

Lonely Lockdown

Life for siblings of disabled children in the UK

About Sibs

Sibs is the only UK charity supporting brothers and sisters of disabled children and adults. It was set up in 2001 in response to demand from parents and professionals for information on how to support siblings of disabled children. Siblings have a lifelong need for information. In childhood, siblings grow up often receiving less attention, have more worries than their peers and face some challenging situations in their home lives. As adults, siblings rarely receive acknowledgement of their expertise or support for their own needs and often have reduced wellbeing. Sibs provides direct support to children aged 7-17 through our YoungSibs website where children can find information and get answers to their questions from Sibs staff. We provide email siblings and run a network of peer support groups for adult siblings. Sibs also provides training and workshops for parents, professionals and adult siblings.

Background aims and process

In May 2020, Sibs conducted a survey of parents in order to better understand how the needs of siblings of disabled children were affected by lockdown. The first survey results made difficult reading: 75% of parents felt their sibling child's mental health had worsened in lockdown; 50% of siblings were providing more care; a third were missing family and friends. Ten months on and in lockdown 3, we wanted to explore if and how things had changed for siblings of disabled children.

Sibs, in collaboration with University College London (UCL) researcher Dr Georgia Pavlopoulou, decided to launch a second survey in February 2021. The survey was open for 4 weeks. We repeated a number of the questions from the first survey in order to be able to draw comparisons and also added more detailed questions. We wanted to further understand the nature of any school support, how the relationships between siblings and their brothers and sisters

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had been affected and what some of the greatest challenges were for children and young people. We hope the results of this second survey will help to highlight the impact which lockdown has had on the majority of siblings and go on to inform a recovery response.

Participant characteristics and key findings

640 parents completed the survey, of them:

- The majority of the parents taking part in the survey were from families with 4 members (47%)
- The ages of sibling children in the survey, spanned the whole of the childhood years. (0-17)
- The most common reported disabilities for the brothers and sisters of siblings were developmental disability including autism (70%), learning disability (56%) long term health condition (22%). Responses were also received from parents of children with complex health needs, rare conditions, sensory impairment, genetic conditions and those with undiagnosed conditions.
- 91 % of families were white, 6% were BAME, the remainder preferred not to say, or identified as another cultural grouping.

Negative impacts on mental health for siblings of disabled children

We have seen an increase in parents reporting mental health concerns in siblings of disabled children in this survey with **81% of siblings experiencing worsened mental health.**

- **84% said it affected their mood**
- **51% found it difficult to sleep**
- **16% lack of appetite**
- **61% lack of interest in usual hobbies and pastimes**

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Parents reported that many of their children were showing multiple signs of difficulty. A number of parents additionally reported episodes of anger, stress and anxiety.

"Stress at being the target of her older sister's anger with no respite"

"A general reluctance to engage with the outside world unless he has too"

"Anxiousness around contracting covid at school and potentially infecting sibling and family members at home who are shielding"

However, there were a small number of positive impacts on mental health:

"More free time and head space"

"Positive without school"

"Their mental health has not been affected"

Furthermore, we have also seen some parents sharing some improvements during lockdown 3, particular with reference to some young people being able to access education.

"This lockdown has been better as she has accessed school due to being a young carer"

"They have isolated for a whole year and see a hit to their mental health not being able to see anyone or go to school."

However, there were a small number of positive impacts on mental health:

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"Positive without school"

"Their mental health has not been affected"

Parents struggling to support siblings

Parents experienced a number of challenges in supporting siblings

- **20% reported struggles in sharing time with siblings**
- **27% giving siblings enough attention**

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- **15% struggled to offer help with schoolwork**
- **16% parents found it difficult supporting siblings' mental health**

Many parents found it difficult to rate this question, because they felt that many of these issues were difficult for them and they were juggling multiple needs.

"It's too difficult to categorise for siblings of a child with a life limiting condition, not only are they facing the usual struggles during lockdown but they have to shield to protect the life of their sibling, this causes a huge amount of frustration and sometimes unintended resentment. The added strain and responsibility that's been added to their shoulders is near impossible to support on top of the standard mental health and schooling issues."

"Only one child can be properly supported at any one time, there is not enough of me to go round. Supporting my mental health and self-care has also been a huge challenge and has not gone unnoticed by my eldest child which worries me. How can we promote healthy mindsets and outlooks when there is no physical or mental breathing space in which parents can centre themselves as well?"

"It has been impossible to support my other children properly with schoolwork or even keep them safe. One of them suffered a near fatal accident as a result."

Loneliness and struggles with completing schoolwork at home

Parents reported that **40% of siblings experience high levels of isolation** missing their family members and friends. Friends and families are an important support network for siblings and unsurprisingly this has been an area of loss for children and young people in this period.

"Different issues for different siblings.....but definitely feeling isolated, home schooling and missing friends and family"

57% were impacted by disabled brother or sister's behaviours including finding time and a quiet space to complete schoolwork at home.

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"Trying to switch learning online to school n back due to isolating and lockdown he's fed up and wants to consistency and time to adjust"

Siblings as young carers with no respite

43% of families report that **siblings are providing more care** during lockdown. Many families have described feeling forgotten, with services unable to provide any care in many cases, and for others at very limited levels. This has often meant parents relying on siblings to fill in the gaps, helping out when they have to work and provide more care overall than usual.

"More time with her, which means more time being shouted or sworn at"

"While I don't ask my eldest to perform many care tasks for his sibling, I have required his help on occasion where my priority has had to be managing the safety of his sibling....I have noticed an increased reliance during lockdown as one parent has remained at work....I no longer feel confident to handle some things alone anymore and must have an extra hand, even if its only a 6 year old hand."

"Both my son and daughter have provided a watchful eye so I can have a quick shower. Making sure she doesn't injure herself. Providing entertainment to keep her busy during lockdown. My daughter has provided some hygiene care for her disabled older sister when she unexpectedly got her period and I was unaware and cooking. She sometimes has also helped with dressing. They have both been forced to do schoolwork quietly so their sister isn't overwhelmed with new constant noise in the house."

85% of the families did not have any access to respite care during the lockdown, which was reported to have critical implications for siblings and parental wellbeing. Again, the picture was varied with offers of respite being limited to particular circumstances.

"Sibling No - Autistic son has short breaks but no one to take him out and nowhere to go."

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"Sibling child stayed with aunt, uncle and cousins for 2 nights while parents were at hospital with her brother for surgery"

"Tiny amount of emergency respite"

"Severely restricted respite compared to normal.... there was none for 6 months but then some started but only a few days."

Parents wish list to support siblings

Parents identified the following types of support as essential to help siblings cope better during the pandemic.

- **53% respite**
- **27% financial help**
- **25% exercise equipment**
- **37% outdoor play equipment**
- **33% more support from school**
- **24% iPads, computers and electronic games**
- **10% Information**

Access to respite came out strongly as a need and we know from an additional question, this was a gap. Again, families would have been grateful of some practical support that would help their sibling child such as games and play equipment, but no provision was made.

"Being removed from services or groups that we relied upon for information sharing was so difficult. I felt as though I was blindly navigating a confusing and ever-changing maze sometimes during lockdown. People did check in with us but they couldn't see what was happening here and so we just muddled on through."

"Support from senior policy makers eg government to protect shielding families and support by not threatening fines if children kept at home continuing their studies. We are being forced to send sibling child back to school or face fines, no alternative help being offered."

"Extra internet and more technology so could have contacted school and friends and support when needed, not coming second place for this to her brother."

Mixed findings in school support

The picture of support from schools was very mixed across this latest lockdown. From no support at all, to excellent support and every stage in between. Some parents reported being able to send a sibling child to school in the latest lockdown, for others this was not offered, even when requested. Some siblings were offered school places, but turned them down, because of concern around safety and infection. For many the offer of a school place for siblings seemed to relate to the parental keyworker status, rather than a young carer or vulnerable child status. Most parents reported that their sibling child had the same access to school support as other children rather than something over and above universal services. Examples were given of resorting to paying for private counselling services or moving child to a private school where there was more support. Three families mentioned that they had started home educating their children, others have moved siblings to new schools during this time to pursue better quality support. A number of parents felt that their only way they could receive support was when they hit a crisis point.

Positive support:

"We received 2 phone calls during the 1st lockdown. 2nd lockdown nothing at all and the 3rd lockdown they actually offered us school places for both children as I wasn't coping with working and trying to home school."

"Calling her when her brother was in hospital to make sure she was ok, made allowances for work not turned in"

"Brilliant - unquestioningly accepted her full time as a vulnerable child"

"The school provided us with one laptop, feedback from teachers, well-being calls, mental health workshop"

Limited support:

"One class google meet a week! As the sibling of an autistic child no support whatsoever, I tried to get one or both into school but couldn't"

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"My daughter continued school during the third lockdown due to my key worker status. School have not acknowledged or engaged with me regarding notification of her official young carer status."

"They have tried their best but my disabled son only received 20 mins of 1:1 online support which meant that I had to help my disabled son all of the time which meant that my other boys had to do work with little support. I don't think the school really recognise the carer role that many siblings have."

Lack of support:

"Staff seem oblivious to how the life of sibling carer might be different to any other child. They're very good at supporting our disabled child, though."

"No support offered at all despite announcing my sibling child's brother was beginning another round of chemotherapy. They didn't even reply to the email."

"They didn't at all, until I rang and explained how his sister's seizures had started to affect his mental health and they took him back full time"

"They have had absolutely no interest in him. We received one response to say 'it's difficult for everyone'

"They have had the same support as other children in their classes. There is no additional support offered because of them being a sibling of disabled children (2)."

Limited school attendance

- **24% had attended school**
- **67% were not at school**

Nursery schools were still open for young children during lockdown, and many families talked about how this had worked for them. Families who were shielding had not sent their child to school. Some children were offered places, but the families decided not to take up the place. This was due to a number of factors including shielding, anxiety from sibling child and safety concerns.

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"I deregistered them due to not feeling the government was taking the risk to children seriously, but also the MH of my eldest was so bad he couldn't face school anymore."

"Only did two days but as there was no support in the class just sat in front of a computer, he didn't get any work done so didn't bother going back."

"A place was offered but mental health my son thought he would bring covid home to his disabled brother and sister and they would die from it"

Changes in siblings' relationships

- **14% reported that siblings seem to be getting on better with each other**
- **41% did not notice any changes in the siblings' relationship**
- **40% reported that siblings' relationships have been worse during the lockdown**

A lot of parents talked about this as a changing picture, with lots of ups and downs, good days and bad days. Many parents talked about how the quality of the relationship is heavily dependent on the behaviour and mood of their disabled child.

"Its complex, in some ways I think it has improved. My daughter and son can engage more in play together, which a year ago didn't seem possible. In other ways it seems worse....my son often bears the brunt when play goes awry. There are times when it just feels as though we are all struggling to occupy the same space."

"They are playing together more but the fighting and aggression has got a lot worse"

"Ups and downs - very good at first then not good at all, now better. Depends on autistic child's mood"

"Up and downs, some irritations and the fact that his autistic brother seems to get away with things that he shouldn't."

"Because my son was shielding we tried to keep them apart. And now that distance seems to have remained"

Access to technology

- **94% of siblings had been able to access technology**
- **2% had not**

A high proportion of siblings had access to technology of some sort, although often it meant sharing a device between multiple siblings. Some parents mentioned being able to loan a laptop from school.

"Only on phone which is difficult"

"We have had technical difficulties and had to borrow a laptop from school which we couldn't sign into so she missed a whole week of learning before half term"

"The technology is limited so they have to share"

The importance of maintaining contact with extended family and friends

Parents talked about a whole range of ways in which siblings engaged in contact with friends and family. Zoom calls, Whatsapp, Xbox, iPad, calls via school settings were accessed by lots of siblings. Some children were still able to see grandparents or other relatives if they had formed a support or childcare bubble. However, many parents talked about the fact that some siblings struggled to maintain friendships virtually and found it hard to navigate friendships out of school parameters. Other siblings refused to engage in this type of contact altogether. Grandparents featured highly in the responses – where the siblings were still able to engage either in person or remotely. Many talked about the fact that siblings missed grandparent contact, particularly for those whom the relationship provided necessary respite. Many families of disabled children have been shielding and will continue too, which means for siblings the isolation continues.

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"He's spent a lot of time on FaceTime and Roblox but has really missed face-to-face time with children his own age, especially play dates or clubs that are just for him. It's been very hard to arrange anything just for him and inevitably when we do things as a family we tend to build timings and choices around his brother's needs."

"Yes- grandparents in our bubble during 2nd & 3rd lockdown which has been a great help"

"She backed away from zoom meetings with her social group. She cried this weekend as she felt she was closer to her brother and lockdown had allowed us to do things other families did."

"No. We are a shielding family and didn't leave the house in the first lockdown and have no support bubble or childcare bubble. We also can't meet anyone in the park or anything this time as I've too many kids so if I bring all of them (as I have to!) Then we can't meet any friends as we'd be over max numbers. We're totally isolated."

At the end of the survey we offered space for parents to comment on their thoughts and experiences. There was a great deal parents wanted to share about their sibling children. Many parents talked about just how hard it had been for their families, but how proud they were of the strength, love and care provided by siblings, many of whom had become young carers. They also reflected on the importance of feeling heard and understood by school staff, alongside the despair at lack of support. Shielding families have felt particularly forgotten, which means shielding siblings are also have fallen under the radar of educational and healthcare professionals. Lack of services and support meant that disabled children's behaviour had deteriorated in many instances, meaning that siblings were experiencing repeated incidents of concern. These behaviours felt frightening for siblings.

Many parents felt that services just did not understand what it was like for their sibling children and they worried about the impact lockdown would have on their future lives and wellbeing. Returning to school also brought anxieties for siblings who were worried about mixing with others again and what this might

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mean for the health of their families. Many siblings were delighted to return to school to see their friends and resume a routine. These words were repeated many times. Awesome. Amazing. Forgotten. Scared. Stoic.

"My daughter just wants the same attention as her brother but with everything cancelled she gets no 1-1 time with a parent and when her brother is around she always takes a backseat. It is heart-breaking."

"Since returning to school and spending more time apart during the day from his brother, he's been choosing to share a bedroom with him at night. I think this is his way of adjusting to another change. It's not impacting on his sleep and seems to be giving them both some security."

"Her sister is high functioning autistic and superb at masking at school, therefore I doubt school have even thought about her during lockdown. Being stuck at home and the butt of her sister's anger/anxiety/meanness is awful and we try our best. I really feel for my poor little girl. Getting my eldest back to school has been challenging however our youngest is up and ready, desperate to get there!"

"My sibling child is very mature for her age so some of her worries and anxieties don't seem to have been noticed by school"

"He is a kind and thoughtful child who has to work harder than most 5 year olds I know in order to support his disabled sister and because his parents have to devote more time to her and have less time available for him. He is a generous soul despite all of that - we are so proud and lucky to have him in our lives."

"The siblings have miss out on support from me as their brother needs more help and they have never once complained."

"Lockdown for families with a disabled child is a different world to lockdown for families without a disabled child."

"Disabled child adores his sibling, but shows it by headbutting him. Sibling is really good with him, partly because he doesn't know any differently as he was 7months old at the start of lockdown so his older brother is all he knows of other children"

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"Our daughter has been getting weekly phone calls of young carers which she has enjoyed, her face lights up when she knows the phone call is for her"

"They feel worried because they are scared their brother might die if he caught COVID, they are worried if get went to school, they may bring back COVID and be responsible for transmitting the virus. They feel lonely because we've had to shield and have no social contact with friends."

"She is the forgotten child, not asd, not shielding herself but from a shielding household- children like her are the forgotten children with exceptional pressure on them due to circumstances."

"They are forgotten about more than the disabled child and the disabled child has been forgotten so that says it all"

"Thanks to this question I realise I put my other kids in second place, they are just young kids, I teach them to take care of their brother and sometimes I forget they are kids, they deserve more attention."

"Able to attend school as keyworker child but has not done so as desperately didn't want to without friends. Self-harming because of fears of having to care for sibling if/when parents die"

Summary

Siblings of disabled children are an overlooked group of children, many of whom have had to bear the brunt of the lack of services and support to their families in lockdown. Many are providing care. Children as young as 5 have been supporting exhausted parents to look after their brothers and sisters. Siblings are often the glue that holds families together. But at what cost? We can and should do better in acknowledging the needs of these children who show fortitude and strength but have experienced prolonged exposure to stress. Time and time again families have shared that small actions can and do make a difference. A phone call from school, a zoom meeting with a young carer worker, a break so a sibling can socialise and rest, a teacher taking an interest – actions which can mean the world to a sibling who is struggling to get their needs met.

Recommended Actions

We expect the impact of this crisis on siblings' mental health, to be felt for a long time to come

- We urge schools to identify pupils who have a disabled brother or sister. Many children are also returning to school having become young carers for the first time. Many will need additional support to acknowledge this change.
- Schools should identify a member of staff to be a sibling champion. Having a visible commitment to this group helps children to embrace difference, normalise their experiences and help them to feel heard.
- Access to short breaks and other essential services have a direct impact on the wellbeing of siblings. We support the Disabled Children's Partnership call for a dedicated, funded COVID-19 recovery plan for disabled children and their families, that clearly includes siblings.
- The safeguarding of siblings must be taken seriously by local authorities. The current crisis has exposed siblings to increased violence and risk – it is vital that families receive statutory support in order that they can protect siblings.

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- The pandemic has had both an immediate and lasting effect on the mental health of many siblings who will need access to appropriate support from CAMHS services in the months and years to come as part of a recovery plan.

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March 2021