

Sibs

For brothers and sisters
of disabled children and adults

“Coming second all the time”

**Life in lockdown for siblings of disabled
children**



June 2020

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 receive support for their own needs and often have reduced wellbeing. Sibs provides direct support to children through our YoungSibs website so that children can find information and get answers to their questions from Sibs staff. We provide phone and email support for adult siblings and run a network of peer support groups for adult siblings. Sibs also provides training and workshops for parents, professionals and adult siblings.

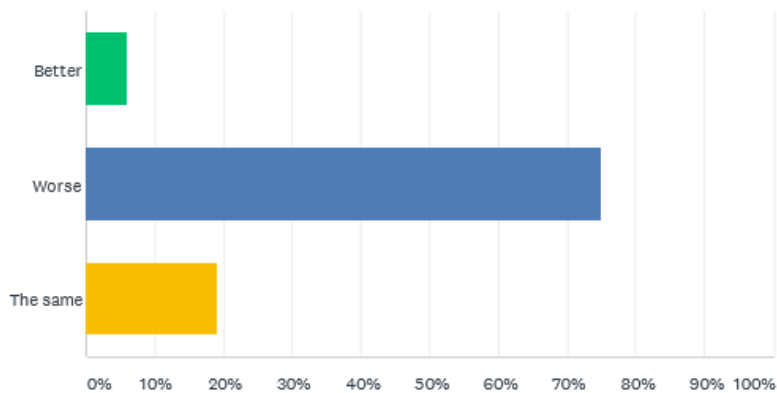
Background and context

Lockdown and the Covid-19 pandemic have changed life as we know it in the UK. For siblings growing up with a disabled brother or sister, it has had a significant impact on their lives. Sibs wanted to find out more about the largely hidden story of young siblings under the age of 18, many of whom are providing additional care and support in a time of national crisis. Siblings contribute enormous support to their families and provide friendship and care to their brothers and sisters.

Many siblings rely on school, family and friends for their own support and respite. Without these support mechanisms how would young siblings manage and cope and what is the lasting impact on their wellbeing? How are families coping to meet the needs of each of their children? To find out more, we released a survey asking just 5 questions which was open for 10 days in May 2020. 876 parents responded.

Q1 How has lockdown affected the mental health and wellbeing of your sibling child?

Answered: 881 Skipped: 0



ANSWER CHOICES	RESPONSES	
Better	6.02%	53
Worse	75.03%	661
The same	18.96%	167
TOTAL		881

Q2 What has been your biggest challenge in supporting your sibling child/children?

The answers were given in a free text box – parents shared the challenges in their own words. The responses have been divided into 6 key categories.

Time and attention

36% of parents specifically mentioned the lack of time and attention they feel they can give to their sibling children in lockdown. Many talked about the lack of external services and support, which increased pressure on care and meant that siblings were the ones that ended up missing out on their parent's time.

"Time! Most of my time is spent occupying my eldest (disabled) child and the younger two are left to their own devices, whether for schoolwork or leisure time."

"Finding the time to sort both children. One needing to do school work the other needing suction oxygen and nebs, it's hard to split yourself in two. I'm constantly telling E to wait Mummy won't be long....."

"Time.....almost impossible to home school them with a disabled children in the same environment. Disabled child needs one to one so no time for the siblings."

Help with schoolwork

15 % of parents talked here about trying to meet the needs of each of their children, who have different abilities, differing requirements from schools and with a lack of peace and quiet for siblings to complete schoolwork. A number of parents reflected that their sibling child should have been offered a place at school. Many talked about the struggle with technology and siblings having to share one iPad or computer.

"Watching her struggle with schoolwork etc. and seeing the hurt on her face when yet again we're dealing with her brother rather than giving her the time and attention she needs."

"Time apart from her Brother with SEN, he's smashed her iPad and multiple school resources so she's no longer able to complete all schoolwork or communicate with friends or do schoolwork."

"Trying to give them time and support with their schoolwork when their visually impaired brother needs so much more time and help. Hearing it's not fair and you love him more than us daily."

Entertainment, distraction and supporting

11% of the replies talked about the challenges of trying to keep their sibling children entertained, distracting them and trying to support their needs often in very challenging circumstances.

"Giving my time to homeschool, reassure, play and eat with her as we have no daytime carers coming in with my son's terminal illness."

"Managing such different needs due to the huge changes and the ways they both respond to change. Keeping up with typical activities and keeping one socialised whilst adapting the normal routines so drastically with another is very challenging. Definitely the difference in how both need support with such a huge change."

"Trying to reassure him that he's safe and trying to keep him active and keep structure in his day, he's learning to cook as he always is independent, but suffers anxiety."

Safety

8% of parents specifically mentioned the issue of keeping siblings safe from their brother or sister's behaviour.

"Finding an escape for her when her brother's behaviour is overwhelming and making sure that we spend some time doing something special with her so she doesn't feel forgotten when so much time is taking up with looking after him."

"Finding 1:1 time and controlling bullying from her asd brother. She has poor self-esteem and high anxiety."

"Keeping her safe from being hit from disabled child."

Mental health, worry and anxiety

We already asked a separate question, where 75% of parents responded by saying their sibling child's mental health had worsened during lockdown. In answer to this further question, some parents explained in more detail what some of those challenges were.

"She gets upset quicker and the smaller things that he does which annoy her and managing that. Also there is no respite for her as his dad won't take him at the minute due to COVID"

"She has started to self harm and she's stopped eating. Cahms won't accept a referral so we've no support for her."

"Mental health, my youngest has worried so much about even silly things that aren't a problem. It's been heartbreaking as she's normally a very bubbly loud child."

"My child has expressed that they want to end their life."

Understanding

A final theme in answers to this question, was centred on understanding – both in siblings understanding the needs of the disabled child, but also the wider

lockdown restrictions. A number of families particularly mentioned the challenges of shielding as a family and the impact this has on the sibling child.

"Helping her to understand why it is ok for her brother to break some of the lockdown rules but not the rest of our family eg when we could only exercise once a day but he still had to go out at least twice."

"Explaining everyday that the disabled child needs more help."

Trying to get him to understand that G is slightly different and requires additional support. He is noticing that G appears to get away with more things than he does."

"Hates his brother doesn't have to do school work and he does – been some battles"

Q3 What do you think the most difficult thing has been for your sibling child in lockdown?

Parents were again given a free text box to record anything of significance for their sibling child. Their responses covered six main themes.

Feeling isolated – missing friends and family

34% specifically mentioned that their child was finding it hard being separated from friends and family. Loneliness was a recurrent theme throughout.

"Not seeing friends and seeing mum always busy and assuming that means they can't ask. My littlest says worry when she asks for something. 😞"

"Having no escape from her sister! She has REALLY missed her friends and being able to go play at their houses."

"Not seeing their own friends/able to pursue their own interest/having to always 'wait' whilst their sibling gets attended to."

"Not seeing grandparents"

Behaviour

11% of parents talked about the impact for siblings of living in lockdown with a brother or sister who has behaviour which challenges. Many siblings are exposed to behaviour which is violent, aggressive and scary. In times of lockdown there is no escape.

"Being exposed to her Brothers 'meltdowns' causing the whole family stress to the point where it feels like it will implode".

"Witnessing meltdowns from their brother and not being able to get out as we would normally take her to family if things kicked off."

"Being with her brother 24/7 and having to deal with his meltdowns, screaming, aggressiveness. Watching him self harm every day he attacks her daily (hair pulling). She has also begun to worry about him a lot."

"No break from the strain of living in a house with disabled sibling who has violent outbursts, noise beyond belief demanding just needing some head space to live and study and relax all the clubs and sports she attends help her mental health and one to one time with myself has stopped."

"Being hurt and belittled constantly"

"Being a punch bag."

A break or respite

99 respondents mentioned the lack of respite or a break from the home environment as being very significant for siblings. Many of the usual options siblings use to manage these difficulties are just not available during this crisis.

"Lack of respite from his brother and having to see his brother go through a mental breakdown."

"Not having a break to be his own person."

"Unable to have their own time out of the house away from constant reminders of siblings needs."

"Lack of respite for them. School gives them a break from the fighting and arguing from my disabled child."

Lack of attention and having to entertain themselves

96 parents talked about this being one of the most difficult elements for their sibling child/children. The loss of support from services, from families and communities has meant families having to fend for themselves, leaving siblings to cope with little help.

"Not getting any attention of their parent as keeping my other child safe takes over everything."

"Being left to entertain themselves."

"Coping with their autistic brother's extremely challenging behaviour that takes up all our attention leaving them feel pushed out."

"Being left to their own devices a lot while I take care of their sibling with disabilities"

Alone time/space/escape

As well as a missing breaks outside of the home, 88 parents also mentioned that siblings also struggled to find safe space or time alone at home too. A number of respondents talked about living in cramped housing with no safe outside place for siblings to play or have a breather from the situation.

"We are a family of 6 living in a 3 bedroom flat, single mum, both twins with disabilities, having not enough space to play, twins climbing tables, chairs, dining tables, taking them out, they climb again, falling which us sad that they don't understand because of their condition and some behaviour issues."

"Dealing with the meltdowns and not being able to escape it, not getting a break or time away."

"Not having enough space"

"Having alone time, not being pressured into playing games"

Exercise and leisure

Restrictions on exercise and leisure in lockdown, particularly on families who are shielding or self-isolating has meant that for some siblings there has been no option even for daily exercise.

"Not having the freedom to go out. We can't leave due to isolating and E finds it very hard. We can't just go for walks, bike rides etc."

"Staying in, not going out, not getting enough exercise, fresh air, not seeing friends and feeling abandoned."

"Not being able to have their time away at their clubs etc away from the house, giving them 'their time'"

"Not going anywhere. Their normal routine is off. They haven't seen their nana, or gone to the shop or church"

School and schoolwork

80 parents specifically mentioned the challenge of having enough time to support schoolwork or struggling to access more help for siblings' education. It is also difficult for siblings to focus on schoolwork if they are worrying about their brothers and sisters and coronavirus.

"Self schooling. My 7 year old has had to motivate and manage his own time. Keep himself on task etc."

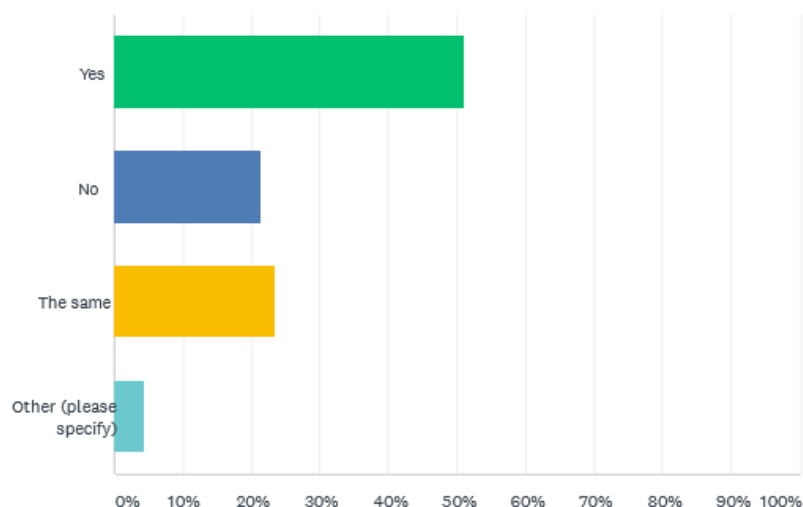
"Homeschooling disabled autistic child and trying to support learning disabled child to do work as well as siblings, it's hard on all of us."

"Staying focused and motivated to carry on with home learning with no or little adult supervision."

"Coping with school work and expectation, on top of knowing her brother could die as he is so at risk."

Q4 Is your sibling child having to provide more care to their brother or sister?

Answered: 881 Skipped: 0



ANSWER CHOICES	RESPONSES	
Yes	50.96%	449
No	21.34%	188
The same	23.38%	206
Other (please specify)	4.31%	38
TOTAL		881

Just over 50% of parents said that their sibling children were having to provide more care and support in lockdown. Parents also explained in the "Other" box that those who were not providing care, were usually too young to do so. Parents explained that although some siblings had been providing care, they had to withdraw from it because of the impact on their own mental health.

"She has to help, mum works night shift and is key worker so she has to be mums eyes whilst I try to get rest on the sofa. Sibling is a fantastic kid and really helps where she can."

"Sibling is having to go into school as the effect on her mental health was so severe."

"Initially did but has completely stopped now as it was making him poorly and he couldn't cope."

"Having to look after sibling when I was at work."

Q5 What would have helped you and your sibling child during lockdown?

Many of the parents responding to this question recognised that there were no easy answers – at a time of crisis, many support systems and services were just not available and many families talked about just getting on with things as best they could. However, there were a number of solutions put forward that they felt would have made a difference practically to their sibling child/children.

- Respite
- Financial support
- Space
- Exercise equipment
- Entertainment and toys
- Outdoor play equipment
- Having a safe and accessible garden
- iPads, computers and electronic games
- Recognition and rewards

"Something to make her feel special"

"The iPads the biggest issue as meltdowns has seen his and his sister's smashed. I got them cheaper versions but this means they cannot call friends or family off it so are stuck with each other now fighting. Sibling is now having to do more school work in order to get brother to sit down and actually do it."

"One computer and 5 kids!"

"Something for her to show her what a valuable job she was doing with her older sister and recognise that sometimes it's hard work."

Support from school

A number of parents commented that they would have appreciated more support from school for their sibling child.

"More input from sibling's school"

"The school should have contacted her as a young carer. Phone calls would have been good"

"An acknowledgement from schools that where there is a child with a disability in the house that getting schoolwork done might be harder and an acceptance of other work that the family can attempt together with graduated approaches to the work. That's doable but teaching 3 kids doing 3 different topics at 3 different levels from 3 different schools isn't"

"Clearer steer towards the fact they could attend school. We had to reach crisis point first."

"I am not sure that a lot could have been done differently as this is just what we have to do at the moment. I have found that the school has phoned regularly to check on my disabled child but no-one has called to check on her sister despite the fact she is a young carer and has support at school. I think regular calls to my daughter too would have helped her."

Other support

There were a few other comments from parents about wishing their sibling child could connect with other siblings, find appropriate information particularly for teenagers such as podcasts and YouTube videos made by siblings. Parents also recognised that lockdown reduced support for siblings from the wider family – they felt that having access to extended support would have made the situation easier for siblings.

Positives

Very few parents mentioned any positive impacts of lockdown, but there were some comments about how families had bonded and pulled together and had more time to tackle some of the difficulties within their families. 6% parents felt that the mental health of their sibling child had improved during lockdown.

"Things have been easier as I have not been at work so much and have been around more to support them both"

"It has not been too difficult, they are very patient with their brother."

Summary

Siblings are often an overlooked group of children in both school and wider communities for whom lockdown has had a tremendous impact on their health and wellbeing. Services for siblings have decreased dramatically in the last decade, this coupled with the limited support for their brothers and sisters in lockdown, will have a profound effect on the wellbeing of siblings. We expect the impact on their mental health of this crisis, to be felt for a long time to come. Sibs will continue to work with schools, professionals and families to ensure that the needs of siblings are recognised and understood.

Recommended Actions

- That siblings are recognised as a group of children who are vulnerable to isolation - very many are "children in need" and in many cases are young sibling carers. Siblings deserve greater attention and better planning for their needs.
- That the safeguarding of siblings is 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.
- Schools need to identify pupils who have a disabled brother or sister – not just as young carers, but from a wider context of vulnerability. Many siblings will need of additional pastoral support and/or academic support when they return to the school environment.
- Recognition that the pandemic has had both an immediate and lasting effect on the mental health of siblings, who will need access to appropriate support from CAMHS services in the months and years to come. Many siblings will have experience psychological difficulties due to lack of respite, isolation and dealing with behaviours which challenge from their brothers and sisters.
- Siblings live in households where there is increased risk of poverty and deprivation. Financial support for siblings should be made available in the same way it has been made available to support their disabled brothers and sisters, so that they too can access resources such as technology for education, social support and relaxation.