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How To Fix The NDIS

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Seven years have passed since a campaign for the National Disability Insurance Scheme (NDIS) was launched by disability service providers and several funded advocacy bodies. Its architects presented the scheme to governments as an apparently innovative and visionary solution to the crisis in disability support.

Despite, or perhaps because of, the limited knowledge of disability by policy makers, politicians and journalists, the scheme was seized upon as a 'solution'. Across the board, governments and oppositions alike swallowed the marketing hype that NDIS would 'revolutionise disability services'. This phrase was good marketing when the campaign was launched because it appealed to those who knew the disability system was dysfunctional, and the phrase is still used today.

But seven years on, it has become clear to many people with disabilities and their families and friends, and belatedly to some policy makers, that NDIS requires significant reform if it is to achieve its stated goals. These goals are to fund the services needed for people with disabilities to achieve individual goals, become as independent as possible, develop skills for day-to-day living, participate in the community, engage in work and earn money.

NDIS was launched in 2013 as a conventionally structured statutory authority, with a conventional corporate managerial culture, equipped with a brief to centralise the financing, planning and delivery of diverse support for 490,000 people in varied, decentralised, largely hidden and informal communities. It is hard to conceive of an organisational structure and business model that could be less fit for purpose.

This is how NDIS works. A team of NDIS 'planners' produce an individual plan for each participant, which specifies the portfolio of external support they deem necessary for participants to achieve their individual goals and become as independent as possible in daily living. Allocations averaging about \$35,000 annually are assigned to each plan. In theory, participants have a right to self-direct the allocations of this money (deciding on how it is spent, through their preferred providers), and a right to self-manage (making the purchases of support and transactions themselves, online or manually).

In practice, the exercise of self-direction is severely constrained by the weight of historical patterns of service delivery and established market players, who retain excessive influence in the preparation of individual plans, and retain many of the coordinating functions for themselves (paid for out of the average \$35,000 allocation to each NDIS participant). These providers supply support workers at a charge-out rate of up to \$70 per hour, which the National Disability Insurance Agency (NDIA, the NDIS management authority) wants to pull back to \$50 per hour. Participants



who self-manage their support workers are able to cut this rate to around \$30 per hour. Today, after three years of operation, less than 3 per cent of NDIS participants self-manage their support workers, the same figure as in the decade preceding NDIS. The NDIA is now actively discouraging self-management through the introduction of prohibitive financial hurdles for those taking this option.

Online self-management of transactions and financial expenditures is now extremely common in banking, retailing, entertainment and leisure industries. To most outside observers and families of people with disabilities, participant-directed online systems for the self-management of individual NDIS plans should have been one of the first things put in place in NDIS. To date, however, more than \$1 billion has been spent by the NDIA building information technology systems for service providers to gather data for NDIS. The NDIA has no plans for a twenty first century management system for participants and their families to self-manage. Despite the language of 'person-centred' methodologies, the operational culture of NDIS is firmly 'provider-centred' in practice.

These features of NDIS were anticipated by many disability activists and families from day one of the NDIS campaign. When they expressed fears in 2010 and 2011 that creation of a mega-bureaucracy with an inflated budget would not fix the system's problems, they were ignored by the industry and funded advocacy groups.

Many outsiders are astonished to learn that the model underlying NDIS was subject to no consultation or critical assessment from the disability sector. The much-lauded grassroots campaign for NDIS consisted of the mobilisation of individuals, families and services to 'sign-up' to support NDIS and to write letters to members of parliament, but the organisational and business model was quarantined from scrutiny. Critics of the model were bullied into silence. Campaign funds came freely from service providers, through a levy on services exacted by the peak provider body, *National Disability Services*. Many providers redirected money from charitable donations earmarked for children with disabilities to what was effectively a political campaign.

For providers and funded advocacy groups, the return on investment in this campaign was the promise of more money flowing into their sector, whatever the implications might be. Consultants in the field knew NDIS would be a gravy train, and threw themselves into the campaign. Small innovative brokers and support coordinators with a commitment to the 'personalisation agenda' in social policy were more skeptical on seeing the big traditional providers pour money into the campaign, but they nevertheless felt drawn to be inside the tent. The promise of more funding trumped all other considerations.

The supreme irony here is that innovative person-centred practice had been undertaken quietly and selectively in various parts of Australia from the mid-1980s with negligible cost to the taxpayers, which state and federal governments could have championed and replicated if they wished. They didn't. Two examples are worth citing.

Mamre Family Association in Brisbane is an innovative family-based disability support provider established in the early 1980s, influenced by the work of French Catholic philosopher Jean Vanier. Vanier's work emphasises informal and natural support for people with disabilities, in families and

neighbourhoods, rather than formal, professionalised services. From the late 1980s, Mamre (a Hebrew word meaning 'mountains of friendship') enabled families in Brisbane to self-manage individualised support packages, allowing them to directly select and employ their own support workers. Mamre received conventional block funding from the government, arranged it in individualised formats for families to administer and pay for their preferred support requirements. Mamre's role was to advise and enable. It absorbed the costs of introducing this new paradigm of personalised support without any additional expenditure of taxpayers' money.

In East Gippsland, a remote region of Victoria, families with sons and daughters with disabilities were permitted by the Department of Human Services in the 1990s to obtain their own support from unconventional sources. They were permitted to employ neighbours and family members to provide support, even though users of services in other parts of the state were not permitted the same innovative approach. It was accepted that remote circumstances required a 'bending' of normal processes in order to make do. City users of services were not permitted the same flexibility. Indeed, the Department insisted that East Gippsland people didn't publicise their 'personalised' arrangements in the 1990s lest city people asked for the same flexibilities.

Personalised, self-directed disability supports like these in East Gippsland and Brisbane could have been deepened and extended around the country, without an oversized statutory authority with a mega-budget. But policy makers, politicians and journalists with limited knowledge of disability weren't aware of these quiet, intimate innovations. They were more accustomed to a model of 'reform' that required legislation, statutory authorities, managerial cultures and public relations campaigns. NDIS, to them, looked more like 'real' social reform than suburban families quietly selecting and employing their own support workers, in their own names, in their own homes, to coach their sons and daughters to form social relationships and live as independent a life as possible.

Instead of a thousand no-cost, family and peer-generated Mamres, we got NDIS at a set-up cost of \$37 billion. Given Australia's current financial predicament, this was a wrong turn of enormous magnitude.

What then is to be done?

Though belated, it's time to have the debate about preferred models of disability support that we didn't have in 2010 and 2011. Four starting points are essential for this discussion.

The first is that support systems need to be built around familial and natural support systems (families, friends and neighbours). NDIS activists and management assume paid, formal support systems are primary in importance, and that familial care is secondary. This assumption is fundamentally flawed, but it lies at the root of the NDIS model.

Second, the financial cost of NDIS is hugely excessive, in large part because of the ideological preference for the paid and formal rather than the familial and informal. Because no politician has been prepared to state this honestly, government cannot address the burgeoning, and ultimately unsustainable, cost of NDIS.



Third, NDIS is not an 'insurance' scheme. There is no self-financing contributory mechanism drawn from the pool of the insured. Policy makers, service providers and journalists should stop misrepresenting the scheme as an 'insurance' scheme: it perpetuates the wildly inaccurate perception that the scheme is self-financing and sustainable.

Finally, politicians need to grow a spine and begin speaking honestly about a scheme they know to be excessively bureaucratic and costly. To start the process, they should sit down at kitchen tables with the parents of sons and daughters with disabilities who tried to tell them this seven years ago.

Vern Hughes is the director of Civil Society Australia, and authored a 2006 IPA report titled, The Empowerment Agenda: Civil Society and Markets in Disability and Mental Health.

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