



# Sibs 20 YEARS

For brothers and sisters  
of disabled children and adults

20 years of belonging  
Impact Report 2021



### Playmate. Ally. Friend. Protector. Carer. Teacher. Champion. Advocate

Over the course of a lifetime, siblings of disabled brothers and sisters take on many different roles.

**As a child** they may help to care for their brother or sister and enjoy spending time together, maybe even teaching them new skills. Often Siblings grow up far quicker than their peers and feel a sense of responsibility for their brother or sister. But while they are fiercely loyal and care about their brother or sister, they may also feel jealous they don't get as much attention or feel worried about who will care for their sibling when their parents are no longer able to. They may feel different to their friends, and sad that they're missing out on activities and time with their parents.

**As an adult** they may be faced with juggling the competing demands of supporting their brother or sister, alongside work and caring for their own children or elderly parents. Adult siblings tell us that at times they're overwhelmed with feelings of worry and anxiety about the impact of their brother or sister's disability on their lives. Some feel guilty that they're not doing enough, or that at times they have uncaring thoughts about their brother or sister.

## Like siblings, we are there for life

We are the only UK charity representing the needs of siblings of disabled people. We are there for the 500,000 child siblings and at least 1.7 million adult siblings in the UK, who have grown up with a disabled brother or sister.

During their lifetime, siblings have a lifelong need for information, they often experience social and emotional isolation, and have to cope with difficult situations. They also want to have positive relationships with their disabled brothers and sisters and to be able to choose the role they play in future care and support.

Over the last 20 years, we've created a community of siblings with disabled brothers and sisters and provided tailored support to them, wherever they may be on their sibling journey.

### Our mission

To enhance the lives of siblings by providing them with information and support, and by influencing service provision throughout the UK

### Our vision

Every sibling in the UK who is growing up with or has grown up with a disabled brother or sister will have access to information and support about sibling issues.

# Case Study

Hayden and Ellie



Ellie Howell, 16, was five when her younger brother Hayden, 13 was diagnosed with Duchenne muscular dystrophy, a degenerative muscle disorder. From that moment Ellie had to adapt to a new life – Mum not being able to take her places because she was at the hospital with Hayden. Putting up with the stares from people when they see a child in a wheelchair and coming to terms with the fact that her brother has a life-limiting disease.

“My childhood was very different compared to others my age. Unlike some siblings, I’ve never had to care for Hayden completely because my parents do the majority. But I do see certain things that they don’t, like the looks he gets from other kids at school when he’s in his walker, and I tend to be overly conscious of what people think.”

“Growing up, I’ve had to learn that what I want to do ultimately comes after hospital appointments and clinical trials. Which I completely understand, but it’s upsetting nonetheless. I’m an over thinker, sometimes to the point of obsessiveness. So when thinking about the future, I tend to look really far ahead, to a time where my parents are gone, and wonder whether I’ll have to put down whatever I’m doing in life at that point to go and care for Hayden. The idea of that scares me.

“Sibs has helped me by giving me the opportunity to see that there are plenty out there just like me. I would love to see more positivity about disabilities like my brother’s. It doesn’t have to be depressing, it’s just the way things are, and with support from Sibs, I genuinely believe that being a sibling to a disabled person is just one of life’s challenges, and that it’s nothing we can’t face together.”

## Message from the Chair

### Joining Sibs was like coming home



Saba Salman

Joining Sibs was like coming home to a place I had never visited, but where I felt instantly welcome and understood.

In 2015, a friend introduced me to what she described as a unique charity that I might be interested in reporting on. As I worked on that article for The Guardian with Sibs founder Monica McCaffrey, I began to realise that my role as a sibling had left me with a specific - but unmet - need for advice and support.

I discovered that Sibs was an organisation tailor-made to plug such gaps, made up of a network of people who share similar experiences, from the joyful and illuminating, to the frustrating and challenging. I joined Sibs as a trustee not long after that article, happy to find myself among people who just “got it”. Six years on and now as its chair, I still feel the same way during every meeting, event and conversation.

I’m not alone. I recently heard from a sibling who had just come across the charity and whose reaction was beautifully familiar: “Other people share my experiences and worries around the future. I had to stop reading the website because I was getting tearful at work. Amazing charity.”

Sibs’ work is indeed amazing, underpinned as it is by the organisation’s singular role as the only UK charity representing the needs of siblings of disabled people. Sibs influences people and services across the country, for example through its projects for children, young people and adults or its direct support, training and awareness-raising work.

Covid-19 and lockdown has made this an extraordinarily difficult year for everyone, but particularly for siblings and their families. The pandemic and social isolation intensified the existing loneliness already familiar to young siblings. Adult siblings face additional challenges like navigating an increasingly chaotic social care system and dealing with (or supporting brothers and sisters to cope with) anxiety, loss and grief. Sibs’ mission has never been more crucial.

For 20 years, Sibs has championed siblings’ rights and needs - in schools, communities, the voluntary sector and within government. We have educated health and care professionals to not just acknowledge and understand the needs of a previously overlooked group of people, but to actively support them.

I am enormously proud to be part of Sibs and to introduce this report that gives a glimpse of our exceptional work and the siblings, allies, families, professionals and advocates who drive it.

#### **Saba Salman**

Chair of Sibs, author/editor, journalist, adult sibling

## Message from the Chief Executive

### Creating a community for siblings to belong



Clare Kassa

I didn't meet another sibling until I was in my twenties. Until that point I hadn't realised that being a sibling was "a thing". I hadn't acknowledged that there were other people who would share the joys, challenges and the stresses we as siblings face, right from our early childhood years. A turning point for me was being invited to a meeting back in 2001 with other adult siblings, the meeting in which the Sibs charity was born. Monica McCaffrey, Sibs founder and first CEO shared that she "*set up Sibs so that siblings like me could have the acknowledgement and validation of our lifelong experiences and to have our voices heard by our families, service providers, and policy makers.*" I am grateful for Monica's pioneering and inspirational work on behalf of siblings in the UK, which has given us the organisation I am so proud to lead today.

Siblings, whose lives have been impacted by disability and ill health, are particularly vulnerable to isolation and anxiety. Despite this, the needs of siblings are frequently overlooked. Often invisible to care providers, commissioners and professionals, their contribution is underestimated and their needs are unmet. However, many siblings are carers and regardless of their carer status, their lives are impacted by their experiences. They need support and acknowledgement.

For the last 20 years we've shone a light on the needs of siblings. During those 20 years we've built a community of siblings, we've fought for them to be recognised as a group in their own right and we've developed child and adult specific support services. Through our written information, online and individual support, training and groupwork we have reached over 44,000 siblings and sibling supporters in the UK during the last year alone. Siblings turn to us, often during a crisis: after a parent's death; when services have let them down or just when there is nowhere else to turn. Siblings often refer to us as a lifeline. We don't underestimate the power of being the service they turn to when all else seems to be lost.

Of course, the impact of the Covid-19 pandemic on siblings has been devastating: young siblings isolated at home away from critical support structures; many becoming young carers for the very first time. Adult siblings have faced incredible worry when not able to visit brothers and sisters, or having to move mountains to provide care and support, often at a cost to their own health and wellbeing. I'm proud that during the pandemic, I've seen Sibs at its most agile and responsive.

**We listen. We understand. We care. We act.**

The last 18 months have been tough, but thanks to the dedication and skills of our small staff team, trustees and volunteers, we are still here, still providing transformational support and still determined to give a voice to our sibling community.

Of course, none of this work would have been possible without our partners and funders, to whom we owe enormous thanks. By standing by us you've enabled us to continue to stand by siblings.

Our sibling community is strong and growing. Sibs provides a place where siblings belong, where they can share experiences and where together we can support them to navigate the complex and ever-changing journey of siblinghood.

**Clare Kassa**  
Chief Executive

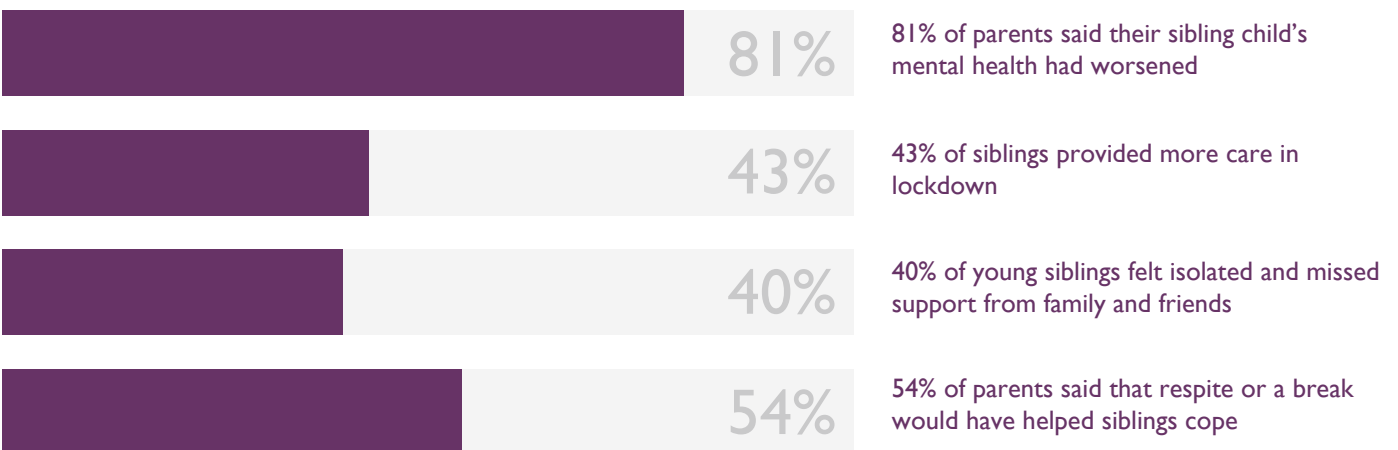
## Our Covid response

The Covid-19 pandemic has acted like a magnifier for existing challenges faced by siblings, like isolation and anxiety. Thousands of young siblings suddenly became carers when services stopped home visits, while many more adult siblings had to put their own lives on hold to support their brothers and sisters, as well as their elderly parents. Some had to urgently and rapidly step in to provide care, whereas others were prevented from seeing their brother or sister, causing significant emotional distress.

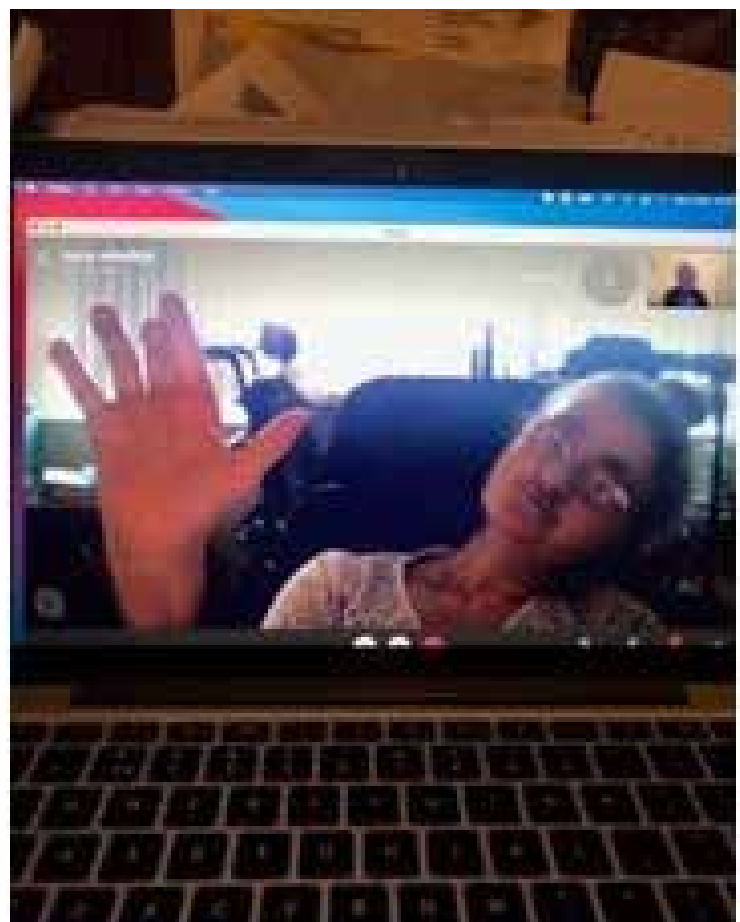
In response we sought to provide the latest information to siblings to help reduce uncertainty and anxiety, building online connections to reduce isolation. We developed a Covid hub on our website with information and signposting for further support. Our online support groups helped adult siblings to stay connected with their brother or sister. While our online support service answered Covid-related questions from young siblings, parents and adults.

During the pandemic we wanted to fully understand the impact on young siblings and published two reports. Our first report, 'Life in Lockdown' in May 2020 showed how the first lockdown had been traumatic, isolating and difficult for siblings. Our follow up report 'Lonely Lockdown' in collaboration with UCL (University College London) sadly revealed that as the pandemic and resulting lockdowns continued, overall the mental health of siblings got worse.

The impact of the pandemic on siblings continues and we are calling on the government to ensure support for siblings is part of the government's recovery plan.



Jane and Mary Kaye



Our Impact at a glance

# In 20 years we have...

Supported over **340,000** siblings, their families and professionals who work with them

Facilitated over **250** workshops for parents on the needs of young siblings

Trained over **1,000** people to run young sibling support groups

Established **23** adult sibling peer support groups as part of SibsNetworkUK

Developed a **unique** online service for young siblings aged 7-17

Trained **56** schools in our Sibs Talk intervention programme

Built a community of over **18,000** followers on our social media platforms



# Sibs

For brothers and sisters  
of disabled children and adults

## In 2020/21 we provided...

**539** parents with information and advice on supporting their sibling children

**540** professionals information and training to support siblings

**700** adult siblings with downloads of our new eBook on self-care for siblings

**142** adult siblings with individually tailored advice and support

**205** places at adult sibling support groups

### We launched

**8** online information sessions for adult siblings

**2** new reports on lockdown experiences for young siblings

**12** new spotlight mini blogs produced for young siblings

### We trained...

**8** new adult sibling group facilitators

**17** new sibling group leaders to run groups for young siblings

### We informed...

**51,301** unique visitors to our website

**8,630** followers on Twitter and 7,076 on Facebook

### We engaged...

Our first celebrity Patron - radio DJ and television presenter, Jo Whiley - who is also a passionate advocate for her disabled sister, Frances.

Jo Whiley



## We are here for the duration

Siblings are in the lives of their disabled family member longer than anyone - including parents and service providers. The impact of a disabled brother or sister on a sibling changes and evolves over time. We are there for the duration. From childhood to adulthood, bereavement and beyond, we are the one constant in an ever-changing situation.

## Supporting children

Siblings of disabled children can face a range of issues including disrupted sleep and anxiety about their brother or sister's health. Many act as young carers. Children and young people growing up with a disabled brother or sister often get less attention from parents and have more worries and responsibilities than their peers.

Many young siblings experience daily challenges in their lives such as public prejudice and finding it hard to get schoolwork done. Siblings also need recognition for the positive aspects they bring to family lives, such as learning new skills to help their brother or sister and being supportive of their needs

## Young Sibs Service

Our Young Sibs website offers advice and support to 7 – 17 year olds and received 8,622 unique visits in 2021. We post monthly blogs on topics including; talking about disability, staying safe and tips for mental health. Siblings used our Young Sibs service to ask specific questions, such as:

youngSibs

**“How can I help my brother deal with his autism and how can I help him calm down?”**

**“What do I do if I'm constantly feeling annoyed around my sister every day?”**

Our trained staff respond to these specific questions with tailored support and advice. Many young siblings contact us to tell us how much this helps them.

**“Dear Linda, thank you for your email. I'm really really happy now I can play with my brother nicely! I love my brother, thank you.”**

## Reaching and engaging young siblings

We continue to develop our social media channels to help us reach new siblings who may need our support. Interesting and creative content including infographics, illustrations and video content help us further our engagement with siblings. In the summer, we launched our new Instagram page and recently launched our You Tube channel.

## Supporting parents and professionals

We're not just there for children. We're also there for those best placed to make a difference to children - their parents and professionals.

## For parents in 2020/21

We ran 27 online workshops and presented at two conferences. Through our workshops and email support, we helped 539 parents to improve their skills in supporting young siblings.

## For professionals in 2020/21

We delivered a training day on how to run a sibling group for young siblings. Through our range of professional support, we've provided training and information to 540 professionals across the education, health and social care sectors. In November we hosted our first online conference for professionals on models of young sibling support. During the conference 104 delegates heard from a range of experts in the field of sibling support.



## Understanding our impact

“There are certain strangers who come into our lives, pick us up, hold us together and root for us without reason and with NO expectations, but just shower us with kindness. People who restore our faith in humanity. People like the Sibs team. It’s thanks to Sibs I was given the opportunity to share my story two years ago, which has helped to give me a voice as a sibling carer. I know that Sibs is here for me throughout my journey, for the good bits and the not so good bits.” Prakash.

“I greatly appreciate Sibs support service, as I always feel understood and heard, which gives me more strength and resilience to carry on. Fantastic service made me feel much less alone and worried about the future.” Sibling feedback.

In May 2020, we commissioned a research study to evidence the impact of our one-to-one support service to adult siblings. Data was collected between 21 May 2020 and 13 June 2020 when 48 people received support. While the survey was small, it provided strong evidence that our one-to-one support has a positive impact on adult siblings.

100% of those said they would use the Sibs service again and a similar amount would recommend it to other siblings.

94% of respondents strongly agreed that one-to-one support from Sibs increased their confidence to deal with an issue.

## Expanding our support group model, SibsNetwork UK

In January we held two online facilitator training sessions for eight new adult sibling group facilitators. Our sibling support group network, SibsNetwork UK continues to grow and we now have 17 adult sibling groups, including a national online support group and a bereavement support group, with a total of 205 attendees across all groups.

New funding from the National Lottery Community Fund enabled us to hold eight peer support sessions, and a legal information session. These new support sessions enabled us to reach new siblings previously unconnected to Sibs, with 25% of the 99 adults booked onto the session’s unknown to Sibs.

“My brother’s profound learning disability and dual sensory impairments mean he relies on hands-on, face to face communication for it to be meaningful. For that very reason the pandemic has had a huge impact on quality of life and wellbeing for both of us. It’s so hard keeping in touch in a way he can understand.

“Gil recognises our voices and faces, so the ‘Book Creator’ workshop Sibs offered, provided some novel ways for us to meaningfully keep in contact. Already I’m thinking of simple messages I can create using photos and recorded messages - that we’ll visit as soon as we can and make up for all those missed hugs with him! This approach offers easy ways to remind Gil, even though we can’t visit, we are still around and still love him. The Book Creator automatically ‘reads’ the story you put together, so my brother can look at and listen to messages over and over, for reassurance that we haven’t forgotten him.

“This Sibs technology workshop came at the right time and provided some simple solutions to tackle the challenges of this ongoing pandemic. We all left the workshop excited and optimistic we had some new, very practical skills and ideas that would support us to maintain our special sibling bonds.” Annie

## Providing information

In Carers Week, we published our Sibs eBook on self-care for adult siblings. Over 700 copies have been downloaded, and now, with funding from the National Lottery Community Fund, we will be producing print copies to further expand the book’s accessibility and distribution.

Prakash



Annie



# Case Study

Shamini



“I connected with Sibs during the first lockdown, when I was overwhelmed and exhausted caring for my sister with my parents at home, and worried about her going into a care home during the pandemic. I listened to other siblings who were struggling to support their brother or sister because of shielding and insufficient social and health care, or were banned from visiting care homes.

“During the next year and a half, Sibs staff, volunteers and other siblings I met through the online support groups would give me a place to talk honestly about my struggles and worries. This included both when my sister was at home and when she was in a care home for five months (where she suffered emotionally from the enforced separation from her family and physically from problems including getting Covid and being attacked).

“Although some friends and family have been fantastic during the pandemic, some have backed off. I often don’t tell people the details of how difficult things are, I just gloss over the worst or tell them the positive stuff that I think they want to hear. But with Sibs, I could talk about the heartbreak and stress and I knew people understood. They didn’t feel pity or pressure to say something positive; they just listened. In turn, I could listen to other siblings who were caring for their brother or sister at home or trying to support them from a distance.

“I still feel very alone and an oddity compared to my peers, but it does help to know there are other sibs out there who empathise with me, and it’s given me a stronger sense of identity as a sibling carer and an individual. I’m channelling my experience into writing and I hope this will create something meaningful from my life and my sister’s.”

## An evidence-based approach

We are committed to supporting and promoting research into sibling issues. As the only UK charity supporting siblings we offer a unique insight that can greatly enhance research in this area. We continued to work closely with partners in 2020/21 to further knowledge and understanding of sibling issues, and this year worked with UCL (University College London) and The Sleep Charity on research into siblings sleep and loneliness.

We were involved in a consultation with researchers from Royal Holloway University for the Department for Digital, Media, Culture and Sport to explore the challenges face by siblings who needed to prove their identity when supporting their disabled sibling. We were also involved in a consultation with a digital sociologist at the Ministry of Justice on a project to modernise Lasting Power of Attorney.

Research in *Developmental Disabilities* journal published a special issue on sibling relationships in development disabilities, with the summaries hosted on our website. And, finally, we also participated in an international research study comparing sibling support models around the world.

## Influencing and awareness

Raising awareness of siblings will help us to gain more recognition of the role they play and more understanding on why it is important their own needs are met. We worked closely with the media to raise the profile of siblings and secured features in *The Sun*, *The Independent*, *The Mirror* and *The Sunday Times* and *Education Today*. We also worked with producers from two new TV dramas featuring siblings.

Once again we participated in National Siblings Day and saw the highest number of social media interactions than ever before. By continuing to be part of this international day it will help us increase our social presence and be part of global efforts to recognise and celebrate siblings.

## In partnership with...

As a small charity it is vital that we work in partnership with other organisations. This year we worked with Ann Craft Trust on a safeguarding and siblings podcast; Epilepsy Action on sibling information; Clic Sargent on a social media Q&A on the needs of siblings whose brother or sister has cancer, and Mencap's Community Forum as the expert on sibling issues. We will continue to seek out and develop partnership working with third sector organisations.

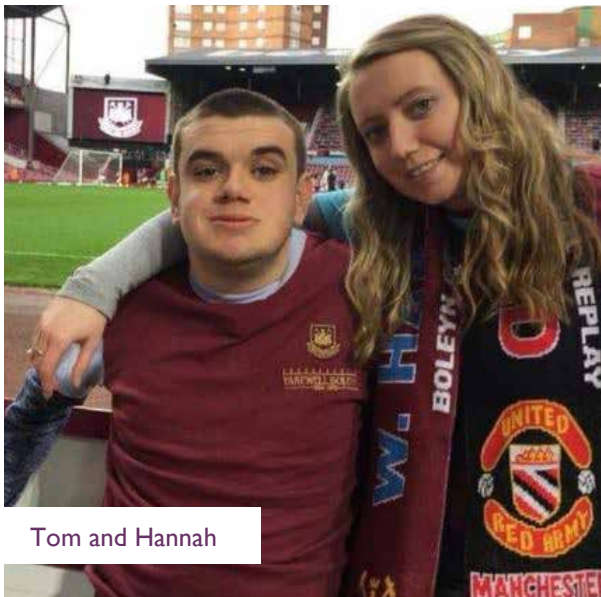


Sibling Support Group, Down's Junior School



For brothers and sisters  
of disabled children and adults

Every child who received a reply to their question, every adult who attended a support group, and every sibling who felt understood, listened to and that they belonged - this is directly because of the support from our funders and volunteers. Thank you.



Tom and Hannah

“I am so grateful to Sibs for connecting me with other people in a similar situation.

I know I have made friends for life.”

## Thank you

We are hugely grateful to all the donors who fund Sibs' work.

Thank you to:

Charities Aid Foundation Resilience Fund. Garfield Weston Foundation. Genetic Disorders UK. Learning Disability England. MariaMarina Foundation. National Lottery Community Fund. Pears Foundation. Persimmon Homes Building Futures Programme. Seeability Creating Connections Programme. The True Colours Trust.

Sibs is the UK charity for brothers and sisters of disabled children and adults.

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