



## Submission

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Senate Community Affairs Legislation Committee

National Disability Insurance Scheme Amendment (Quality and Safeguards Commission and Other Measures) Bill 2017

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**July 2017**

## Publishing Information

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‘Disabled People’s Organisations Australia (DPO Australia) Submission to the Senate Community Affairs Legislation Committee Inquiry: National Disability Insurance Scheme Amendment (Quality and Safeguards Commission and Other Measures) Bill 2017’.

Prepared by Therese Sands on behalf of Disabled People’s Organisations Australia.

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## Contact for this Submission

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## 1. Disabled People's Organisations Australia (DPO Australia)

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Disabled People's Organisations Australia (DPO Australia) is an alliance of four national DPOs in Australia. DPOs are organisations that are governed, led by and constituted of people with disability.

The key purpose of the DPO Australia is to promote, protect and advance the human rights and freedoms of people with disability in Australia by working collaboratively on areas of shared interests, purposes and strategic priorities and opportunities.

DPO Australia is made up of four national peak DPOs that have been funded by the Australian Government to represent the views of people with disability and provide advice to Government/s and other stakeholders.

The four DPO Australia members are:

[First Peoples Disability Network Australia \(FPDN\)](#) is the national DPO representing Aboriginal and Torres Strait Islander people with disability and their families. FPDN utilises a range of strategies in its representative role, including through the provision of high-level advice to governments, and educating the government and non-government sectors about how to meet the unmet needs of Aboriginal and Torres Strait Islander people with disability.

[Women With Disabilities Australia \(WWDA\)](#) is the national DPO for women and girls with all types of disabilities in Australia. It operates as a transnational human rights organisation and is run by women with disabilities, for women with disabilities. WWDA's work is grounded in a human rights based framework which links gender and disability issues to a full range of civil, political, economic, social and cultural rights.

[National Ethnic Disability Alliance \(NEDA\)](#) is the national peak organisation representing the rights and interests of people from Culturally and Linguistically Diverse (CALD/NESB) people with disability, their families and carers throughout Australia. NEDA advocates at the federal level so that CALD/NESB people with disability can participate fully in all aspects of social, economic, political and cultural life.

[People with Disability Australia \(PWDA\)](#) is the national cross disability rights and advocacy organisation run by and for people with disability. Working within a human rights framework, PWDA represents the interests of people with all kinds of disability. Its primary membership is made up of people with disability and organisations primarily constituted by people with disability. It also has a large associate membership of other individuals and organisations committed to the disability rights movement.

## 2. Introduction

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- 2.1 DPO Australia welcomes the opportunity to provide our comments to the Senate Community Affairs Legislation Committee Inquiry into the National Disability Insurance Scheme Amendment (Quality and Safeguards Commission and Other Measures) Bill 2017 (the Bill).
- 2.2 The Bill outlines amendments to the National Disability Insurance Scheme (NDIS) Act 2013 under two Schedules:
- Schedule 1 establishes a NDIS Quality and Safeguards Commission; and
  - Schedule 2 outlines amendments to the NDIS Act 2013 based on the outcomes of an independent review of the Act in 2015.
- 2.3 This NDIS Act 2013 is critical to the implementation of human rights for people with disability as it gives effect to Australia's obligations under the Convention on the Rights of Persons with Disabilities (CRPD) as well as certain obligations under the International Covenant on Civil and Political Rights (ICCPR), the International Covenant on Economic, Social and Cultural Rights (ICESCR), the Convention on the Rights of the Child (CRC), the Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW) and the International Convention on the Elimination of All Forms of Racial Discrimination (ICERD).<sup>1</sup> Any amendments to the NDIS Act must further advance the rights of people with disability.
- 2.4 This submission provides our key comments regarding the amendments under both Schedules.

## 3. Schedule 1

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### NDIS Commission and need for Royal Commission:

- 3.1 The issue of violence, abuse and neglect has been the subject of national and State based inquiries over recent years as well as the subject of recent media reports and exposes.<sup>2</sup> The evidence overwhelmingly demonstrates that violence, abuse and neglect against people with disability is prolific and an issue of national importance requiring urgent attention.
- 3.2 DPO Australia strongly supports the establishment of an independent national statutory mechanism that has broad powers and functions to protect, prevent and respond to

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<sup>1</sup> Section 3(1) and 3(1)(h)(i), Part 2, Objects and principles, *NDIS Act 2013*.

<sup>2</sup> As noted in Explanatory Memorandum to this Bill, p. ii; and 'End the Violence: Call a Royal Commission into Violence and Abuse Against People with Disability', Civil Society Statement to the Australian Government, May 2017, Disabled People's Organisations Australia, <http://dpoa.org.au/civil-society-statement-rc/>

violence, abuse and neglect experienced by people with disability.<sup>3</sup> This position was reflected in one of the 'headline' recommendations from the Senate Community Affairs References Committee Inquiry into violence, abuse and neglect against people with disability in institutional and residential settings.<sup>4</sup>

- 3.4 In this context, we welcome the establishment of the NDIS Quality and Safeguards Commission (the NDIS Commission) that will have powers to register and regulate NDIS providers, respond to complaints, develop national worker screening standards and oversee behaviour support and the use of restrictive practices. We acknowledge that the Bill provides the NDIS Commission with extensive compliance, enforcement, monitoring and investigation powers in many aspects, and these are critical for people with disability to have protections from violence, abuse and neglect when using supports and services under the NDIS. We also note that some elements of the NDIS Commission are weaker than others, and a number of these elements are discussed within this submission.
- 3.5 However, DPO Australia remains disappointed and concerned that the establishment of the NDIS Commission will not provide comprehensive protection against violence, abuse and neglect for all people with disability across a broad range of service systems and situations. We note that our support for an independent, national statutory mechanism and the recommendation from the Senate Community Affairs References Committee was not confined to the NDIS. DPO Australia has consistently highlighted that the NDIS Commission will only provide protection to the 10% of people with disability who directly access NDIS supports. It will not have a mandate to address individual or systemic issues outside of the NDIS. This means that the majority of people with disability, as well as NDIS participants when interacting with other service systems, will only have protection through existing regulatory and policy frameworks that have to a large extent been shown to provide inadequate protection. Failures of regulatory and systemic systems have been found in the State based and national inquiries mentioned in 3.1.
- 3.6 In addition, and in line with the overarching recommendation from the Senate Community Affairs Committee Inquiry,<sup>5</sup> DPO Australia along with many other organisations and individuals strongly support the establishment of a Royal Commission into violence, abuse and neglect against people with disability.<sup>6</sup> The establishment of the NDIS Commission does not address the broad concerns raised in the Senate Community Affairs Inquiry nor negate

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<sup>3</sup> See e.g., Frohmader, C., & Sands, T. (2015) *Australian Cross Disability Alliance (ACDA) Submission to the Senate Inquiry into Violence, abuse and neglect against people with disability in institutional and residential settings*. August 2015, Australian Cross Disability Alliance (ACDA); Sydney, Australia, para 42.6, p. 12

<sup>4</sup> See recommendation 2, paras 10.16 and 10.17, p. xv, Senate Community Affairs References Committee: [http://www.aph.gov.au/Parliamentary\\_Business/Committees/Senate/Community\\_Affairs/Violence\\_abuse\\_neglect/Report](http://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/Violence_abuse_neglect/Report)

<sup>5</sup> Recommendation 1, para 10.10, p. xv, Senate Community Affairs References Committee: [http://www.aph.gov.au/Parliamentary\\_Business/Committees/Senate/Community\\_Affairs/Violence\\_abuse\\_neglect/Report](http://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/Violence_abuse_neglect/Report)

<sup>6</sup> See e.g., 'End the Violence: Call a Royal Commission into Violence and Abuse Against People with Disability', Civil Society Statement to the Australian Government, May 2017, Disabled People's Organisations Australia, <http://dpoa.org.au/civil-society-statement-rc/>

the need for a Royal Commission, despite views to the contrary expressed in the Government's response to the Senate Inquiry report.<sup>7</sup>

**Recommendations:**

- a) Reviews of legislation that establishes the NDIS Commission should consider the effectiveness of protections for NDIS participants, the gaps in protections arising from the interface from the NDIS Commission and other mainstream regulatory frameworks, and whether the mandate of the NDIS Commission should be expanded.
- b) Establish a Royal Commission into violence, abuse and neglect against people with disability in parallel to the establishment of the NDIS Commission.

**NDIS Rules:**

- 3.7 We note that the Bill provides the architecture for the NDIS Commission, including the role of the NDIS Commissioner. The effectiveness of the NDIS Commission in protecting people with disability from violence, abuse and neglect depends heavily on the NDIS Rules, which will be developed in response to the provisions in the Bill.
- 3.8 This means that many of the specific elements of implementation of the functions of the NDIS Commission, in line with the objects and principles of the NDIS Act will require strong monitoring and enforcement measures.
- 3.9 Given the importance of the NDIS Rules for effective implementation of the functions of the NDIS Commission, it is critical that the development of the NDIS Rules involves engagement and consultation with people with disability and their representative and advocacy organisations. Such engagement and consultation reflects the proposed amendments outlined for section 4(9) in Schedule 2 of the Bill that emphasises the centrality of people with disability and the need for their inclusion in a "co-design capacity" (discussed below under Schedule 2).

**Recommendation:**

- c) The NDIS Rules should be developed with people with disability and their representative and advocacy organisations in line with the principle that people with disability are central to the NDIS and should be included in a co-design capacity.

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<sup>7</sup> 'Australian Government response to the Senate Community Affairs References Committee 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', 2 March 2017, [http://www.aph.gov.au/Parliamentary\\_Business/Committees/Senate/Community\\_Affairs/Violence\\_abuse\\_neglect/Government\\_Response](http://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/Violence_abuse_neglect/Government_Response)

### Independence of the NDIS Commissioner:

- 3.10 There are some provisions in the Bill that allow the Commonwealth Minister, by legislative instrument to direct various aspects of the functions of the NDIS Commissioner. In particular, section 181K(1) of the Bill allows the Commonwealth Minister to “give directions to the NDIS Commissioner about the performance of his or her functions and the exercise of his or her powers”.<sup>8</sup>
- 3.11 The Explanatory Memorandum to the Bill states that this provision is “consistent with the establishment of an independent statutory body that is prescribed under the [Public Governance, Performance and Accountability Act 2013]”, and that “directions from the Minister must be of a general nature only”,<sup>9</sup> as qualified by section 181K(2). This section qualifies that the Minister’s directions cannot relate to specific individuals or particular NDIS providers and must not be inconsistent with the Act.
- 3.12 Nevertheless, DPO Australia is concerned that directions could be imposed by the Commonwealth Minister that have the effect of constraining or compromising the independence of the NDIS Commissioner, for example, in investigating systemic issues arising from complaints.
- 3.13 The NDIS is a national scheme requiring cooperation and agreement between all levels of government, and this provision appears to give the Commonwealth greater discretionary powers.

### **Recommendation:**

- d) Proposed section 181K(1) should be limited by a provision that ensures that States and Territories are consulted about, and provide agreement for directions proposed by the Commonwealth Minister for the NDIS Commissioner.

### National policy oversight of restrictive practices:

- 3.14 The NDIS Commissioner’s behaviour support function, outlined in section 181H of the Bill, is based on policy oversight and guidance to NDIS providers, which will be led by a national Senior Practitioner and underpinned by the *National Framework for Reducing and Eliminating the Use of Restrictive Practices in the disability Service Sector* (the National Framework).
- 3.15 The Senior Practitioner will provide “leadership in behaviour support, and in the reduction and elimination of the use of restrictive practices, by NDIS providers”<sup>10</sup> by building capability, assessing skills and experience, providing education, training and advice,

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<sup>8</sup> *National Disability Insurance Scheme Amendment (Quality and Safeguards Commission and Other Measures) Bill 2017*, s.181K(1).

<sup>9</sup> Explanatory Memorandum, *National Disability Insurance Scheme Amendment (Quality and Safeguards Commission and Other Measures) Bill 2017*, paras 337 and 338, p. 59.

<sup>10</sup> *Ibid*, para 318, p. 55.



monitoring registration compliance, undertaking data collection and analysis and undertaking research.<sup>11</sup> State and Territories will continue to authorise restrictive practices within behaviour support plans using the legislative and policy processes within each jurisdiction.

- 3.16 DPO Australia is very concerned that this oversight function for the NDIS Commissioner is very weak given that restrictive practices cause significant breaches of human rights, and can constitute torture, cruel, inhuman or degrading treatment or punishment.<sup>12</sup> There is a strong relationship between the use of restrictive practices and other forms of violence, abuse and neglect against people with disability, which undermines the ability of people with disability and support workers to recognise violence and respond to it as a crime.<sup>13</sup>
- 3.17 The Explanatory Memorandum to the Bill states that these arrangements respond to obligations under the CRPD<sup>14</sup> and to the recommendation from the Committee on the Rights of Persons with Disabilities “to take immediate steps to end such practices”.<sup>15</sup> However, DPO Australia argues that the NDIS Commissioner should have the strongest powers possible with regard to the elimination of restrictive practices. This includes legislative powers to prohibit certain restrictive practices and impose criminal penalties.<sup>16</sup>
- 3.18 In addition, if authorisation of behaviour support plans is to be conducted at the State and Territory level, then there needs to be agreement at the State and Territory level for nationally consistent regulatory mechanisms for authorisation of behaviour support plans. The current mechanisms at State and Territory level are varied and inconsistent, with some consisting of relatively weak policy functions within government departments and others having established regulatory bodies and mechanisms.
- 3.19 Importantly, the NDIS Commissioner should engage in processes that are underway to give effect to Australia’s commitment to ratify the Optional Protocol to the Convention Against Torture (OpCAT)<sup>17</sup> in order to ensure that people with disability are included in the mechanisms that need to be established following ratification.<sup>18</sup> In particular, the NDIS

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<sup>11</sup> Ibid, pp. 55-56.

<sup>12</sup> For further discussion on restrictive practices, human rights and torture, see e.g: Phillip French, Julie Dardel & Sonya Price-Kelly, “Rights Denied: Towards a National Policy Agenda about Abuse, Neglect & Exploitation of Persons with Cognitive Impairment”, People with Disability Australia (2010); Frohmader, C., & Sands, T. (2015), op. cit; People with Disability Australia, ‘Consideration of the 4<sup>th</sup> and 5<sup>th</sup> Reports of Australia by the Committee to the Convention Against Torture’ Submission, (October 2014); Juan E. Mendez, Special Rapporteur, Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, 22<sup>nd</sup> sess, UN Doc A/HRC/22/53 (1 February 2013).

<sup>13</sup> Phillip French, Julie Dardel, & Sonya Price-Kelly, op. cit.

<sup>14</sup> Explanatory Memorandum, op. cit, paras 319 and 320, p. 56.

<sup>15</sup> Committee on the Rights of Persons with Disabilities, UN Doc CRPD/C/AUS/CO/1, para 36.

<sup>16</sup> Recommendation on page 97 contained in Phillip French et.al, op. cit, outlines prohibited practices should include practices that are experimental; that cause pain or discomfort; that are cruel, inhuman, degrading or humiliating; that result in emotional or psychological deprivation or other harm; physical restraint; and seclusion.

<sup>17</sup> Alexandra Beech, ‘OPCAT: Australia makes long-awaited pledge to ratify international torture treaty’, ABC News, February 9, 2017, <http://www.abc.net.au/news/2017-02-09/australia-pledges-to-ratify-opcat-torture-treaty/8255782>

<sup>18</sup> While the Convention Against Torture (CAT) is not one of the treaties list in section 3(i)(i) of the NDIS Act, article 15 of the CRPD incorporates and applies CAT to the specific situation of people with disability.

Commissioner should be engaged in the establishment of an independent national preventive mechanism to monitor places of detention, potentially including disability residential settings, to ensure people with disability are not subjected to mistreatment. This would also more fully respond to the recommendation from the Committee on the Rights of Persons with Disabilities to end restrictive practices, “including by establishing an independent national preventative mechanism to monitor places of detention” for people with disability.<sup>19</sup>

**Recommendations:**

- e) Legislation to establish the NDIS Commission should include legislative powers to enable the NDIS Commissioner to prohibit certain restrictive practices that correspond to criminal penalties.
- f) Nationally consistent regulatory mechanisms for the authorisation of behaviour support plans should be established by State and Territories.
- g) The NDIS Commissioner should engage in processes concerning the ratification of OpCAT in order to ensure mechanisms established are inclusive of people with disability and interface with the NDIS Commission.

**Independent advocacy:**

- 3.20 The important role of independent advocacy in supporting people with disability to address service quality and issues of violence, abuse and neglect is recognised in the Quality and Safeguarding Framework.<sup>20</sup>
- 3.21 However, the Bill does not include any provisions that directly relate to this critical role and the strong likelihood that advocacy will engage regularly with the NDIS Commission. While the role of advocacy may be included more substantially in the NDIS Rules, there are some provisions in the Bill that would be strengthened by the inclusion of advocacy.
- 3.22 In particular, section 73ZA of the Bill provides protection for ‘disclosers’ of information from any civil or criminal prosecution and provides ‘qualified privilege’ in relation to the disclosure. The section covers a number of disclosers that are part of NDIS providers, as well as “a person with disability who is receiving a support or service from the NDIS provider, or a nominee, family member, carer or significant other of that person”.<sup>21</sup>
- 3.23 However, the Bill does not cover independent advocates who may disclose information. This is despite the fact that legal action and malice can, and has been directed at advocates by service providers and / or staff of service providers that have been the subject of disclosures.

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<sup>19</sup> Committee on the Rights of Persons with Disabilities, op. cit., para 36.

<sup>20</sup> 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](https://www.dss.gov.au/sites/default/files/documents/04_2017/ndis_quality_and_safeguarding_framework_final.pdf)

<sup>21</sup> *National Disability Insurance Scheme Amendment (Quality and Safeguards Commission and Other Measures) Bill 2017*, s. 73ZA(1).

Independent advocates should have the same protections against disclosure of information as nominees, family members, carers or significant others of a person with disability.

**Recommendations:**

- h) Independent advocacy should be included in the NDIS Rules to elaborate on the role of independent advocacy in implementing the Quality and Safeguarding Framework and the interface with the NDIS Commission.
- i) Section 73ZA of the Bill should name independent advocates as disclosers of information so that they are covered by the protections contained in this section.

## 4. Schedule 2

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### Decision-making and the CRPD:

- 4.1 DPO Australia is disappointed and concerned that there has been no formal Australian Government response to the final report from the Australian Law Reform Commission (ALRC), *Equality, Capacity and Disability in Commonwealth Law*.<sup>22</sup> This report provided recommendations for amendments to Commonwealth law, including the NDIS Act to enhance compliance with article 12 of the CRPD, *Equal recognition before the law*. This included as a first and overarching recommendation the establishment of national decision-making principles to guide reform.<sup>23</sup>
- 4.2 A recommendation from the 2015 review of the NDIS Act was to “operationalise the ALRC recommendations relating to the NDIS”.<sup>24</sup> The Explanatory Memorandum to the Bill outlines that this recommendation was noted but not implemented as “COAG considered that the principles suggested by the ALRC are already broadly established in the NDIS framework”.<sup>25</sup>
- 4.3 DPO Australia disagrees with this conclusion and argues that provisions in the NDIS Act, such as those relating to nominees, are based on substitute decision-making models that are not compliant with the CRPD. In a practical sense, this means that there is still a focus on whether a person with disability has capacity to make their own decisions, rather than on what supports a person with disability needs to exercise their right to make their own decisions. There is also still a focus on a ‘best interests’ approach to decision-making instead of the ‘will and preferences’ model for decision-making as articulated in article 12 of the CRPD.
- 4.4 The ALRC recommendations in relation to the NDIS Act strengthen the shift to supported decision-making arrangements that comply with the CRPD. The decision not to include them

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<sup>22</sup> Australian Law Reform Commission, *Equality, Capacity and Disability in Commonwealth Laws* (2014), Commonwealth of Australia, <https://www.alrc.gov.au/publications/equality-capacity-disability-report-124>

<sup>23</sup> Ibid, p. 11

<sup>24</sup> Ernst & Young, “Independent review of the NDIS Act”, December 2015, Department of Social Services, p. 68.

<sup>25</sup> Explanatory Memorandum, op. cit., p. 68.

as amendments in Schedule 2 of the Bill is a missed opportunity to enhance the NDIS Act's compliance with the CRPD by ensuring that people with disability are able to exercise their legal capacity on an equal basis with others.

**Recommendation:**

- j) The next review of the NDIS Act should incorporate amendments that implement the recommendations from the Australian Law Reform Commission's report, *Equality, Capacity and Disability in Commonwealth Law*.
- k) The Australian Government should develop a legislative reform framework that establishes national decision-making principles to guide law and policy reform in line with the recommendations from the Australian Law Reform Commission's report, *Equality, Capacity and Disability in Commonwealth Law*

**Chronic health conditions:**

- 4.5 DPO Australia does not support the amendments in the Bill that propose a new paragraph – 24(1)(f) - be added to the end of section 24(1).
- 4.6 The Explanatory Memorandum to the Bill notes that this amendment is aimed at providing “clarity on how the disability requirements are intended to operate for people with chronic health conditions.”<sup>26</sup> The intent is to remove confusion and uncertainty when a person meets the disability requirements under section 24 of the NDIS Act, but is not eligible to receive reasonable and necessary supports under section 34(1)(f) as the supports are “most appropriately funded or provided through another universal service system.”<sup>27</sup>
- 4.7 This amendment should not be accepted for the following reasons:
  - Eligibility for the NDIS depends on whether a person meets the disability requirement, followed by a determination of whether the person is eligible to receive reasonable and necessary supports through the NDIS. The proposed amendment means that the determination of whether a person meets the disability requirement is dependent on whether the NDIS can provide reasonable or necessary supports, or whether those supports should be provided through another service system, such as health. This creates the risk of ruling out groups of people with disability, such as those with chronic health conditions from the NDIS based on decisions regarding whether the NDIS can fund supports for people with disability. This is contrary to the object and principles of the NDIS and is not supported.
  - The confusion and uncertainty regarding eligibility and the provision of reasonable and necessary supports through the NDIS or other service systems is apparent at the policy and practice level of the NDIS. Issues are consistently raised with DPO Australia regarding the determinations of eligibility and the interface with other service systems, the impact

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<sup>26</sup> Explanatory Memorandum, *ibid*, para 411, p. 74

<sup>27</sup> *Ibid*, para 412, p.74

of the transfer of services from State and Territory jurisdictions to the NDIS and the consequent misunderstandings about which service systems have responsibility and the lack of clarity regarding eligibility and appropriate service system for the provision of supports for people with dual or multiple impairments.<sup>28</sup> However, this confusion is more appropriately dealt with through clearer guidance to NDIA to staff, people with disability and the community, and greater transparency and accountability for transfer of services to the NDIS by States and Territories.

- 4.8 In this context, and given the NDIS is still not fully implemented, DPO Australia argues that concerted consideration of these issues needs to be undertaken with people with disability and their representative and advocacy organisations before any amendments are proposed to NDIS eligibility.
- 4.9 DPO Australia also notes that the Productivity Commission Review of NDIS Costs has examined NDIS boundaries and service system interface issues, and made initial recommendations to address this. It is important that the final findings and recommendations from the Productivity Commission, due in September 2017, inform solutions to any confusion regarding eligibility rather than amend the NDIS Act now.

**Recommendation:**

- l) Section 24(1) should not be amended to include the additional paragraph 24(1)(f) as set out in the Bill.

**Centrality of people with disability and co-design:**

- 4.10 DPO Australia supports the intent of the amendments in the Bill to insert, after section 4(9), a new section 4(9A): “People with disability are central to the National Disability Insurance Scheme and should be included in a co-design capacity”.
- 4.11 We note that this intent reflects the NDIS Civil Society Statement to COAG and the National Disability Insurance Agency (NDIA), *Call for stronger engagement with people with disability in the NDIS*.<sup>29</sup> This Statement specifically seeks implementation of mechanisms that genuinely engage people with disability, noting that:
- “Co-design is a founding and integral concept of the NDIS – people with disability need to be integral to every stage of the design, implementation and evaluation of the NDIS.”<sup>30</sup>
- 4.12 While the amendment explicitly recognises the centrality of people with disability, and co-design as the methodology for NDIS inclusion, this amendment will only have practical effect

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<sup>28</sup> We note that case studies that illustrate and examine this issue are included in the submission provided by Community Mental Health Australia (CMHA).

<sup>29</sup> Civil Society Statement to the Australian Government, May 2017, op. cit., <http://dpoa.org.au/call-for-stronger-engagement-with-people-with-disability-in-the-national-disability-insurance-scheme-ndis/>

<sup>30</sup> Ibid, p. 2

if it is supported by policy and guidelines that genuinely articulate what co-design means, and that are developed and agreed between people with disability and the NDIA and governments.

- 4.13 There is currently no agreed policy on co-design principles, processes and implementation, and in many situations, the word ‘co-design’ is merely replacing the traditional methods of engagement with people with disability – consultation forums, reference groups, workshops, meetings, submission processes etc. This is not co-design, and without an agreed policy and protocols, this amendment will likely only result in tokenism.

**Recommendation:**

- m) Implementation of section 4(9A) in the Bill should be supported by a nationally, consistent co-design policy and guidelines that are developed and agreed with people with disability and their representative organisations.

**Intersectionality:**

- 4.14 DPO Australia supports the intent of the amendments to the NDIS Act to include reference in section 5 to reference lesbian, gay, bisexual, transgender and intersex status. However, the proposed amendment to section 5(d) in the Bill is problematic and we do not support it in its current form.
- 4.15 The amendment to section 5(d) of the Bill removes the words “and the gender” and replaces this with the words, “the gender identity, sexual orientation and internet status”. The intent, as explained in the Explanatory Memorandum to the Bill, is “to reference lesbian, gay, bisexual, transgender and intersex status” and to provide consistency with the *Sex Discrimination Act 1984 (Cth)*.<sup>31</sup>
- 4.16 In removing reference to ‘gender’, the proposed amendment removes recognition of the intersection between disability and gender. While the term ‘gender’ is not interchangeable with the term ‘women’, it “refers to socially constructed identities, attributes and roles for women and men.”<sup>32</sup> It recognises how disadvantage and discrimination is experienced differently by women in relation to men. This means that removal of the word ‘gender’ from section 5(d) of the Bill, removes recognition of the specific circumstances women with disability experience because of the intersection between disability and gender.
- 4.17 The NDIS Act gives effect to obligations under the CRPD and CEDAW. The CRPD specifically acknowledges the intersectional discrimination and disadvantage experienced by women with disability by the inclusion of article 6, *Women with Disabilities*. This article is a cross cutting article, meaning that each CRPD article must consider measures to advance the human rights of women with disability.

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<sup>31</sup> Explanatory Memorandum, op. cit., para 402, p. 72.

<sup>32</sup> United Nations Office of the High Commissioner for Human Rights, “Women’s Rights are Human Rights”, 2014, United Nations, p. 35

4.17 The terms 'gender' and 'gender identity' are not synonymous.<sup>33</sup> The *Sex Discrimination Act 1984* gives effect to CEDAW, promotes the principle of the equality between men and women and covers "sex, sexual orientation, gender identity, intersex status..."<sup>34</sup>

4.18 In addition, section 5(d) stipulates that "the cultural and linguistic circumstances...of people with disability should be taken into account". DPO Australia supports this principle. However, we do not believe that it covers the unique circumstances of Aboriginal and Torres Strait Islander people with disability. The CRPD acknowledges:

"the difficult conditions faced by person with disabilities who are subject to multiple or aggravated forms of discrimination on the basis of race, colour, sex, language, religion, political or other opinion, national, ethnic, **indigenous** or social origin, property, birth, age or other status" (emphasis added).<sup>35</sup>

4.19 To give genuine effect to CRPD recognition of the situations experienced by Indigenous peoples, DPO Australia supports a specific principle regarding Aboriginal and Torres Strait Islander people with disability.

**Recommendations:**

- n) Section 5(d) should not be amended to omit "and the gender", but should be amended to state: "the cultural and linguistic circumstances, and the sex, gender, gender identity, sexual orientation and intersex status of people with disability should be taken into account".
- o) Section 5 should include specific recognition of the situation of Aboriginal and Torres Strait Islander people with disability: "The unique cultural and social factors that concern Aboriginal and Torres Strait Islander people with disability should be respected and acknowledged".

**People with disability and appointments to the NDIA Board:**

4.20 DPO Australia is concerned that the proposed amendment to section 127(2) of the NDIS Act confines eligibility for people with disability to be appointed to the NDIA Board to only one of the areas that qualify for membership of the NDIA Board – "(a) the provision or use of disability services".

4.21 The report from the review of the NDIS Act notes that there was considerable stakeholder concern about the lack of emphasis on people with disability being involved in NDIS decision-making, including at the Board level.<sup>36</sup> This also reflects the views raised in the NDIS Civil Society Statement: "It must not be assumed that people with disability do not

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<sup>33</sup> See definitions and discussion in United Nations Office of the High Commissioner for Human Rights, *ibid*, pp. 36-37: "Gender identity reflects a deeply felt and experienced sense of one's own gender, which may or may not conform with the biological sex one is assigned at birth":

<sup>34</sup> *Sex Discrimination Act 1984* (Cth), section 3, Objects.

<sup>35</sup> *Convention on the Rights of Persons with Disabilities*, UN Doc A/RES/61/106, Preamble (p).

<sup>36</sup> Ernst & Young, *op. cit.*, pp. 79-80



have the significant disability, governance, financial and industry expertise required” to be eligible for appointment to the NDIA Board.<sup>37</sup>

- 4.22 If the intent of the proposed amendment in the Bill is to strengthen recognition that people with disability should be strongly considered when selecting Board members, then this recognition should apply to all of the fields listed from (a) – (d) in section 127(2). This also reflects anti-discrimination law. As it stands the amendment can be read as limiting eligibility to ‘the provision or use of disability services’.
- 4.23 DPO Australia also has concerns with the term used in the proposed amendment, ‘person with lived experience of disability’. This term is increasingly being used to cover a broad range of people who have connections to people with disability as well as people with disability themselves. It obscures the central role that people with disability should have in the NDIS, including in decision-making within the NDIA Board, and implies that others can speak, make decisions for and have the same experiences as people with disability themselves. This does not deny expertise held by family members, carers etc, but if people with disability are considered central to the NDIS, then the focus of any amendment should be on strengthening the leadership role people with disability. Any amendment to this section needs to refer to ‘persons with disability’ in recognition of the need to strengthen representation of people with disability on the NDIA Board.<sup>38</sup>

**Recommendation:**

- p) The amendment to section 127(2) in the Bill should not be accepted.
- q) Amendments to strengthen the appointment of people with disability to the NDIA Board, should apply to all the fields listed in section 127(2) of the NDIS Act and should be specifically directed at ‘persons with disability’: “Persons with disability are eligible for appointment under all the fields (a)-(d)”.

DPO Australia thanks the Senate Community Affairs Legislation Committee for the opportunity to contribute our views to this Inquiry, and we would welcome further consultation on any of the matters raised in this submission.



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<sup>37</sup> Civil Society Statement to the Australian Government, May 2017, op. cit., p. 4

<sup>38</sup> Ibid.