

The NDIS: The Mark of Pre-War or Post-War Public Policy Making?

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Abstract

Disability advocates, politicians and the media almost universally heralded the National Disability Insurance Scheme as an historic reform. But is it? For all the money outlaid, people with disabilities will be left with a care system facing many of the same problems as the ones it replaced, as well as many of the same NGO service providers. Has anything really been gained?

Keywords NDIS; charity; outsourcing; NGO; citizenship

Introduction

The Australian Parliament thought it was making an historic mark when it passed into law the *National Disability Insurance Scheme Act 2013* (the NDIS Act). This paper aims to place the NDIS in a proper social, political, legal and historic context. Scheme advocates emphasised that people with disabilities would gain more choice and control. These outcomes were to be achieved through a market model, where individuals with disabilities would be supplied with a budget and, a market of competitive, customer-focused providers would meet their needs.

The claim was clearly made that those with disabilities had experienced substandard and inconsistent support services from block-funded government and non-government service organisations (NGOs). Block funding meant that the specific support services from equipment to personal care were funded for a specific time, with an amount of money which was capped. If an individual made it onto a service waiting list while there were still funds available, they could expect to have at least some of their needs met.

However, even where some needs were met, multiple reports could be cited to suggest that funding specific services or programmes was leaving many without desperately needed

assistance.¹ The fundamental change that the NDIS Act was supposed to bring was the direct funding of individuals to access the services that they needed. As then Prime Minister Julia Gillard told the House of Representatives:

The legislation is designed to allow participants and their families to choose how their funding for supports under a plan is managed. It also sets out how a participant's plan may be reviewed over time to take into account of the participant's changing circumstances...(The) bill sets out the structure for the NDIS, including comprehensive rules to protect personal information and rights to review of decisions. It also sets out the process by which a nominee can be appointed to make decisions on behalf of a participant, while ensuring that the rights of participants are maintained and that nominees must consider the participant's wishes.²

This might sound impressive: individuals with disability in control of their own destiny, perhaps for the very first time in their lives. But, who would these service providers be and, just how much control would participants and their families have? Equally, if the old system forced many to linger on waiting lists in desperate need, was it any more reasonable to move people to a 'market' many would not be prepared for and, some may not want to enter. Many such questions, considering recorded experience with the NDIS, as well as lessons from its international equivalents, need to be asked. This is because, as with every public policy change, there will be advantages and disadvantages.

However, I would suggest that as a community, we have lost more in the assurance of public delivery of essential services, than any NDIS participant has gained in choice and control. The first clue is in the above quotation; note Ms. Gillard's final words: the participant's wishes must be *considered*. This is far from a guarantee of implementation, facilitation, or prioritization. While defenders of the legislation would no doubt cite the need to protect people from harm, as well as preserve public funds, this does not answer the claim of whether

¹ See e.g.: National People with Disabilities and Carer Council, *SHUT OUT: The Experience of People with Disabilities and their Families in Australia* - National Disability Strategy Consultation Report prepared by the National People with Disabilities and Carer Council, © Commonwealth of Australia [2009], <https://www.dss.gov.au/sites/default/files/documents/05_2012/nds_report.pdf>; see also Jackie Ohlin, *Unmet Need in Disability Services: Shortfall or Systematic Failure?* Current Issues Brief 6 1999-2000, Parliamentary Library, Parliament of Australia, <https://www.aph.gov.au/About_Parliament/Parliamentary_Departments/Parliamentary_Library/Publications_Archive/CIB/cib9900/2000cib06> as at 14 December 2017

² Julia Gillard, *Second Reading Speech: National Disability Insurance Scheme Bill 2012*, House of Representatives, *Hansard*, Thursday, 29 November 2012, 13879 <http://parlinfo.aph.gov.au/parlInfo/genpdf/chamber/hansardr/9b96ae59-96ca-4e39-b984-8b520b432ef5/0005/hansard_frag.pdf;fileType=application%2Fpdf> 29 November 2012

the NDIS Act marks any real change for people with disabilities and their families at all. There are clearly limits on this market and, the choice and control people can have. This may be reasonable for those with disabilities which include cognitive capacity. However, if the NDIS is being consistent, all participants should be able to exercise whatever degree of choice and control they can. This paper demonstrates that ‘the NDIS market’ is not delivering on its stated aim and, in the view of some, is as bureaucratic as the system it replaced.

Micheline’s story

Even where an NDIS participant does not have a nominee supporting their decision-making, evidence shows that dealing with the NDIS can be time-consuming, demoralizing and far from empowering. Lawyer, artist, international traveler and mother Micheline Lee is not a person likely to be overwhelmed by much, but for a degenerative muscle-wasting disease. Her article to The Monthly entitled *The Art of Dependency*, laid out her experience of long waits on the telephone, only to be wrongly assessed by the NDIS as someone with minimal support needs, when the progression of her condition actually meant she had high support needs.³

However, even when Ms. Lee was reassessed, her sense of choice and control is demonstrated when she says:

Because the NDIS processes are so complex and obscure, I need to employ a professional called a Support Coordinator under the scheme to interpret the plan and the review rules for me...Before you can do anything under the NDIS, it seems, you need an OT’s (Occupational Therapist’s) report. You are not trusted to make basic decisions on your own. I was told I needed OT approval just to replace the batteries on my electric wheelchair. Another participant reported that a \$25 kettle tipper ended up costing about \$100 because an OT’s report was required. So much waste occurs where the system is overly bureaucratic and its rules are not clear or reasonable. No real opportunity is given for choice and control, and we are forced to rely on the professionals and administrators.⁴

³ See generally, Micheline Lee, *The Art of Dependency*, The Monthly, August 2017, <<https://www.themonthly.com.au/issue/2017/august/1501509600/micheline-lee/art-dependency>> as at 24 July 2018

⁴ Ibid

While Ms. Lee also acknowledges there have been improvements for some who had no supports under the old State-based arrangements, the last paragraph of the above quotation is a significant qualification. It should like a charge usually levelled at a government department, not a service system aimed at giving support recipients choice and control. This should raise questions over just how much change or reform the NDIS really represents; or whether it represents change at all?

In claiming it marks no change at all, I cite Todd Winther, a dissatisfied attendee at a Queensland NDIS seminar in 2011. He told *Ramp Up* that his questions were not answered and, the presentations left him to conclude that “(disability) advocates on a national and state level...are an incestuous group with blinkered vision.”⁵ Arguably this is a blinkered vision that has not changed much, not just for years, but decades and even centuries.

The reason why phrases like ‘blinkered’ and ‘unchanged’ might be used in considering the NDIS is the heavy dependence the Scheme has on charities and other NGOs to deliver services to participants. Ms. Lee, cited earlier, is critical of what she sees as “(governments)...rushing into the privatisation of disability services without adequate quality assurance.”⁶

However, is it really privatisation Ms. Lee should be worried about? In an article for *The Conversation*, Associate Professor Paul Ramcharan gives a summary of the history of the care of the disabled.⁷ Beginning with care by families, to care in monasteries and the first government intervention with the passage of the Poor Laws in 1601, you see a harsh but increasingly more structured approach to care for the disabled and infirmed. Larger scale asylums and institutions emerged.

After the horrors of World War II, there was a great impetus to construct a public welfare state. In the words of Simon Duffy:

In the West the welfare state grew rapidly after World War II. This was a period when the state was in its pomp. Perhaps unsurprisingly, after the Depression and

⁵ Todd Winther, *The NDIS: all style and no substance?*, Opinion: Ramp Up, 22 Feb 2011, <<http://www.abc.net.au/rampup/articles/2011/02/22/3145273.htm>> as at 9 September 2016

⁶ Lee, above n 3

⁷ See generally, Paul Ramcharan, *Understanding the NDIS: a history of disability welfare from ‘deserving poor’ to consumers in control*, *The Conversation*, July 6, 2016 6.07am AEST, <<https://theconversation.com/understanding-the-ndis-a-history-of-disability-welfare-from-deserving-poor-to-consumers-in-control-58069>> as at 24 July 24, 2018

the war years, thinkers of both Left and Right were confident that only the state was competent to solve social problems.⁸

Lee and Duffy speak variously of a rushed withdrawal from, or an attack on, the welfare state. Ramcharan argues when characterising the NDIS specifically, that while the legislation refers at length to the United Nations Convention of the Rights of Persons with Disabilities, another foundation is “neoliberalist ideology and models of consumerism where (consumers) have choice, participation, rights and redress.”⁹ How much choice and control this represents is debateable, when Lee asserts that formal approval was required to buy a battery and a kettle.

The next question to ask is, whatever the level of choice and control, who are the market players that participants (consumers) in the NDIS have to choose from? The answer may explain much of Todd Winther’s frustration and why he felt some disability advocates had a ‘blinkered vision’. The NDIS may be presented by many as a forward-thinking participant-centred reform, but service delivery relies on a distinctly pre-War and pre-welfare state mechanism: charity.

The mark of...no change, consistently

My argument is that you can see the mark of consistency because the church and charitable sector is still at the heart of every service the NDIS Act delivers. While the National Disability Insurance Agency (the Agency) holds the funds, every service that a participant receives comes via a ‘partner NGO agency’. This came as a very unwelcome surprise to a mother of two children with disabilities and, in what follows, you see the difference between Heike Fabig’s expectations for the NDIS as opposed to the reality:

To me, the NDIS promised a radical overhaul of disability services. It promised a people-centered and rights-based approach to disability; a fundamental change from the current crisis-driven charity model.

I don't want my children to grow up feeling they are charity cases who need to be grateful for the benevolence bestowed upon them. I want a system that thinks

⁸ John O’Brien and Simon Duffy (eds), *Citizenship and the Welfare State*, ‘The Need for Roots:’ Centre for Welfare Reform, UK, 2016. 15, https://www.scribd.com/doc/305719429/Citizenship-and-the-Welfare-State#download&from_embed as at 29 August 2016

⁹ Ramcharan, above n 7

in terms of investments rather than costs. Ability instead of disability. Opportunity instead of inability...So I nearly choked on my lunch when I read this week that St Vincent de Paul was named as provider of the new local coordinators for the NDIS pilot in the Hunter Valley.¹⁰

Ms Fabig's surprise, while understandable based on Prime Minister Gillard's speech, misses the mark of recent history, in Australia and the rest of the Western world. Over the last 30 years, public policy has been marked by governments outsourcing service delivery to the private or charitable sector, while simultaneously expecting the same, often needy, and vulnerable clientele, to access the new services. Failure to do so often results in the unemployed, disabled, sick and elderly losing welfare benefits.

This is demonstrated by reforms to Australia's support services for unemployed people. Formerly operated by the Federal Government as the Commonwealth Employment Service (CES), this was tendered out to the charitable sector, which was meant to give unemployed Australians freedom of choice to use the employment services that best met their needs. However, O'Sullivan and others argue that when employment services were privatised, neither unemployed participants nor the new service providers operated in anything like a 'free market' of consumer choice or open competition amongst NGOs.

How the reform was implemented ultimately lead to a system which was increasingly rigid. It sought to manage individual jobseeker outcomes and was an arrangement where a large proportion of case managers in services surveyed in 2008 felt their work was dictated by the AE3000 computer system.¹¹ This was the data management system shared by *Centrelink*, the then Department of Employment and Workplace Relations and, service providers. How services supported individuals (and how much support was offered) was highly influenced by their desire to meet government targets and thus retain funding, which meant collecting compliance data.

Therefore, what government claimed reforms to employment services were achieving and, what the evidence showed is arguably contradictory. For instance, O'Sullivan and others

¹⁰ Heike Fabig, *NDIS: rights-based paradigm shift or same old charity?*, Opinion: Ramp Up, 11 Apr 2013, <<http://www.abc.net.au/rampup/articles/2013/04/11/3734962.htm>> as at 13 September 2016.

¹¹ See Siobhan O'Sullivan, Mark Considine and Jenny Lewis, *John Howard and the Neo-liberal Agenda: regulation and reform of Australia's privatised employment services sector between 1996 and 2008*, (Presented at the Australian Political Studies Association (APSA) Conference) (September 2009) Macquarie University, 10 <http://ssps.unimelb.edu.au/sites/ssps.unimelb.edu.au/files/John_Howard_and_the_Neo-liberal_Agenda_Sept_2009.pdf> as at 9 January 2017

explain that these reforms were being justified (including by the Keating Labor Government) as providing “accurate assessment of the needs of jobseekers and an intensive plan to assist disadvantaged people”.¹² Despite these intentions, coinciding with the belief that competition would improve service delivery,¹³ a Productivity Commission Report in 2001 found individual jobseekers with complex needs were being excluded from services as providers focused on those clients most likely to find employment and, ensure a contractual return for the service provider. In what the Commissioner labelled ‘parking’ and ‘creaming’,¹⁴ the system perversely encouraged assistance to go to those who needed it least, while rationing support for those who needed it most. Paralleling this was an increasing movement of administrative functions from the Commonwealth to providers, which O’Sullivan and others conclude:

Frontline staff employed by private employment agencies had originally been engaged for the purpose of providing in-depth assistance to jobseekers. By 2008, those same staff were increasingly required to provide basic government oversight of job search activities, including more stringent monitoring of jobseekers to ensure they comply with ‘mutual obligation’ requirements. This monitoring type service appears to have displaced a more counselling style jobseeker/case-manager relationship, at least to some extent.¹⁵

NDIS: The same outsourcing model

‘Mutual obligation’ will be considered later, however much the same structural critique can be made of the NDIS. Prior to the NDIS, the State and Territory Governments had primary responsibility for the delivery of disability services. This was usually achieved through a Department of State, such as the Department of Ageing, Disability and Homecare in NSW (ADHC). ADHC had been in existence in NSW, in a public form, since 1943.¹⁶ However, in 2015, the NSW Government announced that it was transferring the disability support

¹² Ibid., 6, quoting Keating, P. J. (1994), *Working nation: policies and programs* (Government of Australia White Paper). Canberra, Australia: Australian Government Publishing Service.

¹³ See *ibid.*, 7.

¹⁴ See *ibid.*, 25, citing Commonwealth of Australia (2002), Independent Review of Job Network: inquiry report. Available online at <http://www.pc.gov.au/_data/assets/pdf_file/0018/54333/jobnetwork.pdf> accessed 21 July 2009.

¹⁵ *Ibid.*, 19.

¹⁶ See Family and Community Services, *Ageing, Disability and Home Care: Home Care Service client handbook*, March 2014, 4 <https://www.adhc.nsw.gov.au/_data/assets/file/0010/257590/3075_ADHC_HC_clientHandbook_May2014.pdf> as at 21 October 2017

components of ADHC (the Homecare service) to the company Australian Unity. The \$100 million received in the transaction would, the Government said, be “reinvested into the disability sector to help with transition to the NDIS”.¹⁷

This press release is important for several reasons. Firstly, it acknowledged that Homecare provided for 70% of disability and aged care support in NSW.¹⁸ Secondly, the pattern of outsourcing human services was being followed in other jurisdictions.¹⁹

Thirdly however, the State Government argued the outsourcing service delivery to the charitable, mutual, or private sectors would give Homecare clients and their families more ‘choice and control.’ Just exactly what this ‘choice and control’ is, particularly alongside the so called ‘good life’ and ‘ordinary life’ phraseology used by the Agency is unclear.²⁰ From the practical point of view of Homecare staff, the Public Service Association was very concerned, not only about a loss in the overall number of staff, their employment conditions, and the effect on clients, but also about what it saw as the privatisation of a range of Government instrumentalities and services across NSW.²¹

The Government countered some of these arguments by pointing out that in 2014, as far as disability services were concerned “the non-government sector already (provided) over 60 per cent of services.”²² To a certain extent, the Government’s position was justified by referring to the 2008-09 Annual Report of ADHC. This was the final time in which the Department would be a standalone agency, rather than a subunit of the Department of Family and Community Services (FACS). At that time, the Department’s CEO highlighted the

¹⁷ Ibid., Media Release Archive, *\$100m to be reinvested in Disability Services after NDIS milestone*, 28 Aug 2015, <[https://www.facs.nsw.gov.au/about_us/media_releases/media_release_archive/\\$100m-to-be-reinvested-in-disability-services-after-ndis-milestone](https://www.facs.nsw.gov.au/about_us/media_releases/media_release_archive/$100m-to-be-reinvested-in-disability-services-after-ndis-milestone)> as at 21 October 2015

¹⁸ See *ibid*

¹⁹ See e.g.: Leah MacLennan, *Elderly and disability care services being outsourced to SA private sector*, Wed 8 Feb 2017, 5:19pm, <http://www.abc.net.au/news/2017-02-08/elderly-and-disability-care-services-outsourced/8252820> as at 21 October 2017

²⁰ Rhonda Galbally, *Reasonable and Necessary Support across the Lifespan: An Ordinary Life for People with Disability*, NDIS Independent Advisory Council Advice 2014, 3 <<https://www.ndis.gov.au/about-us/governance/IAC/iac-reasonable-necessary-lifespan>> as at 20 October 2017. The Advisory Council said, in particular:

The paper takes an ‘ordinary life’ in 21st century multicultural Australia as its starting point because people with disability share the ordinary aspirations of their peers without disability but need reasonable and necessary NDIS support to achieve them. The ordinary life provides clues as to how these aspirations would typically be met providing a useful benchmark to guide understanding of reasonable and necessary support

²¹ See Public Service Association, *NEW SOUTH WALES: State of privatisation*, <<http://psa.asn.au/wp-content/uploads/2015/01/NSW-State-of-privatisation-Jan-2015.pdf>> as at 21 October 2017.

²² Marie Sanson, *Tensions over 14.5k NSW jobs shift in NDIS*, Government News, August 7, 2014, <<https://www.governmentnews.com.au/2014/08/tensions-14-5k-nsw-jobs-shift-ndis/>> as at 22 October 2017

establishment of an Industry Development Fund, to drive service improvement, collaboration, and efficiency between ADHC and the NGO sector.²³ In the same report though, evidence of outsourcing is clear, with ADHC stating:

(ADHC's) move to re-auspice its day programs to the non-government sector continued during the year, with 19 programs (supporting more than 400 clients) re-auspiced to 15 NGOs.²⁴

An important point here however, is how did clients and their families react to such changes, which also involved so-called person-centred planning and care.²⁵ There is a considerable body of literature around 'person-centredness' or patient-centred care in hospitals and care.²⁶ Certainly, many of the same concepts were used to promote and justify the rollout of the NDIS. The NSW Government also justified how it was transferring all its aged and disabled clients to Australian Unity, while all the disabled clients under 65²⁷ were transferred to the NDIS. This was facilitated through a Bilateral Agreement between the State of New South Wales and the Commonwealth Government.²⁸ The Commonwealth entered bilateral agreements with all States and Territories.²⁹

While this might appear to be a publicly run and regulated system, whether we are talking about the NDIS or employment services, the theoretical and operational assumptions remain

²³ See Department of Ageing, Disability and Homecare, Annual Report 2008-09, 6, <<http://www.adhc.nsw.gov.au/data/assets/file/0003/227901/Introduction200809Part1.pdf>> as at 21 October 2017.

²⁴ Ibid., 42.

²⁵ See ibid., 42-43.

²⁶ See generally, Health Issues Centre and the Royal Australasian College of Physicians, *Collaborative Research Project on Patient Centred Care and Consumer Engagement Literature Review*, October 2015, <<https://www.racp.edu.au/docs/default-source/default-document-library/patient-centred-care-and-consumer-engagement-literature-review.pdf?sfvrsn=0>>; see also Melissa Raven, *Patient-centred care and self-management support in primary health care*, Primary Health Care Research and Information Service, Flinders University, Issue 41, March 2015, <http://www.phcris.org.au/phplib/filedownload.php?file=/elib/lib/downloaded_files/publications/pdfs/phcris_pu_b_8440.pdf>; see also National Ageing Research Institute, *What is person-centred health care? A literature review*, February 2006, <<https://www2.health.vic.gov.au/Api/downloadmedia/%7B957EF817-D47F-4895-BC26-29E2ABAEDA46%7D>> as at 23 October 2017.

²⁷ See New South Wales Government, *Eligibility requirements for the National Disability Insurance Scheme Fact sheet*, October 2015, <<http://ndis.nsw.gov.au/wp-content/uploads/2015/08/FACT-SHEET-Eligibility-requirements-for-the-NDIS.pdf>> as at 23 October 2017.

²⁸ See generally Council of Australian Governments, *National Disability Insurance Scheme (NDIS) - Bilateral Agreement between Commonwealth and NSW - 16 September 2015*, Thursday, 17 September 2015, URL <<http://www.coag.gov.au/node/525>> available at <<http://webarchive.nla.gov.au/gov/20160615045056/http://www.coag.gov.au/node/525>> as at 23 October 2017.

²⁹ These are all listed at: Council of Australian Governments, *Disability Care and Support – Related Documents: Agreements*, URL <https://www.coag.gov.au/disability_care_and_support> available at <http://webarchive.nla.gov.au/gov/20160615051821/https://www.coag.gov.au/disability_care_and_support> as at 23 October 2017.

unchanged. The NSW Government could have been talking about employment or disability care services when it said that outsourcing service provision to NGOs allows:

greatest choice. (with) a vibrant and competitive disability services marketplace in NSW: a marketplace where people with disability get not only the best services, but the best outcomes.³⁰

Many of the same promises were made when the CES was transferred to the NGO sector. But, as O’Sullivan and others found, some of the neediest clients were further disadvantaged, as support services attracted funding by concentrating resources on compliance measures. Will the same sort of negative changes occur within the NDIS? Furthermore, why would it not occur with all the same factors present: withdrawn public services, vulnerable clients, and new NGO providers chasing limited funds?

Targeted funding

This point above about limited funds is important. Australia’s welfare system is based on a means-tested regime of limited support payments. While advocates of the NDIS would characterise it as ‘social insurance’³¹ rather than welfare, it has several similarities to the welfare system. Firstly, the NDIS is targeted at those with significant disabilities and, it provides graduated support to those in need, based on their level of impairment.

However, as Lee’s experience highlighted, receiving the correct NDIS assessment does not guarantee you easy access to goods and services. Moving from the individual to the community or macro-level, Gemma Kelly argues that public funds distributed in a highly targeted fashion produces a poorer overall return in terms of social welfare, when compared with general spending measures. Relying on OECD data from the 1970s and 1990s Dr Carey says that “the more we target the ‘poor’, the less resources actually reach them.”³²

She also draws directly on a Productivity Commission analysis of the outsourced employment services sector. Significantly, this says:

³⁰ New South Wales Government, *Transfer of New South Wales disability services*, <<http://ndis.nsw.gov.au/about-ndis-nsw/transfer-of-nsw-disability-services/>> as at 23 October 2017.

³¹ See Ramcharan, n 7

³² Gemma Carey, *Social Service Futures: Is the Productivity Commission still fit-for-purpose?* Power to Persuade, April 19, 2016, <<http://www.powertopersuade.org.au/blog/is-the-productivity-commission-still-fit-for-purpose/18/4/2016>> as at 25 July 2018

More importantly, at the moment we do not know how to ‘get markets right’. Australia has a poor track record when it comes to using market models. The ill-fated Job Network provides many valuable lessons about the ways in which government-created markets can become rigid and compliance driven, leading to poor quality services and poor outcomes for individuals.³³

The NDIS is another government-generated market and considering what has been presented above, there would have to be some questions over whether the disability market will work with any greater effectiveness than the employment services market. It is also unclear whether many NDIS participants are seeking to be active consumers in a marketplace. Commentators like Bo’sher say the number of people who take on self-management will be low, due to the complexity generated by the strict demarcation of what is and is not covered by ‘disability insurance’.³⁴ As a result, Bo’sher said that many, like Lee, hired a Plan Manager or left management entirely to the NDIS Agency. This was broadly reflected in the international experience cited by Bo’sher,³⁵ which will be discussed further, later in this paper. However, there would seem to be a strong possibility of (to paraphrase Carey) the NDIS becoming yet another government-generated market that Australia ‘gets wrong.’

The NSW approach

The NSW Government would reject this analysis. It would likely rely on consultation reports such as *Living Life My Way*,³⁶ to argue that people with disabilities and their families wanted choice and control over the supports and services they received and how they received them; and that such changes were overwhelming positive developments. This shows a subtle but important shift in the policy rationale of Government. In a presentation for a 2016 public sector conference, Deputy Secretary of FACS Jim Longley claimed that the State was moving “from doer to enabler.”³⁷ This meant that on the claimed understanding that people with

³³ Ibid., citing Productivity Commission. *Independent review of the Job Network: inquiry report*. Melbourne: Australia, Productivity Commission; 2002.

³⁴ See Luke Bo’sher, *Self-management: is a new world of cash payments on the horizon?*, Disability Services Consulting, February 12, 2015, <<http://www.disabilityservicesconsulting.com.au/resources/self-management>> as at 20 November 2017

³⁵ See *ibid.*

³⁶ See generally, New South Wales Government, *Living Life My Way: Putting people with disability at the centre of decision making - Outcomes of statewide consultations, May – August 2012*, <https://www.adhc.nsw.gov.au/data/assets/file/0018/262530/Stage_3_consult_report_Aug2012.pdf> as at 23 October 2017.

³⁷ Jim Longley, *Integrating the NSW Disability System to the National Disability Insurance Scheme: Investigating the move from Outsourcing to Commissioning* – 11th Public Sector Shared and Common Services,

disabilities wanted ‘choice and control’³⁸ Government was asking people to manage their own care and supports, as opposed to relying predominantly on a State provider.

One problem with this analysis is whether the State Government’s interpretation of choice and control accorded with what clients and families were expecting. There is some clear evidence that this is not the case. Firstly, while the *Living Life* report certainly cited people saying they wanted to decide who cared for them and what sort of care and support they received, or activities they spend money on,³⁹ the caveats in the report seem to have been minimized by successive Governments. A parent said:

The money needs to be handled correctly and used to enhance lives and improve people’s choices. We need to be really accountable on how people are spending their money. Yes the Government needs to support us, but where do we draw the line and where does the bucket end?⁴⁰

From this and other references concerning people being able to use supplementary funds when public service was too tardy in their response,⁴¹ it is arguable that many people never conceived or desired a time when there would not be public service provision. People were never entirely convinced of a market based system either, with some respondents to the *Living Life My Way* consultations expressing concerns about asymmetrical information, formally free services now attracting fees⁴² and, parents worrying that people with disabilities were vulnerable, so government needed to maintain oversight.⁴³

The NSW Government might say that oversight is maintained via the itemized individual budget, approved by the NDIA. Once approved, it was Mr. Longley’s view that individuals could choose from the services they wanted, rather than being placed with pre-determined State-funded programs.⁴⁴ While this may have been the official view, the question of whether individual choice was as popular as the NSW Government wanted it to be, was an open

2016, 6, <<https://shareservices-publicsector.iqpc.com.au/investigating-the-move-from-outsourcing-to-subscription>> <https://plsadaptive.s3.amazonaws.com/gfiles/_puzAWjim_longley_0.pdf?response-content-type=application/pdf&AWSAccessKeyId=AKIAICW5IOYOPOZOU3TQ&Expires=1508573836&Signature=1eznzdO35iLg1rQ479HJ9Jedlw%3D> as at 23 October 2017.

³⁸ See *ibid.*, 5-6.

³⁹ See New South Wales Government, *Living Life My Way*, above n 36, 27

⁴⁰ *Ibid.*, 31.

⁴¹ See *ibid.*, 27

⁴² See *ibid.*, 13

⁴³ See *ibid.*, 35.

⁴⁴ See Longley, above n 37, 9.

question. When it came to hiring support workers for example, a parent said during consultations:

If you expect people to do all that then you're going to have to give them a lot of input. It's a minefield and in the end you pick it all up and you give it to a provider because it's too hard.⁴⁵

This accords with some international evidence from the United Kingdom. Defenders of 'personal budgets' (as they are called in the UK) say that they give users 'choice and control'.⁴⁶ However, it is a far from universal view,⁴⁷ and each side of the argument dispute the very definition of the problem. John Waters, head of research for UK advocacy body *In Control*, highlights a lack of funding for support services being detrimental to how personal budgets are being rolled out. To abandon the individualized service budgets on that basis would, in Mr. Waters' words:

(means) not telling people what level of help and support they can reasonably expect – and ultimately deny them the right to control their own support and their own lives."⁴⁸

This is clearly both an appeal on the facts, but also an appeal to emotion. But what are the facts? To an extent, these can be hard to pin down, because while the UK Audit Office reported that there was a high level of satisfaction with personal budgets, but while it was possible to look at individual stories, accumulated data collected by local authorities showed "there is no association between higher proportions of users on personal budgets and overall user satisfaction or other outcomes."⁴⁹

Despite this, personal budgets became mandatory for many care receipts,⁵⁰ with Beresford and others suggesting clients were reporting satisfaction with the scheme because of a lack of understanding about what they were being asked. Beresford and others suggested that

⁴⁵ New South Wales Government, *Living Life My Way*, above n 36, 26

⁴⁶ See e.g.: John Waters, *Personal budgets allow people to control their own support and their own lives*, Social care network: practice hub, <<https://www.theguardian.com/social-care-network/2016/may/27/personal-budgets-control-their-own-support-and-their-own-lives>> as at 25 October 2017.

⁴⁷ See e.g.: Peter Beresford, *Personal budgets don't work. So why are we ignoring the evidence?*, Social care network: practice hub, <https://www.theguardian.com/social-care-network/2016/may/05/personal-budgets-health-care-nao-report?CMP=share_btn_tw> as at 25 October 2017.

⁴⁸ Waters, above n 46.

⁴⁹ National Audit Office (UK), *Report by the Comptroller and Auditor General: Department of Health and local authorities - Personalised commissioning in adult social care*, House of Commons, 3 March 2016, 7 <<https://www.nao.org.uk/wp-content/uploads/2016/03/Personalised-commissioning-in-adult-social-care-update.pdf>> as at 26 October 2017.

⁵⁰ See *ibid*

apparent satisfaction with the personal budget system related not to the budget, but more to “the impact of having a service with having no service at all.”⁵¹

Against this background, self-management was promoted as a key component of the NDIS in Australia. In the first year of the NDIS, that about 80 per cent of participants let the Agency or another plan management agency administer their service and support plans.⁵² This broadly corresponds with international evidence suggesting that in comparable jurisdictions, where self-management is as low as 11 percent.⁵³ Where rates of self-management did rise, these participants were children, whose allocation was being managed by their parents. Even then, the rate rose to only to 17 percent, where “active carers...have the time and skills to manage funds for their children.”⁵⁴

This however, is the junction point between the NDIS, the dismantling of the CES and the corporatisation and/or privatisation of public services across State and Federal jurisdictions in Australia. Earlier, I wrote that one problem was whether there was any consensus about what ‘choice and control’ means in practice. Another problem is how this alleged NDIS reform appears to forget history, some of which is very significant for those with disabilities.

Why does the Welfare State still matter?

There is a long religious history of contradictory Biblical interpretations of seeing the disabled as sinful and removed from the Devine, to objects of pity, to lifelong child-like innocents.⁵⁵ Religious opinion ultimately become more concerned about humane treatment of those disabled and deemed unable to work, whereupon people were taken into monasteries or other church-run homes. For the disabled, this continued their separation, not only from the general community, “but also...into specific categories and groups, with differing treatment for each group”.⁵⁶ This commenced what several authors have termed the medical model of

⁵¹ Colin Slasberg, Peter Beresford and Peter Schofield, *Further lessons from the continuing failure of the national strategy to deliver*, Research, Policy and Planning (2014/15) 31(1), 44 <<http://ssrg.org.uk/wp-content/uploads/2012/01/Slasberg-et-al3.pdf>> as at 26 October 2017.

⁵² See *ibid.*, 380

⁵³ See Bo'sher, above n 34.

⁵⁴ See *ibid.*

⁵⁵ See Fiona Campbell, *The Great Divide: Ableism and Technologies of Disability Production*, Centre for Social Change Research, School of Humanities and Human Services, Queensland University of Technology, Thesis Submitted for the full requirement for the award of Doctor of Philosophy (PhD), 2003, 57, citing Cocks E. and Stehlik D. 1996. ‘History of Services’ in Annison J., *Disability*, South Melbourne: Thomas Nelson 8-33, <http://eprints.qut.edu.au/15889/1/Fiona_Campbell_Thesis.pdf> as at 14 March 2017

⁵⁶ Colin Barnes, *Chapter 2 (In ‘Disabled People in Britain and Discrimination: A case for anti-discrimination legislation’): A Brief History of Discrimination and Disabled People*,

disability,⁵⁷ marked by Colin Barnes as drawing much from a Darwinist evolutionary view, which would then morph into a eugenics policy in Nazi Germany that exterminated “between 80,000 and 100,000 disabled people”.⁵⁸

These horrors are cited by O’Brien and Duffy, as one of several key elements which crystalized support for a growing welfare state. With echoes of former Prime Minister Robert Menzies’ 1942 call for a stable, peaceful economic and social order,⁵⁹ they state:

The welfare state did not come into existence for reasons of theory; it was developed as a response to decades of fear, terror and horror. Politicians of all colours came to see that it was going to be necessary to put in place a system of social security in order to avoid the kinds of revolutions, wars and totalitarian states that had grown out of the injustices and insecurities of the previous hundred years or more.⁶⁰

They also cite opinion that, in the Post-War period, only the State was believed capable to deliver many services.⁶¹ Consequently, people in Australia and several other similar Western democracies came to accept and indeed expect, that government spending would account for a sizeable portion of Gross Domestic Product.⁶²

Welfare as an ‘exchange’

A distinct loss of faith in that model has come with the NDIS individual care and support plans, along with the general encouragement to self-mange. This concept can be seen to have

<http://repositoriocdpd.net:8080/bitstream/handle/123456789/495/CL_BarnesC_BriefHistoryDiscrimination_1991.pdf?sequence=1> as at 18 January 2017

⁵⁷ See Campbell, above n 55, 147-155; see also, Louise Humpage, *Models of Disability Welfare and Work in Australia*, Social Policy & Administration, Vol 41, No 3, June 2007, 215–217 <<http://onlinelibrary.wiley.com/doi/10.1111/j.1467-9515.2007.00549.x/full>> 5 November 2016

⁵⁸ Barnes, above n 45

⁵⁹ See Petro Georgiou, *Menzies, Liberalism And Social Justice*, Sir Robert Menzies Lecture Trust, 1999 Lecture (1999), 3, <<http://www.menzieslecture.org/1999.html>> quoting Robert Menzies, *The Forgotten People: Chapter 5 - Freedom from Want*, 10 July 1942, The Menzies Foundation, Menzies Virtual Museum <<http://menziesvirtualmuseum.org.au/transcripts/the-forgotten-people/63-chapter-5-freedom-from-want>> as at 18 March 2017. Mr Menzies said, in particular:

The country has great and imperative obligations to the weak, the sick, the unfortunate. It must give to them all the sustenance and support it can. We look forward to social and unemployment insurances, to improved health services, to a wiser control of our economy to avert if possible all booms and slumps which tend to convert labour into a commodity, to a better distribution of wealth, to a keener sense of social justice and social responsibility. We not only look forward to these things; we shall demand and obtain them. To every good citizen the State owes not only a chance in life but a self-respecting life

⁶⁰ John O’Brien and Simon Duffy, above n 8, 12,

⁶¹ See *ibid.*, 15

⁶² See *ibid.*, 13-14

a parallel in the preceding employment policy ‘mutual obligation.’ This marked an important point in critical thinking about welfare, especially the legal, moral and political basis for its provision. Hartman and Darab argue that welfare has ceased largely to become “a right of citizenship but as the provision of minimum social standards that are appropriate to the stage of capitalist development”.⁶³ These authors argue that this change is based on the convergence of two ideological policy arguments; the first sees work as a ‘social good’ while the second views welfare dependence as a barrier to the attainment of the first.⁶⁴

They argue that the linking of social and political rights to responsibilities to find work as imposing a trade-off which weighs heaviest on the poorest and most vulnerable members of our society.⁶⁵ Hartman and Derb claim that this is a particularly conservative and neo-liberal construct because:

(the) realisation of social rights in western nations has always taken a backseat to the promotion of civil liberties and democratic freedoms, in this latest Australian welfare reform, social rights are not even on the agenda. In this climate, to construct someone as a dependent is to demean him/her.⁶⁶

Something similar has happened with the NDIS. People are implicitly expected to actively ‘want’ self-management as the means to, or the ‘mutual obligation’ exchange for, the ‘right’ of choice. John Howard insists in *Lazarus Rising* that ‘mutual obligation’ was not demeaning but policy which “struck the right balance between the laissez-faire insensitivity of the Americans, and the paternalistic approach of so many European countries.”⁶⁷ He also insists that he was never inclined to place time limits on people’s access to welfare, but this view was based on two clear premises; the first was that payment was continued “so long as

⁶³ Yvonne Hartman and Sandy Darab, *Howard’s Way: Work Choices, Welfare Reform and the Working Wounded* (Paper presented to the Road to Where? Politics and Practice of Welfare to Work Conference, 17-18 July, 2006, Brisbane), 8, quoting Mishra, R. 1999, *Globalisation and the welfare state*, Edward Elgar, Aldershot <<http://www.uq.edu.au/swahs/welfaretoWork/Final/conferencepaperHartman.pdf>> as at 9 January 2017

⁶⁴ See *ibid.*, 9, quoting Dean, H. 2004a, ‘Human rights and welfare rights: contextualising dependency and responsibility’, in *The Ethics of Welfare: Human rights, dependency and responsibility*, ed. H. Dean, The Policy Press, Bristol, pp. 7-28; Dean, H. 2004b, ‘Reconceptualising dependency, responsibility and rights’, in *The Ethics of Welfare: Human Rights, Dependency and Responsibility*, ed. H. Dean, The Policy Press, Bristol, pp. 193-210.; Andrews, K. 2005, ‘A nation of participants – Workplace relations and welfare reform’, *The Sydney Papers*, Autumn, pp. 75-82; Australian Government 2005b, *Welfare to Work: 2005-06 Budget*, Commonwealth of Australia, Canberra.

⁶⁵ See *ibid.*, 9, quoting Dwyer, P. 2004, ‘Agency, ‘dependency’ and welfare: beyond issues of claim and contribution?’, in H Dean (ed.) *The Ethics of Welfare: Human rights, dependency and responsibility*, The Policy Press, Bristol, pp. 135-154.

⁶⁶ *Ibid.*

⁶⁷ John Howard, *Lazarus Rising: A Personal and Political Autobiography*, Harper Collins Publishers, 2010, 487.

(unemployed people) met their community obligations through work for the dole”.⁶⁸ Howard’s other assertion was that the NGO sector understood and could service the needs of the unemployed and underprivileged far better than anyone in government.⁶⁹

Downplaying or dismissing a role for government in employment services may seem strange for a man who spent a large part of his professional life in Australia’s Parliament and eleven of those years as Prime Minister leading the party founded by Menzies. However, Howard is proud to claim his Government “in a world first...effectively privatised employment services.”⁷⁰ While this appears to omit any acknowledgement of the earlier cited Keating Labor Government reforms⁷¹ it shows a political consensus developing around the alleged need to outsource public services.

The NDIS achieves much the same thing in much the same way by the same means, while allowing Labor Prime Minister Gillard to claim that the needs of people with disability will be met. However, this not by means of a broad social compact where the State provides services to the citizen. Rather, everyone who meets the disability criteria in the NDIS Act of ‘permanent and significant impairment’⁷² must then submit a plan for funded supports to the Agency before funds may be released, to be spent with predominantly Agency-approved NGO providers.

This process can be far from smooth. An example of this is Sydney mother and former academic Kirsten Harley. With advancing motoneuron disease she applied for communication technology to address the time when her disease robbed Dr Harley of speech. The NDIA rejected this application. Dr Harley told the ABC that:

My impression of what [the NDIS planner] was saying is that the disease is likely to progress rapidly and therefore it's not worth spending the money...The whole point of the NDIS is to promote independence and to promote a place in society for people with significant disability.⁷³

⁶⁸ Ibid

⁶⁹ See *ibid.*, 488.

⁷⁰ Ibid.

⁷¹ See O’Sullivan, Considine and Lewis, above n 11, 6.

⁷² See National Disability Insurance Agency, *Permanent and significant disability and reasonable and necessary supports Transcript* <<https://www.ndis.gov.au/html/sites/default/files/Reasonable-and-necessary-transcript.docx>> as at 15 December 2017

⁷³ Dan Conifer, *Terminally ill mother fears NDIS 'writing off' people with neurological conditions*, Updated 15 Apr 2017, 3:11pm, Sat 15 Apr 2017, 3:11pm, <<http://www.abc.net.au/news/2017-04-15/terminally-ill-mother-fears-ndis-writes-off-people/8445228>> as at 22 April 2017

In response, the Agency cited its high case load, of 100,000 participants this year, claiming many of these people had no support previously.⁷⁴ This demonstrates the real power of Agency planners over participants and families, even in the allegedly new model of disability service and support system which claims to be person-centred.

Here is an agency in the Agency, relying on NGO service providers to deliver support, while struggling to deal with a large caseload. This is not unlike the effect of the AE3000 computer system used in employment services, mentioned earlier. It is to be wondered whether to manage demand, the Agency and NGO providers will need to adopt similar punitive procedures. Similarly, how many more Dr. Harley's are there out there suffering anonymously. Dr Harley was at least 'fortunate enough' to be able to bring attention to her own complex needs and, the Agency's apparently readiness to dismiss as unreasonable her aim to retain an ability to communicate.

Conclusion

Is this really the mark the Agency and NGO service providers intended to leave? Is this the mark Julia Gillard intended to leave? Probably not, but for people with disabilities to be enabled by the NDIS, many are obliged to enter contracts and make exchanges with NGOs regarding matters that no rights-bearing citizen should have to contemplate, to access publicly funded support as consumers rather than citizens. It is not clear that many people with disabilities or their families wanted facilities such as individualised budgeting. As some cited in the *Living Life My Way* consultation said, they hired providers to navigate the complexities of the new system on their behalf. The removal of disability services from Government Departments like ADHC, alongside the transition to individual funding, has thrown up just as many inequities as those of which the old block-funding system stood accused. When a professional person like Micheline Lee hires a specialist NDIS Plan Manager and, is faced with a highly inaccurate initial assessment of her disability by the NDIS itself, such concerns are only heightened.

The final and most heinous indignity is that from a Post-War consensus about the public provision of key social services, people with disabilities (like me) are now herded into a pre-War dependency on charities, by operation of the NDIS Act. Therefore, my final remark is a question: Am I still a citizen, with any entitlement to truly public services?

⁷⁴ Ibid

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