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Tasmanian, John Coyle, said when the National Disability Insurance Scheme (NDIS) arrived it was like taking the lid off a pressure cooker.

“I have three children. Bridget is my eldest. She’s 22, and she has a chromosomal deletion (Monosomy 1p36 syndrome) which has a global effect on her development.

“Then I have Riley. He is 20, and he has moderate to severe Autism and requires quite different care and support to Bridget, and then there’s Fianna who is 18 and although she is the youngest in age she is the eldest developmentally,” he said.

11 years ago, John’s wife died of breast cancer, after a six-year battle, which was extremely difficult on the entire family.

“While I was caring for my wife, we were desperate for respite but we just couldn’t get a reliable, consistent provision and we were on a waiting list for an ISP (state based Individual Support Package) for about six years,” he said.

“We had ad hoc supports but it wasn’t until years after my wife died I got any sort of regular, appropriate support.”

John said with all the talk about the NDIS being introduced he was like a “little kid” in the back seat of a car, saying “Are we there yet? Are we there yet?”

“I kept punching away because I had a strong vested interest,” he said. “I had two children who will need support for the rest of their lives, and I was crumbling in a heap under the sheer 24-hour, seven-day-a-week, 365-day, pressure of managing it all.

“My daughter, Fianna, who doesn’t have a disability, was struggling too. She felt violated with complete strangers coming into our home early, from Monday to Friday, to help me support her siblings, so she hibernated in her room. She felt exposed to the world.”

John said it wasn’t until the NDIS came along life got better for his family and future projections became more positive.

“Suddenly the pressure levels dropped and I was able to get funding for Bridget to be supported in accommodation just up the road. She comes home on most weekends but it’s changed our household dynamics.

“Now, I’m Riley’s full-time carer and I’ve been able to relinquish my morning support, which has really helped Fianna. She has been able to reclaim her home, and if we do hire someone, it is the same person who comes in. We get to choose them, which means Fianna can get to

know them.

“The providers we’ve been able to choose have been wonderful too!” John said. “They have provided innovative programs and tailored them to suit Bridget and Riley’s needs.

“Bridget is now learning to cook; she does numeracy and literacy, some typing and she’s been able to enhance her computer skills, overall, improving her life skills.

“Riley is also now enjoying regular learning outside of the Education system from an established, experienced disability support provider. He gets taught basic life skills; he’s enhancing his computer skills and he has shown social development and he is enjoying his love of drawing plus lots of craft activities and community access.

“It’s not really until now I’ve actually seen Riley make some relevant social statements, like a sentence that makes sense in the context of what he is doing, and I attribute it to the repetition and consistency of the support plans implemented by his providers. They too are learning and adapting to the new way of doing things.

“As a parent, it has been hard to learn to trust alternative sources of support, especially when your children are extremely vulnerable, but being part of the NDIS and having that choice and control has definitely helped to make those decisions easier, and I am certainly more confident about the future long-term care and support of my very vulnerable children.” John said.

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