

The NDIS – Just another Big Bureaucracy

1. Introduction

The National Disability Insurance Scheme (NDIS) Bill was enacted by Parliament in 2013¹. The impetus for the Bill came from the Productivity Commission. In 2011 the former Gillard

¹ The NDIS was a series of Bills put before Parliament. These were:

1. The [National Disability Insurance Scheme Bill 2012](https://www.legislation.gov.au/Browse/Results/ByID/Bills/Other/C2012B00230), C2012B00230, Introduced On: 29/11/2012, <<https://www.legislation.gov.au/Browse/Results/ByID/Bills/Other/C2012B00230/Explanatory%20Memorandum/Text>> as at 10 February 2017; Explanatory Memorandum <<https://www.legislation.gov.au/Details/C2012B00230/Explanatory%20Memorandum/Text>> as at 10 February 2017; Second Reading Speech presented by the Hon. Julia Gillard MP (Prime Minister) <<https://www.youtube.com/watch?v=71CuHzTnusE>> as at 10 February 2017
2. *Appropriation Act (No. 1) 2012-2013, Act No. 78 of 2012*, (C2014C00172), Schedule 1: Services for which money is appropriated, 67, <<https://www.legislation.gov.au/Details/C2014C00172/71af9003-7172-4ffd-a5c9-cfafba2317f0>> as at 10 February 2017; Second Reading Speech delivered by the Hon Wayne Swan MP (Deputy Prime Minister and Treasurer) Tuesday 14 May 2013, House of Representatives *Hansard*, 3136-3137, <http://parlinfo.aph.gov.au/parlInfo/genpdf/chamber/hansardr/9876e2b9-5961-455f-aa38-455af1c59cb8/0124/hansard_frag.pdf;fileType=application%2Fpdf>
3. The [Medicare Levy Amendment \(DisabilityCare Australia\) Bill 2013](https://www.legislation.gov.au/Browse/Results/ByID/Bills/Other/C2013B00105), C2013B00105, Introduced On: 15/05/2013, Second Reading Speech presented by the Hon. Julia Gillard MP (Prime Minister), House of Representatives, Wednesday 15 March 2013, House of Representatives *Hansard*, 3181-3184 <http://parlinfo.aph.gov.au/parlInfo/genpdf/chamber/hansardr/be0df22c-0b6f-4a7b-a517-08bec7742457/0005/hansard_frag.pdf;fileType=application%2Fpdf> You Tube recording <<https://www.youtube.com/watch?v=d8Z0MXRIOTw>> as at 10 February 2017. There were 11 other related Bills introduced to amend various Acts; see *Hansard*, 3184-3195 <http://parlinfo.aph.gov.au/parlInfo/download/chamber/hansardr/be0df22c-0b6f-4a7b-a517-08bec7742457/toc_pdf/House%20of%20Representatives_2013_05_15_1875_Official.pdf;fileType=application%2Fpdf#search=%22chamber/hansardr/be0df22c-0b6f-4a7b-a517-08bec7742457/0000%22> as at 10 February 2017
4. The [National Disability Insurance Scheme Legislation Amendment Bill 2013](https://www.legislation.gov.au/Browse/Results/ByID/Bills/Other/C2013B00104), C2013B00104, Introduced On: 15/05/2013, <<https://www.legislation.gov.au/Browse/Results/ByID/Bills/Other/C2013B00104/Explanatory%20Memorandum/Text>> as at 10 February 2017; Explanatory Memorandum <<https://www.legislation.gov.au/Details/C2013B00104/Explanatory%20Memorandum/Text>> as at 10 February 2017; Second Reading Speech, House of Representatives *Hansard* 3198-3200 <http://parlinfo.aph.gov.au/parlInfo/download/chamber/hansardr/be0df22c-0b6f-4a7b-a517-08bec7742457/toc_pdf/House%20of%20Representatives_2013_05_15_1875_Official.pdf;fileType=application%2Fpdf#search=%22chamber/hansardr/be0df22c-0b6f-4a7b-a517-08bec7742457/0323%22> as at 11 February 2017
5. The [Social Services Legislation Amendment \(Transition Mobility Allowance to the National Disability Insurance Scheme\) Bill 2016](https://www.legislation.gov.au/Browse/Results/ByID/Bills/Other/C2016B00164), C2016B00164, Introduced On: 13/10/2016, <<https://www.legislation.gov.au/Browse/Results/ByID/Bills/Other/C2016B00164/Explanatory%20Memorandum/Text>> as at 10 February 2017; Explanatory Memorandum <<https://www.legislation.gov.au/Details/C2016B00164/Explanatory%20Memorandum/Text>> as at 10 February 2017; Second Reading Speech, House of Representatives *Hansard*, 1849-1852, <http://parlinfo.aph.gov.au/parlInfo/download/chamber/hansardr/f2541705-5a09-4607-bf3f-1d6fd9b611ff/toc_pdf/House%20of%20Representatives_2016_10_13_4470_Official.pdf;fileType=application%2Fpdf#search=%22chamber/hansardr/f2541705-5a09-4607-bf3f-1d6fd9b611ff/0024%22> as at 11 February 2017
6. The [National Disability Insurance Scheme Savings Fund Special Account Bill 2016](https://www.legislation.gov.au/Browse/Results/ByID/Bills/Other/C2016B00078), C2016B00078, Introduced On: 31/08/2016, <<https://www.legislation.gov.au/Browse/Results/ByID/Bills/Other/C2016B00078/Explanatory%20Memorandum/Text>> as at 10 February 2017; Explanatory Memorandum <<https://www.legislation.gov.au/Details/C2016B00078/Explanatory%20Memorandum/Text>> as at 10

government had referred the issue of inconsistencies and inequities in Disability Services amongst the States and Territories to the Commission.² Many people highlighted the suffering caused by the level of unmet need. As well, several reports that were tabled in Parliament, or produced by committees, public agencies or disability advocates included horrendous accounts of abuse and neglect in understaffed, under-resourced disability services.³ This made people consider the idea of universal coverage, echoing Medicare's role in the health system. It was thought that the establishment of a national disability scheme would be an improvement on the State and Territory based scheme.⁴ At the same time, in

February 2017; Second Reading Speech, House of Representatives *Hansard*, 104-107,
http://parlinfo.aph.gov.au/parlInfo/download/chamber/hansardr/f706773d-28cd-4fb7-b62a-9ed884a645d8/toc_pdf/House%20of%20Representatives_2016_08_31_4425_Official.pdf;fileType=application%2Fpdf#search=%22chamber/hansardr/f706773d-28cd-4fb7-b62a-9ed884a645d8/0100%22>
 as at 11 February 2017

7. The [National Disability Insurance Scheme Savings Fund Special Account Bill 2016](#), C2016B00041, Introduced On: 16/03/2016,
<https://www.legislation.gov.au/Browse/Results/ByID/Bills/Other/C2016/0/disability%20insurance/InForce>> as at 10 February 2017; Explanatory Memorandum
<https://www.legislation.gov.au/Details/C2016B00041/Explanatory%20Memorandum/Text>> as at 10 February 2017; Second Reading Speech, House of Representatives *Hansard*, 1849-1852,
http://parlinfo.aph.gov.au/parlInfo/download/chamber/hansardr/f2541705-5a09-4607-bf3f-1d6fd9b611ff/toc_pdf/House%20of%20Representatives_2016_10_13_4470_Official.pdf;fileType=application%2Fpdf#search=%22chamber/hansardr/f2541705-5a09-4607-bf3f-1d6fd9b611ff/0023%22> as at 11 February 2017

² See Productivity Commission, Disability Care and Support: Productivity Commission Inquiry Report Overview and Recommendations, No. 54, 31 July 2011, iv-vi,
<http://www.pc.gov.au/inquiries/completed/disability-support/report/disability-support-overview-booklet.pdf>>
 as at 12 February 2017

³ There is a vast array of relevant documents. These include:

1. 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>
2. Report of the Disability Investment Group, THE WAY FORWARD: A New Disability Policy Framework for Australia, © Commonwealth of Australia 2009,
https://www.dss.gov.au/sites/default/files/documents/05_2012/dig_report_19oct09.pdf>
3. Centre for Disability Research and Policy, Report of Audit of Disability Research in Australia, Faculty of Health Sciences University of Sydney, May 2014,
http://www.adhc.nsw.gov.au/_data/assets/file/0013/300091/1a-Audit-of-Disability-Research-in-Australia.pdf>
4. Senate Standing Committee on Community Affairs – Report: Adequacy of existing residential care arrangements available for young people with severe physical, mental or intellectual disabilities in Australia, 24 June 2015 © Commonwealth of Australia 2015,
http://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/Young_people_in_aged_care/~media/Committees/clac_ctte/young_agedcare/report.pdf>
5. Senate Standing Committee on Community Affairs – Report: Violence, abuse and neglect against people with disability in institutional and residential settings, including the gender and age related dimensions, and the particular situation of Aboriginal and Torres Strait Islander people with disability, and culturally and linguistically diverse people with disability, 25 November 2015, © Commonwealth of Australia 2015,
http://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/Violence_abuse_neglect/~media/Committees/clac_ctte/Violence_abuse_neglect/report.pdf>

⁴ See Luke Buckmaster (Social Policy Section), *The National Disability Insurance Scheme: a quick guide* Updated 3 March 2017, The Parliamentary Library, Commonwealth of Australia,
https://www.aph.gov.au/About_Parliament/Parliamentary_Departments/Parliamentary_Library/pubs/rp/rp1617/Quick_Guides/NDIS> as at 10 December 2017. In particular, the guide states:

establishing such a scheme, Australia would be meeting its obligations under the Convention on the Rights of People with Disabilities.⁵

The role of the NDIS is to provide care and support to people with disabilities who meet the relevant criteria. The Scheme also aims to support eligible 'participants' to engage in employment. With the introduction of the NDIS the National Disability Insurance Agency (NDIA) was also introduced. The NDIA is the agency that administers the NDIS. The functions and administration of the NDIS are evolving; the rules and guidelines of the NDIA allows for both Commonwealth and State and Territory NDIS Schemes to coexist. Prior to the introduction of the NDIS, services would be directly funded by the government with fixed or block grants. For clients, this meant that to receive a service they had to meet the program criteria and they had to be referred to a program before it was full. The main identified problems with this approach was that there were many people who went without any services at all because the programs had met their funding capacity and were full.

The NDIS was introduced to solve this issue. Its funding is based on meeting individual assessed need. This means that participants are funded directly and they can choose the services they need to access. Whether the NDIS in fact provides a better system of delivering disability services than the old systems of delivery and support will be critically examined in this paper. In assessing whether the NDIS is an improvement the paper will first consider whether it upholds the rights of people with disabilities as set out in the Convention on the Rights of People with Disability and which the NDIS Act has sought to incorporate. Secondly, the paper will draw on the perspectives of individual participants to assess whether it is meeting their needs better than under the old system. The focus will be on participants in the Sydney region.

2. The Question

Stated in the objects to the *National Disability Insurance Scheme Act 2013* (Cth) ('the NDIS Act') is the aim to give effect to the *Convention on the Rights of People with Disabilities* ('the Convention'). In particular, article 26 of the Convention places duties on State parties to:

The NDIS will largely replace the existing system of disability care and support provided under the [National Disability Agreement \(NDA\)](#). Currently, the Australian Government has responsibility for providing employment services for people with disability and funding for states and territories to assist with meeting the objectives of the NDA. State and territory governments are responsible for specialist disability services, such as accommodation support, respite care, community support, community access, and advocacy and information for people with disability.

According to the Productivity Commission's [Report on Government Services 2017](#), 28.9 per cent of the \$8.4 billion spent on specialist disability services in 2014–15 came from the Australian Government, and 71.1 per cent came from the states and territories.

In 2011, the Productivity Commission [recommended](#) that Australia replace the existing system with a unified national scheme to fund long-term, high-quality care and support for all Australians who experience significant disability (to be known as the NDIS). It described the existing system as 'underfunded, unfair, fragmented, and inefficient', arguing that it gave people with a disability 'little choice and no certainty of access to appropriate supports'.

⁵ But see David Gibson, *Disability, inclusion and democracy - an uncomfortable fit* [online]. [Australasian Parliamentary Review](#), Vol. 30, No. 1, Autumn/Winter 2015: 154-161. Availability: <http://search.informit.com.au/simsrad.net.ocs.mq.edu.au/documentSummary;dn=879368575509560;res=IELA PA> ISSN: 1447-9125. as at 11 December 2017.

take effective and appropriate measures to enable people with disability to attain and maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life.⁶

It would appear from the point of view of government that these obligations will be met by bringing certainty of service and support to all eligible people with permanent impairments through the work of the NDIS. Indeed, from the point of view of government the delivery of these supports are supposed to facilitate an ‘ordinary life’. While this phrase is used in the Annual General Report of the National Disability Insurance Agency (NDIA),⁷ it is notable for its absence from the principal enabling legislation, the NDIS Act.⁸ Rather, the refrain of an ‘ordinary life’ appears to be an attempt to summarise the Objects⁹ and Principles¹⁰ stated in the opening sections of the Act. Interestingly, the summation focuses on services and supports necessary to assist someone with a disability. But is this enough?

As was emphasised by the Chair of the Independent Advisory Council, Rhonda Galbally, in a report she issued to the Joint Standing Committee on the NDIS in 2015:

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.¹¹

It is worth noting that earlier in the report, a distinction had been drawn between ‘the good life’ and an ‘ordinary life’. The latter was of a lower order, justified for people with a disability on the grounds that ‘(the) lives of people with disability...start from a lower base – a life lived in services’.¹²

Evidently, different standards exist that could be used to determine the sort of life people with disabilities should enjoy. In view of these differences, the paper seeks to address this question: What sort of life should people with disabilities have in Australia and is the NDIS really designed to support such a life?

3. The Argument

⁶ Explanatory Memorandum, *National Disability Insurance Scheme Bill 2012 (Cth)*, *Statement of Compatibility with Human Rights: Prepared in accordance with Part 3 of the Human Rights (Parliamentary Scrutiny) Act 2011*, 6 <http://parlinfo.aph.gov.au/parlInfo/download/legislation/ems/r4946_ems_2e629de9-8977-4c7e-9886-28db156673e1/upload_pdf/375307.pdf;fileType=application%2Fpdf> as at 11 September 2016

⁷ See National Disability Insurance Agency, *Towards an ordinary life: NDIS Annual Report 2015-16*, Commonwealth of Australia, 2 <<https://www.ndis.gov.au/medias/documents/ha5/h04/8798853726238/NDI7040-AnnualReport2016-vFaccessible.pdf>> as at 12 October 2017

⁸ See generally, *National Disability Insurance Act (Cth) 2013*, No. 20 of 2013, <<https://www.legislation.gov.au/Details/C2016C00934/Download>> as at 12 October 2017

⁹ See *ibid.*, s. 3, which lists a variety of ‘Objects of (the) Act’.

¹⁰ See *ibid.*, s.4, which lists ‘General principles guiding actions under this Act’

¹¹ 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

¹² *Ibid.*, 11

The argument advanced in this paper is that the NDIS should strive to uphold the rights of people with disabilities by meeting their needs. The argument is framed from the perspective that the State has obligations to people with disability that it is required to fulfill. In fulfilling these obligations it is contended that the State should take a ‘person-centred’ rather than a system-centred approach to the delivery of services (discussed further in Methodology). This would involve overcoming what people with disabilities see as the oppressive social practices in which they live, rather than simply adopting a medical model that cannot see past their impairments. This is what Fiona Given of the NSW Disability Discrimination Legal Centre claimed in 2010 was required in order to realise the rights protected by the Convention. It is an approach that:

effectively views disability through the lens of the social model of disability which looks at how the social environment disables a person, as opposed to the medical model which looks at the impairment.¹³

However, the argument advanced in the paper is that if the government has interpreted these obligations to mean ensuring that users of the NDIS live an ordinary life (understood as a life lived in services and with disability omnipresent), then the contention is that such an approach (as services are currently administered and funded) falls short of meeting the standard that has been set in the Convention.

The argument is two-fold. The first relates to the way that the NDIS is to be administered; the second relates to the kinds of services to be funded by the NDIA.

There are a number of interrelated issues with the administration of the NDIS: it is complicated and involves co-ordination between Commonwealth and State and Territory governments; there are issues with the fact that service delivery will be transferred from government to not-for-profit organisations (NGOs); and there are issues with the fact that participants of the system will be required to engage directly with service providers to obtain the services they need. Each of these will be discussed in turn to show that the lives of participants under the NDIS will probably not meet the standard as set by the Convention.

Government administration of the Scheme has been split between States and Territories. This process has been facilitated through Bilateral Agreements between the various States and Territories and the Commonwealth Government.¹⁴ Disputes between participants and providers are matters for the State Ombudsman, while complaints about funding by the National Disability Insurance Agency (NDIA) are matters for the Commonwealth

¹³ Productivity Commission, Transcript of Proceedings: *Inquiry into Disability Care and Support*, Ms. P. Scott, Presiding Commissioner, Mr. D. Kalisch, Commissioner, Mr. J. Walsh, Associate Commissioner, Sydney on Tuesday, 20 July 2010, at 9.31 AM, Spark and Cannon, 752.

¹⁴ These are all listed at: Council of Australian Government, *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. 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.

Ombudsman.¹⁵ This distinction arises because the States, while sitting on the NDIA Ministerial Council,¹⁶ have referred their State-based disability funds, to varying degrees, to the Commonwealth. NSW was the first to sign up to the NDIS and contribute money to the scheme. In the media, this was presented as a benchmark for other jurisdictions to follow.¹⁷

Meanwhile, the Commonwealth is in the process of establishing a Safety and Quality Commission.¹⁸ Currently, legislation enacting amendments to the NDIS Act which will establish the Commission are going through a committee process in Parliament.¹⁹ While the Senate recommended the Bill's passage, it noted with some concern the wide range of safety and quality issues to be determined by the NDIS Rules, rather than including them in the principal legislation.²⁰ Existing measures are summarized by a NSW Government/NDIS fact sheet.²¹ The Commission will not replace the Commonwealth or State Ombudsman offices, but rather:

A national registrar will oversee registration, compliance and quality assurance. The registration process for NDIS service providers will be 'proportionate' – meaning that providers who deliver low risk services will go through a simpler verification process than those who deliver higher risk supports. Registered providers will be required to meet extra quality and competency standards and will be subject to auditing requirements.

¹⁵ See *The NSW Ombudsman and the NDIA*, NDIS Fact Sheet 1, <https://www.ombo.nsw.gov.au/data/assets/pdf_file/0003/19074/NSW-Ombudsman-and-the-NDIS.pdf> as at 14 November 2017

¹⁶ See Section 12 of the NDIA Act 2013, which states:

12 Ministerial Council functions etc.

(1) The Ministerial Council is to:

(a) consider policy matters that relate to the National Disability Insurance Scheme or arise under this Act; and

(b) advise the Minister about such matters; and

(c) make recommendations to COAG about such matters.

(2) The advice and recommendations must not relate to a particular individual.

(3) The Minister must consult the Ministerial Council about policy matters that relate to the National Disability Insurance Scheme or arise under this Act.

¹⁷ See e.g.: *Gillard And O'Farrell Reach Agreement On NDIS Funding In N.S.W.*, Dec 06, 2012, <<https://australianpolitics.com/2012/12/06/gillard-ofarrell-ndis-funding-agreement.html>> as at 30 November 2017

¹⁸ See Christian Porter MP, *New legislation to ensure quality of NDIS services*, 31 May 2017, Media Releases, <<https://christianporter.dss.gov.au/media-releases/new-legislation-to-ensure-quality-of-ndis-services>>; also see Department of Social Services, *NDIS Quality And Safeguarding Framework*, 9 December 2016 <https://www.dss.gov.au/sites/default/files/documents/04_2017/ndis_quality_and_safeguarding_framework_final.pdf> as at 14 November 2017

¹⁹ See Senate Standing Committee on Community Affairs, *National Disability Insurance Scheme Amendment (Quality and Safeguards Commission and Other Measures) Bill 2017*, <https://www.aph.gov.au/sitecore/content/Home/Parliamentary_Business/Committees/Senate/Community_Affairs/NDISQualitySafeguards>

²⁰ See Senate Standing Committee on Community Affairs, *Report: National Disability Insurance Scheme Amendment (Quality and Safeguards Commission and Other Measures) Bill 2017 [Provisions]* 8 November 2017, © Commonwealth of Australia 2017, 7-8 <https://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/NDISQualitySafeguards/Report> as at 14 November 2017

²¹ See Fact Sheet Providing quality and safe supports for NDIS participants in NSW, <<http://ndis.nsw.gov.au/wp-content/uploads/2017/04/Providing-quality-and-safe-supportsfor-NDIS-participants-in-NSW-Fact-Sheet.pdf>> as at 16 November 2017

State and territory governments will continue to manage worker screening checks and authorise the use of restrictive policies. However, a new national senior practitioner will seek to reduce restrictive practices, and a national policy for worker screening checks will be developed.²²

This hardly sounds like a nationally consistent insurance scheme. Instead there will be multiple regulators and oversight bodies at State and Commonwealth level, giving rise to a potentially confusing mismatch of State and Commonwealth regulators. However it is evident that the process relies on the individual participant or family being able and willing to make a complaint to the respective Ombudsman's office. And once the Commission is set up, its success will depend whether on providers are registered with the Commission and that participants and families (as well as providers) are aware of the Commission and its work.

This complex scheme is problematic as it relies more and more on families and individuals with disability being able to navigate a complex array of State and Commonwealth regulating bodies.²³ Another layer of complication is the overwhelming push (particularly in NSW) to move all service delivery capacity to the NGO sector. This does not accord with most post-War policy development.²⁴ Instead, the philosophy underpinning such an approach is informed by neoliberalism. The NDIS came into force within a context of 20 years of neoliberal theory being the dominant policy framework since the Hawke/Keating government.²⁵ In this time, governments at State and Commonwealth level have outsourced or sold off a number of public instrumentalities to the private sector or charitable institutions. The general argument in favour of this reform has been that the private or charitable sectors are more efficient than government, or more focused and aware of client needs. The retraction of the state in the delivery of services is further justified as empowering clients by allowing them to make decisions about service provision. This is seen positively as giving them choices regarding the provision of services and thereby ensuring their needs are met.

When considering disability services and the vulnerable people who access them, this paper asks whether neoliberal policy results in satisfactory outcomes. In arguing that they are unsatisfactory, this paper makes the case that the government has real and abiding duties that

²² Every Australian Counts, *New national framework to ensure quality and safety*, 13 February 2017 <<http://www.everyaustraliancounts.com.au/new-national-framework-ensure-quality-safety/>> as at 30 November 2017

²³ See generally, Carmel Laragy, Karen R. Fisher, Christiane Purcal and Samantha Jenkinson, *Australia's Individualised Disability Funding Packages: When Do They Provide Greater Choice and Opportunity?*, *Asian Social Work and Policy Review* 9 (2015) 282–292, <<http://onlinelibrary.wiley.com/simsrad.net.ocs.mq.edu.au/doi/10.1111/aswp.12068/epdf>>; Cf Wendy Brown, *Sacrificial Citizenship: Neoliberalism, Human Capital, and Austerity Politics*, *Constellations* Volume 23, No 1, 2016. © 2016 John Wiley & Sons Ltd, <<http://onlinelibrary.wiley.com/simsrad.net.ocs.mq.edu.au/doi/10.1111/1467-8675.12166/epdf>>; see generally Fiona Macdonald, *Marketising social care* [online]. *Arena Magazine* (Fitzroy, Vic), No. 149, Aug 2017: 22–25. Availability: <<http://search.informit.com.au/simsrad.net.ocs.mq.edu.au/documentSummary;dn=102343669156755;res=IELAPA>> ISSN: 1039-1010. [cited 11 Dec 17]

²⁴ For an effective historical review of the relationship between the government and the citizen see e.g. Engin F. Isin & Bryan S. Turner (2007) *Investigating Citizenship: An Agenda for Citizenship Studies, Citizenship Studies*, 11:1, 5–17, DOI: 10.1080/13621020601099773, <<https://doi.org/10.1080/13621020601099773>> as at 10 December 2017

²⁵ See e.g. Mark Beeson, and Ann Firth. *Neoliberalism as a political rationality: Australian public policy since the 1980s*. [online]. *Journal of Sociology*, Vol. 34, No. 3, Nov 1998: 215–231. Availability: <<http://search.informit.com.au/simsrad.net.ocs.mq.edu.au/documentSummary;dn=200005021;res=IELAPA>> ISSN: 1440-7833 as at 10 December 2017.

cannot and should not outsource to other parties.²⁶ The argument rests partly on the notion of public citizenship and public accountability for the goods and services rendered to those in our society who are most needy.²⁷

This paper argues that these people deserve public assurance that their needs will be met and that, indeed, if the relevant international covenants have any meaning the State signatory must assume direct and clear responsibility. It is also important to take public notice of the facts about the behaviour of various charitable care agencies exposed by the current McClelland Royal Commission into Institutional Responses to Child Abuse and Neglect.²⁸ This inquiry has provided a template showing how easily things can go wrong when churches and charities are entrusted with too much power and discretion, as well as being accorded great deference.²⁹

Despite these lessons, this paper will show that many of the same church and charitable organisations which were found wanting before the McClelland Royal Commission have been given responsibility to provide support and services under the disability insurance scheme and questions have already been raised.³⁰ The robustness of this decision and the adequacy of safety and quality regimes introduced by the Commonwealth and the States to attempt to ensure client safety will be scrutinised.³¹ Recommendations for reform will also be made based on these findings.

²⁶ For a consideration of this issue from the US perspective see generally, Paul R. Verkuil, *Outsourcing Sovereignty: Why Privatization of Government Functions Threatens Democracy and What We Can Do about it*, 2007, Cambridge University Press, <http://www.langtoninfo.com/web_content/9780521867047_frontmatter.pdf>; see also from an Australian perspective, Richard Mulgan, *Transparency and the Performance of Outsourced Government Services Occasional Paper No. 5*, This research paper was commissioned by the Queensland Office of the Information Commissioner and prepared for the Australia and New Zealand School of Government March 2015, <<http://apo.org.au/system/files/53659/apo-nid53659-12231.pdf>>; Contra: Dr David Kemp MP, *Key Speech: Public Administration in the New Democratic State*, Address to the National Conference of the Institute of Public Administration Australia, Canberra, November 1997, <<http://onlinelibrary.wiley.com/simsrad.net.ocs.mq.edu.au/doi/10.1111/j.1467-8500.1998.tb01378.x/epdf>> as 10 December 2017

²⁷ See generally, Helen Dickinson, Catherine Needham and Helen Sullivan, *Special Issue: Individual Funding for Disability Support: What are the Implications for Accountability?* Australian Journal of Public Administration, vol. 73, no. 4, pp. 417–425 doi:10.1111/1467-8500.12106 <<http://onlinelibrary.wiley.com/simsrad.net.ocs.mq.edu.au/doi/10.1111/1467-8500.12106/epdf>>; from an American perspective compare e.g.: Kimberly N. Brown, "Outsourcing, Data Insourcing, and the Irrelevant Constitution," Georgia Law Review 49, no. 3 (Spring 2015): 607-692, <http://heinonline.org/simsrad.net.ocs.mq.edu.au/HOL/Page?handle=hein.journals/geolr49&div=20&g_sent=1&casa_token=&collection=journals> as at 11 December 2017

²⁸ See e.g.: Rachel Browne, 'Survivors have waited too long': 4000 institutions named in sex abuse royal commission, Sydney Morning Herald, March 27 2017 <<http://www.smh.com.au/national/survivors-have-waited-too-long-4000-institutions-named-in-sex-abuse-royal-commission-20170326-gv716h.html>> as at 26 June 2017

²⁹ There is some case law about undue influence which may be useful here, particularly where the organisation providing support and care services is a religious body; see e.g.: Pauline Ridge, "The Equitable Doctrine of Undue Influence Considered in the Context of Spiritual Influence and Religious Faith: Allcard v Skinner Revisited in Australia" [2003] UNSWLawJl 3; (2003) 26(1) University of New South Wales Law Journal 66, <<http://www.austlii.edu.au/au/journals/UNSWLawJl/2003/3.html>> as at 26 June 2017

³⁰ See e.g.: Samantha Donovan, NDIS staffing demand may see drop in disability service standards Royal Commission hears, Wednesday, July 20, 2016 18:40:00, <<http://www.abc.net.au/pm/content/2016/s4504131.htm>> as at 20 June 2017

³¹ See e.g.: Carmel Laragy, Four Corners: can the NDIS prevent abuse of people with disability? March 29, 2017 11.13am AEDT, <<https://theconversation.com/four-corners-can-the-ndis-prevent-abuse-of-people-with-disability-75286>> as at 20 June 2017

However, it is evident that Australia's approach to disability services is continuing in the neoliberal direction with the establishment of the Safety and Quality Commission. As noted above, the Rules of Conduct are proposed to be inserted in NDIS Rules and not in the NDIS Act. One of the key reasons the Government did not want more of Rules or Code of Conduct in the legislation, was a fear of reducing flexibility in the marketplace. This was openly stated by Minister Porter in the *Hansard* and cited in the Committee's Report.³² Thus, the policy commitment to the market-based approach remains. This approach itself is driven by the understanding (also expressed by the Productivity Commission when it first considered establishing the NDIS) that giving individual participants freedom of choice about the services they access and whom they access them from generates better outcomes. This might be true, but it would also depend on participants wanting to make decisions of this kind.

It is clear that there is much research in this area, and there is some persuasive evidence. For example, Sheldon Loman and others argue that people with disabilities require support to learn how to make decisions and what consequences flow from them. While their examples concentrate on senior school students, they say:

One instructional model for increasing student-directed learning that has been empirically validated, is the Self-Determined Learning Model of Instruction ... The SDLMI is a three-phase model for teaching a self-regulated problem-solving process that allows students to set goals, plan a course of action, evaluate their own performance, and make adjustments to plans or goals as needed ... The instructional process consists of teaching students to pose four questions during each phase of the process that require the student to (a) identify the problem, (b) identify potential solutions, (c) identify barriers to solving the problem, and (d) identify consequences of each solution

The SDLMI instructional model has been shown to help secondary students with disabilities to increase appropriate behavior in classroom and jobsite settings and to achieve transition-related outcomes such as: improved job task performance, improved budgeting and personal hygiene skills, and increased success in making independent transportation arrangements.³³

This may seem to be unquestionably beneficial for the individuals concerned and the wider community. The Productivity Commission made similar observations in its NDIS Costs Report, while conceding that there was likely a greater role for support agencies to help those with little experience of managing their own affairs to do that.³⁴

Despite arguments for self-management, the very same report acknowledged submissions saying that some participants did not want to self-manage 'because it is perceived to be too complicated and burdensome'.³⁵ Furthermore, the Commission had evidence that in the first

³² See *ibid.*, 8.

³³ Sheldon Loman et. al, *Promoting Self-Determination: A Practice Guide*, A National Gateway to Self-Determination: Funded by the US Department of Health and Human Services, Administration on Developmental Disabilities, June 2010, 28-28, <http://ngsd.org/sites/default/files/promoting_self-determination_a_practice_guide.pdf> as at 18 November 2017

³⁴ See Productivity Commission, *National Disability Insurance Scheme (NDIS) Costs* Productivity Commission Study Report, October 2017, 375, <<http://www.pc.gov.au/inquiries/completed/ndis-costs/report/ndis-costs.pdf>>

³⁵ *Ibid.*, 374

year of the NDIS about 80 per cent of participants let the NDIS Agency or another plan management agency administer their plans.³⁶ This broadly corresponds with international evidence suggesting that in comparable jurisdictions self-management is as low as 11 percent.³⁷

Where rates of self-management did rise, these participants were children whose allocation was actually 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’.³⁸ While children are outside the scope of my research, both Bo’sher and Loman’s work make the point about the considerable preparation and training resources that are needed to put self-management into place. Bo’sher highlights a model of care in Sweden, which can be broadly described as a cooperative of people with disabilities combining to hire support services. While this is offered as a successful model, little detail is offered as to whether it is truly applicable in Australia.

The implication which can be drawn from the article is that the Swedish model is not readily applicable. The observations made about steps that could be ‘reasonable and necessary’ in relation to making someone with a disability ready for work are indicative of an Australian model which is both prescriptive and restrictive. In particular, Bo’sher says:

NDIS funds to spend on work readiness cannot be used to purchase dental work to fix gum and teeth issues even if this would be the most useful assistance to getting a job. Self-management may be intended to provide more empowerment, but it still does not allow participants full autonomy over how to most effectively and efficiently achieve their goals.³⁹

Despite all of this, people with disabilities are being transferred to the NDIS. In NSW all clients of the disability services formally administered by the Department of Ageing, Disability and HomeCare (ADHC) will be transferred to the NDIS by 2018 (discussed further in Methodology). There was no option to stay with a State Government run or funded provider. Equally, as an ADAC client, budgeting, scheduling and, other administrative matters were not the clients’ concern, it was done for them. If the above quoted self-management statistics are any guide, few people want to self-manage their plans. And despite the international evidence strongly suggesting the same things, authors continue to press the case for autonomy, choice and self-management being part of a rights based framework that has been coopted by neoliberal market-based philosophies. Their argument is that rights bearing people with disabilities will want to exercise choice when it comes to the ‘market-place’ of service providers.

But how accurate is this construction? Bo’sher’s earlier cited comment suggests that drafters of the NDIS Act have not given NDIS participants much in the way of flexibility to enter into the market. The low take-up of self-management also undermines the view that people with disabilities and their families share a consensus that they should live their lives according to a market or freedom of choice model. Yet, many authors persist with a rights-based approach

³⁶ See *ibid.*, 380

³⁷ See [Luke Bo'sher](http://www.disabilityservicesconsulting.com.au/resources/self-management), *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

³⁸ See *ibid.*

³⁹ *Ibid.*

which seems to almost insist with a religious-like fervor that individual free choice was the only possible result in the development of policy. For example, Samantha Jenkinson wrote in 2008 that it was possible to anticipate future trends for more individualized funding, but also the real possibility of resource constraints in the sector. This would notionally give people choices, but in Jenkinson's words:

On the other hand, there are also fears that workforce and resource issues are leading to possible mini-institutions with 10 bed group homes and cluster housing of 10-20 units which will further isolate and segregate people with disability.⁴⁰

The Jenkins paper sets out the social and ideological theories of contemporary disability policy, but is far less explicit on what to do about practical shortfalls, like lack of support staff. This is where, at a bare minimum, government should provide services that others cannot or will not provide, or which certain groups of people cannot afford to purchase in an open market. Through ADHC the NSW Government was a direct provider of care and support service, emphasizing the aim (if not the practice) of community providing support services to those people with disabilities assessed to be in need.

In view of this analysis the paper argues that the NDIS is not necessarily any better than the old system it replaced. However, in view of its limitations it may be slightly worse and may not be delivering on its promises. The overall effect has been to increase clients' dependence on third-party service providers; that is NGOs rather than State run organisations. Rather than enabling client choices the approach has made them more vulnerable in having to navigate a complex system where their choices have been paradoxically limited in the name of 'free choice'.

Thus, the argument is that far from promoting the human rights of users of the system, the NDIS is undermining the rights of these users in confining them to the charitable sector and isolating them from government and the measures of accountability and support that the public sector provides.

The second argument advanced in the paper relates to the services and supports available to users through the NDIS and funded by the NDIA. If the aim (as set out in the Convention) is 'to enable people with disability to attain and maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life', how can such a life be achieved?

An implicit but curiously unchallenged element of the NDIS is the assumption that disability will continue to be lifelong, with services delivered by charities and funded by government.⁴¹ From a human rights perspective, why should people with disabilities not expect their living standards and expectations for life to rise with those of all other Australians? The Convention itself is ambiguous in terms of the financial obligations State parties owe to people with disabilities (cf Article 4(1)(f), 4(1)(g) and 4(2)) and therefore gives a lot of discretion to State parties in determining what to fund. Under the NDIS Act funding is determined on the basis

⁴⁰ Samantha Jenkinson, *Disability: Local, National and International Trends*, 2008, 1, <http://www.disability.wa.gov.au/Global/Publications/About%20us/Count%20me%20in/Research/trends_local_national_international.doc> as at 30 November 2017

⁴¹ See especially Rod Simms, 'Privatising NDIS services could be a repeat of the VET-fee disaster', *Sydney Morning Herald*, Fairfax Media, <http://www.smh.com.au/action/printArticle?id=1019423500> as at 27 March 2017

of what is reasonable and necessary. However, the scheme's administrators have already been criticised for their interpretation of what is reasonably necessary. In one case it was reported that a woman was denied walking sticks and forced to use a wheelchair.⁴²

With the development of medical technology like stem cells, exoskeletons⁴³ and brain implants,⁴⁴ genetics and cellular technology,⁴⁵ the public expectation of what is reasonably necessary will change. However, as currently understood, the NDIS assumes disability and then assesses the need for equipment and support services based on reasonable necessity.

People with disabilities and their families may become discontent with the charitable dependence norm⁴⁶ as they witness the advancement of science and technology. Could an ordinary life actually mean living without permanent disability?

Furthermore, as reports continue to emerge about shortfalls in care staff needed to make NDIS supports a reality,⁴⁷ the issue of labour force constraints in this area are widely recognised.⁴⁸ While the NDIA devotes part of its Annual Report to 'assistive technology',⁴⁹ this mainly seems to concern bedroom and bathroom mechanical aides, along with smart phone applications.

While these might be useful and potentially necessary, we are missing a real opportunity to use mechanisation and robotics in care.⁵⁰ Such technological investment could relieve many of the heaviest and most complex aspects of care, while giving assurance to family carers that

⁴² See Miki Perkins, Woman with disabilities scores landmark win over NDIS, June 18 2017, *The Age*, Victoria, <http://www.theage.com.au/victoria/woman-with-disabilities-scores-landmark-win-over-ndis-20170615-gwrz7c> as at 22 June 2017

⁴³ See e.g.: E. Tiernan, ReWalk exoskeleton allows paraplegic Paul Jenkins to walk again, *Sydney Morning Herald*, February 13 2017 <http://www.smh.com.au/technology/sci-tech/rewalk-exoskeleton-allows-paraplegic-paul-jenkins-to-walk-again-20170117-gtt5ar.html> as at 22 June 2017

⁴⁴ See e.g.: B Smith., Human trials for Australian-made bionic spine to start next year, February 9, 2016, *Sydney Morning Herald*, <<http://www.smh.com.au/technology/sci-tech/human-trials-for-australianmade-bionic-spine-to-start-next-year-20160202-gmjqdj#ixzz3zik2ip00>> as at 22 June 2017

⁴⁵ See e.g.: M. Strom., Hope for the paralysed: UTS to establish Centre for Neuroscience and Regenerative Medicine, *Sydney Morning Herald*, September 16 2016, <http://www.smh.com.au/technology/sci-tech/hope-for-the-paralysed-uts-to-establish-centre-for-neuroscience-and-regenerative-medicine-20160915-grgudc.html> as at 22 June 2017

⁴⁶ See e.g.: H Fabig, "NDIS: rights-based paradigm shift or same old charity?" *Ramp Up - Disability, Discussion, Debate*, <http://www.abc.net.au/rampup/articles/2013/04/11/3734962.htm> as at 9 January 2017

⁴⁷ See e.g.: AM Political reporter Dan Conifer, NDIS: Report warns workforce understaffed in major cities, raises concerns over readiness, 25 Feb 2017, 6:57am, <<http://www.abc.net.au/news/2017-02-25/ndis-report-warns-major-cities-not-prepared-for-implementation/8303276>> as at 26 October 2017.

⁴⁸ See e.g.: Marilyn Harrington and Dr Rhonda Jolly, *The crisis in the caring workforce*, Briefing Book, Commonwealth Parliamentary Library, <https://www.aph.gov.au/About_Parliament/Parliamentary_Departments/Parliamentary_Library/pubs/BriefingBook44p/CaringWorkforce> as at 26 October 2017

⁴⁹ See National Disability Insurance Agency, above n 7, 34-35

⁵⁰ See e.g.: Sparrow, R., and Sparrow, L. 2006. In the hands of machines? The future of aged care. *Minds and Machines* 16: 141-161, May, http://profiles.arts.monash.edu.au/rob-sparrow/download/InTheHandsOfMachines_ForWeb.pdf; see also, Heather Kelly, Robots: The future of elder care? CNN, July 19th, 2013, 03:42 PM ET, <http://whatsnext.blogs.cnn.com/2013/07/19/robots-the-future-of-elder-care/>; Maureen Dowd, Silicon Valley Sharknado, *The Opinion Pages | Op-Ed Columnist*, July 8, 2014, http://www.nytimes.com/2014/07/09/opinion/maureen-dowd-silicon-valley-sharknado.html?_r=0 as at 19 July 2014. From Ms Dowd's article I note, in particular: "Vinod Khosla, the Sun Microsystems co-founder, has predicted that algorithms and machines will replace 80 percent of doctors in years to come, making medicine more data driven and less like "witchcraft."

their loved ones would be less likely to be abused, neglected or defrauded. Mechanisation could also free some of us who are heavily dependent on our carers from a degree of our dependency; but I note that those who have obtained exoskeletons and similar technologies have had to base themselves overseas to do it.⁵¹ Ultimately, from the point of view of government it is the cost-savings that could result from investment in technology that needs to be considered.

4. Methodology

Concerns relating to the NDIS had been raised prior to its introduction by the Australian Human Rights Commission and a variety of advocacy bodies. The paper will begin by reviewing these concerns. Partly these concerns related to whether the proposed NDIS would reflect the spirit of the Convention. The paper will compare the provisions of the Convention with those of the NDIS Act and consider whether they are commensurate with each other.

However, the examination of these texts only takes us so far. For this reason, the potential shortcomings of the NDIS will be further tested through interviews with long-term users of disability services. The main hypothesis that is tested in this paper is whether the NDIS is providing the support to enable users of the system to live a life that meets the definition in the Convention as set out above. In testing this hypothesis the paper adopts what is referred in the literature as person-centred planning and care.⁵² The claim is that to achieve the aims of the Convention a person-centred approach needs to be adopted. There is a considerable body of literature around ‘person-centredness’ or patient-centred care in hospitals and care.⁵³ Basically such an approach can be contrasted to what John O’Brien calls the ‘system world’. In practice this contrast involves a contest between how an individual may perceive their needs, as opposed to a systemic approach which seeks to apply rules and guidelines to assure a uniformity of outcome. According to him:

Person centered planning escapes the system’s impersonal boundaries and sets loose an eruption of ordinary desires into the trying to be cool world of settled professional judgements about what is realistic, legitimate and possible. Those who administer system rational services and see a person in this way can no longer treat them impersonally without experiencing a sense of somehow doing wrong. Those who part the veil and affirm a person’s dignity, capacity and legitimate desires for a good life are unsatisfied with the compromises that have created system controlled group living

⁵¹ See for example, the webpage of Australian paraplegic speaker and campaigner Amanda Boxtel, now based in the US and Canada, with her walking machine: <http://www.amandaboxtel.com/index.html> as at 20 July 2014; also see e.g.: News - This exoskeleton has been approved for personal use, ScienceAlert Staff, Tuesday, 01 July 2014, http://www.sciencealert.com.au/news/20140107-25786.html?utm_source=feedburner&utm_medium=email&utm_campaign=Feed%3A+sciencealert-latestnews+%28ScienceAlert-Latest+Stories%29 as at 20 July 2014.

⁵² See for example, 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=/elibrary/lib/downloaded_files/publications/pdfs/phcris_public_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.

⁵³ See *ibid*

arrangements, day programs, community experience programs, and almost-but-not-quite real jobs.⁵⁴

In adopting this approach, the paper will conduct qualitative face-to-face interviews with long-term users of disability services to gauge their quality of life pre and post the introduction of the NDIS. The target group will be long-term adult users of the system in New South Wales living on the Northern Beaches of Sydney. Ethics approval will be sought as it is acknowledged that the paper will be delving into sensitive personal information of potentially highly vulnerable individuals and families. One of the key safety mechanisms will be to maintain anonymity of interviewees in the final paper text, while securing any identifying data with the Higher Degree Research Office at Macquarie University, both during and after the period of primary research. Analysis will be guided by the recommendations contained in a paper on handling qualitative data by David R. Thomas.⁵⁵

One reason for confining the interviews to residents in this area is that I live on the Northern Beaches and am limited by my own disabilities to go further afield. The situation in NSW also exemplifies the situation that currently exists across Australia where there has been significant outsourcing of disability services to the private (mostly charitable) sector. As noted above, this process has been facilitated through Bilateral Agreements between the various States and Territories and the Commonwealth Government.⁵⁶ In NSW, these new arrangements have resulted in a situation where participant complaints about service delivery are to be directed to the NSW Ombudsman; complaints about NDIA funding are to be directed to the Commonwealth Ombudsman; and when the new Safety and Quality Commission is established, it will oversee service provider registration.

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. In the case of NSW it was through the Department of Ageing, Disability and Homecare (ADHC). ADHC had been in existence in NSW, in a public form, since 1943.⁵⁷ However, in 2015, the NSW Government announced that it was transferring the disability support components of ADHC to the company, Australia Unity. The \$100 million received in the

⁵⁴ John O'Brien, The Problem with Person-Centred Planning, 2013 TASH Conference, Chicago, version 1.5 – 29 December 2013, <https://www.scribd.com/document/197696717/The-Trouble-With-Person-Centred-Planning#download&from_embed> as at 9 January 2017

⁵⁵ See David R. Thomas, A General Inductive Approach for Analyzing Qualitative Evaluation Data 2006 27: 237, American Journal of Evaluation, <http://aje.sagepub.com/content/27/2/237> DOI: 10.1177/1098214005283748, <<http://journals.sagepub.com/doi/abs/10.1177/1098214005283748>> as at 3 April 2017

⁵⁶ These are all listed at: Council of Australian Government, *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/20160615045056/http://www.coag.gov.au/disability_care_and_support> as at 23 October 2017. 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.

⁵⁷ See Ageing, *Disability and Home Care, Home Care Service client handbook*, Department of Family and Community Services 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

transaction, the Government announced in a press release, would be ‘reinvested into the disability sector to help with transition to the NDIS’.⁵⁸

This press release is important for several reasons. Firstly, it acknowledged that ADHC provided for 70% of disability and aged care support in NSW.⁵⁹ Secondly, it confirmed that the outsourcing of human services was being followed in other jurisdictions.⁶⁰

Thirdly (and most importantly), the State government argued the outsourcing service delivery to the charitable, mutual or private sectors would give ADHC clients and their families more ‘choice and control.’ Just exactly what this ‘choice and control’ is, particularly when considered alongside the standard set in the Convention and notions of the ‘good life’⁶¹ and ‘ordinary life’ mentioned above, will be important to discuss in the interviews. This will involve questions about the level of care/service delivery pre and post NDIS; their experiences of the administration of service delivery pre and post NDIS; and the funding of services pre and post NDIS⁶².

This research will be pertinent in assessing the government’s own position that in taking this course of action it has taken a person-centred planning and care approach.⁶³ In particular, it claimed that the transfer of services to the NGO sector would provide:

⁵⁸ Family and Community Services, 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

⁵⁹ See *ibid*

⁶⁰ See e.g.: Political reporter [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

⁶¹ This a multifaceted concept and more complex when applied in practise to disability; see e.g.: Craig. Wallace, *Disability reform in Australia unfinished business* [online]. Precedent (Sydney, N.S.W.), No. 125, Nov/Dec 2014: 40-45. Availability:

<<http://search.informit.com.au/simsrad.net.ocs.mq.edu.au/documentSummary;dn=857499153442568;res=IELA PA>> ISSN: 1449-7719; see also F Migerode, B, Maes A Buysse, R Brondeel. *Quality of Life in Adolescents with a Disability and Their Parents: The Mediating Role of Social Support and Resilience*. Journal Of Developmental & Physical Disabilities [serial online]. October 2012;24(5):487-503. Available from: Academic Search Premier, Ipswich, MA. <<http://web.b.ebscohost.com/simsrad.net.ocs.mq.edu.au/ehost/pdfviewer/pdfviewer?vid=1&sid=70a27d9a-d112-42c0-8589-31b38f9bb686%40sessionmgr104>> as at 11 December 2017.

⁶² See e.g.: Llinas Flynn. *Concerns over costs of NDIS* [online]. Guardian (Sydney), No. 1799, 18 Oct 2017: 5. Availability:

<<http://search.informit.com.au/simsrad.net.ocs.mq.edu.au/documentSummary;dn=166180228687348;res=IELA PA>> ISSN: 1325-295X.. However, it is debateable whether Australian can ever meet such costs, given historic shifts in our workforce and, nature of our tax base cf: Adam Stebbing and Ben Spies-Butcher *Universal Welfare by ‘Other Means’? Social Tax Expenditures and the Australian Dual Welfare State*, Journal of Social. Policy (C) Cambridge University Press 2010, doi:10.1017/S0047279410000267 <https://www.researchgate.net/profile/Ben_Spies-Butcher/publication/231842880_Universal_Welfare_by_'Other_Means'_Social_Tax_Expenditures_and_the_Australian_Dual_Welfare_State/links/0c96053a2976b98f54000000.pdf> as at 11 December 2017

⁶³ 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, 42-43.

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.⁶⁴

The questions that arise from such a position (and will be asked of the interviewees) is whether, as users of the NDIS, they have the same understanding as the government of what choices, services and outcomes they need to enable them to enjoy the rights as have been set out in the Convention.

Ultimately how these questions are answered will help to determine whether the NDIS needs to change and if it does how it should be changed.

5. Aims of the Research

The paper has multiple aims. One of its more general aims is to give a clear account of the recent shift in the delivery of services from the public to the non-government (and mostly charitable) sector. However, in tracing this shift it is apparent that it has occurred within a context where the Australian government is apparently seeking to fulfill its international human rights obligations through the pursuit of a neoliberal policy agenda. Thus, a more specific aim of the paper is to explore whether this approach is effectively and appropriately upholding the rights of people with disabilities in Australia as stated in the Convention.

In order to assess the NDIS the paper will:

- a) consider the concerns raised by ALRC and other parties about the NDIS and whether it meets the standards set by the Convention;
- b) compare and contrast the NDIS with the old system in NSW with a focus on the experiences of long-term users in NSW;
- c) consider whether the NDIS needs to change.

6. Literature Review

There is limited academic literature on the NDIS, although there is much anecdotal information and media reports, as well as the earlier cited parliamentary and agency reports.

The only two texts clearly focused on the NDIS are:

1. *The National Disability Insurance Scheme Handbook*, Madden, B; McIlwraith, J; Brell, R, 2013, Lexis Nexis; and
2. *How to Thrive Under the NDIS: A Pathway to Sustainability for Service Providers*, Fran Connelley, 2016, FC Marketing.

The first provides an effective outline of the Act and how the scheme is administered. The second provides practical advice to NGO Boards as to how to adjust their operations to meet NDIS requirements. It also provides many case studies, highlighting the history, development, and mission of several providers, as well as outlining a number of scenarios regarding client services.

⁶⁴ 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.

However, neither text could be described as providing academic analysis of the effectiveness or merits of the NDIS. They certainly contain useful material, but they are practical ‘user guides’ whose principal audience is service providers. The perspective of clients and families cannot be presumed to be the same as providers and, it is the views of clients and families this paper seeks to bring to the fore.

Mostly the discussion of the NDIS has been in a range of forums including official organisations such as the ALRC and the Joint Standing Committee, as well as informal discussions in newspapers and blog sites. It would also seem that there has only been one study of the experiences of participants of the NDIS (discussed below).

Prior to its introduction concerns were raised as to whether the NDIS would in fact meet Australia’s obligations to protect the rights of people with disability as set out in the Convention. This is a significant issue particularly as the NDIS Act makes it clear that its intention is to incorporate the Convention.

The references to the Convention in the Act are restricted largely to the Objects of the Act. Indeed, the Australian Law Reform Commission noted that ‘the...(NDIS Act) was enacted with the express objective of giving effect to a number of international conventions’.⁶⁵ However, serious questions have to be raised over whether the Act is commensurate with the Convention. As Helen Dickinson has claimed, while providing pieces of disability specific equipment is relatively easy, the NDIA largely fails to navigate the gulf between what mainstreams organization provide and the kind of human and physical infrastructure needed for people with disabilities to engage with the community.⁶⁶ As Dickinson states:

If the NDIS is to truly make a difference in terms of the rights of people with disabilities, it will need to go beyond care services. Without changes to structural factors that contribute to the inequalities of people with disabilities, the NDIS risks offering limited consumer rights with no natural link to greater societal inclusion, nor will it counter the significant barriers that people with disabilities face in accessing their human rights.⁶⁷

On this basis, disability policy has not really moved out of the welfare and dependence model, but has appropriated the language of the market and, as Dickinson pointedly observes, the intertwining of human rights and markets make for “strange bedfellows”.⁶⁸

Another contestable viewpoint is that the NDIS provides participants with ‘choice and control’. This raises the issue (as discussed by Bo’sher above) about whether the NDIS is promoting participant self-determination or undermining it. On the one hand, it appears that a decision-making model is being imposed on them that does not reflect their needs but the development of policy through the lens of neoliberalism. This is apparently the case in NSW,

⁶⁵ Australian Law Reform Commission, *Equality, Capacity and Disability in Commonwealth Laws IP 44: Legislative and regulatory framework*, <<https://www.alrc.gov.au/publications/equality-capacity-and-disability-commonwealth-laws/legislative-and-regulatory-framework>> as at 1 December 2017

⁶⁶ See Helen Dickinson, *Will the NDIS and individualisation of disability services enhance human rights?*, Right Now – Human Rights in Australia, <<http://rightnow.org.au/opinion-3/will-the-ndis-and-individualisation-of-disability-services-enhance-human-rights/>> as at 1 December 2017

⁶⁷ Ibid

⁶⁸ Ibid

when once the delivery of services was managed for them, they are now expected to manage service delivery when they might not want to. On the other hand, it is evident that their choices in determining what kinds of services they need is limited. This is illustrated in an essay by the lawyer, Micheline Lee, in *The Monthly* where she highlights the impersonal and bureaucratic nature of the Agency. She relates how her NDIS plan was ‘agreed’ to over the phone and how she was not able to see a copy of it until an NDIA delegate approved it. She did not feel as if she was in control, observing:

I am wondering what has happened to the voice of people with disabilities that called for equality, choice and control. Now the rhetoric is dominated by financial sustainability. It is ironic that the administrators of the NDIS whip out the language of meeting targets and budgetary bottom lines to justify their implementation of the scheme, when it is their mistakes that are causing waste.

I don’t think it’s just teething issues. It’s symptomatic of underlying attitudes that haven’t changed. Transformation still has to occur at a cultural level. We come from a long tradition of disability services being delivered as welfare or charity. In this tradition, it’s acceptable to apply different standards to people with disabilities. For instance, we expect insurance cover to be given on terms that are understood and agreed to. Why do we think it’s acceptable for the NDIS plans to be made without the participants even getting the chance to view them beforehand?⁶⁹

Lee’s testimony reveals the conflict that exists between economic, fiscal, and social imperatives. Her article, focusing on personal experience, does not even make passing reference to the Convention, despite the fact that she is a lawyer. Arguably this may be because for people like Ms Lee, while the terms of the Convention may be in the Objects, they do not impact her experience of the NDIS.

Also, the Convention stands alongside the Act, the Intergovernmental Agreements, and the like, through which policy makers believe they are delivering the NDIS. An independent review of the NDIS, conducted by Ernest & Young (EY Report), found insufficient grounds to amend the Objects of the Act. Its discussion recommended making only a slight terminology change to the Act, to align it with the *Carer Recognition Act 2010* (Cth).⁷⁰

When it came to operational provisions of the Act, the EY Report makes a variety of recommendations⁷¹ only one of which relates to any notion of a ‘right’ and this was to call upon the Government to clarify ‘(the) rights of participants to request a review of their plan (under section 48)’.⁷² While this is an important administrative matter which goes to fairness and due process, the same report’s rejection of an amendment to the Objects to include specific mention of the political rights of people with disabilities,⁷³ appears to be at odds with a Human Rights Analysis conducted in 2011 on the prospective NDIS Bill.

⁶⁹ Micheline Lee, Essays *The art of dependency*, *The Monthly*, August 2017, <<https://www.themonthly.com.au/issue/2017/august/1501509600/micheline-lee/art-dependency>> as at 1 December 2017

⁷⁰ See Andrew Metcalf, Independent review of the NDIS Act, December 2015, 11-16 <https://www.dss.gov.au/sites/default/files/documents/04_2016/independent_review_of_the_ndis_act.pdf>

⁷¹ See *ibid*, 3-4

⁷² *Ibid*, 3

⁷³ See *ibid*, 14

This said, for Australia to be truly compliant with the Convention, the NDIS had to connect services like education, employment, healthcare and cultural activities. This is because:

Article 19 is of particular relevance to the proposed NDIS, in that it obligates States parties to ensure “the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community”.⁷⁴

As noted above, there is much evidence that the NDIS is not leading to full and effective integration of people with disabilities in the wider community. This is emphasised by a recent study undertaken at the University of Melbourne. The study involved conducting semi-structured face-to-face interviews with participants living within a Victorian NDIS trial site. The results were recorded in the report, *Choice, control and the NDIS: Service users’ perspectives on having choice and control in the new National Disability Insurance Scheme*. Results were mixed, with some participants reporting improvement and greater choice and control, while others reported no change at all. There were some concerns that some service providers, like local government, were taking the opportunity of the NDIS to ‘opting out of delivering...services, sometimes before the new market was ready to cope with Demand’.⁷⁵ Combined with Commonwealth Government resources constraints, and the claim in a Ministerial Explanatory Statement that slowing the rate of access (increasing waiting times) is still in accord with the Convention,⁷⁶ it is arguable that the Government observes the letter but not the spirit of the Convention.

Part of the problem was that the NDIS was rushed, with Warr and others noting:

It is important to acknowledge that in under five years, Australia is implementing a scheme that England took nearer 25 years to develop and implement.⁷⁷

It was not as if governments were not warned about the problems this would cause, even by those who supported an NDIS.⁷⁸ Now the Commonwealth Auditor General is acknowledging the immaturity of the disability services market,⁷⁹ while others openly question whether the NDIS will deliver.⁸⁰ Equally as the costs have risen, some argue that the NDIS has become

⁷⁴ Dr. Dinesh Wadiwel, Proposed National Disability Insurance Scheme: Human Rights Analysis, April 2011, 12, <<https://www.pwd.org.au/documents/pubs/RP11-NDIS-HumanRightsAnalysis.doc>> as at 3 December 2017

⁷⁵ Warr, D, Dickinson, H, Olney, S, et. al. (2017) *Choice, Control and the NDIS*, Melbourne: University of Melbourne, May 2017, 28, <http://socialequity.unimelb.edu.au/_data/assets/pdf_file/0010/2364499/Choice-Control-and-the-NDIS-Report-Melbourne-Social-Equity-Institute.pdf

⁷⁶ See Explanatory Statement: Issued by the Authority of the Minister for Social Services, *National Disability Insurance Scheme Act 2013 - National Disability Insurance Scheme (Timeframes for Decision Making) Amendment Rules 2016*, 3 <<https://www.legislation.gov.au/Details/F2016L00545/596f3c70-6744-486f-bb53-7ea0ccae53a9>> as at 3 December 2017

⁷⁷ Warr above n 75, 52.

⁷⁸ See e.g. Mark Bagshaw et al., “Raising the Bar”: Achieving the Best Outcomes for People with Disability from the National Disability Insurance Scheme: Discussion Paper March 2013 <http://innov8group.com.au/linked/ndis_raising_the_bar_discussion_paper.pdf> as at 3 December 2017

⁷⁹ Australian National Audit Office, *National Disability Insurance Scheme - Management of Transition of the Disability Services Market*, Wednesday, November 9, 2016, [3.26], <<https://www.anao.gov.au/work/performance-audit/national-disability-insurance-scheme-transition-disability-services>> as at 4 December 2017

⁸⁰ See e.g.: Helen Dickson, *Can the NDIS Deliver?*, Pursuit, <<https://pursuit.unimelb.edu.au/articles/can-the-ndis-deliver>> as at 4 December 2017

much less of a bipartisan policy consensus and more about ‘the political struggle (which) has become more and more fierce over the past six years, but we’re still left with the same question: who is going to pay for it?’⁸¹

This question might well be answered when considering the Commonwealth Government’s commissioned Ernest and Young Report cited earlier, with the Australian Human Rights Commission submission on the human rights implication of the then proposed National Disability Insurance Scheme Bill. Again, the Human Rights Commission cited issues like employment, advocacy, and service procurement as important issues, for the success of the NDIS, for improvement to the lives of people with disabilities and for the fulfilment of the Convention.⁸² It would be to say that, on balance, the Parliament and the Government, took a far more cautious approach, partly because of Scheme rollout speed and cost.

In light of available commentary on the NDIS it would appear that Australia is not meeting its international obligations. The paper then turns to consider whether participants in the NDIS are experiencing problems as a result. This will be tested through the interviews with long terms users of the disability services system in NSW who can compare their experiences of the prior State-run system and the NDIS.

6. Contribution to the Literature

The aim of the Convention may be succinctly stated as attempting to address historical disadvantage and discrimination experienced by people with disabilities. When the NDIS Act was introduced, the then Disability Discrimination Commissioner Graeme Innes claimed it would be a vital measure to address these issues in Australia.⁸³ He quoted shocking figures that:

In Australia today 45 % of people with disability live in poverty, and we are 27th out of 27 OECD countries on this measure.⁸⁴

Whether the NDIS Act is meeting the needs of participants in NSW will be assessed through face to face interviews with long-term NDIS participants and their families. Presently there is a gap in the literature regarding this research. It is notable that thus far there has only been a similar study conducted in Victoria (noted above in the Literature Review). Certainly, there were many claims made for it by advocates and commentators,⁸⁵ but for all those who would

⁸¹ Sophie Heizer. *A short history of the NDIS and the fight over who’s going to pay for it*, Crikey, Feb 17, 2017, <<https://www.crikey.com.au/2017/02/17/short-history-of-ndis-and-the-fight-over-who-will-pay-for-it/>> as at 4 December 2017

⁸² See generally, Australian Human Rights Commission, *National Disability Insurance Scheme Bill 2012 - Australian Human Rights Commission Submission To The Senate Community Affairs Legislation Committee*, 24 January 2013 <https://www.humanrights.gov.au/sites/default/files/20130124_ndis.pdf> as at 4 December 2017

⁸³ NDIS – A Great Step Forward For People With Disability, <<https://www.humanrights.gov.au/ndis-great-step-forward-people-disability>> as at 3 November 2017

⁸⁴ See *ibid*

⁸⁵ See generally, Anne Manne, *Two Nations: The Case for A National Disability Insurance Scheme*, The Monthly, August 2011, <<https://www.themonthly.com.au/issue/2011/august/1314794058/anne-manne/two-nations>> as at 27 July 2016; see also Mike Stokete, *How a forty-year-old proposal became a movement for change*, Inside Story, <<http://insidestory.org.au/how-a-forty-year-old-proposal-became-a-movement-for-change>> as at 9 September 2016; see also Every Australian Counts, *About NDIS: Why do we need the NDIS*, © 2016 NDIS | Transforming lives. All rights reserved, <<http://www.everyaustraliancounts.com.au/about-ndis/why-do-we-need-the-ndis/>> as at 19 April 2017

talk of the goods, services and support it would bring to people with disabilities and their families, have these things been delivered?

The ways in which people with disabilities have been shut out physically, structurally, socially, and economically from many aspects of the Australian community has been well-documented in the commentary.⁸⁶ Some commentators argue that the social exclusion of people with disabilities can be seen in how they are “shut out” of popular culture. Helen Meekosha cited the 2006 *‘Where the Bloody Hell Are You?’* Australian tourism campaign. This she said did what many campaigns before had done, in that:

(In) the images of everyday Australia, the Outback, the beaches, the vineyards and the restaurants, among the dozens of people represented, there is no-one with an identifiable disability. What we do see are images of vital, healthy, “able-bodied” European-descent Australians, with an occasional Aboriginal person as an attraction for the visitors. We see then a nation’s marketing representation of how it believes itself to be; its history, geography, social reality and contemporary divisions are nowhere to be seen.⁸⁷

But addressing the issue of exclusion goes deeper than making people with disability visible to the broader population. The more crucial questions relate to who constructs the problems facing people with disability, what is their rationale, and do those with disabilities perceive the issues the same way? In relation to the NDIS, Cate Thill argues that not only has the professional and medical establishment overwhelmed people with disabilities, but researchers have not always aided understanding by the hypotheses they have constructed. She cites a re-analysis of a 1967 study of intellectually disabled people which found:

(Participants) in (the original) study challenged the label applied to them and analysed their problems as stemming from oppressive social practices rather than their presumed impairments. Instead of listening to these critiques, (the researcher) interprets them as evidence that participants are in denial about their condition. (This) rejects the authority of participants’ voices and their right to be heard since what they have to say is reduced to a manifestation of their supposed impairment rather than

⁸⁶ 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, citing 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, © Commonwealth of Australia [2009], <https://www.dss.gov.au/sites/default/files/documents/05_2012/nds_report.pdf>; <<https://theconversation.com/understanding-the-ndis-a-history-of-disability-welfare-from-deserving-poor-to-consumers-in-control-58069>> as 21 January 2017. Specifically, Ramcharan states:

Resettlement back into the community started around the 1970s in Australia. Community care policies aimed to provide support, education, employment, housing and inclusion services. Forty years after community care started, people with disabilities are living longer. Yet in 2009, [a report based on consultation](#) with people with disabilities found there was still little social inclusion, poor quality disability services and high unemployment.

⁸⁷ Meekosha, Helen, *What the Hell are You? An Intercategorical Analysis of Race, Ethnicity, Gender and Disability in the Australian Body Politic*, Scandinavian Journal of Disability Research, Vol. 8, No. 2-3, 2006, 161, <http://s3.amazonaws.com/academia.edu.documents/7383443/Meekosha%202006.pdf?AWSAccessKeyId=AKIAIWOWYYGZ2Y53UL3A&Expires=1489440202&Signature=eE%2FE3Un1tZPaA%2FkNVIwi98VA2wA%3D&response-content-disposition=inline%3B%20filename%3DWhat_the_hell_are_you_An_intercategorical.pdf> as at 14 March 2017

taken seriously as a significant critique of disabling social processes. This practice of appropriating the lived experience of disabled people is deeply problematic insofar as it benefits the careers of researchers while the social circumstances of disabled subjects remain unchanged.⁸⁸

Thill makes a convincing argument that many people with disabilities, their families, carers and advocates were heavily involved with campaigning for an NDIS. The most obvious example of this was the public 'Every Australian Counts' campaign.⁸⁹ However, highlighting the NDIS assessment process, Thill points out that while the participant prepares a statement of goals and aspirations, these are then subjected to medical and economic tests, which she sees as illegitimate.⁹⁰

Much of Thill's argument provides a basis for my hypothesis, which I would expect to see reflected in the interviews. The hypothesis says that the NDIS is a very bureaucratic scheme, which throughout the period of its rollout has disappointed and failed many people in terms of accessibility and capacity.⁹¹ Perversely, there is some evidence that both these constraints and flaws in the fundamental design of the NDIS has harmed some of the sickest and most vulnerable members of Australian society, which most reasonable people would expect it to provide for.

The clearest example of this may well be 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 recently 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

⁸⁸ Cate Thill, *Listening for policy change: How the voices of disabled people shaped Australia's National Disability Insurance Scheme*, Disability and Society on 17 Dec 2014, University of Notre Dame Australia, ResearchOnline@ND, Arts Papers and Journal Articles School of Arts 2014, citing Ashby, C. (2011). Whose "voice" is it anyway?: Giving voice and qualitative research involving individuals that type to communicate. *Disability Studies Quarterly*, 31(4) and Oliver, M. (1992). Changing the Social Relations of Research Production? *Disability, Handicap & Society*, 7(2), 101-114. doi: 10.1080/02674649266780141 <http://researchonline.nd.edu.au/cgi/viewcontent.cgi?article=1111&context=arts_article> accessed 6 November 2016.

⁸⁹ See *ibid.*, 3.

⁹⁰ See *ibid.*, 12-13.

⁹¹ See e.g.: Social affairs correspondent [Norman Hermant](#), NDIS enrolments surging, but at what expense?, ABC News Posted 3 Mar 2017, 12:20pm, <<http://www.abc.net.au/news/2017-03-03/ndis-enrolments-surging-despite-difficulties-accessing-plans/8321232>>; see also Exclusive by political reporter [Dan Conifer](#) and FOI editor Michael McKinnon, National Disability Insurance Scheme rollout plagued with problems, FOI documents reveal, ABC News, Updated 12 Mar 2017, 2:35pm Sun 12 Mar 2017, 2:35pm, <<http://www.abc.net.au/news/2017-03-12/ndis-rollout-plagued-with-problems-foi-documents-reveal/8346892>>; see also Political reporter [Dan Conifer](#), NDIS: Report warns workforce understaffed in major cities, raises concerns over readiness, *AM*, Posted 25 Feb 2017, 6:57am Sat 25 Feb 2017, 6:57am, <<http://www.abc.net.au/news/2017-02-25/ndis-report-warns-major-cities-not-prepared-for-implementation/8303276>>; see also Social affairs correspondent [Norman Hermant](#), NDIS: Fighting for access to disability support a 'nightmare' for some amid political funding debate, *7.30*, Updated 24 Feb 2017, 6:25pm, Fri 24 Feb 2017, 6:25pm, <<http://www.abc.net.au/news/2017-02-24/fighting-for-access-to-disability-support-a-nightmare-ndis/8297138>> as at 22 April 2017

the NDIS is to promote independence and to promote a place in society for people with significant disability.⁹²

In response, the NDIA cited its high case load, of 100,000 participants this year, claiming many of these people had no support previously.⁹³ This demonstrates the real power of NDIA planners over participants and families, even in the allegedly new model of disability service and support system which claims to be person-centred (as was noted earlier).

Anecdotal evidence in the media and similar outlets indicates that the NDIS is not meeting the needs of participants will guide the line of questioning I will direct to my interviewees. This will include (as mentioned in the Methodology) questions regarding the 'choices' they can make within a system where already concerns have been raised about the adequacy of funding,⁹⁴ alongside questions about the provision of funding for advocacy services, particularly for those most vulnerable participants and families unable (or unwilling) to lobby on their own behalf.⁹⁵ This is in fact a very important point to take up with potential interviewees, who as long-term participants it might have been unclear to them that the old departmental structures would disappear, leaving NDIS participants, families and guardians to largely manage their own affairs. Thus, like other NDIS participants they may have welcomed having more discretion over which services they received, from whom, how and when. However, what they might not have been so prepared for is the sudden withdrawal of existing service providers and supports – a situation which has led the President of PWD Craig Wallace to observe:

'If there's one key failing in this, I think the speed of the roll out means we're sometimes compromising,'⁹⁶

It will also involve asking the interviewees questions about the quality of the services and outcomes they are receiving. Arguably, the promise of the NDIS and the aspirations of many who campaigned for it was that the scheme would put those with disabilities on an equal footing with every other member of Australian society. For example, one of the implications of the 'Every Australian Counts' campaign was that those with disabilities did not count (or did not count as much) as the other members of the Australian community. Certainly, this

⁹² Political reporter [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

⁹³ Ibid

⁹⁴ See e.g.: [Ewan Gilbert](#), NDIS funding levels not satisfactory, disability service providers say, Updated 1 Jul 2014, 6:54am, Tue 1 Jul 2014, 6:54am, <<http://www.abc.net.au/news/2014-06-30/concern-over-ndis-price-for-services/5560886>>; see also [Natalie Whiting](#), NDIS delays proving costly for SA families and disability service providers, *The World Today*, Updated 24 Apr 2015, 2:48pm, Fri 24 Apr 2015, 2:48pm, <<http://www.abc.net.au/news/2015-04-24/ndis-delays-sa-costly-novita-staff-funding/6417462>>; see also social affairs correspondent [Norman Hermant](#), Disability advocates call for Senator Mitch Fifield to be 'more forthcoming' over NDIS funding, Updated 28 May 2015, 12:24pm, Thu 28 May 2015, 12:24pm, <<http://www.abc.net.au/news/2015-05-28/disability-advocates-demand-clarity-over-ndis-funding/6502268>> as at 22 April 2017

⁹⁵ See e.g.: Social affairs correspondent [Norman Hermant](#), Disability advocates fear peak body funding changes could affect representation, Updated 23 Sep 2014, 5:13pm, Tue 23 Sep 2014, 5:13pm, <<http://www.abc.net.au/news/2014-09-23/disability-funding-could-affect-representation:-advocates/5763472>> as at 23 April 2017

⁹⁶ Social affairs correspondent [Norman Hermant](#), NDIS citizens' jury finds scheme successful so far, but with work to do, Updated 16 May 2015, 1:54pm, <<http://www.abc.net.au/news/2015-05-16/ndis-successful-so-far-but-work-to-do-jury-finds/6474578>> as at 22 April 2017

was the view of Helen Meekosha cited earlier, when she argued that people with disabilities were absent from media, cultural and public spaces in Australia.

Yet, if the NDIS was supposed to promote the rights and interests of people with disability and their families which meets the standards set by the Convention, there would need to be change that represents improvement. Having promised generational change and the disability services equivalent of Medicare, how can leading advocate like Craig Wallace now concede the NDIS is a study of compromises? Was it not the Scheme that was going to give people with disabilities access to the kind of daily life everyone else takes for granted? While any assessment of this inherently involves a high degree of subjectivity, several concerns have been raised. The first goes to the question of just how much has really changed. This was certainly the view of the mother of two disabled children Heike Fabig, who wrote of her concerns about the involvement of charitable bodies in the delivery of NDIS services. In particular, she said:

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 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.⁹⁷

The Productivity Commission said itself that many existing organisations would continue to be providers, and that the scope of what they could provide and who they could provide it to would be enhanced by NDIS funding.⁹⁸ The Commission also said that those organisations providing support would be 'less reliant on the charity dollar for reasonable and necessary services'.⁹⁹ The language of 'reasonable and necessary' became part of the Act, specifically sections 34 and 35 of the Act. However, it is noteworthy that it is not the NDIS participant or their family who must be satisfied but the Chief Executive Officer (CEO) of the NDIA who must be satisfied that what is contained in a participant's service and support plan meets criteria set out in section 34 of the Act.¹⁰⁰

⁹⁷ Heike Fabig, *Opinion: NDIS: rights-based paradigm shift or same old charity?* Ramp Up 11 Apr 2013, 1 of 3, <<http://www.abc.net.au/rampup/articles/2013/04/11/3734962.htm>> accessed 13 September 2016.

⁹⁸ See Productivity Commission, above n 2, 201

⁹⁹ Ibid.

¹⁰⁰ *National Disability Insurance Scheme Act 2013 (Cth)*, No. 20, 2013

<<https://www.legislation.gov.au/Details/C2016C00934/Download>> accessed 16 November 2016. Section 34 of the Act states:

34 Reasonable and necessary supports

(1) For the purposes of specifying, in a statement of participant supports, the general supports that will be provided, and the reasonable and necessary supports that will be funded, the CEO must be satisfied of all of the following in relation to the funding or provision of each such support:

(a) the support will assist the participant to pursue the goals, objectives and aspirations included in the participant's statement of goals and aspirations;

(b) the support will assist the participant to undertake activities, so as to facilitate the participant's social and economic participation;

(c) the support represents value for money in that the costs of the support are reasonable, relative to both the benefits achieved and the cost of alternative support;

Here again is an example of a central bureaucratic agent applying what John O'Brien called 'system world'¹⁰¹ standards to override individual participant's aspirations and goals under the NDIS. Certainly, Fiona Given of the NSW Disability Discrimination Legal Centre told the Productivity Commission in 2010 that:

With human rights principles in particular to eliminate institutional models of service it must also enable the development of new elements of the disability support system where needed programs and services do not presently exist. The scheme must be entitlement based. The scheme must not be subject to any form of means test. Eligible persons ought be entitled to assistance as a right and receive assistance at the point of qualification. They should not face the delays and compromises associated with cash-start discretionary schemes.

The target group for the scheme ought to be all persons with impairment who are disabled, able to specifically include persons with psychosocial impairment. The scheme also must not be limited to people classified as having severe or profound disability as proposed by your initial brief; instead we argue that it should be based on the need to have support in order to realise rights articulated under the CRPD. This effectively views disability through the lens of the social model of disability which looks at how the social environment disables a person, as opposed to the medical model which looks at the impairment.¹⁰²

Ms. Given's evidence is interesting, not because of its clear aspirations, but because of how reduced these aspirations has become in the hands of public policy makers. While claiming to be giving people with disability choice, dignity, and control, then Treasurer Wayne Swan said in his 2013 Budget speech:

(The NDIS) could mean the difference between getting the right wheelchair now or waiting three long painful years using a wheelchair that doesn't fit. It could mean the difference between a shower every day, or only once a week.¹⁰³

While receiving a wheelchair that is fitting and bathing regularly are important, Ms Given's testimony is suggestive of a far more adventurous, and largely unfulfilled template.

(d) the support will be, or is likely to be, effective and beneficial for the participant, having regard to current good practice;

(e) the funding or provision of the support takes account of what it is reasonable to expect families, carers, informal networks and the community to provide;

(f) the support is most appropriately funded or provided through the National Disability Insurance Scheme, and is not more appropriately funded or provided through other general systems of service delivery or support services offered by a person, agency or body, or systems of service delivery or support services offered:

(i) as part of a universal service obligation; or
(ii) in accordance with reasonable adjustments required under a law dealing with discrimination on the basis of disability.

(2) The National Disability Insurance Scheme rules may prescribe methods or criteria to be applied, or matters to which the CEO is to have regard, in deciding whether or not he or she is satisfied as mentioned in any of paragraphs (1)(a) to (f).

¹⁰¹ O'Brien, above n 54, 3

¹⁰² Productivity Commission, Transcript of Proceedings, 20 July 2010, Sydney, above n 13, 752

¹⁰³ Wayne Swan, Budget Speech 2013-14, Delivered on 14 May 2013 on the Second Reading of the Appropriation Bill (No. 1) 2013-14, 8, <http://www.budget.gov.au/2013-14/content/speech/download/Budget_speech_2013.pdf> as at 14 April 2017

It will be important in the interviews to gauge the interviewees' understanding of how best they can live their lives and to what extent the NDIS is facilitating or hindering their enjoyment of life.