In April last year Maria Claudia Lutz shared a news story about a missing 11-year-old boy from Victoria among her 467 friends on Facebook:

“An autistic boy missing since Friday! It is my worse nightmare!” wrote the 43-year-old mother from the leafy Sydney suburb of Davidson.

It was a small peek through the curtain into the private world of raising children with disabilities, a never-ending, exhausting and all-encompassing reality for many thousands of Australian families.

The case of Lutz, who, along with husband Fernando Manrique, 44, and their two children, Elisa, 11 and Martin, 10, was found dead after an apparent poisoning murder-suicide, has
thrown the spotlight on caring for children with disabilities.

“There will be parents all around Australia looking at that story thinking ‘there but for the grace of God … because that’s my reality, I’m living that every day’,” says Autism Awareness Australia chief executive Nicole Rogerson.

“And there’s probably a lot of those people saying — but I don’t kill my children!”

While the rollout of the National Disability Insurance Scheme (a new funding system from the federal government) is improving the lives of many people dealing with severe disabilities, money is not the only issue, say advocates.

In the case of the Davidson family, relatives in their homeland of Colombia reveal the well-loved mum was planning a divorce and hoped to return home to find more family help for her children.

And her friends in Sydney, where she was highly regarded for her volunteer work at the special school St Lucy’s at Wahroonga, say she’d just recently finished a teaching degree and was in good spirits after meeting officials from the disability scheme.

“She’d had a meeting with the NDIS and she was so excited she was going to be getting all this help,” friend Peta Rostirola said.

“She even felt guilty for taking that, she was just the most selfless person.”

Acting school principal Warren Hopley sums up the feelings of many by saying: “No one was better known or more loved at St Lucy’s than Maria.

“I don’t think she slept for many hours of the night because of the difficulties.”

Rogerson, whose 20-year-old son has autism, says it is a “tragic irony” that the family was on the verge of getting help.

“The fact that the mum was clued up to the NDIS and help was potentially coming even makes it more tragic,” she said.
“Even the fact they were in a rollout zone — being in North Sydney, help was literally around the corner.

“Help was on its way. For whatever reason, and you don’t know all of them, it certainly adds to the tragedy.”

But Rogerson says many in the autism community were “up in arms” this week because of the rush to judgment that caring for disabled children might have pushed one or both parents over the edge.

“When these sorts of things have happened, before people would say ‘Are they in financial difficulty?’

“Or ‘was there some kind of relationship pressure?’ — but everyone just immediately went to autism.

“While a story like this can highlight the very real stresses families who have to parent multiple children with severe autism can undertake every day, 24 hours, seven days a week, we cannot let that discussion cloud the fact that this is murder and this is domestic violence.

“It’s not OK for any individual, whether a mother or father, to murder their children. Autism should not be an excuse for that.”

The Australian Bureau of Statistics estimates 115,400 Australians, or 0.5 per cent of the population, has an autism disorder, defined by problems in communicating and restricted and repetitive interests and behaviours.

The figures have jumped by 79 per cent since 2009, when 64,400 people were diagnosed.

But, according to Autism Spectrum Association chief executive Adrian Ford, it’s a case of better recognition and effective diagnosis. He says the condition is now recognised at a rate of one in 100 Australians.
“In the past, people now in their 70s might have been treated as nerds or scapegoats,” Ford said.

“There’s been tremendous strides made. Now we understand early intervention, and especially preparing children to go to a mainstream school, can make a difference.”

For families caring with children with severe autism, it’s like “living with a newborn baby”, says Rogerson.

“For families like this, oftentimes they can’t access the community outings the rest of us do, going out to a restaurant or the park or the beach. And particularly when there’s multiple children.”

In decades past disabled children were institutionalised, but in recent times parents have been left carrying the burden on their own.

“Now we have made ourselves feel better as a society,” Rogerson said.
“We don’t institutionalise kids any more. But guess what? We’ve handed the job to mum and dad.

“We didn’t give them any resources, but it made us feel better to have them in the community.

“For a lot of families the stress is just relentless. It could never be an excuse for what has happened to this family, but it raises the question of how people are supported.”

NDIS officials have been surprised to find 25 per cent of all participants in the scheme are on the autism spectrum.

The other forgotten part of the pressure burden on families with disabled children is the fear about how their offspring will cope as adults, find work and survive when the parents are no longer around.

“We need to have a conversation, it’s not just about throwing money at it. It’s a serious conversation about how we have meaningful support,” Rogerson said.

“Not just babysitting these kids for the rest of their life, but what helps them reach a truly meaningful life.”