Submission to Parliament of Australia Senate Standing Committees on Community Affairs, Inquiry into National Disability Insurance Scheme Bill 2012

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Submitted by:
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Women’s Health Victoria
Introduction

About us

This submission is contributed to or endorsed by a number of peak and specialist bodies that work with and for people with disabilities in Victoria.

Federation of Community Legal Centres

The Federation is the peak body for 51 community legal centres (CLCs) across Victoria. A full list of our members is available at http://www.communitylaw.org.au. The Federation leads and supports CLCs to pursue social equity and to challenge injustice.

The work of CLCs commonly entails assisting people who are disadvantaged, vulnerable or marginalised. Our clients are predominantly low-income, and include many young, elderly, Aboriginal and culturally and linguistically diverse (CALD) Victorians. The Commonwealth Government’s Review of the Commonwealth Community Legal Services Program noted that collated data demonstrated that 58% of community legal sector clients received some form of income support, 82% of clients earned less than $26,000 per annum, and almost 9% of clients had some form of disability.¹

Our member centres regularly assist clients with powers of attorney and in relation to guardianship and administration matters, including people who are homeless, have cognitive disabilities or are labelled as mentally ill. CLCs aim to provide a bridge to the justice system so that it is accessible, welcoming and fair for all Victorians. Genuine access to justice also means that there are adequate, appropriate and accessible remedies available to address violation of rights, and that all members of the community have an understanding of the legal system, their rights within it, and their options for achieving justice.

Women with Disabilities Victoria

Women with Disabilities Victoria is an organisation of women with disabilities in Victoria with a diverse and growing membership. Our members have a range of disabilities, backgrounds, lifestyles, and ages. Our board and staff also have disabilities.

We are united in working towards our vision of ‘a world where all women are respected and can fully experience life’. Our gender perspective allows us to focus on areas of inequity of particular concern to women with disabilities; access to women’s health, parenting rights, and safety from gender based violence. We have dedicated particular attention to the issue of men’s violence against women with disabilities, due to its gravity and occurrence in our lives.

AED Legal Centre
AED Legal Centre was established in 2008 to protect the rights of people with disability throughout Victoria who have experienced discrimination as a direct consequence of their disability in the areas of employment and education.

Disability Discrimination Legal Service
The Disability Discrimination Legal Service Inc. (DDLS) is a statewide independent community legal centre that specialises in disability discrimination legal matters. We provide free legal services in several areas including information, referral, advice, casework assistance, community legal education, and policy and law reform.

The DDLS works actively towards the eradication of disability discrimination and facilitates and promotes justice for people with disabilities through community legal education sessions to professional and community groups to raise disability awareness and provide information on the Disability Discrimination Act 1992 (Cth) and the Equal Opportunity Act 1995 (Vic).

We also undertake community development research projects to investigate and challenge current social, economic and legislative issues affecting people with disabilities in the community.

Mental Health Legal Centre
The Mental Health Law Centre is a community legal centre that advances the rights of people with psychiatric disability through the provision of legal services, community legal education and law reform activities.

Villamanta Disability Rights Legal Service
Villamanta Disability Rights Legal Service Inc. is a statewide community legal service that works only on disability-related legal and justice issues, with a particular focus on the rights of people who have an intellectual disability. We provide free casework, a telephone advice, information and referral service and community legal education, as well as working on policy and law reform. We also sell some books and manuals.

Women’s Health Victoria
Women’s Health Victoria is a not-for-profit organisation focused on improving the lives of Victorian women. We undertake strategic health promotion and advocacy to improve women's health, and provide a number of direct services. Our vision is women living well—healthy, empowered, equal.
Overview of our submission

Our organisations welcome the National Disability Insurance Scheme Bill 2012 (the Bill). Many of our clients and colleagues will be participating in the pilot launch in Victoria’s Barwon region or are keenly anticipating the wider rollout of the NDIS.

We understand that this Bill is not intended to cover all of the relevant issues and mechanisms concerning the NDIS. Nevertheless, there are various elements and omissions in the Bill that we believe must be addressed at this stage and in the primary legislation, in order to fulfil Australia’s human rights obligations to persons with disabilities, particularly under the Convention on the Rights of Persons with Disabilities (the Convention).2

The Convention requires Australia to ensure and promote the full realisation of all human rights and fundamental freedoms for all persons with disabilities without discrimination of any kind on the basis of disability.3 This includes genuinely facilitating and supporting the independence and full participation of people with disabilities in Australian society. However, as detailed below, the Bill does not provide for the highest level of freedom to make one’s own choices together with appropriate support and safeguards concerning that decision-making.4

The Bill is therefore also internally inconsistent, because Clause 3 of the Bill provides that one object of the proposed Act is to give effect to certain obligations under the Convention.

We are also concerned that significant aspects of the NDIS have been left to be determined in the NDIS Rules rather than in primary legislation, suggesting that they may not be open to community consultation in the same manner as the Bill. In our view, many of the matters left unclarified deserve primary legislation status, as we indicate below. At the very least, if such matters are to be left for the drafting of the Rules, they should be required to be debated by both Houses of Parliament rather than being a disallowable instrument. In this respect we endorse the submission on the Bill by the Law Council of Australia.

We would be pleased to have any further opportunity to discuss our submission.

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List of Recommendations

1. Clause 3(1)(b) should be amended to:
   ‘support the independence and full and effective participation, including social economic, cultural and religious participation, of people with disability’.

2. The Bill should include a general principle that acknowledges the specific needs of people with disabilities who are women, Aboriginal or Torres Strait Islander, from CALD backgrounds, or who are LGBTI. Policies and standards concerning NDIS assessment processes, access to the Scheme, arrangements and dealings with services, and engagement with accountability processes should all reflect this principle.

3. The Bill should expressly provide that disability services must ensure freedom from abuse and neglect and provide services and supports in a safe environment for all people, free from abuse, neglect, violence and/or preventable injury. Service standards and policy development must detail how this commitment will be translated into practice.

4. Clause 4(11) should be amended to include general principles along the lines of ‘All adults have the right to have their culture and religion recognised and respected’; and ‘All adults have the right to recognition and preservation of their family relationships’.

5. Clause 4(11) should include recognition of the need to support the parenting role of people with disabilities.

6. Independent advocacy support, including affordable or free legal assistance and representation, should be available on demand to all people with disabilities:
   - prior to and throughout eligibility and assessment processes;
   - when any issue or conflict arises with the National Disability Insurance Agency or service providers, including reviews and complaints;
   - to enable them to engage in service quality processes.

7. To avoid any doubt or ambiguity, Part 2 of Chapter 1 of the Bill should include a provision along the lines of:
   ‘A human right or freedom not included in this Part that arises or is recognised under the International Convention on the Rights of Persons with Disabilities must not be taken to be abrogated or limited only because the right or freedom is not included in this Part or is only partly included.’

8. The Bill as it stands leaves significant aspects of the NDIS to the NDIS Rules, such as: the meaning of ‘substantially reduced functional capacity’; the criteria for deciding the reasonable and necessary supports or general supports that will be funded; and whether assessment of reasonable and necessary supports will include a preclusion period where people have received compensation payments. These types of matters should be
incorporated into the Bill after community consultation. At the very least, the Rules should be debated by both Houses of Parliament.

9. The age requirements (Clause 22) should be modified to provide a choice for people with disabilities that are not ageing-related to be able to access the NDIS at any age.

10. Clause 24(1)(a) should be amended so that the sub-clause pertaining to psychiatric disability reads ‘. . . or physical impairments or to a psychiatric condition [; and]’.

11. Given that some family members can be controlling, exploitative and violent in other ways, the family context should be assessed before deciding what role the family should play in considerations by the NDIS Agency.

12. The Bill should include a separate Part which sets out independent external monitoring processes, together with complaint mechanisms that may be activated by participants, prospective participants, and interested third parties when the actions of providers, nominees or the Agency itself are at issue.

13. The Bill should more fully adopt the principles articulated in the Convention on the Rights of Persons with Disabilities by:
   incorporating a presumption that participants have decision-making capacity;
   enabling participants to appoint their own nominees (rather than just request their appointment);
   in situations where participants are themselves unable to make appointments, empowering an external authority comparable to a guardianship and administration tribunal, rather than the CEO, to appoint nominees;
   requiring, in situations where a participant has a decision making impairment that inhibits his or her ability to appoint a nominee, that any preferred nominee of a participant should still occupy that role, unless such an appointment would be deleterious to the participant’s personal and social wellbeing.

14. The Bill should provide more detail about the role of plan nominees, including the principles governing their operation.

15. The Bill should establish a process by which the appointment of nominees can be challenged by interested parties when concerns exist about the personal and social wellbeing of participants.

16. Clause 91(1) of the Bill should be amended to allow the CEO to suspend the appointment of a nominee if he or she has reasonable grounds to believe that the nominee has caused or is likely to cause physical, mental or financial harm to the participant (ie ‘severe’ to be omitted).
17. The Bill should incorporate independent external scrutiny of the actions of nominees, similar to the accountability mechanisms recommended by the Victorian Law Reform Commission in relation to substitute decision makers.

18. The Bill must provide for access to timely and comprehensive internal and external review of all significant decisions and actions taken under the NDIS and affecting participants and prospective participants.

19. Chapter 5 of the Bill should be amended so that the Agency cannot compel a participant or prospective participant to take common law action to obtain compensation.

THE BILL

Chapter 1—Introduction

Part 2—Objects and Principles

To be consistent with the full enjoyment of rights guaranteed to people with disabilities under the Convention,5 Clause 3(1)(b) should not be limited to ‘social and economic participation’ and instead should be amended to:

‘support the independence and full and effective participation, including social economic, cultural and religious participation, of people with disability’.

Recognition of specific circumstances of people with disabilities

We welcome Clause 5(d) in the General Principles, requiring the cultural and linguistic circumstances of people with disability to be taken into account, but we submit that this should be strengthened and that gender considerations must also be included.6 It is essential that the legislation be guided by a principle that acknowledges the specific needs of women, Aboriginal and Torres Strait Islander peoples, people from CALD backgrounds, and LGBTI people, due to the multiple, systemic and specific disadvantages experienced by these communities.

This must then have a flow on effect to NDIS assessment processes, access to the Scheme, arrangements and dealings with services, and engagement with accountability processes.7

5 Convention on the Rights of Persons with Disabilities, Article 3.
6 For more explanation about why it is crucial to address gender considerations, see Women with Disabilities Australia, Gendering the National Disability Care and Support Scheme—Submission to Stage One of the Productivity Commission National Disability Care and Support Inquiry (August 2010); Women with Disabilities Australia and Women with Disabilities Victoria, Submission in Response to the Productivity Commission’s Disability Care and Support Draft Report (May 2011).
7 For more detail on how a gender lens should shape NDIS processes, see Women with Disabilities Australia and Women with Disabilities Victoria, Submission in Response to the Productivity Commission’s Disability Care and Support Draft Report (May 2011).
Freedom from violence

We strongly endorse Principle (6) in Clause 4. Australia is obligated to take all appropriate measures to protect persons with disabilities from all forms of exploitation, violence and abuse, including their gender-based aspects. Our various organisations are all too aware that many people with disabilities, particularly women and those with significant cognitive and communication difficulties, are routinely subject to or are at ongoing risk of very high rates of violence and exploitation, including physical, sexual, emotional and financial abuse.

As for other Australians, such violence and exploitation may be from family members, acquaintances and strangers; but people with disabilities who rely on residential care and other formal support services are also particularly at risk of abuse from disability workers and others. Various factors can also exacerbate the experiences of people with disabilities subjected to violence and therefore intensify the need for targeted and tailored support. Some victims may have acquired their disability due to the violence; for example, violence is the leading cause of death, illness and disability for Victoria women. Women who have suffered family violence, and people with a disability, are at greater risk of homelessness than the general population. The risk of homelessness is even higher if the person has an intellectual disability, mental illness, or more than one disability.

It is therefore crucial that this understanding of the social context underpins the establishment and operation of the NDIS, so that, for example, processes and services can cater to the needs of people without homes and people in temporary accommodation or refuges. Many current services, such as Home and Community Care and the Disability Support Register, tend to require a permanent address. Additionally, many services take a long time to be delivered. For women trying to escape family violence this will mean that they cannot leave. Appendix 1 provides an example of the positive outcomes for

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8 Convention on the Rights of Persons with Disabilities, Article 16.
10 Office of the Public Advocate, Violence Against People with Cognitive Impairments, Melbourne (2010); Victorian Ombudsman, Ombudsman Investigation: Assault of a Disability Services Client by Department of Human Services Staff, Melbourne (2011); Disability Services Commissioner, Learning from Complaints—Occasional Paper No. 1: Safeguarding People’s Right to be Free from Abuse, Melbourne (June 2012).
13 Ibid.
women and children with disabilities when services give due consideration to their circumstances.

Future policy development must detail how this commitment will be translated into practice. As minimum standards, the NDIS must adhere to standards and evidence indicators similar to Victorian industry standards.\textsuperscript{14} The Bill should therefore expressly provide that disability services must ensure freedom from abuse and neglect and provide services and supports in a safe environment for all people, free from abuse, neglect, violence and/or preventable injury. The Scheme must also have processes to operationalise the standards, such as workforce training on recognising and responding to violence and abuse.

**Support for parents with disabilities**

As with Clause 3(1)(b), Clause 4(11) should include general principles along the lines of ‘All adults have the right to have their culture and religion recognised and respected’; and ‘All adults have the right to recognition and preservation of their family relationships’.

Clause 4(11) should include recognition of the need to support the parenting role of people with disabilities. As Women with Disabilities Australia and Women with Disabilities Victoria submitted to the Productivity Commission:

‘Mothers with disabilities have often reported that their “disability support” (such as attendant carer, home help) does not extend to provide any assistance with a baby/child. Women with disabilities who have children are not currently served well by parenting-related services, including maternity/obstetric services such as mother/baby unit for a newborn and family support services. There is a lack of enabling equipment that supports mothers with disabilities, for example, visual alerts for a child’s cry for the mother who is deaf; or a modified cot which assists a mother with poor balance to lift and cuddle her child.’\textsuperscript{15}

**Right to independent advocacy**

Clause 4(7)–(9) provides that people with disability have the same right as other Australians to pursue any grievance, the right to act as equal partners in decisions that affect their lives, and the right to be supported in all their dealings and communications with the Agency in order to maximise their capacity to exercise choice and control.

In order for these rights to be practically realised, enhanced access to legal assistance, and other independent advocacy as appropriate, is an essential requirement of the NDIS. We endorse the Position Statement of Disability Advocacy Network Australia:

\textsuperscript{14} Department of Human Services, *Department of Human Services Standards* (June 2011).

‘In the context of the NDIS and the NIIS, independent advocacy support should be available, on demand, to all people with disabilities:

- Prior to and throughout eligibility and assessment processes
- When any issue or conflict arises with the NDIA or NIIS or service provider
- To engage in service quality processes
- When an issue arises in relation to the services, supports or policies delivered by other (non-NDIS or NIIS) arms of government.’

Participants and prospective participants should be able to obtain affordable or free legal assistance, including legal representation, and other advocacy as appropriate, for applications, plans, complaints and reviews at all stages if required. This necessitates adequate funding of CLCs, Victoria Legal Aid and other independent advocacy organisations. We further refer the Committee to the submission on the Bill by Victoria Legal Aid concerning legal advocacy, which we endorse.

**Other human rights principles**

To avoid any doubt or ambiguity, Part 2 should also include a provision along the lines of:

‘A human right or freedom not included in this Part that arises or is recognised under the International Convention on the Rights of Persons with Disabilities must not be taken to be abrogated or limited only because the right or freedom is not included in this Part or is only partly included.’

**Chapter 3—Participants and their plans**

**Part 1—Becoming a participant**

We are concerned that much of the detail concerning the access criteria, such as the meaning of ‘substantially reduced functional capacity’, is relegated to the Rules, and hence is not available for our analysis and comment. As we outline above, there should be an opportunity for community consultation and, at the very least, rigorous parliamentary scrutiny.

Clause 22 (age requirements), while again leaving much of the decision making criteria to the Rules, potentially violates the human right to make one’s own choices, and unreasonably discriminates on the grounds of age. For example, Clause 22(1)(a) requires a prospective participant to request access to the NDIS before they turn 65. Thus only some people who wish to receive supports under the NDIS, rather than through the aged care system, will be able to exercise that choice.

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We understand that the rationale of the Productivity Commission Report was that people with ageing-related disability should access the aged care system in preference to the NDIS, whereas people reaching Age Pension age and already accessing the NDIS could usually choose which system they accessed. However, in the Bill, people with a disability that is not ageing-related and who are not aware of the provision in Clause 22(1)(a) until it is too late because they have already turned 65, will not be able to access the NDIS. We also refer the Committee to the submission on the Bill from Patricia Malowney, which describes the potential effect of the clause on her own situation. We therefore submit that the age requirements should be modified to provide a choice for people with disabilities that are not ageing-related to be able to access the NDIS at any age.

Clause 24(1)(a) appears to set a higher threshold for people who have a psychiatric disability, by requiring such a person otherwise potentially eligible for the Scheme to have a disability that is attributable to one or more impairments attributable to a psychiatric condition. Given the restrictions already provided for by the remaining proposed elements of Clause 24(1), we submit that it is sufficient for (1)(a) to be replaced by ‘...or physical impairments or to a psychiatric condition; and’.

Part 2—Participants’ plans

Much of the detail concerning participants’ plans, such as the criteria for deciding the reasonable and necessary supports or general supports that will be funded, is relegated to the Rules, and hence is not available for our analysis and comment. As we outline above, there should be an opportunity for community consultation and, at the very least, rigorous parliamentary scrutiny.

With regard to eligibility for reasonable and necessary supports (cl 34), there is an expectation that families will provide a degree of support (cl 34(e); see also cl 4(5) and cl 4(12)). However, some family members can be controlling, exploitative and violent in other ways. The family context must be assessed before deciding what role the family should play in considerations by the NDIS Agency.

We also endorse the submission on the Bill by the Law Council of Australia concerning the lack of specificity in Clause 35(4) with respect to whether assessment of reasonable and necessary supports will include a preclusion period where people have received compensation payments. If such a period were to be included, this would have a significant impact on people’s entitlements, and so the issue should not be left to the Rules.

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18 Productivity Commission, Disability Care and Support Inquiry Report (July 2011), 65 (Recommendation 3.6), 179–182.
Chapter 4—Administration

Part 3—Registered providers of supports

It is crucial that there are strong and clear measures of accountability for registered providers of supports, including monitoring and complaints mechanisms. The Bill does not specify these processes but instead makes them the subject of the Rules (cl 73).

The Bill must include a separate Part which sets out independent external monitoring processes, and complaint mechanisms that may be activated by participants, prospective participants, and interested third parties when the actions of providers, nominees or the Agency itself are at issue.

Part 5—Nominees

International and some Australian jurisdictions are increasingly recognising that in order to promote and protect the rights of people with disabilities, it is necessary to shift away from paternalistic notions, such as those in guardianship and administration legislation of acting 'in the best interests' of persons with disability, and towards a presumption of capacity or at least a continuum of capacity, together with a supported decision making approach.\(^{19}\)

Aspects of the Bill are inconsistent with this approach and with the Bill’s General principles (eg cl 4(8)–(11)). Australia’s human rights obligations concerning persons with disability mean that the Bill should be underpinned by a rebuttable presumption of capacity and a continuum of options from autonomous to supported to strongly regulated substitute decision making. The Bill’s provisions with regard to the appointment and actions of nominees do not conform to this approach.

For example, Clauses 86 and 87 provide that appointments of plan and correspondence nominees may be made on the initiative of the CEO of the NDIS Launch Transition Agency, and not necessarily at the request of the participant. The CEO is only required to ‘take into consideration’ the wishes (if any) of the participant (cl 88(2)(b)). Criteria surrounding CEO decision-making are relegated to the Rules (cl 88(6)(b)).

This Part of the Bill should instead begin from the assumption that many people with disabilities have the capacity to select and appoint their own nominees, while others may be able to make that decision with some support. Others who are assessed as lacking the capacity to make that decision may need a substitute decision maker, in which case thorough and transparent capacity assessment and appointment processes, with easily enforceable rights of review and mechanisms of accountability, must be incorporated into the Bill. Accordingly, in situations where participants are themselves unable to make appointments, it is appropriate that an external authority comparable to

\(^{19}\) See eg Victorian Law Reform Commission, Guardianship Final Report 24 (January 2012).
a guardianship and administration tribunal, rather than the CEO, appoint nominees.

We also endorse the following recommendations concerning nominees from the submission on the Bill by the Office of the Public Advocate:

1. That the NDIS legislation more fully adopt the principles articulated in the Convention on the Rights of Persons with Disabilities by:
   - incorporating a presumption that participants have decision-making capacity;
   - enabling participants to appoint their own nominees (rather than just request their appointment);
   - requiring, in situations where a participant has a decision making impairment that inhibits his or her ability to appoint a nominee, that any preferred nominee of a participant should still occupy that role, unless such an appointment would be deleterious to the participant’s personal and social wellbeing.

2. That the NDIS legislation provide greater clarification about the role of plan nominees by detailing, for instance, the principles governing their operation.

3. That the NDIS legislation establish a process by which the appointment of nominees can be challenged by interested parties when concerns exist about the personal and social wellbeing of participants.

Where participants are assessed as unable to make their own appointments, we refer the Committee to our comments above with respect to eligibility for reasonable and necessary support and the role of families (cl 4(12)). The family context must therefore be assessed before the Agency considers whether a family member might be a suitable nominee.

Clause 91(1) allows the CEO to suspend the appointment of a nominee if he or she has reasonable grounds to believe that the nominee has caused or is likely to cause severe physical, mental or financial harm to the participant. We submit that it is consistent with respect for the human rights of people with disabilities that the word ‘severe’ be deleted from the clause.

There should also be independent external scrutiny of the actions of nominees, similar to the accountability mechanisms recommended by the Victorian Law Reform Commission in relation to substitute decision makers.20

Part 6—Review of decisions

In order to genuinely give effect to human rights principles, including in the Bill (Clause 4(7)), the Scheme must provide access to timely and comprehensive internal and external review of all significant decisions and actions taken under the NDIS and affecting participants and prospective participants. We refer the Committee to the comments of the Law Council of Australia, which we endorse.

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Chapter 5—Compensation payments

We endorse the submission of the Law Council of Australia that it would be inappropriate and unreasonable for the Agency to be able to compel a participant or prospective participant to take common law action to obtain compensation. We echo the Council’s concerns that there may be significant risks and complexities, including legal costs, associated with such an action. In addition, our experience is that many people with disabilities already find it immensely difficult to navigate the legal system and are often unable to obtain the legal and other advocacy assistance that they need to help them do this.21 As submitted above, increasing access to legal and other advocacy to assist people to negotiate the NDIS system should be the priority.

21 Law and Justice Foundation of NSW, Legal Australia-Wide Survey: Legal Need in Australia (2012), xv
http://www.lawfoundation.net.au/ljf/app/6DDF12F188975AC9CA257A910006089D.html
Appendix 1: Disability and Family Violence Crisis Response Initiative—Pilot Project

A woman was referred to a family violence service to access crisis accommodation and support due to experiencing family violence from her immediate family, who were also her carers. The woman had suffered a stroke and had only partial functioning of her body and an acquired brain injury. Upon assessment during the referral process it was ascertained that the woman would require assistance on a daily basis, as she was unable to complete various daily living tasks. The Disability and Family Violence Crisis Initiative Response provided immediate access to attendant care twice a day to assist with meal preparation, personal hygiene and general household duties. Without the funds to purchase this support, an appropriate and immediate response would not have been possible for this woman, and her options in fleeing her situation safely would have been extremely limited and the possibility of her remaining in a violent environment highly likely.

This case study was provided by Bianca Truman, Disability Project Officer Safe Futures Foundation. For further information on the Disability and Family Violence Crisis Fund Initiative contact Heather Thompson heather.thompson@dhs.vic.gov.au