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Siblings of special needs children

Professionals agree that siblings of disabled children can suffer emotional, psychological and social impacts. But anecdotal evidence suggests it's not all negative, says Annie Makoff.

'Growing up, I really didn't think too much about her being different, because it was our whole life. She loved music, I loved music, we used to record things together,' broadcaster and radio DJ Jo Whiley recently told *The Guardian* about her relationship with her sister Frances who has Cri du Chat syndrome and severe learning disabilities.

London-based Carolyn Whitehorne describes her childhood with her autistic younger sister as 'a blast': 'We just got on really well,' she recalls. 'I used to look after her most evenings until my mum got home from work, but I didn't see it as a compromise, it was just part of being an older sister.'

And British actress and comedian Sally Phillips was initially worried about the impact Ollie, her son with Down Syndrome, would have on her middle child Luke. But after speaking to siblings of disabled children, she realised there were a lot of positives to the relationship too. Speaking recently to Radio 4, she said:

'I started obsessively collecting siblings of special needs children, but once I got to 10, I found they were unbelievably sorted people.'

Emotional effects

But according to Dr Janine Coates, senior lecturer in Psychology at Nottingham Trent University, research has shown that siblings of disabled children tend to experience higher levels of stress, loneliness and depression.

Monica McCaffrey, CEO of Sibs, the UK charity for siblings of disabled people, says: 'The siblings whom we are most concerned about are those whose brothers or sisters with SEND have behavioural problems,' she says. 'These are the siblings who are the most likely to have problems with wellbeing and progress at school.'

Karen Tait, senior lecturer at the Faculty of Education and Society at the University of Sunderland points to a number of issues which might arise for a family with a disabled child, such as: huge amounts of time and attention spent on the special needs child at the expense of the other children; disruption to siblings' lives and activities due to hospital appointments or health crises; witnessing the coming and going of various professionals; lack of quality time with parents; or frequent periods living with other family members. The sibling may also feel unable to bring friends to their home.

Academic effects

Academic support can also be an issue, with little or no support for homework or academic progress, because parents are so focused on their disabled child.

'Some young people may even feel guilty about their abilities and step back from the things at which they have excelled,' Tait adds.

As a result, the child may become 'quietly stressed' by retreating into themselves, or 'overtly stressed', adopting negative behaviours because they feel ignored or overlooked.

'For the non-SEN child, it can feel like treading porridge,' says Sophie Langley, parent of a SEN child. 'They may not get the focus they need as much of the parent's attention is directed at the other child.'

It's not surprising then that sibling rivalry may occur in some families, although Tait maintains it is dependent on the cognitive ability of both siblings. Some may compete for parental affection or academic achievements or even through attention-seeking behaviour.

Yet, it is often the stigma attached to the disability that can have the biggest impact on siblings. Behavioural disorders in particular are often attributed to bad parenting, particularly by the mother.

Tait recalls a family she once worked with where the non-disabled child wasn't invited to a party until he

was eight years old because he was 'the brother of the naughty child'.

Positive outcomes

However, living with someone with a disability can also be hugely empowering. Siblings may develop a much deeper understanding of others and it can have a positive impact on parenting styles.

'A lot of people I know have reflected upon their experiences with their disabled sibling and used that to influence their parenting,' Tait explains. Others might go on to have professional roles in the caring profession or put themselves forward for advocacy roles.

In Carolyn Whitehorne's case, her experience with her autistic sister made her emotionally resilient. 'I never wanted to be a burden to my mother as she had enough to think about, so I studied hard, got my first after-school job at 15 and developed a no-nonsense attitude to those who complain about silly things that don't matter,' she says.

Tips for parents

- Ensure the non-disabled child's school is aware of the situation. 'I once told the headmaster that he could have my two youngest at school on time but unwashed and unfed, or late but fed and washed,' parent Sophie Langley says.
- 'Seek out activities which siblings can do together whether that's clubs, playing games or day trips,' advises Carey Ann Dodah, Head of Curriculum at Explore Learning.
- 'Include siblings in family decisions as much as possible whilst devoting special time to the sibling so they can feel appreciated and loved,' says Coates.
- Karen Tait suggests taking a step back and evaluating the way the family is communicating with their children. 'How much time do we give each child? Am I recognising and valuing the able siblings when I can?'
- Allow siblings to articulate their worries and concerns
- 'Don't expect your mainstream child to make up for everything your SEN child cannot achieve,' says parent Emilie-Kate Kidd. 'Your SEN child will be progressing too and their progression is just as important.'
- Search for young carers organisations in your area – these often organise weekly clubs or holiday activities where the non-SEN children can enjoy treats and outings, and mix with other children in the same position.
- Seek advice if you are worried about a sibling - you can talk to an advisor at Sibs, a school counsellor, your GP, or a young carers' worker.

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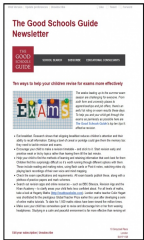
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