

# Sibs

For brothers and sisters  
of disabled children and adults

## If Only You Knew

A report into the school experiences of siblings of disabled children

### Why siblings in school matter

Siblings of children with disabilities, special educational needs or long-term health conditions, are often an invisible and misunderstood group within the school population.

Many siblings have emotional needs that are overlooked because of the needs of their brother or sister or face stigma due to the lack of understanding about the challenges their families may face. Siblings may have more worries and responsibilities than their peers, receive less parental attention, are at risk of bullying and can face many challenges in their home lives.

They are also more likely to have issues with their own educational progress in school, struggling to complete homework, study effectively whilst in school and get enough sleep. Examples of siblings being asked to care for or support a brother or sister during the school day are still commonplace.

Siblings are a crucial part of their families support systems and many provide help, support and care to brothers, sisters and parents. As well as helping with the difficulties, proactive support from school helps to affirm the many positives of the sibling relationship and family life for siblings. Siblings are acutely aware of the challenges their families face.

Our '[Lonely Lockdown](#)' report published in 2021 highlighted the range of experiences facing young siblings during the pandemic. Some siblings received excellent support from school, many more related poorer experiences and very

many found they were ignored completely. Since 2021, Sibs has received an increasing number of queries from teaching staff recognising unmet need and wanting to improve support to sibling pupils.

Sibs was keen to hear directly from siblings about life in school now and launched a new survey in autumn 2023.

### **The survey**

In September 2023 Sibs released a survey for young siblings who are growing up with a disabled brother or sister aged 5-16, to find out more about how they experienced school.

This is the first survey of its kind in the UK and we are grateful to the over 200 young siblings who took the time to share their thoughts and insights into school life. The children and young people who responded also shared some important recommendations about the types of help that would be useful to them.

### **Sharing information with school staff**

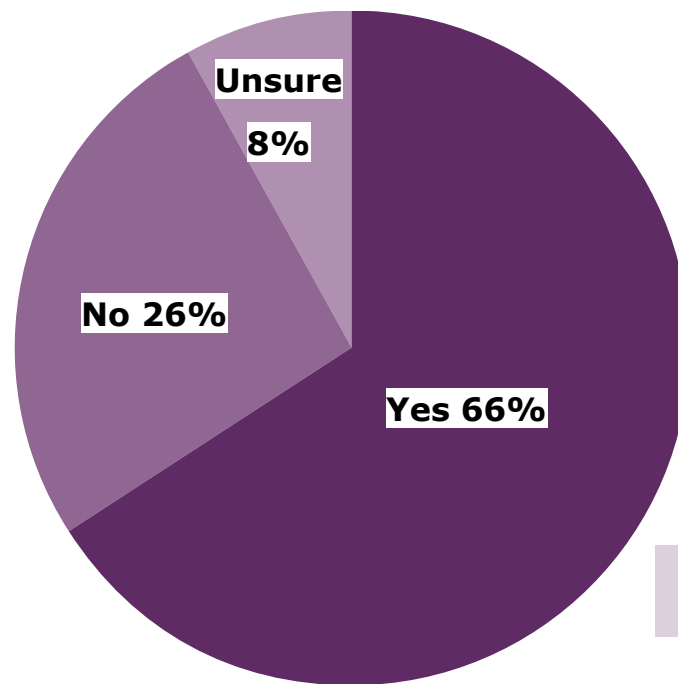
The survey asked children to tell us if they have told any school staff about their disabled brother or sister. The children reported mixed experiences, with some happy to talk about their sibling relationship with teachers, other children considering this to be a private matter, not for sharing.

Some siblings talked about the fact that their parents had shared this information with school but many also considered their brother or sister's feelings and the implications of information being shared.

Some talked about not really having the words to explain their brother or sister's disability to others, especially for those for whom there wasn't yet a diagnosis.

It was encouraging to see that 66% of children had felt able to talk to a teacher about their sibling experience, but this still means that over a quarter of children have been unable or unwilling to share this information.

"I just talk about my brother, not his autism"



"It's embarrassing"

"They know but no one ever says anything"

**33% of children reported that at least 5-6 teachers in school were aware of their sibling situation.**

#### Sibling feedback

"I sometimes need to go to hospital appointments with my brother as we live a long way from Great Ormond street hospital.

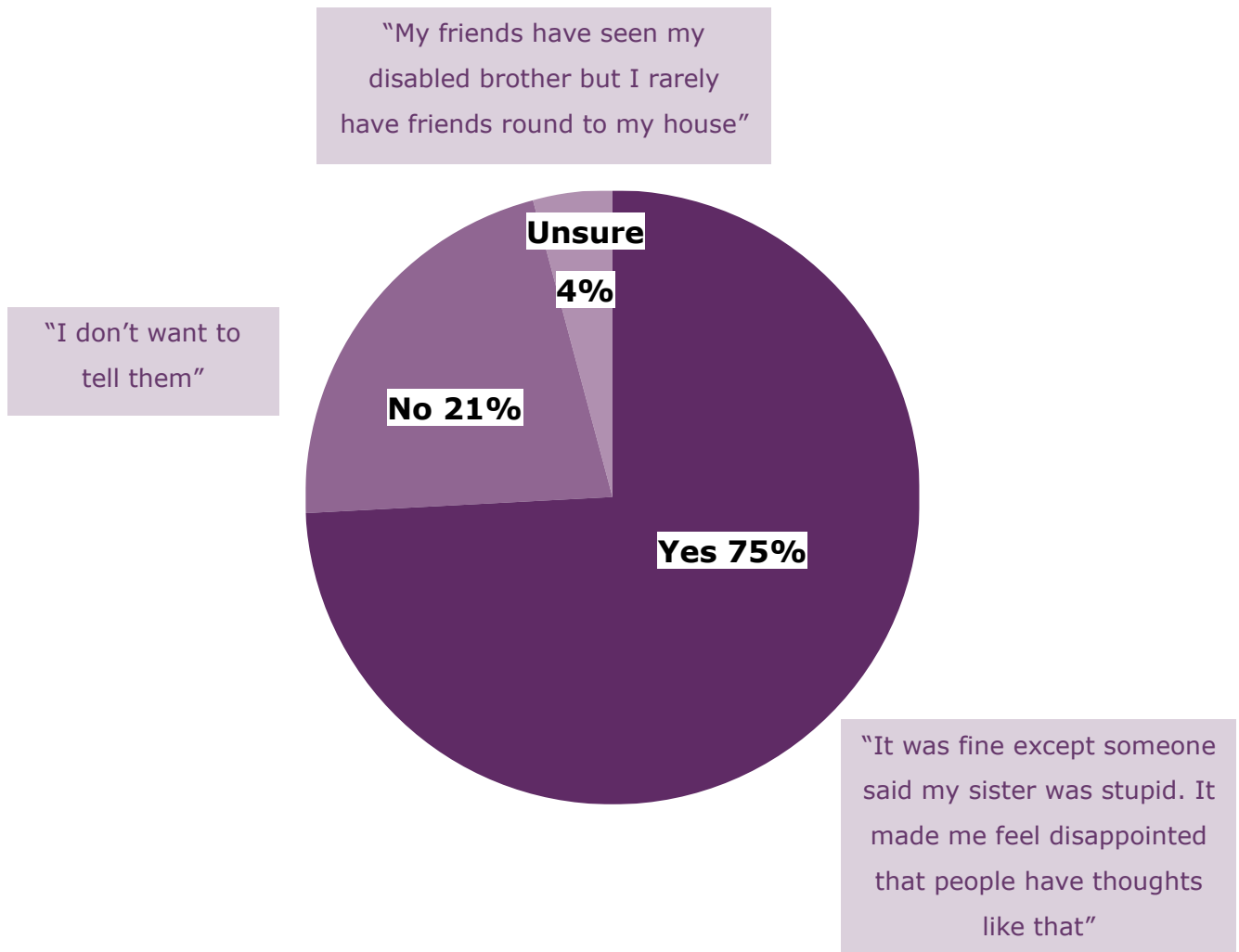
They are OK with this but have no consideration for how his needs affect me every day, not just for the hospital."

#### Sharing with friends

Three-quarters of all young siblings responding to the survey told us they had shared with a friend/s that their brother or sister was disabled. Some felt only comfortable telling close friends, and some had received negative comments from their peers which had changed their friendship groups.

Many talked about the impact on friendships both within school and outside – some siblings sharing the fact that they were unable to have friends over to play or to hang out at home because of a brother or sister's needs.

Some of their friends knew about their sibling situation because their brother or sister was also at the same school. A couple of respondents also told us that their friends had also become friends of their brother or sister.



**30% of children had 5-6 friends who knew about their sibling situation.**

#### Sibling feedback

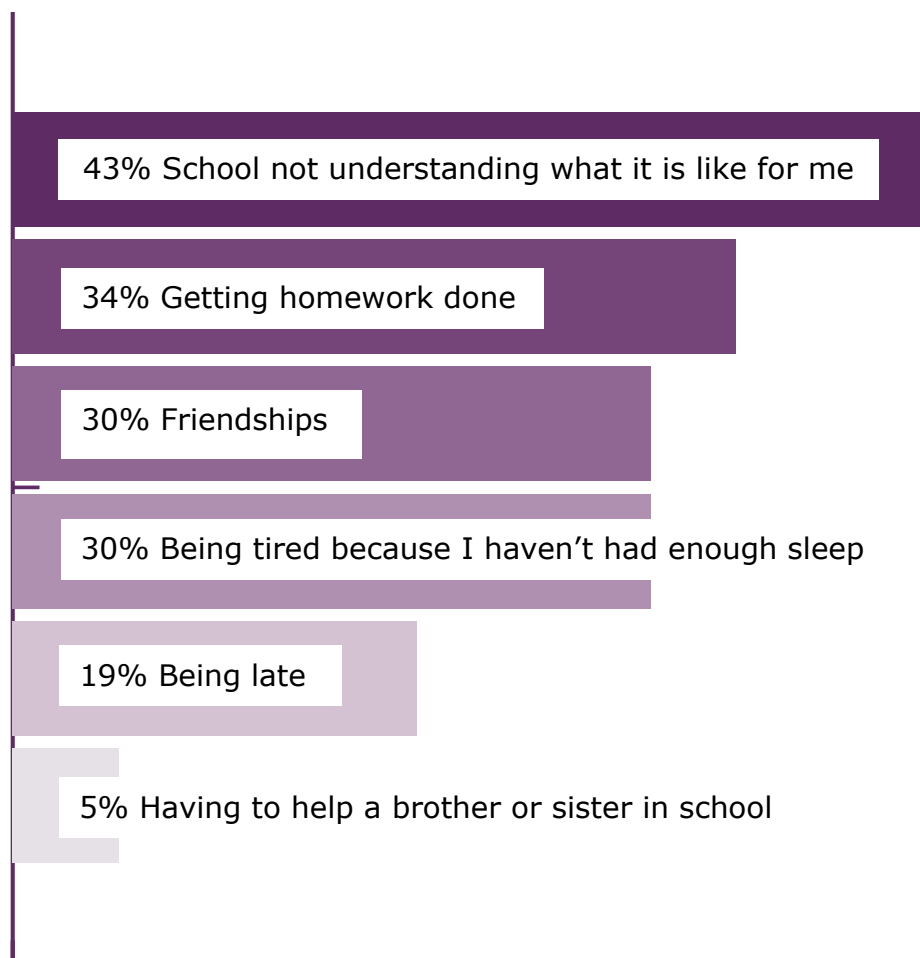
“A friend of a friend was spending lunch with us and was making rude jokes about children with Down Syndrome and I felt upset so I messaged my friend later saying what I thought about it and that I wasn’t happy hanging out with their friend anymore.”

## Sibling feedback

"My friends know because it means they can't come to our house as he can't cope with people he doesn't know. Some are good about it and some aren't friends anymore. I often have to cancel plans last minute because he has a seizure, some understand epilepsy doesn't come with a timetable and some just don't."

## What do you find hardest about school?

Siblings were given a range of options to tell us about some of the challenges during school. School understanding sibling issues, getting homework done, dealing with friendship issues and being tired ranked in the top 4.



Siblings also told us about some of the other things they found hard about life at school:

- Bullying/teasing/unkind comments
- Feeling embarrassed
- Finding it hard to concentrate at school
- Issues not related to siblinghood (such as curriculum)
- Being treated the same as everyone else
- Not meeting others who share the same experiences
- Concerns about parents and family
- Managing complex feelings (good and bad)

### Sibling feedback

“It’s hard to feel good at the start of school because it’s often difficult at home in the morning.”

“I ask my mum and sister to wait so I walk into academy first then they can go in after me. She will shout after me if we walk in together.”

“Hearing other kids talking about him and laughing.”

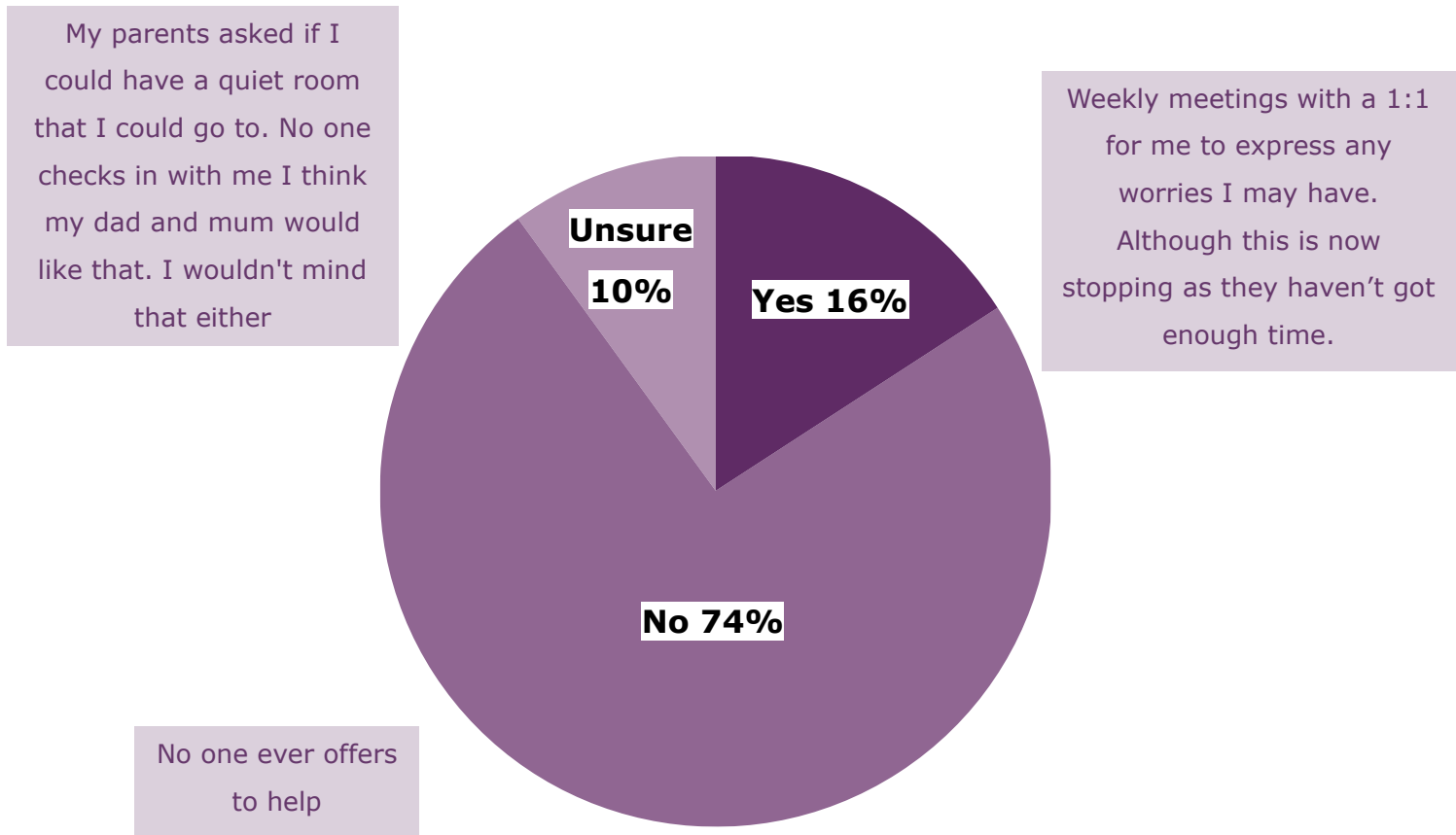
“My sister is autistic and she has sensory difficulties. She often has meltdowns and squeals, and people would give us nasty looks that make it even more difficult going in public places by putting us off. It would be amazing if people understand and accept others with additional needs. Not every disability is visible. And we are not aliens.”

### Do you get any help or support from school?

Disappointingly very few young siblings answered positively to the question about receiving help in school. Some children were being helped with excellent targeted support, such as through a sibling support group or young carer service.

Some children had a need acknowledged but little help on offer. Others mentioned that they knew there was help if they needed it but didn't currently access support.

Most children received no help at all. 10% of children were unsure if they had been offered help to support them as a sibling.



### What help would you like from school?

Most siblings responded to this question with a need for understanding, simple acknowledgements from school staff about their situation, a little leeway with homework tasks and some disability awareness training for their peers.

Some talked about wanting a support group or having someone to talk to if things got tough. They wanted quiet space and time-out if needed. They wanted their teachers to understand and to know that life at home was just really hard sometimes.

A few children talked about how difficult it was to ask for help and would like someone to ask them instead. This is crucial for siblings. If schools are proactive in identifying the right level of support for siblings at an early stage in their academic career, and asking the sibling how they would like the support delivered, this can go a long way to reduce the impact of stress on siblings in schools.

### **Sibling feedback**

"To be seen as me and not just my brother's sister."

"I really want to play with my own friends but I can't because I have to look after my brother."

"Someone to talk to if I need to."

"A small support group with time for me to have my thoughts and feelings listened to."

"Would maybe be good if my teachers approached me and asked if I needed any help as I find it hard to approach them."

"Some understanding. Someone to ask how I am today."

"Compassion, especially around homework, it's just not easy to plan when he has so many seizures every day. Sometimes I am about to leave the house and he has one, so I help my Mum, Sometimes this makes me late, but I get a detention for being late."

"Support to make friends because they don't understand my limitations on home life."

"To understand why I get tired and frustrated and how it affects my mood and ability to learn."

"Understanding about why sometimes I'm not fully switched on in class or when my minds on something. Someone to talk to about how I'm feeling. Time to just be me."



## Sibling feedback

“For school to help other children to understand about hidden disabilities and what it means to the children who have them and their families.”

“I would like some extra attention like my brother gets.”

## Conclusions

Policy and practice around the needs of siblings of disabled children to date have sat firmly within the disabled children and young carers’ agendas. However, the needs of siblings also need a place within the mainstream children’s agenda, especially education.

Not all siblings are young carers (or identified as such even if they are.) Many siblings do not provide care, yet still have fewer choices and opportunities than their peers and can experience problems with their wellbeing and education. Whilst every sibling has the potential to become a young carer during their childhood, care is just one of the many barriers to wellbeing and learning that siblings face.

Siblings provide incredible support, love and care to their families. But they are children too, with their own needs, lives and ambitions. What siblings are telling us they need from schools isn’t complex or costly. They want to be seen and they want sensitive support. Small adjustments and simple solutions can pave the way to better wellbeing for young people living in families facing some of the most complex challenges in the UK today.

## Recommended actions for schools

- 1. Find out who the siblings are in your setting.**
- 2. Ask a sibling how they are and see them for who they are,** not in relation to a brother or sister (or see them as a resource!)
- 3. Ensure that siblings are not taken out of class to support their brother or sister with SEND.** Let siblings know that they are not responsible for the care or support of their brothers and sisters at school.

4. **Provide opportunities for siblings to spend time with each other** as they can find it beneficial to socialise with other siblings who understand what life is like for them. Consider setting up a sibling group.
5. **Ensure that all teachers understand reasons why homework may be late**, school equipment not brought in, stressors at home or why siblings may be late to school, managing these scenarios in a discreet way.
6. **Ensure that you see the siblings for who they are**, not in relation to their brother or sister. Celebrate their strengths and skills.
7. **Use every opportunity to make the sibling a priority** especially as this may not be possible at home. Let siblings come first sometimes.
8. **Provide extracurricular opportunities within the school premises where possible** as parents may struggle to facilitate this in families with a disabled child/children.
9. **Designate a sibling champion** - Having a visible commitment to this group helps children to embrace difference, normalise their experiences and help them to thrive in school.
10. **Discreet support is important** siblings may dislike being marked out as different by teachers as this may be an issue more generally in their daily life.

**Clare Kassa, CEO Sibs Charity**

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## 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 information pages, where children can find information and get answers to their questions from Sibs staff. We provide email support and run a network of peer support groups for adult siblings.

Sibs also provides training and workshops for parents, professionals and adult siblings. For schools, Sibs delivers Sibs Talk, an intervention for primary aged siblings and Sibs Talk Lite are a free set of resources for use within primary and secondary schools.