PEOPLE WITH DISABILITY AUSTRALIA

12 July 2021

Senator Rachel Siewert
Chair
Senate Standing Committees on Community Affairs
PO Box 6100
Parliament House
Canberra ACT 2600

Via email: community.affairs.sen@aph.gov.au

Dear Senator Siewert

Re: National Disability Insurance Scheme Amendment (Improving Supports for At Risk Participants) Bill 2021

People with Disability Australia (PWDA) welcomes the opportunity to comment on the Australian Government's proposed legislation, National Disability Insurance Scheme Amendment (Improving Supports for At Risk Participants) Bill 2021 (hereafter the "At Risk Participants Bill").

PWDA is a leading disability rights, advocacy and representative organisation of and for all people with disability. We are the only national, cross-disability organisation and we represent the interests of the 1 in 5 people with disability in Australia. We are non-profit and non-government organisation, with a long history of working to end violence against people with disability.

We strive for the realisation of our vision of a socially just, accessible, and inclusive community in which the human rights, belonging, contribution, potential, and diversity of all people with disability are recognised, respected, and celebrated with pride.

We do, however, wish to highlight our concerns regarding the development, intention and potential consequences of this legislation should it pass in its current form.

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The privacy breach allowances of the At Risk Participants Bill could breach international human rights obligations

PWDA understands that all that is required to override the Privacy Act is a legal authorisation, which this amendment to the National Disability Insurance Scheme (NDIS) Act 2013 would provide.

The NDIS Act contains important legislation to protect the privacy of Australians. If this privacy is breached, PWDA are a concerned that this could be used punitively against participants of the scheme, including notions that a "past or future health threat" could be misused to share or request private information without a person with disability ever knowing about it.

Because of the new definition, the NDIS Quality and Safeguards Commission is not required under the NDIS (Protection and Disclosure of Information – Commissioner) Rules 2018 to consult with a person about whether they object to the Commission disclosing that it has no information about that person.

This potential breach of our privacy is concerning for many reasons and is one reason why people with disability are already hesitant to speak up in public spheres, including important bodies that could help improve life for people with disability, such as the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability.

Currently, there is an extremely high threshold the NDIS Quality and Safeguards Commission and the National Disability Insurance Agency (NDIA) must meet before protected and private information is disclosed about people with disability.

The NDIS Act provides that disclosure is allowed only when it is "necessary to prevent or lessen a serious threat to an individual's life, health or safety". We find it highly concerning that the Bill ratifies quite expansive data-sharing on the alleged basis of keeping people with disability safe – from future unknown possible events or given past potentially irrelevant events – which then enables unspecified actions to be undertaken, without a person knowing and or the ability to appeal.

This potentially secretive breach of our privacy could mean the NDIA or its data manager(s) has access to our private health information, psychiatry records, or other private records, potentially for the purposes of defending legal actions, such as Administrative Appeals Tribunal hearings, Centrelink prosecutions and other legal action.

This breach of our privacy is a direct breach of the international human rights law Australia is a signatory to, including article 22 of the United Nations Convention on the Rights of Persons with Disabilities (CRPD) which states:

(i) No person with disabilities, regardless of place of residence or living arrangements, shall be subjected to arbitrary or unlawful interference with his or her privacy, family, home or correspondence or other types of communication or to unlawful attacks on his or her honour and reputation. Persons with disabilities have the right to the protection of the law against such interference or attacks.

(ii) *States Parties* shall protect the privacy of personal, health and rehabilitation information of persons with disabilities on an equal basis with others.

The At Risk Participants Bill uses a range of definitions which appear unclear or extremely broad

The At Risk Participants Bill uses a range of definitions which appear unclear or very broad. For example: the Bill does not define what a “proactive individualised” to "lessening a future threat to a person's health “is? What precisely does this mean? And how does it relate to the findings in the Independent Review into Circumstances Relating to the Death of Ann-Marie Smith (Robertson Review)?

Additionally, does this definition include decisions about plan management and plan utilisation? This has not been articulated. Could it feed into supported decision-making in a negative or harmful manner? This is unclear and could have potentially unintended and unjust consequences for scheme participants.

The Bill appears to suggest that NDIS plan breakdown is what drives risk (such the risk of deaths such as Ms Ann Marie Smith’s). If this is what is being suggested, are NDIS plan clarifications being presented as a potential solution?

Therefore, there should be at least a discretion for NDIS Quality & Safeguards Commission to be engaged, rather than leaving it to the discretionary powers of the NDIS Quality and Safeguards Commissioner, the Minister for the National Disability Insurance Scheme or the National Disability Insurance Scheme chief executive officer.

The human rights implications of the At Risk Participants Bill and compliance with the international human rights obligations of the CRPD

As we have highlighted, Australia is subject to international human rights obligations. The At Risk Participants Bill acknowledges this obligation when it states:

Human rights implications

The Bill engages the following rights under international human rights law: the rights of people with disabilities, especially Article 16 of the Convention on the Rights of Persons with Disabilities (CRPD); the right to privacy in Article 17 of the

International Covenant on Civil and Political Rights (ICCPR). Rights of people with disability – Article 16 of the CRPD Article 16 of the CRPD requires that State Parties take measures to protect persons with disabilities from all forms of exploitation, violence and abuse. The Bill promotes the rights of persons with disability to be free from exploitation, violence and abuse, consistent with Australia's obligations.

This particular use of article 16 of the CRPD contradicts article 22 of the CRPD which clearly outlines the right to privacy for disabled people. Thus, this Bill does not comply with the CRPD as it quite clearly overrides the right to privacy.

This Bill in its current form, does not uphold the human rights of people with disability nor does it ensure that all forms of violence, abuse, neglect and exploitation against people with disability can be prevented or penalised.

Rather, it lays out expansive and undefined powers that could potentially be implemented to ensure the NDIA is exempt from investigation on matters pertaining to catastrophic plan breakdowns such as was the case with the late Ann Marie Smith.

We strongly oppose any position that enables or allows perpetrators of neglect or violence off the hook with recourse from people with disability.

PWDA is strongly committed to ensuring that people with disability like Anne Marie Smith receive justice and equality before the law.

Thus, PWDA recommends that this Bill should not pass, and be redrafted in consultation with people with disability and their representative organisations.

We also recommend that the government take on board and implement all ten of the Robertson Review's recommendations, which we have shared in our attachment as a reminder.

We would welcome the opportunity to provide further evidence to the committee. Should you wish to discuss matters further, please contact my Senior Manager of Policy, Giancarlo de Vera, at .

Yours sincerely

Sebastian Zagarella
Chief Executive Officer
People with Disability Australia

Attachment A – The 10 Robertson review recommendations

(1) The Commission should act to identify earlier those people with disability who are vulnerable to harm or neglect. Every stage of decision-making, including corrective regulation, should be alive to factors indicating that a participant may be vulnerable to harm or neglect. (Although not within my terms of reference, the NDIA should also so act in the planning process and continually.) The Commission and the NDIA should have a freer and two-way flow of information for this purpose.

(2) No vulnerable NDIS participant should have a sole carer providing services in the participant's own home. The relevant statutory instruments and guidelines should be amended to provide expressly for this.

(3) For each vulnerable NDIS participant, there should be a specific person with overall responsibility for that participant's safety and wellbeing. That individual should be clearly identified by name and, ideally, introduced in person, to the vulnerable NDIS participant. (Although not within my terms of reference, that individual should be identified in a participant's plan.)

(4) Consideration should be given to the Commission establishing its own equivalent to State and Territory based Community Visitor Schemes to provide for individual face-to-face contact with vulnerable NDIS participants. Such contact is also important in emphasising the personal values necessarily involved in providing services to individuals with disability. The NDIS Act should be amended to provide explicitly for this function. Until that happens, the Commission should continue to support the State and Territory Community Visitor Schemes and any doubt about State and Territory powers under those schemes in relation to NDIS participants should be resolved between the law officers of the Commonwealth and of these States and Territories. The State and Territory Community Visitor Schemes will of course continue to apply directly in relation to those with disability who are not NDIS participants.

(5) Because of the inherent limitations in record based systems in preventing harm or the risk of harm to vulnerable participants, the Commission should conduct occasional visits to assess the safety and wellbeing of selected individual NDIS participants, whether or not a complaint has been made or a "reportable incident" notified. The Commission should miss no opportunity for face-to-face assessment of vulnerable participants. (Although not within my terms of reference the NDIA should also so act.) The Commission and the NDIA should have a freer and two-way flow of information for this purpose so that the NDIS Commission's selection of participants to visit is an informed one.

(6) The statutory definition of “reportable incident” in s 73Z of the NDIS Act should be amended to make it clear that it includes a real or immediate threat of one of the listed types of harm. The word “complaints” in s 73X of the NDIS Act should be defined to remove any doubt that it includes concerns and observations in relation to the provision of supports or services by NDIS providers.

(7) The Commission must at all times be able to know whether a person is or is not an NDIS participant. The Commission should also have readily available access to information held by the NDIA concerning what supports a participant is receiving and the provider of such supports. The Commission should not depend on providers to provide it with such information only after a request.

(8) There should continue to be improvements to the exchange of information and more formal lines of communication between those running the State and Territory emergency services (including police) and schemes for people with disability and the Commonwealth agencies, being the Commission and the NDIA, and vice versa.

(9) To this end, s 67A(1)(e) of the Act should be amended so that the word “serious” is deleted. A threat to an individual’s life, health or safety should be enough to authorise the use of the protected Commission information. Also the word “necessary” should be replaced with a word such as “needed” so that the information may be used even if it is not essential to preventing or lessening a threat to an individual’s life, health or safety. Consideration should also be given to defining the word “threat” in the expression “prevent or lessen a threat” so that it includes preventing or lessening for the future a threat which has passed. (Corresponding amendments should be made to, or considered for, s 60(2)(e) for protected NDIA information.)

(10) The Commissioner should have statutory power to ban a person from working in the disability sector even where that person is no longer so employed or engaged. This aspect is the subject of the National Disability Insurance Scheme Amendment (Strengthening Banning Orders) Bill 2020 currently before the Commonwealth Parliament. The Commissioner should have the same power in relation to NDIS service providers, that is, to include as subject to the power to ban those entities no longer providing those services.