



Kate Strohm, director of Siblings Australia, with Rachel Organ who has a brother with Asperger syndrome. Picture: Mark Brake

SA Lifestyle

He ain't heavy, he's my brother

Sarah Hender, SA Weekend

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RACHEL Organ was a five-year-old on a family shopping trip when she noticed something different about her brother. While she played with teddy bears in the toy department, 10-year-old Chris (not his real name) was with the vacuum cleaners, pulling them apart to see how they worked.

"He got a remote control car for his birthday. I think I saw it running twice," she says. "He was too busy pulling it apart!"

At six, Chris was diagnosed with Asperger syndrome, an autism spectrum disorder characterised by difficulties with social, emotional and communication skills. And, often, high intelligence.

So it was with Chris. But despite an IQ of 164, he didn't make it past Year 10.

"People with Asperger's struggle socially, so school was difficult," says Rachel, now 22. "It's like putting a fish in a fish bowl with no water. As good as he was at swimming, he couldn't swim."

But this isn't a story about Chris; it's about Rachel and other siblings of people with a disability. Although she loved her brother and found his approach to life fascinating, his struggles meant he was unpredictable. That made life challenging for their parents – but it also weighed heavily on Rachel.

She's far from alone.

In South Australia, there are about 50,000 people with a severe and profound disability under the age of 65 (excluding those disabled because of ageing) based on 2015 Australian Bureau of Statistics figures.

Given that most of those people would have, on average, at least one sibling, there's clearly a much broader impact of disability on ordinary families. It may be autism, or Down syndrome, multiple sclerosis, or a range of other conditions, but from a young age siblings of those with the disability must learn to cope with challenges their friends can barely comprehend.

In Chris's case, because his disability was mostly hidden, it was more difficult for people to understand, and support was hard to find. Labelled the naughty child at school, he'd only do what he wanted to do. It was the same in his relationships; only engaging with people if they shared his interest.

As well, he'd get angry, letting fly about things the rest of us might find mildly annoying. At home, these outbursts often resulted in violence. Most of the time, it was Rachel who had to call the police, while her parents restrained her brother.

"I distinctly remember Rachel sitting on the ground, her knees pulled up to her chest and her arms wrapped around them. I saw how badly it was affecting her," her mother Julie recalls.

Knowing her parents were busy with Chris, Rachel learnt to be independent early. "I always felt I wasn't as important as Chris. I still felt valued but any dilemma that Chris had was more important than one of mine and I knew that early on," she says now.

"I thought that was fair enough. Even if it wasn't as important, if Chris felt it was, it had to be dealt with first."

But when Rachel hit high school, and girlfriends and boyfriends arrived on the scene, Chris's outbursts increased with all the extra people in the house. Not coping with life at home, and not finding support at school, Rachel stopped attending halfway through her final year. She'd gone from being an A student to Ds and Es. But, relying on her best friend to send home assignments, she managed to pass Year 12 anyway.

Even though Rachel knew that Chris's violent outbursts were not his fault, she was angry with her brother. She felt she had been robbed of her childhood. Before she could forgive Chris, she had to understand him. Rachel took the first step by choosing Asperger syndrome as the topic for her Year 12 research project. "I was so upset, I felt that it would help me if I could understand him better," Rachel says.

The need to process mixed feelings is common to many people who have grown up with a sibling who has a disability.

Kate Strohm, director of Siblings Australia, grew up with an older sister, Helen, now deceased, who had both an intellectual disability and cerebral palsy.

"Like many siblings, I squashed a lot of the feelings I had, partly not to add to my parents' stress but also because I felt guilty. It's difficult when you have the normal sibling feelings of annoyance or even anger towards this person who can't do the things you can do. You feel such grief for what they go through," Kate says.

Although the sisters were close, it was a different sibling relationship. Kate's sister had communication difficulties, along with intellectual disability, so they could never have a proper conversation. There was no talking about boys or shopping together and, when out and about, people would stop and stare. It was hard for a young child to understand and cope.

LATER in life, Kate wrote a book about her experience, *Siblings: Brothers and Sisters of Children with Disability*, to help understand her own feelings but also to raise awareness to support others in a similar situation. Having seen how little support there was for siblings through her own experiences, she set up Siblings Australia, a national organisation based in Adelaide. It provides support, connection and information to siblings of people with disabilities, and to their parents and professionals to better understand sibling support needs.

To help overcome feelings of isolation, Siblings Australia provides a private online forum, Sibchat, for siblings to connect with each other and share their common experience.

Of course, not all siblings have a difficult time – there is a spectrum of experience out there. Some siblings have taken mainly positive things from their experience and feel that their lives were enriched.

Port Adelaide footballer, Jack Hombsch is one of them. Jack, 23, the oldest of four children, has a younger brother Todd, 19, with Down syndrome, a genetic disorder causing intellectual disability.

Jack only has happy memories of their childhood growing up with Todd in Roxby Downs. He puts this down to growing up in a small rural town surrounded by the support of their extended family, friends and the local school, all of whom knew Todd and were aware of his differences.

Todd was also an easy-going happy boy; there were no difficult tantrums or a lack of co-operation. With Jack's friends growing up with Todd, too, Jack didn't feel that isolation that other siblings might feel growing up with a disabled brother.

"I wouldn't change it for the world," Jack says. "We are very lucky. Todd is happy. I couldn't imagine Todd as a classic normal brother. My brother Nick and I talk about this a lot. Life wouldn't be as funny; he brings us a lot of joy."

"Probably the biggest impact on me was that it has given me a bit of empathy and awareness about others."

Jack is using his insight to help others in his voluntary work. He is an Ambassador for Inclusive Sport SA, an organisation that creates an inclusive environment for people with disabilities to be part of amateur sporting clubs. Todd plays for one of the football teams and last season Jack helped with their training and presented awards at the grand final.

Jack is also an Ambassador to Bedford Industries, a company which provides work opportunities for disabled people. He attends Bedford's work sites and chats to those workers who are football supporters.

"It just breaks up their day a bit," Jack says. "It's nice, because while I do have a bit of a profile you can do a little bit with it. When I finish footy that profile goes and you can't do it any more."

THERE are long-established support programs for people with special needs and their parents, as there should be, but there is limited support for the sibling, the person who is likely to have the longest personal relationship with the disabled person than any other.

Some, like Jack, have a positive experience, but many others do not.

For them, Siblings Australia is the only dedicated organisation nationwide. It has an international reputation, but is mainly operating in a voluntary capacity. With funding cuts over the years, Kate is concerned for the future of the organisation with so little government funding available.

Yet as Rachel Organ found, it helped her by lessening her feeling of isolation.

One of the problems that she had growing up was feeling unable to open up with other people about her problems.

"Not knowing how to talk to people without them changing their perspective about Chris is an issue I've faced my whole life," Rachel says.

"Chris is a brilliant guy and a loyal friend who would do anything for anybody and his behaviours were not his fault but getting people to understand without judging him was impossible."

Rachel only discovered Sibchat six months ago when she was told about it by her university tutor. It was a relief when she could ask others in the same situation about how they went about talking to people who might not necessarily understand.

"It's a really complicated issue and everybody had really different ideas and examples they could give me. It's brilliant to bounce things off people who know what it's like and to have that conversation that you've been dying to have all your life."

Rachel is working hard to turn her difficult experiences into a positive.

The year following her horror Year 12 she recovered. She started a science degree but threw it in after three weeks and went to work instead. During that same year, she enrolled in a double degree of a Bachelor of Education (Primary) and Disability Studies. She also began volunteering with the not-for-profit organisation, Time for Kids, that provides mentoring and support to disadvantaged children throughout South Australia.

Having always wanted her own big sister, she decided to be one herself and mentors a young girl who also has a brother with Asperger syndrome.

They spend a day together every fortnight and keep in touch in between.

"It's important for me to see her doing well," Rachel says. "Our experiences were similar, and I know she feels lonely. I feel like I owe her something, I felt like somebody owed me something. Now I can give that to her so that's good."

Rachel also regularly assists on camping trips with Down syndrome children.

She is now three years into her university studies and has been accepted into the Golden Key Society for High Achievers at university. Her vision is to make change, not just for one classroom but for many. That means going as far as she can with her education studies.

Rachel has not only seen her brother fall through the cracks of the education system but, for different reasons, she nearly did herself. She knows the difference it can make when a teacher takes the time to understand their students. Recalling one of her primary school teachers, Rachel says: "She knew about Chris and my family situation. I remember arriving all stressed in her classroom and within five minutes, the stress had disappeared."

"She called everyone her precious kids and made us all feel very valued. I remember thinking that if Chris had a teacher like mine, things would be different."

ALTHOUGH siblings of people with disabilities share a unifying experience, it can be very different depending upon the disability and the support available. Support can be the defining difference between a family thriving or buckling under the pressure.

These days Rachel and Chris are mates. Chris sends her funny texts every day. He gives his opinion on most aspects of her life, friends, teaching, even dental treatment she is having.

"When he found out I was having my wisdom teeth out, he sent me a flurry of videos on what could go wrong. I won't make that mistake again!" Rachel laughs.

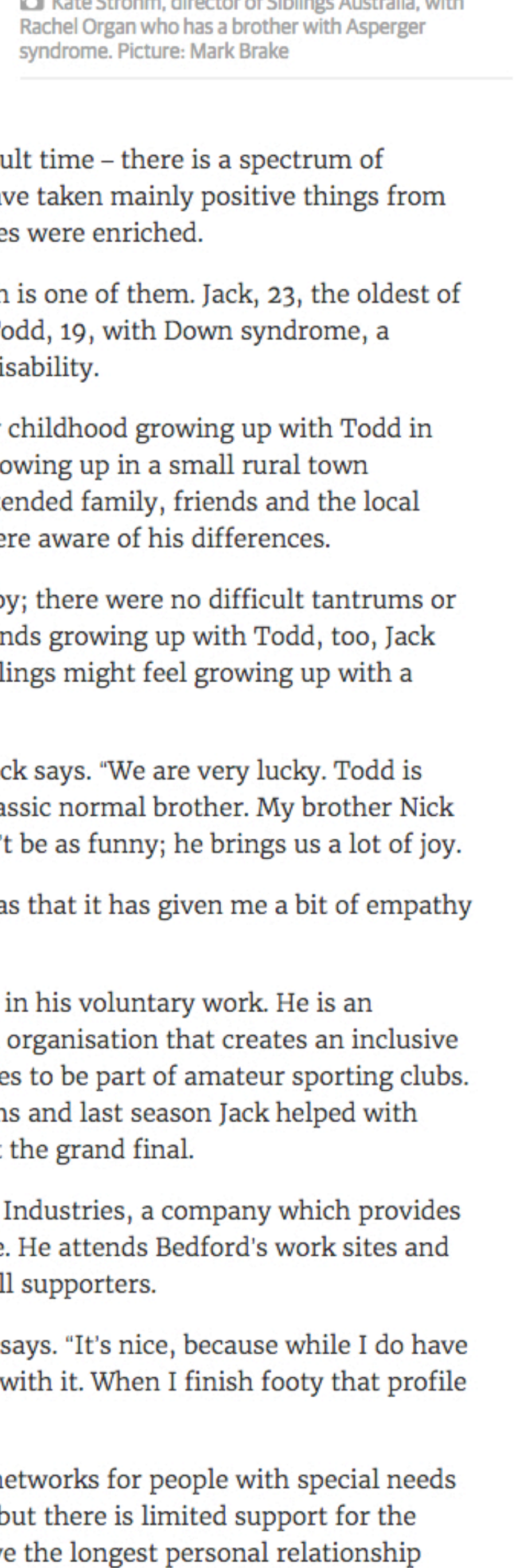
Rachel sees Chris as a blessing.

"There were so many struggles. At the time it was terrifying but I'd go through it all again to end up the way I am now," she says.

"I wouldn't be volunteering or doing my teaching and I probably wouldn't be wanting to make change. Wanting to make change is awesome."

SIBLINGS AUSTRALIA helps siblings of people with chronic conditions by increasing awareness, understanding, skills and capabilities including: giving direct support to adult siblings (helping siblings navigate the NDIS and developing peer support networks); working with parents and professionals who are, in turn, able to better support siblings; and research and advocacy for siblings. Interactive workshops are available for: professional service providers in children's services, disability, health and education and parents, to assist them in supporting their children.

siblingsaustralia.org.au



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Port Adelaide defender Jack Hombsch, 23, with brother Todd, 19. Picture: Matt Turner