

NEW ZEALAND / IN DEPTH

# NZ study finds parents of children with autism have lower quality of life

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*This story discusses suicide and family harm.*



Photo: 123RF

Parents raising children with autism have significantly lower physical health and mental wellbeing than other parents, a new study has found.

The study's lead researcher said a lack of awareness about Autism Spectrum Disorder (ASD) and a lack of support for children and their parents were the main causes.

Daniel Shepherd, an associate professor at Auckland University of Technology, said some of the stories parents shared with researchers were "heartbreaking".

"We do get things like, 'I have thought about killing myself and my child'. A lot of participants lament that the child's autism has actually broken up the family because other family members don't know how to relate or accept autism.

"That doesn't mean parents don't love their children, because they certainly do, but there is certainly the challenge there that's not associated with raising a child that doesn't have autism."

The study, **recently published** in the journal *Research in Developmental Disabilities* is the first of its kind in New Zealand and among only a handful of similar studies globally.

It surveyed the stress levels and health-related quality of life of more than 470 parents of children with autism and found a substantial number reported lower quality of life scores than the general population.

The study found factors such as gender and number of siblings, and parental factors such as gender, age, education and relationship status, did not significantly affect quality of life.

This indicated the challenges of raising a child with ASD were universal and affected parents irrespective of their personal circumstances.

Shepherd said many parents worried about their child's future, and had to cope with the social stigma of having a child with autism because people did not often understand the condition.

"So just that awareness that an autistic child is not the same as a normal child and sometimes their behaviour is not simply reflecting bad parental practices."

Shepherd, who is himself a parent of a child with autism, said the results were not surprising but the research showed the importance of having an holistic approach to supporting children and their parents, especially as the prevalence of the condition was now around one percent of the population.

More cohesion between government agencies, such as health and education, would help ensure children and parents were getting the support they needed, he said.

"Parenting stress and the consequences of low psychological wellbeing influence the wellbeing and behaviour of the child, while the wellbeing and behaviour of the child influences parenting stress and parent wellbeing.

"Hence, in the best interests of the child it's useful to have a two-pronged support strategy, one for the parent and one for the child."

Shepherd said the UK's Autism Act 2009, which created a clear pathway for diagnosis and improved access to services and supports, was a model New Zealand could draw on to ensure services were all joined up.

Autism New Zealand chief executive, Dane Dougan, agreed there was not enough support in place for autistic children and their families, nor awareness of the condition, which led to stressful situations.

"It's not the child themselves [that is the problem], it's the environment around them and the lack of awareness from the general public," Dougan said.

"A conjoined approach would make a huge difference. If we can identify these children as early as we can and then provide better early support for these families, a lot of these kids will go on to live the life they want to live."

Autism New Zealand was advocating for greater awareness of the condition across several government agencies, including health, education, social development and justice.

"We are starting to get some good traction. And this could be a model that could be really helpful for other conditions, such as ADHD or other neurological conditions where currently you don't really know where to go or who to talk to.

"If we can support these families early it creates a whole different mindset."

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**Suicide Crisis Helpline:** 0508 828 865 / 0508 TAUTOKO (24/7). This is a service for people who may be thinking about suicide, or those who are concerned about family or friends.

**Depression Helpline:** 0800 111 757 (24/7) or text 4202

**Samaritans:** 0800 726 666 (24/7)

**Youthline:** 0800 376 633 (24/7) or free text 234 or email talk@youthline.co.nz

**What's Up:** free counselling for 5 to 19 years old, online chat 11am-10.30pm 7days/week or free phone 0800 WHATSUP / 0800 9428 787 11am-11pm **Asian Family Services:** 0800 862 342 Monday to Friday 9am to 8pm or text 832 Monday to Friday 9am - 5pm. Languages spoken: Mandarin, Cantonese, Korean, Vietnamese, Thai, Japanese, Hindi, Gujarati, Marathi and English.

**Acorn Charitable Trust:** 09 281 4857. This organisation offers support for children with neurodivergency and their families.

**Rural Support Trust Helpline:** 0800 787 254

Healthline: 0800 611 116

Rainbow Youth: (09) 376 4155

OUTLine: 0800 688 5463 (6pm-9pm)

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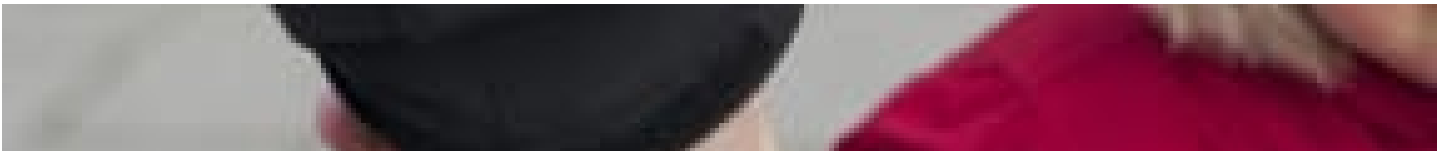
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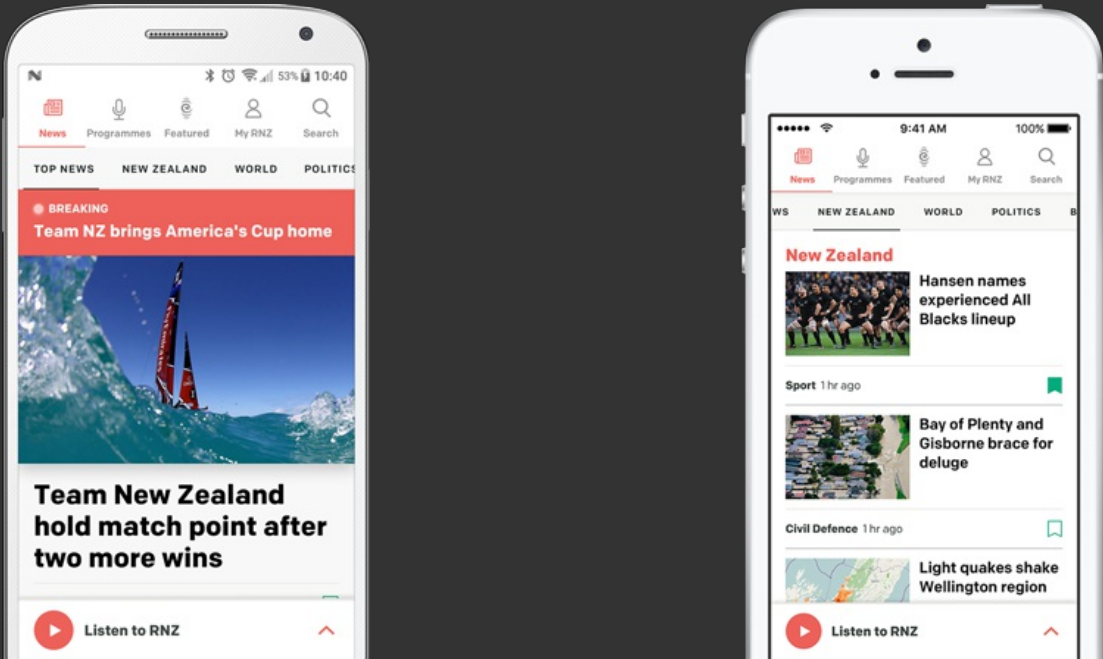


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