

# Politicians receive a compelling invitation from the nation's carers

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**BY the time Julia Gillard returns from the royal wedding, she will have a letter with a less gilt-edged invitation waiting for her.**

It is to spend a day helping care for a person with a severe disability -- to "walk in our shoes" as Sue O'Reilly and Fiona Porter, who signed the letter and who have disabled children, put it. "There are many parents of adults and children with special needs who believe that politicians, although sympathetic, do not really fully appreciate what it is like to be in our situation," they write.

If the Prime Minister is too busy on a weekday, a Saturday or Sunday would be fine, they add, since "it is of course the case that supporting a person with severe dependent disabilities is, for many tens of thousands of carers, a seven-day-a-week role".

To ensure that such an event is more than just a photo opportunity, they suggest Gillard spends at least 10 hours with a disabled person. The same letter has gone to nine other leaders and politicians with responsibilities in the area, including Wayne Swan, Tony Abbott, Julie Bishop, Joe Hockey and Bob Brown.

The campaign for proper recognition of people with disabilities and their needs has come a long way in the three years since the 2020 summit adopted as one of its "big ideas" a new, insurance-based system proposed by Bruce Bonyhady, chairman of disability service provider Yooralla.

The Rudd government referred the issue to the Productivity Commission, whose draft report in February recommended a national disability insurance scheme to replace the present "underfunded, unfair, fragmented and inefficient" system.

An NDIS would provide long-term care and support for about 360,000 Australians under 65 with permanent or very costly disabilities such as autism, Asperger's, some intellectual impairments, multiple sclerosis, congenital conditions, quadriplegia, blindness and deafness.

Rather than money, most would get an entitlement to a package of assistance, including care, transport and other physical help, therapies, aids and equipment. But there also would be an option for people to cash out their entitlement and organise their own support services.

The argument for an insurance rather than welfare approach is that it creates incentives to minimise costs, through, for example, early intervention and employment initiatives that help people become more independent -- what the commission calls spending dollars to save more dollars.

Like Medicare, every Australian would be covered against the risk of a significant disability but it would come at a cost, estimated by the commission at \$6.3 billion a year, which is twice the funding now provided by state and federal governments.

It suggests the money come from the federal budget rather than a specific tax levy. That means finding savings elsewhere, raising taxes or both.

The commission more often brings down reports suggesting how governments can operate more efficiently rather than splashing around large amounts of money. But it says funding the scheme is

"manageable, taking into account a wealthy and growing economy" and that the present system, with rapidly rising costs, is unsustainable.

The extra funding would represent about 1.8 per cent of total federal government spending. The report's most telling argument is that this is an area that should be one of the government's core responsibilities: "It should be noted that, were government to be starting with a blank slate in determining its funding priorities, there would be a strong rationale for provision of disability services to be one of its highest spending priorities."

Despite the government's in-principle support for a new approach, people with disabilities and their carers and supporters are concerned about the issue losing traction in Canberra. There are any number of challenging issues jostling for attention and Gillard is being urged not to make Kevin Rudd's mistake of fighting on too many fronts. Inevitably, too, there is concern about the cost, although none of it would fall within the present budget cycle, with its preoccupation on returning to surplus.

Doubts about Gillard's commitment increased when she failed to include anyone with responsibility for disabilities in her initial announcement of the new ministry after the election. In the revised list she gave the job to parliamentary secretary Jan McLucas. Since then, there has been talk of Gillard and Swan wanting to "manage expectations" -- political speak for lowering them.

In one sense, this is understandable: the commission still has to produce its final report (by July 31), although it is unlikely to change its main recommendations. A change as big as it is suggesting will take time to introduce: the draft report suggests starting the scheme in 2014 in one part of Australia to allow finetuning and fully phasing it in between 2015 and 2018.

The commission's preferred model involves the states and territories ceding responsibilities to the commonwealth, inevitably meaning some tortuous negotiations. The Barnett government in Western Australia already is baulking at the idea, saying its own system is the best.

If Gillard and Swan would like to lower the profile of the issue, advocates of reform are intent on not letting them. They may find excuses for not accepting the "walk in our shoes" invitation but they will run the risk of appearing hard-hearted.

O'Reilly and Porter are looking at widening the idea to asking all politicians to spend a day with a person with a disability. Last year, they launched the Mad as Hell campaign that collected 20,000 signatures from voters pledging to support only parties committed to an NDIS. They are prepared to go further in the next federal election and set up a party to run candidates in marginal seats to direct preferences to whoever commits to including an NDIS in the next budget.

If one thing is clear, it is that this is an issue that will not fade away. On Monday, Bill Shorten, who as parliamentary secretary for disabilities was a vocal advocate for reform and is now Assistant Treasurer, will give the opening address to the National Disability and Carer Conference, which has attracted more than 800 registrations. Whatever reservations Swan and others have, Shorten, together with Community Services Minister Jenny Macklin, remain enthusiasts for an NDIS.

Many in the opposition are sounding even keener. After the last election, the Liberals' Mitch Fifield successfully argued to Tony Abbott that the portfolio should be elevated from parliamentary secretary to ministerial status and that he should stay in the job. "Our starting point is that we recognise that the current system is bust," he tells Inquirer. "We will give the most generous consideration to the Productivity Commission's final report . . . I don't balk at the cost."

In a rare event under the Abbott opposition, Fifield is offering bipartisanship. The NSW and Victorian Coalition governments are strong supporters, with the Baillieu government having set up an NDIS implementation unit and offering to trial the scheme.

O'Reilly and Porter drew their inspiration for their latest initiative from the new Liberal MP for the

Sydney federal seat of Hughes, Craig Kelly, who told parliament in his first speech last November that, as the father of a 14-year-old son with Down syndrome and autism who does not speak, he wanted to tell parents with a special needs child "that you have someone who stands on the floor of this parliament that walks in your shoes".

He added: "As a society we ask our carers to provide over one billion hours of unpaid work a year which, if we the taxpayers had to pick up the tab, would cost well over \$30bn. Simply, as a society, we are asking our carers to do more than their fair share of the heavy lifting."