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20 May 2013, 2.31pm AEST

DisabilityCare now a reality but how can we protect its future?

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DISCLOSURE STATEMENT

Donna McDonald does not work for, consult to, own shares in or receive funding from any company or organisation that would benefit from this article, and has no relevant affiliations.



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The integrity of the scheme relies on listening to the people whose lives are affected by disability. Image from shutterstock.com

Legend has it that before the introduction of Medibank (now Medicare) in 1974, then-prime minister Gough Whitlam convinced the premiers at a Commonwealth-states meeting to introduce a national disability insurance scheme similar to New Zealand's comprehensive insurance scheme, which was established in 1972.

But during a meeting break, his treasurer Bill Hayden apparently persuaded Gough Whitlam to delay this reform as he feared it might undermine his ambitions for the successful introduction of Medibank, which was limited to universal

health cover.

Now, almost 40 years later, **Treasurer Wayne Swan's sixth budget** is finally providing a ten-year funding pathway for the DisabilityCare Australia scheme. It is the first time in Australian history that disability has been at the centre of a federal budget.

The Gillard government has also **successfully legislated** an increase to the Medicare levy to help pay for the new scheme. The increase from 1.5% to 2% equates to an extra dollar a day for an average wage-earner, and is expected to raise A\$20.4 billion over four years.

Lessons from abroad

These days, nearly all countries have some type of **public funding program** covering different aspects of disability assistance. Approaches differ based on the economic prosperity and status of disability rights in individual nations.

The lessons that can be learnt from abroad depend on *what* we want to learn. While New Zealand was quick off the mark in 1972 with its national injury insurance scheme, its scheme now labours under **multi-billion dollar deficits**. Reasons include the reactivation of past injury claims and the increase in disabling conditions arising from ageing.

Australia's DisabilityCare system is based on the premise of a stable revenue source that will provide certainty to people with disability about the support they will receive over their lifetime. But as the **Centre for Independent Studies report** notes, "Given that the NDIS will provide lifetime care and support, it too carries the risk of claims reactivation, or unexpected and increasing claim costs over time."

Still, this might be a cost that Australians will learn to bear.

After all, countries such as Sweden and the Netherlands have high tax rates based on the expectations of care and support for all people with disabilities.

The most defining characteristic of DisabilityCare is that it puts the person with disability at the centre of decision-making about their lives. This concept, known by a range of names such as "individualised funding packages" and "personal budgets", isn't new. It has been tried with varying degrees of success in Northern Europe, United States, Canada and England, as well as by state government

DisabilityCare

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agencies here for at least two decades.

New Zealand was quick off the mark in 1972 with its national injury insurance scheme, it's now in financial trouble. Image from shutterstock.com

In the UK, individualised funding arrangements have been developing since the mid-1990s. In 2007, the UK government committed to rolling out this approach for all of social care. By 2012, this had been achieved for about 30% of the social care population.

We can learn a lot from **England's approach to disability assessment and planning**, including: designing a decision-making system based on the principle of entitlement (not privilege); limiting the government's role in defining the person's budget (and ensuring the person's competence as well as the competence of the system); and letting people work out their own solutions.

Other lessons are to keep the system simple, flexible and pragmatic. The ultimate lesson is when in doubt, do whatever it takes to support people living with disability and their families to help each other.

It is also worth noting that the DisabilityCare Agency will be independent from the government, a safeguard learnt from watching the experiences of other countries.

Lessons from Australia's past

The 1980s represented a high for the disability rights movement in Australia. It was a time of major disability

reform, including the review of the Handicapped Persons
Assistance Act 1974. Other reforms included the
establishment of the Human Rights Commission in 1986
and guardianship tribunals in each state and territory to
safeguard the interests of people with impaired decisionmaking capacity.

At the same time, there were casualties in this reform. Most notably, the deinstitutionalisation movement saw a mass exodus of people with disabilities from large institutions into hopelessly supported community-based services. Powerful relationships between funders and providers of care emerged, and people living with disability were left out of policy processes and decision-making about their own lives.

Instead of liberating people with disabilities into the broader Australian society, community-based service provision continued to segregate and isolate people with disability.

The DisabilityCare Australia scheme will be accompanied with the usual hierarchy of bureaucratic measures designed to protect, safeguard, account for, ration and rationalise. The legislation already signals this. However, the integrity of DisabilityCare will be best protected by the continued participation of the people for whom this scheme is designed: people with disabilities and their families.

If their experiences are ignored or slighted in favour of "experts", then DisabilityCare Australia will become just another out-of-touch, brutalising entity, a bright idea whose blaze dims in the making. We have the deinstitutionalisation experience to remind us to be humble and to listen directly to the people whose lives are being affected.