

# The Saturday Paper

## The pressures of living with sick or disabled siblings



Even in his early years Noah knew, instinctively, that the rough way his brother handled him was unacceptable. By age four, he'd copped enough of Levi's random slaps and hugs that were so tight he could barely breathe. Noah decided to take action. "He just picked up a knife and waved it at Levi, which shocked us all, including his brother," recalls the boys' mother, Elizabeth.

Now a teenager, Noah is one of many Australians whose lives have been complicated by having brothers or sisters with chronic health conditions. As with Levi, who is autistic, this often involves physical and intellectual disabilities. Not all of these siblings experience violence, but many carry the psychological scars of a complicated relationship well into adulthood.

A recent government-funded national survey by Siblings Australia mapping support services for people like Noah and his family highlighted what child psychiatrist Dr Jon Jureidini calls "an appalling lack of acknowledgement and support".

Jureidini, who is attached to the University of Adelaide, said this type of sibling relationship involved many pressures that other children did not experience. "The siblings have to constantly alter their behaviour to accommodate the needs of the other child, while at the same time feeling the other child gets all the attention," he says. "Part of the problem is that their potential distress often goes unrecognised."

Help us make 7am. Become a supporter. Jureidini says while Noah's reaction is unusual and not a recommended strategy, "it speaks to the intensity of the experience of that child".

"I certainly see children who have been assaulted by their disabled sibling," he says. "If inappropriate violence is well managed – and certainly not involving police action – it can have minimal effect [on the victim]. But it can also have a very destructive effect if the violence is persistent and particularly if it's not recognised as a significant problem."

Kate Strohm, the founder of Siblings Australia, says while she does not want to demonise children with certain conditions who struggle to control behaviour or aggression, there is a need to at least acknowledge the existence of this type of hidden violence.

"I kept hearing stories from parents and professionals in workshops I was running about siblings being harmed, which was upsetting, so I decided to survey parents, providers and siblings," Strohm says.

The 2012 research involved 186 participants who spoke about aggression that ranged from overzealous play that might cause some level of harm, to serious injury caused by stabbing with scissors, biting, punching and choking.

On family response, the report says: "Resulting actions by families were also varied, including: parents locking siblings in their room (sometimes overnight), siblings locking themselves in their bedrooms, or parents locking the child with disability in a room. Siblings may be afraid to be left alone with the child with disability."

"The paper highlighted a huge problem and I think it's very much a child-protection issue, not only in terms of the physical impact but also the emotional toll," says Strohm. "I don't want to add to the stigma of disability because not every child is violent, and if they are it's often behaviour they can't control ... But on the other hand we need to be thinking of these children in the domestic violence conversation because it's not always partner and partner."

Strohm stresses violence is only one of the pressures that siblings can encounter but it and other issues could be minimised with a better support network, starting with education for families. "One parent I spoke to told me she'd been trying to talk to her daughter for years to find out if anything was wrong," she says. "One day she approached the subject differently by saying, 'It must be difficult being the sister of a child with a disability', and her daughter burst into tears and it all came out."

Strohm, a former hospital scientist and counsellor from Somerton Park in Adelaide, grew up with an older sister, Helen, who had a severe form of cerebral palsy. The condition left Helen with paralysis down one side, an inability to speak and mild intellectual disability. While the sisters had a loving relationship with no violence, Strohm says that from an early age she began bottling up a mix of conflicting emotions. Like Noah, she rebelled, but in a different way.

"When I was four I stopped dressing myself and one day blurted out to my mother, 'Well you dress her, so you can dress me,'" she says.

Childish resentment soon gave way to sadness at seeing her sister struggle to communicate, guilt at enjoying a normal life and anger towards the people who would stop and stare at Helen during family outings. "I didn't understand my emotions and because as a family we didn't talk about feelings, it was easy to internalise those feelings and feel bad for even having them," she says.

Well into her 30s Strohm suffered from severe anxiety, until she found a psychiatrist who got to the root of her problem and offered her strategies to manage it. In 1999, she founded Siblings Australia to give both children and adult siblings in this situation a voice.

“In adulthood, one scenario is for the sibling who has had enough to cut off from the family. Or the other extreme is where their life is sacrificed to look after their sister or brother when parents can no longer do it,” says Strohm. “Neither is ideal. When you think that a sibling relationship is likely to be the longest one you’ll have in a lifetime, both should be given the opportunity to reach their full potential.”

Siblings Australia, she says, has battled for many years through written submissions, reports and direct meetings to have siblings recognised in government policy, but without success.

“We know this problem affects hundreds of thousands of siblings throughout Australia, but only by deduction from figures on chronic conditions, because as far as government is concerned siblings do not exist as a health issue,” says Strohm.

Noah’s mother, Elizabeth, says the best thing she ever did for her younger son was to find a peer group where he could share his feelings with children who understood.

“Noah always wanted a relationship with his brother, but it has always been very one-sided because autism and the associated high anxiety Levi experiences impacts on his ability to accommodate other people’s interests and feelings,” says Elizabeth. “And Levi doesn’t have a good sense of where his body ends and the other person’s starts. He is also a sensory seeker, so he would go around and smack you on the back of the head or your bottom and Noah would react.

“The conflict between them meant I couldn’t take them out together when they were younger, so Noah missed out on a lot of experiences that Levi had before he arrived.”

Elizabeth is well aware of Noah’s plight but says she is stretched to the limit looking after the pair as a working single mother. “I have tried giving Noah the chance to talk about his feelings, but it’s usually at a time of crisis when I need at least one of them not to have an issue.”

She says there is virtually nothing in terms of specific services for families in this situation.

“There is no counselling for parents and now with the NDIS [National Disability Insurance Scheme] it’s even worse because it will not recognise the impact on siblings. I was fortunate on one of Levi’s NDIS plans to get some financial support for Noah, but then I couldn’t find any services to help him, so it was pointless.”

Elizabeth seems resigned to the fact that life is going to be tumultuous for both herself and her boys. “Everybody in this situation seems to get sacrificed at some point,” she says.

A Department of Social Services spokesperson gave the following written reply when asked if the department provides any specific siblings support: “The NDIS provides support to Australians who have a permanent and significant disability ... Each NDIS participant gets a tailored plan with funding for reasonable and necessary supports to help them live an ordinary life.”

**This article was first published in the print edition of The Saturday Paper on Jul 14, 2018 as "A kin to violence".**