. This year, due to the pandemic, all our **coffee mornings** moved online. We continued to run a monthly virtual coffee morning for parent carers living in East Brighton (Moulsecoomb, Bevendean and Whitehawk), in partnership with the **Sunflower Support Group**, and one for parent carers living in West Brighton (Hangleton & Knoll), in partnership with the **Hangleton & Knoll Project**.

Although our virtual meetings helped many parents to stay connected during Covid, not everyone liked meeting online; some felt they couldn’t talk about their issues with their children at home. To help them stay in touch, we also sent monthly emails with information and updates about SEND services during the pandemic.

Parents who attend our coffee mornings tell us that they feel more informed, included, understood and connected. They also feel emotionally stronger and more resilient.

“It’s great to feel connected and understood and listen to ideas from other parents who’ve been or are going through similar situations.”





Help with disability benefits

“During lockdown, getting help from Amaze with benefits has been as straightforward as ever, even when it couldn’t be over a cup of tea.”

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, and to challenge poor decisions. This year we developed new ways of working remotely with families. This includes phone and email advice, written resources and regular workshops on Zoom. For families or young people who faced the biggest challenges, we continued to offer bespoke services including interpreting support, drafting and collating evidence, and posting claims. This year, our benefits work has been available in Brighton & Hove and East Sussex.

During 2020-21, the annual value of awards amounted to almost £1.5 million. What’s more, the extra income generated by DLA and PIP awards secured by Amaze in previous years and still in payment this year, amounts to in excess of £20 million.



The Compass

Our **Compass Card** provides leisure discounts and offers to help families of children with SEND feel valued and included. At the same time, the information cardholders give us helps to shape SEND provision in Brighton & Hove and West Sussex. The Compass Card is available for 0 to 25s with significant additional needs who live, go to school, or are looked after by social services in these areas.

It’s been a tough year for having fun, but our much viewed **‘Leisure, Learning & Lockdown’** guide provided hundreds of ideas and activities to help get families through lockdown, and helped the Compass community to stay connected. The Compass database is now more important than ever to assist decision makers to shape and improve services for children and young people.

With restrictions lifted, Compass offers are now back and we will continue to add more offers to the Card and put on free Compass Days. We are striving to increase membership and streamline the application process.



“We use the Compass Card/Carers Card all the time for things like swimming, soft play etc. As a single parent, it makes it less overwhelming knowing I’ve spent less money, particularly on days he doesn’t want to cooperate.”





Strategic work: Amaze, PaCC and ESPCF

Ensuring the voices of children and young people and their families are heard sits at the heart of Amaze. Beyond working with families to shape our own services, we work strategically in partnership with others to highlight the needs of vulnerable families, sharing anonymised data from our Compass Registers and intelligence gathered through our other services, to support co-production of local services.

We continue to provide back office and strategic support to **Brighton & Hove Parent Carers' Council** (PaCC) and **East Sussex Parent Carer Forum** (ESPCF). The forums together have over 1000 parent carer members and they reach out to hear the views of families and share their experience and expertise on how services could be improved.

During the pandemic, we all worked tirelessly to represent families' needs and seek solutions to complex situations in a rapidly changing environment. For instance, as part of the **Sussex Carers' Partnership**, Amaze ensured that the local definition of unpaid carer was widened to include all parent carers. This meant that all those parent carers who wanted a Covid-19 vaccination could get one as a priority. We contacted eligible parents using the Compass database. The forums regularly fed back on issues relating to the return and reintegration into schools and colleges, which resulted in reasonable adjustments to Covid safety measures for SEND children and young people.

Amaze has been developing opportunities for young people with SEND to build their confidence and skills to participate more in decisions about service developments and strategies that affect them (co-production).

We have supported young people to set up a '**Your Choice, Your Voice**' group, that listens to the young people involved in Amazing Futures and represents their views. We also run a self-advocacy group in partnership with **Speak Out** (a local charity supporting adults with learning disabilities).

Amaze captures the views of young people and parent carers who use our services or join the children's disability registers, and we share this intelligence and trends with the parent carer forums. This adds value to the broader parent carer voice work held and represented by the forums.

As a member of the **Disabled Children's Partnership**, we backed the **#LeftInLockdown** campaign for targeted Covid-19 recovery policies, especially in relation to the mental health challenges families are facing, waiting years to have their young person's needs assessed, with little support while they wait, or after diagnosis. With the reorganisation of health services into the **Integrated Care System**, **ESPCF**, **PaCC** and **West Sussex Parent Carer Forum** (WSPCF), with support from Amaze, are working together to co-ordinate a pan-Sussex voice for parent carers. The three forums share a seat on the **Foundations for our Future Project Group**, the task force driving the transformation of local mental health services.

We encourage parent carers to join their local parent carer forum, and children and young people with SEND to join their local disability register to ensure their voices are heard by decision makers.



Our funders

We'd like to thank all the agencies, organisations and individuals who helped to fund us in 2020/21.

Statutory funders

Brighton & Hove City Council, East Sussex County Council, West Sussex County Council, NHS Brighton & Hove Clinical Commissioning Group, NHS East Sussex Clinical Commissioning Group, Haringey London Borough Council, Council for Disabled Children, Department for Education

Grants and other funders

Careers & Enterprise Company, Coronavirus Mental Health Response Fund, Ernest Kleinwort Charitable Trust, The Julia and Hans Rausing Trust, Masonic Charitable Foundation, National Lottery Community Fund, Noel Bennett Fund, OneFamily Foundation, Pannett Charitable Trust, Sussex Community Foundation, Sussex Learning Network.

Supporters

And thank you to all our wonderful Amaze supporters, runners, cyclists, companies and community champions. Special mentions to Bewilder Box, Co-op, Grand Hotel, Guyatri News, Waitrose, Adam Kay, Chris Evans and Adrian Elkin.



Statement of financial activities for year ended 31 March 2021

	Unrestricted funds (£)	Restricted funds (£)	2021 Total funds (£)	2020 Total funds (£)
INCOME & ENDOWMENTS FROM				
Donations and legacies	49,249	262,507	311,756	205,130
Charitable activities				
Grants	578,246	-	578,246	573,110
Services	283,054	-	283,054	345,447
Investment income	926	-	926	767
Other income	36,829	-	36,829	-
Total	948,304	262,507	1,210,811	1,124,454
EXPENDITURE ON				
Raising funds	69,943	-	69,943	80,177
Charitable activities				
Staff costs	804,250	193,997	998,247	850,492
Property costs	1,701	10,072	11,773	61,238
Administrative costs	2,309	25,820	28,129	109,636
Other costs	2,893	42,482	45,375	49,794
Total	881,096	272,371	1,153,467	1,151,337
NET INCOME/(EXPENDITURE)	67,208	(9,864)	57,344	(26,883)
Transfers between funds	(4,090)	4,090	-	-
Net movement in funds	63,118	(5,774)	57,344	(26,883)
RECONCILIATION OF FUNDS				
Total funds brought forward	508,981	6,236	515,217	542,100
TOTAL FUNDS CARRIED FORWARD	572,099	462	572,561	515,217





Thank you

Our staff and volunteers

The work described in this report is made possible by our incredible staff team who continue to go above and beyond, many of whom are also caring for a disabled child at home.

Amaze is also supported by a large family of volunteers who give us their experience, expertise and commitment for free. Though we cannot thank all our volunteers individually here, we're 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 Hamdheidari, Sally Howell, Sue McMillan, Fungai Murau, Debbie Tuesley, Alison Plant.



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