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NGO in Special Consultative Status with the
Economic and Social Council of the United Nations

People with Disability Australia (PWDA)

Submission to the Senate Community Affairs Legislation Committee

Re the National Disability Insurance Scheme Bill 2012

25 January 2013

Contact: Ngila Bevan

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(I) Introduction

Introduction to People with Disability Australia

People with Disability Australia Incorporated (PWDA) is a leading disability rights, advocacy and representative organisation of and for all people with disability, which strives for the realisation of a socially just, accessible and inclusive community. PWDA was founded in 1981, the International Year of Disabled Persons, to provide people with disability with a voice of our own.

PWDA is the only national organisation with a cross-disability focus, meaning we represent the interests of people with all kinds of disability. We are a non-profit, non-government organisation.

PWDA's primary membership is made up of people with disability and organisations primarily constituted by people with disability. PWDA also has a large associate membership of other individuals and organisations committed to the disability rights movement.

The strength of our advocacy comes from lived experiences, consultations and a strong commitment to upholding the views of our membership. PWDA believes it is essential for people with disability to have a direct voice in public policy development, rather than this voice being filtered through other stakeholder groups.

PWDA believes human rights are fundamental rights that are intrinsic to every person, regardless of their national, cultural, political, geographic, social, or religious context, and any other personal characteristics, such as gender, race, sexuality, age, or disability.

PWDA believes that all people have an inherent worth, uniqueness, equality and autonomy, and have the ability to realise our potential.

Because of these beliefs, PWDA works to create the conditions necessary for human rights to be enjoyed by all peoples, including those with a disability.

We have a vision of a socially just, accessible and inclusive community, in which the human rights, citizenship, contribution, potential and diversity of all people with disability are respected and celebrated.

Methodology and endorsements

This submission is based on consultations with over 500 people with disability, family members, carers and support providers throughout Australia. Input was sought through an online survey of 10 questions relating to the Scheme and open for 1 month over December 2012 – January 2013, a Facebook and Twitter forum held on 19 January 2013, and extensive individual and group consultations with individuals and members, the board and staff of PWDA, and the disability sector.

This submission has been endorsed by:

- New South Wales Council for Intellectual Disability
- People with Disability Western Australia
- Physical Disability Australia
- Queenslanders with Disability Network

(II) Overarching Comments and Key Recommendations

People with Disability Australia (PWDA) warmly welcomes the introduction of the National Disability Insurance Scheme Bill 2012. Once enacted, this legislation will allow for the structure, implementation, and roll out of an NDIS which has the potential to significantly improve the lives of thousands of people with disability in Australia. We applaud Australian governments for their work on these critical service system reforms that will put choice and control firmly in our hands.

The majority of comments made in this submission reflect concern at provisions that run counter to the enjoyment of human rights by people with disability, or highlight improvements that could be made in order to maximise the enjoyment of rights of people with disability on an equal basis with others. In remaining consistent with international human rights law, amendments to the legislation should consider the following overarching comments and recommendations:

1) The legislation must be entirely consistent with the Convention on the Rights of Persons with Disabilities (CRPD)[1], specifically regarding Equal Recognition before the Law and the presumption of legal capacity (Article 12). Exceptions to this right, albeit intended as safeguards, can frequently become standard practice, and the government must support, promote, and encourage models of supported decision making in order to prevent instances whereby the right of a person with disability to make their own choices is curtailed.

2) People with disability and their representative organisations must be actively involved and closely consulted in all aspects of NDIS policy, design, governance, operation, evaluation and improvement as per the CRPD; and their right to political participation must be promoted (Articles 2, 4, 29, 33). The opportunity for people with disability and their representative organisations to form a comprehensive view of the legislation and provide considered and informed feedback has been severely limited due to the fact that the NDIS Rules are as yet unpublished. People with disability must be consulted on the content of the Rules as a matter of urgency. The Rules should be in the form of a disallowable instrument.

3) Independent information and advocacy support for people with disability must be funded by the Scheme, and people with disability must be made aware of their entitlement to obtain it throughout their duration in the scheme. Related to this, a person should be permitted to have a support person of their choosing accompany them to any NDIS related appointment without that individual having to become a formally recognised person by the Scheme.

4) The principles of flexibility and reasonable accommodation (as defined in CRPD Article 2) must be mainstreamed throughout the NDIS legislation. People with disability should not be penalised in cases where they have a reasonable excuse for failing to respond to a notice, provide information,

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[1] Specifically Living in the Community (Article 19), Personal Mobility (Article 20), Freedom of Expression (Article 21), Privacy (Article 22), Participation in public life (Article 29), Participation in Cultural Life (Article 30) and also implementing the Definitions (Article 2), General Obligations (Article 4), Awareness Raising (Article 8), Accessibility (Article 9), Access to Justice (Article 13), Freedom from Exploitation, Violence and Abuse (Article 16), Respect for the Home and Family (Article 23), Data Collection (Article 31), Implementation and Monitoring (Article 33).

or attend a meeting within the specified time limits. Improvements in the provision of supports, accessible information, and mainstream infrastructure may ameliorate these concerns to some extent. However, it remains a reality that the geographical make up of Australia makes communication, medical services, supports, and advocacy provision scarce and/or inaccessible for people in some areas, or for those experiencing actual or perceived stigmatisation or discrimination.

5) The provision of reasonable and necessary supports by the NDIS must never be means tested, and the principle that the cost of access and participation in the NDIS as neutral should be mainstreamed throughout the legislation. The Agency should also make best endeavours to support, subsidise, or at the very least limit a participant's exposure to the incurrence of costs. For example, by utilising existing information where possible instead of requiring new assessments, examinations, other supporting material, or obligatory plan managers. The importance of this is also significant to the points raised in point 4 above.

6) The Scheme must incorporate a consumer complaints and resolution mechanism(s) to handle complaints about the Agency and all registered and non-registered support providers and plan managers. The mechanism must be equipped to deal with allegations of violence, abuse, neglect and exploitation; either separately or in harmonisation with the National Disability Abuse and Neglect Hotline.

7) The current legislation allocates extensive decision making powers to the CEO, and PWDA is concerned about the extent to which these powers will be delegated to State/Territory, regional and/or local Agency staff. The knowledge and experience of local decision makers who are informed and aware of local constraints, opportunities and cultural sensitivities may be welcomed by people with disability. However, caution must be exercised regarding the form and extent to which powers such as the appointment of substitute decision makers and plan managers, removal of parental authority, and the disclosure of protected information are delegated. A robust review and appeals mechanism is critical to ensure the uniform application of decision making across Australia.

8) PWDA is anxious about the extent to which the legislation permits the Agency to perform every role required by a participant to access and use the NDIS; from eligibility, planning, choosing supports, managing a budget, seeking information, obtaining assistance and acquittal of spending. Ubiquitous with this role is the prerogative of the Agency to narrow the options available to participants if they either choose to use Agency services or supports, or are compelled to. The legislation must explicitly state that alternative options are available to people with disability at every point in their journey through the Scheme, and funding must be made available to realise those alternatives, support innovation and diversity in support delivery, and maximise choice and control for people with disability.

(III) Commentary on Chapters 1-7

- ### Chapter 1: Introduction (Sections 1- 12)

Part 2 – Objects and Principles

The legislation should be couched within an overarching human rights framework, making clear reference to the realisation of the human rights of people with disability. Accordingly, the provision of reasonable and necessary supports must enable people with disabilities to exercise their political, social, economic and cultural rights; and should acknowledge attributes of a person with disability such as age, cultural, religious, gender, and sexual orientation in the delivery of those supports.

The realisation of rights for people with disability is underpinned by the presumption of legal capacity, and this must be reflected throughout the legislation as a whole without limitation.[2] The social, economic and cultural participation of people with disability cannot be realised if political rights (for example the right to make free choices, the right to privacy, the right to be treated fairly, and the right to be consulted about decisions affecting you), are curtailed or denied.

Political participation for people with disability includes respect and recognition of their role as expert consultants in the design, operation, evaluation and improvement of the NDIS; as well as their role as potential advisors, volunteers and employees within the system. People with disability must be closely consulted and actively involved in all aspects of the Scheme's implementation, not regarded simply as participants or recipients of support.[3]

People with disability must be able to receive no-cost support and assistance from an independent advocate in order to ensure that they are able to enjoy their rights and discharge their responsibilities as provided by the Scheme, and in order to access mainstream supports. The entitlement to receive this assistance must be included in the legislation and reflected throughout the Bill. (*See also Commentary on Chapter 2*).

Under no circumstances should eligibility to receive reasonable and necessary supports be determined through means testing of any kind.

Specific amendments to text

Note: Text in bold indicates the insertion of additional words by PWDA. Text which has been struck through indicates suggested deletions.

Section 3(1)(b) Support the independence and **political,** social, economic **and cultural** participation of people with disability;[4]
Section (3)(1)(h) Give effect to ~~certain~~ obligations that Australia has as a party to **the human rights instruments, with primary reference to** the Convention on the Rights of Persons with Disabilities.[5]

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[2] Convention on the Rights of Persons with Disabilities (CRPD) Article 12

[3] CRPD Article 4(3), Article 33(3) and Article 29(b)

[4] Amend throughout legislation where applicable.

Section 4(2) People with disability should be supported to participate in and contribute to **political**, social, economic **and cultural** life ~~to the extent of their ability.~~

Section 4(3) People with disability ~~and their families~~ ~~and carers~~ should have certainty that **they** ~~people with disability~~ will receive the care and support they need over their lifetime.

Section 4(8) People with disability have the same right as other members of Australian society to be able to determine their own ~~best~~ interests, including the right to exercise informed choice and engage ~~as equal partners~~ in decision **making** that will affect their lives, ~~to the full extent of their capacity.~~

Section 4(11) Reasonable and necessary supports for people with disability should:
(a) Enable people with disability to exercise their political, social, economic, and cultural rights;
(b) Be age, gender and culture appropriate;
(c) Support people with disability to lead ~~good~~ **fulfilling** lives and maximise their independence; and
(d) Support the capacity of people with disability to undertake activities that enable them to participate in the community and in **open** employment.

Additional paragraphs to ***Section 4***:

- **People with disability have the right to receive free, independent advocacy support.**
- **The role of people with disability as stakeholders as well as participants in the Scheme is to be acknowledged and respected.**
- **People with disability and their representative organisations should be actively involved and closely consulted in the development of legislation and policy related to the National Disability Insurance Scheme.**
- **Reasonable and necessary supports are to be provided without means testing of any kind.**

Section 5:
(a) People with disability should be involved in decision making processes that affect them, **and if required supported to** ~~where possible~~ make decisions for themselves;
(b) People with disability should be encouraged to engage in the life of the community;
(c) ~~The judgements and decisions that people with disability would have made for themselves should be taken into account;~~
(d) The **gender, sexuality and gender diversity**, cultural**,** and linguistic circumstances of people with disability should be ~~taken into account~~ **acknowledged, respected and supported**;
(e) The supportive relationships, friendships and connections with others of people with disability should be recognised **and respected.**

Section 8 The agency has more general functions, such as: **(c) facilitating greater community inclusion by promoting the accessibility of generic services and infrastructure.**

Section 9 Developmental delay:
(a) Is attributable to a ~~mental~~ **psychosocial, intellectual** or physical impairment or a combination of ~~mental~~ **psychosocial, intellectual** and physical impairments
(b)(iii) Cognitive, **social and adaptive** development

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[5] Mirrors the language used in the Sections 2(1)(b) and 3(2) of the Human Rights and Anti-Discrimination Bill 2012.

• Chapter 2: Assistance for people with disability and others (Sections 13-17)

In order for the NDIS to deliver maximum choice and control to its participants and potential participants, it is paramount that people with disability are encouraged, supported, and are able to obtain independent advice and information about the operation and administration of the Scheme (as laid out in Chapters 3 and 4) and the options available to them regarding disability supports, disability support providers and plan management.

Accordingly, the legislation must explicitly provide for funding to be available for entities other than the Agency to provide these services. Failing this, the Agency may become the sole or de facto provider of information and advice about the Scheme. Consequently, participants may lean towards relying on the Agency (and Agency registered providers) as their default provider of supports and plan management; simply due to convenience or a lack of information about alternatives. Not only would this begin to replicate the monolithic structure of the current disability system, it would also suffocate the possibilities for innovation in support delivery envisaged by the NDIS, and hamper the realisation of increased choice and control for people with disability which is so integral to the Scheme's success.

Similarly, provision must be made for the funding of independent advocacy to support people with disability in their engagement with the Agency and other parties. People with disability must be made aware of their entitlement to this support. (*See also Commentary on Chapter 1*).

Both the entities described above are also required to assist in the identification of those people on the margins of society who are entitled to access the Scheme. For example, Aboriginal and Torres Strait Islander people, people within the criminal justice system or other places of detention (including juveniles), people living in institutions and congregate care facilities, children in out of home care, people experiencing homelessness and/or residing in boarding houses, gay, lesbian, bisexual, transgender and intersex people, people living with chronic illness such as HIV/AIDS and those otherwise experiencing stigma and/or discrimination of a nature that prevents their interaction with mainstream and/or general supports.

Specific amendments to text

Section 14 The Agency may provide assistance in the form of funding for persons or entities:
(a) For the purposes of enabling those persons or entities to assist people with disability to:
(i) Realise their potential for physical, social, emotional, intellectual, **sexual and spiritual** development;
(ii) ~~Participate in~~ Exercise their **political,** social, economic **and cultural** ~~life~~ rights;
(iii) Obtain independent information about the National Disability Insurance Scheme, and
(iv) Obtain independent advocacy support.

Section 15(1) The Agency may provide information about the following:
(a) Matters relevant to the National Disability Insurance Scheme;
(b) The functions of the Agency;
(c) The availability of independent information and independent advocacy support; and
(d) The entitlement to obtain independent information and independent advocacy support.

- **Chapter 3: Participants and their plans (Sections 18-50)**

Part 1 – Becoming a participant

Access to the NDIS must be available to anyone who legally resides in Australia, regardless of their age or nationality. The Scheme is premised on the recognition that all people with disability are inherently valued and respected members of society, and are entitled to supports in order to enjoy their rights on an equal basis as others. It is a violation of the international human rights instruments to which Australia is a party to discriminate on the basis of age and/or nationality. The Draft Human Rights and Anti-Discrimination Bill 2012 also makes it unlawful to discriminate against a person on the basis of age in any area of public life.

There are many people older than 65 years who have had a disability their whole life, and many who will acquire one through causes unrelated to ageing (for examples, motor neurone disease or multiple sclerosis). The aged care system in its current form cannot provide the highly specialist disability supports required by many of those people. Moreover, the age cut off implies that older people should not be provided with the opportunities to exercise choice and control over their lives like their younger counterparts, and that they deserve only generic rather than reasonable and necessary supports to meet their needs.

Similarly, there are many people with and without disability who have legally resided in Australia for a number of years but who are not permanent residents (particularly New Zealanders who are entitled to work indefinitely without seeking permanent residency). They may contribute to Australian society through employment, taxation including Medicare and flood levy's for example, raising a family and involvement in the community. Denying these people access to the NDIS implies that their non-Australian nationality overrides these contributions, rendering them valueless if and when that person requires the support of the society it has helped to build. For many non-permanent residents who acquire a disability this will mean they can no longer live in Australia and will be forced to emigrate as a consequence of their disability. This is shameful, and demonstrates a weak commitment to the rights of people with disability and their inherent dignity.

The disability requirement for an impairment to be defined as permanent should be replaced by **long-term** as per Article 1 of the CRPD[6], and would acknowledge those impairments for which duration is unknown or diagnosis inconclusive but are likely to be long term (for example some autoimmune conditions). This would also synthesis the provisions relating to early intervention as the duration of impairment may be unpredictable in the initial stages.

A person should become a participant to the Scheme when the CEO decides that they meet the criteria. However, people with disability should not suffer financial or other detriment due to the failure of the CEO to act within their own timeframes, assessment backlogs, the idleness or unavailability of third parties or 'another person' required to provide supporting information, or delayed decision making due to inconclusive or conflicting medical or other reports.

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[6] CRPD Article(1) Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.

In these instances, once determined eligible the CEO should have the discretion to prioritise that person's progress through the remainder of the system. This is especially important for people living in rural, remote or low service areas where obtaining the information or advocacy support required for access to the scheme may be time-consuming, difficult to impossible, and/or costly. Accessing the Scheme should be cost neutral for the potential participant, and existing supporting information should be utilised wherever possible.

Part 2 – Participants plans

The language of 'goals' should be removed from the legislation. Like other people in society, a person with disability should not be required to set themselves goals or targets, measurable or otherwise, in order to lead a fulfilling life, maintain their well-being, access the community and enjoy their human rights.

A participant's plan belongs to and is personal to them; it is not the property of the CEO. As such they should be permitted to vary it as and when it suits them in order to adapt it to their changing circumstances (including periods of crisis) and/or priorities as they see fit. The CEO need only require notification outside of any prescribed time for review if the variation(s) impact upon the personal budget of the participant. Flexibility will always be required, and a person should only have to ensure that funding is spent on reasonable and necessary supports, rather than strictly in line with their plan or personal budget.

Moreover, the CEO should only be required to '**agree**' to the content of a participant's plan rather than to 'approve' it. The plan belongs to the participant as a statement of their life intentions. The role of the CEO is to agree that these intentions correspond to the requirements of the Scheme, not to pass judgement on the value or worth of the plan.

The provision permitting the CEO to determine that a person may not manage their plan if it presents an unreasonable risk to the participant is of great concern. There is no elaboration as to what those risks may be, or what factors would be considered in making the determination. Presumably, the provision is intended to prevent recklessness, frivolity, and/or other mismanagement. However, the potential for this provision to be routinely applied to classes of people such as those with psychosocial and/or cognitive impairments, or those with histories of addiction, poor credit, destitution, or contact with the criminal justice system is worrying. Use of the provision in this way may also potentially constitute discrimination against those people.

Facilitation of the preparation of a participant's plan by the CEO must include informing the participant about independent sources of information about planning, independent planning services and the entitlement to advocacy in preparing the plan and engaging with the Agency. (S*ee also commentary to Chapters 1 and 2*).

People with disability should not suffer detriment because a support they require is offered as part of a universal service agreement and is unavailable or inadequate for their needs. The Agency must ensure that supports provided under this provision meet the reasonable and necessary requirements of the participant.

A participant should be informed of the intention to revoke their participant status, and must have a right to respond and review and unfavourable decision. (*See also commentary to Chapter 4, Part 6*).

Specific amendments to text

Section 20 If a person (the *prospective participant*) makes an access request, the CEO must, within 21 days of receiving the access request:
(a) Decide whether or not the prospective participant meets the access criteria; or
(b) Make one or more requests under subsection 26(1).
If the prospective applicant does not meet the access criteria they must be provided with written reasons for that decision.

Section 21(3) Delete entirely

Section 24(1)(a) The person has a disability that is attributable to one or more intellectual, cognitive, neurological, sensory, **chronic health** or physical impairments or to one or more impairments attributable to a ~~psychiatric~~ **psychosocial or genetic** condition;[7]

Section 24(1)(b) The impairment or impairments are likely to be ~~permanent~~ **long-term**;
Section 24(1)(e) The person's support needs in relation to his or her impairment or impairments are likely to continue ~~for the person's lifetime~~ **long-term**.
Section 24(2) For the purposes of subsection (1), an impairment or impairments that vary in intensity may be ~~permanent~~ **long-term**…[8]

Section 30: **Add paragraph to mirror the requirements regarding revocation of status as laid out for support providers in Section 72.**

Section 31 The preparation, review and replacement of a participant's plan, and the management of the funding for supports under a participant's plan, should ~~so far as reasonably practicable~~:
(k) Provide the context for the provision of disability ~~services~~ **supports** to the participant and, where appropriate, coordinate the delivery of disability services where there is more than one disability service provider.

Section 33(1) A participant's plan must include a statement (the *participant's statement of ~~goals and~~ aspirations*) prepared by the participant that specifies:[9]

Section 32(2) A participant's plan must include a statement (the *statement of participant supports*), prepared with the participant and ~~approved~~ **agreed** by the CEO, that specifies:[10]

Section 34 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:
(e) The funding or provision of the support takes account of what it is reasonable to expect families, carers, informal networks and the community **are willing and able to provide, and what the participant wants;**

Section 35(1) The National Disability Insurance Scheme rules may prescribe:

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[7] Make same change to wording of **Section 25(a)(i)**
[8] Make same changes to wording of **Section 27** where relevant.
[9] Amend throughout legislation where applicable.
[10] Amend throughout legislation where applicable.

(a) A method for assessing, or criteria for deciding, the reasonable and necessary supports or general supports that will be funded or provided under the National Disability Insurance Scheme~~; and~~

(b) ~~Reasonable and necessary supports or~~ general supports that will not be funded or provided under the National Disability Insurance Scheme; and

(c) ~~Reasonable and necessary supports or~~ general supports that will or will not be funded or provided under the National Disability Insurance Scheme for prescribed participants.

Section 36(3) The CEO may ~~prepare the statement of participant supports, or~~ ~~decide whether to~~ ~~approve~~ **agree** a statement of participant supports, before all the information and reports requested under subsection (2) are received by the CEO, but must give the participant a reasonable opportunity to provide them.

Section 40(2) The *grace period* for a temporary absence of a participant is:
(a) ~~6~~ **12** weeks beginning when the participant leaves Australia; or
(b) If the CEO is satisfied that it is appropriate for the grace period to be longer than ~~6~~ **12** weeks—such longer period as the CEO decides, having regard to the criteria (if any) prescribed by the National Disability Insurance Scheme rules for the purposes of this paragraph.
Participants must only inform the CEO of their absence if it:
(i) Is intended to continue for longer than the grace period, or
(ii) It impacts upon their personal budget

Section 43(5) If the funding for supports under a participant's plan is to be managed to any extent by a registered plan management provider specified by the Agency, or by the Agency, the CEO must, ~~so far as reasonably practicable,~~ have regard to the wishes of the participant in specifying who is to manage the funding for supports under the plan to that extent.

Section 46(1) A participant who receives an NDIS amount, or a person who receives an NDIS amount on behalf of a participant, must spend the money ~~in accordance with the participant's plan~~ **on reasonable and necessary supports.**[11]

- **Chapter 4: Administration (Sections 51-103)**

Part 2 - Privacy

It is essential that information gathered by the CEO from persons other than the participant or prospective participant is obtained, used, and stored in a manner that respects that person's right to privacy.[12] Moreover, that information obtained from third parties and used to inform the CEO's decisions made about a participant or prospective participant is made available to that person and can be challenged.

The provision whereby protected information about a participant or potential participant can be disclosed for 'research', 'actuarial analysis' or 'policy development' purposes of the NDIS are too vague. Information shared on these grounds must be de-identified and quantitative and/or statistical only in nature.

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[11] Make same change to wording of **Section 53(2)(b)**, and throughout legislation where applicable.

[12] UN CRPD Article 22 and the National Privacy principles

The purpose and decision making criteria behind the public interest exception to the protection of information is unclear and concerning. The provision is unusually wide, granting the CEO power to disclose information about individuals and/or groups of individuals (who would presumably share a similar characteristic) for any purpose, or to any Commonwealth, State or Territory Department, Centerlink, or Medicare. Such cases may amount to discrimination against people with disability, as only people with disability would have their privacy violated in this way. This may also amount to intersectional discrimination. For example, if protected information was being shared only about people with disability from a particular ethnic group, with a specific criminal history, or having the same disability type. It is also unclear what the aforementioned government agencies are permitted to use the information for.

Part 3 Registered providers of supports

It is an inherent conflict of interest for the same entity to manage a person's funding for supports and also to provide those supports. The problem would be exacerbated in cases whereby the Agency is undertaking these roles, in addition to being the funder and provider of information about the Scheme. This provision should be removed from the legislation.

It is essential that the complexity and accessibility of the registration process strikes a balance between ensuring safeguards, quality assurance measures, and adequate business administration practices are in place, and encouraging the use and development of a diverse range of supports and providers. The difficulty of becoming a registered provider should rest on the interplay between the type of support being offered and to whom.

In its current form, the requirements of the legislation would tend to favour registration only by the more traditional large support providers operating with numerous staff and regulated by the relevant industry standards. This process may be suitable for those providers. It is not, however, suited to the registration of individuals who provide a support for one or two other people, a disability support organisation, NGO, or a co-operative. It is important that any registration criterion recognises the central role that entities such as these should play in the delivery of supports, and the maximisation of variety, choice and control in the provision of supports. The registration of plan managers must be dealt with in a similar way; providing opportunity for a person to choose simple, personalised options such as permitting their friend or accountant to become their plan manager without unreasonable obstacles.

Indeed it is unclear from the legislation what the role of unregistered support providers or plan managers is intended to be. This is of significant importance as there are frequent instances throughout the Bill whereby participants are required to use only registered providers of supports. However, there is no indication in the Bill that registration will be subject to continued review, or linked to a consumer complaints mechanism of any kind.

Part 5 – Nominees

PWDA considers the provisions in Part 5 to be a form of substitute decision making, and as such does not support this element of the legislation. All people with disability enjoy legal capacity to have rights and to act on an equal basis with others as laid out in Article 12 of the Convention on the Rights of Persons with Disabilities. Article 12 requires States to provide support to people with disability so that they can exercise their legal capacity; i.e. to provide for models of supported decision making which facilitate people with disability to make free and informed choices and participate in decisions that affect them.

The provisions regarding Nominees do not support the exercise of a participant's legal capacity to make choices. Instead, they provide for a regime of substitute decision making whereby a Nominee can make decisions on behalf of a person with disability. Of significant concern is the reference to giving the view of the participant mere 'appropriate weight'. These powers relate to all aspects of the persons engagement with the NDIS, which translates to substantial influence and control over the life of that person, as the substantive elements of the NDIS relate to the expression of a person's aspirations, their general well-being, how that person is supported to participate in the community, and the realisation of their human rights. There would also be significant potential for abuse and exploitation of the person with disability by their Nominee if these relationships were dysfunctional.

It is unacceptable to introduce a provision into this legislation which makes the assumption that there will be people with disability who should not be involved in decisions that affect them, or who will require a person to make decisions for them, or people for which it may be more administratively convenient or timely to manage through a Nominee. Furthermore, the provisions around Nominees clearly contravene the Objects and Principals of the Act detailed in Sections 3 and 4, and the principles relating to plans outlined in Section 31 of Part 2.

Australia has existing State and Territory guardianship legislation and tribunals in each jurisdiction with powers to appoint substitute decision makers, guardians, financial managers, to review and monitor their actions, and to consider the welfare of the person they act for. Therefore, the powers relating to Nominees are not only unnecessary but introduce a quasi-form of guardianship which would operate outside of the safeguards provided by the legislation and tribunals. The provisions granting the CEO power to appoint Nominees are particularly alarming, especially as how the CEO's powers will be delegated have not been addressed. Similarly, the possibility that a 'body corporate' may act as a Nominee raises clear conflict of interest and performance issues, especially if they are also a plan manager or provider of supports to that person or group of people.

There are more appropriate and progressive approaches to the issue of how to provide formal assistance to a person who may want or need help in engaging with the Agency or discharging their obligations under the Act. Primarily this requires promotion of and information about supported decision making models to families, providers of support, independent advocacy organisations and Agency staff. Independence, participation, choice, and control are key principles of the NDIS. The aspects of social transformation envisaged by the Act cannot be achieved if people with disability are disempowered and disrespected by provisions in the legislation which provide exceptions to the presumption of legal capacity. (*See also commentary to Chapter 1*)

Part 6 – Review of decisions

All decisions made by the CEO relating to the participant or potential participant must be reviewable (including applications for registration as a support provider or plan manager which are supported by a participant). Accordingly, all unfavourable decisions must be accompanied by detailed reasons for the decision.

The procedures of the Administrative Appeals Tribunal are too formal and legalistic for the purpose of NDIS appeals. It would be more appropriate for a specific NDIS Appeals Tribunal to be constituted, perhaps as a section of the Social Security Appeals Tribunal, or established separately along similar lines. One advantage of this approach would be the distinct and easily locatable case law that would develop over time; ensuring uniformity and transparency in the application of CEO decision making across Australia. People with disability and other people with the relevant skills, knowledge and experience should sit on any NDIS Appeals Tribunal or panel.

Specific amendments to text

Section 51(1) A participant or a prospective participant must notify the CEO if:
(a) An event or change of circumstances happens that affects, or might affect, his or her access request, status as a participant or ~~plan~~ **personal budget**;[13]

Section 60(2)(d) The making of the record, or the disclosure or use of the information, by the person is made:
(iii) With the express ~~or implied~~ authorisation of the person to whom the information relates;[14]

- ## Chapter 5: Compensation payments (Sections 104-116)

If a person acquires a disability in a circumstance whereby compensation may be recoverable, it is likely to be in the interests of public policy, as well as the person concerned, for that avenue to be pursued. It would be perverse for liable parties to avoid accountability for personal injuries caused due to the existence of the NDIS, and equally, it is the right of the injured party to benefit from that accountability through compensation. The financial sustainability of the NDIS may also be jeopardised by failures to recover compensation where it was available. Therefore, taking legal action to sue for compensation in cases with a reasonable prospect of success should be encouraged.

However, no person should be obliged to pursue legal action for compensation as a prerequisite to accessing the NDIS and receiving disability supports. A person should be able to become a participant of the Scheme as soon as their eligibility has been established. It is the fact of their disability that means they require disability supports, and these needs are unrelated to how the disability was acquired or whose fault, if anyone's, it was. NDIS funded supports are necessary for many people with disability in order for them to enjoy their human rights on an equal basis as people without disability. Compelling a person to forego the opportunity to realisation of their rights in the pursuit of an uncertain financial reward is reprehensible. The legislation must be amended to enact these principles.

Notwithstanding the above, personal injury litigation can be incredible stressful and traumatic. It may last a number of years, cost a great deal of money, and can take up a significant amount of the plaintiffs time, energy and emotional resources – particularly at a time when they may be adapting to life as a person with disability and navigating the disability support system. The decision to litigate is a serious one, and is

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[13] Amend throughout legislation where applicable.

[14] Make same changes to wording of **Section 66(1)(b)(ii)**

frequently an option of last resort. It is unfair, and potentially damaging to people with disability, for the government to remove the option for a person to decide the extent to which they are willing to live this experience.

The role of the National Injury Insurance Scheme (NIIS) needs to be examined in relation to this Chapter. The potential role of the Agency or other entities in providing support and services to personal injury litigants also requires further exploration.

- ## Chapter 6: National Disability Insurance Scheme Launch Transition Agency (Sections 117-181)

The role of people with disability in the governance, evaluation, and ongoing design and improvement of the NDIS is vital. People with disability are experts in their own lives. Moreover, and as recognised by the CRPD[15], people with disability and their representative organisations should be actively involved and closely consulted about all legislation and policies that affect them. This not only encourages and increases the opportunities for people with disability to be politically engaged, to speak out with confidence and to hold others accountable; it is also a platform for further social and cultural participation and raising community awareness of the issues that affect people with disability. Timely, meaningful, and effective consultation is also the most valuable and expedient way for government to ensure that the Scheme develops in a way which meets the needs of people with disability, and does so within the finite resources available. The amendments below are reflective of this position.

Specific amendments to text

Section 118(1) The Agency has the following functions:
(a) To deliver the National Disability Insurance Scheme
(b) To deliver and report on the realisation of the Objects of the Act as detailed in Section 3, including advice on improvements to legislation, rules and policy which would assist in achieving the Objects of the Act.

Section 118(1)(2) In performing its functions, the Agency must use its best endeavours to:
(a) Act in accordance with any relevant intergovernmental agreements;
(b) Act in a proper, efficient and effective manner; **and**
(c) Actively involve and closely consult people with disability and their representative organisations.

Section 124(1) The Board has the following functions:
(b)To determine objectives, strategies and policies to be followed by the Agency **in implementing the Objects of the Act as detailed in Section 3.**

Section 127 **The provisions in Sections 152, 153 and 155(2)(c) regarding the Disclosure of Interests, and termination of appointment in cases of non-compliance, should also apply to members of the Board. Section 127 should be amended accordingly.[16]**

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[15] CRPD Articles 4(3) and 33(3).

Section 127(6) In appointing the Board members, the Minister must ensure that the Board members collectively possess an appropriate balance of skills, experience ~~or~~ **and** knowledge in the fields mentioned in subsection (2).
(7) In appointing the Board members, the Minister must ensure that at any time there are at least 2 Board members with lived experience of impairment or impairments that result in substantially reduced functional capacity as defined in the Act.

Section 132 A Board member must not engage in any paid **or unpaid** employment that, in the Minister's opinion, conflicts or may conflict with the proper performance of the member's duties.[17]

Section 144(1) The Advisory Council's function is to provide, on its own initiative or at the written request of the Board, advice to the Board about the way in which the Agency:
(a) Performs its functions relating to the National Disabilty Insurance Scheme; and
(h) Performs its functions relating to the realisation of the Objects of the Act as detailed in Section 3;
(i) Closely consults with and actively involves people with disability and their representative organisations

Section 144(3) Advice provided by the Advisory Council must not relate to:
(a) A particular individual; or
(b) The approval of a person or entity as a registered provider of supports or the revocation of that approval; or
~~(c) The corporate governance of the Agency; or~~
~~(d) The money paid to, or received by, the Agency.~~

Section 147(5) In appointing the members of the Advisory Council, the Minister must:
(b) Ensure that:
(i) At least 4 of the members are people with disability who have skills, experience or knowledge relating to disability ~~services~~ **supports and/or have lived experience of impairment or impairments that result in substantially reduced functional capacity as defined in the Act.**

Section 172:
(7) The annual report must be made public in a timely manner and be broadly available in accessible formats.

Section 172(2) The annual report must include the following for the period to which the report relates:
(c) Information (including statistics) and analysis that relates to either or both of the following in the period:
(i) Participants
(ii) Funding or provision of supports by the Agency.
(d) Analysis that relates to progress made in implementing the Objects of the Act as detailed in Section 3 from the point of view of:
(i) Participants;
(ii) The Agency; and
(iii) The Advisory Council.

Section 172(4) without limiting subsection (1), the plan must include details of the following matters:
(b) The performance indicators for the assessment of the Agency's performance of its functions, **including progress made in implementing the Objects of the Act as detailed in Section 3**

Section 174(2) The report must include information (including statistics) that relates to either or both of the following in the period to which the report relates:
(a) Participants in each host jurisdiction;
(b) Funding or provision of supports by the Agency in relation to each host jurisdiction.
This information will be made publically available in a timely manner.

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[17] Make same change to wording of **Section 134(2)(c)**

- **Chapter 7: Other matters (Sections 182-210)**

Part 1 – Debt recovery

The term 'debt' should only be used to refer to NDIS funding spent by a person with disability on supports that cannot be regarded as reasonable and necessary or were obtained fraudulently by the individual participant. These are the only circumstances which reflect the moral component of one person incurring a debt to another.

The other instances whereby a person may be required to return money received to the Agency (such as through computer error, death of the participant or misrepresentation) should be redefined as '**overpayments'**. This term reflects the fact that these situations can arise due to the fault of a person other than the recipient person with disability such as the Agency itself, a guardian, plan manager or support provider). It is unreasonable for people with disability to be treated as debtors in these circumstances, and incur the stress and stigma that this entails. Penalties for poor record keeping should also be considered with a view to what was reasonable for the person to have retained under their particular circumstances at the time.

Legal proceedings for the recovery of a debt or overpayment should not be commenced after the 6 year recovery period from when it was incurred. As the administrator of the Scheme the onus is on the NDIA to distribute funds appropriately, and it is reasonable to expect a debt or overpayment to be noticed and acted upon within this period.

Specific amendments to text

Change the word debt to **debt or overpayment** throughout Chapter 7 where applicable.
Change the word debtor to **over-payee** throughout Chapter 7 where applicable.

Delete paragraphs ***183(3)(4)(5)*** entirely.

Insert the following after Section 190(3): **For the purposes of paragraph (2)(b), the debtor has no capacity to repay the debt if recovery would result in financial hardship, or an inability to access reasonable and necessary support**.

Section 195(b) There are special circumstances ~~(other than financial hardship or the disability of the debtor)~~ that the CEO is satisfied make waiver appropriate.

Section 208(2) The review is to be undertaken by a person chosen by the Minister with the agreement of the Ministerial Council, **and will be undertaken in close consultation with people with disability and their representative organisations.**

Section 208(3) The terms of reference of the review must be agreed by the Ministerial Council **in close consultation with people with disability and their representative organisations.**

People with Disability Australia (PWDA) thanks the Senate Community Affairs Legislation Committee for the opportunity to make this submission.

Ngila Bevan
25 January 2013