Carers cut off services under Australian disability scheme

Max Newman 20 January 2017

Under the Australian Government's National Disability Insurance Scheme (NDIS), millions of primary and secondary carers of people with disabilities face losing the current minimal assistance they receive, such as essential respite services.

A report released last month by the Anglicare charity, entitled *Carers: Doing it Tough, Doing it Well*, outlines the carer-focused programs being dismantled under the NDIS roll out, without adequate replacement.

These services include case management programs, some designed specifically for older parents caring for younger people, to support their health, well-being and pursuit of life goals. Most significantly, respite services—designed to give carers much-needed breaks from direct care—are being shut down in areas where the NDIS has commenced.

The report states that in Australia there are nearly 2.7 million carers. Of them, 850,000 are primary carers, with their day-to-day lives entirely bound up with the care and welfare of someone, typically a family member, with profound needs.

According to the report, carers provide more than 1.9 billion hours of unpaid care each year, including care for "a person with a disability, for a frail aged person or for a person with a chronic illness."

Yet, the needs and role of carers are "not formally recognised as part of NDIS packages." As the report says, "there is no formal assessment of the needs of the carer, no funding package for the carer and no guarantee of involvement in the assessment of the care recipient's needs."

Supporting somebody with a disability, particularly over longer-term periods, has a significant personal impact on carers. The report explains that it negatively impacts "physical health, stress and anxiety, personal wellbeing, family relationships, employments, income and disconnection from community life, often leading to

isolation and social exclusion."

Carers are often also in poor economic situations as a result of the "combined effects of loss of employment and financial expenses associated with caring." Moreover, around 38 percent of carers have a disability themselves.

The impact on carers' emotional and mental health can be great. The report cites one study which found that 40 percent of a sample size of 60 carers fitted the criteria "for a possible psychiatric disorder."

Sue King, Anglicare advocacy and research manager, told the media: "Respite isn't actually necessarily being highlighted in the NDIS but we know that respite, for the carer, is really important. It's not really clear how carers are going to be supported under the NDIS ... if you can't sustain carers into the future the entire system will collapse."

Cheryl Paradella, a carer for her 18-year-old son who has Asperger syndrome and Tourette's syndrome, and her 17-year-old daughter who also has Asperger syndrome and a complex mental health disorder, lost all respite services when the NDIS was rolled out six months ago in Campbelltown, a southwestern Sydney suburb.

"We were told no one would be worse off under the NDIS but, in actual fact, we are worse off because respite is not automatically provided for carers," Paradella told Fairfax Media. Respite services were the only way she and her husband, who has post-traumatic stress disorder, managed. "I really have no idea what's going to happen," she said. "I don't know how we'll cope."

Officially, respite and carers programs are being "absorbed" into a second tier of the NDIS, consisting of "information, referral, web services and community engagement." According to forecasts by the Productivity Commission, whose 2011 report to the last Labor government formed the basis of the NDIS, some four million people with a disability and 800,000 primary carers are to be covered by this second tier.

For carers, the only dedicated support service announced so far is an Integrated Carer Support Service (ICSS), which is still in the design phase. Only \$37 million has been committed over four years for its implementation. Currently, all that is running is a web site called Carers Gateway, which many older carers cannot access because they struggle to use the Internet.

This second tier is also supposed to cover all those people with disabilities who miss out on the 490,000 places within the scheme. This particularly affects those with psychosocial disability—mental health problems that cause social and employment difficulties.

The dismantling of carers' services and the overall reduction of funding for people with disabilities is completely in line with the goals of the NDIS. Announced by the Gillard Labor government in 2012, the insurance scheme was touted as a "flagship" progressive reform. In reality, it was always a pro-business and cost-cutting blueprint, outsourcing services to private operators.

The NDIS was announced amid a raft of other austerity measures, including cutting payments to single parents and trying to force some 400,000 people off disability support pensions and into low-paid work.

Moreover, the Labor government increased the Medicare levy from 1.5 to 2 percent to partially fund the NDIS, forcing working people to bear the financial cost. Even this will cover less than half the government's promised NDIS obligations at full rollout in 2019-20.

To fill some of the NDIS funding hole, the current Liberal-National government announced in its December mid-year economic review that over the next four years \$3.7 billion would be stripped from the Education Investment Fund, which was supposed to finance university infrastructure. As a result, students will suffer a further deterioration in university facilities and services.



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