

Disability Council NSW

Submission to the Independent Review of the Operation of the National Disability Insurance Scheme Act 2013

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Locked Bag 4028, Ashfield NSW 2131 Ph: (02) 8879 9100

www.disabilitycouncil.nsw.gov.au email: disabilitycouncil@facs.nsw.gov.au

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Disability Council NSW

The Disability Council NSW (Council) was established under the *Community Welfare Act 1987* (NSW), and was transferred under the *Disability Inclusion Act 2014* (NSW) on 3 December 2014. Council's main responsibilities under the Act are to:

- Monitor the implementation of Government policy;
- Advise the Minister on emerging issues relating to people with disability, and about the content and implementation of the NSW State Disability Inclusion Plan and Disability Inclusion Action Plans;
- Advise public authorities about the content and implementation of Disability Inclusion Action Plans;
- Promote the inclusion of people with disability in the community and promote community awareness of matters concerning the interests of people with disability and their families;
- Consult with similar councils and bodies, and people with disability; and
- Conduct research about matters relating to people with disability.

The Council consists of a diverse group of 10 members. Each member is appointed for up to four years by the Governor of NSW on the recommendation of the Minister for Disability Services. Members are selected to be on Council because:

- They have lived experience of disability.
- They have particular expertise on disability issues.
- They want to improve the lives of people with disability.

Council is funded by the NSW Government through the NSW Department of Family and Community Services (FACS) and is supported by a secretariat team within FACS.

Executive Summary

The National Disability Insurance Scheme (NDIS) is a significant intergenerational reform that aims to deliver real and measurable change to the lives of people with disability. Expectations about the extent, standard and distribution of supports to people with disability under the NDIS are high. For these expectations to be met, the NDIS must be underpinned by a robust legislative framework that firmly entrenches the principles of equity, choice, freedom and control.

Council's review of the Act largely revealed that there are apparent disconnects between the objects and principles of the Act and provisions that dictate who can access the NDIS, how participant plans are prepared and reviewed and what supports are provided. It is apparent that many people with disability may be excluded from the NDIS or disadvantaged in the supports they can access because of their residency status, cultural, Indigenous and/or linguistic background, where they live and/or their ability to navigate the NDIS without an independent advocate.

This submission makes a number of recommendations intended to improve the efficacy of the *National Disability Insurance Scheme Act* 2013 (the Act), with particular emphasis on ensuring equity of access to the NDIS and reasonable and necessary supports.

This submission addresses the following themes identified by the Independent Review of the Operation of the National Disability Insurance Scheme Act Discussion Paper:¹

- 1. Objects and principles
- 2. Design of the legislative framework
- 3. Becoming a participant
- 4. Participant plans
- 5. Registered providers of supports
- 6. Nominees
- 7. Reviewable decisions
- 8. Compensation and debt recovery
- 9. Governance

As this review takes place during the very early stages of the NDIS roll out, Council looks forward to the opportunity to provide further and more detailed feedback on the operation of the NDIS Act at a later stage when there are greater insights available from NDIS participants.

¹ EY, Independent Review of the Operation of the National Disability Insurance Scheme Act 2013 (Cth) (September 2015) available at: http://www.ndis.gov.au/sites/default/files/NDIS%20Act%20 Review%20-%20Discussion%20Paper_0.pdf

List of Recommendations

Recommendation 1: That the terminology in sections 3 and 4 of the Act be amended to ensure the Act mandates the achievement of objectives and principles and is not just aspirational.

Recommendation 2: That a new principle be inserted into section 3 confirming the need to ensure all people are supported and assisted to receive equal access to reasonable and necessary supports under the NDIS.

Recommendation 3: That section 5(c) should be amended so that the decision the person with disability would have made for himself or herself is the determining factor of the decision, not one of many considerations taken into account.

Recommendation 4: That a new principle be inserted in section 5 of the Act that recognises that people with disability have the same right to take risks a reasonable person would take, and that people acting on their behalf should not prevent the person from taking these risks.

Recommendation 5: That a new principle be inserted in section 5 of the Act that requires people acting or doing things on behalf of others to disclose any conflicts of interest to the NDIA.

Recommendation 6: That s 209 of the Act be amended to ensure that in making the NDIS rules the Minister is explicitly required to have regard to the objects and principles of the Act and give them greater weight than financial considerations.

Recommendation 7: That the residence requirements be amended so that all people with the right to live and work in Australia, including holders of temporary visas, can apply to access the NDIS.

Recommendation 8: That s 99 of the Act be amended so that prospective participants can seek review of a direction under s 26(2)(b) of the Act to undergo a medical, psychiatric, psychological or other examination.

Recommendation 9: That s 26(2)(b) of the Act be amended so that the CEO must have regard to the impact, including financial and emotional impact, on the prospective participant of requiring that participant to undergo an examination at a particular place.

Recommendation 10: That the NDIS Act and relevant rules about participant plans be amended to ensure that it is explicitly clear that advocacy and interpreting services will be available to participants and will in no way reduce the amount of supports a participant receives.

Recommendation 11: That the provisions relating to participant's plans be amended to correct the power imbalance between the CEO and the participant and ensure that the participant retains choice and control over the supports in their plan.

Recommendation 12: That s 47 of the Act be amended so that if a participant gives a changed version of their statement of goals and aspirations to the CEO, the CEO <u>must</u> review the participant's plan and determine whether changes need to be made to their statement of participant supports.

Recommendation 13: That the Act be amended to include:

- (a) a new principle in s 3 that acknowledges that no single service provider should dominate the supports a person receives; and
- **(b)** stricter requirements in s 70 to ensure an objective assessment of any conflicts of interest where the manager of the funding for supports also provides supports

to strengthen the protection of a participant's choice and control.

Recommendation 14: That the existing NDIS Nominee Scheme detailed in the Act be replaced by the supporters and representatives scheme proposed by the Australian Law Reform Commission.

Recommendation 15: That s 91 of the Act be amended to impose a mandatory requirement that the CEO reports cases of severe physical, mental or financial harm to the relevant authorities.

Recommendation 16: That the list of reviewable decisions in s 99 be repealed so that all decisions of the CEO are reviewable. At the very least, the following decisions should be amenable to review:

- Decisions made under sections 26, 36 and 50 that a participant must provide information and/or undergo an assessment or medical, psychiatric or psychological examination;
- A decision made under section 44 that a person cannot manage their funding; and
- A decision made in relation to repayments of debts and recovery or nonrecovery of debts under Chapter 7 Part 1.

Recommendation 17:That the NDIS Act be amended to make provision for a well-defined and accessible complaint mechanism by which the operations of the NDIS and the Agency can be reviewed <u>independently</u> and with which the Agency is compelled to comply.

Recommendation 18: Council recommends that appropriate provision be made in the Act for advocacy and or/legal representative support to assist people with disability seeking a review of decisions by the NDIA.

Recommendation 19: That, as a minimum, if the CEO requires an individual to take legal action, the Act should contain provisions to allow the individual to transfer their legal rights to the Agency which may then act on their behalf.

Recommendation 20: That s 127 of the NDIS Act be amended to include a requirement that at least 2 members of the Board must have a disability, in addition to the other criteria for being appointed to the board.

Recommendation 21: That NDIA Board Members be required to disclose any conflicts of interest, as is required by members of the NDIS Independent Advisory Council.

Recommendation 22: That the Act include a reporting requirement to ensure that the progress of the NDIS be benchmarked against the objectives of the National Disability Strategy.

Introduction

Council welcomes the opportunity to make a submission to the Independent Review of the Operation of the *National Disability Insurance Scheme Act* 2013 (the Act).

The National Disability Insurance Scheme (NDIS) is an unprecedented reform to the way supports are provided for people with disability in Australia. For the benefits of the NDIS to be realised, it is essential that the legislative framework, guidelines and rules that operationalise the NDIS give effect to the principles of equity, choice, freedom and control.

It is imperative that the Act gives effect to an NDIS that is accountable, sustainable and provides certainty to people with disability as to what supports are provided and how they can be obtained.

Council is eagerly anticipating the significant improvement in quality of life that people with disability, and their families and carers, will have by participating in the NDIS.

Council is concerned that the review of the Act is premature given that the NDIS is still in the early stages of roll out and the Information, Linkages and Capacity building and quality and safeguards frameworks are yet to be implemented. However, as the Act mandates the timeframe for review,² Council understands the legislative imperative behind the timing of this review.

Nevertheless, at this early stage in the NDIS continuum, Council has identified a number of issues that need to be resolved if the provisions of the Act are to support its objectives and principles.

Underscoring Council's discussion and recommendations is the fundamental need for the principle of equity to be firmly embedded in the Act. Council is particularly concerned about the potential for the Act and rules to exclude people from accessing the supports they need because of their residency status, cultural and linguistic background and/or their ability to navigate the NDIS without an independent advocate.

Council also strongly urges the independent reviewers of the Act to actively engage people with disability and their families in the review process, as people with disability are most acutely affected by any changes to the Act. Council is concerned that many people with disability and those most affected by the Act would not have been able to provide input to the independent review because of the unreasonably short period between when the review was announced and when submissions closed. People with disability, and their advocates, are the experts in the practical lived experience of the NDIS. They must be heard in the scrutiny and ongoing review of the Act to ensure that it delivers real improvements to people with disability.

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² National Disability Insurance Scheme Act 2013 (Cth) (NDIS Act) s 208.

Objects and principles

The Act and Australia's obligations under the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)

Council submits that the Act must strongly enshrine <u>all</u> of Australia's obligations under the UNCRPD.

Wording in section 4 of the Act appears to suggest that the objects and principles are ideals rather than things that can be practically realised. For example, the use of the word "should" and the qualifiers "to the extent of their ability" and "to the extent of their capacity" suggest that the principles are aspirational and may not be possible to achieve.

It would be preferable to replace the word "should", wherever it occurs, with something more unequivocal and positive like must, and to remove unnecessary qualifiers to the principles of the Act.

Council believes these changes are more than just semantics and that it is important the Act is clear that principles and rights referenced in section 4 give effect to Australia's obligations under the UNCRPD and are more than just an ideal to be implemented if practical.

Recommendation 1: That the terminology in sections 3 and 4 of the Act be amended to ensure the Act mandates the achievement of objectives and principles and is not just aspirational.

The need for a principle of equity

Australia has obligations under the UNCRPD to ensure equality and opportunity³ for all people with disability. Council is concerned that there is currently no specific principle in the Act that enshrines the importance of equity in both access to the NDIS and the supports that are provided.

A specific principle that places a positive duty on those acting under the Act to ensure equal access to supports under the NDIS is necessary. This is because there are significant challenges and possible additional burdens for people from specific groups (including those from culturally and linguistically diverse (CALD) and Indigenous backgrounds) seeking to access supports under the NDIS. Language and cultural differences make it more difficult for people with disability to understand information and successfully negotiate what are often complex systems of support. What is 'reasonable and necessary' for one person who accesses the NDIS will not be the same for another, and it is important that participants are not disadvantaged because they need additional resources such as advocates or interpreters to access their 'reasonable and necessary' supports.

³ United Nations Convention on the Rights of Persons with Disabilities (2008) *Article 3 – General Principles* available at http://www.refworld.org/docid/45f973632.html.

People with Disability's Citizen's Jury of the NDIS reported that equal service provision has been an issue across the NDIS trial sites. Where you live, whether you have accessed any supports prior to the NDIS and your cultural, linguistic or Indigenous background can all affect the ability to access to the NDIS and the quality of supports available.

The limited data available from the NDIS trial sites highlights that there are still fewer than expected Aboriginal and/or Torres Strait Islander participants in the trial sites that commenced on 1 July 2013, with the exception of the Victorian trial site. ⁵ Similarly, there is a clear underrepresentation of people from CALD backgrounds in the NDIS. ⁶ Considering the large proportion of people from CALD backgrounds in Australia, it is disappointing that the Act and relevant rules do not provide an adequate framework for supporting people from CALD backgrounds to access the supports they need. Although the National Disability Insurance Agency (NDIA) Annual Report 2013-14 resolved to prioritise improving interaction with CALD and Indigenous communities, ⁷ according to the June 2015 NDIA report to the COAG Disability Reform Council, the CALD engagement in trial sites remains at a low 4%, an increase of only 1% since 30 September 2014. ⁸

Further, for some people from CALD backgrounds, their access to the NDIS and the supports they need may be limited by the need for an interpreter. If the cost of an interpreter is to be included in a participant's plan, it is possible that a choice will need to be made between fewer supports with an interpreter or more supports without an interpreter. This is a situation that clearly fails to uphold Australia's obligation under the UNCRPD to ensure that people with disability are entitled to recognition and support of their specific cultural and linguistic identity ⁹

Council believes that to truly give effect to this obligation under the UNCRPD, the Act must include a principle of equity so that people from CALD and Indigenous backgrounds are not disadvantaged in the amount of and quality of supports they need because of their cultural, linguistic or Indigenous identity. Similarly, people

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⁴People with Disability, *National Disability Insurance Scheme Citizen's Jury Scorecard* (May 2015) available at http://www.pwd.org.au/admin/ndis-citizens-jury-scorecard-project.html

⁵ National Disability Insurance Agency, 8th Quarterly Report to COAG Disability Reform Council (30 June 2015) available at http://www.ndis.gov.au/sites/default/files/Q4-Report-to-COAG-Disability-Reform%20Council.pdf

⁶ The Federation of Ethnic Communities' Councils of Australia (FECCA), *Access and Equity in the context of the NDIS* (June 2015) available at http://apo.org.au/files/Resource/access-and-equity-in-the-context-of-the-national-disability-insurance-scheme-june-2015.pdf

⁷ National Disability Insurance Agency *2013-2014* Annual Report, p 23, available at: http://www.ndis.gov.au/document/891

⁸ National Disability Insurance Agency, 8th Quarterly Report to COAG Disability Reform Council (30 June 2015) available at http://www.ndis.gov.au/sites/default/files/Q4-Report-to-COAG-Disability-Reform%20Council.pdf

⁹ United Nations Convention on the Rights of Persons with Disabilities (2008) *Article 30 – Participation in cultural life, recreation, leisure and sport* available athttp://www.refworld.org/docid/45f973632.html.

living in rural and remote areas should not be disadvantaged by lack of choice and lack of access to an independent person who can advocate for them and provide advice.

A principle of equity embedded in the Act should, in practice, necessitate:

- the provision of interpreters outside the money allocated to a participant's plan so that a participant is not disadvantaged and does not have to choose between an interpreter and more services;
- assistance for people accessing supports for the first time to ensure they receive timely access to the NDIS and can access the supports they need;
- additional resources to engage people with disability from CALD and Aboriginal and Torres Strait Islander backgrounds to become participants of the NDIS;
- support for the development of culturally competent service provision;
- automatic access for NDIS participants to the Community Visitors Scheme, so that there is at least one independent person with whom they have contact;
- incentives to encourage diversity in service providers in rural and remote areas; and
- funding for advocacy outside a participant's plan to ensure that participants have the best chance of securing quality supports they need.

Council believes that all of the above are imperative to ensuring that the NDIS upholds its object of giving effect to Australia's obligations under the UNCRPD and delivers real change to the lives of people with disability.

A strong commitment to consistency and equity in service delivery enshrined in the Act will ensure a fair and equitable system for participants, no matter where they reside, their cultural background or their disability.

Recommendation 2: That a new principle be inserted into section 3 confirming the need to ensure all people are supported and assisted to receive equal access to reasonable and necessary supports under the NDIS.

General principles guiding actions of people who may do acts or things on behalf of others

Council considers that Section 5 of the Act (General principles guiding actions of people who may do acts or things on behalf of others) is weak and can be strengthened.

The use of the words "should" and "should be taken into account" must be replaced with more unequivocal language. Anyone acting on behalf of another person <u>must</u> take the wishes of that person as paramount even where they may conflict with their own opinions or beliefs. People with disability must be involved in the decision making process and be properly supported to make decisions for themselves about

their aspirations and use of supports. It is not sufficient to assume that a person cannot or does not wish to make those decisions. The decision the person with disability would have made for himself or herself is to be the determining factor –not something that must "be taken into account." People with disability also have the same right to take risks a reasonable person would take and they should not be prevented from taking these risks.

Council is concerned that the Act does not require those acting or doing things on behalf of others to disclose any conflicts of interest when they provide information to the NDIA about the details of decisions made on behalf of another person. This is of particular concern in circumstances where the plan manager or provider of supports is also supporting the person with disability to make their decisions. The Act should be amended to include a requirement that people acting or doing things on behalf of others must disclose any conflicts of interest that could affect their ability to provide impartial support.

These changes may ensure that section 5 provides stronger protection to people with disability who need support to make decisions and uphold the object of the Act to 'enable people with disability to exercise choice and control in the pursuit of their goals and the planning and delivery of their supports.' 11

Recommendation 3: That section 5(c) should be amended so that the decision the person with disability would have made for himself or herself is the determining factor of the decision, not one of many considerations taken into account.

Recommendation 4: That a new principle be inserted in section 5 of the Act that recognises that people with disability have the same right to take risks a reasonable person would take, and that people acting on their behalf should not prevent the person from taking these risks.

Recommendation 5: That a new principle be inserted in section 5 of the Act that requires people acting or doing things on behalf of others to disclose any conflicts of interest to the NDIA.

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¹⁰ *NDIS Act* s 5(c).

¹¹NDIS Act s 3(1)(e).

Design of the legislative framework

Council is concerned that the current design of the legislative framework does not allow for sufficient scrutiny of rules that dictate who can access the NDIS and what supports a participant may receive.

Under the Act, the NDIS rules can determine many things that are central to how the NDIS functions including:

- prescribed circumstances of impairments that may receive support, and/or criteria to be used to assess this;¹²
- eligibility criteria for access to the NDIS¹³
- prescribed descriptions of what counts as 'reasonable and necessary supports'¹⁴
- the types of early intervention supports likely to be provided, and/or criteria to be used to assess this 15
- methods and criteria for determining how to treat compensation a person receives ¹⁶

Council acknowledges that it may be practical to leave the detail of the NDIS to be developed in the NDIS rules as the rules can be easily changed to reflect lessons learnt during implementation and the changing operational needs of the NDIS. However, this flexibility allows a wide range of matters covered by the rules to be changed without parliamentary and public scrutiny of their development and/or implementation. It is also unlikely an individual will be able to challenge any of the rules, as this would need to be done through the court system and few people with disability would have the expertise or resources to mount a legal challenge.

Further, there is no legislative requirement that the NDIS rules take into account Australia's obligations under the UNCRPD or the objects and principles of the Act. This dilutes the significance and impact of the Act's objects and principles as the rules provide detail of how the NDIS operates. Under the current legislative framework, it is perfectly open to the Minister to make NDIS Rules that dictate who can access the NDIS and what supports they receive without reference to the objects and principles of the Act. Under s 209, the only factor the Minister is required to take into account under the Act is the "the need to ensure the financial sustainability of the National Disability Insurance Scheme." 17

As a consequence, the principles of choice and control which are so fundamental to the NDIS can be overlooked as long as the need to ensure financial sustainability is

¹²NDIS Act s 27.

¹³NDIS Act s 17, 22, 23, 27.

¹⁴NDIS Act s 35.

¹⁵NDIS Act s 27.

¹⁶NDIS Act s 35.

¹⁷NDIS Act s 209.

taken into account. An example of this is Part 3 of the *National Disability Insurance Scheme (Supports for Participants) Rules* 2013. This part clearly positions value for money¹⁸ and whether there are comparable supports which would achieve the same outcome at a substantially lower cost¹⁹ as the first consideration in assessing proposed supports. There is no requirement in the rules for assessing supports to consider whether those supports might contribute to the fulfillment of the objectives of the Act including that reasonable and necessary supports should support people with disability to pursue their goals and maximise their independence.²⁰

Recommendation 6: That s 209 of the Act be amended to ensure that in making the NDIS rules the Minister is explicitly required to have regard to the objects and principles of the Act and give them greater weight than financial considerations.

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¹⁸ National Disability Insurance Scheme (Supports for Participants) Rules Part 3 Rule 3.1.

¹⁹ National Disability Insurance Scheme (Supports for Participants) Rules Part 3 Rule 3.1(a). ²⁰ NDIS Act s 3(11)(a).

Becoming a participant

The Residence Requirements under the Act

Council is concerned that the access criteria do not further the objects and principles of the Act. In particular, Council considers that the residence requirements are too narrow and are inconsistent with both Australia's obligations under the UNCRPD and other comparable programs.

The residence requirements of the NDIS are unnecessarily restrictive and automatically preclude access to the NDIS for people on temporary visas, including asylum seekers and refugees waiting for their protection visa applications to be processed and people on temporary work visas. They do not account for situations created by current immigration law and policy where many asylum seekers and refugees who arrived by boat are likely to suffer significant delays in the processing of their visa applications²¹ and will only ever be granted temporary visas.²² Although people with disability in this cohort may be in Australia for many years on successive temporary protection visas, the residence requirements under the NDIS Act ensure they will never have access to the NDIS.

There is nothing in the UNCRPD to suggest that the obligations on member states to promote and protect the human rights of people with disability, including the right to live in the community with the supports they need, 23 only extend to citizens or permanent visa holders. Council strongly believes that if the NDIS is to truly achieve its object of giving effect to the UNCRPD²⁴ then all people with disability who have the right to live and work in Australia should have access to the NDIS.

The residence requirements are also anomalous considering that under other comparable schemes including Community Aged Care Packages and Extended Aged Care in the Home (EACH), there are no residency or citizenship requirements that prevent people from accessing supports. ²⁵ Moreover, to access Medicare

²¹ Many asylum seekers who arrived by boat after 13 August 2012 are still waiting for the statutory bar imposed by s46A of the Migration Act 1958 (Cth) on making a protection visa application to be lifted to enable them to apply for a protection visa. The Department of Immigration and Border Protection anticipates that it could take more than three years to process all of this cohort's applications. ²² *Migration Act 1958* (Cth) s 91H.

²³ United Nations Convention on the Rights of Persons with Disabilities (2008) Article 19 -Living independently and being included in the community available at http://www.refworld.org/docid/45f973632.html.

²⁴ NDIS Act s 3(1)(a).

²⁵ Australian Government Department of Social Services, *Home Care Packages Program* (2015) available at: https://www.dss.gov.au/our-responsibilities/ageing-and-aged-care/agedcare-reform/home-care-packages

benefits a person only has to be 'lawfully present in Australia'²⁶ and 'not subject to any limitation as to time imposed by law.'²⁷

The residence requirements are also at odds with the principle of the Act that confirms "people with disability should be supported to receive reasonable and necessary supports, including early intervention supports." The NDIS recognises the fundamental importance of early intervention supports for people with disability, and yet many children with disability on temporary visas who may later gain permanent visas will be denied access to these crucial early intervention supports. As a consequence of this, the economic burden of supports for these people who were denied early intervention supports when on temporary visas and later access the NDIS when they hold a permanent visa may be far greater.

For the objects and principles of the Act to truly be realised, all people with disability who have the right to live and work in Australia must be entitled to access the NDIS.

Recommendation 7: That the residence requirements be amended so that all people with the right to live and work in Australia, including holders of temporary visas, can apply to access the NDIS.

Power of the CEO to request prospective participants undertake medical assessment

Council is concerned that the power of the CEO to make a request that a prospective participant undertake a medical assessment may unfairly disadvantage many prospective participants.

An individual requesting access to the NDIS may be compelled to undergo a medical, psychiatric or psychological examination on the CEO's request. The report must be provided within 28 days or another period of time specified by the CEO. Failure to provide the report within the time period leads to an assumption that the individual no longer wishes to access the NDIS, unless the CEO is satisfied that it was reasonable for the participant not to comply with this time period. ³⁰

Council is concerned that the current provisions of the Act allow the CEO to direct a prospective participant to undergo a medical, psychiatric, psychological or other examination at a particular place.³¹ This is particularly concerning because a request under s 26(1)(b) of the Act that a person undergo an examination is not a reviewable decision.³² This could mean that in order to access the NDIS, prospective participants could be directed to be assessed by a doctor they do not know. For many

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²⁶ Health Insurance Act 1973 (Cth) s 3.

²⁷ Health Insurance Act 1973 (Cth) s 3.

²⁸ NDIS Act s 26 (1)(b).

²⁹ NDIS Act s 26 (2)(b).

³⁰ NDIS Act s 26 (3).

³¹ NDIS Act s 26(1).

³² NDIS Act s 99.

people with disability, especially people with intellectual disability, this may cause unnecessary distress for the individual, which is compounded by the requirement in s 85 of the Act that the person conducting the examination must consent to an individual's nominee being present during the examination. ³³This may especially be a problem for people who have only ever consulted a GP and are directed by the CEO to consult a specialist. For these people, preliminary meetings and/or other activities to build rapport with the specialist may be necessary to eliminate the issues caused by lack of familiarity between the person with disability and the specialist.

Further, medical assessments and examinations can be very expensive and it is possible that the cost of undertaking assessments required by the CEO may preclude some prospective participants from accessing the scheme. The Act must make it clear who pays for examinations required to prove eligibility for the NDIS, as is the case in other comparable schemes. Council notes that a preferable approach may be the approach under the Worker's Compensation Scheme where if an authority requests an employee undergo a medical examination, the authority is required to pay the cost of conducting any examination and the expenditure reasonably incurred in connection with the examination.³⁴

Recommendation 8: That s 99 of the Act be amended so that prospective participants can seek review of a direction under s 26(2)(b) of the Act to undergo a medical, psychiatric, psychological or other examination.

Recommendation 9: That s 26(2)(b) of the Act be amended so that the CEO must have regard to the impact, including financial and emotional impact, on the prospective participant of requiring that participant to undergo an examination at a particular place.

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³³ NDIS Act s 85(1).

³⁴ Safety, Rehabilitation and Worker's Compensation Act 1988 (Cth) s 57.

Participant plans

Advocacy Supports

Council is concerned that the current legislative framework's definition of what constitutes "reasonable and necessary supports" does not make it clear whether the cost of advocacy will consume part of a participant's individual funding package. This is of particular concern where a participant could be forced to choose between more supports or less supports with advocacy support.

Council notes that The Council of Australian Governments Disability Reform Council recently agreed that systemic advocacy and legal review and representation will be funded outside of the NDIS.³⁵ However, this does not confirm the role of individual advocacy. There is a need for explicit recognition in the Act and rules that where a participant needs an advocate the cost of this should not reduce the funds available for other supports. It is unrealistic and unjust to expect a person with disability to put money aside in anticipation of the system failing them.

For many people with disability, developing the capacity to exercise choice and control will be a long process. Many people with disability and their families do not have the capacity, knowledge or skills to advocate on their own behalf without this assistance. This is particular the case for people from CALD backgrounds and people from Aboriginal communities and people with intellectual disability. The people is needs may be expressed on their behalf and there is a risk that they may be more aligned with a carer's, family member's or service provider's needs rather than their own. The role of independent advocacy is crucial in ensuring people with disability can effectively navigate the complex system of NDIS supports in order to make informed decisions on their lives with minimum risks.

Council is aware of unmet need for advocacy services across NSW, including in the NDIS trial sites. Individuals in the NDIS trial sites who have not had the support of individual advocates have faced barriers to accessing the NDIS as they have been extremely disadvantaged in meetings about their NDIS package^{37.} People with Disability's Citizens Jury also recognised the importance of individual advocacy and noted that access to self-advocacy/peer support, education and training to support participants in making informed choices should be considered as valid expenditure of

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³⁵ Council of Australian Governments, *Disability Reform Council Communiqué* (April 2015) available at: http://www.ncoss.org.au/resources/DNF/eupdates/150429-COAGCommunique.pdf

³⁶ Federation of Ethnic Communities' Councils of Australia (FECCA) *Engaging people with disability in the multicultural sector: barriers to accessing services and employment* (2014) available at http://www.fecca.org.au/images/Documents/disability%20survey%20report.pdf
³⁷ Reported by Colleen Pearce, Public Advocate, Office of the Public Advocate Victoria at the Council for Intellectual Disability NSW Conference "We Are Worth The Investment! People with Intellectual Disability and the NDIS" on 17 July 2015.

NDIS funds.³⁸ Individual advocates are critical to ensure NDIS participants engage in the planning process and secure packages that are appropriate to their needs. These advocates must be independent of the service system, providing impartial support.

As highlighted in the discussion above on the need for a principle of equity in the Act, interpreting services must also be provided outside the funding in a participant's plan. This includes Auslan interpreting and other deafblind supports. This is essential to ensure that participants are not disadvantaged and their supports limited because of the additional cost of an interpreter to allow them equal access to supports. To give effect to the principles of the Act, participants should never have to choose between extra supports and interpreting and/or advocacy services.

Recommendation 10: That the NDIS Act and relevant rules about participant plans be amended to ensure that it is explicitly clear that advocacy and interpreting services will be available to participants and will in no way reduce the amount of supports a participant receives.

Imbalance of power between the CEO and participants in preparing plans

Council is deeply concerned that most of the power in the preparation of and approval of a participant's plan rests with the CEO. One of the previous failures of disability policy has been the lack of choice and control of people with disability over the supports they can obtain to meet their needs. If the NDIS is to uphold its objects and principles, then the legislative framework underpinning the NDIS must make it clear that the participant is involved in and in control of their plan.

A participant's plan only comes into effect when the CEO has approved it.³⁹ In approving a participant's plan, the CEO has the final say about the validity of a participant's supports and will be guided by the methods and criteria in the NDIS Rules about what are reasonable and necessary supports and how they will be funded.⁴⁰ As raised above under "Design of the Legislative Framework" Council is concerned that the NDIS rules may not always prioritise the individual's rights and needs since the only factor that must be taken into account in their creation is the financial sustainability of the NDIS.⁴¹ Council is also concerned that the *National Disability Insurance Scheme (Supports for Participants) Rules* 2013 do not provide sufficient certainty around what supports will be approved by the CEO. This is especially true for housing supports, as the rules do not define or clarify when the NDIS will provide "the user costs of capital... where a person requires an integrated

³⁸ People with Disability, *National Disability Insurance Scheme Citizen's Jury Scorecard* (May 2015) available at http://www.pwd.org.au/admin/ndis-citizens-jury-scorecard-project.html

³⁹ NDIS Act s 37.

⁴⁰ NDIS Act s 33 (5)(d).

⁴¹ NDIS Act s 209.

housing and support model and the cost of the accommodation component exceeds a reasonable contribution from individuals."⁴²

Another example of the imbalance of power between the CEO and participants in preparing participant plans is the circumstances in which a review of a participant plan might be conducted. At any time, a participant may give the CEO a changed version of their statement of goals and aspirations;⁴³ however, the CEO is not required to review the participant's supports upon receiving a changed statement of goals and aspirations. 44 While a participant can request a review of their plan at any time. 45 the CEO retains the power to decide whether or not to review the plan. 46 The CEO however, can at any time on their own initiative, conduct a review of the participant's plan. 47 Council considers this to be unacceptable as it may result in a situation where the support being provided is incompatible with the goals and aspirations of the individual. This is in conflict with the principles and objects of the Act that champion the right of individual choice and control. In the Council's view, when an individual provides to the Agency a new statement of aspirations, it must reasonably be assumed that the supports may also need to change, unless the individual specifies at the time of providing the changed version that they do not wish to change their supports.

Recommendation 11: That the provisions relating to participant's plans be amended to correct the power imbalance between the CEO and the participant and ensure that the participant retains choice and control over the supports in their plan.

Recommendation 12: That s 47 of the Act be amended so that if a participant gives a changed version of their statement of goals and aspirations to the CEO, the CEO <u>must</u> review the participant's plan and determine whether changes need to be made to their statement of participant supports.

⁴² National Disability Insurance Scheme (Supports for Participants) Rules 2013 r 7.19 (d).

⁴³ NDIS Act s 47(1).

⁴⁴ NDIS Act s 47(2).

⁴⁵ NDIS Act s 48(1).

⁴⁶ NDIS Act s 48(2).

⁴⁷ NDIS Act s 48(4).

Registered providers of supports

Mechanisms to ensure participant choice and control over providers of supports

Council is concerned that the legislative framework does not sufficiently protect the right of people with disability to choose and control their providers of supports and avoid a situation where one provider of supports dominates all areas of a participant's plan.

Many providers of supports provide a diverse range of supports including housing, day programs, respite and supported employment. With the increasing commercialisation of disability supports, it is likely that large providers of supports will continue to grow and other providers of supports will diversify to provide a wider range of supports. In this context it is imperative that an individual is not pressured or influenced by convenience to access all of their supports from the one support provider.

Council is concerned that there is both no principle in the Act that acknowledges that no single support provider should dominate a participant's plan and no provision that requires the manager of supports to be different to the provider of supports. The CEO can approve a person or entity to both manage the funding for supports under a plan and provide supports. As Council notes that the National Disability Insurance Scheme (Registered Providers of Supports) Rules 2013 requires organisations seeking to be both providers of supports and registered plan management providers to have mechanisms in place for dealing with conflicts of interest. However, Council considers this protection weak and doubts that in practice internal conflict of interest management systems will be sufficient to ensure the choice and control is retained by the participant.

In particular, participants who have their plans managed by a provider of supports that also provides them with housing supports may experience disadvantage and a lack of choice. They may be at particular risk of feeling pressured to choose the same provider to provide housing supports and other supports out of convenience, or because that support provider might nominate their own services as the best fit for the participant's needs. If a participant's supports are managed and provided by the same provider, it is less likely that support provider will objectively evaluate whether a participant's supports are the best and most effective supports for that participant. This may reduce the anticipated change and improvement to the choice and control individuals will have under the NDIS, and is likely to de-incentivise providers of supports to create innovative new supports to meet participant's needs

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⁴⁸ NDIS Act s 70(1).

⁴⁹ National Disability Insurance Scheme (Registered Providers of Supports) Rules 2013 r. 1.14.

Recommendation 13: That the Act be amended to include:

- (c) a new principle in s 3 that acknowledges that no single service provider should dominate the supports a person receives; and
- (d) stricter requirements in s 70 to ensure an objective assessment of any conflicts of interest where the manager of the funding for supports also provides supports

to strengthen the protection of a participant's choice and control.

Nominees

Council agrees with the Australian Law Reform Commission's (ALRC) recommendations in its report on *Equality, Capacity and Disability in Commonwealth Laws*⁵⁰ that the existing NDIS nominee scheme should be replaced by a scheme for 'supporters' and 'representatives'. This would effectively result in the current 'correspondence nominee' role being subsumed by the supporters, and 'plan nominees' replaced by representatives. Council considers this scheme proposed by the ALRC to be a more effective scheme that upholds Australia's obligations under the UNCRPD and is more compatible with federal and state legislative frameworks.

Council also especially supports ALRC's view that it is inappropriate to use individual participant funding for the decision making support of supporters and representatives.

Recommendation 14: That the existing NDIS Nominee Scheme detailed in the Act be replaced by the supporters and representatives scheme proposed by the Australian Law Reform Commission.

Mandatory reporting of severe physical, mental or financial harm of nominees

Council is aware than various host jurisdictions are discussing mandatory reporting in relation to service providers for people with disability which may assist in providing a framework for reporting by the NDIA.

Recommendation 15: That s 91 of the Act be amended to impose a mandatory requirement that the CEO reports cases of severe physical, mental or financial harm to the relevant authorities.

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⁵⁰ Australian Law Reform Commission, *Equality, Capacity and Disability in Commonwealth Laws* (August 2014) available at https://www.alrc.gov.au/publications/equality-capacity-disability-report-124

Reviewable decisions

Shortcomings of the current review process

Council is concerned that the legislative framework does not provide an appropriate review process considering the importance and impact of the decisions that the NDIA makes about access to the NDIS and the supports that will be provided.

The Council, and more importantly, the community have high expectations of the NDIS to deliver real change to the lives of people with disability, their carers, advocates and families. Where decisions made by the CEO are not amenable to review by a clear, transparent and independent review process, there is a risk that many people may be denied access to the supports they need.

The current review system is unnecessarily restrictive and complex. In the case of *Burston and National Disability Insurance Agency*,⁵¹ it was held that the Administrative Appeals Tribunal did not have the requisite authority to review a decision that refused additional supports because that decision was made under s 48(2) of the Act (which allows a participant to request a review at any time and compels the CEO to decide whether to review or not) and not s 100(6) of the NDIS Act (which requires a 'reviewer' to review a reviewable decision upon request). This technical distinction denied the appellant access to review of the decision to refuse additional supports and caused unnecessary delay and expense of time and resources. In this case, the Tribunal Member noted that the decision underlies the importance of making it clear to participants what kind of reviews are available because there are different implications of different types of reviews.

Council submits that the difficulties created by the different types of reviews and the problem that arose in *Burston and National Disability Insurance Agency* could be avoided if all decisions are made reviewable and the list of reviewable in s 99 of the Act is repealed. This will ensure greater compatibility with the objects and principles of the NDIS Act.

Further, Council considers the current process of review where a 'reviewer' reviews decisions⁵² and the only other mechanism for review of these decisions is the Administrative Appeals Tribunal (AAT)⁵³ to be insufficient.

This is particularly the case as:

There is a conflict of interest between the needs of the individual and what
may be reasonable in this instance, and the CEO's requirement to ensure
sustainability of the scheme.

⁵¹ Burston and National Disability Insurance Agency [2014] AATA 456.

⁵²NDIS Act s 100.

⁵³NDIS Act s 103.

 The capacity of people with disability to seek and obtain justice through the legal system is known to be more limited than for others in the community. Requiring people with disability in unequal power relationships to go down this path to seek redress will severely restrict complaints and deny many people with disability their right to make a complaint.

There needs to be an extra tier between the "reviewer" stage and the AAT stage to both allow lower cost, quicker and more efficient reviews and reduce the volume of requests to review decisions at the AAT. This is particularly important given the NDIA can act not only as regulator and funder but also as the planner, fund-holder and plan management provider.

Recommendation 16: That the list of reviewable decisions in s 99 be repealed so that all decisions of the CEO are reviewable. At the very least, the following decisions should be amenable to review:

- Decisions made under sections 26, 36 and 50 that a participant must provide information and/or undergo an assessment or medical, psychiatric or psychological examination;
- A decision made under section 44 that a person cannot manage their funding; and
- A decision made in relation to repayments of debts and recovery or non-recovery of debts under Chapter 7 Part 1.

Recommendation 17:That the NDIS Act be amended to make provision for a well-defined and accessible complaint mechanism by which the operations of the NDIS and the Agency can be reviewed <u>independently</u> and with which the Agency is compelled to comply.

Provision of legal assistance for review

Council understands the financial reasoning behind section 200A that does not permit or require the NDIA to fund legal assistance for prospective participants or participants in relation to review of decisions under the Act, but is concerned this may unfairly disadvantage people with disability seeking a review.

Council submits that it will be very difficult for many people with disability to go through the review process without appropriate assistance. The NDIS legislative framework is new and complex and, as this submission has identified, there are many provisions which may unfairly disadvantage participants and cause them to seek a review. Advocacy and/or legal representation is imperative given the immense capacity for decisions of the NDIA to influence the daily lives of people with disability.

Recommendation 18: Council recommends that appropriate provision be made in the Act for advocacy and or/legal representative support to assist people with disability seeking a review of decisions by the NDIA.

Compensation and debt recovery

Council is concerned that the compensation provisions under the Act may have negative consequences for people with disability and may restrict their access to the NDIS.

There is no explicit recognition in subsection 104(3) of the Act of whether financial ability or personal trauma are mitigating circumstances as to why a person should not commence a legal action to seek compensation. This recognition is important as the person may lack the financial means to commence a legal action or may have chosen to avoid the traumatic experience of litigation. It is unnecessarily harsh to require a person to commence a legal action for compensation in these circumstances.

Council understands that this clause is required to avoid "doubling up" of funding where what the NDIS is funding can be otherwise covered by another insurance policy.

However, given the difficulties which many people with disability may believe they face in accessing the justice system, the requirement to take action may be sufficient reason for some to be compelled to withdraw an access request. Further, section 105 implies that funds under the NDIS may be withheld until action is taken. This is harsh and may unfairly disadvantage people with disability who are unable or unwilling to commence legal action to recover compensation.

Recommendation 19: That, as a minimum, if the CEO requires an individual to take legal action, the Act should contain provisions to allow the individual to transfer their legal rights to the Agency which may then act on their behalf.

Governance

Appointment of Board Members

Council is disappointed and deeply concerned that there is no requirement under s 127 that NDIA Board Members have disability or personal experience of disability. While Council acknowledges that it is necessary for board members to have skills in financial management and corporate governance, if the Act is to truly uphold its objects and principles then these skills must be complimented by the perspective of board members with disability. This will give the board the balanced skill set that is required for overseeing the NDIS.

Council is also concerned that NDIA Board Members are not required to disclose any conflicts of interest, as is required by members of the NDIS Independent Advisory Council. ⁵⁴

Recommendation 20: That s 127 of the NDIS Act be amended to include a requirement that at least 2 members of the Board must have a disability, in addition to the other criteria for being appointed to the board.

Recommendation 21: That NDIA Board Members be required to disclose any conflicts of interest, as is required by members of the NDIS Independent Advisory Council.

Reporting

Council is concerned that the reporting framework does not include a requirement to measure the effectiveness of the NDIS against the objectives of the National Disability Strategy (NDS). The NDIS is a pivotal part of the National Disability Strategy, and also Australia's commitment to uphold the UNCRPD. Benchmarking the NDIS against the objective of the NDS will serve the dual purpose of tracking progress of the NDS and informing Australia's mandatory reporting under the UNCRPD.

Recommendation 22: That the Act include a reporting requirement to ensure that the progress of the NDIS be benchmarked against the objectives of the National Disability Strategy.

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⁵⁴ NDIS Act s 152, 153.

Reference List

Australian Government Department of Social Services, *Home Care Packages Program* (2015) available at: https://www.dss.gov.au/our-responsibilities/ageing-and-aged-care/aged-care-reform/home-care-packages

Australian Law Reform Commission, *Equality, Capacity and Disability in Commonwealth Laws* (August 2014) available at https://www.alrc.gov.au/publications/equality-capacity-disability-report-124

Burston and National Disability Insurance Agency [2014] AATA 456

Council of Australian Governments, *Disability Reform Council Communiqué* (April 2015) available at: http://www.ncoss.org.au/resources/DNF/eupdates/150429-COAGCommunique.pdf

Federation of Ethnic Communities' Councils of Australia (FECCA) Engaging people with disability in the multicultural sector: barriers to accessing services and employment (2014) available at http://www.fecca.org.au/images/Documents/disability%20survey%20report.pdf

Health Insurance Act 1973 (Cth)

Migration Act 1958 (Cth)

National Disability Insurance Agency *2013-2014 Annual Report*, available at: http://www.ndis.gov.au/document/891

National Disability Insurance Agency, 8th Quarterly Report to COAG Disability Reform Council (30 June 2015) available at http://www.ndis.gov.au/sites/default/files/Q4-Report-to-COAG-Disability-Reform%20Council.pdf

National Disability Insurance Scheme Act 2013 (Cth)

National Disability Insurance Scheme (Registered Providers of Supports) Rules 2013

National Disability Insurance Scheme (Supports for Participants) Rules 2013

People with Disability, *National Disability Insurance Scheme Citizen's Jury Scorecard* (May 2015) available at http://www.pwd.org.au/admin/ndis-citizens-jury-scorecard-project.html

Safety, Rehabilitation and Worker's Compensation Act 1988 (Cth)

The Federation of Ethnic Communities' Councils of Australia (FECCA), *Access and Equity in the context of the NDIS* (June 2015) available at http://apo.org.au/files/Resource/access-and-equity-in-the-context-of-the-national-disability-insurance-scheme-june-2015.pdf

United Nations Convention on the Rights of Persons with Disabilities (2008) available at http://www.refworld.org/docid/45f973632.html