

THE SATURDAY PAPER

NEWS

New figures reveal the human toll of a five-year NDIS funding fight, with hundreds of families pushed to relinquish their children into state care. By *Rick Morton*.

Exclusive: 500 children forfeited to state in NDIS standoff



For the past five years, the National Disability Insurance Agency has squabbled with state governments over who pays to support children with a profound disability. In that time, hundreds of families have been pushed to the brink. The care they were promised never came.

The National Disability Insurance Scheme was intended to provide clearer support to people living with disabilities, but its poor implementation has led to an increase in the number of children forfeited into state care. *The Saturday Paper* can reveal that at least 500 children were relinquished by their families during this period. Essentially, they were given up to institutions by parents who could no longer cope.

These figures show that the scale of trauma and distress created by the NDIS rollout is far beyond what has been previously reported. It likely remains a conservative estimate, given how closely this data is held, and in some cases hidden, by state governments.

In recent weeks, a new agreement struck between the NDIA and state and territory governments has come into force, which more clearly defines who has financial responsibility across disability support, housing and child protection.

Advocates hope it will mean, in practice, a change for the better. But given the issues that have plagued the NDIS since its inception, few are holding their breath. An NDIA spokeswoman has already hinted the agreements may

mean little for some children already given up by their families, especially in Western Australia, where parents can lose the right to make decisions about their sons and daughters even under “voluntary” arrangements.

The spokeswoman said the new memoranda only “cover circumstances where the parents are still engaged with their child and have not relinquished their guardianship role”.

Long before the NDIS, families struggled to care for their children living with profound disabilities – but the \$22 billion scheme pledged to end this problem, along with the dark and abusive past of state-run institutions. Instead, for more than five years after trials began in 2013, nothing changed.

The question of why any parent would give up their child, surrendering them to “voluntary out-of-home care”, is a difficult one to answer. It is not the same for every family.

AS WITH OTHER PARTS OF THE NDIS, THOSE WITH THE HIGHEST NEEDS ARE FREQUENTLY THE LEAST ABLE TO NAVIGATE THE SYSTEM.

Children forfeited into state care represent some of the more complex cases in the country – young people in need of the most intensive, round-the-clock support. They often have multiple, intersecting disabilities – such as autism, intellectual impairments and psychosocial conditions – which combine in ways that render treating any one of them in isolation near impossible.

As one disability advocate explained, parents of such children may find they are able to cope for the first few years. But teenagehood is more difficult, particularly for boys, as once-small children become young adults.

Under the old disability support system, families who gave up their children to the out-of-home care system often felt they had no other choice, especially if there were younger siblings who may be in harm’s way. But that scheme was “fragmented” and woefully underfunded, according to the Productivity Commission.

The “vision” for the NDIS was that it would be a scheme that found those most in need and gave them the support to live, says Mary Sayers, chief executive of Children and Young People with Disability Australia (CYDA).

“The idea for the NDIS was that if you needed \$1 million in support, you got \$1 million in support,” she says. “The last thing we want to see is families relinquishing the care of their children not because they do not love them but because they have been left without that wraparound support.”

As the NDIS began to unfold through trial sites and then transition to a full scheme from 2016, it quickly became a bureaucratic mess. Spiralling costs prompted its managers to withhold or cut back on funding.

These directives are not, as far as we know, in writing. However, they are written into the support packages of individuals, who saw their funding cut by half or two-thirds, or almost entirely erased, without warning or any apparent change in circumstances.

Among other things, the scheme was the one great hope for families who found themselves caring for a child with a severe disability. The NDIS, they were told, was coming to help them.

In early 2013, just 10 weeks before NDIS trials first began in four locations, state and Commonwealth governments finally agreed on a set of boundaries for the scheme.

These boundaries, called the “applied principles”, divided responsibilities. The NDIS would cover disability support for 460,000 eligible people to live in the community. It would not pay for support that was traditionally offered in “mainstream” services funded by other jurisdictions.

For example, the NDIS would pay for a child’s early intervention – but not if that child was at school, because state governments fund schools. This was the case also if they were within the health, prison or clinical mental health systems. As it turns out, it covered the child protection system as well.

The problem with that agreement, made before the real-world testing of the NDIS had even begun, was that it did not account for complex cases that cross two, three or more of those boundaries.

Holding fast to these nebulous responsibilities, the NDIA refused to move on funding for more than five years. Governments have been reluctant to reveal the real number of children affected by this row.

Work done by the Australian Federation of Disability Organisations and CYDA shows the number taken into care because of a “breakdown in funding for support and accommodation” is about 300 children in Victoria, New South Wales and Queensland alone.

Figures provided to *The Saturday Paper* from various departments indicate a large gap between records kept by states and cases heard by advocates. The figures are murky, however, because governments have different thresholds for classification and do not always count cases that are not current.

Nationally, about 160 children are currently subject to out-of-home care arrangements due to their disability support needs. According to the official data, there are 46 children in voluntary care in Victoria, 38 in Queensland, 15 in Western Australia, five in the ACT since 2014, and at least five in South Australia as at March 2017.

Then there are countless stories of parents who came close to breaking point, the ones who considered giving up their children before authorities came to their senses.

In the autumn of 2017, one family’s crisis pushed the Tasmanian mental health system into total dysfunction.

The episode started with a mother who was unable to cope with the demands of caring for her son, then 15 years old, who had complex disabilities including autism and powerful physical behaviours that were difficult to manage.

The standoff between the NDIS and multiple departments in the Tasmanian government led to the shutdown of an adult four-bed psychiatric ward in Launceston, where the boy was housed for three months. There was, in the state’s view, nowhere else to put him – but once he was there, the adult patients had to be moved.

The ward’s previous occupants, who had severe psychiatric conditions, were shipped to Hobart or Burnie – in turn putting strain on those hospitals. In one case, as Hobart beds were taken up in the shuffling, a local man was taken to Launceston by the same state authorities who knew that hospital was full. He was returned to Hobart the same day.

Help eventually came in the form of a house with disability support that would allow the teenager to live with 24/7 support. It was 80 kilometres away from his family, but, as his advocate, Dominique Vittori, tells *The Saturday Paper*: “At least it wasn’t a psych ward.”

Vittori, who represents Speak Out Advocacy in north-west Tasmania, currently has two cases of children who have been relinquished in the past year.

Despite Vittori’s experience, a spokesman for the Department of Communities Tasmania told *The Saturday Paper*: “There is no record of this ever happening in Tasmania.”

Vittori says the department “was aware of everything and it is still the case that there is a lack of suitable accommodation for people with high support needs”.

He believes there are more cases like this: “I don’t know every case in Tasmania that may have happened. Far from it. I think we have only just touched the surface. The state says they have had no cases. Well, I’ve had two this year.”

Vittori says this has been a big battle, with a significant impact on children and their families. “I have seen the trauma for families and their children who have had to go through this process. It is not something you can take back. The NDIS has not wanted to take responsibility from day one for what they say is a state responsibility.”

Queensland’s Child Safety minister, Di Farmer, says the number of children requiring care arrangements because of their disability needs “has remained relatively stable pre and post” the establishment of the NDIS.

“In Queensland, parents remain legal guardians of their child under these arrangements and are actively involved in all aspects of decision-making,” she says.

That is not the case in all regions, however. The Australian Federation of Disability Organisations says that in Western Australia parents have not always remained the legal decision-makers in the context of children in out-of-home care.

“There remains a lack of clarity and transparency regarding the application of policy which affects which families get a negotiated plan agreement (between child protection and disability services and therefore retains legal guardianship) and which families end up having their child taken in to care with all rights taken away from them,” the federation noted in an August policy paper.

“Indigenous families with children with disability are particularly vulnerable in these circumstances.”

This is a crucial point. As with other parts of the NDIS, those with the highest needs are frequently the least able to navigate the system. It is overdesigned to the point that it punishes people with low education and people who are single parents working or studying and raising children, the kind who have little actual time or capacity to decipher the reams of paperwork. It is a system that hurts the poorest, the people who cannot afford thousands of dollars of assessments to prove they have a disability that is itself quite obvious. These barriers are multiplied if a person is of Aboriginal or Torres Strait Islander descent, or if they do not speak English as a first language.

In other words, the system works best for those who can afford to fight for their best outcome – in time, money or emotional capacity.

And what chance the parents in WA, who have already given up all their rights to their child in the face of miserable support options? Will they ever get that child back?

WA's Department of Communities did not respond to a request for comment by deadline.

A spokeswoman for the NDIA said that from September 1 this year the agency began funding 24/7 staffing for children in accommodation outside of the family home, as well as disability supports. “States and territories are responsible for board and lodging for children in these arrangements,” she said, “as well as co-ordinating mainstream services as needed.”

What that means in practice is yet to be seen. The agreement with states and territories is new, although advocates warn it is only a slightly more detailed sketch of the same responsibilities that have existed since the NDIS began. The roles remain confused and the system difficult to navigate.

How real people, in entirely different workplaces, in multiple systems, end up applying those definitions is not known. That has always been the catch with the NDIS: the gulf between what is promised and what is delivered remains unbridged, and hundreds of children and families have fallen into the gaps.

This article was first published in the print edition of The Saturday Paper on Oct 12, 2019 as “Exclusive: 500 children forfeited to state in NDIS standoff”. [Subscribe here.](#)



Rick Morton
is *The Saturday Paper's* senior reporter.
