

**AFDO Submission to the Senate Community Affairs
Committee
Draft National Disability Insurance Scheme Legislation 2012**

About the Australian Federation of Disability Organisations (AFDO)

The Australian Federation of Disability Organisations (AFDO) has been established as the primary national voice to Government that fully represents the interests of all people with disability across Australia.

The mission of AFDO is to champion the rights of people with disability in Australia and help them participate fully in Australian life.

AFDO member organisations took part in development of this submission. Current members are:

National Members

[Blind Citizens Australia](#)

[Brain Injury Australia](#)

[Deaf Australia Inc.](#) (formerly Australian Association of the Deaf)

[Deafness Forum of Australia](#)

[National Association of People Living with HIV/AIDS](#)

[National Council on Intellectual Disability](#)

[National Ethnic Disability Alliance](#)

[Short Statured People of Australia](#)

State Members

[Australia for All Alliance Inc.](#)

[Disability Resources Centre](#)

[People with Disability WA](#)

[Disability Justice Advocacy](#)

Associate Members

[Australian Aphasia Association](#)

[Arts Access Australia](#)

[Australian DeafBlind Council](#)

[Australians for Diversity Disability Employment](#)

[The Anne McDonald Centre](#)

[Disability Advocacy & Complaints Service of South Australia](#)

[Wise Employment](#)

Introduction

AFDO welcomes the opportunity to comment on the draft NDIS Legislation, and indeed, welcomes the legislation itself. The NDIS

presents a once-in-a-generation opportunity for transformative change in the lives of people with disability, and it is vital that the voices of people with disability are heard throughout its development.

AFDO has three broad criticisms of the draft legislation as it stands. They are:

The need to enshrine human rights in the legislation's intent and outcomes

At present, the legislation does not provide for an approach centred on the United Nations Convention on the Rights of Persons with Disabilities (UN CRPD), let alone other human rights covenants which are relevant to the rights based participation of citizens. If the legislation is to be interpreted well by a range of people for years to come, it must enshrine these rights more explicitly.

The need to assume capacity and provide support accordingly to people with disability

In a number of sections the legislation talks about people with disability who are a 'significant risk' or who need support to make decisions. Neither of these statements works from a basis of assumed decision making capacity, which would recognise that all of us make some decisions in our lives about what we like and who we spend time with.

The need to ensure the scheme is flexible in its requirements of people with disability

The autonomy of people with disability is further disrupted by the powers placed within the hands of the CEO or their delegated authority. Only some of these powers can be overturned through a right to appeal, and appeals outside the Agency are likely to be legalistic, time consuming and difficult, with no 'middle road'. A lack of a right to advocacy, and a lack of an alternative dispute resolution mechanism outside of the agency make it a fundamentally unfair system.

Chapter 1 – Introduction

Part 2 – Objects of Act

Given that the objects of the Act are about the practical goals of the NDIS, they contain only a very limited direct reference to human rights obligations and the UN CRPD.

3.1(h) says that:

1. The objects of this Act are to:

(h) give effect to certain obligations that Australia has as a party to the Convention on the Rights of Persons with Disabilities.

The intent of the wording ‘certain objects’ is most likely to be about ensuring that there is a clear expectation that the NDIS won’t be able to respond to every part of every article of the UN CRPD. However, it also allows for later suggestions that ‘certain articles’ do not need to be addressed at all by the NDIS, without any further explanation. It also fails to address other human rights obligations which would be relevant to the NDIS, including the Convention on the Rights of the Child and the Convention on the Elimination of Discrimination Against Women. An alternative would be to use wording like that in the draft Anti Discrimination and Human Rights Bill, which says under 3.2.1b:

“...in conjunction with other laws, to give effect to Australia’s 9 obligations under the human rights instruments and the ILO 10 instruments”

3.2 currently says –

These objects are to be achieved by:

(a) providing the foundation for governments to work together to develop and implement the National Disability Insurance Scheme launch; and

(b) adopting an insurance-based approach, informed by actuarial analysis, to the provision and funding of supports for people with disability.

While the UN Convention on the Rights of Persons with Disabilities is mentioned in the clause above outlining the objects, the way the objects will be achieved should also include building and measuring the success of the Scheme within a human rights based framework, not just an insurance based approach (which is not always a good method for ensuring human rights).

4.4 says:

People with disability should be supported to exercise choice and control in the pursuit of their goals and the planning and delivery of their supports.

This general principle speaks to a much broader problem with the underlying assumptions of this legislation: namely, it talks about 'supporting' people with disability to have choice and control over goals, rather than assuming that capacity for choice and control is inherent and acting accordingly. After all, human beings have the ability to express preferences, likes and dislikes; these things are the beginnings of how we choose and how we exert control over the world.

Thinking differently would mean saying that support to exercise choice and control may be needed, and should be given to each person with disability to the maximum extent required to fulfil their inherent ability. At present the draft NDIS legislation works on the basis that there may be circumstances where taking over control and choice for the person is appropriate, rather than enabling the person with assistance. Whether or not the term 'support' is meant to imply a collaborative relationship has become irrelevant, because the goal of that support is fundamentally different.

This view is carried over into the next clause, which says:

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

It is the intention of the Parliament that, if this Act requires or permits an act or thing to be done by or in relation to a person with disability by another person, the act or thing is to be done, so far as practicable, in accordance with both the general principles set out in section 4 and the following principles:

(a) people with disability should be involved in decision making processes that affect them, and 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 cultural and linguistic circumstances of people with disability should be taken into account;

(e) the supportive relationships, friendships and connections with others of people with disability should be recognised.

Again, limits are placed on a person's capacity by the wording of the law. A person with disability can be involved in decision making processes 'where possible'. Thinking differently would mean a person should be supported to make decisions when they need assistance.

Furthermore, this clause makes assumptions about what isn't a decision; 'relationships, friendships and connections with others' are all decisions made about who we like, what we want to do and who helps us, unless our freedom of movement or association has been restricted. Viewed this way, people with disability who have friends, family and other interested people in their lives have made a set of decisions about how their lives should be. These decisions should be acknowledged as such, and they should be supported to the fullest extent possible.

6 Agency may provide support and assistance

(1) The Agency may provide support and assistance (including financial assistance) to prospective participants and participants in relation to doing things or meeting obligations under, or for the purposes of, this Act.

Note: For example, the Agency might assist a participant to prepare the participant's statement of goals and aspirations by assisting the participant to clarify his or her goals, objectives and aspirations.

(2) However, subsection (1) does not permit or require the Agency to fund legal assistance for prospective participants or participants in relation to review of decisions made under this Act.

6.1 does not require the Agency to provide assistance to prospective participants and participants. It 'may' do so, but is not obliged to. Furthermore, this assistance – however provisional – is only to be provided to potential participants and participants, not to people with disability who may contact the Agency for information and referral, or to past participants who may need assistance from the Agency; for example, a person who has exited into the aged care system may need assistance to gather documentation of their support needs.

The obligation to provide assistance needs to be just that – an obligation. It also needs to explicitly include recognition that 'assistance' should involve independent individual or systemic advocacy. Independent individual or systemic advocacy should be used to assist people with disability, including past, present and potential participants. It should be offered as needed for any aspect of the scheme.

Overall participation of people with disability in the NDIS

Both the objectives and general principles of the NDIS should include reference to the goal of including people with disability in every aspect of the scheme, not just as participants. People with disability should be included as decision makers, employees, participants and carers.

Part 3 – Simplified Outline

This outline does not use simple language, making it harder for people with disability to use it as a guide to the Act.

Part 4 – Definitions

The draft legislation contains references to a number of other laws, especially in this Part. This will make reaching the actual definitions more difficult for some people with disability, limiting their ability to understand the legislation. The Act should provide for full definitions from other legislation to be found easily, either in

the text of this legislation itself or in a designated rule, schedule or other device.

4.9 Definitions

carer means an individual who:

- (a) *provides personal care, support and assistance to another individual who needs it because that other individual is a person with disability; and*
- (b) *does not provide the care, support and assistance:*
 - (i) *under a contract of service or a contract for the provision of services; or*
 - (ii) *in the course of doing voluntary work for a charitable, welfare or community organisation; or*
 - (iii) *as part of the requirements of a course of education or training.*

The definition of 'carer' is restricted to unpaid carers, which may become complicated as the NDIS is implemented and participants choose to pay a known, currently unpaid carer for certain tasks.

developmental delay means a delay in the development of a child under 6 years of age that:

- (a) *is attributable to a mental or physical impairment or a combination of mental and physical impairments; and*
- (b) *results in substantial reduction in functional capacity in one or more of the following areas of major life activity:*
 - (i) *self-care;*
 - (ii) *receptive and expressive language;*
 - (iii) *cognitive development;*
 - (iv) *motor development; and*
- (c) *results in the need for a combination and sequence of special interdisciplinary or generic care, treatment or other services that are of extended duration and are individually planned and coordinated.*

The restriction of a developmental delay to children under the age of six is concerning for many, because it means that a child must

have a diagnosis of condition and a prognosis of permanent impairment requiring lifelong support by the time they are six.

Children with disability are often only just in the school system at this age, and may not have had screening or testing for delays or disabilities until they reach school. For some families from culturally and linguistically diverse backgrounds, entering the school system is not enough to ensure that a disability or delay is picked up; disability can be misconstrued as a lack of English language skills leading to delayed language or “poor” behaviour.

Some families may face practical or emotional delays in getting a firmer diagnosis or prognosis for their child. Families in rural and regional areas have limited access to specialists of all types. Other families simply do not want to face a permanent disability, and will delay making further judgements. In some instances, it may take longer to determine whether a child’s condition is permanent. In all of these circumstances, children who had been getting support may no longer receive it when they turn six.

AFDO strongly believes that the legislation should not give an upper age limit for developmental delay; except to say that it should be diagnosed in children.

Definition of Disability – The disability requirements outlined elsewhere in the legislation apply only to eligibility for paid supports under the NDIS. They do not address the fact that people with disability may be utilising the NDIS for information and referral, or as employees, carers or Board members. This wide variety of roles needs to be addressed through a definition of disability. AFDO believes the most appropriate definition of disability is the one used in Article 1 of the UN CRPD, namely:

Persons with disabilities includes 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.

Definition of Disability Support Organisation – While the legislation defines registered plan management organisations, and registered support organisations, it does not define organisations

which may provide support with planning for people who can undertake their own plan management. Such organisations shouldn't need to be registered, but should be accounted for under the legislation (and in the provision of support funding). This may include organisations which provide information or advice, toolkits, coordination functions, training and/or access to peer support networks for a person who is undertaking their own planning.

Although the definition of a Disability Support Organisation needs to be broad enough to cover all of these functions, it should also specifically exclude support provision agencies (service providers) from being DSOs. Likewise, it should clearly define the difference between the Agency, a planning organisation and a DSO; the Agency's role should be about plan approval, not plan provision or planning support.

Definition of Advocacy – with the addition of a requirement that advocacy be available under the NDIS, the legislation will need a clear definition of advocacy. This should stipulate that advocacy is independent and works to promote the wishes of the person with disability. It should also define advocacy types which are relevant to the NDIS.

Right to access supports: At present, this legislation does not rule out the possibility of means testing or co-payments for future supports. It should enshrine a right to access supports based on eligibility which does not include co-payments or means testing.

7 Provision of notice, approved form or information under this Act etc.

(1) The contents of any notice, approved form or information given under this Act, the regulations or the National Disability Insurance Scheme rules to a person with disability must be explained by the giver of the notice, approved form or information to the maximum extent possible to the person in the language, mode of communication and terms which that person is most likely to understand.

(2) An explanation given under subsection (1) must be given both orally and in writing if reasonably practicable.

While this clause provides for information being in a format which is 'understood' by a person, for some groups of people with disability comprehension is not the issue. People who have sensory disabilities or reading disabilities (such as dyslexia), simply need the information in a format they can access. The language in this clause needs to clarify the difference between accessing and understanding information.

Chapter 3 – Participants and their Plans

20 CEO must consider and decide access requests

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).*

26 Requests that the CEO may make

- (2) If:*
 - (a) information or one or more reports are requested under subsection (1); and*
 - (b) the information and each such report are received by the CEO within 28 days, or such longer period as is specified in the request, after that information or report is requested;*

the CEO must, within 14 days after the last information or report is received:
 - (c) decide whether or not the prospective participant meets the access criteria; or*
 - (d) make a further request under subsection (1).*

- (3) If:*
 - (a) information or one or more reports are requested under subsection (1); and*
 - (b) the information and each such report are not received by the CEO within 28 days, or such longer period as is specified in the request, after that information or report is requested;*

the prospective participant is taken to have withdrawn the access request, unless the CEO is satisfied that it was reasonable for the prospective participant not to have complied with the request made by the CEO within that period.

The CEO is required to request information within a specific timeframe, but it may be impossible for people with disability, their families or carers to estimate the length of time it will take to get some information. This is particularly true for any medical information which must be acquired from a specialist, where waiting lists for appointments – especially non urgent, form filling ones - are notoriously long.

While the CEO can extend the process by making further requests for information, these also require a stipulated timeframe. Although it is clear that the intention of this section is to ensure that the system moves promptly and that people who disengage at the application process stage can be readily identified, it may unintentionally place barriers in the way of those who have to move through other intricate systems to get the information required.

The legislation should allow participants or their representatives to identify a need for a longer timeframe, rather than simply saying the CEO can grant such an extension.

To combat some of the other barriers to the provision of information, the law should also give a right to assistance – financial or practical – with privately supplied assessments where a need can be demonstrated. For example, a single parent on income support should not be forced to wait eighteen months to access a specialist assessment for autism if allied health workers agree that the child exhibits signs of developmental delay. Entry times for the NDIS should not be based on whether or not one has privileged access to assessments.

It is concerning that the CEO has the power to enforce a medical assessment on any participant or potential participant. This could mean that regular reassessments to ‘prove’ disability become standard practice, which is not in the best interests of people with permanent disabilities, or the system administering supports. To

that end, the legislation should specify that the CEO should not be able to request an assessment if there is already existing proof of a stable disability and/or support need.

Additionally, 26 gives the CEO the power to request that a person have an assessment at a specific place. A person with disability must have the right to appeal such a request; it may be that they have had previous bad experiences or trauma in a specific place or with a specialist. They may also reject a particular diagnosis, and should have the right to do so. They may feel that a short term assessment of their abilities is not conducive to getting good information about their impairment/s or support need/s.

This information should be taken into account as well as any assessment; a person making an application should also have the power to provide information of their own for consideration by the CEO.

These principles – the need for an ability to challenge the place or specialist nature of an assessment, the need for assistance with the costs and logistics of assessment, and the need to provide alternative information – should apply where-ever the CEO is granted the power to compel assessments.

22 Age requirements

(1) A person meets the age requirements if:

(a) the person was aged under 65 when the access request in relation to the person was made; and

AFDO strongly opposes an age cap of 65 for the NDIS because:

1. People with disability do not receive adequate disability support from the aged care system;
2. Many people acquire disability after the age of 65;
3. People who acquire a disability before the age of 65 may take until after 65 to seek out supports for that disability, even if they needed the support earlier;
4. To deny people with disability access to adequate disability supports is a breach of their fundamental human rights as outlined in the UN CRPD.

23 Residence requirements

- (1) *A person meets the residence requirements if the person:*
- (a) *resides in Australia; and*
 - (b) *is one of the following:*
 - (i) *an Australian citizen;*
 - (ii) *the holder of a permanent visa;*
 - (iii) *a special category visa holder who is a protected SCV holder;*

AFDO believes that the current residency requirements unnecessarily exclude people with disability living in Australia who have an intent to stay here. This might include refugees, family sponsored migrants and people on longer term working visas. For people in all of these categories, a years-long delay in receiving critical disability supports amounts to an abuse of human rights. In particular, this deprivation contravenes the UN CRPD by making it difficult for people with disability to migrate to Australia under Article 18. For example, a person with a physical disability who wanted to move to Australia to pursue work opportunities would have to find a way to source their own personal care support through family or paid staff whose salaries would come from their own wages, making the choice to migrate complicated, if not impossible.

(3) *Without limiting paragraph (1)(c), National Disability Insurance Scheme rules made for the purposes of that paragraph:*

(a) *may require that a person reside in a prescribed area of Australia on a prescribed date or a date in a prescribed period in order to meet the residence requirements; and*

(b) *may require that a person has resided in a prescribed area for a prescribed period in order to meet the residence requirements; and*

(c) *may require that a person continue to reside in a prescribed area of Australia in order to meet the residence requirements.*

AFDO believes that once a person has received NDIS funding, that funding should travel with them when they move; since the Scheme is expected to be national in the longer run, and since participants will have control over how and where their packages are spent, this is the simplest way to ensure that participants retain their supports and thus their basic human rights.

While the Rules will provide further details about the residence requirements, it is important to have an assurance that people who are transient – such as people experiencing homelessness, people in institutions or people who move because of family migration – are catered for within the bounds of what is decided.

24 Disability requirements

(1) A person **meets the disability requirements** if:

(a) *the person has a disability that is attributable to one or more intellectual, cognitive, neurological, sensory or physical impairments or to one or more impairments attributable to a psychiatric condition; and*

(b) *the impairment or impairments are, or are likely to be, permanent; and*

(c) *the impairment or impairments result in substantially reduced functional capacity to undertake, or psychosocial functioning in undertaking, one or more of the following activities:*

(i) *communication;*

(ii) *social interaction;*

(iii) *learning;*

(iv) *mobility;*

(v) *self-care;*

(vi) *self-management; and*

(d) *the impairment or impairments affect the person's capacity for social and economic participation; and*

(e) *the person's support needs in relation to his or her impairment or impairments are likely to continue for the person's lifetime.*

(2) *For the purposes of subsection (1), an impairment or impairments that vary in intensity may be permanent, and the person's support needs in relation to such an impairment or impairments may be likely to continue for the person's lifetime, despite the variation.*

For many people with disability, the need to declare a disability is permanent before they can receive support is difficult, if not impossible. For some it may be an emotionally confronting

process. People living with Chronic Fatigue Syndrome, for example, struggle to find doctors who can diagnose their condition and who will say that the condition is 'likely' to be permanent.

Receiving critical supports should not be dependent on whether a disability is permanent, but only on whether it has a significant impact on a person's ability to participate.

Plans – general comments

This section sets up a pattern of the Agency 'owning' a participant's plan; the CEO has ultimate approval of the plan, and the plan must contain a section which is prepared 'with the participant' regarding their supports (33.2). This does not require the participant to be the key decision maker, or a decision maker at all in terms of the supports they are provided with.

Furthermore, the level of detail that the CEO (or delegated authority) has to approve within the plan could make the NDIS extremely centralised, with little or no explicit ability for plans to be approved and examined in a local context. This will be particularly difficult for people living in rural and regional areas, and for those from non-English Speaking or Aboriginal and Torres Strait Islander backgrounds, who may value local community input more than others.

32 CEO must facilitate preparation of participant's plan

- (1) If a person becomes a participant, the CEO must facilitate the preparation of the participant's plan.*
- (2) The CEO must commence facilitating the preparation of the plan within 14 days after the person becomes a participant.*

This section does not describe clearly what 'commencing facilitation' of a Plan might look like. With no clear definition, it could be taken that sending notification of the participant's acceptance into the NDIS launch would be sufficient.

Furthermore, this does not address the need for Plans to be completed in a timely fashion. While planning time will be varied for different participants, there should be a requirement for a reasonable timeframe within which a plan is completed.

This is especially important because participants without plans, as the legislation stands, will not be able to access supports under the NDIS. The law should also make provision for interim support arrangements if the planning process is going to take an unusually long time, or if the participant's needs are urgent.

33 Matters that must be included in a participant's plan

Overall, a participant should have the right to refuse to include any of the information that 'must' be in their plan if they have concerns about their privacy or feel that the information could be used in such a way as to have a negative impact upon them. For example, a person who had goals, dreams and aspirations around their sexuality should have a right to ensure that this is not known by family members who are otherwise involved in their planning.

They should have a right to make sure that this goal was not mentioned directly in either part of their plan, or that such a part of their plan could only be seen by nominated people.

Likewise, if an evaluation concludes that a person has 'challenging behaviours' and this is set to be one of the considerations within the person's plan, they – or their advocate – should have the ability to challenge it.

*(2) A participant's plan must include a statement (the **statement of participant supports**), prepared with the participant and approved by the CEO, that specifies:*

- (a) the general supports (if any) that will be provided to, or in relation to, the participant; and*
- (b) the reasonable and necessary supports (if any) that will be funded under the National Disability Insurance Scheme; and*
- (c) the date by which, or the circumstances in which, the Agency must review the plan under Division 4; and*
- (d) the management of the funding for supports under the plan (see also Division 3); and*
- (e) the management of other aspects of the plan.*

The participant's plan should also include information about any other supports which are being provided outside of the NDIS, and any assistance the NDIS is giving to a participant, either to use or coordinate those supports.

Unmet need should also be identified in a participant's plan. While the NDIS itself will not always resolve all support issues, it should have a stake in identifying them and proactively working towards solutions.

34 Reasonable and necessary supports

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:

- (a) the support will assist the participant to pursue the goals, objectives and aspirations included in the participant's statement of goals and aspirations;*
- (b) the support will assist the participant to undertake activities, so as to facilitate the participant's social and economic participation;*
- (c) the support represents value for money in that the costs of the support are reasonable, relative to both the benefits achieved and the cost of alternative support;*
- (d) the support will be, or is likely to be, effective and beneficial for the participant, having regard to current good practice;*
- (e) the funding or provision of the support takes account of what it is reasonable to expect families, carers, informal networks and the community to provide;*
- (f) the support is most appropriately funded or provided through the National Disability Insurance Scheme, and is not more appropriately funded or provided through other general systems of service delivery or support services offered by a person, agency or body, or systems of service delivery or support services offered:
 - (i) as part of a universal service obligation; or*
 - (ii) in accordance with reasonable adjustments required under a law dealing with discrimination on the basis of disability;**

(g) the support is not prescribed by the National Disability Insurance Scheme rules as a support that will not be funded or provided under the National Disability Insurance Scheme;

(h) the funding of the support complies with the methods or criteria (if any) prescribed by the National Disability Insurance Scheme rules for deciding the reasonable and necessary supports that will be funded under the National Disability Insurance Scheme.

AFDO is concerned that the CEO (or delegated authority) has to be satisfied that **all** of the above criteria have been met. There may be many instances where a number of criteria are met, but others are not; in particular (c), which is about value for money, and (d) which is about current good practice. It should be possible for a participant to receive a support which is so new it is not considered 'good practice' yet, but which will meet every other criteria. Ultimately, these criteria should be part of a balanced overview of the person's situation, not a checklist without regard for benefit.

Additionally, AFDO is concerned that this may lead to people being refused some supports if they do not accept other supports. As an example, it is very common for health and allied health professionals to take the approach that hearing aids and cochlear implants are an essential and cost effective support and express the view that deaf people who have these supports do not need Auslan - and by extension interpreting support. Many deaf people reject this view and prefer not to have hearing technology supports. The current criteria could lead to a situation where Deaf people are refused supports such as interpreting, note-taking and real time captioning because they have chosen not to have hearing technology supports.

40 Effect of temporary absence on plans

(3) If a participant for whom a plan is in effect is temporarily absent from Australia after the end of the grace period for the absence, the participant's plan is suspended from the end of the grace period until the participant returns to Australia.

(4) For the purposes of this section, a person's absence from Australia is temporary if, throughout the absence, the person does not cease to reside in Australia (within the meaning of paragraph 23(1)(a)).

This section should make allowances for people who are unable to return to Australia within the grace period because of emergencies beyond their control, such as natural disasters or bereavement.

44 Circumstances in which participant must not manage plan to specified extent

(2) The statement of participant supports in a participant's plan must not provide that the participant is to manage the funding for supports under his or her plan to a particular extent if the CEO is satisfied that management of the plan to that extent would:

(a) present an unreasonable risk to the participant; or

(b) permit the participant to manage matters that are prescribed by the National Disability Insurance Scheme rules as being matters that must not be managed by a participant.

(3) The National Disability Insurance Scheme rules may prescribe criteria to which the CEO is to have regard in considering whether a participant managing the funding for supports under the plan would present an unreasonable risk to the participant.

AFDO strongly believes that losing autonomy because someone is presumed to be a risk is both impractical and contrary to human rights because it is a subjective definition which has little to do with the ability to make decisions. Some decisions in life are inherently risky, and making them serves to bring us greater skill and enriched lives. Furthermore, to base a decision about autonomy on 'risk' is to perpetuate a negative, non-human rights basis for the deprivation of the liberty of people with disability.

Should there be a need for plan management of any kind, it should be on the basis that all mechanisms to build the decision making capacity and to provide opportunity for practical experience of decision making have been thoroughly investigated and applied. For an overview of different models of support which could be

used as part of the NDIS, please see the Victorian Law Reform Commission's Guardianship Report.

Reframing management of plans as a capacity building exercise means they are less likely to be restrictive to an extreme, and less likely to be long-term where it is not necessary for management to be long term.

Division 4—Reviewing and changing participants' plans

47 Participant may change participant's statement of goals and aspirations at any time

(2) If a participant gives a changed version of the participant's statement of goals and aspirations to the CEO, the plan is taken to be replaced by a new plan comprising:

(a) the changed version of the participant's statement of goals and aspirations; and

(b) the statement of participant supports in the existing plan.

To change the goals and aspirations of a participant plan without at least considering whether this changes the statement of participant supports in an existing plan makes no sense. At best, it makes a mockery of asking people with disability to provide their goals and aspirations. At worst, it means that a significant change in goals and aspirations – such as a shift from wanting to live at home with parents to wanting to move out – goes unaddressed in the kinds of supports which are provided.

It is true that a change in goals and aspirations need not lead to a change of planning for supports if the supports are flexible enough, however, this should not be the default assumption of the legislation. If a participant changes their goals and aspirations, then there should be a determination made about whether a review of supports is necessary.

Conversely, a person with disability who has episodic, but otherwise mostly stable, support needs may find themselves unable to have their support needs change without a corresponding change in their plan. A change in a plan to reflect a change in supports may also be detrimental to people who change

their supports for very private reasons, such as instances of abuse or neglect which they are not comfortable with having in a plan. So the legislation should make a provision for decision making on a case-by-case basis about whether a change in supports means a change in the plan.

51 Requirement to notify change of circumstances

(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; or

(b) the participant or prospective participant becomes aware that such an event or change of circumstances is likely to happen.

The idea that a participant should notify the CEO of something that is 'likely to happen' is unreasonable in the extreme. It leads to a situation where someone may be considered at fault or penalised because something they weren't sure would happen actually occurred. 'Likely' is a very nebulous term.

This is especially unreasonable given that the CEO has the power to notify Centrelink and Medicare of any issues relevant to them. For example, if a person feels it is 'likely' that they will get a job, or will move in with a partner, they may find themselves faced with a review of pension payments because the NDIS agency has notified Centrelink of a potential change.

69 Application to be a registered provider of supports

(1) A person or entity may apply in writing to the CEO to be a registered provider of supports in relation to either or both of the following:

(a) managing the funding for supports under plans;

(b) the provision of supports.

Note 1: If the funding for supports under a plan is managed by the Agency, supports are to be provided only by a registered provider of supports (see subsection 33(6)).

Note 2: A registered plan management provider of supports may in certain circumstances manage the funding for supports under a plan (see subsection 42(2)).

No plan management provider for supports should be able to manage funding for supports. This is a clear conflict of interest which will create a lack of transparency and a lack of control for people with disability. It is especially concerning because there are many other, non-disability specific options for managing the funding for supports, such as accountancy and legal firms.

This clause should not operate in a way which limits choice by creating unnecessary complexity in registration processes, and should recognise the human rights of people with disability to choose where-ever possible. Registration processes should also be as accessible as possible to people with disability who want to become individual providers under the NDIS.

74 Children

(5) Subsections (1) and (2) of this section do not have effect in relation to a participant who is a child if:

(a) the CEO is satisfied that the child is capable of making decisions for himself or herself;

The UN CRPD talks about recognising the ‘evolving capacity of children’. This means that a judgement about whether or not a child can make decisions for him or herself should not be a simple matter of ‘yes or no’. A child may begin to make some decisions well, while others are still difficult. Furthermore, a child may gain better decision making capacity by being encouraged to practice making their own decisions.

The law should reflect the gradual acquisition of decision making capacity that most people go through as they grow up, and make allowances for it in terms of the judgements the CEO is able to make.

Part 5—Nominees

AFDO believes that the plan nominee position is currently about averting risk, and is thus untenable within a human rights based approach to disability support. Instead, plan nominees should fulfil a capacity building role, which is about developing decision making capacity with a person with disability and giving them opportunity to have control over their own lives through practical experience with decision making.

Under such a revision of the law, a nominee may only be appointed under very strict conditions. There should be a very clear process for demonstrating that a person with disability has been given all other options for support to make their own choices and manage their own plan before a plan nominee can be appointed.

If it is deemed to appoint a plan nominee where there is evidence of abuse and/or neglect of the person by someone in their life this needs to be done under strict guidelines, including plans to improve capacity through supported decision making and a process for review.

To make sure plan nominees are held accountable and are not used widely, the NDIS law should require that:

- There are clear criteria for who can be appointed as a plan nominee, including that service providers should not be nominees;
- There are clear criteria for why a plan nominee can be appointed, including that this should not be because the person 'poses a risk' but that other supports do not meet their need for decision making assistance adequately;
- There are clear criteria for how a plan nominee can be appointed, including the need to use a tribunal system rather than vesting appointment in one person or delegated authority, and a need to ensure that a person with disability is not forced to pay for assessments which lead to the appointment of an involuntary nominee;

- Plan nominees are given standard education and training (especially on how to build capacity);
- Plan nominees are reviewed regularly (once every twelve months);
- There should be a clear plan for building the capacity of the participant while a plan nominee is in place;
- The NDIA should provide a publicly available systemic report on nominee use every year;
- The NDIA should be compelled to build the capacity of capacity building organisations (such as self advocacy groups).

The legislation currently acknowledges and legitimises guardianship laws across the country. This will not - and cannot - work well with any nominee system, because those State and Territory laws are inconsistent.

Some points about correspondence nominees:

- Plan nominees and correspondence nominees should be obliged to work together and communicate with each other where necessary;
- Correspondence nominees should be obliged to let their participant know about all NDIS correspondence.

99 Reviewable decisions

AFDO does not believe that reviewable decisions should be prescriptive. Any decision made by the Agency which a person – be they a participant, nominee or an interested party – believes has an adverse effect should be reviewable.

Otherwise there is simply too much power placed in the hands of the CEO or delegated authority; by creating a ‘white list’ that ignores some elements of what the CEO is able to do under the legislation, the law also leaves large scope for unintended consequences where people with disability are left voiceless.

100 Review of reviewable decisions

(2) A person who is directly affected by a reviewable decision may request the CEO to review the reviewable decision. If the person is given a notice under subsection (1) the person must make the request within 3 months after receiving the notice.

There should be no limit on the timeframe for reviewing most decisions, unless the decision itself has a timeframe for being enacted. For example, a decision about approval of emergency supports should be reviewed very quickly.

(6) The reviewer must, as soon as reasonably practicable, make a decision:

- (a) confirming the reviewable decision; or*
- (b) varying the reviewable decision; or*
- (c) setting aside the reviewable decision and substituting a new decision.*

103 Applications to the Administrative Appeals Tribunal

Applications may be made to the Administrative Appeals Tribunal for review of a decision made by a reviewer under subsection 100(6).

AFDO strongly objects to the review process going from an internal review mechanism to a highly legalised one, with no steps in between. It is critical that people with disability have access to a non adversarial, easy to access process such as mediation or the use of an Ombudsman. Once an alternative dispute resolution process has been undertaken, matters should go to a less formal tribunal structure, which functions like the Social Security Appeals Tribunal (SSAT) in that it has short average case closure times, is cheap and allows people with disability to represent themselves.

Furthermore, the end point of the process should not be one where people with disability are at a disadvantage to an Agency which will have legal resources at its disposal. The legislation should either compel the Agency to provide funding for legal support for final appeals, or should change the final appeal mechanism.

Chapter 5—Compensation payments

Part 1—Requirement to take action to obtain compensation

104 CEO may require person to take action to obtain compensation

This part of the legislation should be removed in its entirety before the Bill is passed. A requirement to seek compensation is inherently unfair because even where it takes into account all the circumstances listed, the outcome – and the toll in terms of time, money and emotional distress – could never be truly known at the outset. People with disability would bear some financial cost even in ‘no cost’ judgements because of the need to pay for legal experts, assessments and other things vital to seeking compensation.

Furthermore, the ability to compel an individual to seek compensation undermines the universal insurance model that the NDIS is meant to represent; as the legislation currently reads, it would be universal but only for people not compelled to seek funding elsewhere.

Furthermore, the Agency will have a vested interest in ensuring that some people seek compensation because of section 107, which means the agency can collect debts for supports which are covered by compensation payouts.

127 Appointment of Board members

(2) A person is eligible for appointment as a Board member only if the Minister is satisfied that the person has skills, experience or knowledge in at least one of the following fields:

- (a) the provision or use of disability services;*
- (b) the operation of insurance schemes, compensation schemes or schemes with long-term liabilities;*
- (c) financial management;*
- (d) corporate governance.*

(6) In appointing the Board members, the Minister must ensure that the Board members collectively possess an appropriate balance of skills, experience or knowledge in the fields mentioned in subsection (2).

147 Appointment of members of the Advisory Council

(5) In appointing the members of the Advisory Council, the Minister must:

(a) have regard to the desirability of the membership of the Advisory Council reflecting the diversity of people with disability; and

(b) ensure that:

(i) at least 4 of the members are people with disability who have skills, experience or knowledge relating to disability services; and

(ii) at least 2 of the members are carers of people with disability and have skills, experience or knowledge relating to disability services; and

(iii) at least one of the members is a person who has skills, experience or knowledge in the supply of equipment, or the provision of services, to people with disability; and

(iv) any other members are persons with skills, experience or knowledge that will help the Advisory Council perform its function.

For the NDIS to meet its objective of ensuring control by people with disability, the Board and Advisory Council should be made up of those most invested in its success: people with disability. AFDO believes that there are enough people with disability who have appropriate skills and knowledge to create a good pool of candidates for a person with disability-only Board and Advisory Council. At a bare minimum, people with disability should make up a clear majority on both bodies, which is not the case at present.

169 Staff

This section does not mention any requirement to proactively hire staff, utilise staff of other agencies, or to hire consultants who have disability or lived experience of disability as a matter of priority.

172 Annual report

The annual report of the Agency must include a report against the Articles of the UN CRPD as measures of the Agency's success.

177 Corporate plan

The corporate plan should include reference to, and details of, a Disability Action Plan developed by the Agency.

182 Debts due to the Agency

(1) If:

(a) a payment is made to a person that is, or purports to be, a payment of an NDIS amount to or in respect of a participant; and

(b) the person is not entitled for any reason to the payment of the NDIS amount;

the amount of the payment is a debt due to the Agency by the person and the debt is taken to arise when the person receives the payment.

(2) Without limiting paragraph (1)(b), a person is taken not to have been entitled to the payment of an NDIS amount if the payment should not have been made for one or more of the following reasons:

(a) the payment was made as a result of a computer error or an administrative error;

(b) the payment was made as a result of:

(i) a contravention of this Act, the regulations or the National Disability Insurance Scheme rules; or

(ii) a false or misleading statement or a misrepresentation;

(c) the participant died before the payment was made.

A participant should not have to repay a debt under certain circumstances. Under 2(a), a participant should not be forced to repay any debt unless it can be proven that they knew about the administrative error – for example, if a person received a large payment well over their usual amount, it is reasonable to imagine they would recognise an error. A \$200 limit for debts is not

sufficient to cover the possibility that larger debts may be accrued over a long period of time through a series of small overpayments. Smaller anomalies might be quite reasonably attributed to other things or may even go unnoticed for a while. Participants should not be penalised for an error which would be difficult to spot or recognise.

Under 2.b.ii, again it should be required that a person had a reasonable expectation of knowing that they were in contravention of a rule or law. Intricate information about this Act, regulations and rules may be too complex for some people with disability to follow, even if they are perfectly capable of managing their own funding. In this instance, debts should not be automatically applied; it should be based on an obvious disregard for the rules or legislation.

Part 5—Legislative instruments

209 The National Disability Insurance Scheme rules

It is AFDO's understanding that the NDIS Rules will be disallowable instruments, tabled in Parliament and then automatically approved after fifteen sitting days if there are no objections. AFDO strongly believes that the NDIS Rules require more scrutiny, and should at the very least be affirmed by Parliament. Ideally the Rules should be required to be subject to public consultation before they reach Parliament.