

BROTHERS & SISTERS

WORDS: PAUL COCKBURN

These days the needs of disabled kids and their parents are at least recognised, if not always well supported. But what about their brothers and sisters?



Caitlin Bannatyne, from Dunbartonshire, is now coming to the end of her first year in Secondary School.

However, one of the last things she did while in Primary, according to mum Fiona, was to stand up in front of the whole school and give a talk about her younger brother Ry, and how his autism affects her life.

The talk was an eye-opener for many who heard it, and not just about the everyday realities of a condition like Autism. Caitlin reminded everyone about the people who are all-too-often overlooked in the general desire to support disabled children and their parents/carers – their non-disabled brothers and sisters.

At the time, Caitlin spoke of the siblings group she regularly attends, and why it's so important. Her mum Fiona has certainly seen the difference. "It's given her a lot more confidence meeting other kids who have had the same kind of family life as she's had," she told

Young and Able. "It's nice for them to be able to talk about it, instead of hiding it."

LOOKING TO THE SIBLINGS

Monica McCaffrey is the founder and director of Sibs, the national charity focused on 'enhancing the quality of life for the whole family' by supporting the child and teenage brothers and sisters of disabled people.

"Parents usually come to us when they are worried about a sibling," she told Young and Able magazine. "Maybe the relationship between the parent and the sibling has broken down, or the sibling's behaviour has changed – their work at school has deteriorated, or they're not getting on with their disabled brother or sister. Or the sibling really isn't understanding the nature of the disability and therefore isn't tolerant of something the disabled child is doing.

"We provide one to one phone sessions for parents so they know exactly how to help the sibling with a specific issue; for example, how to explain the disability," she added.

THE ISSUES

So how can a child's disability affect their siblings, particularly when they're also young children? "The major issue is siblings feeling they don't get the same amount of attention from their parents," said Monica. "Sometimes that's down to very practical reasons; maybe having to change a disabled child takes a longer time, or the parents are having to fight for particular educational support. A lot of a family's focus goes towards the disabled child.

There can be a huge sense of unfairness there for the sibling.

"We also find that a lot of children don't have a good understanding of the nature of their brother or sister's disability," she added. "Unfortunately, that can lead to a breakdown in the friendship between the sibling and the disabled child. For example, if a child has autism and pushes the sibling away, that's just the way they are, but the sibling can interpret that as 'my brother/sister hates me/doesn't like me'."

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Children, particularly when young, can also end up stressed by 'wrong' explanations about what's happening. "Siblings of very ill children sometimes think that they too will become very ill," Monica said. "Siblings need a clear, matter of fact, honest description of the condition; being able to talk about it helps rule out some of the misunderstandings and ultimately worries that the siblings might have."

ISOLATION AND GUILT

This can be vital. These days parents can generally talk about their worries with relatives, neighbours or support groups; the siblings of disabled children generally have nowhere to turn – not even at school, where teachers may well be unaware of the full extent of the situation at home. "Siblings can feel quite isolated and that's where our sibling groups come in," Monica explained. "Siblings say that the best things about going to a group is knowing that they are not the only one."

Another emotional factor is sibling's guilt when it comes to their thinking badly of their disabled brother or sister. "Guilt is not something that young siblings can always articulate," Monica said. "Jealousy in siblings of disabled children follows a similar pattern to typical sibling relationships, but can be more intense due to the disabled child getting more attention from parents. And siblings are very conscious of the fact that they are more privileged in some sense, being more mobile or healthy than their brother or sister."

Left unaddressed, such feelings can intensify as siblings get older and find it increasingly hard to ask for more attention from their parents because they can see the situation and recognise that there's not enough time to go around.

KEEPING THE PEACE

"One of the messages that we give to parents is to let siblings know that it's very healthy and it's very normal to ask parents for attention and to want to have time and attention from parents," Monica said. "It's also OK for them to complain about the things they're not happy about.

"One of the things we do with parents is to show them how to listen to siblings feelings," she said. "Parents can find this hard to do, especially when one child is complaining about another. However, children will often continue to complain when their feelings have not been acknowledged.

"When siblings have their feelings recognised and validated, it not only massively improves the relationship between the sibling and the parent, it also massively improves the relationship between the sibling and the disabled child. Being listened to is really, really important to siblings," Monica said. ●

TOP TIPS

According to Sibs, the key issues for the young siblings of disabled children are: the levels of attention they receive from parents; having a proper understanding the impact and consequences of an impairment or long-term health condition; and having "positive coping strategies" for the things they have to deal with – from people staring in public to not being able to travel together as a family on the same bus – that can be an everyday occurrence.

It's also important not to unnecessarily limit the sibling's activities. "One of the messages we have to get across to parents is that just because the disabled child can't do something, it doesn't mean the sibling shouldn't be able to do it."

At the same time, siblings really do want things they can do together as a whole family, and with their disabled brother or sister – so it's worth encouraging such things.

SIBLINGS GROUPS: HOW THEY WORK

"While we work for the benefit of the whole family, we find it better to work with the individual members," explained Monica McCaffrey. "When the parent is there, slightly older siblings tend not to say the things they really think, because they want to protect them.

"Siblings don't want their parents to hear that sometimes they hate their brother or sister, or are sometimes very angry at their parents about the level of attention that they give to their brother or sister. I think that's true of any child of a certain age in any setting.

Sibling groups organised through Sibs involve both recreational and discussion-based activities. "Siblings can share their experiences and, with a trained group facilitator 'running' the group, can come up with helpful strategies for coping with things like public prejudice, bullying, and worry," Monica added. "They can also share ideas for games to play with their disabled brothers and sister. Siblings feel a real sense of belonging when they attend a sibling group.