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National Disability Advocacy Program Review  
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To whom it may concern:

**Submission to  
REVIEW OF THE NATIONAL DISABILITY ADVOCACY PROGRAM**

The National Disability Insurance Scheme (NDIS) brings hope to people with disability and their families in their struggle for an ordinary life. It also brings new challenges to the social advocates and their organisations that supported it.

The NDIS has the ambitious goal of supporting the independence, and social and economic participation of people with disability by affording them choice and control in the planning and delivery of their support. Put simply, the NDIS guarantees reasonable and necessary support to those who need it and shifts the authority for decision-making from the service industry to the person.

Australians think the NDIS is a good idea. There was bi-lateral agreement to an increase in the Medicare levy, with little push-back from the community. Nevertheless, the disability sector understands this shift in authority will not occur without a struggle. Many people with disability have never had the opportunity to determine the direction of their lives and there

are many others who have assumed this to be their responsibility and life's work. The NDIS will require social advocates to keep it 'on song' and to monitor and safeguard this important cultural shift.

Wolf Wolfensberger<sup>1</sup> defined social advocacy as “speaking, acting, and writing on behalf of a disadvantaged person or group—to promote, protect and defend their welfare and justice”. Social advocacy is not for the feint-hearted and Wolfensberger suggests advocates can be effective only if they have minimal conflict of interest, are primarily concerned with fundamental needs, and can remain “emphatically and vigorously” loyal and accountable to the people for whom they are advocating. He cautions newcomers that social advocacy is personally costly.

In some countries, advocates are imprisoned, tortured and killed as a matter of course. This is unlikely to happen here, but many people have paid a high price over the years for their advocacy to close institutions, to include children in regular schools, to get into buildings or to seek justice through the courts. Some of the best individual advocates are people with disability and their families, who have little to lose except their dignity and reputation. The best systemic advocacy continues to be done by community organisations that have remained focused, courageous, tenacious and independent. Certainly, governments would not have addressed the dire state of the private hostel industry, developed a guardianship regime, closed many of its institutions or considered an NDIS without compelling arguments and ongoing pressure from disability advocacy organisations. Without these advocates bringing these issues to the attention of the government at the time, Australia would have a shameful reputation for the neglect and abuse of their most vulnerable citizens.

The Hawke Government in 1986 understood well that social advocacy was critical to keep its disability programs effective and relevant, and funding was allocated accordingly. With the devolvement of the disability program to the States and Territories in the 1990s, state-based funding also became available. Receiving government funds on the one hand gave organisations and individuals greater staying power, but on the other, it confronted one of Wolfensberger's basic elements for effective social advocacy—minimal conflict of interest. The NDIS now throws four new challenges to social advocacy sector.

1. The NDIS, in the main, relies on market forces to ensure the effectiveness and relevance of disability services. People with disability have control over their funds

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<sup>1</sup> Wolfensberger, W. (2003). Advocacy. In D. Race (Ed.), *Leadership and change in human services: Selected readings from Wolf Wolfensberger* (pp. 119-149). London: Psychology Press.

and can choose who serve them. Choice and control work well for those who have the capacity to envision a good life and plan the supports they need. They do little for those who do not have this capacity, are socially isolated, or have come to accept a diminished life after years of disempowerment. These folk are at risk of blame, neglect and abandonment because they do not use the authority now available to them, and there will be many services who will be content to continue business as usual. Ultimately it will be left to social advocates to promote, protect and defend the welfare of people who cannot, or choose not to determine how they could live well.

2. The NDIS has adopted an insurance-based approach, informed by actuarial analysis to ensure its sustainability. There is now an imperative for advocates to understand this new language of disability economics, previously not required in the “hand-out” mentality of previous funding programs. Australians will be watching how their contributions are spent. Social advocates will be required to provide substantiated economic reasoning to support their arguments for human rights and social inclusion, and this will require a new skill-set, particularly within individual, family and systemic advocacy.
3. Advocates will be required to take a broader focus. The success of the NDIS is contingent on some ‘heavy lifting’ by mainstream services, including hospitals, schools, housing, and transport. The Council of Australian Government’s National Disability Strategy 2010-2020 lays out a bold plan for this to happen. Currently, it resembles a ‘toothless tiger’ with little accountability for the three levels of government that committed to it. Social advocates will be required more than ever before to keep the pressure on those mainstream services, and to prevent the Strategy from becoming an embarrassment that governments prefer to forget.
4. Advocacy organisations will benefit from greater financial independence. It is time to think how this work can be done differently. Social advocates have amply demonstrated their power, tenacity and grit, and how they can work effectively in insecure funding arrangements. They will be even more effective once they have financial independence from the programs they are most likely to affect, and some high level acknowledgement from governments at all levels that social advocacy will always be necessary.

With these challenges in mind, I recommend the following:

- 1. The National Disability Advocacy Program monitors the issues for the most vulnerable people within the NDIS. The disability advocacy organisations will be among the first to recognise where, who and how the NDIS is failing;**
- 2. Systemic disability advocate organisations build their capacity to understand and contribute to the actuarial assessments of financial sustainability within the NDIS.**
- 3. The National Disability Advocacy Program provides an action plan with performance measures towards the commitment in the 2010-2020 National Disability Strategy; that is, to “support independent advocacy to protect the rights of people with disability”<sup>2</sup>.**
- 4. There are no impediments for disability advocacy organisations within their agreements with NDAP to seek and use independent funding for their advocacy work.**

Yours sincerely



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<sup>2</sup> Council of Australian Governments. (2011). *2010–2020 National Disability Strategy: An initiative of the Council of Australian Governments*. Canberra: Australian Government.